



## CONVERSATIONS ABOUT CARE:

# The Law and Practice of Health Care Consent for People Living with Dementia in British Columbia



## ABOUT THE CCEL

The CCEL carries out scholarly research, writing, analysis, and community engagement relating to legal and policy issues that impact us as we age. As part of its work the CCEL consults with stakeholders, collaborates with community agencies, and publishes legal, policy and practice resources, including recommendations for law reform, and public information materials. The CCEL is a division of the BC Law Institute, BC's non-profit independent law reform agency.



## ABOUT THE ALZHEIMER SOCIETY OF B.C.

Families across British Columbia are affected by Alzheimer's disease or other dementias. The Society's vision is a world without Alzheimer's disease and other dementias, and that world begins with a more dementia-friendly society, where people affected by dementia are acknowledged, supported and included. Working in communities throughout the province, the Society supports, educates and advocates for people with dementia, as well as enabling research into the disease. As part of a national federation, the Society is a leading authority on the disease in Canada.

**Alzheimer Society**  
BRITISH COLUMBIA

This project was generously funded by the Law Foundation of British Columbia.



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# Note from the BCLI Chair

*Conversations about Care* is our first collaboration with the Alzheimer Society of B.C. Capacity issues have been at the heart of many previous projects of the British Columbia Law Institute and the Canadian Centre for Elder Law. The Health Care Consent Project was our first opportunity to focus specifically on the experiences of people living with dementia.

This project examined the laws governing health care consent for people living with dementia in British Columbia. It also went a step further to explore policy and practice, particularly in long-term care facilities, where some of the most vulnerable members of our communities reside.

This report includes 34 recommendations. They address law reform, access to justice and legal aid, health care professional legal education, and systemic barriers to informed consent. The recommendations were developed by an inter-disciplinary advisory committee, and informed by both legal research and consultation. As part this project we spoke with a broad range of stakeholders, including people living with dementia, family caregivers, and professionals who deal with health care consent as part of their work. The recommendations invite the Government of BC, health professional regulators, and other key stakeholders in BC to consider how to develop the most robust legal framework and support best practice.

On behalf of the boards of directors of the British Columbia Law Institute, I would like to express gratitude to Project Advisory Committee members for the time and expertise they contributed to this challenging project. The recommendations contained in this report have the full support of all fifteen members of the Project Advisory Committee. Achieving consensus across such divergent perspectives was difficult, and committee members truly rose to the challenge. It is our hope that the process of working to address everyone's concerns has allowed us to develop a robust list of recommendations that will make a difference for people living with dementia in this province.

Thomas L. Spraggs



Chair,  
British Columbia Law Institute  
February 2019

# Acknowledgements

The Canadian Centre for Elder Law and the Alzheimer Society of B.C. (the Society) would like to acknowledge the work of the Health Care Consent Project Advisory Committee. Members of the Committee generously shared their time and expertise. In addition to participating in committee meetings to help us better understand the issues and develop meaningful recommendations, many members connected us with key informants, noted up draft versions of the report, identified important resources, and participated in presentations. The project took longer than anticipated, and our committee members stayed with us for the full journey toward report completion.

We would like to thank all the stakeholders who participated in consultation. People living with dementia patiently described their concerns to us. Family caregivers took time out of their delicately balanced schedules of work and caregiving to help us understand the strengths and weaknesses of the current regime. Health care professionals and others who deal with informed consent in their work shared honestly, and sometimes made time for multiple conversations with us. We are also grateful for Inclusion BC for inviting us to speak with some of their families and advocates, and for Alzheimer Society of B.C. Resource Centres across the province for hosting focus groups. This report, being grounded in lived experience, would have been impossible without all this support.

Many organizations invited us to talk about health care consent over the lifetime of this project. Thank you to:

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- The Continuing Legal Education Society of BC.



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Finally, we are grateful the staff of the CCEL and the Society who helped this report come together. BCLI Research Lawyer Rachel Kelly spent almost two years of her work life researching health care consent issues for us. CCEL National Director Krista James managed the project, led consultation, and wrote the report. Staff Lawyer Valerie LeBlanc assisted with minutes. BCLI Executive Director Kathleen Cunningham provided ongoing guidance. Office Manager Elizabeth Pinsent provided administrative support. Amy Cox conducted social science research and took notes at a number of focus groups. Summer students Gurinder Cheema assisted with citations, and Allison Curley transcribed interviews. We are also enormously grateful to the following volunteers who transcribed hours and hours of key informant interviews: Alexis Haig, Tasha Lorenzen, and Catrina Thomas.

Barbara Lindsay, Director, Advocacy & Education and Marketing & Communication, Alzheimer Society of B.C. chaired committee meetings, and supported the project from birth to completion. Jennifer Stewart, Manager, Advocacy & Education for the Society, provided guidance and support. Eva Boberski, Provincial Coordinator, Information for the Society, organized consultation focus groups. Natalie North, Coordinator, Marketing & Communications for the Society, reviewed the entire report, and organized photography with the support of Daisy Couture, UBC Co-op student for the Society. Jasmine Chauhan, UBC Co-op student for the Society, provided additional support.

# Executive Summary

## PROJECT RATIONALE

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Respect for the right to make informed decisions about health care treatment is deeply important to many of us. Medication can have a significant impact on quality of life, pain management, and life expectancy, and decisions in relation to health care engage fundamental values and personal bodily integrity. The notion that someone else can require us to take medication may be welcome to people who trust the family members and health care providers who oversee their care; for others, this prospect may be terrifying. Regardless, people with capacity issues that impact their ability to make their own decisions about health care reflect a vulnerable population. The recognition of their legal rights is of great importance.

In recent years, there has been increasing interest in medication practices involving older people, including polypharmacy, off-label use, over-medication, and excessive prescription of anti-psychotics. Many tools have been developed to support enhanced practice in these areas. However, while informed consent is a key aspect of appropriate prescribing, there has been almost no attention to consent in the context of law, policy and practice discussions of health care for older people. Debate and dialogue regarding health care often belie a well-meaning view of older people as passive recipients of care at the expense of consideration of their right to make their own decisions.

While health care consent law applies to everyone, the issue raises particular challenges in relation to people living with dementia—not only because dementia can impact mental capacity, but also because people living with dementia confront assumptions that they are mentally incapable of making their own health care decisions, regardless of their actual abilities. Most forms of dementia are more prevalent among older people, and our population in British Columbia is aging. As a result, health care consent for people living with dementia will become an increasingly important legal and health policy issue.

This project on health care consent was developed to explore the law, policy, and practice with respect to health care consent for people living with dementia in BC. *Conversations about Care* examines law and practice in concert both to ensure legislation reflects the realities of practice, and to consider whether the barriers to good practice are a problem related to the substance of legislation, its implementation, or a combination of both. The goal is to ensure our legal framework in relation to informed consent is sufficiently robust to protect the rights of people living with dementia and their legal substitute and supportive decision makers for health care, and to enhance and clarify the law where needed.

## PROJECT SCOPE

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This project examined laws which impact health care consent in BC. We reviewed legislation governing:

- Informed consent to health care;
- Substitute and supported decision making for health care;
- Medication use in long-term care; and
- Involuntary committal for psychiatric treatment.

The goal of the project was to consider the law in practice. Therefore we also studied the broader framework that impacts the relationships between people living with dementia and their health care providers, and the right and ability to request a review of decisions related to health care treatment. As a result this approach, our project scope also included:

- The regulation of health care professionals and staff in BC;
- Codes of ethics, practice guidelines, and other documents developed by the various regulatory bodies and practice associations in order to support best practice;
- Education and professional development of health care professionals and staff in relation to health care consent;
- Review fora available to people who wish to challenge a health care treatment decision, or a finding that they are incapable of consenting to treatment; and
- Access to legal assistance in relation to health care decision making and advance planning for health care.

## PROJECT LEADERSHIP

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This project was a collaboration of the CCEL and the Alzheimer Society of B.C. (the Society) grounded in the following four shared values, which we discuss in Chapter 1:

- Recognition of human rights and citizenship;
- Respect for the autonomy and agency of people living with dementia;
- Support for inclusion in decision making; and
- Appreciation of lived experience as a knowledge foundation.

Research focus and recommendations were developed in partnership. Although the CCEL wrote the report, the Society participated in many presentations on the work. The Society also recruited people living with dementia and family caregivers to participate in consultation, and provided photographs to illustrate people living with dementia and their family caregivers.

As with many CCEL projects, a volunteer Project Advisory Committee provided ongoing guidance regarding research and consultation methodology, key stakeholders, and recommendations to flow from research. Committee members are listed in Chapter 1 of this report. The interdisciplinary committee met eleven times over the lifetime of the project, and worked with CCEL staff outside of meetings to assist with the development of recommendations that could be supported by all the members of the committee.

## RESEARCH METHODOLOGY

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Although staff conducted legal and social science research to inform the writing of this report, consultation formed a significant part of research. Consultation included:

- 65 key informant interviews with people whose work involves consent to health care for older people living with dementia;
- 13 focus groups with people who shared their personal experiences with medication and consent. We met with 14 people living with dementia, and 44 family caregivers;
- 8 conference and community presentations where we integrated a question and answer session offering health care professionals and staff an opportunity to identify their concerns regarding the law and practice of health care consent; and
- An online survey of family caregivers, to which 28 people responded.

Many recommendations flow from our analysis of the legislation impacting health care consent in BC. However, most of the recommendations were developed in response to issues identified through consultation with people living dementia, family caregivers, health care professionals, and other people who engage with health care consent in the context of their work or personal lives. As noted in the discussion of shared values informing this project, this report is grounded in the lived experience of people who see informed health care consent occurring in community.

As a result, consultation occurred early on in the project, and helped to shape the issues we addressed. Reflecting this approach, quotations from stakeholders appear throughout this report. The quotations do not reflect the views of the CCEL and the Society: in some places they highlight challenges and concerns; in others they reflect prevalent misunderstandings of the law which must be addressed.

## REPORT STRUCTURE

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This report contains 7 chapters:

- **Chapter 1** introduces the project rationale, scope, and methodology.
- **Chapter 2** describes dementia, and medication which may prescribed for people living with dementia.
- **Chapter 3** sets out health care consent law in BC, including the different types of supportive and substitute decision makers, and their rights and duties. We also discuss avenues for challenging health care decisions, decision making authority, and incapability assessments, and identify the overlap between health care consent and mental health law for people living with dementia.
- **Chapter 4** describes the law governing use of restraints in long-term care, and the meaning of a chemical restraint.
- **Chapter 5** identifies the people and institutions who are involved in providing health care to people living with dementia. We review the regulation of health care professionals and staff, and discuss their education regarding health care consent.
- **Chapter 6** summarizes what we learned from consultation with people living with dementia, family caregivers, health care professionals, and other stakeholders who engage with health care consent issues in their work.
- **Chapter 7** brings together legal research and consultation findings for discussion of 34 recommendations aimed at enhancing compliance with, or improving, health care consent law in BC.

The remainder of this Executive Summary outlines findings and recommendations. Appendix A contains a complete list of the recommendations.

## FINDINGS AND RECOMMENDATIONS

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BC is one of the few provinces in Canada to have developed a comprehensive health care consent statute that codifies the common law doctrine of informed consent. The *Health Care (Consent) and Care Facility (Admission) Act (HCCA)* clarifies the rights and responsibilities of health care providers and temporary substitute decision makers for health care. The statute confirms the principle that decision making autonomy is paramount, and that neither a best interests approach, nor paternalist thinking, is relevant to the decision making of adults who are capable of making their own health care decisions. BC is also one of the only jurisdictions in the world to have developed a framework for supported health care decision making, through the *Representation Agreement Act (RAA)*.

The *HCCA* provides a solid foundation for health care consent law in BC. However, there are number of areas where the law and practice could be improved. This report brings together legal research and consultation to identify recommendations aimed at enhancing compliance with, or enriching, the law

regarding health care consent in BC. Chapter 7 of the report, which is divided into four parts, includes recommendations which aim to:

1. Create greater clarity and consistency in the law;
2. Support the best practice of health care providers with respect to health care consent;
3. Address systemic barriers to informed consent; and
4. Enhance access to legal information and representation regarding health care consent rights.

## **1** Law Reform Recommendations: Creating Greater Clarity and Consistency in the Health Care Consent Law

**Part 1** includes legislative amendments which aim to:

- Clarify or enhance the rights of people living with dementia and their substitute decision makers to participate in health care decision making; and
- Remedy inconsistencies between various statutory provisions which are relevant to health care decision making for people living with dementia.

Most of the recommendations in this Part 1 relate to the *HCCA*, the *Community Care and Assisted Living Act (CCAL Act)*, and one of the regulations created pursuant to the *CCAL*, namely, the *Residential Care Regulation (RC Regulation)*. However, we also make recommendations that impact the *Mental Health Act (MHA)*, *RAA*, the *Patients Property Act (PPA)*, and the *Adult Guardianship Act*.

**Part 1** is divided into two sections which address:

- Health care decision making rights and responsibilities; and
- Use of restraints in long-term care

### **Health Care Decision Making Rights and Responsibilities** (Recommendations 1-7)

*Health Care (Consent) and Care Facility (Admission) Act*

Recommendations 1-3 of this section consider reform of the *HCCA*. Currently the Act creates a framework which:

- Imposes an obligation on health care providers to obtain timely informed consent prior to treatment;
- Codifies the right to revoke consent;
- Starts from a presumption that all adults are mentally capable of making their own health care decisions;

- Includes a standard for capacity to consent to health care;
- Requires health care providers to consider if an adult has capacity as part of the consent process;
- Delineates the kinds of information a health care provider is required to provide such that consent will be informed;
- Codifies the right to ask questions, and receive answers about proposed health care;
- Sets out exceptions that permit emergency treatment and assessment without prior consent;
- Develops a scheme for substitute decision making where an adult does not have capacity to make a decision regarding proposed treatment; and
- Creates a mechanism for documenting instructions regarding possible future treatment in the form of an advance directive.

Two elements we concluded were not adequately addressed within the statute are:

- Recognition that capacity is decision-specific; and
- Incorporation of supported decision making.

Both Project Advisory Committee members and a number of key informants confirmed that good practice requires timely consideration of a person's capacity. However, many stakeholders noted that incapability assessments do not occur as often as they should, and that health care providers often presume lack of capacity for people living with dementia. Although the capacity standard for health care treatment decisions in the *HCCA* links capacity to understanding of the proposed treatment, the statute would be improved by stronger language recognizing that capacity can vary. Such language is found in other modern health care consent statutes in Canada.

Both legislation and consultation confirmed that in non-emergency situations health care decision making is a process that requires dialogue. Some people living with dementia may not be able to make their own health care decisions independently, or may have communication difficulties; however, they may still have the capacity to meaningfully participate in health care decision making—particularly if they receive support from a person they trust.

Health care professionals, people living with dementia, and family caregivers all characterized the engagement of supportive (and non-abusive) family and friends as best practice. Although BC law recognizes supported decision making for health care through the *RAA*, key informants indicate that representation agreements are not widely used in health care settings. People living with dementia expressed frustration about circumstances in which the support of the person they trust was not available because health care staff had separated them in order to provide care or assess health care needs. The *HCCA* is currently silent regarding supported decision making. It recognizes the right of people with capacity to make the health care decisions to participate in case planning and decision making; people with capacity issues have no right to participate.

We recommend that the *HCCA* be amended to include language that:

1. Recognizes that capacity can vary in the following manner:
  - A person may be incapable with respect to some decisions regarding treatment, and capable with respect to others; and
  - A person may be incapable with respect to a treatment at one time, and capable at another.
2. States that every adult, regardless of capacity, has the right to:
  - Receive support in decision making provided by a family member or friend whom they trust, if they choose to do so; and
  - Be involved to the greatest degree possible in all case planning and decision making.

Some people living with dementia are involuntarily committed under the *MHA*. Section 2 of the *HCCA* excludes people who have been involuntarily committed under the *MHA* from the benefit of any of the health care consent rights provided for in the *HCCA*, in terms of psychiatric treatment, regardless of their capacity to make health care decisions. The combined impact of section 2 and the deemed consent provisions of the *MHA* are that neither the older person, nor their substitute or supportive decision makers for health care, is entitled to participate in decision making regarding psychiatric treatment. We recommend the Government of BC consider amending the *HCCA* such that the right to support, and the right to participate in case planning and decision making, apply to all adults, including people currently excluded by the combined impact of section 2, and the deemed consent provisions of the *MHA*.

#### *Community Care and Assisted Living Act and Residential Care Regulation*

Stakeholders raised concerns regarding what health care can legitimately be consented to in advance via care plans developed for long-term care facility residents. Care plans are mandatory for people admitted for a period of longer than 30 days, and must include medication, as well as details regarding any agreement with respect to the use of restraints. The *HCCA* permits health care providers to get consent for many health care interventions in advance if they form part of a plan for minor health care for health problems that the adult is likely to have in the future, based on their current health conditions.

The *RC Regulation* states that the care plan must be developed with the participation of the resident or the substitute decision maker “to the extent reasonably practical”. This language is inconsistent with the unequivocal right to informed prior consent to treatment, and is confusing, as an exception for urgent treatment already exists. This language raises particular concern as many family caregivers with whom we consulted shared experiences involving lack of prior consent to medication administered in long-term care, and spoke about how challenging it was to get long-term care facility staff to find the time to speak with them.

To address their concerns, we recommend that the *RC Regulation* be amended to:



- Clarify that informed consent of the resident—or the substitute decision maker if the resident does not have capacity to consent—must be obtained prior to finalizing or amending any aspects of the resident’s care plan that relate to health care treatment; and
- Require that care facilities maintain detailed policies on staff and health care professional obligations with respect to health care consent and substitute decision making.

We also recommend the *Residents’ Bill of Rights* included in the *CCAL Act*—which must be displayed prominently in care facilities—be amended to include clear language informing people in reasonable detail of their health care consent rights.

#### *Adult Guardianship Act and Patient’s Property Act*

In BC there are three different kinds of substitute decision makers for health care created pursuant to different mechanisms. The obligations of representatives, temporary substitute decision makers (TSDMs) under the *HCCA*, and personal guardians, also known as committees of the person under the *PPA*, are not consistent. Particularly:

- The representative has a duty to consult with the adult, and comply with current wishes;
- The TSDM has a duty to consult; and
- The committee (guardian) has a duty to involve the adult.

This inconsistency adds uncertainty to a legal framework that health care providers, people living with dementia, and family caregivers already find confusing. Further, it is not clear that the BC approach to the duties of guardians is consistent the general principles contained in the United Nations Convention on the Rights of Persons with Disabilities, which Canada ratified in 2010. Consequently, we recommend reform of guardianship law be explored in order to bring greater consistency to the statutory duties of all substitute decision makers for health care in BC.

### **Hospital and Care Facility Use of Restraints** (Recommendations 8-12)

All licensed long-term care facilities must comply with the *RC Regulation*, which sets out rules for the use of restraints, including chemical restraints. The meaning of chemical restraint is not set out in legislation; however, the concept includes some uses of medication, and the *HCCA* applies to all medication use in long-term care. Based on research and consultation, chemical restraints are used to address dementia-related behaviour that health care providers find challenging to safely manage in long-term care, such as physically aggressive behaviour.

Our review of the restraint provisions of the *RC Regulation* identified many inconsistencies with *HCCA* and other legislation relevant to health care decision making, which creates a lack of clarity regarding who may agree to the use of a restraint. We make a number of recommendations to enhance clarity, and bring the *RC Regulation* into alignment with the robust rights set out in the *HCCA*. We recommend foremost that the *CCAL Act* and the *RC Regulation* be amended to require that in non-emergency situations, consent to the use of any form of restraint must be obtained in the same manner as consent to health care under the *HCCA*. The *RC Regulation* provisions should include:

- A presumption of capacity;
- A requirement that the consent be informed;
- A hierarchy of substitute decision makers; and
- An independent decision maker of last resort, such as the Public Guardian and Trustee (PGT).

We also recommend the *RC Regulation* should be amended to:

- Require consent of either the adult, or their substitute decision maker, when emergency use of a restraint continues for more than 24 hours;
- Recognize the right of the adult, or the substitute decision maker, to revoke their consent to the use of the restraint.
- Require that the resident's substitute decision maker, if any, be informed of any emergency use of a restraint as soon as possible after its use;
- Define chemical restraint; and
- Include a requirement that long-term care facilities have detailed policy on the use of restraints in both emergency and non-emergency situations.

## 2

### Professional Development Recommendations: Supporting Best Practice of Health Care Providers with Respect to Health Care Consent (Recommendations 13-25)

Research and consultation indicated a need for enhanced understanding of the *HCCA* and related legislation among health care professionals and long-term care facility staff, particularly with respect to the following four topics:

- When are they required to obtain informed consent?
- How and when should they obtain consent from substitute decision makers?
- When should they contact the PGT, and how can the PGT intervene?
- When (if ever) can the *MHA* be invoked to involuntarily commit a person living with dementia?

Almost every key informant expressed the view that further education on health care consent law would be helpful for their profession, or at their workplace.

The professional colleges play a key role in supporting the best practice of health care professionals. Although the newly created BC College of Nursing Professionals has published practice guidelines to support health care consent practice, the College of Physicians and Surgeons of BC has not. Instead, it adopted the Canadian Medical Association (CMA) Code of Ethics. The Code contains a principle which erroneously implies that physicians practicing in BC may make health care decisions for adults

who do not have mental capacity, so long as their decisions are grounded in respect for known wishes and best interests.

The College of Speech and Hearing Health Professionals, which did not have a practice guideline on consent until recently, remedied this gap in 2018 by adopting the BC Ministry of Health's *Health Care Providers' Guide to Consent to Health Care* as a clinical practice guideline. The guide is an excellent resource; however, given our consultation findings, it should be improved to address a number of areas of confusion amongst health care professionals.

We make the following recommendations to support health care professional understanding of health care consent law in BC:

- The College of Physicians and Surgeons of BC should disseminate to all members materials aimed at supporting physicians to understand their obligations with respect to health care consent and substitute decision making;
- The BC Ministry of Health's *Health Care Providers' Guide to Consent to Health Care* should be amended to address language interpretation, supported decision making, the requirement to obtain consent for non-psychiatric treatment where a person is involuntarily committed under the *MHA*, and the role of the PGT with respect to health care consent;
- The General Practices Services Committee Divisions of Family Practice and the UBC Faculty of Medicine Divisions of Geriatric Medicine and Geriatric Psychiatry should undertake educational work aimed at supporting physicians to better understand their obligations with respect to health care consent and substitute decision making; and
- The BC College of Nursing Professionals should publish, and widely disseminate to all registrants, material on a nurse's informed consent obligations, with a particular focus on the licensed practical nurse (LPN) and registered nurse's (RN) role with respect to consent to health care treatment prescribed by physicians in long-term care.

Although health care assistants (HCAs) are not regulated professionals responsible to obtain consent to health care treatment, in long-term care they are the staff with the most day-to-day contact with residents, providing care under the supervision of RNs and LPNs. HCAs receive their training in colleges throughout BC and abroad. The BC curriculum is the responsibility of the Government of BC. HCAs who work for publicly funded employers or facilities must be registered with the BC Care Aide and Community Health Worker Registry (the Registry). HCAs also access information on professional development through the Registry. Based on our review, it is not clear that the HCA curriculum includes health care consent and substitute decision making, and, in particular, the HCA's role in the process. We recommend that:

- The BC Ministry of Health and the Ministry of Advanced Education, Skills and Training review and amend the HCA Core Competency Profile (March 2014) and/or the HCA Provincial Curriculum (2015) to ensure that HCAs receive training on health care consent and substitute decision making; and

- The Registry develop an educational module for HCAs on health care consent and substitute decision making.

In Part 2 we also make recommendations regarding the need to:

- Develop educational modules on incapability assessment with respect to health care decision making and care facility admission;
- Amend College of Physicians and Surgeons of BC Bylaws to address documentation of health care consent;
- Deliver training on dementia to all staff providing services or care to older people;
- Develop a best practice guideline for health care providers on engaging people living with dementia in health care decision making;
- Develop a province-wide policy on whether and under what circumstances (if ever) the use of involuntary commitment under the *MHA* is appropriate for older people living with dementia;
- Track data and publish findings on involuntary commitment for older people living with dementia; and
- Increase resources available to all employees, physicians, and contractors to ensure they fully understand their obligations with respect to health care consent and substitute decision making.

### 3

### **Structural Change Recommendations: Addressing Systemic Barriers to Informed Consent** (Recommendations 26-29)

Stakeholders identified a number of systemic issues that pose barriers to informed consent for people living with dementia. Strain on time and resources were recurring themes of our discussions with key informants, particularly regarding long-term care. Many health care professionals and staff felt they were doing their best under very challenging circumstances, and that the system itself requires some change in order to allow them to have meaningful and timely conversations about health care treatment with people living with dementia, their family caregivers, and their substitute and supportive decision makers. In Part 3 we recommend that:

- The provincial health authorities explore strategies for making social work services more available in order to better support older people living with dementia, their family members, and their supportive and substitute decision makers with health care decision making;
- The Doctors of BC and the Ministry of Health collaborate to develop incentive payments to encourage and support physicians to engage in robust conversations to support informed, and undertake incapability assessments when appropriate.

- The First Nations Health Authority, Indigenous Health within the Ministry of Health, and Aboriginal Health leads within each of the other health authorities engage in discussions with Indigenous communities in order to better understand and address barriers to informed consent experienced by Indigenous people in BC; and
- The Ministry of Health develop a plan to expand access to language interpretation to people living with dementia who reside in affiliated or contracted long-term care facilities, as well as their family members and supportive and substitute decision makers, and improve awareness regarding the services.

## 4

### **Access to Justice Recommendations: Enhancing Access to Legal Information and Representation regarding Health Care Consent Rights (Recommendations 30-34)**

#### **The Right to Review Health Care Consent Decisions**

Given the importance of the rights at stake, people who face a loss of health care decision making autonomy require an accessible forum for challenging both findings of incapability, and specific health care decisions made by substitute decision makers. Both legal research and stakeholder consultation identified a lack of procedural fairness rights and access to justice for people with capacity issues, and people perceived as having reduced capacity, as a key problem facing people living with dementia.

In recognition of these barriers, BC previously had in place a Health Care and Care Facility Review Board, which was dissolved in 2004. Research and stakeholder consultation suggests it is worthwhile to consider bringing back a capacity and consent review tribunal for BC. Many of the details regarding the appropriate system for BC are beyond the scope of this project focused on health care consent. We recommend the Government of BC implement an independent non-court review mechanism to enable people to challenge:

- Findings of incapability to consent to health care treatment;
- Choice of temporary substitute decision makers;
- Care facility admission decisions; and
- Decisions made by substitute decision makers with respect to the person's health care, including the use of restraints.

#### **Legal Representation**

In this report we discuss a range of legal avenues for challenging health care decisions and decision making authority for people living with dementia who may have capacity issues. Most options require an application to court. Legal aid is not generally available for advice or representation in relation to such matters, other than a review panel constituted by the Mental Health Review Board; however, the Legal Services Society does have some discretion to award funding in unique situations. We recommend the structure of legal aid be amended to include funding for prompt legal advice and

representation regarding any legal action or proceeding that could remove or restore health care decision making autonomy, including:

- Applications pursuant to s. 33.4 of the *HCCA*, including capacity to consent to admission to a care facility;
- Challenges to applications for a committee of the person pursuant to the *Patients Property Act*; and
- Involuntary committals, and reviews of involuntary committals, under the *Mental Health Act*.

The need for greater uptake for representation agreements for health care came up frequently in consultation. A person wishing to make a representation agreement under section 7 of the *RAA* may be unable to hire a lawyer because they lack capacity to retain and instruct counsel. In *Conversations about Care* we reiterate a recommendation from the BCLI *Report on Common-Law Tests of Capacity* that the *RAA* should be amended to provide that a person with capacity to make a representation agreement with standard provisions under section 7 also has the capacity to retain and instruct counsel for the purpose of advising on the agreement.

### **Knowledge of Health Care Decision Making Rights and Responsibilities**

Some people living with dementia and their family members require a better understanding of their rights and responsibilities as part of the health care consent process. Many health care professionals and social workers expressed concern that substitute decision makers do not understand their role. Although various agencies in BC are engaged in providing public legal education about health care consent, and substitute and supportive decision making, the need for information is not currently being met in BC. We identify the time of admission to long-term care as a useful moment to increase awareness, and recommend that long-term care facilities be required to provide written educational information on health care consent rights and substitute and supportive decision making rights and responsibilities to both residents and their substitute or supportive decision makers.

Bearing in mind the low uptake of representation agreements for health care decision making in BC, we also recommend that the Government of BC develop a comprehensive public education plan regarding supported and substitute decision making for health care, including representation agreements, and also including providing additional funding to support non-profit agencies to further engage in this work. The development of the regime for representation agreements in BC was a significant achievement for BC. The gains are limited by the absence of comprehensive public education in this area.

## IMPORTANT TOPICS OUTSIDE OF PROJECT SCOPE

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Project staff and Advisory Committee members discussed the appropriate scope of research and recommendations. In two areas we struggled to agree on appropriate scope. They were:

- Mental health law; and
- Care facility admission legislation.

A number of family caregivers shared experiences involving people living with dementia being involuntarily committed under the *MHA*. Comments by key informants regarding rationale for committal indicate that the act is sometimes being used in manner that is not consistent with the law. The impact of use of the *MHA* is significant: it results in a loss of the right to participate in decisions regarding psychiatric treatment, regardless of capacity to make these decisions. In this report we include two recommendations aimed at supporting practice under the *MHA*. We do not, however, make any in-depth recommendations regarding reform of the *MHA*. This decision was made largely due to the breadth of our consultation work, which addressed the use of the *MHA* for people living with dementia only, but also because our Project Advisory Committee was divided on this issue. A number of committee members felt very strongly that it was important for this report to include a call to repeal legislative overrides on health care consent rights contained in the *MHA*; an equal number felt that recommendations for mental health law reform were beyond project scope.

During the course of this project the Government of BC announced that it will be implementing the long awaited care facility admission provisions of the *HCCA*. At the time of writing, implementation has been further delayed to 2019, and regulations have not yet been published. Although care facility admission is intimately tied to health care consent—particularly for older people—we have not reviewed the provisions in this study, largely because it is not possible to get an accurate picture of the law in the absence of an opportunity to review the regulations.

Although the absence of legislation for substitute decision making for care facility admission in BC is problematic—and indeed appears connected to why the *MHA* is sometimes being invoked for people living with dementia—Project Advisory Committee members expressed a variety of perspectives on the legislation as it is currently written. Some members were greatly concerned that the care facility admission provisions do not adequately respect either the wishes or the liberties of vulnerable adults.

Care facility admission legislation may have a significant impact on the lives of older people in BC. The CCEL and the Society welcome the opportunity to comment on the legal framework for care facility admission when the regulations are available for review.

# List of Abbreviations

<b>AGA</b>	<i>Adult Guardianship Act</i>
<b>APP</b>	Alternative Payment Programs (physician remuneration funding model)
<b>BCLI</b>	British Columbia Law Institute
<b>BPSD</b>	Behavioural and Psychological Symptoms of Dementia
<b>CCAL Act</b>	<i>Community Care and Assisted Living Act</i>
<b>CCAL Reg</b>	<i>Community Care and Assisted Living Regulation</i>
<b>CCEL</b>	Canadian Centre for Elder Law
<b>CIHI</b>	Canadian Institute for Health Information
<b>CLeAR</b>	The BC Patient Safety and Quality Council Call for Less Antipsychotics in Residential Care Initiative
<b>CMA</b>	Canadian Medical Association
<b>CMPPA</b>	Canadian Medical Protective Association
<b>CPSBC</b>	College of Physicians and Surgeons of British Columbia
<b>CRPD</b>	United Nations <i>Convention on the Rights of Persons with Disabilities</i>
<b>DSM-5</b>	The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 5th edition, a handbook used internationally to guide the diagnosis of mental disorders.
<b>FFS</b>	Fee-for-service (physician remuneration funding model)
<b>GPSC</b>	General Practice Services Committee
<b>HCCA</b>	<i>Health Care (Consent) and Care Facility (Admission) Act</i>
<b>HCA</b>	Health Care Assistant
<b>HPA</b>	<i>Health Professions Act</i>
<b>HPRB</b>	Health Professions Review Board
<b>LCO</b>	Law Commission of Ontario
<b>LPN</b>	Licensed practical nurse
<b>MAR</b>	Medication Administration Record
<b>MSP</b>	Medical Services Plan
<b>MHA</b>	<i>BC Mental Health Act</i>
<b>MOST</b>	Medical Order for Scope of Treatment
<b>NCAS</b>	Nursing Community Assessment Service
<b>NP</b>	Nurse practitioner
<b>PCQO</b>	Patient Care Quality Office
<b>PGT</b>	Public Guardian and Trustee of British Columbia
<b>PIECES</b>	Physical, Intellectual, Emotional, Capabilities, Environment and Social assessment framework
<b>PPA</b>	<i>Patients Property Act</i>
<b>PRN</b>	The term commonly used in medical practice to describe a physician order to administer medication as needed, or as circumstances require, as opposed to on an ongoing regular basis. The abbreviation comes from the Latin phrase, <i>pro re nata</i> .
<b>RAA</b>	<i>Representation Agreement Act</i>
<b>RN</b>	Registered nurse
<b>SDM</b>	Substitute decision maker
<b>TSDM</b>	Temporary Substitute Decision Maker (under section 16 of the <i>Health Care (Consent) and Care Facility (Admission) Act</i> )



# Glossary of Terms

**Advance Directive** A written and formally executed instruction to accept or refuse specific future health care treatment if the author becomes incapable in the future of making such decisions. Advance directives must meet the requirements set out in the *Health Care (Consent) and Care Facility (Admission) Act* to be valid.

**Anti-psychotic Medications** Drugs for treatment of psychotic disorders such as schizophrenia and bipolar disorder. In geriatric psychiatry these drugs may be helpful in the management of psychotic disorders, mood disorders, delirium, psychosis and aggression.<sup>1</sup>

**Behavioural & Psychological Symptoms of Dementia (BPSD)** A term used to describe symptoms of disturbed perception, thought content, mood or behaviour that often occur in people living with dementia.<sup>2</sup> These may include delusions, hallucinations, depressive symptoms, agitation and hostility.<sup>3</sup> In this report we prefer the term dementia-related behaviour.

**Best Practice** “A Best Practice is an intervention, method or technique that has consistently been proven effective through the most rigorous scientific research (especially conducted by independent researchers) and which has been replicated across several cases or examples.”<sup>4</sup> In comparison, “Promising Practices demonstrate their effectiveness through the most rigorous scientific research, however there is not enough generalizable evidence to label them ‘best practices’.”<sup>5</sup>

**Chemical Restraint** The administration of psychotropic medication to prevent harm to a resident or others in situations where a resident has lost behavioural control, or where there is imminent risk of loss of control in behaviour. There is significant variation in understanding amongst health care professionals, staff, and regulators as

to what is considered a chemical restraint versus health care treatment.

**Committee of the Person** A person appointed by the court under the *Patients Property Act* to make personal decisions (as opposed to financial and property decisions) on behalf of a person whom the Court has declared incapable of making such decisions for themselves. Types of decisions that can be made by a committee of the person may include health care decisions and where the person should live. The *Health Care (Consent) and Care Facility (Admission) Act* uses the term “personal guardian” instead of “committee of the person”.

**Consent to Health Care** An informed, voluntary decision made by a capable adult aged 19 or over, or their authorized substitute decision maker, to accept or refuse health care treatment offered by a health care provider. The requirements for a valid, informed consent to health care are set out in the *Health Care (Consent) and Care Facility (Admission) Act*.<sup>6</sup>

**Dementia** An overarching term for a set of symptoms caused by disorders affecting the brain, that may affect memory, thinking, problem-solving, language, and executive function. These symptoms can impact a person’s ability to perform everyday activities, as well as mood and behaviours.<sup>7</sup> Alzheimer’s disease is a specific form of dementia.

**Extended leave under the Mental Health Act** A decision made by a designated facility pursuant to ss. 37 or 38 of the *Mental Health Act* to place an involuntary patient on leave in the community or in a facility. Leave terms will include conditions with which the involuntary patient must comply.

**Geriatrician** A physician with specialization in the prevention, diagnosis, and treatment of older people, particularly those with chronic, complex medical conditions.<sup>8</sup>

**Geriatric psychiatrist** A psychiatrist with subspecialty training who focuses on the assessment, diagnosis, and treatment of complex mental disorders which usually occur in older people.<sup>9</sup>

**Health Care** Defined in the *Health Care (Consent) and Care Facility (Admission) Act* as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health.” In BC “health care” does not include personal care or admission to a care facility.

**Health Care Assistant** Front line care providers, commonly known as care aides in BC, who provide care in a variety of institutional and community settings, including home support agencies and long-term care.<sup>10</sup>

**Health Care Provider** For the purposes of consent law, a health care provider is someone who is licensed, certified, or registered to provide health care under the *Health Professions Act* or the *Social Workers Act*.<sup>11</sup> There are currently 25 self-regulated professions under the *Health Professions Act*.

**Long-Term Care** Commonly referred to as seniors’ homes, nursing homes or residential care, long-term care facilities provide 24-hour professional care to people with complex health care needs who can no longer be cared for in their own homes or an assisted living residence.

**Major Neurocognitive Disorder** The equivalent term for dementia used in the most recent edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (the DSM-5), which is used internationally for diagnosing mental disorders.

**Medical Order for Scope of Treatment** A physician order reflecting resident and substitute decision maker wishes which document the level or degree of medical intervention that should be provided to a person if they do not have decision making capacity at the requisite time. The medical order is not a legal planning document like a representation agreement or an advance directive.

**Neurodegeneration** Progressive damage to the brain caused by the loss of cells and breakdown of connections within the brain over time. Diseases which cause dementia are forms of neurodegenerative conditions.

**Person-Centered Care** Person-centred care is a holistic philosophy and an interactive process that recognizes every person is a unique individual with their own values, history and personality, and equally deserving of recognition of dignity, autonomy, and the right to participation in society. Person-centred care starts with attentiveness to the unique person’s strengths and abilities, and needs and desires regarding care, and emphasizes active engagement of the person in the caregiving relationship.<sup>12</sup>

**Personal Care** Care usually provided by health care workers to residents of care facilities that falls outside the scope of health care, and include tasks such as feeding, dressing and personal hygiene.

**Psychotropic** “A drug that affects brain activities associated with mental processes and behavior,” such as anti-psychotics, anti-depressants, and anti-anxiety drugs.<sup>13</sup>

**Representative** A person authorized by a representation agreement to make or help make certain decisions on behalf of the adult who made the representation agreement. The type of decisions a representative can make will depend on the authority given to them in the representation agreement.

**Representation Agreement** An agreement made by a person under the *Representation Agreement Act* to provide another person (the representative) with authority to make certain decisions on their behalf, or to help them make certain decisions. The agreement will specify the types of decisions the representative may make, and could include decisions about personal care, health care, or the routine management of financial affairs. A more comprehensive agreement may include decisions about where the person should live, their involvement in educational and recreational activities, where they should work, and whether they should be restrained to provide health or personal care.

**Restraint** In the long-term care facility context, restraint means “any chemical, electronic, mechanical, physical or other means of controlling or restricting a person in care’s freedom of movement in a community care facility, including accommodating the person in care in a secure unit.”<sup>14</sup>

**Special Care Unit** A separate unit found in some long-term care facilities which is specifically tailored to care for adults with advanced dementia, and which is typically secured to prevent residents from leaving.

**Substitute Decision Maker** A capable adult who is authorized to make health care decisions on behalf of an incapable adult as either their court ordered guardian (committee of person), representative appointed by a representation agreement, or a temporary substitute decision maker under the *Health Care (Consent) and Care Facility (Admission) Act*.

**Supported Decision Making** Supported decision making is an alternative to substitute decision making. Supportive decision makers “support” people to:

- Understand the issues involved in a decision;
- Understand the consequences of a decision;
- Access appropriate assistance or information to them make a decision;
- Express their views, and act as interpreter where needed;
- Help others to truly hear or understand them; and
- Help people and institutions appreciate that they have needs, rights, values, preferences and goals, and to appreciate the autonomy, dignity and wisdom of people with disabilities—in other words, help prevent discrimination and bias.

BC law recognizes supported decision making using representation agreements.<sup>15</sup> However, supported decision making also occurs without a formal agreement.

**Supportive Decision Maker** A person who supports another with decision making (described above).

**Temporary Substitute Decision Maker (TSDM)** An adult chosen by a health care provider from a hierarchical list of individuals (usually the spouse, adult child, other relative or close friend) to make a health care decision on behalf of an adult who does not have capacity to make the decision. TSDMs must make decisions in accordance with the requirements set out in the *Health Care (Consent) and Care Facility (Admission) Act*.



## CHAPTER 1

# Introduction

*Medications and poly-pharmacy, anti-psychotics is a huge topic so that some people are aware of that. But not through the consent lens.*

– Physician

This chapter outlines:

- Why we undertook this project focused on health care consent for people living with dementia;
- What subjects were included in research, consultation, and project recommendations;
- How we completed this work, particularly, the different ways we engaged community, health care practitioners, and other stakeholders with relevant expertise or experience; and
- What values informed project design, focus, and findings.

### 1.1 RATIONALE FOR THIS PROJECT

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In recent years, there has been increasing interest in medication practices involving older people, including polypharmacy, off-label use, over-medication, and excessive prescription of psychotropic medications,<sup>16</sup> particularly anti-psychotics. However, while informed consent is a key aspect of appropriate prescribing, there remains very little attention to consent in the context of law, policy and practice discussions of health care for older people living with dementia. Debate and dialogue regarding health care for older people often belie a well-meaning view of seniors as passive recipients of care



at the expense of consideration of their right to make their own decisions. This project on health care consent was developed to address our collective cultural blind spot when it comes to aging with dementia, and informed consent to health care.

Recent data confirms that health care decision making for older people often occurs without proper consent: in a recent survey of long-term care conducted by the BC Seniors Advocate, 38% of residents reported they had not been consulted about their medications, and only 65% of family members said that they had been consulted about medication changes.<sup>17</sup> Decisions regarding medication have a significant impact on quality of life and life expectancy, and older people and substitute decision makers often do not appreciate the right to ask questions, explore alternatives, and provide, refuse or revoke informed consent.

The 2018 National Dementia Conference Report noted that participants emphasized the importance of building capacity to fully involve people living with dementia and their family caregivers in health care decision making.<sup>18</sup> Inadequate practice with respect to health care consent is contrary to the law, and respect for the right to consent to health care matters to us all. In this project we focus on people living with dementia because:

- Dementia impacts many British Columbians;
- Medication prescribing for older people living with dementia raises particular challenges;
- People living with dementia confront stigma about their decision making abilities; and
- Health care consent rights are fundamental to the liberty and self-determination of people with disabilities.

In this section we explore how these four areas render health care consent is a particularly urgent topic people living with dementia.

### 1.1.1 Dementia Impacts Many British Columbians

Based on sheer numbers alone, health care consent for people living with dementia is becoming a significant practice issue. Data compiled by the World Health Organization indicates that the prevalence of dementia within the population doubles for each five-year increase after age 65.<sup>19</sup> As such, British Columbia has recognized that while “dementia is not a normal part of aging, the risk of developing dementia does increase with age.”<sup>20</sup> Dementia is particularly prevalent among our oldest seniors: research from the Alzheimer’s Society of Canada projects an increase in prevalence among adults over age 85 over the period 2008–2038 from 33% to 43% (men) and 46% to 52% (women).<sup>21</sup> Estimates of prevalence amongst seniors generally in Canada vary from 6 to 15%.<sup>22</sup>

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*[Family physicians] don't have time to phone every family every time they add a medication, because—and it's very true—that you could phone someone, they could phone you back, you could phone them back. It's not easy to get this to happen.*

– Geriatric psychiatrist

The recent 2016 Statistics Canada census confirmed Canada’s rapidly aging population. In 2016, seniors, who outnumbered children for the first time in Canadian census records, accounted for almost 17% of the overall population.<sup>23</sup> BC, and particularly Vancouver Island, has one of the fastest growing populations of seniors in Canada.<sup>24</sup> We also have a record high number of seniors age 85 and older in Canada: in 2016, 2.2% of the population fell into that age group, and the number of people age 85 and older rose by 19.4%—almost 4 times the rate of the growth of the overall population, which grew by only 5%.<sup>25</sup> In BC, we thus have an increasing number of seniors, and an older senior population than in previous years.

As our population continues to age, many of us will be impacted by dementia—we may be living with dementia ourselves, caring for someone living with dementia, helping someone living with dementia with decision making, or making health care or other decisions for someone living with dementia. The impact of dementia on our families and communities will continue to grow as the proportion of seniors in BC’s population continues to increase over the next few decades.<sup>26</sup> Although prevalence can be difficult to estimate, due to the challenges of getting a diagnosis, research suggests that currently between 60,000 and 70,000 British Columbians have been diagnosed with some form of dementia.<sup>27</sup> That number is expected to rise to 87,000 by 2024.<sup>28</sup>

### 1.1.2 Medication Prescribing Raises Challenging Practice Questions

Medication prescribing for older people living with dementia raises challenging ethical, medical, and practical issues. Over-medication and inappropriate medication are of particular concern with respect to older people because they may be at an increased

risk of adverse effects, due to the way that older bodies process medication.<sup>29</sup> Almost any form of medication can have side effects, which can range from unpleasant to debilitating or life-threatening. The greater the number of medications, the greater the risk of drug interactions and potential side effects.

Best practices developed with respect to use of anti-psychotics—and medication generally—thus require prescribing health professionals to:

- Explore non-pharmacological management first (where safe to do so);
- Consider less toxic medications whenever possible;<sup>30</sup>
- Start dosage at low levels (start low and go slow);<sup>31</sup> and
- Monitor ongoing well-being for adverse events to ensure that the medication use reflects the best balance between symptom improvement and negative side effects.<sup>32</sup>

Recent studies have focused on practice in long-term care due to the dependency and frailty of the adults living in these environments, and the lack of ongoing presence of family to provide input and oversight. Particularly, a large percentage of long-term care residents are living with some form of dementia.<sup>33</sup> In 2017 the BC Seniors Advocate reported the prevalence of dementia in long-term care at approximately 66%.<sup>34</sup>

In recent years, a number of studies have expressed concern regarding potential over-medication and inappropriate medication prescribing for older people in long-term care. Although poor medication practices with respect to almost any form of medication can cause problems, use of anti-psychotics has been a focus.

In *Placement, Drugs and Therapy*, the office of the Seniors Advocate reported, based on data gathered through the Canadian Institute for Health Information (CIHI),<sup>35</sup> that up to 51% of residents in BC care facilities were taking nine or more different drugs.<sup>36</sup> The report examined use of psychotropic medications in long-term care, as data on use of such medication is tracked through the InterRAI Resident Assessment Instrument.<sup>37</sup> The Seniors Advocate identified extensive use of two kinds of psychotropic medications in long-term care— anti-psychotics and anti-depressants—as an area of particular concern, reporting that 34% of seniors in long-term care are prescribed anti-psychotic medications.<sup>38</sup> Similarly, a 2011 Ministry of Health report revealed both significant use of anti-psychotics, and concerns regarding lack of appropriate consent to treatment, and engagement of family, in developing care plans.<sup>39</sup> A 2018 report by CIHI indicated that while educational supports have helped to reduce anti-psychotic drug use among seniors with dementia in BC between 2011–2012 and 2015–2016 from 40% to 31%, inappropriate anti-psychotic use remains a concern.<sup>40</sup>

The Ministry of Health has stated that use of anti-psychotics in long-term care is primarily in response to the increasing number of residents living with dementia.<sup>41</sup> As one researcher has explained:

[M]edication use in nursing homes (NH) occurs under some of the most complex circumstances in all of medicine. Most NH residents are frail, with multiple medical conditions typically related to cardiovascular disease, arthritis, stroke and diabetes. Nearly half are over age 85 and have disabling dementia that impairs their ability to communicate or

perform daily activities. NH residents also receive, on average, seven to eight medications each month, putting them at high risk of medication-related problems including use of inappropriate antipsychotics.<sup>42</sup>

In response to the above identified issues with respect to anti-psychotic medication, various resources have been developed in BC to support enhanced practice with respect to medication:

- The BC Ministry of Health published a *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care* in 2012.<sup>43</sup>
- The BC Care Providers Association published a *Best Practices Guide for Reducing Anti-Psychotic Drug Use in Residential Care* in 2013,<sup>44</sup> which was updated in 2018.<sup>45</sup>
- The BC Patient Safety and Quality Council developed the CLeAR (Call for Less Antipsychotics in Residential Care) Initiative, which has focused on both improving non-pharmacological approaches to dementia-related behaviours, and thoughtful prescribing of medications for medication-responsive symptoms. For those facilities who have participated in this voluntary initiative, significant reductions in prescribing of antipsychotics has occurred.<sup>46</sup>

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*He said to me, 'I'm not telling them I have Alzheimer's'. . . You know, there's a lot of people who are not saying anything because they don't want to be discriminated against.*

**– Person living with dementia**

Ultimately, however, issues in relation to medication prescribing are not limited to the long-term care environment: approximately 40-60% of people living with dementia in BC are living in community, and research suggests problematic prescribing practices in community settings as well. A recent report by AARP, formerly the American Association of Retired Persons, indicates that while anti-psychotic use has declined in long-term care settings, there is much to be done to improve practice, and reduce use, in community care.<sup>47</sup>

Further, although there has been much focus on the use of anti-psychotic medications for people living with dementia, the right to informed consent applies to all medication and treatment.

In 2012, the Shared Care Committee, one of the four Joint Collaborative Committees of the Government of BC and Doctors of BC, developed a Polypharmacy Risk Reduction Initiative. The initiative aims to raise physician awareness of polypharmacy and support physicians and facilities to implement strategies that will reduce risks for patients and residents who are taking multiple medications.<sup>48</sup> Unlike initiatives aimed at addressing anti-psychotic use, the first phase of this initiative recognized that informed consent is critical, identifying “[p]roviding education and support for residents and family members to inform medication-related decisions” as an ongoing supportive strategy.<sup>49</sup>



### 1.1.3 People Living with Dementia Confront Particular Stigma

The experiences of people living with dementia are shaped not only by neurodegeneration, and the availability of medication and treatment to slow the progression of disease, but also by social attitudes towards them. People living with dementia confront both a general lack of understanding of the condition, and prejudicial assumptions regarding their awareness and intelligence. Just as importantly, people living dementia can internalize these assumptions regarding their mental abilities, resulting in a dynamic “wherein people with dementia may voluntarily begin to limit themselves as they respond to being treated with less respect and as if they were less competent.”<sup>50</sup>

Health care decision making for people living with dementia is deeply impacted by prevailing attitudes regarding dementia. Health care and caregiving relationships are relationships of power, and respect for the decision making rights of people living with dementia requires recognition of their capacity to participate in the decision making process. When people living with dementia are presumed incapable, they become excluded from intimate decisions about health care, and robbed of essential aspects of their autonomy.

Although ageism is common,<sup>51</sup> arguably people living with dementia are particularly at risk of exclusion from decision making, as compared with other older people, because myths and assumptions about dementia are linked to abilities presumed integral to decision making, such as recall and judgement. As we discuss further in this report, people living with dementia are sometimes presumed to be incapable of all decision making, even when no assessment of their cognitive abilities has occurred. However, many people living with dementia are capable of participating in health care decision making for themselves, either independently, or with the support of friends, family, and others.

### 1.1.4 Health Care Consent Rights are Fundamental to Liberty and Self-determination

The right to give or refuse consent is a fundamental right grounded in the common law, protected under the *Canadian Charter of Rights and Freedoms*,<sup>52</sup> and recognized in BC’s *Health Care (Consent) and Care Facility (Admission) Act (HCCA)*.<sup>53</sup> The centrality of this right to liberty was summarized by Robins JA in the seminal Ontario Court of Appeal decision of *Fleming v. Reid*:

The right to determine what shall, or shall not, be done with one’s own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent. With very limited exceptions, every person’s body is considered inviolate, and, accordingly, every competent adult has the

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*My daughter, my husband and I went and sat with the doctor. He looked at my daughter and husband and asked should we do this, and when is a good time to do this? I was appalled. My daughter left the room and was mortified that I was invisible. I know I ended up doing the surgery. I took the power back.*

– Person living with dementia

right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals to make choices about their medical care. It is the patient, not the doctor, who ultimately must decide if treatment -- any treatment -- is to be administered.<sup>54</sup>

For people living with complex health issues, and particularly adults living in long-term care, autonomy and self-determination are limited by the amount of choice they have over medication and treatment issues. For some people, health care is provided on a daily basis; for people who are frail, or who have with higher needs, health interventions occur more frequently, and can be very invasive. Medication may be administered multiple times a day. In some instances, medication can be sedating, or otherwise further undermine independence or awareness. Even in community care situations, decisions regarding treatment need to be made regularly, and can have a significant impact on quality of life.

Older people living with dementia are a vulnerable, growing subset of BC's population. However, ultimately the issue of informed consent to health care treatment matters to everyone. This project's research will hopefully support a more robust understanding of the right to informed consent in BC that will benefit anyone receiving treatment, or consenting to treatment on behalf of another person. Project findings will be of benefit to people living with disabilities other than dementia who can also experience exclusion from health care decision making due to stereotypical assumptions about mental capacity, lack of respect for the right to informed consent, and sometimes even an absence of respect for the value of their lives.

Caring for people living with dementia is challenging and important work. Excellent resources exist to support policy and practice. However, there remains a need to develop a rights-based understanding of health care consent to complement the dominant health care orientation. This project was developed to further that goal.

## 1.2 PROJECT SCOPE

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*Conversations about Care* examines the law, policy, and practice of consent to health care for people living with dementia in BC. Health care consent is a topic that is not easily contained. Proper study requires a review of legislation developed by government, and legal principles which have emerged from court decisions. In this report we review legislation governing:

- Informed consent to health care;
- Substitute and supported decision making for health care;
- Medication use in long-term care; and
- Involuntary committal for psychiatric treatment.

The goal of the project was to consider the law in practice, both to ensure legislation reflects the realities of practice, and to consider whether the barriers to good practice in BC are related to the substance of legislation, its implementation, or a combination of both. Therefore we also study the broader

framework that impacts the relationships between people living with dementia and their health care providers, and the right and ability to request a review of decisions related to health care treatment. Our project scope thus also included:

- The regulation of health care professionals and staff in BC;
- Codes of ethics, practice guidelines, and other documents developed by the various regulatory bodies and practice associations in order to support best practice;
- Education and professional development of health care professionals and staff in relation to health care consent;
- Review fora available to people who wish to challenge a health care treatment decision, or a finding that they are incapable of consenting to a treatment; and
- Access to legal assistance in relation to health care decision making and advance planning for health care.

As a result of this attention to the realities of practice, consultation (discussed in greater detail below) represented a large part of project research.

This project aims to clarify and enhance the law. We offer recommendations for reform where the legal framework has shown itself to be inadequate in terms of respecting rights, or reveals inconsistencies that form barriers to best practice. Significant comparative legal research is included to help identify alternative approaches.

In this report we explore the legislation governing the practice of the diverse health care professions who provide care to people along their journey with dementia. While recent research and media have shined a spotlight on the use of anti-psychotics in long-term care, the right to consent, refuse, and revoke consent to medication applies to all non-emergency medication and treatment, including those decisions made in community, hospital, and long-term care settings. In some instances, different laws and regulations apply depending on the site of care.

Although access to medically assisted death is an area of concern to some people living with dementia, we have not conducted any research and consultation specifically in relation to this topic. We view end of life and palliative care decision making, including access to medically assisted death, as complex topics deserving of separate focused attention. However, we hope that any discussion of these topics will reflect some of the unique barriers to decision making facing people living with dementia and their families, as well as the importance of supporting robust conversations about care to facilitate informed consent.

Project staff and Advisory Committee members had many discussions about the appropriate scope for our research and recommendations. In two particular areas we struggled to agree on appropriate scope. They were:

- Mental health law; and
- Care facility admission legislation.

In the end, we did not include in-depth reform of either of these areas of law in our recommendations. However, both topics have significant impact on the experiences of people living with dementia. We include discussion of these areas of law in this summary of scope to outline concerns raised throughout our project, and explain why these areas of law are not addressed in Chapter 7 of this report.

### 1.2.1 Mental Health Law

As we explain in greater detail in Chapters 3 and 7, the *HCCA* applies to all health care treatment—excluding psychiatric treatment under the involuntary committal provisions of BC’s *Mental Health Act (MHA)*.<sup>55</sup> In this report we summarize BC’s mental health law as it applies to people living with dementia. We identify concerns regarding practice, and we make recommendations for enhancing practice in this area. However, we do not make recommendations for in-depth reform of mental health law in BC. A number of committee members felt very strongly that it was important for this report to include a call to repeal legislative overrides on health care consent rights contained in the *MHA*; an equal number felt that recommendations for mental health law reform were beyond project scope.

The use of the *MHA* to involuntarily commit people living with dementia results in a loss of health care decision making rights, regardless of mental capacity to make these decisions. This is a practice which appears discriminatory, unconstitutional, and unfair to both people living with dementia, and their friends and family. Law reform work, academic literature, and jurisprudence have questioned the appropriateness of the deemed consent provisions of BC’s *MHA*. The Supreme Court of Canada, in reviewing a decision of the Consent and Capacity Review Board of Ontario, has applied the doctrine of informed consent to the mental health context. The Court stated, quoting the 1990 *Enquiry on Mental Competency: Final Report*, that it is problematic “to conflate mental illness with lack of capacity,”<sup>56</sup> noting that “[t]he right to refuse unwanted medical treatment is fundamental to a person’s dignity and autonomy. This right is equally important in the context of treatment for mental illness.”<sup>57</sup>

A recent report by the Community Legal Assistance Society on BC’s mental health system concluded that the deemed consent model is not compliant with the *Canadian Charter of Rights and Freedoms* or the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>58</sup> and recommended that the Government of BC “[r]eview and amend the deemed consent model to establish equal health care consent rights for physical and mental health care decisions.”<sup>59</sup> At the time of writing, the Council of Canadians with Disabilities has commenced a *Charter* challenge to the deemed consent provisions of the *MHA* and related provisions of the *Representation Agreement Act* and the *HCCA*.<sup>60</sup>

We have not included recommendations regarding in-depth reform of the *MHA*, largely due to the breadth of our consultation work. Our consultation addressed the use of the *MHA* for people living with dementia only. We did not consult more broadly with people living with mental illness, or with lawyers, advocates, psychiatrists, nurses, social workers, and others who see the *MHA* applied in their work with younger people. Our consultation was not sufficiently broad and comprehensive to support recommendations for reform of the *MHA*, which would apply beyond the experiences of people living with dementia. However, it is not possible to make law reform recommendations with respect to the *MHA* that would impact only to people living with dementia.

That said, our research and consultation suggests that it would be worthwhile to consider reform of mental health law in BC. We encourage the appropriate agency to conduct robust consultation to explore this issue, and point out that thorough consultation on this subject must include people living with dementia, and their families, friends, and advocates.

### 1.2.2 Care Facility Admission Law

In BC we do not yet have a legal framework for substitute decision making for care facility admission for adults who are incapable of making the decision themselves. During the course of this project the Government of BC announced that it will be implementing the long awaited care facility admission provisions contained in Bill 26.<sup>61</sup> At the time of writing, implementation has been further delayed to 2019, and regulations have not yet been published. This legislation was originally passed in 1993, but did not become law at that time.<sup>62</sup> After re-enactment in 2006<sup>63</sup> the provisions were further amended in 2007.<sup>64</sup> There has been limited consultation on the legislation since the early 1990s before the original 1993 bill was passed.

Although care facility admission is intimately tied to health care consent—particularly for older people—we have not reviewed the provisions in this study, largely because it is not possible to get an accurate picture of the law in the absence of an opportunity to review the regulations. However, we note that Project Advisory Committee members expressed a variety of perspectives on the legislation as it is currently written. Some expressed concern that the legislation prioritizes a best interests standard over the wishes, values, and beliefs of the adults potentially being admitted to a care facility, and authorizes potential deprivations of liberty through involuntary admission to a facility without the existence of adequate review mechanisms. These members questioned whether the legislation complies with *Charter of Rights and Freedoms* and the United Nations CRPD,<sup>65</sup> and encouraged the government to engage in further public consultation before finalizing the care facility admission legislation.

Some members of the Committee maintained that the current state of affairs is problematic because there is no legal process in place whatsoever governing consent to care facility admission, and therefore no legal protections in place for having the right to consent to admission, or a specific admission itself, reviewed.

Further, many Project Advisory Committee members emphasized that health care consent and care facility consent are not equivalent concepts, and do not lend themselves to equivalent treatment at law. A number of committee members noted that while an assessment of incapability to consent to health care treatment must be specific to the treatment issue at hand, incapability to consent to care facility admission is a more complex question generally requiring a more comprehensive assessment of incapability.

Care facility admission legislation may have a significant impact on the lives of older people in BC. The CCEL and the Society welcome the opportunity to comment on the legal framework for care facility admission when the regulations are available for review.

## 1.3 PROJECT METHODOLOGY

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### 1.3.1 Project Leadership

This project was a collaboration of the CCEL and the Alzheimer Society of B.C. (the Society). Project work was shared and the themes of this report were developed in collaboration. The CCEL staff undertook legal and related social science research, wrote this report, and conducted key informant interviews. CCEL staff also developed research memoranda and agendas to support each Project Advisory Committee meeting. The Society recruited consultation participants from supporters in the community, and organized and attended almost all the consultation focus groups, which were facilitated by CCEL staff. The Society worked with a professional photographer to develop images illustrating people living with dementia and their family caregivers for this report.

Throughout the lifetime of the project, the partners undertook many community presentations to health care professionals and long-term care facility staff to help raise awareness of the project, the urgent health care consent issues engaged, and the legal rights and responsibilities involved. We anticipate dissemination of findings will continue between the partners in a collaborative manner.

#### Project Advisory Committee

As with many CCEL projects, a Project Advisory Committee provided ongoing guidance regarding research and consultation methodology, key stakeholders, and recommendations to flow from research. The committee was formed by bringing together a diverse range of people from various stakeholder bodies, as well as people with particular subject matter expertise relevant to the project. Consistent with the slogan “nothing about us without us”, the committee included a person living with dementia.

Committee members served as volunteers, and contributed a significant amount of their time to this project. This project would not have been possible without their extensive subject matter expertise. A number of committee members brought both professional experience and personal experience as a family caregiver to their understanding of the issues.

The Project Advisory Committee members were:

- **Dr. Heather D’Oyley**, Geriatric Psychiatrist, Vancouver Coastal Health
- **Dr. Elisabeth Drance**, Family member (caregiver) and Geriatric Psychiatrist, Vancouver Coastal Health and Providence Health Care
- **Tara Fitzgerald**, Quality Leader, Seniors Care, BC Patient Safety & Quality Council. Following her resignation from the Council, Tara was replaced by Colleen Kennedy, Executive Director, Health System Improvement and Engagement, and Geoff Schierback, Leader, Health System Improvement
- **Isabel Grant**, Professor, Peter A. Allard School of Law, University of British Columbia
- **Laura Johnston**, Lawyer, Community Legal Assistance Society
- **Michael Kary**, Director of Policy and Research, BC Care Providers Association

- **Alison Leaney**, Provincial Coordinator, Vulnerable Adults Community Response, Public Guardian and Trustee
- **Sarah Khan**, then Acting Executive Director, Seniors First BC (due to illness of various staff, a number of Seniors First BC staff attended committee meetings, including Berta Lopera, Gordon Marshall, Kevin Smith, Martha Jane Lewis, and Grace Balbutin)
- **Barbara Lindsay**, Director, Advocacy & Education and Marketing & Communication, Alzheimer Society of B.C.
- **Isobel Mackenzie**, Seniors Advocate, Province of BC
- **Jim Mann**, Person living with dementia, dementia advocate
- **Dr. Deborah O'Connor**, Professor, School of Social Work, and Co-director, Centre for Research on Personhood and Dementia, University of British Columbia
- **Lisa A. Peters, QC**, Partner, Lawson Lundell LLP, and Board Member, BC Law Institute
- **Micheal Vonn**, Policy Director, BC Civil Liberties Association
- **Penny A. Washington**, Partner, Dispute Resolution & Litigation, Norton Rose Fulbright

We strove for consensus of the committee regarding all recommendations, with the understanding from the outset that the final report would be a publication of the CCEL and the Society, and that, if necessary, areas of dissent would be noted. In the end, all the recommendations contained in this report are supported by the full committee. However, in some instances a number of committee members, particularly members who work for advocacy agencies, would have taken a stronger position regarding reform in the absence of the desire for consensus.

Ministry of Health officials provided some background information to the committee and otherwise attended meetings of the committee as observers only. The content of this report does not reflect the position of the Ministry of Health or the Province of British Columbia.

### 1.3.2 Consultation Process

Qualitative research, generally understood as gathering information about people experiences through conversation, was a key component of project work, complementing our textual study of legislation, academic literature, and other written sources, including materials produced by various Alzheimer's agencies from around the world. The consultation activities we employed as a form of qualitative research included:<sup>66</sup>

- **Key informant** interviews with people whose work involves consent to treatment and medication for older people living with dementia (N = 65);
- **Focus groups** with people living with dementia and their family caregivers (events = 13; N = 58; 14 = people living with dementia; 44 = family caregivers);
- **Conference and community presentations** where we integrated a question and answer session offering practitioners (nurses, social workers, lawyers, directors of care

facilities, etc) an opportunity to identify their own concerns around health care consent (events = 8); and

- **Online survey** of family caregivers (N = 28).

Findings from each stream of consultation are summarized in Chapter 6.

### Key Informants

Most interviews were conducted by telephone with one interviewee. We conducted a few group interviews, e.g., with staff from the Ministry of Health and the Public Guardian and Trustee. A detailed list of key informants is included in the materials as Appendix B.

Interviewees included the following professionals:

- Physician
- Geriatric psychiatrist
- Geriatrician
- Registered nurse
- Registered psychiatric nurse
- Pharmacist
- Social worker
- Lawyer
- Licensed practical nurse
- Speech and hearing professional

We interviewed people holding diverse positions with the provincial health authorities, including the First Nations Health Authority. Interviews included people working in the position of:

- Director of care
- Ethicist
- Policy advisor
- Practice consultant
- Manager of programs
- Abuse and neglect specialist
- Director of risk and compliance

Interviews included people whose practice covered:

- Home and community care
- Long-term care



- Assisted living
- Geriatric mental health
- Acute care (hospital setting)
- Private practice
- Tertiary mental health

We spoke with representatives from some of the BC regulators: physicians and surgeons; nursing professionals; speech and hearing professionals.

We spoke with people who represented other parts of the field such as:

- Family Caregivers BC
- Public Guardian and Trustee
- Advocate for Service Quality
- SafeCare BC
- BC Patient Safety and Quality Council
- PosAbilities (a representative attended the Inclusion BC focus group)

Quotations from key informants and focus group participants are included throughout this report where they help clarify the views of professionals and community on the issues. Quotations do not express the views of the CCEL or the Society. People quoted are identified by practice area to contextualize their comments without compromising anonymity. Many people could have been identified with multiple categories, e.g., a nurse who works for a health authority or a director of care who is also a physician. In each case, we chose the category that was most relevant given their particular comment.

## Community Focus Groups

The Society felt strongly that caregivers and people living with dementia should be invited to distinct focus groups in order to permit frank discussion. A few participants were not happy with this separation. For some caregivers, this approach resulted in frustration and inconvenience, because family caregivers usually provided transportation or accompaniment. One person described her caregiver and herself as a team, and expressed frustration at being separated for the purpose of the discussion.

It should be noted that the separation was artificial in some ways:

- As there is a genetic link with dementia, a number of the people living with dementia had previously been family caregivers.
- Some of the family caregiver participants brought professional experience to the discussion as they were also health care professionals.
- Some family caregivers who attended had been a family caregiver for a person living with dementia who had since passed away, and were now volunteer caregivers for other people in the community.

For the caregiver groups, we opened up the session to anyone who had been a caregiver of a person living with dementia at any point in their lives.

A key difference in the caregiver versus people living with dementia groups is that all the people living with dementia were still living independently in community, or semi-independently with the support of family. Caregivers shared experiences across the life course of dementia from early diagnosis to end of life, including experiences with health care providers in community and within care facilities.

### List of focus groups

Date	Community	Group	Attendance
April 18	Victoria	People living with dementia	4
April 18	Victoria	Family caregivers	5
April 19	Nanaimo	People living with dementia	1
April 19	Nanaimo	Family caregivers	3
April 25	Kelowna	Family caregivers	6
May 1	Burnaby	People living with dementia	2
May 2	North Vancouver	People living with dementia	6
May 3	Vancouver	Family caregivers	5
May 9	North Vancouver	Family caregivers	9
May 12	Vancouver	People living with dementia	1
May 24	Teleconference	Family caregivers	6
August 21	Inclusion BC	Family caregivers and staff with non-profits	6
August 24	Chinese	Family caregivers	4

### Community Presentations

The CCEL undertook a significant number of presentations very early on in the life of the project to assist us to understand the legal problems and the practical challenges. Presentations were identified as an effective way to reach large numbers of health care professionals and other health care staff. The eight presentations are listed below:

1. Tapestry Geriatric Services conference (April 7, 2017)—poster presentation
2. Simon Fraser Gerontology Friesen Conference with BC Psychogeriatric Association (May 19, 2017)—panel
3. BC Care Providers Association Annual conference (May 31, 2017)—panel
4. Provincial Home Health Advisory Committee (Ministry of Health)—June 12, 2017—individual presentation
5. Fraser South Directors of Care Group (June 20, 2017)—individual presentation
6. Canadian Bar Association, Elder Law Section (June 21, 2017)—individual presentation
7. BC Health Regulators (September 27, 2017)—individual presentation
8. 14th Annual Leadership Program for Physicians and Leaders in Long Term Care (November 18, 2017)—panel

## Survey of Family Caregivers

Finally, an online survey of caregivers was developed in an effort to reach family caregivers who might not have enough time to attend an in-person event. The online survey was open throughout September 2017 until October 6, 2017. It was promoted by the Society and Family Caregivers BC to people within their networks. We also distributed posters through the Vancouver Public Library system. We shared the survey online through Twitter and Facebook. The BC Seniors Advocate shared the survey on their Twitter feed, as did the Canadian Network for the Prevention of Elder Abuse, and our online posts about the survey got re-tweeted regularly.

There were 28 survey respondents. Key demographic background on survey respondents was:

- 60% cared for their mother; 19% for their father; 14% for their spouse.
- 81% said the person living with dementia lives/lived in BC.
- The majority (56%) had been a caregiver for 1-5 years; 26% for 5-10 years.
- 30% said the person is currently residing in long-term care; 19% said the person resides with the caregiver; 15% said the person lives alone; 30% said the person living with dementia had passed away.
- 55% said they made or assisted with decisions with the involvement of another decision maker. 70% said they experienced challenges working together. The challenges were very diverse, and no single theme emerged.

## 1.4 VALUES INFORMING THIS PROJECT

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As the CCEL is a division of the BC Law Institute (BCLI), we strive to conduct impartial, non-partisan, and objective research. That said, the partnership with the Society supporting this project was formed with certain values informing collaboration, research focus, and goals for change. In this section, we outline some of the values or lenses informing this project and the recommendations for law, policy, and practice change put forward at the end of this report. The four values were:

- Recognition of human rights and citizenship;
- Respect for the autonomy and agency of people living with dementia;
- Support for inclusion in decision making; and
- Appreciation of lived experience as a knowledge foundation.

### 1.4.1 Recognition of Human Rights and Citizenship

An overarching value informing this report is a recognition that within the health care system (and also the larger community) people living with dementia are not only patients or clients who deserve the best person-centered care available, but also citizens entitled to full respect for their human rights.<sup>67</sup> In this sense, the report applies a human rights lens to our understanding of health care consent law in BC.

Both federal and BC human rights laws prohibit discrimination in the provision of services to the public, which includes health care services.<sup>68</sup> Indeed both the College of Physicians and Surgeons and the Canadian Medical Association have recognized that human rights law applies to health care, and in particular, to medical care.<sup>69</sup>

Similarly, the Supreme Court of Canada has held that the *Canadian Charter of Rights and Freedoms* also applies to the provision of publicly funded medical services.<sup>70</sup> Constitutional scholar Martha Jackman writes that the reasoning in *Eldridge v. British Columbia (Attorney General)* suggests that, apart from medical services provided by a hospital, other quasi or non-governmental bodies and their staff must adhere to the *Charter* when delivering government funded health care services, and that such bodies might include nursing homes and long-term care facilities.<sup>71</sup> There is no question that equality rights apply to health care delivery in BC.

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*My dad's doctor was exceptional. But it was uncomfortable with me because as [his dementia] progressed, the conversation turned to just me, just looking at me and ignoring my dad like he was two years old. He was still very aware, and he was still a human being.*

– Family caregiver

The list of prohibited grounds of discrimination contained in all human rights statutes across Canada includes disability. Although the experience of living with dementia varies significantly from person to person, depending upon various factors—such as the underlying disease causing neurodegeneration, and the progression of the disease—dementia meets most contemporary legal definitions of disability.

Prohibited grounds are generally not defined in legislation, and indeed, neither the BC *Human Rights Code* nor the *Canadian Human Rights Act* defines disability. However, most legal definitions of disability include the experiences of people living with dementia. The Ontario Code defines disability broadly in a manner that could include dementia, stating “disability” means:

- (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or
- (e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*.<sup>72</sup>

In its comprehensive *Framework for the Law as It Affects Persons with Disabilities*, the Law Commission of Ontario writes that disability can “manifest in physical, sensory, mental, intellectual, communications or learning impairments and perceived

disabilities, as well as the experience of multiple disabilities.”<sup>73</sup> The Supreme Court of Canada has also taken a broad approach to disability that includes perceptions of inability, noting that a “handicap” may be the result of “a physical limitation, an ailment, a social construct, a perceived limitation or a combination of all of these factors.”<sup>74</sup> In this sense, the concept of disability thus includes “both the experience of socially constructed (or environmental) barriers and the embodied aspects of the experience of disability.”<sup>75</sup> Disability is stated in the CRPD to include “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”<sup>76</sup> This definition clearly includes the experiences of many people living with dementia.<sup>77</sup>

Also, both professional and advocacy sectors have embraced the notion that dementia can be a disability: dementia is included in the most recent edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, commonly known as the DSM-5 (under the equivalent term “major neurocognitive disorder”),<sup>78</sup> and the Dementia Alliance International has taken the position that dementia can be disability.<sup>79</sup>

The experience of disability reflects a relationship to the structural and social environments in which people live, including, in particular, the interpersonal relationships that mark our lives. As the recent majority decision of the Supreme Court of Canada in *BC Human Rights Tribunal v Schrenk* reminds us, discrimination exists as a function of relationships of power.<sup>80</sup> For a person living with dementia, relationships with health care providers have a significant impact on experience. Stakeholder feedback throughout this project confirms that health care professionals and staff wield a considerable amount of power vis-à-vis people living with dementia, both as knowledge-keepers, and as gateways to needed services and care.

The connection between disability and dementia opens up an equality rights platform from which to advocate for better treatment of people living with dementia. Consequently, there has been a recent move by dementia advocacy organizations towards the adoption of a human rights framework as a means of empowering people with dementia to stand up for their health-related human rights. For instance, in April 2016, the Council of Alzheimer’s Disease International committed its 83 national Alzheimer Associations to a human rights-based policy.<sup>81</sup> A human rights approach raises the issue of whether uneven access to decision making rights linked to dementia amounts to discrimination, particularly where the denial is linked to prejudicial views of people living with dementia as less able to make their own decisions.

#### **1.4.2 Respect for the Autonomy and Agency of People Living with Dementia**

This project collaboration is grounded in respect for the agency of people living with dementia, viewing them as not only as recipients of care, but also as individuals with goals, values and dreams. Respect for decision making autonomy is a fundamental tenet of modern guardianship and health care consent law in BC. For example, the *Adult Guardianship Act* states as one of its guiding principles, that “all adults are entitled to live in the manner they wish and to accept or refuse support, assistance or protection as long as they do not harm others and they are capable of making decisions about those matters.”<sup>82</sup> Further, the *Representation Agreement Act* and *HCCA* both stipulate that substitute decision

making should emphasize a person's own values and wishes, and move to a best interests approach only when the person's wishes are unknown.

The CRPD, the first binding international human rights instrument to deal with the rights of people with disabilities, also contains strong language recognizing the decision making autonomy of people with disabilities.<sup>83</sup> The general principles of the Convention include:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination; and
- (c) Full and effective participation and inclusion in society...<sup>84</sup>

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*I think [what's important is] constantly educating people that these are seniors; they are not children, and the rights that we have for decision making for children are not the same as we have for seniors.*

– Social Worker

These general principles align with the basic principles underlying the law of consent to health care as it has been articulated in court decisions such as *Fleming v Reid*, which emphasize the presumption of capacity, autonomy in decision making, and the right to human dignity.

States have an obligation under the Convention not only to enact appropriate legislation, but also to promote standards and guidelines, to take account of these rights in their policies and programs, to promote research in goods, services and facilities as well as new assistive technologies, to promote adequate human rights training for relevant professionals, and to provide accessible information.<sup>85</sup> The CRPD enunciates a number of rights which are relevant to the issue of consent in a health care context, particularly for older people living with dementia in long-term care.<sup>86</sup>

In practice, decisions vary significantly in their complexity. People living with dementia can be capable of making all of their own decisions, some of their own decisions, or none. Moreover, although dementia ultimately impacts cognition, not all decisions are entirely based on logic and deliberation: “many are intuitive and based on emotions, needs, values, preferences or habits.”<sup>87</sup>

### 1.4.3 Support for Inclusion in Decision Making

In recent years, Alzheimer's societies have made a strong push for the development of dementia-friendly communities worldwide. Dementia-friendly community initiatives support the inclusion of people living with dementia in all aspects of society through education aimed at:

- Reducing stigma;
- Enhancing awareness of, and capacity to recognize, dementia;
- Teaching people to communicate effectively and compassionately with people living with dementia; and

- Creating physical environments that are welcoming and accessible for all.<sup>88</sup>

Application of a dementia-friendly approach to health care decision making raises the question of how to best support people living with dementia to participate meaningfully in conversations about their own health care. People with cognitive, memory, and language issues may face challenges in understanding information, asking questions, and expressing their views about medication and treatment. These challenges can be particularly present in stressful circumstances. This reality does not necessarily mean they cannot make decisions, or share their perspective; however, it may mean that meaningful participation requires accommodation or support—and sometimes just extra time. For some of the participants in our consultation focus groups, particularly long-time couples, they make decisions in dialogue with a family member, and so, for them, support means recognition of helpful trusting relationships, and working in partnership with family caregivers.

Article 12 of the CRPD notes that “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and requires states to “take appropriate measures to provide access by persons with disabilities to support they may require in exercising their legal capacity.” In effect, the provision requires that all people, regardless of disability, be accorded the right to make their own decisions, and be granted the support required to exercise their decision making autonomy.

Canada has expressed concern that Article 12 puts the legitimacy of substitute decision making in question, and as a result has entered a reservation with respect to Article 12 that “preserves Canada’s ability to continue to use substitute decision-making arrangements in appropriate circumstances and subject to appropriate and effective safeguards.”<sup>89</sup> However, regardless of this reservation, at the very least the Convention requires that people with disabilities be provided with as much support as possible in order to maximize their capacity to participate in decision making to the point where substitute decision may be required.

Similarly, in BC and Canada courts have interpreted human rights laws to require fairly significant accommodation where access to services and rights is limited for a reason linked to disability. In some instances decision making autonomy can be sufficiently bolstered by supportive relationships and strategies such that people living with dementia will have capacity to make their own health care treatment decisions. In such circumstances resorting to substitute decision making may be an unnecessary and illegal incursion on autonomy even under domestic human rights law.

In this vein, the *Conversations about Care* starts from the proposition that engaging people living with dementia in their health care decisions will not only lead to better, more person-centered care, but also is a requirement of human rights law. Health care consent practices that do not support the participation of people living with disabilities generally, and people living with dementia in particular, are thus discriminatory.

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*That rushing is stopping you from really understanding what your mother/father/sibling is experiencing with dementia... because there's activity everywhere, there's noise everywhere... doctors or nurses coming to talk to you and saying, or asking you questions, or saying things to you, and you're supposed to try and remember, and you know it's just, it's sort of like a recipe for disaster.*

– Family caregiver

#### 1.4.4 Appreciation of Lived Experience as a Knowledge Foundation

As discussed earlier, qualitative research was a key source of information throughout this project in helping us understand how health care consent laws are applied in practice. For this project we:

- Held consultation focus groups with people living with dementia and family caregivers;
- Interviewed people who deal with health care consent in their work;
- Conducted an online survey of family caregivers in order to offer busy caregivers an avenue for participation that might be more accessible; and
- Delivered various presentations on health care consent, many of which included a question and answer component that offered people an opportunity to share their views and concerns.

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*I've worked alongside some very amazing registered nurses in all environments, home health—you know name it. I've watched them all. So I've seen registered nurses who will quickly forget their training to analyze and balance out the disease process. They'll just go straight to drugs. They take the path of least resistance.*

– Nurse

In *Conversations about Care* we generally use the term consultation instead of qualitative research, and we describe the consultation scope in more detail above under “methodology”. In this section we share a few words about why, ideologically, the CCEL and the Society chose to ground the research in an understanding of lived experience.

Lived experience refers to “personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.”<sup>90</sup> This kind of knowledge can be contrasted with knowledge and information acquired by reading texts. In law reform work, legislation, court decisions, and legal commentary are dominant sources of information.

We consider lived experience to be a key source of information in helping us to understand how the law is applied in community—regardless of the project—for a number of reasons. For this project the lived experience approach allows us to include the voices of people living with dementia, both in the form of direct quotations, and also in helping us to better understand and prioritize the issues that point to a need for change. Given that people living with dementia confront stigma, discrimination, and social exclusion, it was important to us to include and amplify their voices, particularly with respect to a project that confronts the practice of health care professionals, staff, and institutions that wield a great deal of power. This project on health care consent seeks to support people living with dementia to be heard not only in their own personal lives, but also in terms of our law reform work. In some BCLI projects we offer community the opportunity to comment on a consultation paper; for this project we did not want to produce any commentary on the law until we had first heard from people living with dementia.



Although some researchers might limit the notion of lived experience to people who experience oppression, for the purposes of this project we also consulted people who deal with health care consent as part of their work. We asked stakeholders from health care about what is working well, and what is not, and we asked them to identify challenges to best practice. We also spoke to lawyers and advocates about the law and practice of health care consent for people living with dementia. In some instances our Project Advisory Committee members also contributed lived experience that helped us to understand the issues in practice. We hope that building a law reform report around challenges identified in community will help us to develop a report that identifies problems and solutions that matter most to British Columbians.

## 1.5 STRUCTURE OF THIS REPORT

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This report is divided into six chapters.

- **Chapter 1** introduces the project rationale, scope and methodology. The chapter also identifies values underlying project focus and recommendations.
- **Chapter 2** sets out the social science foundation informing our legal research, providing a basic introduction to dementia, medication, and poly-pharmacy.
- **Chapter 3** sets out health care treatment decision making law in BC, including the different types of supportive and substitute decision makers and their rights and duties. We also discuss avenues for challenging health care decisions, decision making authority, and incapability assessments, and identify the overlap between health care consent and mental health law for people living with dementia.
- **Chapter 4** describes the law governing restraint in long-term care, and the meaning of a chemical restraint. We compare BC with the legal framework for restraint in other jurisdictions.
- **Chapter 5** maps out the people and institutions engaged in obtaining consent and providing medication to people living with dementia in long-term care. We review the regulation and education of health care professionals and long-term care facility staff on the topic of health care consent, and provide a brief overview of staffing and physician remuneration.
- **Chapter 6** summarizes what we learned from consultation with people living with dementia, family caregivers, health care professionals, and other stakeholders who engage with health care consent issues in their work.
- **Chapter 7** brings together legal research and consultation findings for discussion of recommendations aimed at enhancing compliance with, or improving, the law regarding health care consent in BC. We set out 34 recommendations.

The report includes four appendices:

- **Appendix A** lists the 34 recommendations.
- **Appendix B** is a table of the key informants we interviewed as part of consultation.

- **Appendix C** outlines the questions we asked key informants.
- **Appendix D** is a copy of the online family caregiver survey.

Each chapter of this report is fairly self-contained. **Chapters 3-5** set out different aspects of the law that are relevant to understanding the overall legal landscape governing consent to health care for people living with dementia. These chapters are intended to summarize but not criticize the law.

**Chapter 7** is quite lengthy, and can be read on its own. However, some nuances will be missed if a reader does not review the whole report. For the sake of completeness and clarity, we include in the chapter aspects of the previous chapters—both legal material and consultation findings—that are relevant to the discussion of each issue. As a result, readers will find there is some repetition of the content of other chapters in **Chapter 7**.

We include anonymous quotations from consultation participations throughout the report. The quotations are intended to help readers to better understand the urgent practical issues and personal challenges that arise for people living with dementia, family caregivers, health care professionals, advocates, care facility staff, and others in the context of health care decision making. The quotations do not reflect in the views of the CCEL or the Society, and they sometimes reflect misunderstandings about the law.



## CHAPTER 2

# Introduction to Dementia

*They are saying they have 41 patients. They don't have time to understand people. You know, when you have Alzheimer's you don't have a lot of verbal capacity, so swatting something away is her way of communicating.*

**Family caregiver**

This chapter provides a basic introduction to non-legal concepts critical to understanding themes emerging from research and consultation, and recommendations found in Chapter 7 of this report. This chapter:

- Defines dementia, including describing different types of dementia and its stages;
- Introduces the concepts of polypharmacy, and behavioural and psychological symptoms of dementia;
- Explains the relationship between a diagnosis of dementia and an assessment of incapability; and
- Reviews various types of medication prescribed for people living with dementia, including some of their benefits and side-effects.

Readers with a specialized health or medical practice may already be very familiar, if not much more familiar, with the concepts explored in this chapter. We hope that people working in law and policy, and health professionals not specialized in dementia, will find this chapter provides a helpful foundation.

## 2.1 UNDERSTANDING DEMENTIA

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### 2.1.1 What is Dementia?

Dementia<sup>91</sup> is a general term used to describe a range of symptoms caused by disorders of the brain.<sup>92</sup> Dementia is caused by physical changes in the brain, and is a progressive and degenerative disease, meaning symptoms will worsen over time.<sup>93</sup> Dementia degrades mental function as a result of loss of cells and breakdown in connections within the brain over time, a process referred to as “neurodegeneration.”<sup>94</sup> The equivalent term for dementia used in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition, commonly known as the DSM-5, is “major neurocognitive disorder”.<sup>95</sup>

It is challenging to generalize about dementia. The experience of dementia varies significantly from person to person. The Alzheimer Society of Ireland writes:

Each person’s experience with dementia is unique. Not every person will experience all the signs and symptoms of their type of disease. Other illness or health care issues can occur. As a result, how the disease will progress varies from one person to another.<sup>96</sup>

For some, dementia advances quickly; for others, it takes years to reach what is considered the advanced stage, where 24-hour care is required.<sup>97</sup> Although research tends to suggest the average life expectancy is approximately 4.5 years after diagnosis, this data is based primarily on people living with dementia in their 80s and 90s, and people diagnosed at a younger age tend to live longer (an average of over 10 years if diagnosed between the ages 65–69).<sup>98</sup> Further, average life expectancy can vary depending on the type of dementia (discussed below), and there is limited research on life expectancy for people diagnosed with early or younger onset dementia (diagnosed prior to age 65).<sup>99</sup> All this is to say that health care for people living with dementia is not primarily about end of life care. People can live with significant independence and function for many years following a diagnosis, and may be capable of making their own health care decisions.

Symptoms of dementia can include difficulty in thinking, problem-solving, communicating, and reasoning, as well as loss of memory, the ability to focus and pay attention, and visual perception. Changes in mood, emotional control, and social behaviour often occur.<sup>100</sup> As the disease progresses, these symptoms will reduce a person’s ability to perform the activities of daily life, such as the ability to maintain personal hygiene, dressing, and eating. People living with dementia may not remember the location of the bathroom in a house where they lived for forty years, and at advanced stages, may lose the power of speech.

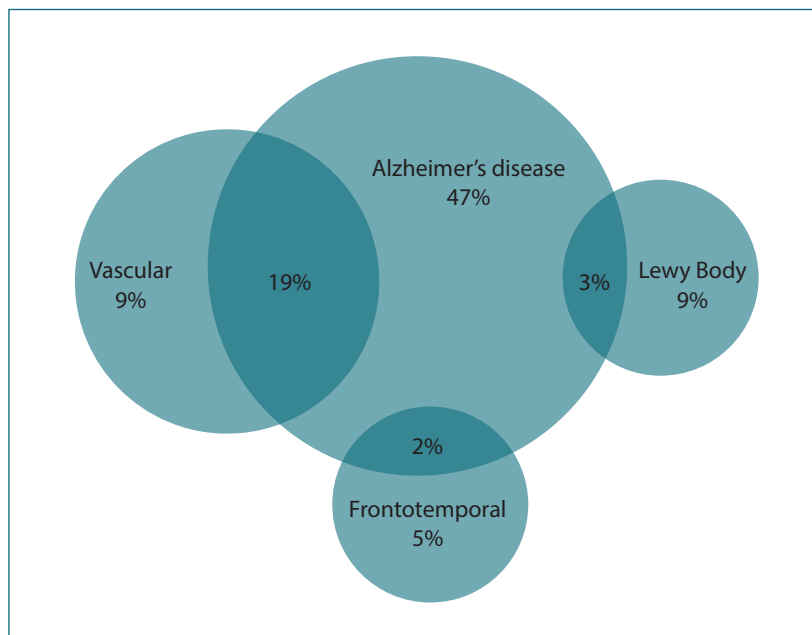
The Alzheimer’s Association of America writes that “dementia is often incorrectly referred to as “senility” or “senile dementia,” which reflects the formerly prevalent but incorrect belief that serious mental decline is a normal part of aging.”<sup>101</sup> The Alzheimer Society of Canada indicates that “almost 40 percent of people over age 65 experience some form of memory loss”, characterizing memory loss without the underlying presence of disease as “age-associated memory impairment.”<sup>102</sup> While some memory loss can be a normal part of the aging process—such as increasing difficulty recalling the names of new acquaintances or forgetting tasks—people living with dementia struggle with more

significant memory issues, such as not recognizing a family member, not recalling the names of family members, or needing to pause frequently to find the correct word when communicating.<sup>103</sup>

### 2.1.2 Types of Dementia

Dementia is not a specific disease. There is a wide spectrum of types of cognitive impairment and dementia, and these conditions have varied causes and consequences. Many diseases can cause dementia, including Alzheimer’s disease, vascular dementia, Lewy Body disease, head trauma, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson’s disease, Huntington’s disease dementia, and dementia due to HIV, among others.<sup>104</sup> These conditions can have similar and overlapping symptoms. Below we discuss some similarities and differences between the more prevalent form of dementia.

Alzheimer’s disease is the most common form of dementia, followed by vascular dementia (with or without Alzheimer’s), dementia with Lewy bodies, and frontotemporal dementia. People can also have a combination of different types of dementia.<sup>105</sup>



**Figure 1:** Prevalence of Different Types of Dementia<sup>106</sup>

#### Alzheimer’s Disease

Alzheimer’s disease is the main cause of dementia, accounting for 60 to 80 percent of cases.<sup>107</sup> Alzheimer’s occurs due to physical changes in the brain, including a buildup of certain proteins and nerve damage.<sup>108</sup> The disease often progresses slowly. Sources provide diverse statements regarding average life expectancy after diagnosis, ranging from four to eight<sup>109</sup>, and eight to ten years.<sup>110</sup> Some people, however, may live as long as 20 years after diagnosis, depending on other factors.<sup>111</sup> Alzheimer’s

causes changes in the brain years before signs of the disease become evident.<sup>112</sup> This time period is referred to as preclinical Alzheimer's disease.<sup>113</sup>

Difficulty remembering newly acquired information is the most prevalent early symptom of Alzheimer's because the disease typically originates in the part of the brain responsible for learning.<sup>114</sup> However, as the disease progresses, and damage spreads throughout the brain, other symptoms emerge, including increasing confusion, mood and behaviour changes, and increasing difficulty with basic activities ranging from speaking to walking.<sup>115</sup>

### **Vascular Dementia**

Next to Alzheimer's the most common types of dementia are vascular dementia co-occurring with Alzheimer's (19%), and vascular dementia (9%)—see the above diagram.<sup>116</sup> Vascular dementia is caused either by blocked blood vessels in the brain (a lack of blood or ischemia), or by bleeding within the brain (hemorrhage) which occur as a result of strokes, or other brain injuries.<sup>117</sup> Since brain damage is often caused by an evident stroke, changes in thought processes can be sudden, as compared with Alzheimer's disease.<sup>118</sup>

Symptoms will vary depending on the damage to blood vessels, and the part of the brain impacted; as a result, a person living with vascular dementia might not experience significant memory loss.<sup>119</sup> Common post-stroke symptoms of vascular dementia can include difficulties with language that affect speaking or understanding—a condition known as aphasia.<sup>120</sup> Where the vessel and nerve damage is caused by multiple smaller strokes, or other forms of disease, the changes in a person's abilities and behaviour will be more gradual, and can include: “impaired planning and judgment; uncontrolled laughing and crying; declining ability to pay attention; impaired function in social situations; and difficulty finding the right words.”<sup>121</sup>

Not all cognitive and other symptoms of brain damage following stroke indicate vascular dementia. When memory, thinking, and reasoning problems have been severe enough to have a “significant impact on daily life”, a person may be diagnosed with vascular dementia.<sup>122</sup> A person with vascular dementia may get worse with each stroke, or as a result of blood vessel damage occurring over time without resulting in stroke. Decline can thus also occur with leaps and plateaus.<sup>123</sup>

### **Dementia with Lewy bodies**

Lewy Body Dementia accounts for approximately 5-15% of dementia cases.<sup>124</sup> This type of dementia occurs due to clumps of protein accumulating in different parts of the brain.<sup>125</sup> In addition to memory loss and confusion, dementia with Lewy bodies can often be distinguished through additional symptoms such as sleep disturbances, hallucinations, imbalance, and movement difficulties.<sup>126</sup>

### **Dementia Associated with Parkinson's Disease**

Parkinson's disease is a neurodegenerative condition that is caused by the death of cells that normally produce dopamine.<sup>127</sup> The disease is most commonly associated with problems related to movement and motor control, resulting in noticeable tremors.<sup>128</sup> It is estimated that 50 to 80 percent of people

living with Parkinson's disease will eventually experience Parkinson's disease dementia, with an average time of ten years for the development of the dementia from the onset of Parkinson's.<sup>129</sup> Dementia associated with Parkinson's disease can present with: "changes in memory, concentration and judgement; trouble interpreting visual information; muffled speech; visual hallucinations; delusions, especially paranoid ideas; depression; irritability and anxiety; and sleep disturbances."<sup>130</sup>

### Frontotemporal Dementia

Frontotemporal dementia, denoted by the brain region in which cell loss first occurs, refers to a group of illnesses that are characterized by changes in personality, behaviour, and language.<sup>131</sup> As a result, memory loss may not be predominant in the early stages of the illness.<sup>132</sup> Frontotemporal dementia can occur due to a range of different underlying disorders causing degeneration of the frontotemporal region.<sup>133</sup> Unlike other forms of dementia, frontotemporal dementia is not strongly associated with aging.<sup>134</sup>

### Mixed Dementia

Mixed dementia is dementia in which multiple types of dementia-causing brain abnormalities are present.<sup>135</sup> The most common scenario is Alzheimer's in combination with vascular dementia, but other forms of dementia can co-occur.<sup>136</sup>

## 2.1.3 Stages of Dementia

Dementia is a progressive degenerative condition. As dementia progresses, significant changes to the person's personality, abilities, memory, and mood can occur. Health clinicians generally refer to stages of dementia reflecting mild, moderate, and severe symptoms; however, the number of stages identified in literature varies. Viewing dementia through a lens of stages or phases can be helpful in illustrating the progressive nature of dementia; however, the approach can over-simplify disease progression. In reality, the dementia journey may be different for people living with different types of dementia, and factors can impact progression, including: "emotional resilience"; overall physical well-being and health; medication usage; and available support.<sup>137</sup> As a result, changes in people's capacity to live independently, and to make their own health care treatment decisions, can accompany each stage of dementia.

The BC Ministry of Health has characterized the stages of dementia in the following manner:

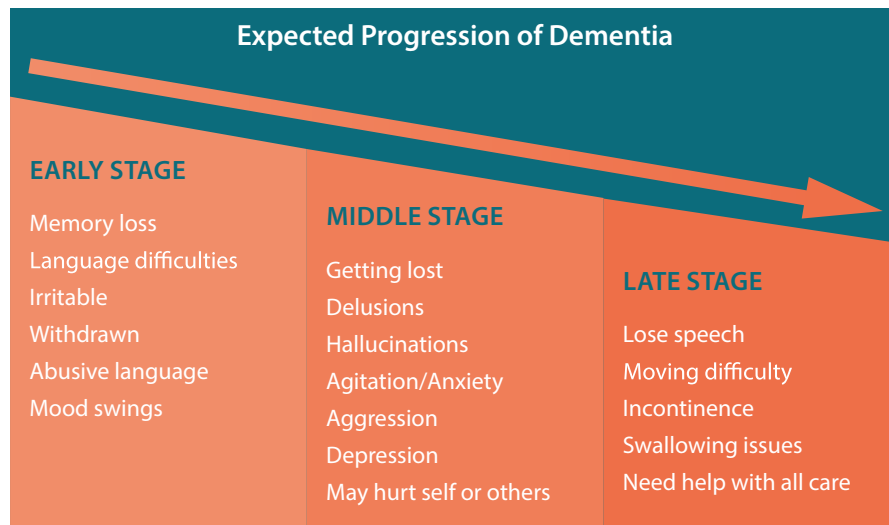
**Mild:** The person who has mild dementia is still able to function somewhat independently. However, memory loss and thinking impairment are present, often with mild word-finding difficulties. Common challenges include difficulty remembering basic words and people's names. Caregivers may report stress due to the functional changes in the person with dementia.

**Moderate:** The person who is in a moderate stage of dementia will experience further decreases in memory, thinking, language and concentration skills. This results in an

increased need for supervision and assistance. In this stage there can also be changes in behavior, and a potential for getting lost. The caregiver is at risk for stress, depression, general health deterioration, and loss of productivity at work.

**Severe:** The person who is in the severe stage of dementia experiences a considerable loss of memory, language, and living skills. As a result, they cannot be left unsupervised and require assistance in all activities of daily living. A high level of dependence on the caregiver can increase the risks to the caregiver’s health and ability to continue to manage care at home. Severe dementia often requires admission to a residential care facility, and may indicate the need for end-of-life-care.<sup>138</sup>

The above breakdown, like many dementia scales, tends to match best the progression of disease for people diagnosed with Alzheimer’s as compared with other forms of dementia.<sup>139</sup> Initial milestones often include discontinuing driving, needing help with daily activities, developing new health care professional relationships, and receiving a diagnosis.<sup>140</sup> As the condition progresses, the need for assistance increases, and eventually, almost constant supervision is required. As noted by Hanson et al., “[a]dvanced dementia is characterized by profound memory deficits, inability to recognize family members, sparse speech, incontinence, and dependency in all activities of daily living, including eating.”<sup>141</sup>



**Figure 2:** Stages of Dementia<sup>142</sup>

As mentioned earlier, the progress of brain damage, and consequent experience of symptoms of dementia, will be impacted by the type of dementia. For people living with vascular dementia, changes can be sudden, especially if a person experiences repeated major strokes; change will be more gradual if strokes are smaller. For people with Lewy Body dementia, “abilities may fluctuate drastically, even during the course of day” in the early stages of the disease.<sup>143</sup> A person living with frontotemporal dementia may present initially with behavioural changes but good memory. Indeed, the DSM-5 description of “major neurocognitive disorder”, the American Psychiatric Association’s equivalent



term for dementia, is broad; memory loss, which is typically associated with a general understanding of dementia, is not a required symptom for a diagnosis.<sup>144</sup>

### 2.1.4 Diagnosing Dementia

A dementia diagnosis can present a gateway to better support and care, and early diagnosis can improve quality of life and support advance planning.<sup>145</sup> However, there can be many challenges to diagnosing dementia. The Ministry of Health identifies the following barriers to diagnosis:

- A general lack of understanding of dementia and misconceptions about what constitutes “aging” without the presence of underlying disease;
- Widespread fear regarding the stigma attached to a diagnosis of dementia; and
- Lack of professional confidence and skills required to provide an accurate diagnosis.<sup>146</sup>

A proper diagnosis of dementia requires an investigation of a person’s overall health. Other health issues can cause behaviours and other symptoms that may appear initially to be a sign of onset of dementia, some of which can be resolved with treatment, such as urinary tract infections, thyroid problems, medication side-effects, and vitamin deficiencies.<sup>147</sup> Although a person’s family physician is involved in the process, and makes the referral to specialists, it is likely a specialist—such as a geriatric psychologist, a neurologist, or a geriatrician—who will make the dementia diagnosis.<sup>148</sup>

The DSM-5 diagnostic criteria for a major neurocognitive disorder are:

- A. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition) based on:
  1. Concern of the individual, a knowledgeable informant, or the clinician that there has been a significant decline in cognitive function; and
  2. A substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing or, in its absence, another quantified clinical assessment.
- B. The cognitive deficits interfere with independence in everyday activities (i.e. at a minimum, requiring assistance with complex instrumental activities of daily living such as paying bills or managing medications).
- C. The cognitive deficits do not occur exclusively in the context of a delirium.
- D. The cognitive deficits are not better explained by another mental disorder (e.g. major depressive disorder, schizophrenia).<sup>149</sup>

As compared with earlier versions of the DSM-5, memory impairment is no longer a requirement in the diagnosis. A diagnosis of Alzheimer’s specifically does require memory impairment.<sup>150</sup>

The BC Ministry of Health recommends that objective evidence to support the diagnosis be obtained through use of a standardized assessment tools, such as:

- Standardized Mini-Mental State Examination to test cognition;
- Clock Drawing Test to test executive functioning; and
- Montreal Cognitive Assessment to test for mild cognitive impairment and early dementia.<sup>151</sup>

However, the diagnostic process is not at all reducible to these well-known assessment tools. The diagnostic process would generally include a patient history, physical exams, and neurological tests,<sup>152</sup> input from the person who may have dementia, and possibly collateral information from family and caregivers. The process raises ethical questions about how assessors prioritize the input from the person who may have dementia with collateral sources when they don't match. Ageism permeates medical practice as much as any other environment, and so there is always a risk that the perspective of an older person will be accorded less respect.

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*There is a lot of ageism, and almost like an assumption that people are unable to consent.*

– Nurse

A diagnosis of dementia is intended to encompass the spectrum of severity, ranging from the mildest to the most severe stages of dementia. What distinguishes dementia from mild cognitive impairment is the extent to which the ability to function at work or in usual daily activities is diminished. This assessment of ability and function in turn rests on a judgment made by a skilled clinician, based on the circumstances of the patient, as well as the description of daily life obtained from both the patient and a knowledgeable external referee.<sup>153</sup> However, it can be difficult to identify a precise threshold between mild cognitive impairment and dementia on the one hand,<sup>154</sup> and mild dementia and normal aging on the other. As a result, there has been considerable controversy over the decision to include mild cognitive impairment in the DSM-5.<sup>155</sup>

### 2.1.5 Dementia and Mental Capacity for Decision Making

As noted above with respect to the DSM-5 criteria for major neurocognitive disorder, a diagnosis of dementia is not determinative of mental capacity to make any or all health care decisions. As we discuss in Chapter 3, capacity for decision making is not generalizable; it exists relative to a particular decision. A clinical interview offers the best approach to assessment of incapability.<sup>156</sup> The MacArthur Competence Assessment Tool for Treatment “is emerging as the ‘gold standard’ for assessing capacity to consent to medical treatment.”<sup>157</sup> The tool examines four abilities:

1. Understanding of the disorder and its treatment, including associated benefits/risks;
2. Appreciation of the disorder and its treatment (requires insight into how these will affect the patient individually);
3. Reasoning processes, which examines why and how a decision was made and the potential to compare consequences; and
4. Ability to express a choice.<sup>158</sup>

Research indicates people with mild to moderate dementia are able to evaluate the risks and benefits of treatment options in order to make treatment decisions,<sup>159</sup> and express preferences.<sup>160</sup> People living with dementia are not a homogenous group, and a dementia diagnosis does not mean people immediately either stop talking, or otherwise expressing themselves. Moreover, even people with advanced dementia can still vocalize, express joy and sadness, display a sense of humour, communicate a desire to eat or not eat, dance, express a wish for affection, intimacy, and touch, and so on. Further, as Smebye et al. note:

[N]ot all decisions are based on logic and deliberation; many are intuitive and based on emotions, needs, values, preferences or habits. Even with significant cognitive decline, persons with dementia can still be “valuers” i.e. they can, on the basis of what they unre-  
flectively identify with, still evaluate, interpret and derive meaning in their lives. The ability to value is independent of cognition and the pertinent question is if the person can still value and experience.<sup>161</sup>

Therefore, in spite of cognition challenges, research indicates that people living with dementia may have a clear sense of preference and values, and be capable of expressing their views.

Philosophers and legal theorists have questioned whether personality or identity changes precipitated by dementia which impact values and preferences mean that people living with dementia can no longer make authentic decisions.<sup>162</sup> The issue is whether new or altered preferences can still inform authentic health care decision making—that is to say, decisions that reflect a person’s true wishes. Writers distinguish between the self with dementia and the original self. The well-known philosopher Richard Dworkin has argued that the views of this original self ought to take precedence.<sup>163</sup>

There is nothing within the law that prevents us from changing our mind about the things that matter to us, regardless of disability or disease. However, for people living with dementia, there may be a related temptation to pathologize value changes as reducible to brain degeneration. Certainly, people living with dementia are just as likely as anyone to change values and preferences as a result of life experience. Indeed, as a dementia diagnosis can be a life-changing or traumatic event, some changes in values or preferences can be expected. Also, arguably, the experience of living with dementia or any kind of disability brings with it a new kind of intimate knowledge grounded in experience that could impact decision making.

Still, changes in values and preferences may present ethical dilemmas regarding which values to honour in the context of substitute decision making.<sup>164</sup> Determining whether such changes impact on decisional capacity requires a proper incapability assessment addressing capacity for the specific decision at issue.

### **2.1.6 Behavioural and Psychological Symptoms of Dementia**

The term Behavioural and Psychological Symptoms of Dementia (BPSD) is commonly used by psychiatrists, clinicians, academics, and others to refer to “symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients living with dementia.”<sup>165</sup> The term is

intended to capture diverse, non-cognitive symptoms of dementia, such as delusions, hallucinations, depressive symptoms, agitation, and hostility.<sup>166</sup> From a clinical perspective, understanding BPSD is considered integral to making appropriate recommendations for treatment, including the prescription of psychotropics, and both pharmacological and non-pharmacological approaches. In this report we occasionally use the term BPSD because it is referenced in secondary sources and also consultation; however, we also wish to highlight some concerns regarding its use. We prefer the term dementia-related behaviours, and we explain our rationale for using this alternative expression in this section.

While cognitive impairment is central to a diagnosis of dementia, research indicates that non-cognitive symptoms are almost always present throughout the illness. Some studies have suggested these psychiatric symptoms are present in around 80% of people living with dementia;<sup>167</sup> others have stated up to 98% of people living with dementia will be affected at some point in the disease's life-course.<sup>168</sup>

Research indicates that depression and apathy are frequently observed in people living with mild cognitive impairment and early stage Alzheimer's disease, which may increase in frequency as dementia worsens. Delusions, hallucinations, and aggressive behaviour are more common in moderate to severe stages.<sup>169</sup> Apathy is among the most frequent and enduring behavioural symptom identified across all dementia stages. As noted by Gitlin et al, "[a]gitation, another chronic and persistent problem reported by families, involves emotional distress, excessive psychomotor activity, wandering, aggressive behaviours, irritability, disinhibition, and vocally disruptive behaviours."<sup>170</sup> Symptoms often co-occur, and are associated with functional and cognitive decline.<sup>171</sup>

There is great variety in experience. Although symptoms occur at any disease stage, some appear more often than others.<sup>172</sup> While symptoms occur universally for almost all people living with dementia,<sup>173</sup> some types of behaviour or symptoms can be specific to the type of disease.<sup>174</sup> For example, depression is most common in vascular dementia, and hallucinations are more frequent in Lewy body disease than in Alzheimer's disease.<sup>175</sup>

Mention of the term BPSD is central to this report because the concept is tied to use of anti-psychotic medication to manage, change, or limit the behaviours of people living with dementia; however, use of the term raises some concerns. Although BPSD sounds like it is a diagnosis, the term is in fact referring to a broad range of behaviours that arise in the context of a dementia. Moreover, it is not clear that the behaviours are exclusively due to the neurodegenerative disease. Many could be situational, interpersonal, or psychological in causation. The behaviours could be the expression of grief, denial, loss of control, shame—indeed very reasonable responses to the experience of living with an incurable, progressive disease that destroys the brain, and is associated with so much stigma, coupled with increasing challenges with language and communication.

One of the challenges with the term is that it locates the problem solely in the person living with dementia, when in fact behavioural symptoms are often multidimensional in cause, as outlined by the P.I.E.C.E.S. Canada model.<sup>176</sup> Careful assessment of the contributing factors can identify environmental, interpersonal, and physiological factors that may be contributing to the behaviour of the person living with dementia. A number of Project Advisory Committee members noted that the BPSD approach contributes to exclusively interpreting the person's situation through the lens of dementia, which often leads to more fearful or reactive responses to situations than expected or

required. The sensitivity of the person living with dementia to external circumstances means reactive approaches can be counter-productive.

Behavioural symptoms of dementia may result from more than one cause. As Smith and Buckwalter explain, the type and extent of symptoms result from complex interactions among the type of dementia, longstanding personality traits and patterns of behaviour, drug interactions, and environmental factors:

...Agitation can be caused by the need to urinate, as well as by depression. Anxiety and sudden withdrawal at mealtimes may result from a noisy, crowded, or chaotic environment, the person's inability to identify utensils or the food itself (because of agnosia), or dysphagia and the fear of choking. Hitting, biting, and screaming at bath time may be the result of pain, uncomfortable room or water temperature, embarrassment or a lack of privacy, or the fear of sexual assault. ... Considerable observation is often required to understand the "problem" from the perspective of the person with dementia.<sup>177</sup>

In this sense, what have been called BPSDs are increasingly recognized as "an attempt to communicate an un-met need... Within this framework, dementia-related behaviours are considered meaningful expressions, ranging from disengagement (e.g., apathy) to mild discomfort (e.g., pacing) to urgent need (e.g., physical aggression)."<sup>178</sup> As people living with dementia experience increased vulnerability to their environment, "behavioural symptoms may result from the confluence of multiple, some potentially modifiable, interacting factors, including internal (e.g., pain, fear) or external (e.g., over-stimulating environment, complex caregiver communications) features."<sup>179</sup>

People living with dementia can also be experiencing other kinds of mental illness, which may or may not be significantly related to the dementia. Mental illness can be difficult to diagnose in people living with dementia due to problems with language, memory, and insight. As noted below:

Depression is common in [Alzheimer's disease], with a prevalence of approximately 20% and even higher in [vascular dementia] and dementia with Lewy bodies]. It can be very difficult to diagnose depression accurately in dementia. The patient may not be able to report their symptoms reliably due to impaired memory and insight. Observations and collateral history can therefore be important in making the diagnosis. Depression symptoms are often present in patients with dementia in the absence of coexistent depression.<sup>180</sup>

Although BPSD has become a practical label for different types of behaviour linked to dementia, the generalization does not capture the diverse and unique experiences of people living with dementia struggling to cope with disease, and exhibiting behaviours that many, including sometimes themselves, find challenging. It is thus a broad term that must be applied with care. We use the term occasionally in this report because it is commonly invoked in practice; however, the term remains problematic to the extent that it generalizes so broadly, and risks pathologizing a normal struggle with disease progression and stigma, loss of independence, and communication and environmental challenges.

## Dementia and Aggressive Behaviour

One of the most challenging behaviours linked to dementia is verbally and physically aggressive behaviour. The rate of aggressive behaviour tends to correlate with the loss of independence and cognitive decline.<sup>181</sup> For people residing in the community, such behaviour has several adverse consequences, correlating strongly with injury, mental suffering, cognitive decline, loss of independence, hospitalization, earlier admission to an institutional setting, such as long-term care, and other sub-optimal outcomes.<sup>182</sup> Physically aggressive behaviour also affects caregivers, leading to chronic mental distress, depression, injury, and abuse.<sup>183</sup>

Aggressive behaviour is closely associated with moderate to severe depression, male gender, and greater impairment in activities of daily living, even after adjustment for delusions, hallucinations, sleep disturbance, and severity of cognitive impairment.<sup>184</sup> As noted by Talerico, Evans and Strumpf, “[a]ggression is seen most often in response to personal space invasion during care activities like bathing.”<sup>185</sup> Increasingly research is adopting the viewpoint that aggressive behaviour may represent an expression of unmet needs, rather than primarily manifestations of the bio-physiology of the disease. As Algate et al. explain:

When cognitively impaired (CI) persons can no longer meet their needs or goals, they may become aggressive to deal with the resulting frustration. Thus, aggression might reflect diminished ability to deal with frustration or ambiguity. Some neuropsychological changes such as disinhibition, may interfere with their ability to self-regulate or execute behavior independent of environmental influences. A person with a hostile pre-morbid personality may become more aggressive as damage to the cortex results in disinhibition of these tendencies. Likewise, inappropriate assistance with activities of daily living (ADLs) may threaten personal abilities, obstruct goal-directed activity and lead to aggression.<sup>186</sup>

More studies and educational initiatives are highlighting that identifying unmet needs in people living with dementia may improve the precision and efficacy of interventions, and therefore the quality of life for both people living with dementia and their caregivers.<sup>187</sup> Studies have found that impaired communication is associated with all forms of aggressive behaviour, including circumstances where the older person is also either depressed or disoriented. For example, in videotaped sequences of dementia patients exhibiting agitated behaviours, researchers concluded that agitation frequently acted as a form of communication.<sup>188</sup> Ragneskog et al. note that “[t]wo underlying reasons seem to be that the patient had loss of control over the situation and [has] deficient autonomy.”<sup>189</sup>

## 2.2 MEDICATION FOR TREATING SYMPTOMS OF DEMENTIA

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Although there is presently no cure for most forms of dementia, and no medication that can alter the progression of the disease, there are drugs that can temporarily slow the worsening of symptoms in some people.<sup>190</sup> People who respond well to treatment can experience improvements in their quality of life for several years.

The same medications used to treat Alzheimer's are among the drugs sometimes prescribed to help with symptoms of other types of dementias. In this Part 2 we provide a brief overview of two categories of medication:

- Medications to address memory symptoms and cognitive changes, including changes in language, thinking abilities, and motor skills; and
- Medications to manage mood or behavioural issues, such as depression, insomnia, hallucinations and agitation.

In some non-typical situations, reversible dementia can be caused by other underlying problems, such as hypothyroidism,<sup>191</sup> highlighting the importance of a full medical assessment for a person presenting with cognitive symptoms. A person living with dementia may or may not have other health conditions for which medication or other treatment has been recommended. These medications are not discussed in this chapter.

This chapter focuses on pharmacological interventions because it is intended to provide the background for a discussion of informed consent to health care. However, non-pharmacological approaches can also alleviate some symptoms of dementia,<sup>192</sup> and likely form part of a robust health care plan. Alzheimer's societies recognize many lifestyle choices as being supportive of brain health, as well as overall well-being, such as:

- Staying socially connected;
- Participating in regular physical activity;
- Engaging in mentally stimulating activities;
- Getting adequate sleep;
- Reducing stress; and
- Maintaining a healthy diet and good nutrition.<sup>193</sup>

Some of the above goals can be harder to achieve when living with dementia, for example, people with dementia may forget to eat, lose interest in preparing meals, or not eat a healthy combination of foods. They may also forget to drink enough, leading to dehydration or constipation.<sup>194</sup> In addition, sleep is often profoundly disturbed in people living with dementia, which can lead to problems with memory, cognition, problem solving and daily function, as well as increase the risk of depression and aggression.<sup>195</sup> Further, people living with dementia often experience increased stress as a result of impaired problem solving, confusion about their environment, and over-reactivity of the limbic part of their brain, which helps control emotion, learning, and memory. Consequently, Alzheimer's Societies also emphasize the importance of developing stress management strategies.<sup>196</sup>

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*What choice did I have to move her to any other place in the [community]? Cause I toured them all, and I was horrified by what I had seen, and she was still cognitive enough to know that she didn't like them either. So I agreed to have her on a tranquilizer. So I have to lie to her every time she gets on that theme about how much she doesn't want to take this, this pill, so I tell her it's for an allergy, and I do that therapeutic fibbing thing.*

**– Family caregiver**

Although psychotropic medications have been the focus of much media attention, they represent but some of the types medication that may be prescribed for a person living with dementia. The right to informed consent to health care applies to all forms of medication.

### 2.2.1 Medication for Memory Loss

Currently there are two main classes of drugs used to treat the symptoms of Alzheimer's disease, which may also help with mild-moderate vascular dementia. They are:

- Acetylcholinesterase inhibitors; and
- Memantine.<sup>197</sup>

These medications are not effective for ameliorating cognitive symptoms in all types of dementia, for example, the use of cholinesterase inhibitors and memantine for the frontotemporal dementia is not shown to slow the progression of illness.<sup>198</sup>

#### Acetylcholinesterase inhibitors

Acetylcholinesterase inhibitors are the foundational treatment of Alzheimer's disease. They help by improving "the ability of impaired nerve endings to transmit messages from one nerve cell to another."<sup>199</sup> Three cholinesterase inhibitors are available in Canada to treat symptoms in people with mild to moderate Alzheimer's disease: Aricept, Exelon, Reminyl.<sup>200</sup> Positive benefits, which include increased attention, thinking, memory, praxis, language, comprehension and communication, appear to be applicable to mild, moderate and severe Alzheimer's disease.<sup>201</sup>

Depending on the medication, the user may experience different side effects. The main side effects of these drugs include gastrointestinal symptoms, like diarrhoea and nausea, loss of appetite and sleep disturbances (vivid dreams, wakefulness, or sedation).<sup>202</sup> In people with cardiac conduction disorders, serious side effects may include a slowed heart, otherwise known as bradycardia.<sup>203</sup>

At some point in the progress of the disease, the nerve endings will degenerate to the point that that these drugs are no longer effective.<sup>204</sup> These medications may be helpful for two to three years, possibly longer.<sup>205</sup>

#### Memantine

Memantine (also known as Ebixa, Novo, or Teva-Mamantine)<sup>206</sup> is prescribed alone or in combination with a cholinesterase inhibitor.<sup>207</sup> Memantine regulates the activity of glutamate, which is a neurotransmitter in the brain that is key to learning and memory.<sup>208</sup> Excess glutamate can be released from damaged cells, thereby encouraging further cell damage.<sup>209</sup>

The scientific evidence for the effectiveness of Memantine is positive. In a systemic review of double-blind, parallel-group, randomized control trial studies of memantine showed improvement in cognition, activities of daily living, and behaviours in people with moderate to severe Alzheimer's after 6 months of use.<sup>210</sup> The most frequently reported adverse events in memantine trials were dizziness,



headache and confusion, and a small group of patients have reported agitation.<sup>211</sup> Research indicates that acetylcholinesterase inhibitors and memantine may have an effect on behavioural symptoms.<sup>212</sup>

## 2.2.2 Medications for Management of Psychosis and Other Behavioural Disturbances

The choice of strategy for treatment of dementia-related behaviours raises challenging questions. Pharmacological approaches are often considered “off label” use, which refers to the fact that the drugs are being used for an unapproved indication, or in an unapproved age group, dosage, or route of administration<sup>213</sup>—in this case often for older people, or people living with dementia.

Best practices indicate that it may be appropriate to consider psychotropics for people living with dementia when:

- there is a significant risk of harm to the patient or others; or
- agitation with aggressive symptoms [is] persistent, recurrent or severe enough to cause significant suffering and distress to the person in care, or may cause significant interference with the delivery of care.<sup>214</sup>

However, use of such medication for people living with dementia has been well-studied, and shown to have either significant side effects, or limited benefits. As such, best practices indicate they should only be used with caution, and only in very specific circumstances.<sup>215</sup>

Many different classes of medications have been used to treat dementia-related behaviours. We discuss them briefly below.

### Anti-psychotic Medicines

Low doses of anti-psychotic medicines may help relieve severe psychotic and behavioural symptom, like agitation, wandering, and self-harm.<sup>216</sup> Drugs that are sometimes used to treat hallucinations, paranoia, and severe agitation in people who have dementia include aripiprazole, haloperidol, and risperidone.<sup>217</sup> When such medications are given to people who are older and frail, they induce a lethargy that can mask symptoms of other problems. Possible side effects of the use of anti-psychotics for older people include:

- Sedation and cognitive decline;
- Extrapyramidal symptoms, such as restlessness, tremors, rigidity, and involuntary movement;
- Anticholinergic effects, such as constipation, urinary retention, and blurred vision;
- Cardiovascular effects, such as orthostatic hypotension (low blood pressure upon standing<sup>218</sup>);
- Weight gain; and
- Diabetes.<sup>219</sup>

The side effects may make some symptoms of Alzheimer's disease worse, such as apathy, withdrawal from family and friends, and inability to think clearly.

Regulators have issued concerns about prescribing anti-psychotics for older people. There are currently no US Food and Drug Administration (FDA) approved pharmacologic interventions for treatment of dementia-related behaviour.<sup>220</sup> Health Canada has approved few pharmacologic interventions, and issued warnings regarding some medication use, including, according to the BC Ministry of Health, "advisories stating that people with dementia who use antipsychotics may die sooner than those who don't use these drugs."<sup>221</sup> Health Canada has approved use of Risperidone only for "short-term symptomatic management of aggression or psychotic symptoms in patients with *severe dementia of the Alzheimer type* unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others," specifically excluding the use in people with other forms of dementia, while emphasizing the increased risk of death.<sup>222</sup>

Studies which resulted in these advisories found that the rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group. In other words, the risk of death in drug-treated patients was 1.6 times more likely to result in death than those who were not given drugs.<sup>223</sup>

### Anti-anxiety Medicines

Anti-anxiety medicines, including minor tranquilizers, may relieve anxiety and mild agitation; however, they can also trigger further agitation in some older people.<sup>224</sup> Benzodiazepines may increase confusion, and upset a person's balance, raising the risk of falls.<sup>225</sup> Research has linked greater benzodiazepine use with quicker cognitive and functional decline for people with Alzheimer's disease, and in older people in general.<sup>226</sup> To avoid these problems, these drugs usually are stopped gradually after a few weeks of use.<sup>227</sup>

### Anti-convulsant Medication

Anti-convulsants, such as Valproate and carbamazepine, have been used in a variety of settings to control agitation, violent behaviour, and mood swings, including behaviours related to dementia, when other pharmaceutical approaches are ineffective. Research thus far indicates many potential side effects, such as sedation, low sodium levels, blood disorders, and rashes.<sup>228</sup> As noted by Neugroschl and Wang, "[g]abapentin and lamotrigine are used clinically, and are better tolerated by patients."<sup>229</sup> There is some evidence that the use of Carbamazepine may be effective, but the dosing, tolerability and medication interactions associated with this medication limit its clinical usefulness.<sup>230</sup> However, lamotrigine can cause a severe life threatening rash.<sup>231</sup>

### Anti-depressants

Diagnosing depression in people living with dementia can be a challenge because dementia and depression can produce similar symptoms, such as apathy, social withdrawal, and loss of interest in activities.<sup>232</sup> Serotonin reuptake inhibitors (SSRIs: fluoxetine, sertraline, paroxetine, citalopram, fluvoxamine) are largely considered to be among the most efficient anti-depressants to treat depression

in Alzheimer's disease.<sup>233</sup> However, there have been mixed results from research as to the effectiveness of some anti-depressants to treat depression in Alzheimer's disease and other dementias.<sup>234</sup> A recent research study concluded that there is limited evidence that anti-depressants are effective in treating depression for people living with dementia, or improving cognitive function.<sup>235</sup>

## Pain Medications

People living with dementia experience pain—as anyone may. Untreated pain contributes to further complications in treatment and care, and is a major contributor to reduced quality of life and disability.<sup>236</sup> Adequate pain management is not only important to overall well-being for people living with dementia; it can also lead to improvements in both behaviour, and the ability to perform activities of daily life.<sup>237</sup> In addition to the discomfort and distress caused by pain, the pain may be the underlying cause of behaviour which caregivers are finding challenging to manage, which can lead to inappropriate treatment with psychotropic medication.<sup>238</sup>

However, as pain is a symptom, and a matter of subjective evaluation, it can be challenging to recognize, diagnose, and treat the pain experienced by people living with dementia, at least partly because people living with dementia may have difficulty communicating the source of pain, or articulating their experience of it.<sup>239</sup> In addition, as noted in *Pain and Disability: Clinical, Behavioral, and Public Policy Perspectives*:

How an individual reacts to physical symptoms—be they pain or any other symptom—depends on his or her past experience with illness, personality and coping styles, familial and cultural norms, as well as interpersonal interactions. How symptoms are perceived and the meaning attributed to them may, in turn, powerfully influence their subsequent intensity and duration, the nature and extent of help-seeking behavior, and whether the person comes to view him- or herself as sick, impaired, and deserving of disability benefits.<sup>240</sup>

Research indicates that the pain experienced by older people is often inaccurately assessed in long-term care, leading to greater incidence of disease that could otherwise have been treated.<sup>241</sup> Further, clinical studies suggest that under-treatment of pain in older people with cognitive impairments is common, and poorly managed.<sup>242</sup>

Adequate pain control depends on good evaluation, and careful consideration of a person's drug treatment plan. Despite the challenges noted above, tools do exist to support health care professionals and staff in observing pain in a relatively objective manner.<sup>243</sup> As people living with dementia may not be able to provide an accurate history of pain symptoms, it is important to consistently review whether pain may be a contributing factor to a change in behaviour.

Like other drugs mentioned in this chapter, Tylenol and opioid pain medications can have side effects which can contribute to sedation, confusion, and mild cognitive impairment.<sup>244</sup> However, if prescribed carefully, a useful dose can sometimes be found that optimizes pain control and minimizes side effects.

### 2.2.3 Polypharmacy and Adverse Drug Reactions

Polypharmacy and inappropriate prescribing are risk factors for adverse drug reactions, which commonly cause severely negative outcomes in older people.<sup>245</sup> While polypharmacy is not homogeneously defined, generally it refers to the use of more than four<sup>246</sup> or five medications<sup>247</sup> simultaneously. Polypharmacy is common among older people: one population-based study found that 34% of older people were taking six to nine drugs.<sup>248</sup> Polypharmacy in older people has been demonstrated to be positively associated with an increased risk of having a diagnosis of dementia, with the rates of dementia diagnosis increasing steadily with the number of medications used.<sup>249</sup>

Adverse drug reactions in older people represent a serious and growing public health problem.<sup>250</sup> Older people are at an increased risk of adverse drug reactions because of age-related pharmacodynamic and pharmacokinetic changes.<sup>251</sup> Pharmacodynamics is “the effect of a drug on its target site”<sup>252</sup> while pharmacokinetics refers to “drug absorption, distribution, metabolism, and excretion.”<sup>253</sup> Additionally, as older people are often prescribed multiple medications, they are at increased risk for drug to drug interactions. For example, previous studies have shown that the use of psychotropic medications and opioid analgesics together increase the risk for hip fracture nearly three-fold compared to non-users of either medication.<sup>254</sup> Researchers have identified other medication combinations that present particular risks for older people.<sup>255</sup>

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*I think doctors, if we feel that we're doing the right thing, and the patient seems to be kind-of going along with it, or we haven't heard otherwise from the family, we sort of carry on with our work.”*

– Physician



## CHAPTER 3

# The Legal Framework Governing Health Care Consent in BC

*A person in a care facility needs [to provide] consent half a dozen times a day—wheelchair strap, bedrails, pureed diet, locked unit etc. . . Consent [needs to] to be lawful; but it's not reasonable.*

– Health authority staff

This chapter is the first of three chapters outlining aspects of law and regulation relevant to health care consent in BC. In this chapter we describe:

- The meaning of health care in BC law;
- The concept of informed consent—both the principles developed through court decisions, and the legal framework set out in BC's *Health Care (Consent) and Care Facility (Admission) Act (HCCA)*;
- Who has a legal obligation to obtain informed consent;
- The concept of mental capacity, and how it is determined;
- Statutory exceptions to the legal requirement to obtain informed consent to health care treatment;
- The concepts of substitute and supported decision making;
- Types of substitute decision makers for health care in BC;
- The relationship between mental health law and health care consent law in BC;

- Review options available to people living with dementia, their family members, and substitute or supportive decision makers who have concerns about health care treatment decisions, choice of substitute decision maker, and determinations regarding capacity for health care decision making;
- Access to justice issues facing people living with dementia who wish to challenge decisions relevant to health care.

Chapter 3 is the most lengthy of our three chapters on the law. We discuss the law in relation to use of chemical restraints in long-term care separately in Chapter 4. Chapter 5 examines the regulation of health care professionals, staff, and institutions involved in informed consent.

### 3.1 WHAT IS HEALTH CARE?

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Health care is an enormously broad concept, including a wide range of medication, treatment, and services delivered in diverse locations. Health care occurs in community, within people’s homes, and in the offices of physicians, psychiatrists, and other health care professionals. It happens in community health centres, mental health units, and pharmacies, and in facilities, ranging from acute care units in hospital to adult day programs a person attends daily, weekly, or monthly, to long-term care or assisted living facilities. In many of these environments the boundary between home and facility becomes blurred, because sites of care are temporary or ongoing communal living spaces where staff provide support or care—such as respite care, adult day programs, group homes for people with disabilities, assisted living residences, and long-term care facilities.

In the Royal Commission report on health care in Canada, Roy Romanow described the range of health care we experience across our lives as follows:

At one end of the spectrum are a wide variety of services that are covered by the public health care system: public health programs aimed at the prevention of illness such as the immunization of children; visits to family physicians, pediatricians or gynecologists; diagnostic tests; and day surgery. Moving across the spectrum, we find the complex and intense care that requires the increasing use of advanced technology as well as highly trained specialists and large support teams. In addition, long-term or continuing care is typically provided in nursing homes or other specialized residential settings for people who require ongoing medical attention and support but who do not need to be treated in hospitals. Palliative care is provided to people who are dying and is available in hospitals, hospices and, to a growing extent at home. Home care is an increasingly important component of health care that can allow people to avoid hospitalization or recover at home following a shorter hospital stay.<sup>256</sup>

The type of health care we receive will vary depending on a number of factors, including:

- the state of our health;
- our financial ability to pay for non-publicly-funded care;

- the availability of services in our community; and
- the values and beliefs that underlie our choices about care.

As will be discussed throughout this report, what kind of care we are offered or receive will also depend on our ability to exercise choice effectively within the various environments and relationships within which health care is delivered.

In BC, the *HCCA* defines health care broadly to include “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health,”<sup>257</sup> including:

- (a) a series or sequence of similar treatments or care administered to an adult over a period of time for a particular health problem,
- (b) a plan for minor health care that
  - (i) is developed by one or more health care providers,
  - (ii) deals with one or more of the health problems that an adult has and may, in addition, deal with one or more of the health problems that an adult is likely to have in the future given the adult’s current health condition, and
  - (iii) expires no later than 12 months from the date consent for the plan was given, and
- (c) participation in a medical research program approved by an ethics committee designated by regulation”.<sup>258</sup>

Health care thus includes not only single treatments and procedures, and a course of treatments over a period of time, but also treatment plans that capture both current health issues, and those likely to arise in the future, as well as participation in a research initiative. In other words, health care includes discrete and continuing activities. As will be discussed later in this report, the inclusion of treatment plans within the legislation can result in some uncertainty about when and how often health care professionals and staff working in long-term care must obtain informed consent to provide treatment.

### 3.1.1 Major versus Minor Health Care

BC law creates a distinction between minor health care and major health care. Major health care includes major surgery, any treatment involving a general anesthetic, and major diagnostic or investigative procedures,<sup>259</sup> specifically including radiation therapy, intravenous chemotherapy, kidney dialysis, electroconvulsive therapy, and laser surgery.<sup>260</sup> Everything else is minor health care, including routine tests and routine dental treatment.<sup>261</sup> The distinction matters because in some instances the legal requirements regarding consent may hinge on whether the care is categorized as major or minor. For example, in long-term care a number of forms of minor health care can be consented to in advance through the care plan. Further, some forms of major health care cannot be consented to by a substitute decision maker (see Section 3.7 below). However, informed consent to treatment by the appropriate decision maker is required whether the care is classified as minor or major care.

### 3.1.2 Health versus Personal Care

At law, not every intervention provided by health care staff to support a person's well-being meets the definition of health care. In both institutional care settings, and the home environment, health care staff and contractors deliver some services that are categorized as personal care as opposed to health care. Personal care includes assistance with activities of daily living, such as bathing, dressing, and toileting. The consent provisions of the *HCCA* do not apply when performing personal care services; although it should be noted that the common law doctrine of informed consent, discussed below, applies to the provision of personal care services.<sup>262</sup>

It is not always clear which tasks are health care, and which are not.<sup>263</sup> The recent BC Supreme Court decision of *Bentley v. Maplewood Seniors Society* clarified that feeding with a spoon or glass was a personal care service, and not a form of health care, even when administered by health care staff, within a long-term care environment.<sup>264</sup> The Court found the legislation did not support the family's right to refuse personal care services on the person's behalf because the provisions of the *HCCA* did not apply.<sup>265</sup>

### 3.1.3 Withdrawal of Care may be Health Care

The Supreme Court of Canada decision of *Cuthbertson v. Rasouli* discussed the meaning of the term health care. Although the case was decided pursuant to Ontario legislation, which uses the wording "treatment", as opposed to "health care," the definition in each province's statute has similarities.

The case concerned whether the withdrawal of life support fell within the definition of "treatment" contained in Ontario's *Health Care Consent Act*.<sup>266</sup> The Court considered the meaning of "health related purpose", a phrase common to both BC and Ontario legislation—the BC version is "purpose related to health care"—and found that the legislation did not limit the concept of a health-related purpose to what is considered medically beneficial to the patient, but rather defined the concept more broadly. The court considered the meaning of the terms "therapeutic" and "preventative," noting the following *New Oxford Dictionary of English* (1998) definition of "preventive":

[42] The same dictionary defines "preventive" as describing a medicine or other treatment "designed to stop disease or ill health from occurring" or "designed to keep something undesirable such as illness, harm, or accidents from occurring" (p. 1469)...<sup>267</sup>

Ultimately, the Court found that "treatment" includes the withdrawal of treatment.

It is uncertain whether withdrawal of life support is health care in BC. In *Bentley*, the BC Supreme Court decision accepted that the meaning of health care was broad in BC, but not broad enough to include oral nutrition and hydration, and cautioned against importing definitions from other provinces and territories. The judge stated:

It is clear that jurisdictions in Canada have taken different, in fact sometimes contradictory, approaches to the definition of health care. There is no evidence in this case that



in passing the *HCCCFA Act* in 1993 the British Columbia legislature considered other jurisdiction's definitions of health care.<sup>268</sup>

However, the Supreme Court of Canada's discussion of the meaning of "health-related purpose", "therapeutic" and "preventative" in *Rasouli* may still provide some guidance on the meaning of health care in the BC, beyond the issue of oral nutrition and hydration.

### 3.1.4 Health Care Decisions versus Care Facility Admission Decisions

BC law draws a distinction between health care decisions and care facility admission decisions. Both were covered in the original drafting of the *HCCA*; however, at the time of writing, the care facility admission provisions<sup>269</sup> are not yet in force. Fourteen years after its initial introduction to Parliament in 1993, and after several amendments, repeals and further amendments, the BC Government announced on March 9, 2017 that it would bring into force Part 3 of the *HCCA*, as recommended by BC's Ombudsperson.<sup>270</sup> The announcement came as part of the government's announcement that BC would be investing \$500 million dollars over the next four years as part of a Ministry of Health action plan to improve care for seniors across the system.<sup>271</sup> The newly elected government has announced subsequent delays; however, at the time of writing, the plan appears to be that care facility regulations will soon be published, and the legislation and regulations brought into force in 2019.

Currently, the process of care facility admission is largely unregulated, with neither the *Community Care and Assisted Living Act (CCAL Act)* nor the *Hospital Act* containing any specific regulation of the admission process, including regarding consent. In terms of planning in advance for decision making regarding care facility admission, a standard section 7 representation agreement cannot cover admission to a long-term care facility.<sup>272</sup> Authority for care facility admission requires an agreement made under section 9, and is thus subject to the higher capacity standard discussed below.

Once brought into force, care facility admission provisions will apply to admission to a "care facility," defined as:

- Community care facilities licensed under the *CCAL Act*;
- Residences providing care to more than two persons, in the form of three or more prescribed services within the meaning of the *Act* but which are not licensed under the *CCAL Act*;
- Private hospitals under Part 2 of the *Hospital Act*; and
- Extended care hospitals providing long-term care under the *Hospital Act*.<sup>273</sup>

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*Oftentimes health care professionals really aren't educated in what kind of choices people have... I took one lady to a doctor's appointment, and she was a First Nations elder, and I took her to a doctor's appointment and the doctor looked at me and said, why isn't she in a home? And I said, because she doesn't want to.*

– Social worker

*There are situations where people are suffering horrific pain. You know, significant pain. And their legal substitute decision makers refuse the appropriate clinical interventions to help them. And not only is the adult in pain, the incapable adult, but, you know, others are hearing an adult in pain, and health care professionals are watching a person be in pain... we've had people with really awful hallucinations. Scary, horrifying, you know? And then people are refusing treatment.*

– Health authority staff

It is the manager of a care facility (not a health care provider) who will have the duty to ensure consent is obtained prior to admission, whether from the adult or the substitute decision maker (with the exception of admission without consent in emergency circumstances).<sup>274</sup>

The absence of care facility admission provisions has created challenges with respect to facility admission for people living with dementia who do not have capacity to provide consent. If there is neither a representative nor a personal guardian with authority to consent to care facility decisions, the absence of legislation in this area can result in circumstances in which no one has authority to consent to admission.<sup>275</sup>

## 3.2 INFORMED CONSENT TO HEALTH CARE

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### 3.2.1 The Common Law Doctrine of Informed Consent

Health care consent law has its roots in the common law. The modern common law doctrine of informed consent has arisen relatively recently, commencing with the foundational 1980's Supreme Court of Canada decisions of *Hopp v. Lepp*<sup>276</sup> and *Reibl v. Hughes*.<sup>277</sup> These cases have been described as having “had a monumental effect on consent litigation in Canada.”<sup>278</sup> They have been characterized as resulting in a more patient-centred approach to the standards of disclosure, which accord greater respect for individual autonomy and judgment, in contrast with the more paternalistic approach to physician knowledge which previously dominated.<sup>279</sup>

A doctor's duty to disclose information regarding a patient's treatment can be traced back to at least the second half of the 20<sup>th</sup> century, and is rooted in common law principles of beneficence, autonomy, and the right to bodily integrity. As put by Robins JA in *Fleming v. Reid*:

The right to determine what shall, or shall not, be done with one's own body, and to be free from non-consensual medical treatment, is a right deeply rooted in our common law. This right underlies the doctrine of informed consent. With very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination.<sup>280</sup>

The Supreme Court again confirmed the modern doctrine of informed consent in *AC v. Manitoba*, citing an excerpt from the leading case of *Malette v. Shulman*:<sup>281</sup>

A competent adult is generally entitled to reject a specific treatment or all treatment, or to select an alternate form of treatment, even if the decision may entail risks as serious as death and may appear mistaken in the eyes of the medical profession or of the community. Regardless of the doctor's opinion, it is the patient who has the final say on whether to undergo the treatment ... The doctrine of informed consent is plainly intended to ensure the freedom of individuals to make choices concerning their medical care.<sup>282</sup>

The doctrine requires health professionals to obtain a patient's consent prior to the administration of medical treatment,<sup>283</sup> and to abide by a patient's wishes to refuse treatment regardless of the consequences to the health of the patient. In other words, a competent patient cannot be forced to accept medical treatment in their "best interests" in the face of their refusal. The patient's consent must be voluntary, and informed by knowledge of the nature of the procedure, its risks, benefits, and alternative treatments.<sup>284</sup>

The Courts have confirmed that the right to bodily integrity also includes the right to withdraw consent to treatment already commenced.<sup>285</sup>

### Material Risk and the Duty of Disclosure

Former Chief Justice Laskin first articulated the scope of the duty of disclosure in *Hopp v. Lepp*, holding that a patient's consent must be informed by information disclosed by the doctor prior to treatment.<sup>286</sup> In particular, the doctor has a duty to answer questions and provide information as to the nature of the treatment, its gravity, and material and special risks:

[I]n obtaining the consent of a patient for the performance upon him of a surgical operation, a surgeon, generally, should answer any specific questions posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation.<sup>287</sup>

Laskin CJ elaborated on the question of what constitutes a "material risk" in *Reibl v. Hughes*:

[E]ven if a certain risk is a mere possibility which ordinarily need not be disclosed, yet if its occurrence carries serious consequences, as for example, paralysis or even death, it should be regarded as a material risk requiring disclosure.

Material risks have been interpreted as "significant risks that pose a real threat to the patient's life, health or comfort."<sup>288</sup> Statistical probability of a risk occurring is relevant, but not necessarily the sole factor to be used to determine the materiality of a risk.<sup>289</sup> A risk which is statistically extremely unlikely to eventuate may still be considered material if the risk has serious consequences, such a stroke, paralysis or death.<sup>290</sup> Special risks which may not be relevant to most patients may be important to the

particular patient, and as such should be disclosed as a material risk. However, while the doctor has the burden of determining whether a patient has unique circumstances warranting disclosure of special risks, the patient has an obligation to communicate that “the patient’s position, interests, or values are unusual in some potentially significant way” with the doctor.<sup>291</sup>

The duty of disclosure requires not only that risks be disclosed, but also that general information as to the nature of the procedure, and any alternatives to the treatment be provided.<sup>292</sup> Time to digest the information is required, as is a suitable environment for assessing the information.<sup>293</sup>

A valid withdrawal of consent also requires that the patient understand the nature and consequences of the withdrawal.<sup>294</sup> In the circumstances of a withdrawal of consent after treatment has commenced, the doctor may be required to disclose further information before consent to proceed once again could be considered informed. In such a case, “[t]he appropriate approach is, once again, to focus on what the patient would like to know concerning the continuation of the process once the consent has been withdrawn.”<sup>295</sup>

### The Reasonable Person Standard in Health Care Law

Modern health care consent law rejected the earlier professional standard of disclosure, which purely referenced medical standards to determine what should be disclosed to the patient. The “reasonable patient” standard of disclosure requires a doctor to pre-disclose what a reasonable person in the plaintiff’s position would consider relevant to their health care decision making.<sup>296</sup> The “reasonable patient” standard comprises a mixture of objective and subjective factors, including consideration of medical knowledge of material risks of a procedure, and what the patient themselves would consider relevant.<sup>297</sup> More recent cases have affirmed and elaborated on the principles enunciated in these seminal cases, clarifying the standard for disclosure. In 1993, the Supreme Court Canada stated in *Ciarlariello v. Schacter*:

*Reibl v. Hughes, supra*, indicates that the disclosure which must be made to a patient will often be more than that which the medical profession might consider appropriate to divulge. Although expert medical evidence on this issue is still relevant, it is no longer decisive in determining whether or not sufficient information was given to a patient to enable that patient to make an informed consent. The test now focuses on what the patient would want to know.<sup>298</sup>

Importantly, there is no corresponding obligation of a capable adult to make a health care decision others might consider reasonable. A capable adult can make any decision they choose regarding their own health care. The reasonable person standard applies exclusively to the physician’s duty of disclosure.

### The Adult’s Understanding of Medical Information

The Supreme Court in *Ciarlariello* has also affirmed that the duty to disclose includes a duty on the doctor to ensure that the patient understands the information provided:

Prior to *Reibl v. Hughes*, there was some doubt as to whether the doctor had the duty to ensure that he was understood. However, Laskin C.J. made it quite clear in that case that it was incumbent on the doctor to make sure that he was understood, particularly where it appears that the patient had some difficulty with the language spoken by the doctor... Indeed, it is appropriate that the burden should be placed on the doctor to show that the patient comprehended the explanation and instructions given.<sup>299</sup>

In *Ciarlariello*, the doctor was aware of the patient's difficulties with the English language, and of the stress she was under, and took care to ensure the woman understood the nature of the procedure. The trial judge found that she demonstrated her understanding by her ability to converse with, and respond appropriately to, questions and instructions given to her by the doctors. As such, the Court concluded that despite the fact that a translator was not present during the angiogram, the patient had given valid consent to continue with the procedure.<sup>300</sup>

Robertson provides examples of other circumstances in which a person's understanding of a doctor's disclosure was in issue, including after a long labour, or when a doctor used overly technical terminology.<sup>301</sup> The doctor's burden to ensure comprehension is not exhaustive: "the burden is placed on the doctor to show that she took reasonable (not exhaustive) steps to ascertain whether the patient understood the message being conveyed."<sup>302</sup>

In the subsequent Ontario Court of Justice case of *Lue v. St. Michael's Hospital*, the court stated that with respect to establishing whether consent by the patient is "informed", "[t]he focus has been on what the physician imparts, not on how the patient receives it, absorbs it and acts on it. The effect on the recipient of the information and the ability to comprehend the options presented are equally as important as the message the physician communicates."<sup>303</sup> The Court went on to set out a list of objective criteria by which the degree of patient understanding can be determined, beyond a physician's assertion. These include whether:

- The patient asked pertinent questions;
- Sufficient time was spent providing the information;
- Visual aids were used, if relevant;
- Information was put in writing; and
- The patient utilized family assistance in understanding the information.<sup>304</sup>

### Exceptions to the Common Law Duty

There are several common law exceptions to the duty of a physician to disclose information to a patient prior to treatment. They are:

- Therapeutic privilege;
- Waiver of the right to information; and
- Emergency circumstances.<sup>305</sup>

Therapeutic privilege is where a doctor may be justified in withholding information on the basis of the fragile emotional state of the patient, thereby avoiding causing the patient too much anxiety.<sup>306</sup> Despite recognizing that consent had to be based on sufficient information, the therapeutic exception privilege was still very prominent in the earliest informed consent cases which appeared in US case law in the 50's. The concept that such information sharing could be restricted to avoid harm to the patient was still firmly in play. The exception was considered in Canada, in a decision of the Alberta Court of Queen's Bench, where it was interpreted very narrowly,<sup>307</sup> and it was argued by some that the exception should only be applied in rare circumstances.<sup>308</sup>

A second exception to the duty of disclosure is where a patient waives the right to information, agreeing to trust the doctor's judgment instead. A third exception is where a competent adult requires emergency health care but is unable to consent because, for instance, they are unconscious.<sup>309</sup>

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*Everyone knows in medicine that every drug has a side effect, including Graval. So you don't give a pill without recognizing the side effects and, again, you don't give a pill without consent.*

– **Physician**

### 3.2.2 Informed Consent under the BC's Health Care Consent Law

#### Consent Rights

While all jurisdictions have some form of substitute decision making legislation, only Ontario, BC, Prince Edward Island, Quebec, and the Yukon have a general statutory requirement to obtain informed consent prior to providing medical treatment.<sup>310</sup> Health care consent legislation in these jurisdictions clarifies and enhances health care consent rights.

In BC the *HCCA* confirms that every adult who has mental capacity to make the decision has the right to accept, refuse, or discontinue any form of health care, regardless of the potential impact of that decision on their health. In most instances—we discuss the exceptions below—consent from the appropriate individual is a prerequisite for providing health care. The *HCCA* describes the right to health care consent as follows:

Every adult who is capable of giving or refusing consent to health care has

- (a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death,
- (b) the right to select a particular form of available health care on any grounds, including moral or religious grounds,
- (c) the right to revoke consent,
- (d) the right to expect that a decision to give, refuse or revoke consent will be respected, and
- (e) the right to be involved to the greatest degree possible in all case planning and decision making.<sup>311</sup>

The language of the statute confirms that notions of best interests have no place in managing people's choices about their own health care; rather, for capable adults, autonomy of decision making is paramount. Adults who have capacity to make health care decisions are permitted to make choices that may result to harm to themselves, and even end their lives.<sup>312</sup>

As set out in the above discussion of common law, a fundamental aspect of the right to consent is that it includes not only the right to make the choice, but also the right to sufficient information in order to make an informed decision. The *HCCA* states that a health care provider is required to “give the adult the information a reasonable person would require to understand the proposed health care and to make a decision,” including information about:

- (i) the condition for which the health care is proposed,
- (ii) the nature of the proposed health care,
- (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and
- (iv) alternative courses of health care.<sup>313</sup>

The law also requires that “the adult has an opportunity to ask questions and receive answers about the proposed health care.”<sup>314</sup> The requirement to provide this degree of contextual information in order support decision making underscores that consent must be specific to a procedure or course of treatment. For a person receiving ongoing care, consent can be a multi-stage process, where the adult provides consent for various aspects of care throughout the health care relationship. Consent must also be provided voluntarily, without fraud or misrepresentation.<sup>315</sup>

Importantly, the language of the statute implies discussion and dialogue with the adult considering health care. The law states that during the process of obtaining consent the health care provider must communicate with the adult in a manner appropriate to the adult's skills and abilities, and allow family or close friends to assist the adult to communicate.<sup>316</sup> Difficulty in communication should thus not be a barrier to decision making. Consent can be given orally, in writing, or may be inferred from conduct, such as offering an arm for an injection or opening a mouth to receive medication. It can also be given, with some restrictions, by way of an advance directive (discussed further below).<sup>317</sup>

The inclusion of the above language in the statute is very important from a disability and human rights perspective. It tempers the reference to “a reasonable person” with consideration of the unique abilities of the person who is providing consent, imposing on health care providers seeking consent the obligation to communicate with people exercising consent rights in a manner that accommodates disability related needs, and abilities connected to communication. Such obligations have particular relevance for people living with dementia, who may have difficulty with memory and language.

The elements of consent in all jurisdictions are essentially the same, with the exception of Quebec's Civil Code, which does not contain statutory elements of consent. All consent to treatment statutes require that the consent relate to the proposed treatment, be informed, voluntary, and not obtained through misrepresentation or fraud. There exist only minor differences in the information that health care providers must provide in each jurisdiction in order for consent to be informed.<sup>318</sup>

## Exclusion for Psychiatric Treatment

Unique to BC, an adult who is involuntarily committed under the province’s mental health statute does not have the right to consent to psychiatric treatment, regardless of whether or not the person has capacity to consent to treatment, and even where the adult has been transferred to another facility, or released into community on leave.<sup>319</sup> The *HCCA* contains an exclusion which effectively protects the operation of the provisions of BC’s *Mental Health Act (MHA)*, discussed below in Section 3.8, which give the director of a designated facility the authority to make psychiatric treatment decisions for an adult involuntarily committed under that law.<sup>320</sup> Consent to health care for a physical illness or injury, however, is still governed by the *HCCA*, despite any involuntary admission.

## The Care Plan

The obligation to get prior informed consent applies to the proposed health care. The *HCCA* defines “health care” broadly to include:

- (a) a series or sequence of similar treatments or care administered to an adult over a period of time for a particular health problem,
- (b) a plan for minor health care that
  - (i) is developed by one or more health care providers,
  - (ii) deals with one or more of the health problems that an adult has and may, in addition, deal with one or more of the health problems that an adult is likely to have in the future given the adult’s current health condition, and
  - (iii) expires no later than 12 months from the date consent for the plan was given, and
- (c) participation in a medical research program approved by an ethics committee designated by regulation.<sup>321</sup>

Therefore a person may consent to either a specific medication, or a “plan for minor health care” that addresses both existing health problems, and problems that are likely to occur in up to a twelve month period. Surgery is an example of a form of treatment that cannot be addressed in advance via the care plan—surgery is, by statutory definition, a form of major health care,<sup>322</sup> as are kidney dialysis, radiation therapy, and intravenous chemotherapy. The list of items that constitute major health care is very short, and therefore, a great variety of treatments can be consented to in advance via the care plan. Where a person has capacity to consent to a form of treatment themselves, they are always entitled to refuse treatment when it is offered. However, if the person does not have capacity, and a substitute decision maker participates in the development of the care plan, the care plan operates as a kind of advance substitute consent regarding anticipated care needs.

The *RC Regulation* identifies what must be included in a care plan.<sup>323</sup> In terms of items that might fall within a definition of health care, a care plan must include:

- (i) medication, including self-administered medication if approved under section 70
- (4) [*administration of medication*],
- (ii) behavioural intervention, if applicable, and



(iii) if there is agreement to the use of restraints under section 74 (1) (b) [when restraints may be used], the type or nature of restraint and the frequency of reassessment.<sup>324</sup>

The use of the phrase “to the extent reasonably practical” in the *RC Regulation* appears inconsistent with the requirement for consent to the provision of the health care which forms part of the care plan. The regulation states:

- 83(2) A care plan must be developed, to the extent reasonably practical,
- (a) with the participation of
    - (i) the person in care, or
    - (ii) if the person in care is not capable of participating, the person in care’s parent or representative, and
  - (b) in a manner that takes into account the unique abilities, physical, social and emotional needs, and cultural and spiritual preferences of the person in care.

### 3.3 WHO IS REQUIRED TO GET CONSENT?

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In BC, it is the legal obligation of the health care provider to obtain informed consent. A health care provider is someone who is licensed, certified, or registered to provide health care under the *Health Professions Act*, or the *Social Workers Act*.<sup>325</sup>

There are currently 25 self-regulated professions under the *Health Professions Act*.<sup>326</sup> They include:

- Physicians and surgeons<sup>327</sup>
- Nurses, including registered nurses, registered psychiatric nurses, and licensed practical nurses
- Occupational and physical therapists
- Audiologists
- Chiropractors
- Dentists, denturists, and dental hygienists
- Dietitians
- Massage therapists
- Opticians
- Pharmacists
- Podiatrists
- Psychologists
- Speech language pathologists

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*The best practice you know, when there is a serious illness, the physician would actually come and do an assessment rather than order over the phone. I mean, I receive complaints all the time from the nurses saying that the physician refused to come to see the person.*

– Nurse

As such, the obligation to obtain consent cannot fall to a health care assistant, or even the director of a care facility (unless the person is also a health care provider). Unlike nurses, physicians and allied health professionals, care aides and health assistants—referred to in this report in the care facility context as health care assistants (HCAs)—are not registered professionals, nor are they licensed.<sup>328</sup> They are not included in the definition of “health care provider” contained in the *HCCA*, and so do not have a statutory duty to get consent for the care they provide.<sup>329</sup> Facility administrators also do not have any statutory obligation under the *CCAL Act* to ensure consent was provided within the agency for which they oversee care. However, HCAs provide the bulk of the day-to-day care of residents, under the supervision and direction of registered and licensed practical nurses. We discuss their work in greater detail in chapter 5.

## 3.4 MENTAL CAPACITY

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### 3.4.1 What is Mental Capacity?

At law, the terms mental capability and mental capacity are used interchangeably, with the term capacity figuring in some statutes or jurisdictions, and the term capability in others. In some instances, the term competence is also used, although not in BC legislation. For the purpose of this report we use the term capacity.

Definitions of capacity vary across jurisdiction and have evolved over the years. The key to most recently revised definitions is the notion that a capable adult must be able to understand information, evaluate relevant data, and appreciate the consequences of the decision. Elsewhere we have characterized this approach to the definition as a functional approach.<sup>330</sup> In this sense capacity is about a person’s decision making process, and it is neutral as to the outcome of that process.<sup>331</sup> Also, whether a person has capacity is not determined by the presence of disability or disease, but rather by their particular cognitive processes, and their experience of living with that disability or disease.

The *HCCA* takes a functional approach to capacity. The Act states:

How incapability is determined

7 When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands

- (a) the information given by the health care provider under section 6 (e), and
- (b) that the information applies to the situation of the adult for whom the health care is proposed.

The *HCCA* reflects a decision-specific approach to capacity by linking the capacity test to the decision at issue.<sup>332</sup> This decision-specific approach reflects the idea that a person could be capable of some health care decisions, but not others. Considering more specifically the community we consider in this report, some people living with dementia may be able to consent to health care, some not. Some may be able to consent to some forms of health care, but not others. For people with dementia, decision making capacity can change from day to day, and even hour to hour. A person could be capable of

making their health care decisions regardless of whether they are capable of making other decisions that are personal, financial, or legal in nature.

As we have noted in another report, Canadian law generally recognizes that there is no single or global test of capability; “instead, the law has developed many different tests of capacity, each geared to a specific type of transaction or relationship.”<sup>333</sup> Some of these tests have emerged out of the common law; some have been codified in statutes. In the context of health care consent, the concept was developed in court decisions, and later codified in the *HCCA*. As noted earlier, this makes BC fairly unique among Canadian jurisdictions: only Ontario, BC, Prince Edward Island, Quebec, and the Yukon have a general statutory requirement to obtain informed consent prior to providing medical treatment.<sup>334</sup>

### 3.4.2 Determining and Confirming Capacity

The language of the *HCCA* requires a health care provider to confirm capacity on multiple occasions. The Act requires the health care provider not to seek substitute consent “unless he or she has made every reasonable effort to obtain a decision from the adult.”<sup>335</sup>

Where a health care provider has selected a temporary substitute decision maker due to a determination that the adult does not have capacity, the Act requires the health care provider to confirm in writing that the adult is still incapable no more than 21 days before the health care treatment is to begin.<sup>336</sup> The section adds that “whether or not the health care that is the subject of the decision made under subsection (1) has begun, if at any time a health care provider has reasonable grounds to believe that the adult may be capable of giving or refusing consent to health care, the health care provider must again determine whether the adult remains incapable.”<sup>337</sup> If the adult has capacity, the authority of the substitute decision maker is terminated, and the health care provider must obtain consent from the adult.<sup>338</sup>

## 3.5 EXCEPTIONS TO THE REQUIREMENT TO OBTAIN CONSENT

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There are three limited exceptions under the *HCCA* to the requirement to obtain the prior consent of the adult to health care treatment: incapacity;<sup>339</sup> emergency;<sup>340</sup> and preliminary examination.<sup>341</sup>

### 3.5.1 Incapacity

Where an adult has been determined by the health care provider to be incapable of making a decision, the health care provider can still provide the recommended treatment if the adult’s substitute decision maker has authority and capacity to consent, and does so.<sup>342</sup> The substitute decision maker consenting on the adult’s behalf may be the adult’s personal guardian or representative,<sup>343</sup> or where no personal guardian or representative exists, a temporary substitute decision maker appointed under this legislation (temporary substitutes are discussed below)<sup>344</sup> The health care provider has the same obligations to the substitute decision maker as to the adult receiving health care, whether it be a personal guardian, representative, or temporary substitute decision maker, in terms of ensuring consent is voluntary and

informed, namely, that the means of communication is appropriate, that the substitute decision maker in fact has capacity, and regarding the manner in which consent may be expressed.<sup>345</sup> Who can act as a substitute decision maker and the rules governing their conduct are discussed below.

### 3.5.2 Emergency

If an adult is found to be incapable of consenting to health care, a health care provider may provide the health care immediately “in order to preserve the adult’s life, to prevent serious physical or mental harm or to alleviate severe pain,”<sup>346</sup> so long as there is no capable substitute decision maker reasonably available given the circumstances to give or refuse consent.<sup>347</sup> In addition, where practicable, the health care provider must obtain a second opinion supporting the need for emergency treatment, and of the adult’s incapacity.<sup>348</sup> Further, there is a blanket provision preventing the health care provider from providing emergency health care which is believed on reasonable grounds to be contrary to the capable adult’s known expressed wishes.<sup>349</sup> This latter provision was included by way of amendment to the *HCCA* in 2002 in order to align the legislation with what was already occurring in practice at the time, and as clarified by appeal court decisions and legislation in Ontario.<sup>350</sup> If a substitute decision maker becomes available after treatment has commenced, their request to withdraw the treatment must be respected.<sup>351</sup>

### 3.5.3 Preliminary Examination

The *HCCA* permits health care providers to undertake triage or another kind of preliminary examination, treatment, or diagnosis of an adult, without first obtaining the consent of the adult, if either the adult indicates they are seeking health care, or failing this, the adult’s spouse, near-relative or close friend does so.<sup>352</sup>

As noted above, the issue of involuntary psychiatric treatment is not governed by the *HCCA*, but instead by the *MHA*, and is discussed separately below. It should also be noted that there are also some exceptions to the requirement to obtain consent contained in legislation other than the *HCCA*, such as the *Public Health Act* in the context of the control of contagious diseases.<sup>353</sup> However, discussion of these topic is outside the scope of this report.

These three broad exceptions are fairly standard in Canadian health care consent statutes. Ontario and PEI use the definition of “treatment” to exclude the requirement to obtain consent in the case of assessment or examination,<sup>354</sup> whereas BC and the Yukon make an express exception to the consent requirement in the case of preliminary examinations, to the same end. PEI and Ontario, but not other jurisdictions, exclude from their definitions of “treatment” treatment that poses little or no risk of harm to the person, thereby removing any requirement to obtain consent in such instances.<sup>355</sup> Quebec’s Civil Code concerns consent to “care of any nature” which is stated to include “examination, specimen taking, removal of tissue, treatment or any other act.”<sup>356</sup>

Each of these provinces’ legislation contains an exception to the requirement to obtain consent in the case of an emergency involving a situation where:

- There is a risk of imminent serious bodily harm, pain or suffering if treatment is not provided without delay;
- The person does not have capacity to consent; and
- A substitute decision maker is not available.

There are minor variations in the wording of this exception. In Quebec, however, this exception is tempered by the requirement that even in an emergency, consent must be obtained “where the care is unusual or has become useless or where its consequences could be intolerable for the person.”<sup>357</sup> All of these jurisdictions, except Quebec, include an exception in the case of a substitute decision maker who has refused treatment in an emergency where the health care provider believes the substitute decision maker has not complied with their statutory obligations in refusing the treatment.

### 3.6 SUPPORTED DECISION MAKING

Some people who do not have the capacity to make health care decisions independently may be able to make decisions with support. The concept of supported decision making emerged from disability advocacy as an alternative to guardianship. The Mental Disability Advocacy Centre characterizes the following principles as being at the heart of supported decision making:

- The person retains their full legal capacity;
- The person himself/herself makes the decision. The role of supporters is to assist this person to reaching his/her own decisions;
- There is a relationship of trust between the person making the decision and the supporters;
- Such a system must be borne of the free agreement of the adult and the supporter(s);
- There is usually a supporting group or network around the person making the decision;
- The role of supporters is to assist the person making the decision to communicate his/her intentions to others and help him/her understand the choices at hand; and
- Supporters are usually unpaid and could include friends, family, and/or members of the community.<sup>358</sup>

The concept of supported decision making is grounded in the idea that “interdependence is a normal method of decision-making for everyone,”<sup>359</sup> and decision-making is inherently social. Many people naturally make decisions in consultation with people they trust; however, for some people with disabilities, supported decision making effectively enhances capacity, allowing a person who might otherwise be

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*The legal representative is someone you consult with about values, about goals of care, about advance care planning, not about day-to-day medication decision making.*

– **Physician**

considered incapable to participate robustly in decision making. Supported decision making regimes recognize the rights and responsibilities of the supportive decision makers.

In BC, supported decision making is legally recognized under the *Representation Agreement Act (RAA)*, which allows a person to enter into an agreement authorizing another person to help them with their decision making.<sup>360</sup> The word “supported” is not found anywhere in the legislation. The word “help” is used in section 7 of the Act. Section 7 states that “[i]n a representation agreement made under this section, an adult may authorize his or her representative to help the adult make decisions, or to make decisions on behalf of the adult.”<sup>361</sup> Representation agreements made under section 7 can cover:

- Personal care;
- “[R]outine management of the adult’s financial affairs”;<sup>362</sup>
- Most major and minor health care; and
- Some legal decisions and instructions to a lawyer.<sup>363</sup>

The statute distinguishes between agreements created pursuant to sections 7 and 9 of the Act. The Act sets out a more onerous standard of capacity for section 9 agreements (discussed below), which can address personal and health care decisions that arguably permit greater invasion on the person’s autonomy. Although the word “help” does not appear in section 9, the section permits an adult to “authorize his or her representative to (a) do anything that the representative considers necessary in relation to the personal care or health care of the adult.”<sup>364</sup> This broad reference to powers may include supported decision making.<sup>365</sup>

The representation agreement regime for supported decision making provides legal recognition and legal structure to a social relationship that ideally supports capacity for decision making on a range of subjects chosen by the adult creating the agreement, including, potentially, many health care decisions. By virtue of the legal recognition, third parties, such as health care professionals, have an obligation to recognize the role of the supportive decision makers, and share with them information relevant to decision making.

BC is one of the first jurisdictions in the world to have recognized supported decision making through legislation. There was a strong tradition of supported decision making that existed before the legislation came into effect in BC, which fueled advocacy for inclusion of supported decision making in the *RAA*. Some types of supported decision making relationships are now recognized in the laws of Yukon, Alberta, and Saskatchewan. Yukon and Alberta are the only other jurisdictions in Canada where adults may enter into agreements regarding supported decision making.<sup>366</sup> In other jurisdictions, court intervention is required to grant authority.

Although not set out in BC legislation, our research<sup>367</sup> indicates that supportive decision makers “support” a person to:

- Understand the issues involved in a decision;
- Understand the consequences of a decision;

- Access the appropriate assistance or information to help them make a decision; and
- Express their views, and act as interpreter where needed.

A supportive decision maker can help others to:

- Truly hear or understand a person who requires support;
- Appreciate the person’s needs, rights, values, preferences and goals; and
- Respect the person’s autonomy, dignity and wisdom—in other words, help prevent discrimination and bias linked to disability.

Yukon’s *Decision-Making Support and Protection to Adults Act* contains a description of the responsibilities of an associate decision-maker, which is the name for a supportive decision maker in that jurisdiction.

**Responsibilities of an associate decision-maker**

5(1) Except as a supported decision-making agreement otherwise provides, the responsibilities of the associate decision-maker are

- (a) to assist the adult to make and express a decision;
- (b) to assist the adult to obtain relevant information;
- (c) to advise the adult by explaining relevant information and considerations;
- (d) to ascertain the wishes and decisions of the adult and assist the adult to communicate them; and
- (e) to endeavour to ensure that the adult’s decision is implemented.<sup>368</sup>

Supported decision making may be a good option for some people living with dementia who have diminished capacity for independent decision making. A representation agreement for supported decision making allows health care providers to obtain consent from the person living with dementia as opposed to one of the substitute decision makers discussed in Section 3.7 below.

The *HCCA* briefly recognizes the role of supported decision making for health care. Section 8, which addresses the “duty to communicate in an appropriate manner”, states that:

**Duty to communicate in appropriate manner**

8 When seeking an adult’s consent to health care or deciding whether an adult is incapable of giving, refusing or revoking consent, a health care provider

- (a) must communicate with the adult in a manner appropriate to the adult’s skills and abilities, and
- (b) may allow the adult’s spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.<sup>369</sup>

## 3.7 SUBSTITUTE DECISION MAKING

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### 3.7.1 Types of Substitute Decision Make

A fundamental aspect of health care consent law is the concept of a substitute decision maker. The substitute decision maker is the person or agency authorized by court, statute or agreement to make decisions on another person's behalf. The concept of modern substitute decision making has been described as preserving, rather than undermining, decision making autonomy because the substitute is taxed with making decisions in a manner consistent with person's values. Margaret Isabel Hall writes:

Substitute decision-making enables the autonomy of the person whose decision-making processes are impaired by enabling her substitute to effect the decisions she *would have made* if able to do so. The substitute is not a replacement; he or she operates as a kind of decision-making amanuensis, effecting decisions that “really” belong to the other. Proceeding on the basis that persons generally make decisions like those they have made in the past, the substitute is able to maintain the identity of the individual by perpetuating this kind of consistent decision-making.<sup>370</sup>

The Law Commission of Ontario has thus characterized the modern substitute decision making as embodying a “substituted judgment” rather than a “best interests” approach.<sup>371</sup>

The common law doctrine of informed consent deals with the obligations of health care providers with respect to consent to health care by capable adults. At common law, only a guardian appointed by the court, or the court itself under its *parens patriae* authority, may make health care decisions for a person who lacks capacity.<sup>372</sup> Even spouses are not permitted to make substitute decisions for health care under the common law. In the absence of substitute decision making legislation, family members would have to apply to the court to be made personal guardians, or to request an order authorizing treatment, if a treatment decision did not fall within the emergency exception.<sup>373</sup> Consequently, legislators in all Canadian jurisdictions have enacted substitute decision making statutes.

There are many different kinds of substitute decision making relationships for health care in BC. Each is created through different legal processes. A health care decision maker could be:

- A representative authorized under a representation agreement;
- A committee (also known as a personal guardian) granted decision making authority by a judge pursuant to an application for committeehip under the *Patients Property Act (PPA)*; or
- A temporary substitute decision maker, chosen by the health care provider in accordance with the *HCCA*.

Further, if a person is involuntarily committed under the *MHA*, consent for psychiatric treatment authorized by the director is deemed to have been provided by the patient.<sup>374</sup>



If an adult is not capable of consenting to treatment, a committee is first in line to make a health care treatment decision on the adult's behalf.<sup>375</sup> If there is no committee or representative, the health care provider is required to make reasonable efforts to get a health care decision from a temporary substitute decision maker pursuant to section 16 of the *HCCA*. The decision maker of last resort, if there is no other appropriate person as per the *HCCA* (that is to say, no family or close friends), is the BC Public Guardian and Trustee (PGT), or a person chosen by the PGT. The PGT's role is discussed further below.

The section below provides more information on each of the three different types of substitute decision maker for health care.

## Representative

In BC a person may create a representation agreement, pursuant to the *RAA*, granting another person the authority to make health care decisions for them, or, as is discussed in Part F above, to assist them with decision making.<sup>376</sup> Representation agreements can cover health, personal, financial and/or legal decision making; the adult entering into the agreement and granting authority to another person may choose the scope of authority. In the event that a person does not have capacity to make a health care decision, the representative may make health care decisions within the scope of authority covered by the agreement. The representative differs from all other substitute decision makers for health care by virtue of being chosen by an adult who enters into a representation agreement. Appointing a representative can be a form of advance care planning. A person can stipulate within the agreement the circumstances which will trigger powers to take effect, such as when the person does not have the capacity to make a treatment decision.

The *RAA* distinguishes between standard agreements made under section 7 of the Act, and non-standard agreements under section 9 of the Act. With respect to health care decisions, a standard agreement enables the representative to make decisions on the adult's behalf with respect to "major" and "minor" health care (as defined in the *HCCA*).<sup>377</sup> While the agreement cannot authorize the representative to refuse life-saving treatment, it may cover a range of end of life health care decisions, such as medications for comfort and pain.<sup>378</sup>

Although the scope of powers always depends on what authority the adult chooses to include in a representation agreement, a non-standard agreement may grant broader decision making authority. It can enable the representative to do anything the representative considers necessary in relation to the adult's health care, including making decisions about whether the adult should live in a long-term care facility, and to give or refuse consent to specified kinds of health care for the adult, even where the adult refuses to give consent at the time the health care is provided.<sup>379</sup> Under a section 9 presentation agreement, representatives may give or refuse consent to health care necessary to preserve life—if they have been given the power to make such health care decisions.<sup>380</sup> Neither type of representation agreement can provide the representative with the authority to make decisions set out in section 5 of the *Health Care Consent Regulation*, which we describe further below (in Section 3.7.3).<sup>381</sup>

## Capacity standard

The capacity standard for a representation agreement depends on whether the agreement is made under section 7 or 9 of the Act. The statute is clear that an adult can enter into a standard 7 representation agreement even if the adult is incapable of other decisions. The Act states:

### **Test of incapability for standard provisions**

**8** (1) An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of

- (a) making a contract,
- (b) managing his or her health care, personal care or legal matters, or
- (c) the routine management of his or her financial affairs.

The statute provides the following list of factors that must be considered in determining whether a person has capacity to make a section 7 representation agreement, or change or revoke any provisions of such a representation agreement:

- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- (d) whether the adult has a relationship with the representative that is characterized by trust.<sup>382</sup>

The thrust of the factors is to ensure the adult wants the agreement, and trusts the person whom they have chosen.

For section 9 agreements, the capacity standard is arguably higher, requiring the adult to understand the scope of authority and the provisions of the agreement:

### **Test of incapability for non-standard representation agreements**

**10** An adult may authorize a representative to do any or all of the things referred to in section 9 unless the adult is incapable of understanding the nature and consequences of the proposed agreement.

The capacity standard for a section 9 representation agreement is akin to the general standard for entering into a contract.

## **Committee or Personal Guardian**

A “committee of the person”, referred to as a personal guardian in the *HCCA*, may be appointed by court order pursuant to the *PPA*.<sup>383</sup> The committee may be granted “custody of the person,”<sup>384</sup> and as such have the authority to make all health care decisions on the person’s behalf, except as might be

specifically restricted by the court.<sup>385</sup> The committee must make decisions for the benefit of the person and the person's family,<sup>386</sup> but is required to foster the person's independence, and encourage their involvement in any decision-making.<sup>387</sup> The *HCCA* provides that a health care provider can provide health care to an adult who is unable to make her own decision if the personal guardian (or representative) consents.<sup>388</sup>

### Temporary Substitute Decision Maker

The *HCCA* sets out (in descending order of hierarchy) who may act as a temporary substitute decision maker (TSDM) in cases where the adult is found by the health care provider to be incapable of consenting to the proposed health care, and there is no personal guardian, representative, or relevant advance directive (advance directives are discussed in the following section). The Act requires the health care provider to choose the first available and qualified person from the following list, in a descending manner:

- (a) the adult's spouse;
- (b) the adult's child;
- (c) the adult's parent;
- (d) the adult's brother or sister;
- (d.1) the adult's grandparent;
- (d.2) the adult's grandchild;
- (e) anyone else related by birth or adoption to the adult;
- (f) a close friend of the adult;
- (g) a person immediately related to the adult by marriage.<sup>389</sup>

Further, the TSDM must meet the following criteria:

- (a) be at least 19 years of age,
- (b) have been in contact with the adult during the preceding 12 months,
- (c) have no dispute with the adult,
- (d) be capable of giving, refusing or revoking substitute consent, and
- (e) be willing to comply with the duties in section 19.<sup>390</sup>

In the event that no one is available, or meets the criteria, or there is a dispute as to who should be appointed, the health care provider must choose someone authorized by the PGT, and this individual may be a person from the PGT.<sup>391</sup>

Although the Act uses the term "temporary", the reliance on a TSDM is often not temporary in practice. As long as an adult does not have capacity, and has neither a representative nor a committee, the same person may be chosen repeatedly to make health care decisions, provided the person fulfils their duties, and the authority is not questioned. However, each time a health care provider requires a treatment decision by a substitute, they should be considering anew whether the adult has capacity, and who is the appropriate person to choose from the list.<sup>392</sup> Changes in circumstances could point to the appropriateness of a different substitute decision maker: for example, a dispute with the adult; lack

of ongoing contact with the adult; or another person higher up in the list becoming available to make health care decisions.

The health care provider is required to contact the PGT for health care decisions (both major and minor health care) if there is no one else available,<sup>393</sup> and “is not required to make more than reasonable efforts” to choose the first available and qualified person from the hierarchical list.<sup>394</sup> The law does not permit a health care provider to provide non-emergency care without the consent of a capable adult, or their substitute decision maker, if the person does not have capacity.

A TSDM has authority to give or refuse consent to health care,<sup>395</sup> including the authority to refuse consent to life-preserving care in circumstances in which:

- There is substantial agreement from health care providers that the decision to refuse substitute consent is medically appropriate; and
- The TSDM has complied with legislative requirements regarding consultation with the adult, and compliance with known wishes, or when these are unknown, is acting in the adult’s best interests.<sup>396</sup>

Along with representatives and committees, a TSDM does not have authority to consent to the specific kinds of health care described below in Section 3.7.3.<sup>397</sup>

### 3.7.2 Decision by Advance Directive

The *HCCA* permits an adult who has capacity to create an advance directive, which is a document that provides written directions regarding future health care treatment.<sup>398</sup> Advance directives are governed by Part 2.1 of the *HCCA*. Instructions in an advance directive effectively amount to consent to, or refusal of, treatment.<sup>399</sup> In BC, a health care professional may take instructions directly from an applicable advance directive, without consultation with a substitute decision maker, in the event that a person does not have capacity to make a treatment decision.<sup>400</sup>

A health care provider must look to any advance directive for health care instructions only if a health care provider “does not know of any personal guardian or representative who has authority to make decisions for the adult in respect of the proposed health care”.<sup>401</sup> In this sense, an advance directive is third in the hierarchy of substitute decision-making mechanisms. A health care provider must make a “reasonable effort” to determine whether the adult has an advance directive, or a personal guardian or representative.<sup>402</sup> If treatment is commenced without awareness of an advance directive, the treatment must be withdrawn if an advance directive which refuses the treatment subsequently becomes known.<sup>403</sup>

An advance directive has limited application: a health care provider is not required to follow an advance directive, and must instead obtain the consent of a substitute decision maker, if they reasonably believe any of the following applies:

- The instructions given do not address the health care decision to be made;

- The instructions given are unclear so that it cannot be determined whether consent has been given or refused;
- The adult's wishes, values or beliefs in relation to a health care decision significantly changed while the adult was still capable, and since the instructions were written; or
- There have been significant medical advances since the advance directive was made<sup>404</sup> that might substantially benefit the adult with regards to the health issues addressed in the directive.<sup>405</sup>

In BC the health care provider has the task of interpreting the advance directive.<sup>406</sup>

#### Capacity standard

An adult is capable of making an advance directive if they can understand the nature and consequences of the proposed advance directive, meaning that the adult understands:

- The scope and effect of the instructions given; and
- That a substitute decision maker will not be appointed to make decisions covered by the advance directive, except in certain circumstances.<sup>407</sup>

### 3.7.3 Substitute Consent Cannot be Provided

The *Health Care Consent Regulation* sets out types of health care treatment to which temporary substitute decision makers and representative cannot consent:

#### **Health care to which temporary substitute decision maker cannot consent**

- 5 (1) The following types of health care are prescribed for the purposes of section 18 (1) of the Act:
- (a) abortion unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;
  - (b) electroconvulsive therapy unless recommended in writing by the treating physician and at least one other medical practitioner who has examined the adult for whom it is proposed;
  - (c) psychosurgery;
  - (d) removal of tissue from a living human body for implantation in another human body or for medical education or research;
  - (e) experimental health care involving a foreseeable risk to the adult for whom the health care is proposed that is not outweighed by the expected therapeutic benefit;
  - (f) participation in a health care or medical research program that has not been approved by a committee referred to in section 2;
  - (g) any treatment, procedure or therapy that involves using aversive stimuli to induce a change in behaviour.

The above list provides a blanket restriction on substitute consent for some kinds of treatment (psychosurgery), and requires additional support for substitute consent for others (abortion and electroconvulsive therapy).<sup>408</sup>

### 3.7.4 Ranking of Substitute Decision Makers

What if there is both a representative and an advance directive? When an adult is found to be incapable of making autonomous health care decisions, consent must be sought in ranked order as follows:

1. From a personal guardian appointed pursuant to the *Patients Property Act*<sup>409</sup>
2. From a representative appointed pursuant to the *RAA*<sup>410</sup>
3. From an applicable advance directive, pursuant to the *HCCA*<sup>411</sup>
4. From a temporary substitute decision maker, pursuant to the *HCCA*.<sup>412</sup>

A personal guardian sits at the top of the consent hierarchy. Unless the court orders otherwise, a representation agreement is terminated when a personal guardian is appointed.<sup>413</sup>

While the decision making powers of a representative will generally take priority over an advance directive,<sup>414</sup> an adult can specify in their representation agreement that a health care provider need not obtain a representative's consent for health care decisions covered in the adult's advance directive.<sup>415</sup> This effectively prioritizes the advance directive over the representation agreement. When a representation agreement does take priority, a representative must follow the adult's known expressed wishes, including those expressed in an advance directive.<sup>416</sup>

As discussed above, TSDMs are chosen to make decisions only when there is no personal guardian, representative with applicable authority, or applicable advance directive.

### 3.7.5 Duties of a Substitute Decision Maker

With respect to health care decision making, representatives, TSDMs, and committees have statutory duties. However, their duties are described differently in legislation. Generally all substitute decision makers have similar overarching ethical obligations; for example, the representative must:

- (a) act honestly and in good faith,
- (b) exercise the care, diligence and skill of a reasonably prudent person, and
- (c) act within the authority given in the representation agreement<sup>417</sup>

This following discussion focuses on duties relevant to engaging people living with dementia in decision making.

#### The Duty to Consult

The TSDM and the representative both have a duty to consult—although the duty is framed slightly different in each statute. The representative is required to:

- (a) consult, to the extent reasonable, with the adult to determine his or her current wishes, and
- (b) comply with those wishes if it is reasonable to do so.<sup>418</sup>

However, the *RAA* allows a person to contract away their right to be consulted. The Act states that the above section does not apply if:

- (a) a representative is acting within authority given to the representative under section 9, and
- (b) the representation agreement provides that in exercising that authority the representative need only comply with any instructions or wishes the adult expressed while capable.<sup>419</sup>

Such circumstances would apply, for example, to a non-standard representation agreement which provides authority to give consent even though the adult refuses, or to “physically restrain, move and manage the adult and authorize another person to do these things, if necessary to provide personal care or health care to the adult” as per section 9.<sup>420</sup>

In contrast, the TSDM must consult with the adult “to the greatest extent possible” “before giving or refusing substitute consent.”<sup>421</sup> Based on the language of the respective statutes, the representative may have a greater obligation, that is to say, to comply, and not just to consult.

In 2014, the *PPA* was amended to introduce a duty parallel to the duty to consult. Section 18(2) states that, “[a] committee must, to the extent reasonable, foster the independence of the patient and encourage the patient’s involvement in any decision making that affects the patient.”<sup>422</sup> This meaning of this provision has not yet been interpreted by the court.

Although the substitute decision making framework in BC requires all substitute decision makers to involve adults in decision making regardless of capacity, the health care provider does not appear to have a parallel role to facilitate this process. The *HCCA* includes a “right to be involved to the greatest degree possible in all case planning and decision making”; however, that right is limited to adults who are capable.<sup>423</sup>

In summary, based strictly on statutory language:

- The representative has a duty to consult and comply;
- The TSDM has a duty to consult; and
- The committee has a duty to involve the adult.

### The Duty to Consider Previously Expressed Wishes

Both a representative and a TSDM are required to comply with previously expressed wishes made while the adult was capable.<sup>424</sup> The *RAA* states that:

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*Within one day or one week the resident could be demonstrating different abilities, so you’ve always got to take that into consideration for that day.*

– **Former Director of Care**

(3) If subsection (2) applies but the adult's current wishes cannot be determined or it is not reasonable to comply with them, the representative must comply with any instructions or wishes the adult expressed while capable.<sup>425</sup>

A TSDM is required to “comply with any instructions or wishes the adult expressed while he or she was capable.”<sup>426</sup> The *PPA* does not contain a similar restriction on the exercise of decision making authority; however, section 16 permits the Court to impose restrictions or conditions on the committee's powers to act.<sup>427</sup>

The PGT publishes a handbook for committees<sup>428</sup>, which recommends speaking to the adult directly about their wishes regarding major health care, as well as consulting with family members and friends as to prior wishes, values and beliefs, where appropriate.<sup>429</sup> The PGT recommends the committee use the provisions of the *HCCA* as a guide when making health care decisions, since the responsibilities of a TSDM (to whom these provisions apply) and a committee making health care decisions are similar. These recommendations are summarized in the handbook as a 3-step process as follows:

- Any known instructions or wishes made by the adult when the adult was capable
- If there are no known prior instructions or wishes made when the adult was capable, the decision is to be made in accordance with known applicable values and beliefs
- If there are no such known values and beliefs then a decision is to be made in the adult's best interests as defined in the Act.<sup>430</sup>

The 2007 bill to amend the *Adult Guardianship Act* contains provisions not yet in force which would repeal the *PPA* and introduce the alternative language of “personal guardian” (as an alternative to the term “committee”), and impose obligations on personal guardians in BC similar to those found in the *RAA* and the *HCCA*. Section 29 of the *PPA*, which is not in force:

- Sets out general ethical obligations parallel to those in the *RAA*;
- Creates a duty to comply with previously expressed wishes; and
- States that if no wishes are relevant to the decision at issue, the guardian “must act in the adult's best interests, taking into account the adult's known beliefs and value.”<sup>431</sup>

With respect to health care decisions, the factors the personal guardian must consider are identical to the ones listed in the *HCCA*.<sup>432</sup>

### The Duty to Make a Decision in the Adult's Best Interests

Both a representative and a TSDM must make a decision based on best interests, if the adult's wishes are not known.<sup>433</sup> A representative is required to consider the adult's values as well before resorting to a best interests approach to decision making. For a TSDM, the adult's current beliefs and wishes are one factor the TSDM must consider when deciding what is in the adult's best interests.<sup>434</sup> Other factors are:



- (b) whether the adult’s condition or well-being is likely to be improved by the proposed health care,
- (c) whether the adult’s condition or well-being is likely to improve without the proposed health care,
- (d) whether the benefit the adult is expected to obtain from the proposed health care is greater than the risk of harm, and
- (e) whether a less restrictive or less intrusive form of health care would be as beneficial as the proposed health care.<sup>435</sup>

In this sense, the *HCCA* is arguably more prescriptive with respect to the meaning of the concept of best interests.

The *PPA* contains quite different language. Section 18(1) states that “[a] committee must exercise the committee’s powers for the benefit of the patient and the patient’s family, having regard to the nature and value of the property of the patient and the circumstances and needs of the patient and the patient’s family.” As noted earlier, while there is some case law to suggest that subsection 18(1) is limited to financial decision making,<sup>436</sup> the case law and commentary characterize the relationship between committee and the adult as fiduciary in nature, which requires the committee to act in the best interests of the person.<sup>437</sup>

Although the “best interests” of the adult are always a paramount consideration in guardianship cases in BC, the courts have not completely fleshed out the meaning of the concept of “best interests” in terms of the role of a personal guardian or committee. The concept is frequently invoked in jurisprudence without a definition.

## 3.8 INTERSECTIONS WITH MENTAL HEALTH LAW

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### 3.8.1 British Columbia’s Unique Mental Health Legal Framework

People living with dementia are sometimes involuntarily committed under the *MHA*, a decision that has a significant impact on health care consent rights. A person living with dementia may be involuntarily admitted based on the physician view that the patient’s dementia is a mental disorder requiring treatment, or due to some other mental health condition. Some physicians are of the view that dementia alone is a mental disorder; however, this perspective has been criticized. As noted earlier, dementia is now included in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (the DSM-5), under the equivalent term, “major neurocognitive disorder”.<sup>438</sup>

Although this project was not intended to review and reform mental health law in BC, below we set out the law with respect to involuntary admission and consent to psychiatric treatment in order to provide a comprehensive picture of BC’s health care consent regime.

Mental health law has taken a unique course in BC. People who are involuntarily committed under the *MHA* do not have the right to make their psychiatric treatment decisions. They are “deemed” to have consented to any psychiatric treatment authorized by the director of a designated facility, a decision which in practice is made by the treating physician.<sup>439</sup> The deemed consent has no excluded treatments,

*Perhaps it's easier, more paternalistic, more authoritarian perhaps to use the Mental Health Act from the hospital's point of view. Rather than have all the difficult conversations. Families might not be ready from a psychological and emotional point of view, or they are in disagreement, and they can't decide who should do what.*

## – Psychiatrist

and therefore includes electroconvulsive therapy and psychosurgery. Consent to non-psychiatric treatment is governed by the *HCCA*, despite any involuntary admission.

Under the *MHA*, people may be involuntarily admitted to a designated psychiatric facility for examination and treatment based on a physician's opinion they have a "mental disorder", and the person:

- (i) requires treatment in or through a designated facility,
- (ii) requires care, supervision and control in or through a designated facility to prevent the person's or patient's substantial mental or physical deterioration or for the protection of the person or patient or the protection of others, and
- (iii) cannot suitably be admitted as a voluntary patient.<sup>440</sup>

Treatment under subsection (i) is further defined in the act to mean: "safe and effective psychiatric treatment and includes any procedure necessarily related to the provision of psychiatric treatment."<sup>441</sup> The physician must complete a certificate in Form 4 in order to admit the adult involuntarily.<sup>442</sup> The person may be detained for up to 48 hours in the first instance with a medical certificate of one physician, and for up to one month with a medical certificate from a second physician.<sup>443</sup> Detention can be further extended in accordance with section 24 of the Act.

Form 5, which is titled "Consent For Treatment (Involuntary) Patient", requires that the "nature of the condition, the reasons for and the likely benefits and risks of the treatment" be explained to the patient.<sup>444</sup> The form *may* be signed by the patient, in which case the director must attest that the patient was capable of understanding the nature of their authorization to undergo the treatment.<sup>445</sup> If the patient does not sign the form, the director is given the power to sign the consent form on behalf of the patient, without assessing incapability to consent to treatment.<sup>446</sup> In doing so, the director attests that the "patient is incapable of appreciating the nature of the treatment and/or their need for it and is therefore incapable of giving consent."<sup>447</sup> The director is given the power to sign the consent form on behalf of the patient by virtue of section 8, which states:

A director must ensure

- (a) that each patient admitted to the designated facility is provided with professional service, care and treatment appropriate to the patient's condition and appropriate to the function of the

designated facility and, for those purposes, a director may sign consent to treatment forms for a patient detained under section 22, 28, 29, 30 or 42...

In practice, however, the director's powers are delegated to health care providers, and Form 5s are completed by treating physicians and nursing staff. It has been noted that the Form 5 process renders the incapability assessment of the person irrelevant to treatment, and arguably "conflates mental capacity to make a treatment decision with agreement to proposed treatment."<sup>448</sup>

### 3.8.2 Comparison with Other Canadian Jurisdictions

Other jurisdictions have taken quite different approaches to treatment decisions for adults who have been committed under mental health law. There are roughly three different approaches taken in other provinces and territories:

1. Patients capable of making decisions with respect to their mental health treatment cannot be involuntarily committed:

Saskatchewan,<sup>449</sup> Newfoundland,<sup>450</sup> and Nova Scotia<sup>451</sup>

The impact of this approach is that the situation of a capable involuntary patient never arises, and consequently avoids the issue of consent to treatment in the involuntary patient context. As Robertson states, "[t]he purpose of this requirement is to avoid the situation which has arisen in some provinces where mentally competent patients who refuse treatment are committed, thereby effectively 'warehousing' them in hospital indefinitely without treatment."<sup>452</sup>

2. Patients capable of making decisions with respect to their mental health treatment have the right to refuse treatment, subject to an override by a review body based on the patient's "best interests"

Alberta,<sup>453</sup> and Yukon<sup>454</sup>

The legislation of New Brunswick and Quebec also contain a right to refuse treatment, but subject to different criteria for when refusal can be overridden.<sup>455</sup>

3. Patients capable of making decisions with respect to their mental health treatment have the right to refuse treatment

Ontario,<sup>456</sup> Manitoba,<sup>457</sup> Prince Edward Island,<sup>458</sup> Northwest Territories, and Nunavut<sup>459</sup>

If treatment is refused by capable involuntary patients in these provinces, there is no power to override the patient's decision.<sup>460</sup>

In the event of incapability, most provinces provide that treatment decisions are to be made by a substitute decision maker, usually identified by a ranked list of family members, or the Public Guardian and Trustee as a last resort.<sup>461</sup> The person with authority to make treatment decisions for incapable involuntary patients varies from province to province, and may either be a person or a state authority.<sup>462</sup> For example:

- Saskatchewan and Newfoundland: treatment must be authorized by the attending physician.<sup>463</sup>
- New Brunswick: a tribunal must authorize treatment.<sup>464</sup>
- Quebec: a court must authorize treatment.<sup>465</sup>
- Ontario: a private substitute decision maker appointed pursuant to health care consent legislation may authorize treatment, so long as treatment decisions are made in accordance with the legislation.<sup>466</sup>

In a jurisdiction that does allow refusal of treatment, a substitute decision maker usually provides the consent or refusal in accordance with criteria dictated by the particular province's legislation. For example,

- Alberta: the substitute decision maker must make the decision based on the patient's "best interests".<sup>467</sup>
- Ontario and Prince Edward Island: the substitute decision maker must make a decision based on the person's valid previously expressed capable wishes applicable in the circumstances, and where these are unknown, in the person's "best interests".<sup>468</sup>
- Yukon: where the wishes of the patient are unknown, the decision should be made based on the patient's known beliefs and values, and where these are unknown, in the patient's "best interests".<sup>469</sup>
- Manitoba and Nova Scotia: the substitute decision maker is bound by the patient's expressed capable wishes except where this would endanger the health or safety of the patient or others. Otherwise the decision must be made in the patient's best interests.<sup>470</sup>

Each of these jurisdictions has developed mental health legislation that provides for greater involvement of the patient, family, substitute decision makers, and public guardians in decision making as compared with BC.

### 3.8.3 Involuntary Committal of Adults Living with Dementia

Involuntary commitment is only permitted under the law if a person is not suitable for voluntary treatment. It is possible that a person with a pre-existing serious mental illness could also be diagnosed with dementia later in life, which could render addressing their mental health needs more complex. However, mental health facilities were not designed to address the physical and mental health, and other social and health care needs, of an older adult population.

In terms of health care decision making, three significant impacts of involuntary commitment are:

- The person living with dementia does not have the right to consent to their own psychiatric treatment, regardless of capacity;

- Substitute and supportive decision makers chosen by the person living with dementia have no right to make decisions regarding psychiatric treatment, or participate in decision making regarding psychiatric treatment; and
- A guardian or committee of the person appointed by a judge to make health care decisions for the person has no authority to make decisions regarding psychiatric treatment.

The BC Ombudsperson has criticized the use of involuntary commitment to place older people into long-term care when they do not have capacity for care facility admission decisions.<sup>471</sup> In its review of the provision of health care for seniors in BC, the Ombudsperson noted that using the *MHA* to admit a senior to a designated facility for treatment, including for treatment for dementia, ought to be “an extraordinary situation” where to do so is the “only viable option that will allow for his or her protection.”<sup>472</sup>

The legal process is that:

- The adult is placed in a designated mental health facility—usually a hospital—and detained pursuant to the involuntary admission procedures set out in section 22 of the *MHA*;
- The initial period of committal is renewed on an ongoing basis in accordance with section 24 of the *MHA* as needed; and
- The adult is transferred to a long-term care facility pursuant to the section 37 of the *MHA*, which permits patients extended leave from a designated facility.

This involuntary detention can be challenged by application to the Mental Health Review Board, or directly to the Supreme Court;<sup>473</sup> however, at least one expert has noted that these remedies are rarely used to challenge the detention of older people.<sup>474</sup> Section 37 provides:

...if the director considers that leave would benefit a patient detained in the designated facility, the director may release the patient on leave from the designated facility providing appropriate support exists in the community to meet the conditions of the leave.<sup>475</sup>

Leave conditions can be imposed on the patient. Importantly, although the adult is not residing in a psychiatric facility, they are still “involuntary patients” for the purposes of the *MHA*, and subject to its regulation. Therefore, the person receives psychiatric treatment for their “mental disorder,” which could include anti-psychotic medications, without the right to make such decisions, or have their substitute or supportive decision makers participate in decision making.<sup>476</sup> The involuntary committal approach can shut out family caregivers and spouses.

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*He has a very nice room... but he doesn't just have a mental condition; he has Alzheimer's. What I would like for my husband is that he would get a little music one day, or go out for meals. They keep him in bed. Someone brings him a tray, and when I come at noon, I have to prop him up, because he is drowsy... he is on all kinds of medication, and the staff say, 'oh, he had a snack.' He is there to die.*

– Family caregiver

## 3.9 REVIEW OF HEALTH CARE DECISIONS AND ACCESS TO JUSTICE

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In this section, we outline the review options available to people living with dementia, their family, and supportive or substitute decision makers who have concerns about health care decision making.

Family members who are dissatisfied with health care team actions regarding consent are generally directed toward the complaint mechanisms discussed below. These options appear to have very limited potential to effect real and timely change for people living with dementia who feel their rights have not been respected. Rather, these mechanisms look to systemic solutions that could improve health care delivery.

For people who wish to change the health care treatment decision, challenge a finding of incapability, or change their substitute decision maker, the first three legal processes discussed below are key.

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*Once a person is determined incapable, then that person becomes just quiet about the whole thing, is taken to the facility, even when they are capable. They have no way of reaching out because they are deemed incapable, especially if they have disabilities, such as hearing or visual impairments.*

– Advocate

### 3.9.1 Review Bodies

The current review mechanisms available are:

#### Applications to a court or tribunal

- Court review of decisions under the *HCCA*;
- Court review of a committee order (declaration of incapability) and the appointment of a committee under the *PPA*;
- Mental Health Review Board review of involuntary committal order under the *MHA*;
- Court determination of a civil law suit in negligence; and
- Human Rights Tribunal determination of a complaint alleging discrimination under the BC *Human Rights Code*

#### Complaint to review bodies

- Patient Care Quality Offices and Review Boards;
- Licensing of Community Care Facilities;
- Assisted Living Registry;
- Health care professional regulatory bodies and the Health Professions Review Board; and
- Ombudsperson.

## Courts and Tribunals

### Court Review of Decisions under the HCCA

People may apply to the court for orders relating to implementing and interpreting advance directives and health care consent decisions made by substitute decision makers.<sup>477</sup> On such an application, the court may make a broad range of decisions, as follows:

- (a) order the adult to attend at the time and place the court directs and submit to one or more assessments of incapability;
- (b) give directions respecting
  - (i) the interpretation of a provision of an advance directive, or any other health care instruction or wish, made or expressed by an adult when capable, or
  - (ii) who should be chosen to provide substitute consent under this Act for an incapable adult;
- (c) confirm, reverse or vary a decision by
  - (i) an adult's representative or personal guardian, or
  - (ii) a person chosen to provide substitute consent under this Act, to give or refuse consent to health care or admission to a care facility;
- (d) make any decision that a person chosen to provide substitute consent under this Act could make.<sup>478</sup>

In addition, any person can apply to the court for an order voiding an advance directive on the basis that fraud, undue pressure, or some other form of abuse or neglect was used to induce an adult to make, change or revoke an advance directive.<sup>479</sup>

The following people may apply to court for an order:

- (a) a health care provider responsible for the care of an adult who is incapable of giving or refusing consent to health care;
- (b) an adult's representative or personal guardian;
- (c) a person chosen under this Act to give or refuse substitute consent to health care or admission to a care facility on behalf of an adult who is incapable;
- (d) an adult who is assessed as incapable of giving or refusing consent to health care or admission to a care facility.<sup>480</sup>

The Court has the power to order an assessment that could result in a finding of capacity, change the substitute decision maker, or void consent which was not provided in a manner consistent with the Act. Further, nothing in the Act limits the inherent jurisdiction of the Supreme Court to act in a *parens patriae* capacity, which gives the court broad jurisdiction to make an order to protect a person who does not have capacity.<sup>481</sup>

### Review of Committeeship Order

A year after a committeeship order is made, any person may apply to the Supreme Court for an order that the person is no longer incapable.<sup>482</sup> The application requires affidavits of two medical practitioners.<sup>483</sup> If the application is successful, the older person living with dementia would become entitled

to make their own health care decisions, subject to the health care provider's obligation to consider capacity each time health care is proposed. An application can be made to rescind the appointment of a committee, and have another committee appointed pursuant to s. 6 of the *PPA*.

#### Review of Decisions under *Mental Health Act*

Under section 31 of the *MHA*, a person who has been involuntarily committed has a procedural right to request a second medical opinion on the appropriateness of the treatment authorized by the director at particular intervals. However, while the director "must consider whether changes should be made in the authorized treatment" after receiving the second medical opinion, they are not required to accept the opinion, even if the second medical opinion is in direct conflict with the first physician's opinion.

A patient who has been involuntarily committed under section 22 of the *MHA* is entitled to a review panel hearing at specified intervals to determine whether committal should continue.<sup>484</sup> The review panel, however, has no power to review the appropriateness of the patient's treatment regime. The intervals are as follows:

- Within the first two one-month periods of committal: a requested review panel hearing must be held within 14 days of the request.<sup>485</sup>
- After the first two months of committal: a requested review panel hearing must be held within 28 days of the request.<sup>486</sup>
- After that: a review panel hearing may only be requested when at least 90 days have passed since the result of the last hearing.<sup>487</sup>

The review panel must issue a determination with 48 hours of the hearing, and provide written reasons for the decision within 14 days of issuing the determination.<sup>488</sup>

Judicial review of a determination of a review panel is possible pursuant to section 24.2 of the *MHA*. Such an application must be filed in the BC Supreme Court within 60 days from the date the review panel decision was issued. Further, the person who has been involuntarily committed, or anyone else, may apply for a writ of *habeus corpus*, an old legal remedy which allows a person to appear before a judge to review the lawfulness of any detention.<sup>489</sup> However, "*habeus corpus* is rarely used to challenge mental health detentions."<sup>490</sup>

In addition, a patient or a person on their behalf may apply to the court for an order that the person not be apprehended, transported or admitted to a designated facility, or be discharged from one pursuant to section 33(2) of the *MHA* if they believe that there is not sufficient reason or legal authority for a certificate.

#### Civil Liability in Negligence

The *HCCA* does not contain civil remedies for breach of the legislation. However, the law of negligence applies to a breach of statutory duty in Canada.<sup>491</sup> A breach of statute is considered evidence of negligence, rather than a separate tort.<sup>492</sup> A defendant will not be held liable in negligence if they can prove they acted reasonably in the circumstances,<sup>493</sup> particularly because the *HCCA* contains a clause



protecting people from liability “in the performance of a duty or the exercise of a power or function under this Act if the person has acted in good faith and used reasonable care.”<sup>494</sup>

Informed consent cases in BC have generally been brought pursuant to the established common law doctrine of informed consent, in tort.<sup>495</sup> The Court has affirmed the fundamentality of establishing informed consent as a defence to allegations of professional negligence.

[I]t has been firmly entrenched in the jurisprudence that a physician may be found negligent even where the medical treatment complies with the expected standard of care, if he or she has failed to obtain the patient’s informed consent to the treatment that has caused the injury.<sup>496</sup>

In one recent negligence decision involving an older person with capacity issues the Court briefly referenced section 9 of the *HCCA* in support of the common law position on the acceptable method of giving consent. The plaintiff had alleged negligence and battery of her deceased mother in relation to a failed resuscitation effort on the basis that the plaintiff had not provided informed consent to the resuscitation. The Court of Appeal dismissed the plaintiff’s appeal, and allowed the doctor’s appeal, finding that the evidence demonstrated the doctor had implied consent, and perhaps express consent, to attempt resuscitation. In doing so, the Court of Appeal referenced section 9:

[104] Dr. Sweet submits that even if one were to accept that there was a conflict on the evidence regarding express consent, the law is clear that where a physician reasonably infers a patient is consenting or has consented to particular treatment, consent may be inferred. As pointed out in *Glabolt v. Ross* 2011 BCSC 1133 (CanLII) at paras. 186, the Health Care (Consent) and Care Facility (Admission) Act, R.S.B.C. 1996, c. 181 codifies this common law principle. Section 9(1) thereof provides that consent to health care may be “expressed orally or in writing or may be inferred from conduct.” The Court in *Glabolt* also cited a passage from the judgment of Mr. Justice Linden in *Allan v. New Mount Sinai Hospital* (1980) 1981 CanLII 1694 (ON SC), 109 D.L.R. (3d) 634 (Ont. H.C.J.), *rev’d on other grounds* (1981) 1981 CanLII 3002 (ON CA), 125 D.L.R. (3d) 276 (Ont. C.A.) that:

Whether a doctor can reasonably infer that a consent was given by a patient, or whether he cannot infer such consent, and must respect the wishes of the patient, as foolish as they may be, always depends on the circumstances. [At 641.]

[105] The trial judge correctly stated this principle at para. 124 of her reasons, paraphrasing a passage from Picard J.A. and Gerald Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 4th ed. (2007) to the effect that “[c]onsent or implied consent to medical treatment negates the commission of the tort of battery; ... consent may be oral or written, but it does not necessarily have to be explicit; consent may also be implied from the words or conduct of a patient”. The plaintiff has not sought to persuade us that this is not a correct statement of the law.<sup>497</sup>

However, ultimately, the case was decided in accordance with tort law principles, without reference to the *HCCA*. The Supreme Court of BC confirmed this approach in a recent decision involving an allegation of negligence in the context of a failure to obtain informed consent:

The landmark decisions in this area all connect liability with a failure to ensure informed consent based on the tort of negligence: *Hopp v. Lepp*, [1980] 2 S.C.R. 192 and *Reibl v. Hughes*, [1980] 2 S.C.R. 880. Consequently, a determination of the issue of informed consent requires consideration of the standard elements of negligence: the existence of a duty of care; the failure to meet the requisite standard of care; and a causative connection between that failure and the injuries alleged.<sup>498</sup>

The test for causation in medical negligence cases involving a failure of a health care provider to disclose has been described as a “modified objective” one, requiring the decision-maker to consider a combination of objective and subjective factors in determining whether the failure to disclose actually caused the harm complained of.<sup>499</sup> The test, as stated in the Supreme Court case of *Arndt v. Smith*, requires:

...that the court consider what the reasonable patient in the circumstances of the plaintiff would have done if faced with the same situation. The trier of fact must take into consideration any “particular concerns” of the patient and any “special considerations affecting the particular patient” in determining whether the patient would have refused treatment if given all the information about the possible risks.<sup>500</sup>

It has been noted that this test has proven difficult for plaintiffs to meet because judges tend to conclude that the plaintiff would have deferred to the health care provider’s recommendations to proceed, even if the risks had been disclosed.<sup>501</sup> Cases alleging negligence on the part of a health care provider on the basis of a failure to obtain informed consent to health care are common in BC; however, cases involving older people with capacity issues are rare.<sup>502</sup>

#### BC Human Rights Tribunal

Provincial human rights law prohibits discrimination in the provision of services to the public, which includes health care services.<sup>503</sup> A person may file a complaint with the BC Human Rights Tribunal regarding discrimination in the provision of health care services which are generally available to the public.<sup>504</sup> Discrimination on the basis of age and mental and physical disability are grounds which may be particularly pertinent to older people living with dementia who thinks their right to informed consent was not respected due to discrimination.<sup>505</sup> Remedies available to the Tribunal in dealing with a complaint include an order that the contravening party:

- Cease the discrimination and ameliorate the effects of the discriminatory practice;
- Provide the person with the opportunity or right that was denied to them; or
- Pay the aggrieved party compensation.<sup>506</sup>

## Complaints to Review Bodies

A number of complaints processes may be available to people living with dementia; however, complaint process remedies tend to address systemic practice issues rather than resolve an individual's circumstances.

### Patient Care Quality Office and Review Boards

In 2008, the BC Government introduced the *Patient Care Quality and Review Board Act* as a means of establishing a complaints process for patients, clients, and facility residents with respect to quality of health care. The Act established an independent review mechanism by way of Patient Care Quality Review Boards.<sup>507</sup> A quality office and review board now exists in each health authority.

Patient Care Quality Offices (PCQO) and Review Boards may address complaints relating to any health care or service:

- Provided by a health authority or another person pursuant to a contract with a health authority;
- Funded in whole or in part by a health authority; or
- Delivered in a hospital or private hospital (which includes an extended care facility) or a licensed community care facility.<sup>508</sup>

Long-term care facilities which are licensed by, or receive funding from, a health authority fall within the ambit of the PCQO and Review Boards,<sup>509</sup> including actions by health care assistants<sup>510</sup> which are not technically the provision of health care, such as housekeeping, food, security, and parking services.<sup>511</sup> Care provided by nursing staff or other health care professionals at a licensed long-term care facility may be the subject of a complaint to both the PCQO and the appropriate regulatory college.

This jurisdiction does not include complaints about:

- Health professionals providing services in private practice, where the services are funded by MSP or PharmaCare (e.g. general practitioner and pharmacist services),<sup>512</sup> and
- Involuntary admissions under the *MHA*.<sup>513</sup>

Where complaints involve physicians or other health care professionals that have been contracted or employed by a health authority, the Review Board will assess the nature of the complaint to determine if they are the most appropriate agency to deal with the complaint. The Review Board may refer the complaint to the relevant regulatory college.

As individual complaint reviews are not publicly available, it is difficult to get a sense of the kind of actions the Board will take in response to a request for review. Legislation permits a board to make recommendations to the Minister of Health and the health authorities regarding improving the quality of patient care in BC;<sup>514</sup> however, the health authorities are not legally obligated to implement any recommendations unless so directed by the Minister. Instead, they are required to carefully consider and formally respond to each recommendation.<sup>515</sup>

The Patient Care Quality Review Board 2016/2017 Annual Report to the Ministry of Health identified the following top five concerns raised through the complaint mechanism process:

- Care issues, such as deficiencies in care, misdiagnosis or medication-related concerns;
- Attitude and conduct;
- Accessibility, such as wait times for surgery or test results, or availability of services;
- Communication; and
- Discharge arrangements.<sup>516</sup>

The Review Boards publish an annual report on recommendations for which they have received a response from a health authority. The most recent report contains several recommendations relevant to health care consent for older people, including a recommendation that:

The health authority initiate an in-service training module for all personnel who work with patients who are near or in the end-stages of life to determine what the protocols for informed consent and the revocation of a representation agreement are with reference to:

- *The Health Care Act*;
- *The Representation Agreement Act*;
- *The Adult Guardian Act* (sic);
- *The Public Guardian and Trustee Act*; and
- *The Health Care (Consent) and Care Facility (Admissions) Act*.<sup>517</sup>

In response, the Interior Health Authority has agreed to “develop an Inter-professional Practice Guideline and supporting checklist for situations when an incapable adult’s legal representative is believed to be unable or unwilling to fulfill their responsibilities under the *Representation Agreement Act*.”<sup>518</sup> Training for social workers will be provided on the Guideline, as they are a resource for those working in end of life care.<sup>519</sup>

With respect to a recommendation for Vancouver Coastal Health Authority regarding a complaint related to “Quality of Care, Poor Communication, Lack of Translation Services and Lack of Consent at a Hospital”, the Review Board made a number of recommendations, including:

1. The health authority conduct a review or survey of its nursing and medical staff at this hospital to determine whether they have been fully educated on when and how to use interpreter services, focusing on the health authority policy requirements that interpreters are used when there is a language barrier of any kind.
2. The health authority ask the hospital chief of medicine investigate whether the approach to consent in this case is an aberration or is a systemic reflection of hospital culture, and whether it is determined to be a systemic issue or not:
  - a. Review hospital’s consent process;
  - b. Determine what solutions are going to be implemented to adhere to the consent process;

- c. Undertake what changes are necessary if this is a systemic issue; and,
- d. Report back to the hospital Chief Operating Officer.<sup>520</sup>

The annual report identifies care, including “medication-related concerns” as one of the top five concerns. Remedies available through the PCQO appear to address systemic issues, rather than provide for individual remedies; however, reporting by the Review Board does confirm that informed consent is an issue of concern.

#### Complaints to Licensing of Community Care Facilities

Long-term care facilities must be licensed in accordance with standards or requirements set out in the *Community Care and Assisted Living Act (CCAL Act)*.<sup>521</sup> One of the primary duties of a Licensing Officer, as delegated by a Medical Health Officer under the *CCAL Act*, is to investigate complaints and/or allegations that a care facility does not meet the requirements of the *CCAL Act* and its regulations.<sup>522</sup> Licensing Officers have the power to inspect care facilities in response to a complaint, and to undertake follow-up inspections of the purposes of ongoing monitoring.<sup>523</sup> Each health authority has a local licensing program to which complaints can be directed.<sup>524</sup> Actions which a Licensing Officer may take in response to a complaint are:

- Attempt to resolve the issue through discussions with the licensee;
- Suspend a license, or attach conditions to it;
- Impose a fine; or
- Cancel the licence and close the facility.<sup>525</sup>

#### Complaints to the Assisted Living Registry

Complaints about an assisted living facility can be made to the Assisted Living Registry, which has the authority to investigate complaints that the operation of a facility has put the health and safety of residents in the facility at risk.<sup>526</sup> The Assisted Living Registrar has the power to suspend or cancel a registration, or attach conditions to a registration where it is found that the facility has not met requirements imposed by the *CCAL Act* or the conditions of its license.<sup>527</sup>

#### Health Professions Review Board

The Health Professions Review Board (HPRB), which was created in 2009, is an independent, quasi-judicial, administrative tribunal established under Part 4.2 of the *Health Professions Act*. Its stated mission is “to provide the public with independent, transparent and respectful review and early resolution processes that determine or resolve the health professions issues under review in an unbiased, timely and cost-effective manner.”<sup>528</sup> The HPRB reviews decisions made by the inquiry committee of any of the designated health professions’ colleges.<sup>529</sup> The HPRB is effectively an independent appeal mechanism with the power to:

- Confirm the original decision;
- Direct the inquiry committee to make a substituted decision; or
- Send the matter back to the inquiry committee for reconsideration.<sup>530</sup>

Our research indicates that college complaints reviewed by the HPRB alleging non-compliance with the consent requirements of the *HCCA* are uncommon. Further, the cases involving allegations of a failure to obtain informed consent by a physician or surgeon were mostly not relevant to the themes of this project, tending to involve allegations that a surgeon had failed to inform a patient of a potential complication which the patient had ultimately experienced.<sup>531</sup> In addition to these types of cases, several consent decisions reviewed included a notation by the Inquiry Committee, not that the physician or surgeon had failed to obtain consent, but that documentation of consent was lacking. In such cases, the Inquiry Committee generally incorporated a recommendation that the physician make improvements to their consent documentation processes.<sup>532</sup> The College of Physicians and Surgeons of BC has confirmed that they receive very few complaints regarding consent for people living with dementia.<sup>533</sup>

However, several 2016 decisions are worth mentioning because they suggest the College of Physician and Surgeon's Inquiry Committee lacks a robust understanding of the law of informed consent. In one case, a family member complained about in-home palliative care provided by a physician to her 90-year-old father who had cancer.<sup>534</sup> The family member, who was the substitute decision maker, alleged that the physician failed to obtain her informed consent for certain pain medications which were given to the Complainant's father, and which the Complainant alleged precipitated his death. Ultimately, the Inquiry Committee was not critical of the physician's care of the patient, and found that the pain medication provided to him 19 hours before he died was not the cause his death. The HPRB confirmed the Inquiry Committee's disposition. However, as set out by the HPRB in the following excerpt, the Inquiry Committee was apparently of the view that there are practical limits to a physician's obligations to have informed consent discussions with patients and their families:

[36] Regarding the issue of consent, the Inquiry Committee agreed that the Registrant did not obtain the consent of the complainant or his family prior to injecting the Nozinan. But the Inquiry committee concluded that "it is not always reasonable or practical for a physician to have an informed consent discussion with patients and families prior to the administration of every medication." A review of the medical records confirms that the father was having trouble with pain management at the time of the injection. This was corroborated by accounts from the nurse and Registrant, who noted that "physical suffering in the form of pain behaviour (moaning) was witnessed and documented by the doctors and RNs during his hospital stay and by myself and the Home Care Nurse when visiting his home."

[37] The Complainant disagreed with the Inquiry committee findings on consent related to the final injection of Nozinan prior to her father's death. The Complainant believes that the Registrant has a professional obligation to obtain consent from the (family members) prior to providing end of life treatment to (the father), particularly when the medications, as provided, could cause sudden death. The Complainant felt that, as a "substitute decision maker," she would have "definitely refused" to take such kind of end-of-life treatment...

The HPRB did not address in any detail the Complainant's argument that the physician had an obligation to obtain informed consent prior to the administration of the pain medication even though the Inquiry Committee found that informed consent for the medication had not been obtained. The HPRB simply reiterated the Inquiry Committee's conclusion that "the treatment offered to the

Complainant did not warrant criticism”, and determined that the Inquiry Committee’s decision fell within the range of possible, acceptable outcomes, and as such, constituted a reasonable disposition. The HPRB did not view lack of informed consent to be a significant practice error.

A second problematic decision of the HPRB concerned a complaint by a patient against a private practice psychiatrist. The patient alleged the physician had not advised her of the risks of the type of therapy being proposed, and as such she had not provided informed consent prior to commencing treatment.<sup>535</sup> In its decision, the HPRB noted the College’s submission that:

they did not consider the matter of consent through the lens of this legislation and that it is beyond the scope of the Review Board to inquire into the application of this legislation. Further, the College submits that the HCCCFAA “...is not applicable to this matter as it is legislation enacted to protect the interests of individuals whose ability to make health care decisions is limited or incapacitated, rather than for individuals who voluntarily submit to medical treatment.”

The HPRB recognized the College’s failure to properly consider the *HCCA* in this case, and its misinterpretation of the role of the *HCCA*.<sup>536</sup> Regardless, the HPRB was ultimately “satisfied that the requirements for consent as required by HCCCFAA, s.6 and the evidence of consent by the Complainant as required in HCCCFAA s.9(1) are demonstrated in the Record.”<sup>537</sup> They found that the Complainant had provided consent by way of conduct, by virtue of her regular attendance at psychotherapy sessions. The Board’s decision was largely focused on concerns regarding the illegibility of file notes, rather than the Complainant’s right to be informed of risks.

#### Office of the Ombudsperson

The Office of the Ombudsperson will investigate complaints about administrative decisions or actions of public agencies. Such complaints may relate to situations involving inadequate reasons, unreasonable delay, unfair procedures, rudeness, negligence, oppressive behaviour, or unlawfulness.<sup>538</sup> Public agencies within the jurisdiction of the Ombudsperson include hospitals, health authorities, and health-related agencies, including the Medical Services Plan and Pharmacare.<sup>539</sup> The Ombudsperson may investigate complaints in relation to processes and procedures employed by the public agency in taking an action or making a decision, rather than the merit of the actual action taken or decision made. The Ombudsperson does not have the power to substitute its decision on a clinical matter such as appropriate treatment, or a finding of incapability to make a decision regarding health care. The Ombudsperson also has the power to initiate its own investigations into systemic matters and produce reports. The report of the Ombudsperson into systemic issues in relation to seniors’ care is, often cited in *Conversations about Care*, is an example of such a report.<sup>540</sup>

### 3.9.2 Access to Legal Aid

Legal aid in BC is provided by the Legal Services Society of BC in the form of legal information, advice and representation to low-income people who meet certain financial and other eligibility requirements.<sup>541</sup> The service is primarily funded by the provincial government, with some non-government grants.<sup>542</sup> Assistance is delivered in BC via a mixed model that includes:

- A tariff system to fund legal counsel for people who qualify for assistance;
- Legal information clinics across the province;
- Family legal advice justice centres;
- Court house duty counsel;
- Various legal advice telephone services; and
- Some specific services for Indigenous people.<sup>543</sup>

Legal representation is also provided through various community programs funded primarily by the Law Foundation of BC and the Ministry of Justice.

The legal aid tariff is only available in minimal circumstances, largely for criminal matters likely to involve personal liberty deprivations. In the civil context, legal aid is largely restricted to family law matters involving violence and the safety of children.<sup>544</sup> Limited legal aid may be available for some matters involving *MHA* issues and restricted immigration matters likely to involve removal from Canada.<sup>545</sup>

Legal aid is not available for any of the matters discussed above, other than some reviews under the *MHA*, and some human rights matters. In particular, legal aid is not available to obtain advice or representation regarding:

- A formal or informal finding of incapacity to make a health care decision;
- A health care provider's choice of TSDM;
- A health care decision made by a substitute decision maker, including a decision regarding use of a restraint under the *RC Regulation*<sup>546</sup>;
- The interpretation by a health care provider or substitute decision maker of an advance directive or other health-related wish expressed while capable; or
- An application to be appointed committee of the person pursuant to the *PPA*.

Lack of legal aid funding not only impacts low income people who do not have the financial means to pursue a court application, but also those people who, because of a finding of incapability, may have difficulty accessing their financial assets.

### 3.9.3 Capacity to Retain and Instruct Counsel

The test for capacity to instruct counsel is a common law test deriving from the general principles of contract law and the law of agency.<sup>547</sup> The test is considered to have a relatively high threshold since it requires an understanding of legal and financial issues.<sup>548</sup> Effectively, the person must be capable of understanding the retainer's terms, and "forming a rational judgment of the effect upon his interests".<sup>549</sup>

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*People lose all their rights, and they don't have access to money, so they don't have access to lawyers or an advocate of any kind, and nobody is really looking out for their rights. And when you are in a locked ward, or if you are under a committee order, some people have said 'this is worse than being in prison'; you have less rights than a prisoner does in jail.*

– Lawyer



Determining capacity to instruct and retain counsel requires an assessment of the facts of each case, and it is not the subject of an articulated test.<sup>550</sup>

The Law Society of BC Code of Professional Conduct for BC (the Code) imposes some limitations on a lawyer's ability to represent "clients with diminished capacity;" however, the language of Rule 3.2-9 is clear that lawyers are permitted to represent clients who have capacity issues. The rule stipulates that "When a client's ability to make decisions is impaired because of minority or mental disability, or for some other reason, the lawyer must, as far as reasonably possible, maintain a normal lawyer and client relationship."<sup>551</sup> The Code includes language that recognizes the variability of mental capacity, underscores that capacity is not determined by disability, and grounds the ethical rule in a test determined by the particular legal matter at issue:

[1] A lawyer and client relationship presupposes that the client has the requisite mental ability to make decisions about his or her legal affairs and to give the lawyer instructions. A client's ability to make decisions depends on such factors as age, intelligence, experience and mental and physical health and on the advice, guidance and support of others. A client's ability to make decisions may change, for better or worse, over time. A client may be mentally capable of making some decisions but not others. The key is whether the client has the ability to understand the information relative to the decision that has to be made and is able to appreciate the reasonably foreseeable consequences of the decision or lack of decision. Accordingly, when a client is, or comes to be, under a disability that impairs his or her ability to make decisions, the lawyer will have to assess whether the impairment is minor or whether it prevents the client from giving instructions or entering into binding legal relationships.<sup>552</sup>

In contrast, the test for capacity to make a section 7 representation agreement for supportive or substitute decision making, as set out in section 8 of the *RAA*, is generally considered to have a low threshold. The Act states explicitly that "An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of (a) making a contract..."<sup>553</sup>

In its report on Common-Law Tests of Capacity the BCLI identified the relationship between these two capacity tests as creating a barrier to retaining counsel for people with capacity issues. The report notes that "in practice legal counsel tend to shy away from accepting a retainer from a person whose mental capacity is in issue in a court proceeding. So such people can find themselves caught in a grey area in the law."<sup>554</sup>

Law Society of BC Practice Advisor Barbara Buchanan QC has written that the inability to enter into a contract with a lawyer will generally pose a barrier to representation, even in relation to the drafting of a representation agreement. She states that:

...a lawyer should typically not act for a person who is otherwise incapable of entering into a retainer agreement with the lawyer. The Ethics Committee has not, as yet, given an opinion on whether it would recommend a change to BC Code rule 3.2-9 to clarify whether

a lawyer may act for a client for a section 7 representation agreement in a situation where the client may be otherwise incapable of making a contract.<sup>555</sup>

To resolve this issue, the BCLI ultimately recommended that BC should amend several acts, including the *Adult Guardianship Act*, *HCCA*, *MHA*, and *PPA* “to provide that if the capacity of a person is in issue in a proceeding under the act the person is deemed to have capacity to retain and instruct counsel for the purpose of representation in the proceeding”.<sup>556</sup>



CHAPTER 4

# Consent and Chemical Restraint

*As soon as you leave the facility, they are going to do what they are going to do. You have to not only care for the individual, you have to advocate through the whole damn system. That's the pain of this: you are not only caring for your loved one, 36 hours a day. But you are also fighting with the system.*

– Family caregiver

BC has developed legislation governing the use of restraints in long-term care. The *Residential Care Regulation (RC Regulation)* sets out rules for agreement to the use of a restraint in the context of long-term care, which apply to medication being used as a form of restraint. In this chapter we:

- Review the legal framework for agreement to use of a restraint in long-term care;
- Contrast it to the general consent provisions set out in the *Health Care (Consent) and Care Facility (Admission) Act (HCCA)*, and with the common law;
- Discuss approaches taken in some other jurisdictions, particularly to explore the meaning of a chemical restraint, which is not currently defined in BC law; and
- Explore the meaning of the concept of chemical restraint.

This chapter is important to the topic of health care consent for people living with dementia because the *RC Regulation* and the *HCCA* appear to provide for different rights and obligations, depending on whether the medication use is classified as a form of restraint.

The health care consent provisions of the *HCCA* make no reference to restraint. In this chapter we do not analyze the care facility admission provisions of the *HCCA*, which may be brought into force in 2019. However, we note that they include basic prohibitions against using restraints for discipline, punishment or convenience.<sup>557</sup> These statutory safeguards are limited in application to restraint by “physical means” or in a “prescribed manner”.<sup>558</sup> It is unknown yet whether any other means of restraint will be prescribed, and what they might be.

The law across Canada governing the use of restraints, and in particular chemical restraints, is sparse and variable. Some jurisdictions have regulated use; others have not. One commentator has noted, “there is widespread variation in the quality of existing legislation in this field and a low common denominator.”<sup>559</sup> Even under the common law, the duty to restrain under some certain circumstances remains unclear.

The use of restraints in a health care setting, whether it be long-term care or a mental health context, comes face to face with issues of consent, since the controversial use of restraints often involves the application of a restraint without consent—either by the person being restrained, or by a substitute decision maker. While a restraint is not always considered the provision of health care, its use in a health care setting, particularly in the context of facilities wishing to control or limit the behaviour of people living with dementia, is highly relevant to the themes of this report.

## 4.1 THE LAW OF RESTRAINT IN BC

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### 4.1.1 Common Law

In Canada, even where no statutory authority to restrain exists, there is a common law right and duty to restrain a person under care in emergency situations to protect the person or others from harm.<sup>560</sup> The existence of this duty was referred to in a Supreme Court of Canada decision from the 1970s.<sup>561</sup> A few later cases (largely from Ontario) have further discussed this common law duty.<sup>562</sup> The duty has been referred to in at least one BC decision.<sup>563</sup> The cases contain little commentary on the scope of this common law duty, beyond stating that “[t]he test for the use of restraints is stringent.”<sup>564</sup> Although the scope of the power is unclear, one writer has suggested that it is likely the common law duty would be limited by the following:

- There would need to be a reasonable belief that a patient poses an imminent danger to the safety of staff members and other patients, or to the patient’s own safety.
- Any forcible administration of medication would need to be delivered with reasonable skill and care, and represent the least intrusive option available.
- The power to restrain would likely endure only so long as there is a genuine threat of violence or aggression.<sup>565</sup>

### 4.1.2 Statutory Regime Governing Restraint in Long-Term Care

The law on the use of restraints in long-term care is set out in the *RC Regulation*,<sup>566</sup> as prescribed by the *Community Care and Assisted Living Act (CCAL Act)*.<sup>567</sup> All long-term care facilities licensed under the *CCAL Act* must comply with the *RC Regulation*, including the provisions regarding the use of restraints, which we describe in this chapter.

As we discuss in greater detail in Chapter 5, older people living with dementia receive care in many different environments. There are circumstances in which the restraint provisions of the *RC Regulation* do not apply. For example:

- Long-term care delivered in private hospitals or extended care hospitals is governed by the *Hospital Act*, which does not regulate the use of restraints.<sup>568</sup>
- Practice involving people on extended leave under the *Mental Health Act* is governed by mental health law, which does not limit the use of restraints.
- There is no statute that applies to the use of restraint in community, such as in a person's private home, or in an adult day centre. In terms of medication used as a restraint, the *HCCA* would apply to those circumstances. Non chemical restraints would be governed by the common law.

However, it is anticipated that the new regulation associated with Part 3 of the *HCCA* which is expected to come into force in 2019 will widen the application of the restraint regulations in the *RC Regulation* to a broader range of care facilities, including hospitals.<sup>569</sup>

The *RC Regulation* defines restraint as “any chemical, electronic, mechanical, physical or other means of controlling or restricting a person in care’s freedom of movement in a community care facility, including accommodating the person in care in a secure unit”.<sup>570</sup> Chemical restraint is not defined in the legislation, nor is any other kind of restraint.

### Who can Agree to use of a Restraint?

In non-emergency situations, a restraint can be used if written agreement is provided by both:

- (i) the person in care, the parent or representative of the person in care or the relative who is closest to and actively involved in the life of the person in care, and
- (ii) the medical practitioner or nurse practitioner responsible for the health of the person in care.<sup>571</sup>

The *RC Regulation* defines a “parent or representative” collectively as:

...a person who... in the case of an adult, has authority...under the *Health Care (Consent) and Care Facility (Admission) Act* or the *Patient’s Property Act*, or under an agreement under the *Representation Agreement Act* to make health or personal care decisions on behalf of the adult,<sup>572</sup>

adding that “nothing in this regulation confers on the person any greater authority to make health or personal care decisions than the person has under those Acts or under an agreement under the *Representation Agreement Act*.”<sup>573</sup> The notion of a

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*I think in the hospitals, for example, in acute care, it's very well known what you need to do. But I think that in residential care—it's bit of a gong show.*

– Health authority staff

representative in section 74 seems intended to reference a legal substitute decision maker for health care or personal decisions.

While the *HCCA* sets out a clear hierarchy of who is entitled to provide substitute consent—starting with spouse and ending with the Public Guardian and Trustee (PGT) as substitute decision maker of last resort—the *RC Regulation* seems to grant the licensee discretion to choose from whom to get agreement in writing to the use of a restraint. The licensee may get agreement from:

- The person in care;
- The parent or representative of the person in care; or
- The relative who is closest to and actively involved in the life of the person in care.<sup>574</sup>

There is no requirement in the legislation to first determine the capacity of the person in care to make a decision about whether restraints are used, nor is there a test for capacity to make restraint decisions embedded in the legislation. Neither the *RC Regulation* nor the *CCAL Act* contains a presumption of capacity. As such, on a strict reading of section 74(1)(b), the licensee may get agreement to use the restraint from a relative regardless of whether or not the adult in care has capacity.

The provision does not identify a role for the PGT as either decision maker of last resort for restraints, or to resolve disputes over who is entitled to agree to the use of the restraint. As a result, while the PGT may make decisions regarding restraint if appointed by a court as committee,<sup>575</sup> or as health care decision maker of last resort where the restraint use relates to the provision of health care,<sup>576</sup> the office does not otherwise have authority to consent to restraint use.

### Emergency Use of a Restraint

In the absence of agreement, restraints may only be used “if the restraint is necessary to protect the person in care or others from *imminent* serious physical harm”: section 74(1)(a).<sup>577</sup> Such use is referred to in the Schedule D of the *RC Regulation* as an “emergency restraint”.<sup>578</sup> The distinction between the use of restraints in emergency circumstances versus by agreement reinforces the notion that use of various restraints may be anticipated and documented in the person’s care plan, in advance. While many BC facilities have adopted a least restraint policy to inform practice and promote consistency, legislation remains fairly broad and permissive.

In the case of an emergency use of a restraint, the licensee has obligations following the emergency to:

- (a) provide, in a manner appropriate to the person’s skills and abilities, information and advice in respect of the use of the restraint to
  - (i) the person in care who was restrained,
  - (ii) each person who witnessed the use of the restraint, and
  - (iii) each employee involved in the use of the restraint, and
- (b) document in the care plan of the person in care the information and advice given.<sup>579</sup>

The section is silent regarding communication with the substitute decision maker for health care. Episodic use of restraints to address recurring situations that involve a safety risk to staff or other residents does not seem to require either communication with, or agreement by, a substitute decision maker. However, elsewhere in the *RC Regulation* emergency restraint is included in a class of reportable incidents,<sup>580</sup> and the occurrence of a reportable incident triggers a duty to notify “the parent or representative, or contact person, of the person in care.”<sup>581</sup>

The section requires the licensee provide the person who was restrained with “information and advice” in respect of use. It is not clear what kind of advice is required.

### Ongoing Use of a Restraint

The language of the *RC Regulation* is somewhat unclear in terms of the consent or agreement requirements regarding ongoing, non-emergency use. The *RC Regulation* indicates that ongoing use of restraints can be addressed in a resident’s care plan. Section 75 of the regulation states that:

- (3) If a restraint is used under section 74 (1) (b) and the use of the restraint continues either continuously or intermittently for more than 24 hours, a licensee must
  - (a) reassess the need for the restraint on the earlier of
    - (i) the time specified in the care plan of the person in care, and
    - (ii) the time specified by the persons who agreed, and
  - (b) as part of the reassessment, consult, to the extent reasonably practical, with the persons who agreed to the use of the restraint.<sup>582</sup>

The section suggests a requirement to consult with the substitute decision maker for health care in the event of ongoing use; however, the language of “to the extent reasonably possible” is vague. There is no reference in this section to either “agreement” or “consent”.

Elsewhere, as noted above, the *RC Regulation* indicates that non-emergency use requires agreement in writing by “the person in care, the parent or representative of the person in care or the relative who is closest to and actively involved in the life of the person in care”, which, subject to the ambiguities noted above, likely means the person in care or a substitute decision maker for health care, if any. Regardless of any uncertainty regarding the difference between agreement and consent, discussed below, “agreement” sets a higher bar than a requirement to “consult”.

Where the use of a restraint has been agreed to under s. 74(1)(b) (in a care plan), there are additional conditions on the use of the restraint which imply that restraint use should be a last resort alternative. Section 73(2) states:

- (a) all alternatives to the use of the restraint must have been considered and either implemented or rejected;
- (b) the employees administering the restraint must
  - (i) have received training in alternatives to the use of restraints and determining when alternatives are most appropriate, and the use and monitoring of restraints, and

- (ii) follow any instructions in the care plan of the person in care respecting the use of restraints;
- (c) the use of the restraint, its type and the duration for which it is used must be documented in the care plan of the person in care.<sup>583</sup>

The *RC Regulation* clearly states that restraint use that starts out as an emergency intervention, but continues for more than 24 hours, requires agreement from either the person being restrained, or “the parent or representative” or “relative who is closest to and actively involved in the life of the person in care.”<sup>584</sup> Where such an agreement is made, the following information must be included in the person’s care plan:

- (a) the type or nature of the restraint used;
- (b) the reason for the use of the restraint;
- (c) the alternatives that were considered to the use of the restraint, and which, if any, were implemented or rejected;
- (d) the duration of the restraint and the monitoring of the person in care during the restraint;
- (e) the result of any reassessment of the use of the restraint;
- (f) employee compliance with the requirements of Division 5 [*Use of Restraints*] of Part 5.<sup>585</sup>

Section 75 of the *RC Regulation* sets out the requirement for continued reassessment of the need for the restraint, the time periods for reassessment, and matters of consent and consultation for continued use of the restraint. The Regulation requires that “a licensee must reassess the need for the restraint at least once within 24 hours after the first use of the restraint.”<sup>586</sup> The reassessment requirement is limited to the first use.

The rationale for requiring agreement for the first use of a restraint for a specified period of time, but not for immediate subsequent uses of a restraint once that initially agreed-to period is over, is not apparent. In a similar vein, the *RC Regulation* does not provide for a mechanism for revoking agreement to the use of a restraint.

### The Meaning of “Consent” versus “Agreement”

The *RC Regulation* uses the term “agreement” instead of “consent” when addressing decision making regarding restraints. It is not clear why the term “agreement” is used. Our review of the context in which the two terms are used suggests they are essentially equivalent terms.

Black’s Law Dictionary offers the following distinct definitions of the terms “agreement” and “consent”:

Consent (n): “A voluntary yielding to what another proposes or desires; agreement, approval, or permission regarding some act or purpose, esp. given voluntarily by a competent person; legally effective assent”<sup>587</sup>



Agreement: “A mutual understanding between two or more persons about their relative rights and duties regarding past or future performances; a manifestation of mutual assent by two or more persons”<sup>588</sup>

However, the Supreme Court of Canada notes that rules of statutory interpretation direct us to explore meaning with an eye to overall context:

... the modern rule of statutory interpretation requires that “the words of an Act are to be read in their entire context and in their grammatical and ordinary sense harmoniously with the scheme of the Act, the object of the Act, and the intention of Parliament” (E.A. Driedger, *Construction of Statutes* (2nd ed. 1983), at p. 87.<sup>589</sup>

We have been unable to find an expressly stated intention of government in developing these restraint regulations. The provisions require agreement “in writing”. It is possible that requirement for agreement in writing was intended to set a higher bar than consent, which “may be expressed orally or in writing or may be inferred from conduct.”<sup>590</sup> In this report we treat the notions of consent and agreement as equivalent terms for the purposes of discussing health care and use of restraints. However, for some decision makers the powers to agree or to consent differ. For example, as noted earlier, the PGT can consent to chemical restraints which are a form of health care as TSDM, and agree to restraints more broadly where they are Committee of the Person, that is to say, where they have decision making authority that includes both health care and personal care.

## Policies and Documentation

A licensee must have written policies and procedures regarding the use of restraints in an emergency. There is no such requirement for the non-emergency use of a restraint.<sup>591</sup> In addition, a licensee must keep a record of all reportable incidents.<sup>592</sup> As noted earlier, the use of a restraint in an emergency situation is considered a “reportable incident” under Schedule D of the *RC Regulation*, and as such must be reported to a medical health officer.<sup>593</sup> A medical health officer has responsibility for the granting of licenses to community care facilities, while the director of licensing has the power to inspect facilities for compliance with licensing conditions, audit facility operations, and investigate particular matters, including reportable incidents.<sup>594</sup>

## Special Care Units as a Form of Restraint

Some long-term care facilities have units which are specifically tailored to care for adults with advanced dementia, and which are typically secure units intended to prevent the adult from leaving the area unattended. According to the definition of “restraint” in the *RC Regulation*, which expressly includes “accommodating the person in care in a secure unit,”<sup>595</sup> a person living in a special care unit of a long-term care facility is subject to ongoing restraint. The restraint regulations do not deal with restraint by way of a secure unit in a unique manner, and as a result, the provisions regarding agreement to the use of restraint, as well as reassessment and other requirements, would apply.

As discussed above, a person other than the substitute decision maker for health care may agree to the use of a restraint in some instances. The proposed substitute consent scheme for care facility admission

mirrors the provisions of the *HCCA*,<sup>596</sup> and differs from the agreement provisions of the *RC Regulation* for restraint use. As a result, it is possible that the person who has authority to consent to admission to a care facility may be different from the person who has authority to agree or not agree to have the person housed in a special care unit of the facility.

### Summary of the Regulation of Restraint in BC

Overall, the provisions indicate that use of restraint:

- Should be a last resort option;
- Must be reassessed within 24 hours—following the first instance of use;
- Is permitted without agreement in urgent situations involving a safety risk;
- Must be documented, including type of restraint and duration of use;
- Must be agreed to in writing, where agreement is required under the *RC Regulation*; and
- Can be agreed to in advance via the plan of care.

In terms of communication regarding use, the *RC Regulation* requires:

- Following emergency use, the person who was restrained must be provided with “information and advice”;
- In the case of ongoing use, at minimum, some kind of communication with the person entitled to agree to the use of restraint; and
- Either “consultation” with the person who agreed to the use, or agreement in writing by the person in care or the person entitled to make the decision (likely some kind of substitute health care decision maker)—or perhaps both.

In terms of who may agree to the use of a restraint, the *RC Regulation*:

- Does not require a capacity determination prior to getting agreement from a substitute decision maker;
- Appears to grant discretion to the licensee to choose from whom to get agreement, with respect to restraints that are not also a form of health care; and
- Uses the term “representative” in the context of determining who has authority to agree to the use of a restraint.

## 4.2 COMPARATIVE RESEARCH ON RESTRAINT LAW AND POLICY

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Our review identified some concerns with the *RC Regulation* provisions regarding use of restraints in long-term care, which we discuss in Chapter 7. In this chapter we canvass approaches taken in other jurisdictions, particularly within Canada, to see if they offer alternatives worth consideration.

Health care consent legislation in Ontario, PEI and the Yukon expressly provides that the consent legislation is subject to the common law duty to restrain when immediate action is necessary to prevent serious bodily harm to the person or to others.<sup>597</sup> Ontario's *Long Term Care Homes Act* also expressly preserves the common law duty alongside detailed legislative requirements.<sup>598</sup> These provisions make it clear that consent is not required in such circumstances, but do not elaborate on what the common law duty entails. All jurisdictions are bound by the common law duty to restrain, subject to any relevant enactments.

There is great variability among Canadian jurisdictions in the legislative coverage and treatment of restraints in health care settings. In the mental health context, Kaiser has described legislation as failing to adequately protect patients. He states that even in jurisdictions which have enacted legislation on the topic, there still exists “excessive discretionary power and no mandatory prevention, last resort or other protective doctrines.”<sup>599</sup>

#### 4.2.1 Restraint in a Mental Health Setting

The majority of jurisdictions' mental health statutes (Ontario, Alberta, Manitoba, PEI, Yukon, Nunavut, Northwest Territories)<sup>600</sup> provide authority to restrain a patient in the context of an involuntary admission to a psychiatric facility, and describe restraint in a consistent manner similar to Manitoba's definition below:

to place under control when necessary to prevent harm to the patient or to another person by the minimal use of such force, mechanical means or medication as is reasonable having regard to the patient's physical and mental condition.<sup>601</sup>

It is common for Canadian jurisdictions to require the documentation of any use of a restraint in a mental health facility.

Quebec places a “minimal use” restriction in its legislation, which also applies in long-term care, as well as a recording requirement as follows:

118.1. Force, isolation, mechanical means or chemicals may not be used to place a person under control in an installation maintained by an institution except to prevent the person from inflicting harm upon himself or others. The use of such means must be minimal and resorted to only exceptionally, and must be appropriate having regard to the person's physical and mental state.

Any measure referred to in the first paragraph applied in respect of a person must be noted in detail in the person's record. In particular, a description of the means used, the time during which they were used and a description of the behaviour which gave rise to the application or continued application of the measure must be recorded.

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*If they're admitted under extended leave, you don't need to get consent from the Representative or whoever. But I always did. Because it's good practice to involve the family, or involve the friend... So, I would consider it bad practice not to.*

– **Physician**

Every institution must adopt a procedure for the application of such measures that is consistent with ministerial orientations, make the procedure known to the users of the institution and evaluate the application of such measures annually.<sup>602</sup>

New Brunswick's mental health statute authorizes the use of restraints in psychiatric facilities, but does not limit their use in any way.<sup>603</sup> The Act states that an "examination certificate... is sufficient authority ... for the attending psychiatrist, without consent ... to administer such restraint as, in the attending psychiatrist's opinion, is necessary."<sup>604</sup> In BC, restraints are not referenced in the *Mental Health Act*, and the Director is given wide latitude with respect to the use of restraints, with patients having been "deemed to consent" to treatment; when detained, patients are "subject to the direction and discipline of the director."<sup>605</sup>

Nova Scotia, Saskatchewan and Newfoundland do not address the issue of the use of restraints in a psychiatric context.<sup>606</sup>

#### 4.2.2 Restraint in a Long-Term Care

Issues of consent and restraint are equally contentious in long-term care. In this context, restraint regulation again varies considerably between Canadian jurisdictions. Regulation of restraint in care facilities commonly occurs through legislated minimum standards. In the select provinces reviewed in more detail below, it is common for such minimum standards to require facilities to have a restraint policy. However, the level of detail required varies considerably, as does the required substantive content of the policies. A requirement in these standards that residents must consent to the use of a restraint (in non-emergency situations) is the exception, rather than the rule.

Long-term care standards are generally not put in the regulation or Act so that they can be more easily reviewed and updated on a regular basis. A regulation usually provides the government with the authority to produce standards, incorporates the government published standards by reference, and makes compliance with them mandatory.<sup>607</sup> Compliance with such standards is always a licensing requirement.

Below we review Ontario, Quebec, Alberta, Nova Scotia, Saskatchewan, and Prince Edward Island in order to provide a broad cross-section of the types of restraint regulation in the long-term care in Canada. Ontario is reviewed in greater detail because it contains the most comprehensive requirements, and similar to BC, the jurisdiction has opted to address restraints in its legislation governing long-term care. We also consider the law in the states of Washington and California.

##### Ontario

Ontario's *Long Term Care Homes Act* ("*LTCH Act*") contains legislative provisions with respect to the use of restraints. While the Act bears some similarities to BC's *RC Regulation* (described in detail above), it is more comprehensive in some respects, particularly with respect to recording obligations. The Act primarily relies on the common law duty to restrain. Noteworthy is the requirement in Ontario's *LTCH Act* that licensees must have a written policy to minimize the restraining of residents,

as well as a requirement that licensees enforce the policy.<sup>608</sup> The Regulations set out a comprehensive list detailing what this policy must cover, but do not provide any substantive requirements.<sup>609</sup> The *LTCH Act* provides:

30. (1) Every licensee of a long-term care home shall ensure that no resident of the home is:
  1. Restrained, in any way, for the convenience of the licensee or staff.
  2. Restrained, in any way, as a disciplinary measure.
  3. Restrained by the use of a physical device, other than in accordance with section 31 or under the common law duty described in section 36.
  4. Restrained by the administration of a drug to control the resident, other than under the common law duty described in section 36.
  5. Restrained, by the use of barriers, locks or other devices or controls, from leaving a room or any part of a home, including the grounds of the home, or entering parts of the home generally accessible to other residents, other than in accordance with section 32 or under the common law duty described in section 36.”

No definition of restraint is provided. However, the law contains the following guidance on what is *not* considered a restraint:

- “The use of a personal assistance services device...to assist a resident with a routine activity of living.”<sup>610</sup>
- “The administration of a drug to a resident as a treatment set out in the resident’s plan of care.” Treatment is not defined in the Act.<sup>611</sup>
- “The use of barriers, locks or other devices or controls at entrances and exits to the home or the grounds of the home... unless the resident is prevented from leaving.”<sup>612</sup>
- “The use of barriers, locks or other devices or controls at stairways as a safety measure.”<sup>613</sup>

Under the *LTCH*, the general rule is that a restraint can only be used in accordance with the common law duty to “restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person or to others”.<sup>614</sup> There are some exceptions to this general rule in the case of physical restraints, which can be used if their use has been agreed to in the resident’s plan of care in accordance with section 31 of the Act.<sup>615</sup> Section 31 of the Act has a number of requirements, including that “the restraining of the resident has been consented to by the resident or, if the resident is incapable, a substitute decision-maker of the resident with authority to give that consent.”<sup>616</sup>

In Ontario, the *LTCH Act* requires that any use of a restraint must have been ordered by a physician or a registered nurse.<sup>617</sup> However, the *LTCH Act* also preserves the common law duty to restrain when immediate action is necessary to prevent serious bodily harm to the person or to others, which presumably permits restraint without a health care provider’s order given the emergency nature of the situation.<sup>618</sup> In BC, agreement of a physician or nurse to the use of the restraint must only be obtained in non-emergency circumstances.<sup>619</sup>

Unlike BC's *RC Regulation*, which set out the circumstances in which restraint may be used, the Ontario legislation instead relies on the existence of the common law duty, without specifying the parameters of the common law duty. While BC refers to an "emergency" predicating the need for the restraint, Ontario instead focusses on a situation requiring the prevention of imminent harm. Both require a resident (or substitute decision maker) to consent to the use of a restraint when the restraint is used as part of their care plan. However, in Ontario, a *chemical* restraint cannot be used as part of a care plan; chemical restraints are limited to use in accordance with the common law, that is to say, when they are necessary to protect the person or others from imminent harm.

In comparison with the BC requirement to document type and duration of use, the *LTCH Act* and Regulations places significant record keeping obligations on licensees with respect to instances of the use of a restraint. For chemical restraints, the Regulations require, at minimum, documentation of the following:

1. Circumstances precipitating the administration of the drug.
2. Who made the order, what drug was administered, the dosage given, by what means the drug was administered, the time or times when the drug was administered and who administered the drug.
3. The resident's response to the drug.
4. All assessments, reassessments and monitoring of the resident.
5. Discussions with the resident or, where the resident is incapable, the resident's substitute decision-maker, following the administration of the drug to explain the reasons for the use of the drug.<sup>620</sup>

Similar documentation is required for the use of a physical restraint, including documentation of consent obtained.<sup>621</sup>

Also, Ontario has enacted the *Patient Restraint Minimization Act*, 2001 which advocates for the minimization of restraint in patient care.<sup>622</sup> The Act applies to public and private hospitals, but not psychiatric facilities, where mental health legislation continues to govern, or to long-term care facilities, where the *LTCH Act* governs. The *Patient Restraint Minimization Act* attempts to enhance the law of patient restraint. However, it leaves much to be done by way of regulation, and regulations have not yet been legislated. Without the details and the significant clarification that associated regulations would provide, the Act remains deficient.<sup>623</sup>

The *Patient Restraint Minimization Act*, states that a hospital or facility shall not restrain a patient except under two sets of circumstances, entitled "Enhancement of Freedom" and "Prevention of Serious Bodily Harm."<sup>624</sup> Both circumstances require that "the restraint...is necessary to prevent serious bodily harm to the patient or another person." The "Enhancement of Freedom" circumstance also requires that the restraint give the person greater freedom and enjoyment of life, and requires the consent of the person or the person's substitute decision maker.<sup>625</sup> The second "Prevention of Harm" circumstance does not require consent or enhanced freedom, but simply that the regulatory criteria for the use of the restraint be met.<sup>626</sup> This circumstance is expressly stated to be unaffected by the common law duty to restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person or to others.<sup>627</sup> It is unclear whether there is any difference between this legislated

authority to restrain, and the common law duty to restrain. It is also unclear when the hospital may rely on the first set of circumstances, as opposed to the second.<sup>628</sup>

### Summary of Key Differences from BC

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Key differences from BC Law:

- Every long-term care home must have a policy regarding the use of restraint which applies to non-emergency use, as opposed to only emergency use, which includes how use will be evaluated to ensure minimization and compliance with the law;
- Use of a chemical restraint cannot form part of a care plan; and
- The regulation sets out specific additional documentation requirements when chemical restraints are used

### Quebec

Quebec has imbedded some requirements governing restraint into its *Civil Code*, section 118.1, which apply to both mental health and long-term care, and are discussed above in subsection 4.2.1. Although we have been unable to find a copy of Ministerial Orientations regarding section 118, commentary on them suggests that the decision to use controls must be made with informed consent of the person or their family/guardian.<sup>629</sup>

### Summary of Key Difference from BC

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Key differences from BC Law:

- The *Civil Code* uses the language of “harm upon himself or others” instead of “emergency”; and
- Must document time during which restraints were used, and the behaviour which gave rise to the application or continued application of restraint.

### Alberta

In Alberta, minimum requirements in the provision of health care services in nursing homes are contained in the *Continuing Care Health Service Standards* (“CCHSS” or the “Standards”) published by the Ministry of Health.<sup>630</sup> These Standards are made pursuant to the *Nursing Homes General Regulation*<sup>631</sup> under the *Nursing Homes Act*,<sup>632</sup> and pursuant to a Ministerial Directive under the *Regional Health Authorities Act*.<sup>633</sup> They address the health and personal care services provided by nurses, therapists, health care aides, and other health care professionals in the nursing home setting.<sup>634</sup> The Standards apply to “Operators,” defined as “[a] legal entity that receives public funding for the provision of Health Care directly to Clients.”<sup>635</sup> These Standards include standards with respect to the use of restraints.

Chapter 16 of the CCHSS requires operators of care facilities to maintain and implement policies with respect to the use of restraints. Restraint is defined as “[a]ny measure that is pharmacological,

environmental, mechanical or physical that is used with the intention of protecting a Client from self-harm or preventing harm to another person.”<sup>636</sup> The Standards make it clear that administration of an anti-psychotic medication can be considered the use of a restraint, and goes so far as to require specific measures in those circumstances:

- (g) where an antipsychotic medication is used as a pharmacological Restraint:
  - (i) a Medication Review by a Physician and the Interdisciplinary Team will occur at a minimum of once a month to ensure the appropriateness of the medications prescribed; and
  - (ii) where the antipsychotic medication is no longer required, a Physician or pharmacist will document instructions regarding the process for gradual dose reduction and discontinuation.<sup>637</sup>

However, the Standards do not clarify when medication would be considered a restraint.

With respect to the use of restraint, the Standards require nursing homes to include in their policies that:

where a Client has been assessed as exhibiting a behaviour or a Responsive Behaviour that puts the Client or others at risk of immediate harm, the Regulated Health Care Provider may initiate the process to utilize a Restraint

A Responsive Behaviour is defined as:

A significant subset of the behavioural and psychological symptoms of dementia (BPSD) that are thought to be an expression of: a) an unmet need; b) a response to a stimulus in a Client’s environment; c) a psychological need; or d) a response to the approach of Health Care Providers or other Clients.<sup>638</sup>

There is no requirement that the resident or a substitute decision maker provide consent before anti-psychotics can be administered as a restraint. The Regulated Health Care Provider (who is a member of a regulated health profession under the *Health Professions Act*)<sup>639</sup> has authority to initiate the restraint utilization process. Although any Regulated Health Care Provider can initiate the process, standards with respect to documentation of the use of restraints indicate that documentation must include “a Physician’s order, within 72 hours of initiation of the Restraint, authorizing the use of the Restraint.” This requirement clarifies that a physician must authorize the use of a restraint; however, it is unclear on a reading of the CCHSS whether a physician’s authorization needs to be prior to the commencement of the use of the restraint, or within 72 hours of its use.

The meaning of “immediate harm” is very broad. The requirement in the Standards that a medication review by a physician and the interdisciplinary team “occur at a minimum of once a month to ensure the appropriateness of the medications prescribed,”<sup>640</sup> indicates that permitted use goes beyond the common law understanding of an emergency. This standard supports the longer term use of anti-psychotics to manage behaviour.

The Standards also specify a number of substantive requirements which must be included in the nursing home’s policies, including:



- supportive interventions must be considered prior to the utilization of a Restraint;
- if supportive interventions are considered and deemed ineffective or inappropriate in the circumstance, the least restrictive Restraint may be utilized;
- information on the use of Restraints must be provided to the Client or the Client’s legal representative, if applicable, when possible prior to its use and at any Interdisciplinary Team conferences that occur during the time the Restraint is in use;
- the method and frequency for monitoring the Client when the Restraint is in use; and
- criteria for the discontinuation of a Restraint.<sup>641</sup>

The Standards also require detailed documentation of the use of any restraint in a resident’s chart and care plan, and the nursing home’s policies must include the following in this regard:

- (a) the behaviour that put the Client or others at risk of harm;
- (b) the supportive interventions that have been considered and trialed;
- (c) indications for the initial use of the Restraint;
- (d) a Physician’s order, within 72 hours of initiation of the Restraint, authorizing the use of the Restraint;
- (e) the method and frequency for monitoring the Client when the Restraint is in use; and
- (f) assessment of the Client while the Restraint is being used and review of the ongoing need for the Restraint.<sup>642</sup>

### Summary of Key Differences from BC

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In Alberta, requirements are addressed in a standard published by the government that applies to all health care professionals and care home operators that receive public funding.

The Standards:

- Clarify that administration of an anti-psychotic medication can be considered the use of a restraint; and
- Impose detailed documentation requirements where restrains are used.

As the Standards do not require consent prior to administration of a chemical restraint, and appear to expand the circumstances under which use of a chemical restraint will be appropriate beyond the scope of the common law, they do not provide a model BC ought to consider in terms of enhancing regulation.

### Nova Scotia

Minimum standards for licensed nursing homes and residential care facilities in Nova Scotia are contained in the Department of Health and Wellness’ document entitled “The Long Term Care Program Requirements: Nursing Homes and Residential Care Facilities,” made in accordance with the *Homes for Special Care Act and Regulations*.<sup>643</sup>

Restraint is defined in the Program Requirements as:

Anything that is intentionally used to limit the movement or behaviour of a resident and over which the resident has no control. Restraints may be physical, environmental or chemical. A resident is restrained if he or she cannot remove a physical device, leave a specific area, or refuse a chemical restraint.<sup>644</sup>

However, restraints are not regulated beyond a requirement that nursing homes and long-term care facilities develop and follow a least restraint policy.<sup>645</sup>

### Summary of Key Difference from BC

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Key difference from BC law:

- Requires nursing homes and long-term care facilities to develop and follow a least restraint policy.

### Saskatchewan

In Saskatchewan, all special-care homes and other designated facilities that provide publicly funded long-term care must operate in accordance with the minimum standards set out in the Program Guidelines for Special-care Homes (the “Program Guidelines”).<sup>646</sup> The Program Guidelines include a section intended to “provide direction for the use of restraints in the special-care home environment”. Restraint is not defined in the Program Guidelines. The section requires special-care homes to maintain a policy on restraints which accords with accepted professional standards, and which includes a number of minimum requirements.

The Program Guidelines distinguish between “commitments” to be made by a special-care home, and “requirements.” The Program Guidelines require “a commitment that restraints are used as a last resort when the resident’s behaviour or medical condition could interfere in the residents’ health and safety or the health and safety of others”, and “a commitment that strategies designed to reduce the use of restraints will be implemented.”<sup>647</sup> It is unclear how binding such commitments are. On the other hand, it is a requirement that prior to and during restraint usage there is evidence of the following:

- i. A less intrusive intervention has been implemented and demonstrated to be ineffective;
- ii. Initial and on-going comprehensive assessments of the resident;
- iii. Other professionals have been consulted that specialize in the care and treatment of difficult to manage behaviours, this may include a continuing care consultant;
- iv. A written order for a restraint has been prescribed by the attending physician and/or registered nurse (nurse practitioner) and reviewed as indicated through the resident assessment process; and
- v. The responsible person (person legally authorized to act on behalf of the resident) for the resident has been consulted regarding the use of restraints.<sup>648</sup>

These minimum standards indicate that a restraint must be ordered by the attending physician or nurse practitioner, with no distinction made between different types of restraint. While the “responsible person” for the resident must be consulted regarding the use of the restraint, there is no requirement that the resident’s consent, or the consent of the “responsible person”, be obtained. The Program Guidelines do not distinguish between emergency and non-emergency use of restraints; however, the common law duty to restrain will apply.

### Summary of Key Differences from BC

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Key differences from BC law:

- Detailed documentation requirements exist.

### Prince Edward Island

The PEI Department of Health and Wellness publishes minimum standards for licensing of Community Care Facilities and nursing homes in accordance the *Community Care Facilities and Nursing Homes Act and Regulations*.<sup>649</sup> Separate standards are published for Community Care Facilities,<sup>650</sup> which provide light care with no nursing supervision (“CCF Standards”) and nursing homes,<sup>651</sup> which provide a higher level of care with nursing supervision (“Nursing Home Standards”). Neither standard defines “restraint.”

Use of restraints is prohibited in Community Care Facilities. In nursing homes, use is permitted only where the nursing home implements a “least restraint” policy:

4.4.26 The facility has a least restraint policy, supported by written procedures, directing restraint use when the risk of resident self-injury or to others is significant. Restraints are used only as a last resort and are a temporary measure when all other means to prevent or reduce the risk prove unsuccessful.<sup>652</sup>

The language of “significant risk” purports to expand on the common law duty to restrain in emergency situations which involve an immediate or imminent risk of harm. There is nothing in these standards which require the risk to be imminent before restraint may be used. However, the Nursing Homes Standards require the nursing home’s policy to ensure that “[p]harmaceutical and/or least restraint are initiated only when other measures are ineffective.”<sup>653</sup> This process requires staff to observe, assess and document triggers for altered behaviour over time, and to employ social and environmental interventions to reduce distress before considering use of a restraint.<sup>654</sup>

Legislation, regulations, and Nursing Home Standards are all silent on consent. PEI’s health care consent legislation, as outlined above, expressly provides that health care consent law is subject to the common law duty to restrain when immediate action is necessary to prevent serious bodily harm to the person or to others.<sup>655</sup> The Act does not touch on the question of consent to the use of restraints in a non-emergency situation.

## Summary of Key Differences from BC

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Key difference from BC:

- Use of restraint is permitted in nursing homes only where the home implements a least restraint policy;
- Restraint may be used in a nursing home if there is a significant risk of injury to self and others; and .
- Law is silent with respect to consent to restraints in the non-emergency context.

### Washington

The law governing informed consent in long-term care facilities (called nursing homes in Washington), including the regulation of restraints, is the *Washington Administrative Code*, Chapter 388-97 (“WAC”). The WAC provides that a resident has the right to be free from physical and chemical restraints which are imposed for purposes of “discipline or convenience, and not required to treat the resident’s medical symptoms”<sup>656</sup> or have the effect of “preventing or limiting independent mobility or activity.”<sup>657</sup>

As with BC, the definition of “health care provider” encompasses a wide range of health care professionals, such as doctors, nurses, dentists, psychologists, physical therapists and pharmacists.<sup>658</sup> However, the definition also includes employees or agents of the health care professionals listed, facilities, and institutions which employ any of the health care professionals listed, such as hospitals, clinics and nursing homes, as well as those facilities’ officers, directors employees or agents, so long as they are working within the scope of their employment.<sup>659</sup> This definition aims to make these categories of health care providers potentially liable for an action alleging a failure to obtain informed consent to health care.<sup>660</sup>

There is significant discussion of patient’s rights in the regulations. The WAC places an obligation on nursing homes to ensure the informed consent process is followed.<sup>661</sup> Specifically, nursing homes are obliged to inform the resident of the right to consent to or refuse care at the time of resident assessment and care plan development, and again with any condition changes.<sup>662</sup> Further, the nursing home must inform the resident at the time initial care plan decisions are made, and periodically thereafter, of the right to change their minds about an earlier consent or refusal decision.<sup>663</sup>

As a condition of licensing, Department of Health regulations also require hospitals in Washington to adopt and implement policies which define patients’ rights to be involved in all aspects of their care, including the right to refuse treatment and to be informed.<sup>664</sup> This practice has been described as a “policing role in the informed consent process.”<sup>665</sup> Further, hospital accreditation standards in Washington require that “[t]he hospital honors the patient’s right to give or withhold informed consent.”<sup>666</sup> Hospitals must maintain detailed policies on informed consent, and consent must be obtained in accordance with these policies.<sup>667</sup> In Washington state, the resident rights (as set out in the *Washington Administrative Code*) which must be provided orally and in writing to the resident, clearly set out the resident’s right to be fully informed, and to consent or refuse treatment.<sup>668</sup>

Federal legislation requires, as a conditions of participation in Medicare and Medicaid programs, that “patient’s rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment”.<sup>669</sup> Hospitals must use informed consent processes to ensure the information necessary for patients to make informed decisions is provided to them and/or their representatives.<sup>670</sup>

Washington State has been innovative in the development of the formal concept of “shared decision making,” with the passing of shared decision making legislation in 2007 as part of a pilot project.<sup>671</sup> Currently, the law in Washington allows for the shared decision making process to culminate in a signed “acknowledgment of shared decision making,” as an alternative means of meeting the health care provider’s informed consent requirements. “Shared decision making” is essentially a discussion between the health care provider and the patient about the proposed treatment, which includes the use of a “patient decision aid”. A “patient decision aid” is a written, audiovisual, or online tool that provides balanced information about the patient’s condition and proposed treatment options, benefits and harms. Washington State’s Health Authority has statutory authority to certify patient decision aids. The certification process is in the early stages, and is ongoing.<sup>672</sup>

### Summary of Key Differences from BC

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Key differences from BC law:

- Consent to treatment can be provided by way of an approach called “shared decision making”;
- The definition of “health care provider” includes employees or agents of health care professionals, facilities, and institutions which employ any of the health care professionals;
- Nursing homes must ensure the informed consent process is followed;
- Hospitals and nursing homes must implement policies delineating patients’ rights to be involved in all aspects of care, including the right to refuse treatment and provide informed consent; and
- Nursing homes must inform the resident of the right to consent to, or refuse care, at the time of care plan development, and again with any condition changes.

### California

California law generally relies on the common law of informed consent, requiring health professionals to obtain consent of the patient, or the patient’s legal representative, prior to providing treatment, or risk a charge of battery, negligence or professional misconduct.<sup>673</sup> “Informed consent” is defined in the *California Code of Regulations* (“CCR”) as “the voluntary agreement of a patient or a representative of an incapacitated patient to accept a treatment or procedure after receiving information in accordance with [particular sections of the regulations].”<sup>674</sup>

The CCR place an obligation on facility staff to verify that the patient’s health record contains documentation that the patient has given informed consent to the treatment, prior to administering a psychotherapeutic drug (or physical restraint or other device).<sup>675</sup> As discussed with respect to

Washington, hospitals must ensure that proper consent documentation is included in a patient's medical records where written consent is required.<sup>676</sup>

Patient rights specific to skilled nursing facilities in California (essentially health facilities which provide 24-hour inpatient care to patients who primarily require skilled nursing care on an extended basis, and which include nursing homes),<sup>677</sup> are also set out in the *CCR*. There is an express statutory obligation to obtain a resident's informed consent in the context of skilled nursing facilities prescribing anti-psychotics to residents who have decision making capacity.<sup>678</sup>

The *CCR* refers specifically to a patient's right to be informed of material information relevant to the administration of psychotherapeutic drugs or physical restraints (or other device):

(5) To receive all information that is material to an individual patient's decision concerning whether to accept or refuse any proposed treatment or procedure. The disclosure of material information for administration of psychotherapeutic drugs or physical restraints or the prolonged use of a device that may lead to the inability to regain use of a normal bodily function shall include the disclosure of information listed in Section 72528(b).<sup>679</sup>

Skilled nursing facilities must have written policies regarding these patient rights, and such policies must be made available to the patient, and any representative of the patient, or the public.<sup>680</sup> With respect to informed consent, patient rights specific to skilled nursing facilities include general rights to be informed of one's health status, and to participate in care planning as well as a very clear right to consent or refuse treatment, with a corollary right to be given all information material to making a decision about treatment.<sup>681</sup> The information that must be disclosed includes the expected information around reasons for treatment, nature of treatment, duration, side effects, and alternatives. The law also includes a requirement that the health care professional must tell the patient "that the patient has the right to accept or refuse the proposed treatment, and if he or she consents, has the right to revoke his or her consent for any reason at any time."<sup>682</sup>

### Summary of Key Differences from BC

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In California a number of legislative provisions exist specifically related to anti-psychotic use, including the right of a resident with capacity to provide informed consent to use.

### US Federal legislation

US federal legislation places an obligation on health facilities to inform people of their health care consent rights. The Federal US *Patient Self-Determination Act* places an obligation on hospitals, skilled nursing facilities, home health agencies, and hospice programs which receive Medicare or Medicaid funding to inform people of their rights under State law to make their own health care decisions, including the right to accept or refuse medical treatment.<sup>683</sup> While informed consent rights are codified in state law, this federal legislation has played an important role in raising awareness of consent rights nationally.<sup>684</sup>

### 4.3 WHEN IS MEDICATION A FORM OF RESTRAINT?

The question of whether, and under what circumstances, the use of an anti-psychotic or other form of medication can be a form of restraint, and as such be subject to restraint regulation in BC, is of critical importance in the context of consent law. As discussed above the *RC Regulation* essentially creates an alternate consent scheme for restraints. In this Part 3 we explore the meaning of a chemical restraint. We review domestic and international sources.

#### 4.3.1 Definitions of Chemical Restraint—Health Care Perspective

Most generally, chemical restraint refers to a form of medical restraint in which a medication is used to restrict the freedom or movement of a patient, or in some cases used to sedate a patient. H Archibald Kaiser provides the following fairly plain language definition of a restraint in his work:

The common element among many conceptions of seclusion and restraint involves extraordinary controls over the movement or behaviour of an individual by various non-consensual means. Broadly speaking, these involuntary interventions will prevent a person from physically leaving an area, or will restrict normal bodily movements, or will limit behavioural expression. Seclusion or restraint fall outside the parameters of conventional treatment. . .<sup>685</sup>

The College of Nurses of Ontario includes the following definition of restraints in their Practice Standard, offering some concrete examples:

Restraints are physical, chemical or environmental measures used to control the physical or behavioural activity of a person or a portion of his/her body. Physical restraints limit a client's movement. Physical restraints include a table fixed to a chair or a bed rail that cannot be opened by the client. Environmental restraints control a client's mobility. Examples include a secure unit or garden, seclusion or a time-out room. Chemical restraints are any form of psychoactive medication used not to treat illness, but to intentionally inhibit a particular behaviour or movement.<sup>686</sup>

The Patient Safety Institute of Canada also divides restraints into three categories – physical, environmental and chemical. With respect to chemical restraints, it states:

In mental healthcare settings, there are instances where medications may be used to both treat symptoms and manage behavioural emergencies. Therefore, not included in the definition of chemical restraint are psychotropic medications that are used for treatment purposes as

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*It's subtle, but there's such a huge overlap. I don't think they're mutually exclusive. So yes, we do look at medications as a restraint, but mostly we focus, and our language is focused, on using it as comfort. And minimizing distress for the patient. I think our language is also equally focused on safety with staff, other patients, and the patient themselves.*

– Geriatric psychiatrist

part of an ongoing plan of care for an established diagnosis. Medication that is prescribed for PRN (“as needed”) and established with the person as part of his or her plan of care is also excluded. Chemical restraint or Acute Control Medication (ACM) therefore refers to the administration of psychotropic medication in situations where a person may have already lost behavioural control or where there is imminent risk of loss of control in behaviour that will lead to harm to self or others.<sup>687</sup>

The College and Association of Registered Nurses of Alberta succinctly defines chemical restraint as “[a]ny psychotropic drug not required for treatment, but whose use is intended to inhibit a particular behavior or movement”.<sup>688</sup> The Australian Medical Association considers Behavioural and Psychological Symptoms of Dementia (discussed in Chapter 2) to be a medical condition, and as such the use of anti-psychotic medications to alleviate these symptoms is not considered the use of a restraint.<sup>689</sup>

The Australian Government’s Department of Health and Ageing defines restraint generally as “any aversive practice, device or action that interferes with a resident’s ability to make a decision or which restricts their free movement.”<sup>690</sup> They define chemical restraint in detail, providing examples:

Chemical restraint is the control of a resident’s behaviour through the intentional use of:

- prescribed medicines
- over the counter medicines and/or
- complementary alternative medicines.

Chemical restraint is:

- when no medically identified condition is being treated
- where the treatment is not necessary for a condition
- to over-treat a condition. Chemical restraint includes the use of medicines when:
- the behaviour to be affected by the active ingredient does not appear to have a medical cause
- part of the intended pharmacological effect of the medicine is to sedate the person for convenience or for disciplinary purposes. Examples of pharmacological agents used as chemical restraint are antipsychotic, antidepressant, antimanic, anxiolytic and hypnotic drugs.<sup>691</sup>

The South Australian Office of the Public Advocate (“SAOPA”) also takes a position on this issue, stating that “[i]f the primary purpose of administering medication is to subdue or control the behaviour of a person, then the use of the medication is a chemical restraint.”<sup>692</sup> The SAOPA’s policy on restrictive practices in aged care settings, which applies to delegated Guardians of the SAOPA, notes the controversy regarding whether anti-psychotic medication that is used to treat behavioural and psychological symptoms of dementia is a form of restraint, coming down on the side of such interventions being considered a chemical restraint.

A common theme to various definitions of chemical restraint set out above is that it is the use of medicines for purposes other than therapeutic purposes that bring treatment under the umbrella of



chemical restraint. This interpretation of chemical restraint is confirmed by Vancouver Island Health Authority’s Community Care Facilities Licensing Program which publishes information to guide care facilities and defines chemical restraint as “any medication used to control behaviour beyond the point of therapeutic benefit.”<sup>693</sup>

### 4.3.2 Legal Definitions of Chemical Restraint

#### Ontario

A definition of chemical restraint is not provided in Ontario’s *LTCH Act*; however, the Act does state that: “[t]he administration of a drug to a resident as a treatment set out in the resident’s plan of care is not a restraining of the resident.”<sup>694</sup> “Treatment” is not defined in the *LTCH Act*. However, the definition of ‘treatment’ in Ontario’s *Health Care Consent Act* states broadly that:

“treatment” means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan...<sup>695</sup>

A decision of Ontario’s Consent and Capacity Board provides some indication that anti-psychotic medications can be used as both a chemical restraint on behaviour on an emergency basis, without consent, as well as treatment as part of a care plan on a longer-term basis, with consent. In this case, the patient had dementia as a result of a serious acquired brain injury. The matter came before the Consent and Capacity Board as a result of the physician’s application to determine whether the patient’s substitute decision maker was making decisions in accordance with the *HCCA*. The patient had presented a number of challenges to the physicians and staff at the hospital, including hitting, biting, and scratching staff, and he was frequently verbally abusive. The physician wanted to treat the patient with anti-psychotic medications. The physician had been using anti-psychotic medications on an emergency basis as a chemical restraint to respond to some of the behaviour. The physician wanted to use the anti-psychotic medications to treat the patient as part of his care plan, but the substitute decision maker refused to provide consent. Ultimately, the Board found that the substitute decision maker was not acting in the patient’s best interests, and directed her to comply with the proposed treatment plan, which included administration of anti-psychotic medications.<sup>696</sup>

We have been unable to find any legal pronouncement definitively determining whether the prescription of anti-psychotic medications to manage dementia-related behaviours is considered treatment in Ontario as opposed to a chemical restraint. In Ontario chemical restraints cannot be used as part of a care plan, but are limited to use in emergency situations of imminent harm. This may indicate that the prescription of anti-psychotic medications in the longer term, or on a PRN basis, is not considered a chemical restraint in Ontario, and instead treatment.

#### Alberta

Alberta’s minimum standards regulation recognizes that medication aimed at managing the following behaviour is a chemical restraint:

A significant subset of the behavioural and psychological symptoms of dementia (BPSD) that are thought to be an expression of: a) an unmet need; b) a response to a stimulus in a Client's environment; c) a psychological need; or d) a response to the approach of Health Care Providers or other Clients.<sup>697</sup>

## Australia

Other jurisdictions are also challenged by this issue. Australian state and territory guidelines are inconsistent as to whether the administration of anti-psychotic medications for non-therapeutic behavioural management is considered a “restrictive practice” (the term used for restraints in Australia).

In New South Wales, the Guardianship Tribunal has expressed the view that the use of anti-psychotic medications for behaviour management is not a “restrictive practice” for the purposes of consent procedures under guardianship legislation. This use of medication is considered treatment, and so governed by consent law.<sup>698</sup> However, at the same time the New South Wales Government Department of Ageing, Disability and Home Care has made it clear in its policy regarding behaviour support in the disability sector that medication prescribed to manage challenging behaviours on a PRN basis is considered a “restricted practice”.<sup>699</sup> More recently there has been greater consensus on this topic with the very recent development of national rules on restrictive practices.<sup>700</sup> New South Wales, for example, which has adopted the national rules has published a guideline on authorizing the use of restrictive practices which indicates that the use of medication on either a routine or PRN basis may constitute chemical restraint and that chemical restraint may include psychoactive medication where used to influence behaviour.<sup>701</sup>

The South Australian guardianship tribunal has stated that “[i]f the primary purpose of administering medication is to subdue or control the behaviour of a person, then the use of the medication is a chemical restraint.” The Tribunal also views the use of PRN medication, which is used for the primary purpose of controlling behaviour, as a chemical restraint.

Several Western Australian administrative decisions discuss the issue of whether the prescription of certain anti-psychotic medications is considered “medical treatment”, or a chemical restraint for the purposes of the consent procedures set out in the guardianship legislation. In one case, the administrative decision making body at that time took a broad view of the concept of medical treatment, stating that whether the use of a physical or chemical restraint in a nursing home is medical treatment would depend on the reasons for its use, its purpose, and who prescribed its use.<sup>702</sup> In addition, the issue should be determined on a case by case basis.<sup>703</sup> In that case, the Board (as it then was) determined that an anti-psychotic medication given to a man in an aged care facility who had alcohol-related dementia with behavioural disturbances was a chemical restraint.<sup>704</sup> In another later case, the Tribunal similarly assessed anti-psychotic medication given to a man with an acquired brain injury, stating, with respect to the medication, that:

...if the purpose is to intentionally control a person's movement or behaviour (other than the treatment of a diagnosed mental illness), it is my view that the intervention is properly characterised as restraint and not treatment.<sup>705</sup>

The Tribunal concluded that “[t]he effect of the intervention is to control JP’s movement and behaviour and ... it is, in my view, restraint, and should be managed and reviewed from that perspective”, and that the man was therefore in need of a guardian to “consent to the restraint and to ensure that it is reviewed regularly and remains the least restrictive means by which his behaviour is managed.”<sup>706</sup> In another decision, the Tribunal found that the administration of the anti-psychotic olanzapine to a man in a nursing home with degenerative dementia exhibiting aggressive behavioural tendencies was both a restraint in the sense that it was given to “settle” his aggressive behaviour, as well as medical treatment for his medical condition. A guardian was therefore appointed with powers to consent to restraint, as well as consent to medical treatment.<sup>707</sup>



CHAPTER 5

# The Institutions and People Involved in Health Care Consent

*My Dad would take his medication because he believed his doctor was God.*

– Family caregiver

Although the *Health Care (Consent) and Care Facility (Admission) Act (HCCA)* applies to the practice of all health care professionals in BC, no matter where they practice, the regulation of type and site of care can impact rights. The regulation and education of health care professionals and staff can impact practice. The material included in Chapter 5 is intended to:

- Introduce the language used in the health care sector to discuss different types of care relevant to the experience of people living with dementia, many of which are referenced in our discussion of recommendations;
- Identify aspects of regulation that relate to health care consent practice, including professional standards and codes of ethics;
- Discuss the education of the various health care professionals, and non-regulated health care assistants (HCAs), with respect to health care consent;
- Comment on oversight of health care professional practice with respect to consent; and
- Outline how physicians are remunerated for care in BC.

## 5.1 HEALTH CARE INSTITUTIONS AND THEIR GOVERNING STATUTES IN BC

The settings in which older people receive health care in BC are varied and dependent upon the needs of the adult, the availability of space in various types of facility, and access to services in the community within which a person resides. Resources can be scarce, and there is not always a perfect fit between site of care and care needs: for example, the BC Seniors Advocate has noted that some adults currently residing in long-term care would be more appropriately housed in assisted living or community if adequate home support services were available and accessed.<sup>708</sup>

Throughout this report, we refer to diverse types of care—such as home and community care, acute care, and long-term care—some of which are regulated by their own legislation. In most instances regulation is linked to the type of facility in which the person living with dementia resides or receives care, rather than the type of care being provided. For example, as noted below, long-term care can be provided in a long-term care facility or a hospital. Over the course of their dementia journey, people may move back and forth between different sites of care, sometimes even within a single day, such as where a person participates in adult day program, or presents at hospital for urgent treatment. Some people living with dementia are committed under the *Mental Health Act*—the impact of involuntary committal on rights is discussed in Chapter 3.

### 5.1.1 Community Care

Community care includes home care, home or community nursing care, adult day services, and other types of health care typically provided to adults with lower level health care needs in the community, including services colloquially referred to as “home support”. BC law describes the people entitled to such services as “persons with a frailty or with an acute or chronic illness or disability that do not require admission to a hospital as defined in section 1 of the *Hospital Act*.”<sup>709</sup> This type of care is primarily governed by the *Continuing Care Act*<sup>710</sup> and the *Continuing Care Programs Regulation*.<sup>711</sup>

*Home care* or home support services are “direct care services provided by community health workers to clients who require personal assistance with activities of daily living, such as mobility, nutrition, lifts and transfers, bathing and dressing, and grooming and toileting.”<sup>712</sup>

*Home or community nursing care* is nursing care that is provided in either the person’s home, a community clinic, or assisted living. The care includes non-emergency care such as assessment, education, wound care, medication management, chronic disease management, care management, post-surgical care, and palliative care.<sup>713</sup> Community nursing care can eliminate the need for admission to long-term care.<sup>714</sup>

*Adult day services* are supportive group services and community activities which enable an older person (or a person with disabilities) to remain living in their own homes. Services are usually provided one to two days per week, and may include personal care, health care, including nursing and rehabilitation, as well as social and recreational activities.

### 5.1.2 Assisted Living

Assisted living housing is designed for adults who can live independently, but have some physical or functional health issues. Facilities provide housing, hospitality, and personal care services,<sup>715</sup> as opposed to professional health care services, such as nursing support. Assisted living is primarily governed by the *Community Care and Assisted Living Act (CCAL Act)*,<sup>716</sup> *Community Care and Assisted Living Regulation (CCAL Reg)*,<sup>717</sup> and the *Assisted Living Regulation*.<sup>718</sup>

A discussion of assisted living is not central to the themes of this report because staff are not regulated professionals obligated to obtain consent to health care. Adults residing in assisted living must have capacity to make their own decisions.<sup>719</sup>

### 5.1.3 Long-term Care

In BC long-term care is provided in different kinds of facilities, which are regulated by different statutes. Health care consent law, as set out in the *HCCA*, applies to treatment regardless of the site of care.

#### Community Care Facilities

Long-term care includes “residential care for persons with chronic or progressive conditions, primarily due to the aging process,”<sup>720</sup> provided in facilities commonly referred to as seniors’ homes, nursing homes, or care facilities. This form of long-term care is primarily governed by the *CCAL Act*,<sup>721</sup> *CCAL Reg*,<sup>722</sup> and the *Residential Care Regulation (RC Regulation)*.<sup>723</sup> Long-term care facilities typically provide 24-hour professional care to adults with complex health care needs who can no longer be cared for in their own homes, or in assisted living.<sup>724</sup>

Long-term care falls within the statutory definition of “care” under the *CCAL Act* if supervision is provided to “an adult who is (i) vulnerable because of family circumstances, age, disability, illness or frailty, and (ii) dependent on caregivers for continuing assistance or direction in the form of 3 or more prescribed services.”<sup>725</sup> These services include:

- (a) Regular assistance to the person with activities of daily living, including eating, mobility, dressing, grooming, bathing or personal hygiene;
- (b) Medication administration or monitoring as the person takes the medication; storing and distributing medication;
- (c) Maintaining or managing the resident’s cash resources or other property;
- (d) Monitoring the resident’s food intake or whether the person is adhering to a therapeutic diet;
- (e) Providing structured behaviour management and intervention;
- (f) Providing psychosocial rehabilitative therapy or intensive physical rehabilitative therapy.<sup>726</sup>

Short term care, for a period of less than three months is also available, typically to provide respite care, convalescent care, or hospice care for adults with complex needs.<sup>727</sup>

## Private Hospitals and Extended Care Facilities

Private hospitals also provide long-term care. A private hospital is defined as, “a house in which 2 or more patients, other than the spouse, parent or child of the owner or operator, are living at the same time, and includes a nursing home or convalescent home, but does not include a hospital as defined in section 1.”<sup>728</sup> Long-term care delivered in a public hospital is often called “extended care.”<sup>729</sup> Long-term care and extended care are typically located in a wing of an acute care hospital, or a separate building within the vicinity of the hospital.<sup>730</sup> Private hospitals and extended care units of hospitals are governed by the *Hospital Act*, *Hospital Act Regulation* and the *Patients’ Bill of Rights Regulation*,<sup>731</sup> not the *CCAL Act* and its associated regulations.

There exist few legislated minimum standards on physical environment, staffing requirements, admission procedures, care plans, nutrition, medication, the use of restraints, and “reportable incidents” for hospital care as compared with long-term care facilities regulated by the *CCAL Act*. However, while the BC government has not yet brought into force section 12 of the *CCAL Act*, which would bring private and extended care hospitals within the ambit of the *CCAL Act*,<sup>732</sup> the BC government has made some changes in response to concerns raised by the Ombudsperson in its *Best of Care Report*.<sup>733</sup> These changes are aimed at bringing these various sites of long-term care into better alignment.<sup>734</sup> Measures have included:

- Making the *Residents’ Bill of Rights* (Schedule to the *CCAL Act*) applicable to patients receiving care in private hospitals and extended care hospitals under to the *Hospital Act*, and requiring these rights to be displayed prominently;<sup>735</sup>
- Enacting the *Patients’ Bill of Rights Regulation*, which makes specified sections of the *RC Regulation* applicable to private hospitals and extended care facility patients, including standards in relation to privacy, receipt of visitors, complaint procedures, development and implementation of care plans, and sharing of policies and procedures with residents and family members;<sup>736</sup> and
- Introducing regular inspection processes for *Hospital Act* facilities.<sup>737</sup>

## Alternative Level of Care

Alternate Level of Care is a designation given to patients in a hospital setting who have been approved for discharge, but are awaiting placement in a more appropriate facility or community setting.<sup>738</sup> According to a 2015 study of alternative level of care service use in BC, patients may be waiting for long-term care, personal care homes, rehabilitation, respite, convalescence, home support services, or various other services.<sup>739</sup>

This use of acute care beds has a significant impact on access to acute care services, and has been identified as problematic in terms of hospital resource efficiency Canada wide.<sup>740</sup> Further, for frail older people, delays in placement to more appropriate settings increases the chances of rapid deterioration in health requiring further acute care, or premature admission to a long-term care facility.<sup>741</sup> In 2016/17, 16% of inpatient days for patients in BC aged 65 to 84 were designated as alternative level of care, and 26% for those aged 85 or older.<sup>742</sup> In 2016–2017 the average length of stay in alternative level of care decreased from 24 to 22 days for patients aged 65 to 84, and from 24 to 21 days for those aged 85 or older.<sup>743</sup>

### 5.1.4 Acute Care

Older people living in long-term care or in the community are also likely to periodically require the medical health services provided in an acute care hospital. The definition of “hospital” in Part 1 of the *Hospital Act*, excludes private hospitals, but includes a hospital designated primarily for the treatment of persons:

- (a) suffering from the acute phase of illness or disability,
- (b) convalescing from or being rehabilitated after acute illness or injury, or
- (c) requiring extended care at a higher level than that generally provided in a private hospital licensed under Part 2

Transfers between long-term and acute care are common, typically occurring when a resident’s illness or injury cannot be dealt with by nursing staff, or by the resident’s physician.<sup>744</sup>

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*LPNs or RNs—they’re usually sitting in the managerial position. The person who’s really kind of running the show in assisted living is the care aids.*

– **Licensed practical nurse**

### 5.1.5 Palliative Care

Palliative care in BC is provided in a number of settings, including Acute/Tertiary Palliative Care Unit Beds, Community Hospice Beds, and Home-Based Palliative Care Services.<sup>745</sup> Acute/Tertiary Palliative Care Unit Beds are located in acute care settings, or campuses across the province. Acute palliative care is provided for patients with complex needs who require increased nursing staff and daily involvement by physician specialists and others because of their clinical instability, and often, psychosocial issues. Community Hospice Beds located in a variety of settings are designated for short-term residential end-of-life care for adults. These patients receive care focused on comfort. Home Based Palliative Care Services are delivered by a patient’s home health teams with access to more specialized health care professionals such as palliative care physicians, Advanced Practice Nurses, social workers, and pharmacists.<sup>746</sup>

## 5.2 HEALTH CARE PROFESSIONALS AND STAFF WHO PROVIDE CARE TO PEOPLE LIVING WITH DEMENTIA

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Care in home, community, and long-term care settings is provided by a variety of staff and consulting health professionals, some of whom are regulated. As noted earlier, only regulated professionals are obligated to obtain consent, whether from the person living with dementia, or their substitute decision maker. Most health care settings will include a mix of regulated and non-regulated staff.

**Home care** is provided by community health workers. Community health workers may undertake some limited nursing and rehabilitation tasks that have been delegated by other health care professionals.<sup>747</sup> The majority of



community health workers would not be regulated professionals. They must be registered with the Care Aide and Community Health Worker Registry if they work for an employer who receives public funding.

**Home or community nursing care** is typically provided by a licensed nursing professional: either a licensed practical nurse or a registered nurse, which includes a certified practice nurse (particularly in remote locations), or a nurse practitioner.<sup>748</sup>

**Adult day centres** work with a variety of health care and non-health care workers. Licensed nursing professionals may provide health services, in conjunction with other health professionals, such as physical therapists, occupational therapists, and speech and language pathologists. Community health workers may provide personal assistance or nursing or rehabilitation tasks delegated by health professionals. Non-health related services, such as recreation and social programs, are provided by other staff.

**Long-term care** facilities rely on the whole spectrum of health care professionals and non-regulated staff; however, the majority of care is provided by non-regulated HCAs.<sup>749</sup> Nursing services may be provided by licensed practical nurses, or less commonly registered nurses.<sup>750</sup> Pharmacists, physical therapists, occupational therapists and speech and language pathologists also provide specialized services. Physicians, geriatricians and geriatric psychiatrists provide medical diagnostic and treatment services. The majority of physicians attending to residents in long-term care facilities are family physicians, without specialty training in the area of geriatrics.<sup>751</sup>

The *CCAL Act* does not require a physician or a registered nurse to be present on site.<sup>752</sup> The statute requires a licensee to “assist persons in care to obtain health services as required”, and that a physician or a nurse practitioner can be contacted in an emergency.<sup>753</sup> However, it can be a requirement of the facility’s funding agreement with the health authority that a registered nurse remain onsite.<sup>754</sup>

Each profession is required to have a governing regulatory body, called a College.<sup>755</sup> A College has a general duty to act in the public interest in performing its functions.<sup>756</sup> Its statutorily mandated objectives include:

- To superintend the practice of the profession;
- To establish, monitor and enforce standards of practice to enhance the quality of practice and reduce incompetent, impaired or unethical practice; and
- To establish, monitor, and enforce standards of professional ethics.<sup>757</sup>

A full picture of a designated health professional’s duties and obligations with respect to the issue of consent to health care, requires consideration of not only the law, but also any applicable codes or standards, with which health care professionals are required to comply. Codes and standards can go above and beyond legal requirements. In addition, non-binding guidelines produced by a College to

assist a member in their practice are also indicative of the profession's generally accepted standards and expectations.

In sections below we consider four types of health care professional or staff: physicians; registered nurses; licensed practical nurses; and health care assistants. For each type of practitioner we:

- Summarize the role they play in delivering care to people living with dementia, particularly in long-term care;
- Highlight aspects of codes of ethics, practice standards, guidelines relevant to health care consent; and
- Discuss education and professional development with respect to informed consent and substitute decision making for health care.

### 5.2.1 Physicians and Surgeons

Physicians who working with older people in Canada include:

- Family physicians (some with additional “Care of the elderly” training);
- Geriatricians (specialists in geriatric medicine); and
- Geriatric psychiatrists.<sup>758</sup>

People living with dementia will usually have a physician with a general family practice supervising their overall care. The general practitioner will generally refer the person to a specialist, such as a geriatrician, geriatric psychiatrist, or a neurologist, who will be involved in both diagnosis and follow up treatment for dementia.

Information on the role of physicians in long-term care has proven difficult to pinpoint. A 2014 report by the Residential Care Committee of Vancouver Division of Family Practice has noted that “there is no common understanding of what can be expected of the House Doctor or of any physician who attends to residents at a facility.”<sup>759</sup> By contrast, the Society for Post-Acute and Long-Term Care Medicine, otherwise known as the American Medical Director's Association has published a detailed policy statement on the role of the attending physician in the nursing home, which could apply broadly to the Canadian setting. The identified roles include:

- Provide initial patient care, including assessment of new admissions;
- Support patient discharges and transfers, including provision of information and documentation, and follow up with other facility;
- Make periodic on-site visits and respond to acute health needs, including documentation of patient's condition, status and goals, and communication with staff and family;
- Ensure adequate ongoing coverage, including when the physician is unavailable;
- Provide appropriate care to patients, including assessments and care goals;

- Provide appropriate, timely medical orders and documentation; and
- Be aware of, and respect, relevant policies, procedures, and rights, and standards of professionalism.<sup>760</sup>

**Geriatricians** are specialists in geriatric medicine, having completed an additional two-year residency requirement for completion of the Certificate of Special Competence in Geriatric Medicine.<sup>761</sup> The Canadian Medical Association describes a geriatrician as a specialist who “deals with the prevention, diagnosis, treatment, remedial and social aspects of illness in older people, mainly patients 75 years of age or more.”<sup>762</sup> Geriatricians work with others in the health care team to prevent illness and restore optimal health and wellness.<sup>763</sup>

**Geriatric psychiatry** focuses on the diagnosis and treatment of complex mental disorders that uniquely occur in older people. Geriatric psychiatrists work in multidisciplinary teams both within long-term care and other health care settings.<sup>764</sup> Their scope of practice includes treatment of people living with dementia for psychiatric symptoms related to the dementia, complex capacity assessments, polypharmacy, and risk assessments involving the use of psychotropic medication.<sup>765</sup>

### Codes of Ethics, Practice Standards, and Guidelines

The College of Physicians and Surgeons of British Columbia (CPSBC) has not produced a Standard or Guideline with respect to consent to health care of adults.<sup>766</sup> The CPSBC has adopted the Canadian Medical Association Code of Ethics (“the Code”). The Code is an ethical guide for physicians across Canada, and includes a section on “Communication, Decision Making and Consent”. The content of this section is brief and generic, not reflecting the nuances in consent law across the country. However, the Code states in the introductory section that “[p]hysicians should be aware of the legal and regulatory requirements that govern medical practice in their jurisdictions.”

Key general principle included in the Code are:

21. Provide your patients with the information they need to make informed decisions about their medical care, and answer their questions to the best of your ability.
22. Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.
24. Respect the right of a competent patient to accept or reject any medical care recommended.
28. Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.

Importantly, the Code includes the following statement, which is not an accurate reflection of BC law, where the Public Guardian and Trustee is the health care decision maker of last resort:

29. When the intentions of an incompetent patient are unknown and when no formal mechanism for making treatment decisions is in place, render such treatment as you believe to be in accordance with the patient’s values or, if these are unknown, the patient’s best interests.<sup>767</sup>

Of further concern, the paragraph contains no reference to substitute decision makers for health care or advance directives, neither of which is clearly captured by the concept of a “formal mechanisms for making treatment decisions.” In BC the Public Guardian and Trustee is the decision maker of last resort in such circumstances, not the patient’s physician.

The Canadian Medical Protective Association, which is a membership driven body aimed at “[p]rotecting the professional integrity of physicians and promoting safe medical care in Canada”, produces a detailed guide for Canadian physicians on consent to health care. However, being designed for a national audience, this guide also does not reflect the nuances of BC law.<sup>768</sup>

The CPSBC’s Guideline on prescribing practices articulates the physician’s obligation, when prescribing medication, to inform their patient about “drug effects and interactions, side effects, contraindications, precautions, and any other information pertinent to their use of the medication.”<sup>769</sup> CPSBC by-laws set out detailed requirements for physician record-keeping and documentation, which includes a requirement to keep a clear record for each patient of “the specifics of any treatment, recommendation, medication and follow-up plan.” The bylaws do not include any requirement to document the consent process.<sup>770</sup>

### Training Regarding Health Care Consent

Key informants indicated that health care consent is taught in medical school, in family practice residency, and during psychiatry residency. One key informant, who teaches at UBC, indicated the topic has been part of the year four curriculum, but only for the last 5-10 years. As such, only recent graduates would have studied this material unless they sought out information on the topic outside of class time. Stakeholders advised us that workplace culture has a significant impact on practice, such that new grads quickly adapt their practice to what they see in the facility, rather than holding fast to what is taught in school.

Ongoing professional development is a requirement of membership in the College, but there is great freedom in choosing the topics and fora for learning. Independent study, podcasts, and journal reading are included, in addition to conferences and seminars. As compared with other regulated health care professionals, physicians are required to engage in a significant number of hours of professional development every five year cycle—a minimum of 400 and 250 credits depending on whether they maintain their professional development through either the Royal College of Physicians and Surgeons of Canada (specialists) or College of Family Physicians of Canada (general/family practitioners).<sup>771</sup> Accreditation can be obtained for conferences, seminars, fellowships, PhDs/Masters, journal reading, podcasts, curriculum development, teaching, and other self-monitored activities.<sup>772</sup> There does not appear to be any requirement of ongoing professional development regarding legal issues impacting practice.

### 5.2.2 Nursing Professionals

On September 4, 2018 the anticipated BC College of Nursing Professionals (the Nursing College)<sup>773</sup> was formed by the merger of the:

- College of Licensed Practical Nurses of British Columbia;
- College of Registered Nurses of British Columbia; and
- College of Registered Psychiatric Nurses of British Columbia.

In this report we distinguish between registered nurses and licensed practical nurses as they tend to play different roles in the care of older people living with dementia, and they will have been licensed to practice as a function of different training.

## Registered Nurses

RNs can make a nursing diagnosis of a condition but are not authorized to diagnose a disease or disorder.<sup>774</sup> Generally RNs cannot prescribe drugs for treatment of a diagnosed condition, disease or disorder. In very limited situations which typically involve emergency situations, such as a case of anaphylaxis, cardiac dysrhythmia, opiate overdose, and respiratory distress in a known asthmatic, RNs may prescribe.<sup>775</sup> RNs may administer certain drugs known as Schedule 1 drugs which have been ordered by a physician or nurse practitioner. The authority of nursing staff to prescribe, compound, dispense and administer medications to residents of long-term care facilities in BC is primarily set out in the *Nurses (Registered) and Nurse Practitioners Regulation*, which must be read in conjunction with relevant scope of practice nursing standards published by the Nursing College.<sup>776</sup>

Within their scope of practice, RNs can practice autonomously, providing clinical expertise and maintaining therapeutic client relationships. The RN in long-term care provides “health promotion, disease prevention, and curative, supportive, rehabilitative and palliative nursing services as needed.”<sup>777</sup> An RN will conduct needs assessments, and oversee implementation of the resident’s care plan.<sup>778</sup> RNs are also responsible for scheduling and charting.<sup>779</sup> RNs consult and communicate with the resident, their families, and other health professionals.<sup>780</sup> RNs are also required to supervise LPNs and HCAs, who make up the bulk of the staff in long-term care. Nursing treatments which are planned and performed by RNs (with overlapping roles of LPNs) include skin and wound care, medication administration, tube feeding, ostomy care and ventilation assistance.<sup>781</sup>

**Nurse practitioners (NPs)** are RNs with additional training and education at the graduate level.<sup>782</sup> Streams of practice for NPs are family, adult, and pediatric. In terms of practice with older people, NPs practice in acute and long-term care, as well as community care settings.<sup>783</sup> According to the then College of Registered Nurses of BC, only 28 NPs in BC self-identify their work area as “Geriatrics/Long Term Care” and/or “Long Term Care/Nursing Home”.<sup>784</sup> NPs must practice in accordance with the Scope of Practice for Nurse Practitioners as published by the Nursing College, pursuant to the *Nurses (Registered) and Nurse Practitioners Regulation* under the *Health Professions Act*.<sup>785</sup> The main aspect of NP practice which distinguishes NPs from RNs is their ability to autonomously diagnose and treat acute and chronic illnesses, which includes the ability to prescribe certain drugs,<sup>786</sup> and to order x-rays, ultrasound and laser.<sup>787</sup> NPs are also authorized to issue an order to a RN.<sup>788</sup>

A **certified practice nurse** is an RN who has successfully completed a certification program approved by the Nursing College which authorizes the nurse to undertake what would otherwise be considered restricted activities.<sup>789</sup> A nurse may be certified in the following areas: reproductive health, remote

nursing, and RN first call.<sup>790</sup> Nurses certified in remote nursing and RN first call are authorized to diagnose and treat minor acute illness in accordance with established decision support tools. These activities include prescribing, administering, compounding, or dispensing some medications without an order.<sup>791</sup>

RNs, NPs, and certified practice RNs are all required to comply with practice standards produced by the Nursing College with respect to the administration and dispensing of medications.<sup>792</sup> Nurses are authorized to receive orders for “off-label” use of medications, which is essentially the unapproved use of a legal medication. In these circumstances, practice standards require a nurse to be well informed about the medication, the reasons it has been ordered, and its risks and benefits to the client.<sup>793</sup>

### Codes of Ethics, Practice Standards, and Guidelines

The newly created Nursing College produces a Practice Standard on “Consent”, originally published by the College of Licensed Practical Nurses of British Columbia. The practice standard links with other standards, policies, and bylaws of the College, and all legislation relevant to nursing practice. The Standard sets out 12 principles which broadly follow the requirements of the *HCCA*, commencing with an overarching statement that “nurses respect clients’ rights to make decisions about the management of their own health care.”<sup>794</sup> At the outset, the Standard expressly notes the role of employers in supporting nurses to comply with consent requirements.<sup>795</sup> The principles go on to provide that nurses must:

- Assess the capacity of clients to provide consent;<sup>796</sup>
- Obtain the informed consent of the client for the health care services they carry out; and
- Document the consent process.<sup>797</sup>

By way of comparison, physicians do not have a similar professional obligation to document the consent process.<sup>798</sup>

The Standard (in line with the legislation) expressly provides that “it is not appropriate for nurses to take responsibility for obtaining consent for care or treatment provided by another health professional (e.g., surgery, anesthesia).”<sup>799</sup> In this respect physicians or others cannot delegate their duty to obtain informed consent from the patient to a nurse. However, the Standard does place an obligation on nurses who participate in the delivery of care or treatment by other health professionals to:

- Verify that consent has been given for the proposed treatment;
- Ensure clients have sufficient information to make an informed decision; and
- Help clients to understand information and acquire further information.<sup>800</sup>

The College also produces a Professional Standard on Ethical Practice. Some ethical standards relevant to the issue of consent to health care include requirements that the nurse:

- “Provides care in a manner that preserves and protects client dignity;”<sup>801</sup> and

- “Recognizes, respects and promotes the client’s right to be informed and make informed choices.”<sup>802</sup>

### Training Regarding Health Care Consent

While recent graduates may be taught informed consent law in school, as the latest curriculum has a module on the law, we are not certain that all registered nurses were exposed to this content. Nurses get some of their training in college and university; however, many have been practicing for decades or received training abroad, having become licensed to practice in BC by writing examinations developed to meet international or national standards. The Nursing College materials include a jurisprudence learning module. Health care consent law is covered in the materials associated with the course. However, there is no jurisprudence exam required prior to registration. The program is essentially a form of independent learning with accompanying self-assessment.

Key informants indicated nurses access ongoing professional development through the following avenues:

- Sharing documents or articles through emails (sent by Nursing College, health authority or other employer);
- Reviewing material on Nursing College’s website;
- Participating in staff teleconferences with an education component;
- Benefiting from campaigns with targeted training, such as the REACT tool, led by the health authorities; and
- Attending conferences and other learning events.

RNs have no minimum ongoing professional development requirements associated with maintaining registration.

### Licensed Practical Nurses

LPNs play a key role in day-to-day care for people living in long-term care, and will spend significantly more hands-on time caring for long-term residents than an RN or physician. An LPN’s role can overlap with that of a HCA in some areas, such as the provision of personal care services. However, an LPN will also have the responsibility for monitoring and assessing residents, medication administration, wound care, maintaining patient records, collecting samples for medical testing, and dietary care.<sup>803</sup> An LPN may be involved in developing a resident’s care plan, ensuring the care plan is followed, and evaluating the plan’s effectiveness.<sup>804</sup>

Activities which an LPN can perform without an order, and restricted activities that an LPN can perform with an order from a health care professional, are set out in the *Nurses (Licensed Practical) Regulation*.<sup>805</sup> In terms of an LPN’s authority with respect to drugs, an LPN cannot prescribe Schedule I drugs. Like an RN, an LPN can compound, dispense and administer Schedule I drugs for the purposes of treating a limited range of urgent conditions, such as anaphylaxis, without an order, and can compound, dispense and administer Schedule I drugs at any time, with an order.<sup>806</sup> This includes medications which have been ordered on a PRN (as needed) basis.<sup>807</sup>

### Codes of Ethics, Practice Standards, and Guidelines

The Nursing College publishes a practice standard on consent to health care which applies to the practice of LPNs.<sup>808</sup> The standard reflects the law in the *HCCA* with respect to the LPNs obligation to obtain informed consent of the patient prior to administering health care. As with RNs, the Standard notes that LPNs “are not responsible for obtaining consent for health care provided by another health care provider”.<sup>809</sup> However, LPNs do not have an obligation similar to that of the RNs to verify that consent has been obtained. On the other hand, LPNs do have obligations to “[m]ake sure other health care providers are aware when a client needs more information or is reconsidering the plan of care”.<sup>810</sup>

LPNs have a unique client education obligation to “help clients understand that they have the right to refuse or revoke consent at any time and for any reason.”<sup>811</sup> Similar to RN ethical standards, LPNs have an obligation to protect a client’s dignity, and respect and promote their right to make informed choices.<sup>812</sup> Principle 10 imposes on LPNs a unique requirement to be “aware of the difference in power between themselves and clients, and do not use that power to influence the client’s decision.”<sup>813</sup> LPNs also have a professional standard identical to RNs to:

- Respect and protect client dignity; and
- Recognize, respect and promote a client’s right to make informed decisions.<sup>814</sup>

The Canadian Council for Practical Nurse Regulators, a federation of provincial and territorial regulators of LPNs, publishes Standards of Practice which apply across Canada.<sup>815</sup> The Standards are authoritative statements that define the legal and professional expectations of LPN practice nation-wide. While there is no national standard specific to issues of informed consent, supporting patient autonomy and access to information are key aspects of LPN practice reflected in the national Standards of Practice. The Standards require LPNs to:

- “Engage clients in a therapeutic nurse-client relationship as active partners for mutual planning of and decisions about their care;”<sup>816</sup> and
- “Provide relevant and timely information to clients and co-workers.”<sup>817</sup>

### Training Regarding Health Care Consent

Prior to 2011, there had not been a standardized LPN curriculum in BC for over 10 years. Most practicing LPNs were educated during a time when there was significant variation in training. One key informant noted that although in recent years LPNs have acquired greater responsibility, training is not necessarily ensuring that practicing LPNs have adequate understanding of the law. However, LPNs are uniquely required to take a jurisprudence education and exam once every three years, which includes broad elements of health care consent law.<sup>818</sup> Nursing Jurisprudence is broader than case law, being defined by the College as the study and application of law as it relates to the legal principles, regulations and standards that govern the practice of nursing, and includes consent law. Otherwise, there are no mandatory professional development requirements for LPNs in BC.



### 5.2.3 Health Care Assistants

HCAAs are not a self-regulated health care profession, and they do not have a legally defined scope of practice in BC. Registration with the BC Care Aide and Community Health Worker Registry (the Registry) is mandatory for HCAAs who work in publicly funded long-term care facilities.<sup>819</sup> However, the Registry does not regulate practice in the manner of a college. Eligibility for registration requires completion of an educational program in BC recognized by the Registry (or an equivalent program for out-of-province and international HCAAs). The Registry ensures that educational programs in BC follow the provincial curriculum, and implements a common set of training standards.<sup>820</sup> In 2016 the BC Government announced an intention to bring the Registry within the Nursing College, which will regulate HCA practice.<sup>821</sup>

As noted above, HCAAs tend to have the most ongoing contact with a long-term care resident, providing care under the supervision of RNs and LPNs. Personal care tasks include toileting, eating, hygiene and dressing.<sup>822</sup> In some circumstances, nurses can delegate tasks to HCAAs. Delegation to an HCA occurs when the task is one ordinarily performed by a nurse and outside the role description of an HCA.<sup>823</sup> The delegation must be task-specific, with clearly defined limits and be in the best interests of the resident. A nurse cannot delegate a function: a client care intervention that includes assessing and deciding to perform the function.<sup>824</sup> The delegated task may include a restricted activity (which includes the administration of medication), or a nursing activity which is not restricted.<sup>825</sup> The nurse remains responsible for supervision of the HCA in their performance of the task, and the HCA must have the appropriate skills and training to undertake the task.<sup>826</sup>

#### Training Regarding Health Care Consent

HCAAs receive their training in colleges throughout BC. The curriculum for HCA training is the responsibility of two government ministries:

- The Ministry of Health is responsible for setting and reviewing HCA competencies on a regular basis “to ensure that basic competencies are meeting the needs of clients, families and the health care system as a whole”,<sup>827</sup>
- The Ministry of Advanced Education uses this Core Competency Profile to develop and periodically review the curriculum.

Revisions to the curriculum appear to have been last carried out in 2015, with the help of a Steering Committee made up of representatives from various stakeholder groups.<sup>828</sup> In addition to the curriculum, a supplement is produced to “support the delivery and assessment of required learning outcomes.”<sup>829</sup> The Alzheimer Society of B.C. was involved in developing aspects of this supplement.

For internationally-trained nurses, the Nursing Community Assessment Service (NCAS) undertakes a competency-based assessment, upon referral by the Registry. NCAS produces an assessment report indicating an applicant’s strengths and weaknesses. Based on this report, the Registry determines whether an applicant must undertake any remedial education before being registered in BC.<sup>830</sup>

Although continuing education is not mandatory for registered HCAs, the Registry has a mandate to support professional development of HCAs,<sup>831</sup> which it meets by providing easy access to online learning modules on various topics. Dementia care is covered in these modules. However, there does not appear to be any instruction specifically dealing with consent and substitute decision making, and the HCA's role in the consent process, in either the HCA curriculum or professional development modules accessible through the Registry.

### 5.3 PHYSICIAN REMUNERATION IN BC

Currently, there are four funding models for physician remuneration in BC:

- Fee-for-service (FFS);
- Alternative Payment Programs (APP);
- Medical On Call Availability Program; and
- Rural Funding<sup>832</sup>

The main two models used in BC are FFS and the APP, with the majority of physicians being compensated under the FFS model.<sup>833</sup> BC provides two main APP funding methods through the Ministry of Health: service agreements and sessional arrangements. However, a third population-based funding model has been implemented on a very limited basis in BC arising out of a pilot project in 1999, which has yet to be expanded. Physicians may also access additional funding through rural practice programs, which are aimed at recruiting and retaining physicians in rural practice, and through the Medical On-Call Availability Program, which compensates physicians for providing on-call emergency care to new or unassigned patients.<sup>834</sup>

The Medical Services Commission administers the Medical Services Plan (MSP) under the authority of the *Medicare Protection Act*.<sup>835</sup> MSP insures its registrants for medically required services provided by general practitioners, specialists, and some other health care professionals, paying them on a FFS or APP basis.<sup>836</sup> Physicians must be enrolled with MSP in order to receive payments, and must be licensed with the College of Physicians and Surgeons to be eligible to enroll in MSP.<sup>837</sup>

#### 5.3.1 Fee-for-Service Billing

Under the FFS remuneration model, physicians receive payment from MSP per service they provide to their patients, using a separate billing code to identify the type of service provided. Under this model, physicians are essentially self-employed professionals. An enhanced FFS program is available in most provinces and territories in Canada, including BC, which allows physicians and some specialties to access additional compensation for complex and chronic disease management.<sup>838</sup>

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*...The compensation for physicians, to provide support to people living residential care, while it has improved, honestly truly does not reflect the complexity of the work.*

– Geriatric Psychiatrist

We have set out some types of additional compensation available in BC, and some background to their involvement.

As described by Mazowita, an “escalating crisis in family medicine” in the 90s and early 2000’s resulted in the creation of the General Practices Services Committee, whose mandate was to “find solutions to support and maintain full-service family practice in BC.”<sup>839</sup> Solutions to the crisis in BC largely revolved around practice incentives for full-service family doctors, training programs, and recruitment incentives.<sup>840</sup> By way of comparison, other provinces, such as Ontario, opted for significant structural reform.<sup>841</sup> BC financial incentives included new MSP billing fees for compensation of telephone or email consultations, and group visits.<sup>842</sup>

In addition to these earlier operational reforms, the Ministry of Health’s 2015 Primary and Community Care Policy Framework highlights further initiatives in this area, such as the Family Practice Incentive Program. The program currently includes the following incentives:

- Mental health incentive payments for helping plan and manage care for patients with mental health issues, including dementia.<sup>843</sup>
- Two complex care planning and management incentive payments available to family physicians,<sup>844</sup> for patients diagnosed with at least two chronic conditions from a list of conditions, one of which is a “chronic neurodegenerative disease”. Dementia on its own would not warrant the use of these codes.<sup>845</sup>
- Palliative care incentive payments for assisting with care planning for palliative patients.<sup>846</sup>

None of the above are available for patients residing in long-term care. However, Residential Care Initiative incentive payments are available for family physicians. They include the following additional fee payments:

- Patient Telephone Management Fee
- GP Allied Care Provider Conference Fee
- Chronic Disease Management Incentives
- MSP Fees in Residential Care
- Billing for Non-urgent/non-emergent visit
- Billing for Patients in Long Term Care when specially called
- Billing for Patients in Long Term Care when Called to See at Night
- Visits for terminal care
- Billing for phone advice about patients in LTC
- Minor Procedures and Related Tray fees<sup>847</sup>

### 5.3.2 Alternative Payment Program

Alternative models for physician remuneration have become increasingly popular over the last several years, with APPs now making up about 20% of the overall total amount available for physician services in BC.<sup>848</sup> The aim of APPs is to ensure sufficient access to care in health settings and geographic locations in which the traditional FFS model does not guarantee physicians the necessary financial support or stability.<sup>849</sup>

BC Ministry of Health provides for two main alternative funding models: service agreements and sessional models.<sup>850</sup> These APPs fund BC's health authorities for their direct or indirect payment of contracted service, sessional and salaried physicians.<sup>851</sup> The APP is administered by the Physician Compensation Branch within the Ministry of Health. Under a service agreement, a salaried physician will receive a regular payment from an employer under an employment contract based on a period of time in which the services are provided. Sessional arrangements between a health authority and a physician allow the physician to be contracted to provide services for shorter periods of time, and are appropriate for situations in which a full-time staff person is not required.

In addition to these main two alternative funding models, alternative service contracts are available, such as two blended-models, including a Population Based Funding approach, and a Northern Model currently being prototyped.<sup>852</sup>



## CHAPTER 6

# Consultation Findings

*It robs me of energy to constantly follow up with things... it is demanding to build relationships with people in care.*

– Family caregiver

This chapter summarizes what we learned from speaking with stakeholders about health care consent practice in BC. As noted above, consultation input came from four sources:

- **Key informant** interviews with people whose work involves consent to treatment and medication for older people living with dementia (N = 65);
- **Focus groups** with people living with dementia and their family caregivers (events = 13; N = 58; 14 = people living with dementia; 44 = family caregivers);
- **Conference and community presentations** where we integrated a question and answer session offering practitioners (nurses, social workers, lawyers, directors of care facilities, etc) an opportunity to identify their own concerns regarding health care consent (events = 8); and
- **Online survey** of family caregivers (N = 28).

This chapter is divided into three parts:

1. Feedback from people who deal with health care consent in their work (health care professionals, care facility staff, lawyers, advocates, and others);

*There is kind of like a common consensus that if a person is admitted to the hospital, then the family would, that means the family would agree that the physicians will provide professional care for the loved one, right?*

– Nurse

2. Feedback from people living with dementia and family caregivers; and
3. Summary of consultation findings.

In many instances, there was overlap between the concerns of key informants and focus groups participants. However, in some respects there were differences that we did not want to obscure.

We provide a list of key informants in Appendix B. Focus groups are summarized in Chapter 1 under methodology. At the end of this chapter we distill the consultation findings down to 23 key issues that we address in Chapter 7.

## 6.1 HEALTH CARE PROFESSIONALS AND STAFF

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### 6.1.1 Health Care Consent Practice

#### *When do Health Care Providers Seek Informed Consent?*

- 1 There is a type of care or threshold of medical intervention at which all physicians<sup>853</sup> are very clear that consent is required. Usually written consent is obtained in these instances, for example, surgery and dialysis.
- 2 Beyond these more intrusive medical interventions, physician practice with respect to obtaining informed consent varied considerably. While the overwhelming majority of physicians were clear on the general legal and ethical obligation to obtain informed consent to health care, less than a quarter of these physicians stated that they always obtain consent in practice. The level of intervention was often determinative of whether prior informed consent was obtained. Even those physicians who stated they always obtained consent were clear in their observations that other physicians often do not obtain consent.
- 3 Practicality, particularly in long-term care, was a common reason identified by physicians for not obtaining timely informed consent. This view was supported by other relevant stakeholders, including directors of care, non-profit agency representatives, and health authorities.
- 4 Based on our interviews with nurses, they seem knowledgeable on their obligations to obtain consent for nursing interventions. However, a nurse's role vis-à-vis the consent process

*I don't think it's fair to ask families because they just don't have the knowledge base... because they're not doctors. It's very hard for them. What are they consenting to? They don't have the background. They don't have the context.*

– Geriatric psychiatrist

with respect to the provision of health care by physicians was less well understood. One key informant noted that often a nurse may be aware that a physician did not obtain informed consent for a medication they are administering, but practically the nurse does not have the time to remedy the situation, which can put a nurse in a professionally challenging situation.

5 In long-term care, stakeholders from multiple backgrounds, including nurses, physicians and health authorities, noted that it is common practice for nursing staff to seek treatment from physicians for residents over the telephone, based on the nurse's observations and reporting, and for physicians to prescribe medications relying on these observations, without conducting an in-person assessment. One nurse characterized this practice as problematic.

6 Approximately half of the physicians interviewed made statements indicating they were aware that sometimes, particularly in long-term care, no-one is consenting to health care, in instances where a person does not have the capacity to make health care decisions independently, and has no family or representative to act as supportive or substitute decision maker. The physician or facility may contact the Public Guardian and Trustee (PGT) if major health care procedures, such as surgery, are recommended. Otherwise, in these cases physicians, or the health team as a collective, tend to make health decisions for the person who has no capacity and no family, applying a best interests approach. This practice was confirmed by several other stakeholders interviewed, including two social workers, and a director of care. One director of care indicated that decisions are made this way for about 10-15 of the 180 residents under that director's care. One health care professional commented that this dynamic resulted in a "blurring" of roles.

7 Outside of the physicians interviewed, a significant number of key informants said informed consent is not always obtained. These informants ranged in backgrounds from health authorities and nurses to social workers and a director of care.

8 Some key informant stated that in long-term care "you lose your citizenship rights at the door."

### ***Involving Substitute Decision Makers and Family***

9 Despite the variability of practice with respect to obtaining consent, there was general consensus that it was good practice to keep families informed of changes in medication. For those physicians who did not always obtain prior informed consent, which was the great

majority interviewed, informing families of treatment decisions after the fact was common practice—shortly after the fact, or much later, at a care conference. Some physicians leave it up to the family to reach out for updates.

- 10 Key informants noted that substitute decision making is a significant practice issue in long-term care because the vast majority of the population has moderate to severe dementia. People are moving into long-term care later in the progression of disease as there has been a push to keep people in the community for a longer period of time.
- 11 In long-term care, many health care professionals, staff, and directors of care said they adapt their practice regarding consent to suit the expectations and desires of each family. Some families expect discussion and prior consent for every pill; some expect updates following every medication change; others are content with periodic updates via annual care conferences.
- 12 Even where one temporary substitute decision maker (TSDM) or a representative has been chosen, health care professionals generally work with all family members in decision making to gain their perspective, and to achieve consensus where possible. All social workers indicated that family meetings to aid decision making were a common practice. Family meetings with the care team or the health care professional were considered by many key informants—including physicians, social workers, an ethicist, and representatives of the health authorities—as good practice from both an ethics and risk/conflict avoidance perspective.
- 13 A few informants confirmed caregiver reports that family will be asked to stay away from the long-term care facility during a period of adjustment of two or more weeks. These informants stated that during that time frame many medication decisions are often made without involving a substitute decision maker or any family.
- 14 With few exceptions, key informants who observe substitute decision making processes were of the view that family members and substitute decision makers generally have a poor understanding of their obligations as decision maker, particularly around how decisions should be made—favouring acting in what they perceive to be in the person’s best interests, or their own interests, as opposed to the known wishes of the person living with dementia. These key informants included a significant number of physicians, social workers and nurses, as well as representatives from health authorities, and directors of care. A few key informants commented that even where substitute decision making obligations were understood, emotions often prevented appropriate decision making. A common example given was palliative care decisions where the substitute decision maker was not ready or willing to consent to palliative care options, but insisted on all possible medical interventions, despite the age, frailty, and comfort of the patient.
- 15 Some informants shared stories of family members not making good decisions for people living with dementia. Disagreements tended to be regarding:
  - Pain relief—family reluctant about pain medication because the person living with dementia rarely used pain medication;



- Physical restraint—family insisting on bed rails and other restraints to avoid falls in circumstances where the physician felt the restraint increased the risk of harm;
- Feeding and swallowing near end of life—degree of intervention to address swallowing and choking (e.g. tube feeding); and
- Anti-psychotics—general family refusal to treat with anti-psychotics.

**16** Health care professionals noted that circumstances where they have concerns about abuse or neglect in relation to the TSDM making decisions in a manner not in line with statutory obligations are challenging. Some professionals feel confident to take direction from the sibling who is most attentive to what the person living with dementia would have wanted, but do find this an awkward position to be put in as care provider. Both staff and physicians can be uncomfortable making the decision to disqualify a substitute decision maker, and go to the next person in the list within the *HCCA*, especially in the face of threat of legal action.

**17** Some health care professionals spoke of families not having enough knowledge of advance frailty, and what to expect at the end of life, in order to make informed decisions that truly reflect people's wishes and values.

**18** Power dynamics between family and the person living with dementia on the one hand, and the physician on the other, can pose a barrier to informed consent. Some key informants said they notice that families will not question the authority of the physician. Another key informant noted fear of reprisal.

**19** Indigenous people who come from rural or reserve communities will be removed from their communities if they require long-term care, because the Federal Government has not funded the development of long term-care facilities on reserve. Several stakeholders from both policy and nursing backgrounds identified that distance, coupled with lower health literacy rates in Indigenous communities, can result in challenges engaging Indigenous people in decision making.

### *Engaging the person Living with Dementia*

**20** Practices vary in terms of involving people living with dementia in their health care decisions. Often people living with dementia are not involved in their own decisions. There can be an assumption that they do not have enough capacity to participate because they are living with dementia, or have a guardian, which can result in complete exclusion from decision making.

**21** One consultation participant identified ageism as a barrier to good practice, stating that there can be an attitude that older people will not understand the medical information.

**22** Health care professionals and staff are reluctant to accept non-verbal methods of communication—even where people have aged with a disability, and used these communication strategies throughout their lives.

*I think sometimes it's easy for the health care team to, if a person has dementia, to assume that they cannot make any decisions for themselves, and to deal exclusively, directly with the substitute decision maker. So I think that there's room to at least try to include the adult in more of the decisions. I think that's hard because that takes time.*

– Social worker

- 23 One physician said that one of the reasons why physicians do not know how to engage older people in decision making is that they lack training in geriatrics. Similarly, one stakeholder who works in long-term care said that staff do not adequately understand dementia, and require training in this area.
- 24 A significant number of key informants from a variety of professional backgrounds, including health care, law, and social work, stated that one of the problems with practice in community, acute care and long-term care is that an incapability assessment is not conducted. As a result, it will not be clear how much people understand, and how to support them to participate in decision making.
- 25 A number of stakeholders in health care said they had not received training in how to assess incapability, and did not know how to conduct an assessment. One third of physicians interviewed, as well as several additional key informants, stated that family physicians don't generally have the specialized training or skills required to properly assess incapability. One health care professional said staff wind up in uncomfortable situations where the family member wants to make the decision, and insists the person living with dementia does not have capacity, but staff do not have the skills to make the determination.
- 26 Three key informants who are advocates or lawyers stated that health care professionals and staff sometimes just accept the family member's opinion that the older person with cognitive, hearing or speech impairment lacks capacity, and then accept the TSDM's decision.
- 27 One lawyer indicated that they have twice seen physicians sign affidavits expressing the opinion that a person was incapable based on the person's refusal to participate in the incapability assessment.
- 28 Hearing and speech issues can result in a health care professional or staff wrongly assuming the person living with dementia has understood information about medication or treatment, or has provided consent. Many people working in health care do not know how to support older people with hearing issues. One key informant also said that health professionals often do not take account of hearing and speech issues appropriately when assessing incapability, for example, ensuring a resident is wearing their hearing aids during an appointment. One lawyer confirmed that they have seen a family member deliberately withhold hearing aids in the context of an incapability assessment.

*Then I will ask them in private, is this really what you want. Just to confirm that... they are not being coerced by son. If they say no, no, no, I don't want to know, again that can be a cultural thing. For a lot of Asian cultures, autonomy is not as important as family harmony, and your preferences are not as important as what is best for the family... they are making the autonomous decision not to know.*

## – Geriatrician

- 29 Assent without questions or understanding occurs. Older people will sometimes say “yes” even though they don’t understand what the health care professional or staff is saying. One key informant speculated that this was possibly because they want to please, or because they do not want to admit a lack of understanding.
- 30 Finding a substitute decision maker for people who have no family can be a huge challenge. If the person does not have a representative to act as an advocate, there may be no one willing and able to take the time and effort required to ensure the person living with dementia is participating in their own decisions. One key informant said this dynamic is particularly true for people who have aged with intellectual disabilities, and have always been non-verbal: lack of advocacy can result in exclusion from decision making.
- 31 Older people from some cultural backgrounds will sometimes be unwilling to discuss their care with the physician, even if they have full mental capacity. They may insist the health care professional speak with their son or the daughter.

### 6.1.2 Knowledge of Health Care Consent Law

#### *Knowledge of When Consent is Required*

- 32 Although understanding how and when to get informed consent is a core competency for all health professionals, it appears that some physicians do not understand health care consent law.
- 33 From our own assessments of social workers through interviews, as well as through the views expressed by social workers themselves and other health care professionals, social workers generally understand the law well. Health care professionals confirmed they rely on hospital social workers for support in understanding the law.
- 34 Both health care professionals and social workers appear to have good knowledge of the TSDM list under the *HCCA*, and of the role of representatives in health care decision making. However, a significant number of stakeholders including lawyers, health authority staff, social workers, and a director of care said that that care facility staff, health care professionals, and families often mistake a power of attorney as providing the holder with a right to make health care decisions.

*No, it's not our practice, I don't think that people know that, so what you're saying is that, if there's a patient that there's no available substitute decision maker, you can just call the PGT even if they are unfamiliar with the patient? ... No, I don't think we know. I don't think that's known. That's unknown actually. I don't even know who to call for that.*

## – Geriatrician

- 35 There appears to be limited mandatory material on health care consent law as part of college and university curricula for health care professionals. Some physicians said that while health care consent is taught in medical school, and as part of various residencies, knowledge is lacking because the material is not reviewed on a regular basis. Health care professionals identified on the job training as particularly helpful in supporting good practice.
- 36 Almost every single key informant expressed the view that further education on health care consent law would be helpful for members of their profession.
- 37 There is some confusion about the Medical Order for Scope of Treatment (MOST), and whether it is in effect a form of consent in advance to health care. According to one health authority staff, some physicians treat the MOST as a legal document with the authority of a representation agreement.
- 38 Some health care staff and professionals said they assume that family trust them to make the right choices regarding medication and treatment, and so only contact them regarding what they consider to be major health care decisions. Some health care staff presume consent based on the relationship or admission.
- 39 Some health care staff and professionals think notice after the fact meets their legal obligation to get informed consent, even in non-emergency contexts.

### *Understanding of the Role of the Public Guardian and Trustee*

- 40 Within long-term, acute and community care, there seems to be confusion about the mandate of the Public Guardian and Trustee (PGT) with respect to health care decision making. A number of key informants, including physicians, health authority representatives, nurses, social workers, and a geriatrician, expressed confusion about the PGT's role. Some were not aware that they could contact the PGT as temporary substitute decision maker of last resort for patients without a substitute decision maker. Others expected the PGT to mediate or resolve family disputes, which is not within the PGT's mandate.
- 41 Some key informants indicated that they were unaware that the PGT's mandate included minor health care decision making. A number of key informants said they only contact the PGT regarding major or life threatening health care decisions.

*I actually think that's a false issue. I really do. Because if you are a surgeon, proposing a gall bladder, you darn well better know whether that person can consent, and you darn well better find out who can consent. And if you're a family physician taking care of the patient, and you're ordering medications, the same applies.*

– Geriatric psychiatrist

### 6.1.3 Barriers to Informed Consent

#### *Lack of Time and Resources*

42 Many physicians indicated that conversations about medication and treatment deserve, and require, time. Obtaining informed consent requires the time to make sure health care professional understands the patient's views, and the patient understand the medical information. The importance of these conversations as a cornerstone of good practice was affirmed by several directors of care.

43 Particularly in long-term care, an insufficiency of time was repeatedly identified as a factor impeding a physician's ability to properly obtain informed consent, or a staff member's ability to facilitate the consent process, especially where substitute decision makers needed to be contacted off site. Physicians themselves identified this barrier to consent, as did nurses and directors of care. Lack of time was identified as a barrier in two ways:

- (a) sometimes matters are too urgent (though not an emergency); and
- (b) some key informants said that physicians and long-term care staff do not have enough time to get consent for all medication, given their workload. However, a few physicians strongly opposed this view.

44 A number of owners or operators of care facilities identified family conflict as the most significant barrier to informed consent, especially in circumstances where there was no representative, and a number of siblings were equally ranked under the legislation as TSDM. They said staff need to spend a lot of time trying to mediate family disputes, whereas their staff are not really qualified to engage in this work. Health authorities also identified this challenge. In contrast, physicians generally said such dynamics were rare, and when they did arise, the issue could be resolved by meeting as a team of staff and family to discuss the issue, and find a good way forward. Social workers play a prominent role in resolving such disputes; however, not all care facilities employ social workers. Capacity to engage in these challenging discussions about health care seems to be connected to time and resources.

45 Physicians who noted time constraints as a barrier to obtaining informed consent identified heavy caseloads as a problem. At least one physician said pay structures for physician billing do not support them to have sufficient time to dedicate to long-term care residents.

*We're trying to be very pro-active because we've really run into a lot issues when, particularly when clients go into the hospital, and now there's nobody who can make decisions for them, and they're going to residential care.*

– Nurse

- 46 Many informants raised concerns that staffing—both composition and number of staff—posed a barrier to obtaining informed consent, and to good practice generally. Several key informants advocated for legislated minimum staffing levels in long-term care and assisted living as part of the solution to minimizing anti-psychotic use. All informants who commented on staffing were adamant that staffing levels in long-term care facilities were inadequate.
- 47 A number of health care staff expressed the view that they need external assistance with health care decision making, particularly where either there is disagreement among family members of the person living with dementia regarding treatment, or the person living with dementia appears to have no family.

#### ***Paternalism and Lack of Respect for Substitute and Supportive Decision Makers***

- 48 Some comments revealed a view that family members did not have enough knowledge or experience in order to make decisions about complex medical subjects. One geriatric psychiatrist identified a need to undermine the “we know best syndrome” that can be pervasive in health care. In another interview a psychiatrist indicated that they witnessed paternalism in practice regularly.
- 49 At least one lawyer and one social worker identified failure on the part of physicians to recognize a person’s right to choose to live at risk as an obstacle to good practice. The lawyer indicated that some professionals, including many judges, are too quick to move to a best interests approach.
- 50 One psychiatrist indicated that they thought consent rights of substitute decision makers were sometimes overridden by the use of involuntary committal procedures for paternalistic reasons.

#### **6.1.4 Advance Planning**

- 51 Many key informants from diverse professional backgrounds indicated that representation agreements are uncommon, but generally viewed by health care professionals and social workers as useful documents. Health care professionals would like to see greater advance planning, long before a dementia diagnosis. Most of the health care professionals we spoke with say they encourage advance planning for health care decisions, but they feel they are not

*When you go into court you are going into [the courtroom of] any old random judge who may or may not have ever heard of capacity issues, whereas you would expect if it was a capacity review board, they would be fluent with the issue of capacity.*

– Lawyer

the ideal people to provide information on the topic. Several key informants, in particular social workers, were of the view that health care professionals often did not understand advance care planning tools well.

- 52 Social workers and nurses working in community are providing education about representation agreements and advance planning for health care decision making as part of their work.
- 53 We are aware of at least one health authority which has a designated staff member whose role is focused on education of the public and health care professionals on consent and substitute decision making matters.

#### 6.1.5 Access to Justice

- 54 If a person does not have the right to make health care and financial decisions due to a committee order, it can be difficult to retain counsel to challenge the committee because the older person may not have access to funds.
- 55 If a person living with dementia disagrees with a medication decision, or the determination of incapacity, some physicians will bring in an ethicist to assist, or refer the matter to an ethics committee, if available. One geriatric psychiatrist said on occasion he would get a second opinion regarding incapability to make a medication decision. There is a desire to minimize moral distress for all concerned (including staff, family, and the person living with dementia).
- 56 Key informants from the PGT indicated that where they are committee or statutory property guardian, and a person living with dementia wishes to challenge their appointment or one of their decisions as health care decision maker, as a matter of practice the PGT will facilitate access to independent legal counsel, regardless of the older person's financial situation.
- 57 If an alleged abusive decision maker is the representative, their powers can only be challenged by going to court. The PGT's powers to intervene are limited as the PGT cannot be appointed personal statutory personal guardian, and a court application for committee can be costly and slow—at least several months—whereas the medical issue may require a timely decision.

*If they are paranoid, and scared all the time, I mean, you cannot address it just with other methods. I don't think living your life in that state for the rest of your life is a good idea.*

– Geriatrician

- 58 The Seniors First BC Seniors Abuse and Information Line does receive calls regarding health care decisions and incapability assessments. On at least three occasions lawyers with the Elder Law Clinic have successfully challenged findings of incapacity in court.
- 59 With respect to advance planning, some lawyers are very reluctant to do section 7 agreements for a person who has some diminished capacity. Although Law Society of BC rules have changed to permit lawyers to act, and the person may have capacity to create a representation agreement, they may not have capacity to sign a retainer agreement with the lawyer. The capacity to contract is a higher standard.
- 60 Language issues related to dementia or other issues such as stroke recovery can make it difficult for a person to advocate for themselves.
- 61 Lack of an administrative review tribunal for health care decisions creates barriers to access to justice. Relatedly, one lawyer identified lack of knowledge and experience of judges with respect to mental capacity issues as presenting an access to justice issue. The lawyer pointed to the value of an administrative tribunal having authority over all guardianship and health care decision making matters:
- 62 Confidentiality issues can present barriers to access to justice. Courts are open, documents become public record, and the records are generally not anonymized.

### 6.1.6 Anti-psychotics, Chemical Restraints and Consent

- 63 From the perspective of health care professionals—particularly physicians, geriatricians and psychiatrists who have prescribing authority—there does not appear to be a clear distinction between the use of anti-psychotics as a form of health care versus the use of anti-psychotics as a chemical restraint. Half the physicians who commented on the meaning of chemical restraint considered any prescription of anti-psychotic medications to be health care; however, when pushed, most acknowledged that the medication could be used as a restraint, especially in emergency circumstances. Two physicians stated that the use of an anti-psychotic could be both health care and a restraint at the same time. Only one physician was confident regarding when the use of an anti-psychotic was health care versus a restraint. Most felt that anti-psychotic use can be framed as health care treatment if the medication is alleviating suffering in any way, but many informants felt the distinction was a fine line because while intention is



therapeutic, the impact can be restraint. When the use is purely for convenience or comfort of others—there is no distress, and the person living with dementia is just annoying people—physicians agreed that the use is restraint.

64 Regardless of a physician's view on whether the use of an anti-psychotic was health care or a restraint, consent processes did not differ for the prescription of anti-psychotic medications as compared with the provision of other health care in non-emergency situations. Even the two physicians who expressed an opinion that anti-psychotics were often being used as a restraint did not make any distinction in consent processes. When made aware of the *Residential Care Regulation (RC Regulation)* provisions regarding restraint physicians did not understand how they could be helpful.

65 There was very little awareness by physicians of the existence of the *RC Regulation* provisions regulating the use of restraints, including any differences between agreement processes for the use of chemical restraints versus consent processes for the provision of health care. However, most facilities, as well as health authorities, do have a least-restraint policy which outlines procedures.

66 There was some awareness of the *RC Regulation* provisions regulating the use of restraints by non-health care staff, such as by social workers and facility management staff. However, most of these key informants considered the regulations only applicable to physical restraints, and had not considered they might apply to the use of anti-psychotics or other medication.

67 All stakeholders were cognizant of their facilities' "least restraint" policies, with broad acknowledgement that there had been a vast shift for the better in health care practice in terms of the use of restraints in recent years. All health care professionals and staff identified overuse of anti-psychotics as an ongoing issue requiring attention. However, all key informants felt there had been improvement, if not significant improvement, in the last five years, though there had been little attention to consent practices in relation to use of anti-psychotics.

68 Many health care professionals emphasized that while anti-psychotics have been overused in long-term care, they can be a very useful form of medication to help relieve distress in some people living with dementia.

69 The PGT has authority as TSDM to consent to the use of restraints which form part of a health care treatment plan pursuant to the *HCCA*, and to agree to the use of adaptive and

*Some of the First Nations believe that if you even start talking about death you are inviting it. So they're reluctant to go there. They don't want to use the words. They're not comfortable with it. They believe that for people who have crossed over, talking about it can act as a draw.*

– Health authority staff

behavioural restraints under the *RC Regulation* if the PGT is the committee of person. For the PGT, if there is no perceived health benefit of the restraint to the person living with dementia, then it is not health care, and so the PGT cannot consent as TSDM. The restraint provisions of the *RC Regulation* do not specifically name the PGT as having authority to agree to a restraint.

**70** The Seniors First BC Seniors Abuse and Information Line (SAIL) often receives calls regarding suspected inappropriate use of anti-psychotics which they believe contributed to deterioration and death, and were provided without the informed consent of the health care decision maker. Family tend to call SAIL only after the older person has died because they are concerned about retaliation.

**71** Anti-psychotics are not only used within facilities. They are also used in community, and can be a means to prolong the ability of people living with dementia to continue to reside at home with the support of family caregivers, and home and community care.

### 6.1.7 Patterns Identified Related to Specific Groups

**72** Several key informants from health authorities and nursing backgrounds stated that it is common for Chinese-Canadian families to experience difficulties confronting decision making around end of life or palliative care, instead tending to seek the highest level of intervention for their family member, despite a health professional's recommendations to consider less intrusive or palliative care. Key informants viewed culture in these cases as impacting on a substitute decision maker's ability to make decisions in accordance with what the person living with dementia would have wanted, or in their best interests. Balancing these cultural considerations with a patient-centred approach to health care was commonly identified as raising difficult issues.

**73** Language issues pose a significant barrier to consent for non-English speaking families. Interpreters are not always available or sought. Many informants spoke of relying on available staff who spoke the language, or other family members to assume the role of interpreter. The availability of an interpreter does not always remedy this problem. True understanding and engagement is difficult to gauge when interpreters are involved. Interpreter understanding of medical terms or concepts is not always certain.<sup>854</sup>

- 74 Two key informants noted that in South Asian and Chinese communities, it is common for the oldest son to identify himself as the TSDM ahead of the patient's wife. A few key informants from a variety of professional backgrounds identified that sometimes families will insist that the male of the family make the decisions, even where it the daughters who are providing the care, and have all the information about the person living with dementia, and their values and wishes. Informants were of the view that given the propensity for health care professionals and staff to involve wider family groups in discussions, this practice did not usually preclude female family members from involvement.
- 75 Key informants from health authorities and social work identified that in some cultures, there can be a reluctance to talk about death that can pose barriers to decision making. In some cultures, talking about death can be considered "rude and bad-mannered," or imprudent.
- 76 Some key informants from health authorities and with nursing experience on reserves pointed out that some Indigenous people have a strong distrust of institutions, and white people with authority. Colonization, and the residential school system in particular, have both damaged people's sense of autonomy, and created trauma and fear resulting sometimes in a lack of ability to engage with the system, and other times in a culture of assent.
- 77 Indigenous people continue to experience racism in all aspects of health care, which impacts their ability to participate in health care decision making.
- 78 In rural Northern communities, there are fewer resources, and so people tend to have inferior knowledge of their rights. Further, people who are marginalized may make different decisions, value different things, and have less social power, and so their choices are sometimes not respected. And it is harder for people to participate in decision making when they come from a community with limited internet, and where people cannot afford a telephone. On the flip side, a family physician key informant noted that older people in these communities are often less isolated, and more likely to have neighbours or community members who know them well enough to act as TSDM.

### 6.1.8 *Mental Health Act and Care Facility Admissions Procedures*

- 79 There was agreement among the geriatric psychiatrists we spoke with that dementia is a mental disorder, and so involuntary committal under the *Mental Health Act (MHA)* can be

*All of a sudden people were doing things for him, which increased his anxiety. They started increasing the medication, and I learned that the medication can cause strokes. He has vascular dementia driven by cardio-vascular disease.*

– Family caregiver

appropriate where the criteria under the *MHA* is met. However, there is a lack of clarity around when use of the *MHA* is appropriate for people living with dementia. Physicians and Ministry of Health staff confirmed that guidelines do not exist to support practice.

- 80 The *MHA*'s "extended leave" provisions are currently being used as a means of admitting a person with a mental disorder, including dementia, into a long-term care facility, although this approach seems to be only used as a last resort. The overwhelming view is that the use of the *MHA* in this way is problematic but necessary in some circumstances where there is no representative or committee of the person, because TSDMs cannot consent to personal care matters, including admission to a care facility.
- 81 A person living with dementia might get involuntarily committed in circumstances where they were considered to be aggressive and dangerous in long-term care, and the substitute decision maker would not consent to medication.
- 82 Many stakeholders are aware that legislation with respect to admission to care facilities is forthcoming, but are not familiar with the details of the legislation, and therefore could not comment on its advantages, or possible disadvantages. Many informants were hopeful that the new legislation would address a gap in consent law, thereby resulting in fewer involuntary committals.
- 83 There was some suggestion that the *MHA* is being invoked to relieve family members of stressful decision making.
- 84 The use of the *MHA* is often for a short term transitional period, while the person settles into the new care facility. The use may be for a few weeks or a few months if the diagnosis is dementia, and there is a no other psychiatric disorder.
- 85 One lawyer expressed concern regarding an incident where use of the *MHA* was being threatened to get the older person to consent to facility placement. He could not comment on how common this practice was.

*I was on Statin drugs, and if you do any research, they tend to add to confusion... the GP, the drugs he gave me, there are studies that they conflict with my condition. He never even knew about that.*

– Person living with dementia

## 6.2 FOCUS GROUPS WITH COMMUNITY STAKEHOLDERS

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### 6.2.1 Health Care Consent Practice

#### *Health Care Provider Practice*

- 1 Most people living with dementia and family caregivers reported that their specialist, often a geriatric psychiatrist, provided lengthy appointment times that allowed them to ask all the questions they needed to ask about medication and treatment options being considered (up to an hour). A lengthy appointment time was considered crucial to decision making and a hallmark of good practice.
- 2 Comments regarding general practitioners were mixed. Some people reported that they were rushed during their appointments, and there was not enough time to pose questions. Some people, especially people who had maintained the same physician for a long time, said their physician made time for them, granting longer appointments. These people characterized their physician as an important ally in care.
- 3 Family caregivers of adults with intellectual disabilities who are now living with dementia expressed confidence in their role as supportive or substitute health care decision maker. They generally had many years of experience supporting the person living disabilities or making decisions, involving them to the extent possible, and monitoring after changes occurred to gage if and when a decision needed to be revisited. They were skilled at reading non-verbal cues, and understanding unique styles of communication. They also often took their responsibility to engage the person living with dementia, and advocate for them, very seriously.
- 4 Although some people said physicians were very helpful in answering questions about medication, others reported that physicians do not have accurate knowledge about the relevant medication. People reported having to spend a lot of time independently researching side-effects, drugs interactions, and alternative online—as well as the as effects of drugs taken for other conditions on memory and cognition—in order to acquire adequate information for health care decision making. Some people reported not being told about side effects, or how long to take a drug. In general people felt that although specialists were very helpful and knowledgeable, general practitioners did not have enough knowledge about dementia, or the medication they were prescribing or monitoring.

*It's tiring. I have to do all the research myself. And when I ask for particulars, they can't find it. And when they can find it, the log is private, even when it's my own mother.*

– Family caregiver

- 5 Family caregivers of people with intellectual disabilities said that sometimes the health provider's presentation of options for treatment and care betrayed a lack of respect for the value of the lives of people who have significant lifelong disabilities.
- 6 A number of caregivers talked about employing “therapeutic fibbing” in order to get the person living with dementia to accept services or take medication. This appeared to be in circumstances where the dementia had progressed, but a person still had some capacity. One caregiver spoke of employing therapeutic fibbing because staff required a medication that his mother would not agree to.

### *Involving Substitute Decision Makers and Family*

- 7 A number of stakeholders were the representative under a representation agreement. None were committees. Most people found the representation agreement to be a positive in terms of clarifying who within the family had authority as substitute decision maker for health care. Most people found they didn't need a representation agreement. They found that staff recognized children and spouses as health care decision makers when they should. The challenge was more the issue of the extent of involvement and communication, particularly once the person living with dementia resided in long-term care.
- 8 Most people reported that physicians treat the person living with dementia and the family caregiver as a team. Some dedicated part of the appointment time to meeting alone with the family caregiver, and most people characterized this activity as for the purpose of getting the “caregiver perspective”, rather than for obtaining consent. No one was critical of this practice. One person found hospitals were less welcoming of the team relationship, recalling being in the Emergency Department of a Hospital, and being told “Patient only.” He had to insist on bringing in his wife.
- 9 A lot of the comments by family caregivers and people living with dementia focused on the decision making dynamic between them. Both caregivers and people living with dementia often described health care decision making as a collaboration. This was especially true for couples who had been together for most of their adult lives. All people living with dementia who had family caregivers in their lives attended appointments with their caregivers, in part because most people living with dementia required the family member to drive them to appointments. They also welcomed assistance in recalling what was said during appointments.

*The doctors are not trained on Alzheimer's. You become a third person, and they turn to the family if they are present to discuss you like you are an object. It is very dehumanizing.*

## – Person living with dementia

- 10 Many people who were the substitute decision maker for someone living in long-term care characterized the role of a substitute decision maker as a kind of advocate. The work is time-consuming and overwhelming. It requires a great deal of vigilance because the staff are not always keen to communicate with family members, and get consent for medication decisions. A few caregivers described care facility staff as hostile.
- 11 In long-term care, many family caregivers found it difficult to get information on what medication the person living with dementia was taking—let alone participate in decision making—even where they had a representation agreement in place appointing them as health care decision maker. Caregivers spoke of asking for information, and not being provided with answers, and resorting to asking to see the resident chart, which they would be told was confidential information such that they would be required to file a *Freedom of Information and Protection of Privacy Act* request to access any the information contained in the chart.
- 12 One family caregiver reported that the only reason she received information about her parent's medication was that she was also the attorney under a power of attorney, and so she received bills from the long-term care facility's pharmacy regarding medication.
- 13 People often discussed finding out about medication changes after the fact, sometimes only at a care conference many months down the road. A number of family caregivers commented on over-medicating with laxatives and suppositories with caregivers reporting that allowing them more time, and making dietary changes, seemed like better, less invasive solutions, but that staff went straight to the drug solution without consulting family.
- 14 Three family caregivers reported very positive experiences, and excellent communication, with long-term care facility staff. Two of them were caring for someone living in a private facility at fees of \$9,000 and \$10,000 a month.

### **Engaging the Person Living with Dementia**

- 15 Some people living with dementia commented that they needed more time to process information and get answers to their questions because of the impact of dementia on their cognitive abilities. Rushing can cause anxiety, and makes it hard for them to participate, creating a dynamic where it is easier for family caregivers to take over the conversation. Caregivers were equally aware of how negatively rushing impacted health care decision making.

*When someone's difficult in the system, they put a purple dot on your chart. They're now doing that with caregivers.*

– Non-profit

- 16 Although capacity is variable, and many people with dementia have very good days, family caregivers reported that it is not possible to plan medical appointments to coincide with periods of great clarity. They must schedule medical appointments in advance.
- 17 Some people living with dementia shared stories of well-meaning family members trying to take over decision making while they still had capacity. They emphasized how important it is to ask how you can help, and not try to control them. Few people reported this dynamic, but when it did happen it was very upsetting.
- 18 A few people living with dementia didn't seem to appreciate they had choices. They just took the medication their physician prescribed. A few caregivers said their parent would do whatever a doctor suggested. As with key informants, they identified a culture of compliance in their parent's generation, and great deference to physicians.
- 19 A few people reported that the physician would look to the family caregiver to make decisions, and that they had to educate the physician to include the person living with dementia.
- 20 A few caregivers reported that it is harder to involve the person living with dementia in health care decision making when they are in denial that they have dementia.

### 6.2.2 Barriers to Informed Consent

- 21 Family caregivers identified staff turnover in long-term care as a barrier because staying involved in decision making is linked to good relationships with staff.
- 22 For a number of family caregivers, changing jurisdictions resulted in challenges, especially where they moved after a diagnosis, and capacity had diminished such that it was no longer possible to get a representation agreement.

### 6.2.3 Anti-psychotics, Chemical Restraints, and Consent

- 23 Family caregivers seem to have a basic understanding of anti-psychotics, and reported the use of anti-psychotic medication in both community and long-term care. Family caregivers said



*It is a struggle. You have to speak up, ask questions and challenge. But it is overwhelming.*

– Family caregiver

the drugs stabilize mood and calm aggression such that it is possible to keep the person living with dementia at home for a longer period of time.

24 With respect to long-term care, family caregivers shared many stories of people with dementia receiving drugs without consent of the substitute decision maker, including anti-psychotics and tranquilizers, and of staff being very resistant to either discontinuing the drugs, or facilitating dialogue with the physician over whether medication ought to continue.

25 A number of people reported they were told by staff that all residents would be put on the same medication on admission, with one goal being to calm the residents at night when staffing levels were lower.

26 One caregiver whose spouse had been diagnosed a year ago disclosed he was secretly crushing into his wife's food anti-psychotic medication she was refusing to take. However, he indicated she was fully mentally capable to make her own decisions, and attends many medical appointments on her own. He said two nurses recommended sneaking the medication into her food. The medication "makes life bearable." He indicated that previous to her dementia she has been a calm person, but that now she swears, and gets angry often.

27 Some family caregivers felt that the person living with dementia was being over-medicated with an anti-psychotic because the staff did not take the time to understand what the person was communicating, and were too quick to label someone aggressive or resistant to treatment. One family caregiver reported that her father would speak to staff in his mother tongue, which they did not understand, thereby increasing his frustration. She felt he was not aggressive, but rather frustrated because they did not understand him. She said she was willing to interpret but staff would not involve her, and tried to keep the family away. Another family caregiver told us that her mother's habit of swatting her arm was labelled aggressive, whereas she was just trying to communicate through gesture because she was non-verbal.

#### 6.2.4 **Mental Health Act and Care Facility Admissions Procedures**

28 Two caregivers shared confusion about involuntary committal under the *Mental Health Act*. Both women were spouses whose husbands had been involuntarily committed. They did not understand why there was a need for committal. They both said they were very involved in care, and readily available, as well as compliant with doctor recommendations regarding

*I still feel like, you know, we're the ones that still have to make the call. I think we have a duty to inform them and get their input, hear their input, but not to ask for their consent.*

– Physician

medication. Both visited their spouse every day for hours to assist with meals, and other facets of care. One of the women felt she was being pressured into accepting involuntary committal without being provided with an explanation as to why this approach would enhance her husband's care. For both of them the experience was traumatic.

**29** None of the caregivers we spoke with whose spouse had been involuntarily committed were provided with any rights information regarding how to challenge the committal, or a referral to legal resources.

## 6.3 SUMMARY

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Below we summarize the 114 issues emerging from consultation. In order to support thinking about concrete recommendations for change, we group the issues according to whether they indicate primarily findings which:

1. Relate to **practice and practice support**, and lack of compliance with, or enforcement of, the law;
2. Suggest **gaps in legislation**, or a need for law reform; or
3. Point to **lack of knowledge of the law**, and a need for enhanced training, professional development, or public legal education.

### 6.3.1 Findings Related to Practice

#### *Getting Consent*

**Time for conversations about care:** Informed consent requires many conversations about care, values, and options, and often there does not seem to be enough time to have these discussions. This is especially true for people living with dementia, whose capacity may be compromised if they are rushed or stressed.

**Health care consent:** Physicians and other health care staff are often not getting informed timely consent under circumstances where they are legally obligated to do so. Many people working in long-term care do not think that the current long-term care environment permits practice consistent with

*Because I think sometimes things get lost. I think when we rely on say the adult child to relay things to the wife we don't know what they're relaying, or even that they have the vocabulary. Maybe they did not grow up in Canada, and they didn't learn the word for 'advanced kidney disease' in their language. So I think we're at risk of losing some things.*

## – Social worker

the law, due to a lack of time and resources, including the lack of onsite presence of the physician, which appears to be related to the billing model for physician care. Family caregivers often feel excluded from decisions about medication in long-term care. However, the issue of consent does not appear exclusively reducible to structural barriers. Many health care professionals don't think they should have to get consent for every medical intervention—from a legal, ethical or practical standpoint. Some physicians working in community do not have enough knowledge of the medication to support the informed consent process. There appears to be a lack of clarity regarding the role of nursing professionals in facilitating the consent process for health care provided in long-term care by physicians.

**People with no decision maker:** There is likely a significant population of people living with dementia living in long-term care who have no health care decision maker. For these people, the physician and/or the health care team are often making decisions.

**Power dynamics:** Physicians have a tremendous amount of power—whether intentionally or not. Some people:

- Do not know they can make a choice inconsistent with the physician's recommendation;
- Are afraid of retribution if they resist the physician's approach;
- Do not understand their legal rights with respect to health care; or
- Feel significant deference toward the physician that undermines their decision-making autonomy.

### **Chemical Restraints and Anti-psychotics**

**Chemical restraint:** Within the medical community, there is not a consistent understanding of what a chemical restraint is. Generally, physicians do not turn their mind to the concept, and rather consider: is this medication the appropriate intervention given all the circumstances?

**Anti-psychotic use:** Within long-term care, all health care professionals recognize the importance of minimizing anti-psychotic use, believe a reduction in use has occurred in recent years, and feel there is more work to be done in this area. At the same time, many key informants emphasized that anti-psychotics can be an appropriate intervention for alleviating distress in people living with dementia. Most health care professionals do not consider the use of anti-psychotics by people living with dementia as a form of restraint, except, when pressed, if use was strictly for staff convenience.

*I have to go there with the list of questions ahead of time otherwise I forget. So I prepare in advance.*

## – Person living with dementia

### **Communities Facing Particular Barriers to Consent Rights**

**Indigenous people** experience significant additional barriers to health care consent as a function of colonization, ongoing racism, and lack of services within their communities.

**Language interpretation** can be crucial to health care consent; however, professional language interpretation is always not available, particularly in private and contracted long-term care facilities.

A number of **hearing and speech issues** can result in poor incapability assessment, and lack of informed consent, as well as limit access to justice. Hearing and speech professionals need to understand mental capacity better. Other health care professionals require better understanding and practice with respect to recognizing hearing and speech issues, and responding appropriately to provide assistance in this area.

The *Mental Health Act* is sometimes being used inappropriately with respect to people living with dementia, sometimes due to a lack of respect for, or willingness to consult with, substitute decision makers. The Act may be being mis-used in part due to a legal gap that may be remedied by the implementation of the care facility admission provisions.

### **6.3.2 Legal Issues and Law Reform**

#### **Chemical Restraints and Anti-psychotics**

**Chemical restraint regulations:** There is very little knowledge and application of the *RC Regulation* to circumstances involving a chemical, rather than a physical, restraint. Health care professionals do not appear to turn their mind to the concept of chemical restraint when administering medication that could be restraining, such as anti-psychotics.

**PGT and restraint:** The PGT is not specifically named in the *RC Regulation* as able to agree to the use of a restraint. Therefore, the PGT cannot agree to use of a restraint unless it is committee of person under the *Patients Property Act*, or a TSDM under the *HCCA* where the restraint is a component of health care treatment. Therefore, if a person has no committee, and no relatives, there is no person with legal authority to consent to certain kinds of restraint.

*There's very little knowledge about the law in terms of consent... so education would be really helpful. It's very much needed I think.*

– Nurse

### **Access to Justice Issues**

**Access to Legal Aid:** For people living with dementia, and other people who may have reduced mental capacity, access to legal assistance to challenge a finding of incapability, or a specific health care decision, is minimal.

**Lawyers & Advance care planning:** Lawyers can sometimes be reluctant to take on a client for the purposes of drafting a representation agreement given the time it takes to assess incapability, and a lack of certainty in professional conduct rules regarding entering into a retainer agreement with a person who has capacity issues.

### **Substitute and Supportive Decision Making**

Although the legal framework generally provides for a single decision maker, health care decision making is a very **collaborative activity**. Sometimes it involves the person living with dementia and another person they trust. Sometimes it involves a larger network of people. Although family caregivers do not use the term “supportive decision maker”, many of them appear to be engaged in supportive decision making with the person living with dementia. Where health care professionals are attentive to obtaining informed prior consent, they often approach decision making as a collaborative exercise engaging family.

**TSDM list:** The equal weighting of siblings under the TSDM list within the *HCCA* can pose challenges when adult children have divergent views about health care. It is often health care professionals and staff who must sort out disputes, and often they are not comfortable with addressing these situations. There is a common misperception that the PGT has a mandate to intervene to resolve disputes among equally ranked family members. The PGT's dispute resolution tools are either to authorize someone as TSDM, or make the decision as TSDM.

### 6.3.3 Gaps in Knowledge of the Law

#### *Health care Professionals and Staff*

**Professional development and education:** Across all professionals and staff involved in health care decision making, there is a need and desire for greater ongoing professional development with respect to health care consent law in BC.

**Admission and consent to treatment:** There is confusion regarding when consent is required in long-term care. Some health care staff clearly think admission constitutes consent to all treatment recommended by the physician.

**Incapacity assessment:** One barrier to informed consent is that many health care professionals either do not know how to conduct an incapacity assessment, or do not conduct them. Also, it appears that sometimes health care professionals incorrectly rely on the opinion of family members regarding capacity. As a result, it is impossible to know how much a person can participate in health care decision making, and whether it is appropriate to turn to a substitute decision maker.

**Medical Order for Scope of Treatment (MOST) Form:** While useful as a tool for supporting care discussion and documenting preferences, there is some confusion that the form is a legal agreement or an advance planning instrument.

**PGT role:** Among physicians, long-term care staff, and operators, there is confusion about the mandate of the PGT and its role in health care decision making. There is inconsistent practice in terms of when health care professionals or operators appeal to the PGT for assistance, and a lack of understanding regarding what kinds of assistance the PGT can provide.

#### *Substitute Decision Makers and Family*

**Community education:** Given low take up of advance planning tools, it seems that the general public lacks knowledge of available tools, and of the importance of planning for health care decision making in advance.

**Understanding substitute decision making:** Some substitute decision makers do not understand their responsibilities. In particular, they do not appreciate that they are being asked to consider what that person would want, rather than make the decisions based on their own desires and wishes, or even resort to best interests—at least in the first instance. Substitute decision makers may also require more knowledge of frailty and end of life care. Health care decision making is a challenging and important role for which people are inadequately trained—and yet also asked to assume when they are in a time of crisis: caring for a person living with dementia, and supporting someone along the journey to end of life, can be fraught with loss.



CHAPTER 7

# Discussion and Recommendations

*I think certainly things have gotten better in my 25 years... but I think there's a belief out there that still exists, not among everybody, but still is out there, that once you cross the threshold into care, that you kind of, for whatever reason, lose your citizenship rights at the door.*

– Health authority staff

This chapter brings together legal research and consultation findings for discussion of recommendations aimed at enhancing compliance with, or improving, health care consent law in BC. Some of the issues canvassed below emerged exclusively from our review of the law; some issues were identified through consultation; many came up in both contexts. We focus on consultation findings identified in Part 3 of Chapter 6 (above), where we distill the 114 issues emerging from consultation down to 23 findings.

This chapter is divided into four parts. Recommendations aim to:

1. Create greater clarity and consistency in the law;
2. Support best practice of health care providers with respect to health care consent;
3. Address systemic barriers to informed consent; and
4. Enhance access to legal information and representation regarding health care consent rights.

## 7.1 CREATING GREATER CLARITY AND CONSISTENCY IN THE LAW

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BC is one of the few provinces in Canada to have developed a comprehensive health care consent statute that codifies the common law doctrine of informed consent. The *Health Care (Consent) and Care Facility (Admission) Act (HCCA)* clarifies the rights and responsibilities of health care providers and temporary substitute decision makers for health care. The statute confirms the principle that decision making autonomy is paramount, and that neither a best interests approach, nor paternalist thinking, is relevant to the decision making of adults who are capable of making their own health care decisions. BC is also one of the only jurisdictions in the world to have developed a framework for supported health care decision making, through the *Representation Agreement Act (RAA)*.

The *HCCA* provides a solid foundation for health care consent law in BC. The Act:

- Imposes an obligation on health care providers to obtain timely informed consent prior to treatment;
- Codifies the right to revoke consent;
- Starts from a presumption that all adults are mentally capable of making their own health care decisions;
- Includes a standard for capacity to consent to health care;
- Requires health care providers to consider whether an adult has capacity as part of the consent process;
- Delineates the kinds of information a health care provider is required to provide such that consent will be informed;
- Codifies the right to ask questions, and receive answers about proposed health care;
- Sets out exceptions that permit emergency treatment and assessment without prior consent;
- Develops a scheme for substitute decision making where an adult does not have capacity to make a decision regarding proposed treatment; and
- Creates a mechanism for documenting instructions regarding possible future treatment in the form of an advance directive.

In this first part of Chapter 7 we identify a number of legislative amendments which aim to:



*For a lot of older adults, they feel they are not being heard or... and often it's also people who feel that they have some capacity, but they have been denied their voice because there may have been a finding of incapacity, or a condition like dementia.*

– Lawyer

- Clarify or enhance the rights of people living with dementia and their substitute decision makers to participate in health care decision making; and
- Remedy inconsistencies between various statutory provisions which are relevant to health care decision making for people living with dementia.

Most of the recommendations in Section 7.1 relate to the *HCCA*, the *Community Care and Assisted Living Act (CCAL Act)*, and the *Residential Care Regulation (RC Regulation)*; however, we also make recommendations that impact the *Mental Health Act (MHA)*, the *RAA*, the *Patients Property Act (PPA)*, and the *Adult Guardianship Act (AGA)*. The recommendations below build on the robust framework of rights and responsibilities established in the *HCCA*, and aim to bring health care decision making legislation in BC in better alignment with the principles found in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).<sup>855</sup>

Section 7.1 is divided into two sections which address:

1. Health care decision making rights and responsibilities; and
2. Use of restraints in long-term care

### 7.1.1 Health Care Decision Making Rights and Responsibilities

#### Recognize that Capacity is Decision-Specific

The concept of mental capacity is key to health care consent law in BC. Capacity is presumed,<sup>856</sup> and a health care provider must consider whether a person has the mental capacity required to consent to treatment before the adult may consent to, or refuse, proposed health care.<sup>857</sup> The capacity standard set out in the *HCCA* requires the adult to demonstrate understanding of “the information a reasonable person would require to understand the proposed health care and to make a decision,”<sup>858</sup> as well as awareness that the information applies to themselves. The information an adult must demonstrate understanding of includes information about:

- (i) the condition for which the health care is proposed,
- (ii) the nature of the proposed health care,
- (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and
- (iv) alternative courses of health care.<sup>859</sup>

As discussed throughout this report, research indicates that capacity is both variable and decision-specific. In particular, the ability of people living with dementia to understand information, and apply it to themselves, can vary from day to day, and even within a given day. Further, people may have capacity for some decisions, and not others.

Both the common law and legislation set out various capacity standards with respect to different types of decisions. Capacity to consent to health care treatment, hinging as it does on a person's ability to understand information relevant to that particular treatment decision, can also vary depending on the complexity of the information relevant to a particular decision. However, while the *HCCA* uses person-centered language, generally referring to "a person who is (in)capable of giving consent", rather than to a "capable person" or an "incapable person", the statute does not clearly recognize the variability of capacity depending on the nature of the decision in question.

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*The first two appointments he just ignored [my wife]. Now [the physician] is paying attention. We've been married 50 years, known each other 54. We are not by ourselves; we are working together."*

– **Person living with dementia**

The *HCCA* contains two provisions requiring confirmation and redetermination of capacity, which recognize that capacity is not a fixed state, and can vary. The Act requires health care providers to:

- Confirm incapacity closer to the time when treatment is to begin (21 days); and
- Make a new determination regarding capacity if, at any time, a health care provider has reasonable grounds to believe the adult may be capable of giving or refusing consent to health care.<sup>860</sup>

Both Project Advisory Committee members and a number of key informants confirmed that good practice requires timely consideration of a person's capacity. However, many stakeholders noted that incapability assessments do not occur as often as they should, and that health care providers often presume lack of capacity for people living with dementia. These patterns highlight the importance of underscoring the variability of capacity depending on what a person must be able to understand in order to make a particular health care treatment decision, and the timing of the health care decision. Although the capacity standard for health care treatment decisions in the *HCCA* links capacity to understanding the proposed treatment, the statute would be improved by stronger language recognizing that capacity can vary.

Such language can be found in Prince Edward Island's health care consent statute. The *Consent to Treatment Act* states:

**Capacity depends on treatment**

- (3) A person may be incapable with respect to some treatments and capable with respect to others.

**Capacity depends on time**

- (4) A person may be incapable with respect to a treatment at one time and capable at another.<sup>861</sup>

Identical language is also found in Ontario’s *Health Care Consent Act*.<sup>862</sup> In 2004, the Law Reform Commission of Manitoba recommended the adoption of similar language into its consent to treatment statute.<sup>863</sup> We recommend a similar provision be added to the *HCCA* in order to enhance recognition of the capacity of people living with dementia to participate in health care decision making even where they may lack capacity for some decisions.

## RECOMMENDATION 1

### Incorporate Supported Decision Making into BC’s Health Care Consent Statute

Both legislation and consultation confirmed that in non-emergency situations health care decision making is a process that requires dialogue. Some people living with dementia may not be able to make their own health care decisions independently, or may have communication difficulties; however, they may still have the capacity to meaningfully participate in health care decision making, particularly if they receive support from a person they trust.

Supported decision making, which we discuss at greater length in Chapter 3, is a concept with roots in disability rights advocacy. While each supported decision making relationship is tailored to address a person’s unique needs for support, our research<sup>864</sup> indicates that supportive decision makers “support” a person to:

- Understand the issues involved in a decision;
- Understand the consequences of a decision;
- Access the appropriate assistance or information to help them make a decision; and
- Express their views, by acting as interpreter where needed.

A supportive decision maker can help others to: Truly hear or understand a person who requires support;

- Appreciate the person’s needs, rights, values, preferences and goals; and
- Respect the person’s autonomy, dignity and wisdom—in other words, help prevent discrimination and bias linked to disability.

BC law recognizes supported decision making for health care through the *RAA*.<sup>865</sup> Some people living with dementia may have created a representation agreement for supported decision making; others may not have drafted an agreement, but still make decisions with the support of people they trust.

## 1

The *Health Care (Consent) and Care Facility (Admission) Act* should be amended to recognize that capacity can vary in the following manner:

- A person may be incapable with respect to some decisions regarding treatment, and capable with respect to others; and
- A person may be incapable with respect to a treatment at one time, and capable at another.

Two legal developments render a discussion of supported decision making for health care particularly timely in 2018. Firstly, recent amendments to various BC laws related to substitute decision making (*RAA, Power of Attorney Act, HCCA, PPA*) have added a duty to consult with, or involve, the person for whom decisions are being made. In this sense a finding of lack of capacity to make a specific decision no longer means an absolute loss of the right to participate in health care decision making—whether or not the adult has formally appointed a supported decision maker by way of a representation agreement. The duty of a substitute decision maker to consult or involve the adult in decision making highlights the importance of ensuring adults with diminished capacity are supported to participate in decision making.

Secondly, in 2010 Canada ratified the CRPD. Article 12 of the CRPD requires:

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.<sup>866</sup>

The United Nations Department of Social and Economic Affairs considers these provisions to call for supported decision making, holding out the BC *RAA* as providing a model approach.<sup>867</sup>

In spite of the above developments, there remains limited reference to supported decision making in the *HCCA*. Currently the only reference to supported decision making in the *HCCA* is section 8, which states that the health care provider “may allow the adult’s spouse, or any near relatives or close friends, who accompany the adult to help the adult and offer their assistance to understand or demonstrate an understanding” of the information relevant to the proposed health care. The permissive language of the section does not establish or confirm the right to supported decision making for health care. A representative’s authority as a substitute decision maker, but not as supportive decision maker, is recognized under the *HCCA*.<sup>868</sup>

Indeed “consent rights”, which are set out in section 4 of the Act, apply only to an “adult who is capable of giving or refusing consent to health care”.<sup>869</sup> The *HCCA* states:

- 4 Every adult who is capable of giving or refusing consent to health care has
  - (a) the right to give consent or to refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death,
  - (b) the right to select a particular form of available health care on any grounds, including moral or religious grounds,
  - (c) the right to revoke consent,
  - (d) the right to expect that a decision to give, refuse or revoke consent will be respected, and
  - (e) the right to be involved to the greatest degree possible in all case planning and decision making.

Bearing in mind the above discussion of supported decision making, it is not clear why “the right to be involved to the greatest degree possible in all case planning and decision making” noted in subsection

(e) should be limited to an adult who is capable of consenting to treatment. People living with dementia who are not able to understand all the information relevant to a health care decision may still be capable of sharing information about their values and wishes regarding care, or explaining how they feel when they are taking certain kinds of medication, particularly if they have access to support with communication from a person they trust. People living with dementia may have knowledge that is vital to determining the best course of treatment.

Our consultation with people living with dementia and family caregivers confirmed some people use supported decision making; however, people tend not to use the expression “supported decision making” to describe their relationships. Many couples indicated they make decisions together, and say they have the most positive experiences of care when health care professionals and staff recognize the value of their supportive relationships. Family caregivers also described decision making dynamics with their parents which appear to be supportive. However, while some stakeholders discussed creating representation agreements, no stakeholders indicated they had created a representation agreement for supported, as opposed to substitute, decision making.

People living with dementia expressed frustration about circumstances in which the support of the person they trusted was not available because health care staff had separated them in order to provide care or assess health care needs. Family caregivers indicated that one of their key roles in health care decision making is helping to make sure people living with dementia are engaged in the health care decision making process to the best of their abilities.

A number of Project Advisory Committee members cautioned that people the adult *should* be able to trust can sometimes be controlling or abusive, which can be the case with substitute decision makers. Others expressed concern family caregivers connected to the Alzheimer Society of B.C. may be more aware of their responsibilities than others. Certainly, it is possible some family caregivers are not generally as responsible about supporting the voices of person living with dementia to be heard. However, such dynamics do not downplay the value of including supportive caregivers. Indeed other Committee members said it is far more common for professionals and service providers to be controlling or abusive.

As with substitute decision making, health care professionals and staff must understand the role of supported decision makers. Staff must be attentive to power dynamics, and signs of abuse or undue influence. The risk of abuse is not an adequate rationale for limiting access to support where the adult has not created a representation agreement. A representation agreement for supported decision making may reflect the clearest expression of authority; however, based on our consultation findings, awareness of this option is extremely limited. Information from key informants indicates that representation agreements are not widely used in health care settings. However, health care professionals, people living with dementia, and family

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*I think it has to do with the power, this notion that you just don't question whatever the doctor tells you. You just accept.*

– **Social Worker**

## 2

The *Health Care (Consent) and Care Facility (Admission) Act* should be amended to state that every adult, regardless of capacity, has the right to:

- Receive support in decision making provided by a family member or friend whom they trust, if they choose to do so; and
- Be involved to the greatest degree possible in all case planning and decision making.

caregivers all characterized the engagement of supportive (and non-abusive) family and friends as best practice.

As a result, we recommend the *HCCA* be amended to codify the right of every adult, regardless of capacity, to receive support in health care decision making, and to participate in health care decision making to the greatest extent possible. Such provisions will bring the *HCCA* in better alignment with supported decision making values, and with the requirements of the CRPD. The United Nations and others have recognized BC's leadership in the area of supported decision making through the *RAA*. Law reform of the *HCCA* to recognize supported decision making takes this work further. However, it is important that legislation be clear that it up to people to choose to make use of support if they wish to do so; the provision should not establish the right of family and friends to provide support.

### RECOMMENDATION 2

Recommendation 2 does not impact rights and responsibilities under the *RAA*. For people who have empowered a supportive decision maker through a representation agreement, Recommendation 2 would protect the right of the adult to access the support of other people. We are also not recommending that informal supportive decision makers under the *HCCA* be accorded rights and responsibilities parallel to those under the *RAA*. Rather, the goal of Recommendation 2 is to enhance access to supported decision making for people living with dementia who would:

- Be able to participate in health care decision making only if they have access to support from a trusted person; or
- Have enhanced capacity to participate in decision making if support were provided.

Section 2 of the *HCCA* excludes people who have been involuntarily committed under the *MHA* from the benefit of any of the health care consent rights provided for in the *HCCA*, in terms of psychiatric treatment, regardless of capacity for health care decision making.<sup>870</sup> Under the *MHA* consent to psychiatric treatment authorized by the director of a designated facility is deemed to have been provided by the adult.<sup>871</sup>

We spoke with a number of stakeholders regarding involuntary committal of people living with dementia. While we have not conducted a thorough review of mental health law and practice, it is not evident to us why older people living with dementia who have been involuntarily committed should not be accorded the rights described in Recommendation 2. The right to participate in health care decision making and case planning, and to receive support in order to participate in such decision making, could co-exist with ultimate decision making authority resting with the director. Therefore, we recommend the Government of BC consider amending the *HCCA* so

that Recommendation 2 does not result in further inequality of health care decision making rights as between people who have been involuntary committed and all other adults.

### RECOMMENDATION 3

#### Clarify the Right to Consent to Medication in Long-Term Care

*We understand that there's this thing called consent, and I tend to think of it if there's a blood transfusion or a surgical procedure.*

– Physician

Many of the concerns stakeholders articulated regarding health care consent practice revealed some confusion regarding what can legitimately be consented to in advance in long-term care via a care plan, such as PRN orders<sup>872</sup> for medication, and which kinds of treatment require specific prior informed consent. Care plans are mandatory for people admitted to long-term care for a period of time longer than 30 days, and must include medication.<sup>873</sup> A plan for minor health care for up to twelve months is included in the definition of health care under the Act.<sup>874</sup> Effectively this means the care plan operates as documentation of advance consent to certain forms of treatment and care.

There is an inconsistency as between the *HCCA* and the *RC Regulation* in terms of whether consent is required for all medication and treatment provided under the care plan. Although the *HCCA* clearly states that informed prior consent is required to administer medication in non-emergency circumstances,<sup>875</sup> the *RC Regulation* states that the care plan must be developed with the participation of the resident or the substitute decision maker “to the extent reasonably practical”.<sup>876</sup> The language of participation “to the extent reasonably practical” is inconsistent with the unequivocal right to informed prior consent to treatment, and creates confusion, as an exception for urgent treatment already exists. A care plan is intended to guide care over the long term; the notion that it would not be practical to consult with the resident or the substitute decision maker at any point is troubling.

Under the *RC Regulation*, care plans include much more than minor health care. They must include a nutrition plan, a recreation and leisure plan, and other topics depending on the needs of the particular resident, for example, a falls prevention plan for a resident who may be prone to falling.<sup>877</sup> In terms of medication and treatment, the *RC Regulation* states the care plan must include:

## 3

The Government of BC should consider amending the Health Care (Consent) and Care Facility (Admission) Act such that the right to support, and the right to participate in case planning and decision making, apply to all adults, including adults currently excluded by the combined impact of Section 2 and the deemed consent provisions of the Mental Health Act.

Section 81 of the *Residential Care Regulation* should be amended to clarify that informed consent of the resident, or the substitute decision maker if the resident does not have capacity to consent, must be obtained prior to finalizing or amending any aspects of the resident's care plan that relate to health care treatment.

- (a) a plan to address
  - (i) medication, including self-administered medication if approved under section 70 (4) [administration of medication],
  - (ii) behavioural intervention, if applicable, and
  - (iii) if there is agreement to the use of restraints under section 74 (1)
- (b) [when restraints may be used], the type or nature of restraint and the frequency of reassessment.<sup>878</sup>

Although a plan for minor health care and a care plan are not equivalent terms, the language of both statutes indicates that care plans must include the plan for minor health care for the resident, as well as any agreement regarding use of chemical restraints.

Care plans are a key resource for staff in terms of administering medication, and confirming whether consent for certain medications has already been provided by a substitute decision maker. The notion that changes to the care plan relating to the provision of health care might not require prior informed consent raises particular concern given many of the comments by stakeholders regarding lack of prior consent to medication administered in long-term care settings. Many family caregivers spoke about how challenging it was to get long-term care facility staff to find the time to speak with them. Similarly, a number of health care staff expressed the view that care facility admission constituted consent to all health care treatment the health care team felt was in the best interests of the resident, that is to say, an implicit deference to the judgment of the care team not consistent with the law. This approach to practice is particularly problematic because the capacity standard for admission to a care facility is generally considered higher than the standard for consent to treatment: people living with dementia who do not have the right to make a decision regarding admission might still have capacity to make some or all of their treatment decisions.

Given these inconsistencies in BC law, and concerns regarding practice, the *RC Regulation* should be amended to provide greater clarity regarding the requirement of informed prior consent with respect to medication included in a care plan.

#### RECOMMENDATION 4

The *RC Regulation* requires that a care facility have “written policies and procedures for the purposes of guiding staff in all matters relating to the care and supervision of persons in care.”<sup>879</sup> Given concerns regarding practice, including the fact that physicians often prescribe medication over the telephone without examining the resident, and the extensive work pressures on staff, we recommend that long-term care facilities be required to develop policy on informed consent with a view to providing further support to all members of the care team. This is the approach which has been taken in Washington State. As a condition of licensing, the Department of Health regulations require hospitals and nursing homes in Washington to adopt and implement policies



which define patients' rights to be involved in all aspects of their care, including the right to refuse treatment, and to provide informed consent.<sup>880</sup> This innovation has been described as playing a "policing role in the informed consent process."<sup>881</sup>

## RECOMMENDATION 5

*Things are done to people, both in community-living older adults, and particularly for people who are in residential care, without ever asking or considering consent or assent.*

– Nurse

There is a significant power imbalance between physicians and their patients which impacts on health care decision making. Older people may feel intimidated by physicians. Patients may not have the power to act on their knowledge of health care rights. Some people do not know they can make a choice inconsistent with the physician's recommendation; others feel significant deference toward the physician that undermines their decision making autonomy.

The *Residents' Bill of Rights*, which is included as a Schedule to the *CCAL Act*, includes a number of rights grounded in respect for the autonomy and personal dignity of residents of care facilities.<sup>882</sup> The statement of rights, which applies to residents in long-term care facilities as well as private hospitals and extended care hospitals, does not expressly provide for the right to informed consent in health care decision making.

The *Residents' Bill of Rights* includes the following rights:

1. An adult person in care has the right to a care plan developed
  - (a) specifically for him or her, and
  - (b) on the basis of his or her unique abilities, physical, social and emotional needs, and cultural and spiritual preferences....
2. An adult person in care has the right to the protection and promotion of his or her health, safety and dignity, including a right to all of the following:
  - (b) to be protected from abuse and neglect;
  - (c) to have his or her lifestyle and choices respected and supported, and to pursue social, cultural, religious, spiritual and other interests...
3. An adult person in care has the right to participate in his or her own care and to freely express his or her views, including a right to all of the following:
  - (a) to participate in the development and implementation of his or her care plan.<sup>883</sup>

## 5

The *Residential Care Regulation* should be amended to require that care facilities maintain detailed policies on staff and health care professional obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflect the *Health Care (Consent) Care Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

## 6

The Residents' Bill of Rights included in the Community Care and Assisted Living Act should be amended to include clear language informing people in reasonable detail of their health care consent rights, including a specific reference to the rights to:

- Give, refuse, or withdraw consent to any non-emergency medication and treatment, where they have the capacity to consent to that decision;
- Receive the support of a supportive decision maker, if they choose to do so; and
- Have their substitute decision maker make a decision if they do not have capacity.

Legislation requires these rights to be displayed prominently in the care facility, and generally be made known to residents.<sup>884</sup> The display of rights serves not only to educate people about their rights, but also to contribute to creating a culture of respect for rights.

Ontario's *Long Term Care Homes Act* includes a similar list of rights; however, the list also includes the following decision making rights:

11. Every resident has the right to,
  - i. participate fully in the development, implementation, review and revision of his or her plan of care,
  - ii. give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent,
  - iii. participate fully in making any decision concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to or from a long-term care home or a secure unit and to obtain an independent opinion with regard to any of those matters...<sup>885</sup>

Other comparable statements of patient's rights include the right to consent to and refuse treatment. For example, in acute care facilities in California, patients have a right to "[p]articipate actively in decisions regarding medical care."<sup>886</sup> In Washington state, long-term care facility residents must be informed (orally and in writing) of their right to be fully informed, and to consent or refuse treatment.<sup>887</sup>

In BC absence in the *Residents' Bill of Rights* of a reference to the right to consent to health care is a notable gap that should be remedied.

### RECOMMENDATION 6

#### Enhance the Duties of Guardians under the *Patient's Property Act*

In Chapter 3 of the report, we compare the obligations of representatives, temporary substitute decision makers (TSDM) under the *HCCA*, and personal guardians, also known as committees of the person under the *PPA*. We note that, in terms of engagement of an adult in substitute decision making, there are numerous inconsistencies in the duties of substitute and supportive decision makers across these different statutes. In particular:

- The representative has a duty to consult with the adult, and comply with current wishes;<sup>888</sup>

- The TSDM has a duty to consult;<sup>889</sup> and
- The committee has a duty to involve the adult.<sup>890</sup>

In addition to consulting with the adult regarding current wishes about decision, a representative must comply with previously expressed wishes made while the adult was capable if “the adult’s current wishes cannot be determined or it is not reasonable to comply with them”.<sup>891</sup> The TSDM must “comply with any instructions or wishes the adult expressed while he or she was capable;” there is no reasonableness limitation built into the duty.<sup>892</sup> The *PPA* does not contain any requirement to consider wishes expressed while the person was capable which might restrict the exercise of a committee’s decision making authority.

A representative and a TSDM should consider best interests only if the adult’s current or previously expressed wishes are not known.<sup>893</sup> The *PPA* uses very different language from the *HCCA* and the *RAA*, setting out limited statutory duties. A committee is required to “exercise the committee’s powers for the benefit of the patient and the patient’s family, having regard to the nature and value of the property of the patient and the circumstances and needs of the patient and the patient’s family.”<sup>894</sup> In 2014, the *PPA* was amended to require that the committee “to the extent reasonable, foster the independence of the patient and encourage the patient’s involvement in any decision making that affects the patient.”<sup>895</sup>

The 2014 amendment was undertaken in order to help modernize guardianship legislation in BC, and enhance the obligations of guardians. The *AGA* contains further amendments not yet in force which would repeal the *PPA*, introduce the language of “personal guardian” (as an alternative to the term “committee of the person”), and impose obligations on personal guardians in BC similar to those found in the *RAA* and the *HCCA*.<sup>896</sup> These amendments not yet in force create a duty to comply with previously expressed wishes, and if none are relevant to the decision at issue, the personal guardian “must act in the adult’s best interests, taking into account the adult’s known beliefs and values.”<sup>897</sup>

The new duty incorporated into the *PPA* in 2014 may be challenging to reconcile with a committee’s authority to act according to a judgement regarding best interests. Further, in spite of the amendment, there remains a significant discrepancy between the obligations of guardians as compared with TSDMs and representatives. Greater consistency in the statutory duties of various substitute decision makers for health care would make it easier for everyone to better understand the law.

The *PPA* remains inconsistent with the CRPD. Modern best practices require moving away from plenary substitute and best interest decision making, and recognizing of the right of people living with disabilities to participate in decisions that impact their lives. Both government and stakeholders identified the need to modernize guardianship law in BC decades ago with the development of new legislation and the

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*We end up being put in a place of mediator, where really our role is health care. But we spend a lot of time trying to sort people’s issues.*

– Health authority staff

Reform of guardianship law should be explored in order to bring greater consistency to the statutory duties of all substitute decision makers for health care in British Columbia, and greater compliance with the general principles contained in the United Nations Convention on the Rights of Persons with Disabilities.

significant advocacy leading up to the design of the new legislation, which has been partly implemented. BC guardianship law has been in legislative limbo for too long. The government should engage in a law reform process with community consultation to develop a new and more tailored form of adult guardianship, which could include proclamation of Part 2, or new legislation.

## RECOMMENDATION 7

### 7.1.2 Hospital and Care Facility Use of Restraints

#### Remedy Inconsistencies in the Law Regarding Consent to Use of Restraints

All licensed long-term care facilities must comply with the *RC Regulation*, which sets out rules for the use of a restraint.<sup>898</sup> The *RC Regulation*, defines “restraint” very broadly to mean “any chemical, electronic, mechanical, physical or other means of controlling or restricting a person in care’s freedom of movement in a community care facility, including accommodating the person in care in a secure unit.”<sup>899</sup> According to the *RC Regulation*, a restraint can be used if written agreement is provided by both:

- (i) the person in care, the parent or representative of the person in care or the relative who is closest to and actively involved in the life of the person in care, and
- (ii) the medical practitioner or nurse practitioner responsible for the health of the person in care.<sup>900</sup>

The term representative does not mean a representative granted authority pursuant to a representation agreement. *RC Regulation* defines a “parent or representative” collectively as:

...a person who... in the case of an adult, has authority...under the *Health Care (Consent) and Care Facility (Admission) Act* or the *Patient’s Property Act*, or under an agreement under the *Representation Agreement Act* to make health or personal care decisions on behalf of the adult,<sup>901</sup>

adding that “nothing in this regulation confers on the person any greater authority to make health or personal care decisions than the person has under those Acts or under an agreement under the *Representation Agreement Act*.”<sup>902</sup>

Since a chemical restraint is a form of medication, the laws regarding informed consent would also apply to the administration of medication in long-term care. Our review of the restraint provisions of the *RC Regulation* identified inconsistency with

*Any physician ordering any pill on somebody who doesn't have the capacity to make a decision—a substitute decision maker should make that decision. So, you need that under consent. You may need it under the restraint policy too, but you need it under consent.*

– Geriatric psychiatrist

*HCCA* and other legislation relevant to health care decision making which results in a lack of clarity regarding who may agree to the restraint. Below are our key concerns with the provisions:

1. The discretionary language of the provision suggests the licensee may bypass the substitute decision maker and get agreement from “the relative who is closest to and actively involved in the life of the person in care.” The consent of the guardian, representative or TSDM is not clearly required. Where a restraint is also a form of medication, and consent is thus required under the *HCCA*, the *RC Regulation* is thus confusing, and may conflict with the requirements of the *HCCA*.

2. There is no requirement in the legislation to first determine the capacity of the person in care to make a decision about whether restraints are used, nor is there a test for capacity to make restraint decisions embedded in the legislation. As compared with the *HCCA*, and other BC statutes related to decision making, neither the *RC Regulation* nor the *CCAL Act* contains a presumption of capacity. As such, on a strict reading the section, the licensee may get agreement to use the restraint from a relative regardless of whether or not the resident has capacity. In comparison, the *HCCA* requires the health care provider to propose treatment and consider capacity to make the treatment decision.

3. The use of the term “representative” in the *RC Regulation* is confusing. The term is defined in the regulation to mean collectively, “...a person who... in the case of an adult, has authority... under the *HCCA* or the *PPA*, or under an agreement under the *RAA* to make health or personal care decisions on behalf of the adult.” However, the definition also references the *RAA*, according to which a representative is a person or organization empowered under an agreement, and chosen by an adult. The *HCCA* defines a representative to mean “a person authorized by a representation agreement to make or help in making decisions on behalf of another and includes an alternate representative.”<sup>903</sup> To define the concept of a representative to include people not specifically chosen by the adult is misleading given the overall framework for substitute and supported decision making in BC.

4. The use of the term representative is further problematic because not all representatives have the authority to consent to the use of a restraint. The *RAA* states that a representative may consent to physical restraints “if necessary to provide personal care or health care to the adult,” only where the agreement is a non-standard agreement under section 9 of the Act.<sup>904</sup> Granting authority to consent to health care for which an adult refuses would also require a section 9 agreement. Although the *RC Regulation* states, as noted above, that “nothing in this regulation confers on the person any greater authority to make health or

The Community Care and Assisted Living Act (and associated provisions of the Residential Care Regulation) should be amended to require that in non-emergency situations, agreement to the use of any form of restraint must be obtained in the same manner as consent to health care under the Health Care (Consent) and Care Facility (Admissions) Act. The provisions should include:

- A presumption of capacity;
- A requirement that the consent be informed;
- A hierarchy of substitute decision makers; and
- An independent decision maker as a last resort, such as the Public Guardian and Trustee.

The use of the term “representative” should be avoided unless used to reference a representative under a representation agreement.

personal care decisions than the person has under those Acts or under an agreement under the *Representation Agreement Act*,” the provision remains misleading.

5. Section 74 introduces a new kind of substitute decision maker who may agree to the use of restraints, namely, “the relative who is closest to and actively involved in the life of the person in care”. This language diverges significantly from the hierarchical list of health care decision makers included in the *HCCA*, and creates a scenario where a person living with dementia could have a different substitute decision maker for chemical restraints (being a form of medication and therefore subject to the *HCCA*), and physical restraints, which would be governed exclusively by the restraint provisions.

6. The provisions do not identify a role for the Public Guardian and Trustee (PGT) as either decision maker of last resort for restraints, or to resolve disputes over who is entitled to agree to the use of the restraint, which are common. As a result, while the PGT may make decisions regarding chemical restraints if appointed by a court as personal guardian, or as health care decision maker of last resort where the restraint use relates to the provision of health care, the office does not otherwise have authority to consent restraint use.

7. The *RC Regulation* does not place any obligation on health care providers or facility staff to support informed decision making regarding restraints. As discussed below, they are required to provide some information after the fact.

8. Finally, it is problematic for the definition of “parent or representative” to refer to person having authority to make health care or personal care decisions under the *HCCA*, *PPA*, or *RAA*. Such a reference makes sense only where the person is globally incapacitated. Under the *HCCA*, whether a person has authority to make a health care decision always depends on the specific decision being made, and the timing of the decision. The *RC Regulation* suggests that the authority of a TSDM continues beyond a specific health care decision, which is not an accurate reflection of health care law in BC.

The provisions of the *RC Regulation* regarding restraint appear to be strikingly at odds with the principles of autonomy, self-determination, and dignity underlying BC’s health care consent and guardianship laws, and the common law principles that informed the development of health care law in BC and Canada. As currently worded, the provisions creates confusion for health care professionals who are aware of the provision. However, as discussed further below, our consultation findings suggest that many health care professionals consider any medication,

including drugs used as a form of restraint, to be health care treatment, and so subject to the *HCCA*.

BC’s approach to restraint in long-term care described above is fairly unique. With some notable exceptions, generally the regulation of long-term care in Canada is silent regarding consent (or agreement) to the use of a restraint. The Ontario *Long-Term Care Homes Act* has introduced regulatory provisions regarding restraint. These provisions require the consent of the resident, or where incapable, the resident’s substitute decision maker with authority to consent, before a physical restraint can be used.<sup>905</sup>

We recommend the inconsistencies between the *HCCA* and the *RC Regulation* regarding agreement to use of a restraint be eliminated. This reform may have implications for the work of various agencies.

#### RECOMMENDATION 8 (PAGE 198 SIDEBAR)

There also appear to be significant internal inconsistencies within the *RC Regulation* with respect to the requirements for reassessment of the need for ongoing use of a restraint. The *RC Regulation* requires reassessment of “the need for the restraint at least once within 24 hours after the first use of the restraint.”<sup>906</sup> With respect to subsequent uses, the reassessment requirements are less strict. Once the initially agreed-to period is over, the *RC Regulation* requires that the licensee “consult, to the extent reasonably practical, with the persons who [initially] agreed to the use of the restraint.”<sup>907</sup> We do not see any foundation for this difference in process.

#### RECOMMENDATION 9

### Clarify the Obligation to Inform Substitute Decision Makers

*What we found is that, when a person was in that setting [long-term care], then there was this implicit agreement to whatever was to be done to them was just going to be done because they had signed those papers.*

– Non-profit agency

Following the use of restraints in an emergency, the licensee, or a person authorized by the licensee must:

- 73(3)(a) provide, in a manner appropriate to the person’s skills and abilities, information and advice in respect of the use of the restraint to
- (i) the person in care who was restrained,

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Section 75(3) of the *Residential Care Regulation* should be amended to:

- Require consent of either the adult, or their substitute decision maker, when emergency use of a restraint continues for more than 24 hours; and
- Recognize the right of the adult, or the substitute decision maker, to revoke their consent to the use of the restraint.

- (ii) each person who witnessed the use of the restraint, and
- (iii) each employee involved in the use of the restraint, and
- (b) document in the care plan of the person in care the information and advice given.<sup>908</sup>

There is no requirement in this subsection that the licensee inform the resident's substitute decision maker or family members about the emergency use of a restraint. However, an emergency use of restraint is a reportable incident under the *RC Regulation*,<sup>909</sup> and licensees must notify "the parent or representative, or contact person, of the person in care"<sup>910</sup> of any reportable incident.

Consultation with family members of people living with dementia confirms that family members are often not notified promptly, if at all, regarding the use of an anti-psychotic to address behaviour staff find challenging to manage. A number of people commented that communication with long-term care facility staff was difficult. One family caregiver who was substitute decision maker for health care said she only found out about medication changes because she was the attorney under a power of attorney, and so received medication bills. Caregivers spoke of asking for medication information, and being directed to file a *Freedom of Information and Protection of Privacy Act* request because the resident's chart was confidential. Many families struggle to get timely information on medication changes.

There was general consensus among key informants that it is good practice to keep families informed of changes in medication, particularly where the resident has dementia, and family are involved in decision making. Although some physicians leave it up to families to reach out for updates regarding medication changes, every stakeholder with whom we spoke was of the view that substitute decision makers should be notified at some point in the near future regarding emergency changes. Indeed, there does not seem to be any logical reason not to notify substitute decision makers regarding an emergency use of restraint. As such, greater clarity under the *RC Regulation* is warranted to confirm that substitute decision makers for health care are entitled to notification following emergency use of a restraint.

## 10

Section 73(3) of the *Residential Care Regulation* should be amended to require that the resident's substitute decision maker, if any, be informed of any emergency use of a restraint as soon as possible after its use, including:

- The reasons for its use; and
- The duration of its use.

### RECOMMENDATION 10

#### Define Chemical Restraint

The *RC Regulation* defines restraint broadly as "any chemical, electronic, mechanical, physical or other means of controlling or restricting a person in care's freedom of movement in a community care facility, including accommodating the person in care in a secure unit".<sup>911</sup> Chemical restraint is not defined in either the *CCAL Act* or the *RC Regulation*.

Consultation findings suggest that health care professionals prescribing anti-psychotic medications rarely consider whether the medication is being used as a chemical



restraint pursuant to the restraint provisions of the *RC Regulation*. Some of the health care professionals and staff we consulted who work in long-term care were not even aware of the provisions of the *RC Regulation* regarding restraints. Most informants who were aware of the *RC Regulation* thought it applied only to physical restraints, and had not considered the rules might apply to anti-psychotics.

Medication that can be restraining is generally prescribed and administered according to the same processes as other medication identified to meet residents' health care needs. In each instance the physician should consider whether the medication is the appropriate treatment for the resident given all the circumstances. While, as discussed below, it appears that in some instances health care providers are not getting consent when they should, whether or not they are obtaining prior informed consent for non-emergency use of an anti-psychotic seems unrelated to whether the drug is characterized as a restraint. Even the two physicians who expressed an opinion that anti-psychotics were often being used as a restraint did not make any distinction in the consent processes used for their prescription. When made aware of the *RC Regulation* provisions regarding restraints, physicians questioned how the rules impacted practice in terms of the use of anti-psychotics, as all medication is generally viewed as minor health care. At the same time, most key informants were aware of their facility's least restraint policy, and of the importance of reducing anti-psychotic use in long-term care.

Based on both research and consultation, the line between when an anti-psychotic is a medication versus a restraint is not distinct, and the views and practices of health care professionals vary. Only one physician with whom we consulted was confident in delineating when the use of an anti-psychotic was health care versus a restraint. When pressed, physicians and geriatric psychiatrists said that the use of anti-psychotics can be framed as health care treatment if the medication is alleviating suffering in any way; however, many key informants felt the distinction was a fine line because the impact of medication can be restraining even when the intention is therapeutic.

Based on our research, it can be challenging to determine whether and in what circumstances the administration of anti-psychotic drugs to treat dementia-related behaviours is a form of restraint, and there is limited regulation in this area in Canada. The experience in BC raises the question of whether it would be worthwhile to develop a legal definition to support health care professionals and care facilities to properly apply the restraint provisions to their practice. Some elements of the restraint provisions, such as requirements for timely review of use of the restraint, and documentation of agreement to use, as well as restrictions on use, are positive additions to the regulation of the use of restraints in BC. The value of these provisions is lost if people working in long-term care do not appreciate when they should be applied to medication.

A number of key informants expressed the view that anti-psychotic drugs and other psychotropics may form part of an appropriate treatment plan for mental health issues like psychosis, and would not constitute restraint if prescribed for the therapeutic benefit of the person living with dementia, for example, if intended to ease suffering. Based

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*Let's look at a case that is a patient making a lot of noise, and interfering with other people, and is going up and knocking on the nurse's station repetitively. And saying "help me, help me, help me, help me! Imagine that. But that, you know, would be an abnormal or an inappropriate use of an anti-psychotic. Unless it was so bad that other residents were hitting him. You know, like, it caused aggression. Noise in itself, and pacing in itself, wandering in itself, those kinds of things, anti-psychotics would be totally inappropriate. That would be a restraint.*

– Geriatric psychiatrist

# 11

The restraint provisions of the *Residential Care Regulation* should be amended to define chemical restraint as the administration of psychotropic medication to prevent harm to a resident or others in situations where a resident has lost behavioural control, or where there is imminent risk of loss of control in behaviour.

on both consultation and research, anti-psychotics can be appropriate for treating dementia-related behaviours in limited circumstances. It appears that the concept of chemical restraint is useful in helping to distinguish inappropriate use of an anti-psychotic.

We were not able to identify a Canadian statutory definition of chemical restraint. However, located definitions of chemical restraint in other sources. The College of Nurses of Ontario defines a chemical restraint as “any form of psychoactive medication used not to treat illness, but to intentionally inhibit a particular behaviour or movement.”<sup>912</sup> The College and Association of Registered Nurses of Alberta defines chemical restraint very similarly as “[a]ny psychotropic drug not required for treatment, but whose use is intended to inhibit a particular behavior or movement”.<sup>913</sup> Both definitions focus on inhibiting particular behaviour. Vancouver Island Health Authority’s (now Island Health) Community Care Facilities Licensing Program speaks to “controlling” rather than “limiting” behaviour, defining chemical restraint as “any medication used to control behaviour beyond the point of therapeutic benefit.”<sup>914</sup>

The Patient Safety Institute of Canada (the Institute) has developed a more lengthy definition which identifies preventing harm, rather than controlling the person, as the reason for using the medication. Control is referenced only in terms of identifying a patient’s loss of behavioural self-control as the reason that harm may otherwise occur. The Institute characterize a chemical restraint as “the administration of psychotropic medication in situations where a person may have already lost behavioural control or where there is imminent risk of loss of control in behaviour that will lead to harm to self or others.”<sup>915</sup> Although the four definitions vary, the focus of each is the intention of the health care professional prescribing the medication rather than the impact of the medication, which is line with above-noted concerns that the impact of medication can be restraining even when the intention is therapeutic.

Restraint provisions provide important safeguards which apply to all restraints, whether chemical, mechanical, or physical. To bring the use of anti-psychotics and other medications as a form of restraint clearly within the ambit of the *RC Regulation*, and to provide for greater supervision and assessment of the use of such medication, we recommend the *RC Regulation* be amended to clarify when medication is being used as a restraint.

## RECOMMENDATION 11

## Require Policy Regarding Non-Emergency Use of Restraints in Long Term Care

*I said, "Risperidone, no!" Not the doses like this, small doses twice a day, something else, very small, because you know what? They are sleeping there all the time! All these people are sleeping there. And they want them to sleep. Because, they are peaceful... [But] my husband also needs to walk, because when he has Parkinson's, he has stiff muscles, and if he doesn't walk, he will be not able to walk.*

– Family Caregiver

Under the *RC Regulation* a licensee must have written policies and procedures regarding the use of restraints in an emergency; however, there is no such specific requirement regarding the non-emergency use of a restraint.<sup>916</sup> As the use of restraint is an extreme measure that limits liberty and creates additional risk for the resident regardless of whether or not the use is an emergency response, it is not clear why policy is required in one instance, and not the other. Further, Project Advisory Committee members felt that policy guidance regarding non-emergency use of a restraint would be very helpful to staff. We recommend policy be required in the *RC Regulation*.

### RECOMMENDATION 12

12

Section 85 of the *Residential Care Regulation* should be amended to include a requirement that long-term care facilities have a detailed policy on the use of restraints, in both emergency and non-emergency situations, which outlines:

- The consent process; and
- Requirements for advising substitute decision makers.

## 7.2 SUPPORTING BEST PRACTICE IN HEALTH CARE CONSENT

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Research and consultation indicate a need for enhanced understanding of the *Health Care (Consent) and Care Facility (Admission) Act (HCCA)* and the *Mental Health Act (MHA)* among health care professionals and long-term care facility staff, such as health care assistants (HCAs). In this Section 7.2 we identify recommendations aimed at addressing the education and professional development needs of health care staff regarding informed consent obligations, as well as policy or practice guidelines to support best practice.

Almost every key informant expressed the view that further education on health care consent law would be helpful for their profession, or at their workplace. Based on discussion with stakeholders and Project Advisory Committee members, the ideal model of education delivery includes a mix of:

- Early career university or college training;
- On site professional development and training on the topic; and
- Ongoing practice support.

We address education and learning at each of these three points in professional development in this part of Chapter 7.

All key informants working in health care recognize that consent is required for certain types of treatment, for example, for surgery and dialysis. Written consent is usually obtained in these instances. Otherwise, health care professional practice and knowledge of the law with respect to obtaining informed consent varies considerably, particularly among people working in long-term care. The following gaps in knowledge of the law are of particular concern:

1. A number of key informants, including physicians and long-term care staff, did not seem to appreciate that prior informed consent is required by law for non-emergency care, even if the care would fit the *HCCA* definition of minor (rather than major) health care. A number of physicians and other health care staff consider it appropriate practice to inform the family member acting as substitute decision maker after the resident's medication had been changed—sometimes not until an annual care conference occurs.
2. Long-term care staff are not always administering medication and treatment in a manner that respects the rights of people living with dementia and their substitute or supportive decision makers to participate in health care decision making. Some family caregivers expressed concern that HCAs

*What happens is that there's a belief that the consent happens when you cross that threshold into care. . . Without realizing that, every step in that care, everything you do that's different, needs a consent.*

– Health authority staff

were reluctant to share information regarding the resident's care, let alone contact the family member holding a representation agreement in advance of medication changes. It is evident that some family caregivers who are substitute or supportive decision makers experience great difficulty in gaining any information or engagement from health care professionals and staff. Some staff mistakenly believe that when people sign admission papers they are agreeing to all care deemed appropriate by the care team. Further, some comments by physicians betrayed paternalism, and lack of respect for the role of substitute decision makers.

3. There is confusion about the mandate of the Public Guardian and Trustee (PGT), and its role as a health care decision maker, resulting in inconsistent practice in terms of when health care professionals, staff, or operators contact the PGT for assistance. It seems that the PGT is not always being engaged as decision maker of last resort for people who do not have either capacity or family and friends available and suitable to take on that role. Some people living with dementia in long-term care have no health care decision maker, resulting in circumstances where physicians and health care teams are making day-to-day health care decisions on behalf of these people in circumstances where the PGT ought to be engaged.

4. The *MHA* is sometimes being used to involuntarily commit an older person living with dementia without proper consideration of whether the adult meets the criteria under the law, resulting in exclusion of people living with dementia, family members, and substitute and supportive decision makers from health care decision making related to psychiatric treatment. Interviews with some physicians and geriatric psychiatrists indicate lack of understanding of the law. Consultation suggests involuntary committal is being pursued when voluntary treatment might have been possible.

This Section 7.2 contains recommendations which address the knowledge and education of health care professionals and staff in relation to the following topics:

1. Health care consent law;
2. Incapability assessment;
3. Documentation of informed consent;
4. Dementia and capacity support; and
5. The role of the *Mental Health Act* in treating people living with dementia

We also discuss practice support for staff.

## 7.2.1 Professional Development and Education regarding Health Care Consent Law

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*When I do talk about consent, and the obligation piece around risks and benefits, they say, 'my doctor has never done that.'*

– Social worker

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### Physicians

Physicians are key to supporting best practice in health care. They are generally the prescribers of medication, and they hold much authority within health care environments.

The College of Physicians and Surgeons of BC (the College) produces a number of resources to support best practice, including both practice standards and legislative guidelines. Standards play a key role in both practice support and oversight by the College, which looks particularly to standards of practice, rather than legislation, in adjudicating complaints. The College has not developed a standard on health care consent, although it has published a two-page legislative guideline on the consent for care of minors.<sup>917</sup> Of the other four provinces with consent statutes, Ontario and the Yukon's physician regulatory bodies have developed detailed policies or standards on consent to health care.<sup>918</sup> Quebec's Physician Code of Ethics sets out some broad key principles only.<sup>919</sup>

Rather than developing its own practice standard on consent, the College of Physicians and Surgeons of BC has adopted the Canadian Medical Association (CMA) Code of Ethics, which contains a section on “Communication, Decision Making and Consent”. The Code includes principles regarding informed consent, and respect for the decision making autonomy of a “competent patient.” Being a national resource, the Code is silent regarding substitute making and the role of Public Guardian and Trustees. The Code states:

When the intentions of an incompetent patient are unknown and when no formal mechanism for making treatment decisions is in place, render such treatment as you believe to be in accordance with the patient's values or, if these are unknown, the patient's best interests.<sup>920</sup>

This statement of physician responsibilities may be comprehensive for jurisdictions governed exclusively by the common law doctrine of informed consent; however, the principle omits important aspects of the health care consent regime developed for BC. The principle is misleading in that it implies that physicians may make health care decisions for adults who do not have mental capacity, so long as their decisions are grounded in respect for known wishes and best interests. Based on our consultation

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The College of Physicians and Surgeons of British Columbia should disseminate to all members materials aimed at supporting physicians to understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflect the *Health Care (Consent) Care Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

findings discussed above, physicians require more detailed and BC-specific guidance in order to better understand their legal obligations regarding health care consent.

The Project Advisory Committee discussed whether a practice standard should be developed to support physician understanding of the law of consent, and in particular, whether the College should develop a provincial standard, or the CMA should develop a national standard. On the one hand, some members of the committee felt the national body was the place physicians were most likely to look for guidance, for example, as noted above, some provincial colleges have adopted the national Code of Ethics; on the other hand, there are some nuances of consent law that are unique to BC, such as the titles and responsibilities of representatives as supportive and substitute decision makers, and the role of the PGT as health care decision maker of last resort. Another advantage of the national route is the potential to enhance practice across the country. Committee members noted that the process of developing a guideline could take some time, and may not be the fastest way to improve physician knowledge of the law.

As recently as December 2017, the College developed an Accreditation Standard for Patient Care on Consent applicable to non-hospital medical and surgical facilities which discusses legal and ethical obligations with respect to consent.<sup>921</sup> The document identifies some key legal principles and links to a number of resources to support practice, including the College of Registered Nurses of BC standard on consent (now the BC College of Nursing Professionals), a Guide to consent published by the Canadian Medical Protective Association (CMPA),<sup>922</sup> and a guide to consent to health care developed by the Ministry of Health in 2011. The CMPA guide, like the Code of Ethics, does not reflect important nuances of the law in BC; however, the Ministry Health Guide to Consent to Health Care is an excellent resource that follows the *HCCA* closely, and includes both consent flow charts and scenarios involving older patients. The College of Speech and Hearing Health Professionals adopted this Guide as a clinical practice guideline in 2018, and published both a standard of practice<sup>923</sup> and clinical practice guideline on consent<sup>924</sup> after conducting a survey of member practice which identified a need for further education on this topic.

With the above discussion in mind, we recommend that the College of Physicians and Surgeons of BC make use of existing practice resources that reflect BC law in order to enhance members' knowledge of health care consent law; however, we also identify below a number of areas where the Ministry of Health Guide could be improved by addressing some topics currently inadequately covered by the Guide.

## 14

The BC Ministry of Health's *Health Care Providers' Guide to Consent to Health Care* should be amended in the following manner:

- Include discussion of the importance of using professional interpreters, and awareness of hearing and speech issues, in determining capacity, and providing information about treatment;
- Add information on supported decision making by way of a representation agreement;
- Clarify that consent to non-psychiatric treatment is still required under the *Health Care (Consent) and Care Facility (Admission) Act* where a patient is involuntarily committed under the *Mental Health Act*; and
- Provide expanded information on the role of the Public Guardian and Trustee with respect to health care consent.

◀ **RECOMMENDATION 13** (PAGE 206 SIDEBAR)

**RECOMMENDATION 14** ▶

The General Practices Services Committee Divisions of Family Practice and the UBC Faculty of Medicine Divisions of Geriatric Medicine and Geriatric Psychiatry should undertake educational work aimed at supporting physicians to better understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflects the *Health Care (Consent) Care Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

The Project Advisory Committee and other key informants identified the Divisions of Family Practice as a key body working collaboratively within specific communities to enhance local physician care. The Divisions are an initiative of the General Practices Services Committee (GPSC), developed in 2002 as a partnership between the Doctors of BC and the Government of BC. Over the years, the GPSC has focused on a number of areas of practice, including its Residential Care Initiative, which funds community-specific initiatives to improve the care older people receive in long-term care.<sup>925</sup> Activities of the Residential Care Initiative have focused on:

- Increasing the number of physicians providing care to seniors living in long-term care;
- Reducing emergency hospital transfer rates;
- Reducing anti-psychotic use and over-medication;
- Reducing physician response time through after-hours care programs; and
- Increasing proactive physician visits with residents.<sup>926</sup>

Both key informants and Project Advisory Committee members felt that the Divisions of Family Practice could be a powerful partner in enhancing physician education and practice regarding health care consent. The Project Advisory Committee also identified the UBC Faculty of Medicine Divisions of Geriatric Medicine and Geriatric Psychiatry as a key educator of specialists.

## RECOMMENDATION 15

### Nursing Professionals

*You have a nurse who is caring 50 or 25 residents, and she has the timeline, and she has all these medications. She doesn't have time to go back and forth, right? So it's much easier to crush it up in the jam, or hide it in the sandwich.*

– Nurse

Practice standards on consent applicable to licensed practical nurses and registered nurses are produced by the BC College of Nursing Professionals (the Nursing College) to support their members.<sup>927</sup> Like physicians, most nursing professionals have significant flexibility in choice of professional development activities. The exception is licensed practical nurses, who must take a Jurisprudence Exam every three years, which covers consent law.<sup>928</sup>

Based on key informant interviews, nurses appear to vary in terms of knowledge of health care consent law. Generally it seems that recent graduates may have studied health care consent law as a mandatory aspect of university and college curriculum;



however, more senior nursing professionals, who form the majority, would not have benefitted from this newer addition to the curriculum. Further, many nursing professionals may have been trained in other jurisdictions, where the law is different from BC. These nurses will be certified to practice in BC with limited exposure to BC health care consent legislation.

## RECOMMENDATION 16

### Health Care Assistants

Although it is regulated health care professionals who have the duty to obtain consent, in the long-term care context it is often HCAs who have the most contact with a resident throughout the day, providing care under the supervision of RNs and LPNs. RNs may delegate certain tasks to HCAs, including the administration of medication. Such delegation raises issues of accountability regarding informed consent, and speaks to a need for all care facility staff to have a consistent understanding of health care rights and responsibilities.

HCAs receive their training in colleges throughout BC. The curriculum is the responsibility of two government ministries: the Ministry of Health sets and reviews HCA competencies on a regular basis;<sup>929</sup> the Ministry of Advanced Education develops and periodically reviews the curriculum based on this core competency profile. Revisions to the curriculum appear to have been last carried out in 2015 with the help of a Steering Committee made up of representatives from various stakeholder groups.<sup>930</sup> In addition to the curriculum, a supplement is developed and produced to “support the delivery and assessment of required learning outcomes.”<sup>931</sup> The Alzheimer Society of B.C. was also recently involved in developing aspects of this supplement.

The BC Care Aide and Community Health Worker Registry (the Registry) also plays a role in supporting the practice of HCAs. Although registration is generally voluntary, HCAs who work in publicly funded care facilities must be registered. Health care workers in home and community care whose employers receive public funding also must register. For internationally-trained nurses, the Nursing Community Assessment Service undertakes a competency-based assessment, upon referral by the Registry. Based on their assessment report the Registry determines whether the applicant must undertake any transition education before being registered to be eligible to work in BC.<sup>932</sup> The Registry also has a mandate to support professional development of HCAs,<sup>933</sup> which it meets by providing access to online learning modules on various topics via its website.

Based on our review, it is not clear that the HCA curriculum includes any instruction on health care consent and substitute decision making processes, and, in particular, the HCA’s role in the process. The Registry also does not appear to provide

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The BC College of Nursing Professionals should publish, and widely disseminate to all registrants, material on a nurse’s informed consent obligations, with a particular focus on the licensed practical nurse and registered nurse’s role with respect to consent to health care treatment prescribed by physicians in long-term care.

The British Columbia Ministry of Health and the Ministry of Advanced Education, Skills and Training should review and amend the Health Care Assistant Core Competency Profile (March 2014) and the Health Care Assistant Provincial Curriculum (2015) to ensure that health care assistants receive training on health care consent and substitute decision making, including clarification of the role of health care assistants in facilitating the consent process as a member of an inter-disciplinary team.

Working with relevant partners, the Care Aide and Community Health Worker Registry should develop an educational module for health care assistants on health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflects the *Health Care (Consent) Care Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation. The Registry should make this course easily accessible to its registrants, promote it widely, and consider methods of incentivizing registrants to undertake the course.

information on professional development addressing health care consent and substitute decision making.

#### RECOMMENDATION 17

#### RECOMMENDATION 18

### 7.2.2 Assessing Incapability to Consent to Health Care

All adults are presumed to be capable of consenting to their own health care “until the contrary is demonstrated.”<sup>934</sup> Where capacity is at issue, the *HCCA* describes what factors should be considered in determining whether a person is incapable of making a health care treatment decision. The health care provider’s decision must be based on whether or not the person demonstrates understanding of:

- (a) the information given to them by the health care provider regarding the nature of the treatment, its risks, benefits and alternatives; and
- (b) that the information applies to the situation of the adult for whom the health care is proposed.<sup>935</sup>

It is very important to autonomy rights that people not be denied the right to make their own health care decisions unless an incapability assessment has occurred. Based on our consultation, there are a number of problems with practice in this area. Advocates and lawyers raised concerns that assessments are not always being conducted when they should be, and that a lack of capacity is presumed either based on a diagnosis of dementia, or the statement from a family member that the person is incapable of consenting to health care. One lawyer indicated that they had twice seen physicians sign affidavits expressing the opinion that a person was incapable based on the person’s refusal to participate in the incapability assessment. Without a proper incapability assessment, health care professionals and staff do not develop a proper baseline knowledge of the person living with dementia, and of what kind of support they require to participate in decision making.

All health care professionals must have an adequate understanding of capacity in order to recognize signs of incapability; however, not every health care professional will be called upon to conduct an incapability assessment. A number of key informants from the health care sector confirmed that they had not received training in how to conduct an incapability assessment. This lack of education was confirmed by a number of members of the Project Advisory Committee, who were generally of the view that training was not readily available. This dynamic undermines practice, fails to protect legal rights, and creates stress for staff who are often already overwhelmed. One health

care professional said staff wind up in uncomfortable situations where family want to make the decision because they say the person living with dementia is incapable, but the worker does not have the skills to make the determination required under the *HCCA*.

Of all health care professionals, primary health care physicians may have the most long term knowledge of the person living with dementia; however, they don't generally have specialized training in incapability assessment. A number of resources have been developed to support physician understanding of capacity and incapability assessment. However, most assessment and screening tools are geared toward assessing incapability for financial decision making,<sup>936</sup> and no standardized tools exists which align perfectly with legislative capacity standards for health care decision making in BC.<sup>937</sup> The PGT has developed a set of Practice Guidelines for Incapability Assessments under Part 3 of the *Adult Guardianship Act* in collaboration with an inter-disciplinary advisory committee,<sup>938</sup> which does not cover how to assess capacity to consent to health care treatment.

Ultimately, a clinical interview offers the best approach to assessment;<sup>939</sup> however, “no clear best practices on how to do this interview” exist,<sup>940</sup> and achieving consistency in practice points to a need for training.<sup>941</sup> According to Dr. Deborah O'Connor, the MacArthur Competence Assessment Tool for Treatment “is emerging as the ‘gold standard’ for assessing capacity to consent to medical treatment;”<sup>942</sup> however, the tool has some limitations. Research indicates that it can result in a greater likelihood of a finding of incapability for a decision as compared with a clinical interview,<sup>943</sup> and “[u]se of the tool requires substantial training.”<sup>944</sup>

In 2010 Dr. Martha Donnelly worked with an interdisciplinary committee to develop two incapability assessment modules through the University of BC Department of Family Practice. The curriculum formed part of a series of modules entitled “Care for Elders”. The modules, which again focused on capacity for financial and personal decisions, rather than health care or care facility admission decisions, included pre-reading followed by a group learning activity which involved working through practical scenarios with the support of an expert facilitator. Completion of the modules was incentivized through assignment of accreditation value by the College of Physicians and Surgeons, and funding to develop the modules and pay for the facilitators was provided by the Ministry of Health.

However, it is not clear that physicians should be the professionals who conduct incapability assessments, particularly in view of pressures on their time. Other health care professionals, such as occupational therapists, nurses, psychologists, and social workers might be appropriate.

The BC Health Regulators should work with the appropriate regulatory colleges, the British Columbia Ministry of Health, and key organizations such as Doctors of BC, to develop educational modules on incapability assessment with respect to health care decision making and care facility admission. Content should provide guidance on:

- How to engage the person being assessed in the assessment process?
- What is the appropriate involvement of supportive family and friends in the assessment process, and what emphasis should be placed on their views when they differ from the perception of the person living with dementia?
- What is the appropriate involvement of different health care professionals and various members of the care team in the assessment process?
- How to appropriately document findings?
- What is the impact of hearing, speech and language issues on incapability assessment?
- How can variables such as medication and time of day be reflected in the process so as to support the person living with dementia to present with as much capacity as is possible for them?
- What avenues are available to a person who wishes to challenge a finding that the person is incapable of making a health care treatment or care facility admission decision?

## RECOMMENDATION 19

### 7.2.3 Documenting Informed Consent to Treatment

Although the *HCCA* requires a health care provider to consider whether a person has capacity to consent to health care, and to obtain their informed consent, either directly or through a substitute decision maker in cases of incapability, there is no explicit requirement in the legislation to document that this process has occurred.<sup>945</sup> Also, licensees of long-term care facilities in BC do not have legal obligations with respect to the consent process.<sup>946</sup>

In the 2012 *Best of Care* Report, the Ombudsperson recommended that the Ministry of Health remedy this gap to ensure that the consent rights of people in care are respected. They pointed out that:

Without any clear documentation requirements, it is difficult to ensure that informed consent has been obtained and verified before medication is administered to people in care. In order to protect the rights of people in care, the ministry should establish binding legal requirements to document consent.<sup>947</sup>

The Ombudsperson's recommendations in this regard place obligations with respect to documentation of consent on both the health care providers and licensees (operators):<sup>948</sup>

R139: The Ministry of Health take the necessary steps to amend the *Health Care (Consent) and Care Facility (Admission) Act* so that health care providers administering medication in residential care are legally required to document:

- that they have considered whether a person in care is capable of providing informed consent
- who provided informed consent
- when informed consent was provided
- how informed consent was provided
- the duration of the consent

R140: The Ministry of Health take the necessary steps to establish legal requirements for operators to:

- ensure that facility staff verify from the documentation that informed consent has been obtained and is still valid before administering medication
- require facility staff to document their verification of consent prior to administering medication

*Health care consent for people who are not currently felt to be able to make decisions for themselves, in a residential care environment, is poorly managed.*

## – Physician

In making these recommendations, the Ombudsperson noted the existence of limited professional regulation regarding documentation of informed consent in BC.<sup>949</sup> Based on our more recent review of professional guidelines and standards, the Nursing College has produced a comprehensive and legally accurate Practice Standard on “Consent”, which requires nurses to document the consent process; however, no equivalent standard applies to physicians.<sup>950</sup> Although the Nursing College produces a standard on consent to health care, the standard does not discuss documentation of consent.<sup>951</sup>

Registered nurses are required to verify that consent has been given when participating in the delivery of treatment by other health professionals. In the absence of a corresponding obligation on physicians and other health professionals to document the consent process, it is difficult for registered nurses to comply with this standard to verify.<sup>952</sup>

At this time Ontario’s *Long-Term Care Homes Regulation* is the only Canadian law which places an obligation with respect to the consent process on licensees of a care home.<sup>953</sup> We also reviewed legislation in a number of US jurisdictions. In Washington and California facility staff and operators have some obligations with respect to the consent process. In California, facility staff must verify that the patient’s health record contains documentation that the patient has given informed consent to the treatment, prior to administering a psychotherapeutic drug (or physical restraint or other device).<sup>954</sup> In Washington, nursing homes must ensure the informed consent process is followed.<sup>955</sup> As a condition of participation in Medicare and Medicaid programs, US hospitals must ensure written documentation of consent is included in patients’ medical records.<sup>956</sup>

In discussing potential recommendations regarding physician responsibilities with respect to documenting consent, the Project Advisory Committee expressed concern that the recommendation should not be too onerous, considering that health care professionals and care facility staff are already required to complete a significant number of forms.

Both key informants and Project Advisory Committee members suggested building prompts regarding consent into existing forms used by physicians and staff to order medication and fill orders. We discussed whether health care professionals and staff should be required, or prompted, to document consent in the Medication Administration Record (MAR), or the Medical Order for Scope of Treatment (MOST) as a means of more specific action in the spirit the Ombudsperson’s recommendations discussed above. Both forms are part of long-term care patient files. The committee was not confident that the MAR was the right location for documenting consent, given that medication is often ordered by a physician who is not onsite, and the MAR is completed by facility staff. Moreover,

the committee was of the view that a recommendation regarding mandatory amendments to the MAR would require an amendment to the *CCAL Act* or the *RC Regulation*.

The MOST is a medical order of a physician which communicates to other health care professionals and staff the patient's wishes and goals for care in order to help avoid unnecessary or unwanted interventions.<sup>957</sup> The form is generally completed at the time of admission after discussion with the patient, the health care team, and the person's substitute or supportive decision makers. The MOST form contains a section to identify advance care planning documentation, such as advance directives or representation agreements. There is no requirement for the form to be signed by the patient or their representative. The form is not a type of advance directive or otherwise a legal document, in contrast to the Ministry of Health's "No Cardiopulmonary Resuscitation – Medical Order" form, which allows for a signature from the patient or their substitute decision maker, or a valid advance directive, which is subject to strict execution requirements.<sup>958</sup>

Although, the MOST seems to play a key role in practice in most long-term care facilities in terms of documenting wishes regarding care, there is some confusion among both the public and health care staff regarding the purpose and authority of a MOST. A number of Project Advisory Committee members noted that people sometimes think that by participating in completion of the MOST form they are legally appointing a substitute or engaging in legal advance planning. We understand from discussions with the BC Ministry of Health and the Seniors Advocate that a province-wide project to review the MOST form, and to standardize practice with respect to the use of the form across health authorities, is underway.<sup>959</sup> Based on this information, we are not including any recommendations regarding the MOST in this report. However, we note that if the MOST becomes a site for documenting consent, health care staff and physicians should be required to take great care in explaining the purpose of the MOST, and distinguishing it from an advance directive, or a substitute decision maker appointment process.

Currently the College of Physicians and Surgeons' bylaws set out detailed requirements for physician record-keeping and documentation. They include a requirement to keep a clear record for each patient including "the specifics of any treatment, recommendation, medication and follow-up plan", but excluding any requirement to document the consent process.<sup>960</sup> With respect to the content of a patient's medical records, the bylaws require the following:

3-5 (1) A registrant must...

- (b) keep a clinical record on each patient containing
  - (i) the patient's name, gender, personal health number, date of birth, address and dates of attendance,
  - (ii) sufficient information to clearly explain why the patient came to see the registrant and what the registrant learned from both the medical history and the physical examination,
  - (iii) a clear record of what investigations the registrant ordered,
  - (iv) a clear record of either the provisional diagnosis or diagnosis made, and
  - (v) a clear record of the specifics of any treatment, recommendation, medication and follow-up plan...

There is no explicit requirement in the *HCCA*, the College bylaws, or elsewhere that physicians document the consent process other than the Form 1 for major health care noted above.<sup>961</sup> The Ministry of Health, in its “Health Care Providers’ Guide to Consent to Healthcare”, states that “while the [Health Care Consent Act] does not specifically deal with the issue of documenting consent, it is important to document accurately and completely all decisions made and actions performed”, and that “[f]ormal documentation of the fact that consent has been obtained on a chart or a consent form is advised whenever practical”.<sup>962</sup> The Project Advisory Committee viewed a bylaw amendment as a more expedient and effective means of encouraging documentation of consent than law reform.

## RECOMMENDATION 20

### 7.2.4 Understanding Dementia and Supporting Capacity

*Some family medicine residents still graduate from their training program, and have never set foot in a nursing home. It’s not a mandatory piece of education, like how to catch a baby is mandatory, [and] having paediatrics is mandatory. But community geriatrics or any geriatrics is not mandatory in a lot of programs across the country.*

– Physician

A number of practice issues discussed in this chapter, particularly assumptions that people living with dementia do not have capacity to consent to health care, betray lack of knowledge about dementia. This dynamic is reinforced by the above comment regarding a mandatory geriatric component to physician training. The 2016 Senate Committee report on dementia in Canadian society similarly identified lack of specially trained health professionals to care for Canada’s aging population, as well as a lack of basic education in elder care, as significant practice issues. They recommended that:

...the proposed Canadian Partnership to Address Dementia, within the context of the National Dementia Strategy, in collaboration with provincial governments, medical faculties, nursing programs, and their regulatory and licensing bodies, address health human resource capacity, training and professional development with respect to aging and dementia care.<sup>963</sup>

A number of stakeholders living with dementia also said that informed health care consent was undermined by the family physician’s lack of knowledge of medication they were prescribing to treat symptoms of dementia and memory loss.

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The College of Physicians and Surgeons of British Columbia should amend Bylaw 3-5(1)(b) to:

- Require that physicians’ clinical records include a clear record of the health care consent process, including:
  - who provided, or refused to provide, informed consent;
  - how consent was provided; and
  - when the informed consent was provided; and
- Clarify how to update the record when the physician is prescribing medication over the telephone, or through another offsite method.

The College should also educate members regarding changes to the bylaw.

At this time some dementia training is available to health care professionals and HCAs. The 2015 HCA Provincial Curriculum and Supplement emphasizes the role of the HCA in caring for clients with dementia and mental health disorders, palliative care and supporting families. Douglas College offers an online course on Dementia Care based on the HCA Provincial Curriculum.<sup>964</sup> The health authorities periodically offer the Gentle Persuasive Approach (GPA) training to health care staff. The GPA is a one-day evidence-based training program that helps care providers deliver person-centred, compassionate care to people living with dementia. The curriculum focuses on personhood, the brain and behaviour, the interpersonal environment, and gentle persuasive techniques.<sup>965</sup>

There are also a number of voluntary dementia care learning opportunities available on the Provincial Health Services Authority Learning Hub. The Learning Hub is a centralized learning management system which allows each of the health authorities to make available online courses for their employees, medical staff, affiliates, students, and volunteers, as well as operating as a registration for in-person courses. A number of courses on dementia care, aimed at a variety of audiences, are available on this website. For example, courses include:

- A one-day Dementia Care Forum for all staff caring for older people in Vancouver Coastal Health Residential Care;
- A three-hour online course titled “Dementia Care: Fundamental Knowledge, Skills and Competencies for Providing Person-Centred Care aimed at all health care professionals and staff;
- A one-hour online “P.I.E.C.E.S. Overview for Residential Care” aimed at staff working in long-term care and mental health care settings working with older people living with dementia;<sup>966</sup>
- An interactive, game-based online learning program for anyone working with patients with dementia.<sup>967</sup>

Dementia education is one of the Alzheimer Society of B.C.’s strategic priorities. The Society delivers a six-hour workshop, tailored to meet the needs of participants, called *Building a Strong Foundation for Dementia Care*. The workshop is provided across the province, currently on a request basis, but with a plan to initiate more purposeful targeting of the workshop going forward. The workshop is suitable for a wide variety of health care professionals and staff, including HCAs, home support staff, and staff working in day programs and public housing. The Society also recently partnered with SafeCare BC to provide a modified workshop to several hundred care providers under the title *Creating Connections: Working with Individuals with Dementia*.<sup>968</sup>

The Ministry of Health’s 2016 *Provincial Guide to Dementia Care in British Columbia: Achievements and Next Steps* recognizes the need for health care professionals to receive training in both the diagnosis and management of dementia.<sup>969</sup> To this end, the Ministry of Health identified the goal of improving “health-care professional and caregiver knowledge and ability to deliver safe, well-informed dementia care using best practices,” with the specific deliverable to “[i]ncrease and sustain consistent dementia training for health-care professionals and caregivers – including cultural competency training – in all care settings.”<sup>970</sup> Another resources is the Ministry of Health, BC Best Practice Guideline for Accommodating and Managing BPSD, which includes the BPSD Algorithm developed by the



Interior Health Authority’s Antipsychotic Drug Review Committee to support staff to take a person-centered approach to responding to BPSD, and consider alternatives to anti-psychotics.<sup>971</sup>

Based on this review, good resources on dementia do exist. However, based on our stakeholder consultation, and the views of members of our Project Advisory Committee, many health care professionals and staff working in long-term care, community, and acute care require better foundational knowledge of dementia, particularly as this knowledge relates to capacity for health care decision making.

## RECOMMENDATION 21

*You’re always contacting the resident until the resident can’t be involved, and so even a person with dementia has got a lot of capacity to be involved in their own decision-making.*

– **Former Director of Care**

People living with dementia will have varying capacity to participate in decision making and communicate their views about health care. For example, key informants noted that time of day and stress can impact on capacity to participate in health care decision making. Engaging people living with dementia in health care decision making requires creating the circumstances in which they will have the best opportunity to participate.

Health care professionals and staff should consider how to support capacity both at the time of the incapability assessment, and also in the context of decision making involving substitute decision makers, who have a duty to involve the person in decision making. Accommodation should be built into the incapability assessment process. In other words, the question is not just “can this person make the health care treatment decision at issue on their own?” but rather “can the person make the health care decision if provided with available supports?” The requirement for accommodation through supportive communication is specifically imbedded in the *HCCA*. However, other strategies may further support capacity. The Law Commission of Ontario recommended this approach to incapability assessment and accommodation in its report on *Legal Capacity, Decision Making and Guardianship*.<sup>972</sup> The Commission recommended its health care consent statute be amended to clarify:

- a) that legal capacity exists where the individual can meet the test for capacity with appropriate accommodations, and
- b) the requirement that assessments of capacity be carried out in accordance with the approach to accommodation developed under domestic human rights law.<sup>973</sup>

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The provincial health authorities should deliver training on dementia to all staff providing services or care to older people (including, but not limited to, nursing professionals, health care assistants, community health workers, social workers, and physicians) with the goal of advancing knowledge, undermining myths, and reducing stigma.

In order to better support the practice of all health care professionals and staff, a best practice guideline should be developed which addresses how to:

- Engage people who are living with dementia in health care decision making; and
- Maximize the capacity of people living with dementia to participate in their health care decisions.

As discussed above, our research indicates that there exist various resources and best practice tools regarding aspects of care for people living with dementia. However, we have not been able to find any comprehensive best practice tools for health care professionals and staff on the topic of supporting people living dementia to participate in health care decision making. Based on our consultation, and the expanding scope in BC of the duty of substitute decision makers to involve people who may not have full decisional capacity in health care decision making, greater guidance to support practice is needed.

## RECOMMENDATION 22

### 7.2.5 The Role of the *Mental Health Act* in Treating People Living with Dementia

Consultation with both family caregivers and key informants indicates that the *MHA* is sometimes being used to involuntarily commit older people living with dementia. As the quotation on the following page illustrates, the rationalization for committal is sometimes not consistent with the law.

The topic of involuntary committal is relevant to the Health Care Consent Project because people committed under the *MHA* do not have a legal right to make psychiatric treatment decisions, regardless of whether or not they are capable of making such decisions. Involuntary patients in BC are “deemed” to have consented to any psychiatric treatment authorized by the director of a designated facility.<sup>974</sup> Consent to health care for a physical illness or injury, or any health condition, other than the psychiatric disorder for which the person was committed, is governed by the *HCCA*, despite any involuntary admission.

Under the *MHA* a person may be involuntarily admitted to a designated psychiatric facility for examination and treatment upon the certified opinion of a physician that the person has a “mental disorder”, and the person:

- requires treatment in or through a designated facility,
- requires care, supervision and control in or through a designated facility to prevent the person’s or patient’s substantial mental or physical deterioration or for the protection of the person or patient or the protection of others, and
- cannot suitably be admitted as a voluntary patient.<sup>975</sup>

The statute defines “person with a mental disorder” to be:

a person who has a disorder of the mind that requires treatment and seriously impairs the person’s ability

- to react appropriately to the person’s environment, or
- to associate with others.<sup>976</sup>

One of the impacts of committal is that neither the person living with dementia nor family members, substitute and supportive decision makers for health care have a legal right to make any health care treatment decisions related to psychiatric treatment, or to participate in decision making regarding psychiatric treatment. Stories of family caregivers indicate that involuntary committal is occurring even where spouses say they are actively involved in care, and feel they were working with the health care team to access appropriate care. These consultation findings raise questions regarding whether committal is occurring when a person could be admitted voluntarily through the substitute decision maker.

As discussed above, dementia is now considered a mental disorder.<sup>977</sup> However, not all clinicians and legal experts are of the view that dementia itself, in the absence of any other mental illness, is a disorder of the mind that requires psychiatric treatment that would meet the definition of the *MHA* criteria. Based on our consultation, many physicians and geriatric psychiatrists hold the view that under certain circumstances it may be appropriate for people living with dementia to be involuntarily committed. People living with dementia may require psychiatric treatment specifically for symptoms associated with their dementia, or due to another mental illness; however, mental health facilities were not set up to address the complex care needs of older people.

Interviews with key informants regarding practice under the *MHA* identified a number of factors that could contribute to a physician's decision to involuntarily commit older people living with dementia. Importantly, none of these concerns directly relate to the legal criteria for involuntary committal under the *MHA*. Issues identified included:

1. The physician is concerned about self-neglect, or lack of safety in the home:
  - The care facility admission provisions have not been brought into force. As a result, if a person does not have capacity, or a representative or guardian, there may be no person legally entitled to consent to admission to a care facility.
  - The *MHA* process is more familiar to health care professionals than the emergency provisions under part 3 of the *Adult Guardianship Act (AGA)*.
2. The physician thinks involuntary committal will help the person living with dementia to gain access to more appropriate and timely mental health services. One family caregiver confirmed she was asked to agree to an involuntary committal for her husband as a means of getting access to particular services.
  - Some facilities appear to require that a person be involuntarily committed under the *MHA* in order for them to gain admission to that facility.

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*People are not comfortable. And even families, they're not comfortable with being the one that are saying, 'Now mommy, you have to go to hospital. I can't look after you anymore.' That's a very difficult position to be in. So, the Mental Health Act actually save them that discomfort.*

**– Geriatric psychiatrist**

The BC Ministry of Health should develop a province-wide policy on whether and under what circumstances, if any, the use of involuntary commitment under the *Mental Health Act* is appropriate for older people living with dementia.

3. The physician wants greater control over decision making:
  - The physician wants to be able to transfer the resident quickly to another location, for example, from long-term care to a hospital, if the person's behaviour becomes challenging for the long-term care environment.
  - The physician is concerned that substitute decision makers will delay the process of transferring an adult from hospital to a long-term care either because they are not emotionally ready to make the decision, or there is lack of agreement amongst family members.
4. The physician recognizes that police officers will be more willing to intervene to support transfer of a patient who has been involuntarily committed than transfer of an adult who is receiving services under the emergency provisions of part 3 of the *AGA*.<sup>978</sup>

Further, comments by one geriatric psychiatrist suggested the *MHA* was being used to alleviate the family member acting as substitute decision maker from the stress of health care decision making. We understand that within some health care professionals have been instructed by counsel that involuntary committal is appropriate where people living with dementia do not have the capacity to consent to admission to a care facility, and there is no guardian or representative with authority to consent on their behalf.

It is deeply concerning to hear physicians articulating the above factors as rationalization for involuntary committal. Overall, while we have not conducted a robust review of *MHA* practice vis-à-vis people living with dementia, comments by both health care professionals and family caregivers raise serious concerns about inappropriate use of the *MHA* to treat people living with dementia. We are concerned that the *MHA* is being used to facilitate a placement when other options could have been tried, and consent could have been obtained from either the person living with dementia, with or without the support of a supportive decision maker, or by a substitute decision maker.

Some comments by physicians betray a lack of understanding of the *MHA* and the *AGA*, and lack of respect for the rights of supportive and substitute decision makers to participate in health care decision making. The notion that adequate mental health services should only be available to a person living with dementia if they are being involuntarily (and not voluntarily treated) is concerning.

In the scenario whereby a person living with dementia is involuntarily committed, the person is typically placed in a designated mental health facility, usually a hospital, and detained pursuant to the involuntary admission procedures set out in section 22 of the *MHA*, that is to say, for 48 hours upon certification by a physician that the person is "a person with a mental disorder" and in need of protection<sup>979</sup>, and up to one month upon certification of a second medical physician.<sup>980</sup> This period can be renewed on an

ongoing basis.<sup>981</sup> Subsequently the person can be put on leave with the condition that they reside in a long-term care facility. Section 37 provides:

“...if the director considers that leave would benefit a patient detained in the designated facility, the director may release the patient on leave from the designated facility providing appropriate support exists in the community to meet the conditions of the leave.”<sup>982</sup>

Although the adult is no longer residing in a designated psychiatric facility, they are still “patients” for the purposes of the *MHA*, and subject to its regulation,<sup>983</sup> and so substitute decision makers—both those appointed by a court, and those chosen by the older person—lose their authority in relation to treatment related to the psychiatric disorder. Consequently, medications can be administered without the right to refuse consent to such treatment: consent authorized by the medical director is deemed to have been provided by the patient. While the physical health care needs still require consent according to the provisions of the *HCCA*, one Project Advisory Committee member indicated that consent to non-psychiatric treatment is not always being properly obtained, and the deemed consent provisions are sometimes illegally applied to all health care.

The Ombudsperson’s *Best of Care* report notes that the use of the *MHA* to involuntarily admit seniors to long-term care facilities has serious impacts on their civil liberties. The Ombudsperson noted that using the *MHA* to admit a senior to a designated facility for treatment, including treatment for dementia, should be “an extraordinary situation” where to do so is the “only viable option that will allow for his or her protection.”<sup>984</sup> As a result, the Ombudsperson recommended that: “seniors’ civil liberties are appropriately protected by working with the health authorities to develop a clear, province-wide policy on when to use sections 22 and 37 of the *MHA* to involuntarily admit seniors to mental health facilities and then transfer them to long term care.”<sup>985</sup> According to the Ombudsperson’s 2015 updates, there have been no steps toward implementation of this recommendation to date.<sup>986</sup>

Although we have only scratched the surface of this topic, there appears to be a need to support better understanding of when the *MHA* is an appropriate medical intervention for people living with dementia, and to monitor use of the *MHA* for older people living with dementia.

◀ **RECOMMENDATION 23** (PAGE 220 SIDEBAR)

**RECOMMENDATION 24** ▶

Implementation of the *HCCA* care facility provisions may result in a reduction in use of the involuntary committal provisions for older people living with dementia; however, based on our consultation, the use of the *MHA* for people living with

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The provincial health authorities, on behalf of the BC Ministry of Health, should develop a system to:

- Collect data regarding the use of the involuntary commitment and extended leave provisions of the *Mental Health Act*; and
- Make its findings publicly available through annual reporting of statistics.

The data collected should enable an analysis of how the *Mental Health Act* is used with older people living with dementia by tracking information on:

- The demographics of people detained, such as age, gender, and diagnoses; and
- What *Mental Health Act* powers are used, such as involuntary admission frequency and duration, frequency and duration of extended leave, location of extended leave placements, and recalls from extended leave.

dementia does not appear to be strictly limited to circumstances where no one has the authority to consent to admission. Moreover, the care facility provisions will have no impact on the criteria for committal under the *MHA*.

### 7.2.6 Practice Support for Staff

Health care professionals shared that circumstances arise in which people living with dementia appear to lack capacity to make a health care treatment decisions, and it is unclear who may be able to provide substitute consent. Particularly challenging circumstances exist when various family members have different views regarding care, or when people living with dementia seems to have neither family nor close friends to act as temporary substitute decision maker under the *HCCA*. Sometimes health care professionals do not know from whom they should obtain consent. There is confusion about the role of the PGT with respect to health care decision making.

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*For the most part, when folks go into a residential care setting, and become one of 50 or 100 patients, the general way of working is that we assume there is consent because they are not challenging.*

– Health authority staff

A number of physicians and directors of care indicated they can spend a lot of time phoning different agencies when a challenging consent case arises. There is a lack of clarity regarding who to call for practice support: does a person call their College? Licensing? Risk management? The PGT? Chasing down an answer diverts valuable time resources from patient care. These circumstances can be distressing for people living with dementia, family, friends, health care professionals, and staff.

Stakeholder interviews suggest that in acute care social workers often provide one-on-one education to families, physicians, and patients. Ethicists and hospital ethics committees also play a role in supporting best practice. Risk managers can also be a good resource. In addition, adult abuse and neglect specialists play an educational role with respect to the *AGA* and related matters, which can include consent and capacity; however, the consultation portion of that role leaves little time for education, as crisis management with respect to specific cases is time consuming.

We have learned that one health authority has a dedicated position for which the primary role includes education of health care professionals and the public with respect to advance care planning, informed consent, and substitute decision making. Several stakeholders noted the positive impact of that position in terms of knowledge of staff and health care professionals. Consultation findings indicate that social workers across the region are supporting health care staff and physicians to better understand and apply health care consent law.

We spoke with a number of contacts within the provincial health authorities to clarify the availability of social workers across BC to support physicians and staff to deliver health care to people living with dementia, and obtain proper consent to treatment. Based on our limited research:

- Some long-term care facilities which are owned and operated by the health authorities have a social worker;
- Some long-term care facilities under the *Hospital Act* have a social worker, as do other acute care facilities (eg. hospitals);
- Social workers in the role of Family and Social Support Practitioners play a support role for the entire Home Health Team; and
- Some contracted long-term care facilities have a social worker.

Our findings underscore a need for better support of employees and physicians in terms of understanding health care consent, substitute decision making process, and the role of PGT. However, the problem is not strictly due to lack of staffing, but rather lack of awareness of social worker support available to health care staff to help them to understand the law.

This support role could be fulfilled by appointing a designated staff person, or by adopting a team approach according to which various staff play a role in providing information and support. Project Advisory Committee members expressed a concern that this role not be added to the job description of abuse and neglect specialists without extra resourcing being provided.

A concern has been raised regarding whether health authority staff ought to provide support not only to employees but also to physicians in private practice and directors of independently owned care facilities. Health authorities do not have obligations to non-owned and operated facilities, or physicians who are generally not employed by the authorities in staff positions. However, there is past practice of providing such support with respect to other quasi-legal topics, such as, most recently, with respect to Medical Assistance in Dying resources. The Project Advisory Committee felt that providing consistent information regarding health care consent to all staff and physicians would be beneficial to supporting best practice.

#### RECOMMENDATION 25

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The provincial health authorities should explore strategies to increase resources, such as social workers, available to all employees, physicians, and contractors who work in long-term care, and home and community care, to ensure they fully understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee in a manner which reflects the *Health Care (Consent) Care Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

## 7.3 ADDRESSING SYSTEMIC BARRIERS TO INFORMED CONSENT

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A robust discussion of the circumstances surrounding health care consent should not ignore the practical realities of health care delivery. Stakeholders identified a number of structural and systemic issues that pose barriers to health care consent for people living with dementia. Strain on time and resources in long-term care were recurring themes. Key informants identified both composition and number of staff in long-term care as barriers to good practice, including under-staffing, and lack of on-site physician presence. Systemic changes could both enhance practice among all members of the health care team, and support people living with dementia and their supportive and substitute decision makers to have meaningful conversations with health care providers about their desires, needs and concerns with respect to health care. In this part of Chapter 7 we discuss:

1. Staffing composition and levels in long-term care;
2. Physician remuneration; and
3. Participation of marginalized communities in health care decision making.

### 7.3.1 Staffing Composition and Levels in Long-Term Care

Staffing in long-term care facilities is largely governed by the *CCAL Act* and the *RC Regulation*. The *CCAL Act* does not regulate either staffing levels or staffing composition. The *RC Regulation* requires that there be employees on duty at all times that can effectively communicate with all residents, and provide supervision. The *RC Regulation* stipulates broadly that:

- ...the employees on duty are sufficient in numbers, training and experience, and organized in an appropriate staffing pattern, to
- (a) meet the needs of the persons in care, and
  - (b) assist persons in care with the activities of daily living, including eating, moving about, dressing and grooming, bathing and other forms of personal hygiene, in a manner consistent with the health, safety and dignity of persons in care.<sup>987</sup>

Both the *CCAL Act* and the *RC Regulation* also contain language obliging the licensee to employ only persons of good character, and to review references and provide training.<sup>988</sup>



*It would be difficult, from a workflow perspective, to be phoning, and tracking down SDMs [substitute decision makers] every time you needed to change a medication order.*

– Director of care

Hospitals under Part 2 of the *Hospital Act*, which include extended care hospitals, are also subject to limited regulation with respect to staffing. Neither the *Hospital Act* nor the *Hospital Act Regulation* stipulates minimum staffing requirements; however, in terms of staffing composition, a licensed hospital must have a superintendent who is:

- (a) resident on the premises and
- (b) a medical practitioner, a member of the Registered Nurses' Association of British Columbia or a graduate nurse whose qualifications are approved by the chief inspector.<sup>989</sup>

Staffing ratios in long-term care are an issue of contention. While there are no statutorily mandated staffing ratios, in 2009 the BC Ministry of Health provided regional health authorities with a recommended guideline of 3.36 hours per resident day of Direct Care Hours. The guideline included three hours for nursing care (registered nurses, licensed practical nurses, and health care assistants) and 0.36 hours for supporting care (physical, occupational, and recreational therapists; speech language pathologists; social workers; and dietitians).<sup>990</sup>

These Ministry of Health staffing guidelines are not currently being met by many facilities. In 2018 the Office of the BC Senior's Advocate reported in its *Residential Care Facilities Quick Facts Directory* for 2016/2017 that 85% of government funded long-term care facilities did not meet the Ministry of Health's guideline of 3.36 Direct Care Hours per resident day, with a facility average of 3.11 Direct Care Hours being provided.<sup>991</sup> The Residential Care Staffing Review by the Parliamentary Secretary for Seniors released in March 2017 set out an action plan for staffing in long-term care which includes a plan to increase Direct Care Hours, and to implement a province-wide standard in funding and monitoring to support health authorities to reach staffing levels which achieve the recommended 3.36 direct-care hours per resident day averaged across the health authority.<sup>992</sup>

Also, in March 2017, the BC Government announced an increase in investment in seniors care of \$500 million over four years directed at implementation of the government's Action Plan to Strengthen Home and Community Care for Seniors ("The Action Plan").<sup>993</sup> The Action Plan includes a commitment by the Ministry to complete the actions identified in the Residential Care Staffing Review by 2020, in collaboration with the Office of the Seniors Advocate, other provincial ministries (e.g., Advanced Education and Jobs, Tourism and Industry), health authorities, industry partners, and other stakeholders.<sup>994</sup> The Ministry has estimated that an additional 1500 full-time equivalent staff will be required to meet the target Direct Care Hours.<sup>995</sup>

It is beyond our expertise as a legal research and law reform body to develop a recommendation on staffing levels or care ratios in long-term care. However, we note that a number of groups recommend higher numbers than the Ministry of Health's target. The Canadian Centre for Policy Alternatives has recommended that "direct care staffing should be set at a minimum of 4.1 hours per resident per day."<sup>996</sup> The BC Nurses Union recommended that total nursing staff hours should be 4.55 per resident day, with one regulated nurse for every 25 residents, noting that increased contact with a regulated nurse results in a decrease in failure to rescue rates.<sup>997</sup> The Hospital Employees Union recommended a longer term goal of 4.1 hours of direct personal and nursing care as provided by HCAs, LPNs and RNs, and that this number be indexed to rise with resident care needs.<sup>998</sup> In a 2017 report, Ontario indicated its plan to increase direct care hours to a provincial average of 4.0 hours per resident day.<sup>999</sup>

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*A doctor is prescribing life altering meds—without even seeing the person in person.*

– **Family caregiver**

In terms of staffing composition, health care consent in long-term care engages the practice of many different health care professionals and staff. Long-term care services are provided on a day-to-day basis by community health workers and health care assistants (HCA). In addition, nursing services may be provided by licensed or registered nurses, including certified practice nurses and nurse practitioners.<sup>1000</sup> Other health professionals, such as pharmacists, physical therapists, occupational therapists, and speech and language pathologists also provide their specialized services. Family physicians, geriatricians, and geriatric psychiatrists provide medical diagnostic and treatment services.<sup>1001</sup>

Stakeholder consultation indicates that a particular challenge in relation to staffing is that it is difficult to find the time to properly address family conflicts and family caregiver needs for support with health care treatment decisions. Health care staff find the pressure to mediate family disagreements and support family caregivers with health care decision making takes time away from pressing patient care in the context of an already over-burdened system. Key informants also noted that optimal person-centered care for people living with dementia requires more time and resources than are currently available, and that anti-psychotics are sometimes the most appropriate solution partly due to staffing issues.

It appears that a key staffing gap in some long-term care facilities from a health care consent perspective is an absence of social workers to support decision making, especially in emotionally challenging circumstances where trauma, loss, and conflict are negatively impacting the decision making process. Key informants noted that in acute care, and where available, in long-term care, social workers play a positive role in supporting families to understand their rights and responsibilities. However, as noted in our discussion of recommendation 25, social worker assistance is not as widely available to people who have a family member living in long-term care. This is particularly true in privately owned facilities, although some private care facilities do employ social workers to support families, and find them to be a tremendous resource. Given their training in understanding legal systems and supporting communication, social workers could be an excellent resource for assisting residents,

family members, and substitute and supportive decision makers to advocate for their right to participate in health care decision making.

## RECOMMENDATION 26

### 7.3.2 Physician Remuneration

*Families need to feel comfortable that they can, you know they aren't bothering a physician in his busy office to talk about somebody... They need to be heard, and they need to be, you know, kind of respected. And that takes time.*

– Physician

Physicians identified billing codes and fee structures as posing barriers to taking the time for fulsome discussion regarding medication risks and care options, and lengthening appointments to accommodate communication and understanding challenges people living with dementia may experience. Facilitating the ability of physicians to bill for more lengthy appointments for patients with impaired capacity could support better health care consent practice. Further, introducing bill codes for lengthy incapability assessments could also support more robust and regular assessment of incapability to make health care treatment decisions.

Currently, there are four funding models for physician remuneration in BC:

- Fee-for-service (FFS);
- Alternative Payment Programs (APP);
- Medical On Call Availability Program; and
- Rural Funding.<sup>1002</sup>

The main two models used in BC are FFS and the APP, with the majority of physicians being compensated under the FFS model.<sup>1003</sup> Under the FFS model, physicians receive payment from Medical Services Plan (MSP) per service they provide to their patients, using a separate billing code to identify the type of service provided. Under this model, physicians are essentially self-employed professionals. The Medical Services Commission administers the Medical Services Plan (MSP) under the authority of the *Medicare Protection Act*.<sup>1004</sup> MSP insures its registrants for medically required services provided by general practitioners, specialists, and some other health care professionals, paying them on a FFS or APP basis.<sup>1005</sup> Physicians must be enrolled with MSP in order to receive payments, and must be licensed with the College of Physicians and Surgeons to be eligible to enroll in MSP.<sup>1006</sup> An enhanced fee-for-service program is available in most provinces and territories in Canada,

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The provincial health authorities should explore strategies for making social work services more available in order to better support older people living with dementia, their family members, and their supportive and substitute decision makers with health care decision making.

including BC, whereby physicians and some specialties may access additional compensation for complex and chronic disease management.<sup>1007</sup>

As described by Mazowita, an “escalating crisis in family medicine” in the 90s and early 2000’s resulted in the creation of the General Practices Services Committee, whose mandate was to “find solutions to support and maintain full-service family practice in BC.”<sup>1008</sup> Solutions to the crisis in BC largely revolved around practice incentives for full-service family doctors, training programs, and recruitment incentives.<sup>1009</sup> By way of comparison, other provinces, such as Ontario, opted for significant structural reform.<sup>1010</sup> Financial incentives included new MSP billing fees which allowed for compensation of telephone or email consultations and group visits.<sup>1011</sup>

In addition to these earlier operational reforms, the Ministry of Health’s 2015 Primary and Community Care Policy Framework highlights further initiatives in this area, such as the Family Practice Incentive Program. The program currently includes the following incentives:

- Mental health incentive payments for helping plan and manage care for patients with mental health issues, including dementia.<sup>1012</sup>
- Two complex care planning and management incentive payments available to family physicians,<sup>1013</sup> for patients diagnosed with at least two chronic conditions from a list of conditions, one of which is a “chronic neurodegenerative disease”. Dementia on its own would not warrant the use of these codes.<sup>1014</sup>
- Palliative care incentive payments for assisting with care planning for palliative patients.<sup>1015</sup>

None of the above are available for patients residing in long-term care. However, Residential Care Initiative incentive payments are available for family physicians to support care in long-term care facilities, and include the following additional fee payments:

- Patient Telephone Management Fee
- GP Allied Care Provider Conference Fee
- Chronic Disease Management Incentives
- MSP Fees in Residential Care
- Billing for Non-urgent/non-emergent visit
- Billing for Patients in Long Term Care when specially called
- Billing for Patients in Long Term Care when Called to See at Night
- Visits for terminal care
- Billing for phone advice about patients in LTC
- Minor Procedures and Related Tray fees<sup>1016</sup>

The Family Practice Incentive Program does not appear to provide any incentive payments to compensate physicians for the time it takes to assess incapability to consent to proposed health care. Neither does the program provide for any incentive payments which take account of the additional time

required for physicians to engage in a robust informed consent process with people living with dementia. Stakeholders consistently stated that family physicians face significant time constraints which undermined their ability to engage adequately in the informed consent process, which includes, as a preliminary step, conducting an adequate incapability assessment that does not simply rely on the opinion of the patient or the family member.

## RECOMMENDATION 27

### 7.3.3 Participation of Marginalized Communities in Health Care Decision Making

*Someone might assume just because I've checked my grandmother into this facility that I've sort of given up consent, my responsibility, or something like that, right? It's just that low health literacy that were dealing with there, the unfamiliarity with the health system overall that we're dealing with. It really gets in the way sometimes of the patient or the substitute decision maker to make informed decisions.*

– Health authority staff

Key informants noted that some marginalized communities experience additional barriers to participating in health care decision making. In particular, a number of key informants noted that many Indigenous people have a strong distrust of institutions and white people with authority. Colonization, and the residential school system in particular, have both damaged people's sense of autonomy, and generated trauma and fear, resulting sometimes in a lack of ability to engage with the system, and other times in a culture of assent. As noted in the Report of the Truth and Reconciliation Commission, Indigenous people continue to experience racism in all aspects of health care.<sup>1017</sup>

Key informants spoke of low health literacy rates, and a general unfamiliarity with the health care system, in many Indigenous communities, particularly in northern remote communities, which impact on people's ability to ask questions, and provide informed consent or refusal to health care. In rural northern communities, there are fewer resources, and so people tend to have less knowledge of their rights. Further, people who are marginalized may make different decisions, value different things, and have less social power, so their choices are sometimes not respected. Practically speaking, it is harder to participate when you come from a community with limited internet, where many people cannot afford phone service.

Since long-term care is not generally available on reserve, older people who require complex medical care may have to leave their communities and families to access

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The Doctors of BC and the Ministry of Health should collaborate to develop incentive payments to encourage and support physicians to:

- Engage in robust conversations with patients living with dementia about health care treatment decisions in order to ensure their consent is informed; and
- Undertake incapability assessments of patients living with dementia where capacity for a specific health care decision is at issue.

The First Nations Health Authority, Indigenous Health within the Ministry of Health, and Aboriginal Health leads within each of the other health authorities should engage in discussions with Indigenous communities in order to better understand and address barriers to informed consent to health care experienced by Indigenous people in British Columbia.

appropriate care. They may feel there is no alternative to residing in facilities that are not perceived to be culturally and emotionally safe. Language barriers and a lack of language interpretation pose further barriers, particularly where people are housed far from family. While education regarding cultural safety and cultural humility is occurring, and BC health authorities have committed to ensuring staff take what is termed “Indigenous cultural safety training,” this paradigm continues to exist. The concept of dementia may have a different meaning in some Indigenous communities, which can contribute further to communication challenges.

Key informants told us that advance care planning documents are not widely used in Indigenous communities, even as compared with the low uptake in other populations. They noted a reluctance to talk about death that can pose barriers to health care decision making, which raises the question of whether Euro-centric advance health care planning tools built into our laws and institutions are suitable for all communities. In addition, the changeover in 2013 from health care on reserves operating under the federal jurisdiction to the provincial jurisdiction has meant that health care professionals and staff in those communities are often not sufficiently fluent in BC’s advance care planning regime to act as educators for these communities.

In BC, Aboriginal Patient Navigator positions began emerging within the provincial health authorities starting in 1986, first within Northern Health,<sup>1018</sup> in order to address some of the barriers to health care experienced by Indigenous people. Navigators are now employed around the province in order to improve the “health-care experience of Indigenous patients within the hospital system,”<sup>1019</sup> including to address some of the health care access and literacy issues described above, and the First Nations Health Authority is now responsible for the program.

Indigenous health care is a broad topic beyond the scope of this research project. However, our interviews with key informants indicate that Indigenous people continue to experience uniquely challenging barriers to health care consent that require further discussion, consultation, and consideration—some of which may be particularly felt by people living with dementia and their family caregivers. We encourage further inquiry and discussion from government, non-government and Indigenous advocacy groups alike in order to explore how to enhance access to informed health care consent for Indigenous people living with dementia and their family caregivers.

#### RECOMMENDATION 28

Stakeholder consultation also highlighted barriers to health care consent related to language interpretation. Language issues pose a significant barrier to consent for non-English speaking and immigrant families. Given scarce time and resources, interpreters are not always available or sought. Many key informants spoke of relying on available staff who spoke the language, or other family members, to act as

interpreter. This approach is not always appropriate: non-professional interpreters may not have adequate knowledge or skills, and family members will sometimes have their own agenda. Access to professional language interpretation can be crucial to health care consent, and is arguably required under human rights law.

In BC the Provincial Health Services Authority (PHSA) provides spoken language interpretation services through its Provincial Language Service (PLS).<sup>1020</sup> The service is available to health care professionals who work for any agency or service under the BC provincial health authorities, and to private physicians, including specialist offices.<sup>1021</sup> Interpretation is provided either onsite, or remotely by telephone or video conference, and bookings can be made online, or via a 1-800 number that operates 24 hours a day, seven days a week. The service request must be booked by the health care provider<sup>1022</sup>—not the patient—and interpretation is offered in over 150 languages.<sup>1023</sup> Private office-based family physicians and nurse practitioners can access a telephone interpreting service at no cost.<sup>1024</sup>

A representative of the PLS booking service recommended that booking onsite interpreters at least one to two weeks in advance. Telephone interpretation is usually available immediately for a more common language, or within 5-10 minutes for a less common language; however, a special booking code for immediate telephone service is required to make an immediate booking, and is restricted to certain types of services.<sup>1025</sup>

Based on our review the service appears to be fairly comprehensive, with the exception that health professionals who are employees of private and contracted long-term care facilities cannot access the service.<sup>1026</sup> Our consultation findings suggest that the service has not been adequately promoted among health care professionals and staff.

## RECOMMENDATION 29

29

The Ministry of Health should develop a plan to:

- Expand access to language interpretation for people living with dementia who reside in affiliated or contracted long-term care facilities, as well as their family members and supportive and substitute decision makers; and
- Improve health care professional and staff awareness of language interpretation services.

## 7.4 ENHANCING ACCESS TO LEGAL INFORMATION AND REPRESENTATION REGARDING HEALTH CARE CONSENT RIGHTS

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### 7.4.1 The Right to Review Health Care Consent Decisions

The right to make autonomous health care decisions is a fundamental right protected not just by the *HCCA*, but also by the guarantee of life, liberty, and security of the person enshrined in section 7 of the *Charter of Rights and Freedoms*.<sup>1027</sup> A finding that a person living with dementia is incapable of making their own decisions, or a health care decision the person disagrees with, can infringe on this constitutional right. As the Supreme Court of Canada stated in *Carter v. Canada*:

The law has long protected patient autonomy in medical decision-making. In *A.C. v. Manitoba (Director of Child and Family Services)*, 2009 SCC 30, [2009] 2 S.C.R. 181, a majority of this Court, per Abella J. (the dissent not disagreeing on this point), endorsed the “tenacious relevance in our legal system of the principle that competent individuals are — and should be — free to make decisions about their bodily integrity” (para. 39). This right to “decide one’s own fate” entitles adults to direct the course of their own medical care (para. 40): it is this principle that underlies the concept of “informed consent” and is protected by s. 7’s guarantee of liberty and security of the person.<sup>1028</sup>

Given the importance of the rights at stake, people who face a loss of health care decision making autonomy require an accessible forum for challenging findings of incapability, as well as specific health care decisions made by a substitute decision maker. Both legal research and stakeholder consultations identified a lack of procedural fairness rights and access to justice for people with capacity issues, and people perceived as having reduced capacity, as a key problem facing people living with dementia.

Some health care decisions, such as the choice of TSDM, the interpretation of an advance directive, or a decision regarding treatment can be reviewed by the Supreme Court of BC pursuant to section 33.4 of the *HCCA*. Further, the appointment of a committee of the person can also be reviewed by the court (as is discussed in the following section). Our research did not reveal a single published judgment under section 33.4, which raises the question of whether court-based mechanisms of review are accessible to vulnerable populations such as people living with dementia.<sup>1029</sup>

In recognition of this barrier, BC previously had in place a Health Care and Care Facility Review Board, which was created when Part 4 of the *HCCA* was brought into force in 2000.<sup>1030</sup> The board had the ability to review decisions to give, refuse, or revoke substitute consent to health care. As noted by



*I begged them to cut back on the medication... he is under the control of that doctor... So now they have a free hand.*

– Family caregiver

the Ombudsperson, “the board’s structure and mandate was similar to Ontario’s Consent and Capacity Board, although with narrower jurisdiction.”<sup>1031</sup> A three-member panel heard review applications, with hearings to be held within seven days of an application, and decisions had to be made within 72 hours of a hearing.<sup>1032</sup> Applications for review could be brought by the adult, the adult’s spouse, a relative, or friend, the substitute decision maker, the adult’s guardian or representative, the health care provider, a prescribed advocacy organization, or the Public Guardian and Trustee.<sup>1033</sup> A right of appeal of the board’s decisions existed to the British Columbia Supreme Court.<sup>1034</sup>

The board was dissolved in March 2004, by the *Miscellaneous Statutes Amendment Act (No 3)*, which repealed Part 4 of the *HCCA*.<sup>1035</sup> According to the Ombudsperson, “the Attorney General at that time explained that the board had only conducted eight hearings in its existence, and that the work of the board could be more effectively accomplished through other existing dispute resolution processes.”<sup>1036</sup>

In a 2006 study paper the BCLI commented, “[s]ince the Board was not particularly active, the implication was that it must not be worthwhile. However, upon closer examination, the Review Board may have remained largely dormant because it lacked the correct tools, setup or mandate to fill the capacity review void.”<sup>1037</sup> The BCLI concluded that:

With the Board’s demise, the capacity review void has only deepened. However ineffective, the Review Board did at least provide a forum in which one could challenge a specific finding of incapability or health care decision. After it was abolished, the system was left without a non-court capacity appeal process. This has added to the risk of substantive deprivation of Charter-protected procedural fairness rights for persons wishing to challenge a finding of incapability.<sup>1038</sup>

Further, it is equally possible that limited use of the tribunal reflected lack of awareness.

Capacity review boards currently exist in the Yukon and Ontario. In Ontario, a person may apply to the Consent and Capacity Board for a review of a health care professional’s finding of incapacity, and decisions made by substitute decision makers.<sup>1039</sup> In its 2017 report on *Legal Capacity, Decision-Making and Guardianship*, the Law Commission of Ontario (LCO) commented favourably on Ontario’s Consent and Capacity Board as follows:

With respect to the operation of the Consent and Capacity Board (CCB), the sense is that overall, the flexibility of the HCCA appointment mechanisms and the existence of the CCB as an accessible tribunal providing speedy and relatively responsive adjudication,

The Government of British Columbia should implement an independent non-court review mechanism to enable people to challenge:

- Findings of incapability to consent to health care treatment;
- Choice of temporary substitute decision makers;
- Care facility admission decisions; and
- Decisions made by substitute decision makers with respect to the person's health care, including the use of restraints.

The Provincial Government should engage in robust research and consultation to determine the most appropriate and effective mechanism, and undertake education of health care professionals and staff, and the general public, when the process is implemented.

is an appropriate approach. Critiques of its operations tend to focus on the inherent tension between promoting therapeutic outcomes and upholding fundamental rights, the challenges it faces in meeting its mandates for timeliness and expertise, and the balance between achieving timely resolutions and supporting less adversarial approaches to dispute resolution.<sup>1040</sup>

The LCO ultimately recommended expanding the scope of administrative review of decisions related to capacity and consent through the creation of an expert tribunal which would be a unified access point for matters related to legal capacity, decision making and guardianship, whether brought pursuant to the *Substitute Decisions Act*, the Ontario *Health Care Consent Act* or Part III of the *MHA*.<sup>1041</sup> In addition to this significant recommendation, the LCO proposed “a number of measures to broaden the types of applications that can be brought under the *HCCA*, improve access to mediation and other forms of alternative dispute resolution, and to strengthen existing structures and supports to access to the law”.<sup>1042</sup>

The only other jurisdiction which currently provides for review of health care decisions via tribunal is the Yukon. The Yukon Capacity and Consent Board has jurisdiction to review the decisions of health care providers and substitute decision makers, and to provide direction to substitute decision makers<sup>1043</sup> with respect health care provider determinations of capacity, health care provider choice of temporary substitute decision maker, substitute decision maker decisions to give or review consent to major health care, and care facility admission.<sup>1044</sup> The right to review is not limited to the person subject to decision making: any person with a substantial interest in the matter can make a request to the Board.<sup>1045</sup> A substitute decision maker may also seek direction from the Board regarding consent as it concerns the interpretation of previously expressed wishes.<sup>1046</sup> Similar to the proposed meta tribunal for Ontario, the Board also has jurisdiction over some decisions made pursuant to the *MHA*.

The Manitoba Law Reform Commission recommended a similar tribunal in its review of substitute decision making for health care in 2004, characterizing “speedy, more accessible and less expensive routes of appeal” than available via the courts as “extremely important for the protection of incapable patients’ rights.”<sup>1047</sup> In it is generally understood that, as compared with the court system, tribunals provide better access to justice for vulnerable populations. As Chief Justice Beverley McLachlin (as she then was) has noted:

In sum, without administrative tribunals, the rule of law in the modern regulatory state would falter and fail. Tribunals offer flexible, swift and relevant justice. In an age when access to justice is increasingly lacking, they help to fill the gap. And there is no going back.<sup>1048</sup>

Research and stakeholder consultations suggests it is worthwhile to consider bringing back a capacity and consent review tribunal for BC. This is a large topic, and many

of the details regarding the appropriate system for BC are beyond the scope of this project focused on health care consent for people living with dementia.

◀ **RECOMMENDATION 30** (PAGE 234 SIDEBAR)

## 7.4.2 Legal Representation

### Access to Legal Aid for People with Mental Capacity Issues

In Chapter 3 we discuss a range of legal fora for challenging health care decisions and decision making authority for people living with dementia who may have capacity issues. Key mechanisms are:

1. Pursuant to the *HCCA*, a person may apply to court for orders relating to the implementation and interpretation of advance directives, health care consent decisions made by substitute decision makers, and incapability assessment.<sup>1049</sup> On such an application, the court may make a broad range of decisions, including:

- (a) order the adult to attend at the time and place the court directs and submit to one or more assessments of incapability;
- (b) give directions respecting
  - (i) the interpretation of a provision of an advance directive, or any other health care instruction or wish, made or expressed by an adult when capable, or
  - (ii) who should be chosen to provide substitute consent under this Act for an incapable adult;
- (c) confirm, reverse or vary a decision by
  - (i) an adult's representative or personal guardian, or
  - (ii) a person chosen to provide substitute consent under this Act,
  - (iii) to give or refuse consent to health care or admission to a care facility;
- (d) make any decision that a person chosen to provide substitute consent under this Act could make.<sup>1050</sup>

2. Pursuant to the *PPA*, one year after a committee order is made, any person may apply to the Supreme Court for an order that the person is no longer incapable.<sup>1051</sup> If the application is successful, the person living with dementia would become entitled to make their own health care decisions, subject to the health care provider's obligation to make a determination regarding capacity each time health care is proposed. Alternatively,

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*They're basically paralyzed.  
They can't do anything  
without the funds to  
retain a lawyer.*

– Lawyer

an application can be made to rescind the appointment of a committee, and have another committee appointed.<sup>1052</sup>

3. A patient who has been involuntarily detained under the *MHA* is entitled to a hearing by the review panel at specified intervals to determine whether detention should continue.<sup>1053</sup> Judicial review of a determination of a review panel is possible.<sup>1054</sup> In addition, a patient, or a person on their behalf, who believes that there is not sufficient reason or legal authority for a certificate respecting the patient may apply to the court for an order that the person not be apprehended, transported or admitted to a designated facility, or be discharged from one.<sup>1055</sup> Further a *habeas corpus* application can be filed to bring the matter of detention before the BC Supreme Court.

Legal aid is not generally available for advice or representation in relation to the above matters, other than a review panel constituted by the Mental Health Review Board, although the Legal Services Society does have some discretion to award funding in unique situations where a person with a mental illness requires legal advice or representation.

Mental health law is an area of particular concern to people living with dementia and their families. Comments by family caregivers identified a need for access to legal advice when a person living with dementia is involuntarily committed under the *MHA*. At least two informants shared stories of their spouse being involuntarily committed under the *MHA*; both appeared very confused about what had happened, and neither had been advised that they might be able to challenge the decision.

In the civil context, legal aid in BC is largely restricted to family matters, particularly those involving denial of parenting time or contact with children, violence, harassment, trauma, and the safety of children, or removal of children from the province.<sup>1056</sup> Legal aid is not available to obtain advice or representation for people wishing to challenge the following decisions or actions, by way of court application:

- A formal or informal finding of incapability to make a health care decision;
- A health care provider's choice of Temporary Substitute Decision Maker;
- A health care decision made by a substitute decision maker, including a decision regarding use of a restraint under the *RC Regulation*<sup>1057</sup>;
- The interpretation by a health care provider or substitute decision maker of an advance directive or other health-related wish expressed while capable; or
- An application to be appointed committee of the person pursuant to the *PPA*.

In previous work BCLI has argued for the provision of legal aid in the guardianship context.<sup>1058</sup> The BCLI asserted that a failure to provide legal aid in situations where fundamental autonomy rights are at stake may infringe the principles of fundamental justice:

In *New Brunswick (Minister of Health and Community Services) v. G.(J.)*[J.G.] [[1999] 3 S.C.R. 46, S.C.J. No. 47] the Supreme Court of Canada concluded that the failure to provide a parent with legal aid in custody proceedings infringed principles of fundamental

justice. The Court held that, while a blanket right to state-funded counsel does not exist, a limited right to state-funded counsel arises under section 7 of the Charter where the seriousness of the interests at stake, the complexity of the proceedings and the capacities of the parent are such that a fair hearing would not be possible without legal representation.

...

A guardianship application engages the same serious interests, and may involve complex medical testimony. The capacity of the subject adult has already been placed in question by the very nature of the proceedings. Hence, legal representation is essential to ensure that the adult is able to present his or her case effectively. Otherwise, the presumption of capacity is meaningless.<sup>1059</sup>

The BCLI drew an analogy between the serious effects of incarceration, which can trigger legal aid entitlement, and the potentially serious effects of guardianship.<sup>1060</sup> Consequently, the BCLI has recommended legal aid be made available for adults facing guardianship proceedings.<sup>1061</sup> Health care decision making, some of which may include end of life decisions, and major quality of life matters, can have equally serious effects on liberty.

More recently, several developments in 2017 have highlighted the need for legal aid for civil matters where mental capacity is at issue.

1. BC non-profit organizations came together to produce a report which identified their collective priorities for reform and improvement of BC's justice system.<sup>1062</sup> One of the key priority areas where they recommended change was expanded funding for coverage of legal aid in BC for guardianship matters and issues arising pursuant to the *HCCA*. The report asks the government to "Ensure genuine access to justice by strengthening legal aid and legal services", including to "Extend funding for legal services to all people whose liberty is being infringed, including under the following Acts: the *Adult Guardianship Act*, *Mental Health Act*, *Patients Property Act*, *Health Care (Consent) and Care Facility (Admission) Act*."

2. A report by Community Legal Assistance Society (CLAS) pointed out that access to legal aid is particularly urgent for people who have been involuntarily committed, due to an entitlement to rights advice under the Act that is generally met by assigning health care staff with no training in the law to provide legal information.<sup>1063</sup> At this time, the CLAS Mental Health Law Program is only funded to speak with people who have "applied to the Mental Health Review Board for a review panel hearing, had a hearing scheduled, applied to the Mental Health Law Program for representation, and been assigned an advocate or lawyer."<sup>1064</sup> To remedy this gap in prompt access to rights information and legal advice upon involuntary committal, the CLAS report recommends that "the Legal Services Society provide funding for detainees to access legal advice on detention and detention renewal."<sup>1065</sup> In December 2017 the Canadian Bar Association BC Branch issued a statement in support of the CLAS report.<sup>1066</sup>

3. The Canadian Bar Association BC Branch produced an "Agenda for Justice" ahead of the 2017 provincial elections, detailing the organization's vision for improved access to justice in

The structure of legal aid should be amended to include funding for prompt legal advice and representation regarding any legal action or proceeding that could remove or restore health care decision making autonomy, including:

- Applications pursuant to s. 33.4 of the *Health Care (Consent) and Care Facility (Admission) Act*, including capacity to consent to admission to a care facility;
- Challenges to applications for a committee of the person pursuant to the *Patients Property Act*; and
- Involuntary committals, and reviews of involuntary committals, under the *Mental Health Act*.

BC.<sup>1067</sup> A key recommendation was “[a] properly funded Legal Aid Service available to those who need it throughout BC.”<sup>1068</sup>

The new provincial government has recently increased funding for legal aid in the province after over a decade of funding constraints. However, there remains significant concern that the increases are not sufficient.<sup>1069</sup>

Access to legal aid is particularly important for people whose capacity is questioned because they may not have access to their own funds due to a finding of incapability. It is our view that British Columbians should be provided with access to legal information, advice and representation with respect to any:

- Decision that effectively undermines their health care decision making autonomy; and
- Mechanism for challenging that loss of decision making autonomy.

## RECOMMENDATION 31

### Barriers to Capacity to Retain and Instruct Counsel

*Most lawyers are very reluctant to do section 7 Agreements for somebody that's obviously got less than full capacity.*

– Lawyer

The test for capacity to instruct counsel is a common law test deriving from the general principles of contract law, and the law of agency.<sup>1070</sup> The test is considered to be of a relatively high threshold since it requires an understanding of legal and financial issues.<sup>1071</sup> The person must be capable of understanding the retainer’s terms, and “forming a rational judgment of the effect upon his interests”.<sup>1072</sup> Determining capacity to instruct and retain counsel requires an assessment of the facts of each case, and is not the subject of an articulated test.<sup>1073</sup>

In contrast, the threshold for capacity to make a section 7 representation agreement for supportive or substitute decision making is generally considered to be lower.<sup>1074</sup> The Act states explicitly that “[a]n adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of (a) making a contract.”<sup>1075</sup> No guidelines exist, however, for making this capacity determination; the statute states that in determining whether an adult is incapable of making a section 7 representation agreement “all relevant factors must be considered, for example:

- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- (d) whether the adult has a relationship with the representative that is characterized by trust.<sup>1076</sup>

The BCLI has stated that this dynamic creates a legal problem in that a person with capacity issues is legally permitted to make a representation agreement, but may not be able to retain counsel to assist in making the agreement: essentially a person living with dementia may have capacity to create a representation agreement, but not have capacity to sign a retainer agreement. Key informants commented that some lawyers are reluctant to assist people who cannot sign a retainer.

The Law Society of BC Code of Professional Conduct for BC imposes some limitations on a lawyer’s ability to represent “clients diminished capacity;” however, the language of rule 3.2-9 is clear that lawyers are permitted to represent clients who have capacity issues. The rule stipulates that “[w]hen a client’s ability to make decisions is impaired because of minority or mental disability, or for some other reason, the lawyer must, as far as reasonably possible, maintain a normal lawyer and client relationship.”<sup>1077</sup> The Code includes language that recognizes the variability of mental capacity, and underscores that capacity is not determined by disability:

[1] A lawyer and client relationship presupposes that the client has the requisite mental ability to make decisions about his or her legal affairs and to give the lawyer instructions. A client’s ability to make decisions depends on such factors as age, intelligence, experience and mental and physical health and on the advice, guidance and support of others. A client’s ability to make decisions may change, for better or worse, over time. A client may be mentally capable of making some decisions but not others. The key is whether the client has the ability to understand the information relative to the decision that has to be made and is able to appreciate the reasonably foreseeable consequences of the decision or lack of decision. Accordingly, when a client is, or comes to be, under a disability that impairs his or her ability to make decisions, the lawyer will have to assess whether the impairment is minor or whether it prevents the client from giving instructions or entering into binding legal relationships.<sup>1078</sup>

The language of the Code of Professional Conduct appears to ground the ethical rule in a test determined by the particular legal matter at issue, which would seem to suggest a lawyer could draft a representation agreement for a person living with dementia who did not have capacity to enter into a contract generally. Indeed, in an article entitled, “Acting for a client with dementia”, Law Society Practice Advisor Barbara Buchanan QC has written:

For statutory tests of capability, look for the relevant statute and how the statute may have been interpreted by the court. The client may, for example, have the capacity to appoint

The *Representation Agreement Act* should be amended to provide that a person with mental capacity to make a representation agreement with standard provisions under section 7 of the statute also has the mental capacity to retain and instruct counsel for the purpose of advising on drafting the representation agreement.

a representative to help with decisions or to make decisions about personal care, health care, the routine management of financial affairs, and obtaining legal services and instructing counsel under section 7 (standard provisions) of the *Representation Agreement Act (RAA)* and to appoint a monitor.<sup>1079</sup>

However, in the same article she notes that the inability to enter into a contract with a lawyer will generally pose a barrier:

However, a lawyer should typically not act for a person who is otherwise incapable of entering into a retainer agreement with the lawyer. The Ethics Committee has not, as yet, given an opinion on whether it would recommend a change to BC Code rule 3.2-9 to clarify whether a lawyer may act for a client for a section 7 representation agreement in a situation where the client may be otherwise incapable of making a contract.<sup>1080</sup>

In order to address this legal anomaly, the BCLI has recommended that the *RAA* be amended to include the following provision:

An adult who has the capacity to make a representation agreement consisting of the standard provisions authorized by section 7... is deemed to have the capacity to retain and instruct counsel for the purpose of advising on and drafting the representation agreement.<sup>1081</sup>

The recommendation of the BCLI, which may resolve the lack of clarity through a legislative amendment, has not been implemented. We reiterate it here.

#### RECOMMENDATION 32

However, lawyers may still run into barriers in terms of enforcing payment. The Law Society does not appear to be concerned with lawyers drafting representation agreements on a *pro bono* basis, nor with lawyers practicing with non-profits, such as Seniors First BC representing clients with capacity issues who require section 7 agreements.

### 7.4.3 Knowledge of Health Care Decision Making Rights and Responsibilities

#### Information Provided on Admission to Long-Term Care

Based on our consultation with stakeholders, many family caregivers understand their rights and responsibilities as substitute or supportive decision maker for health



care. We also noted that some people living with dementia and their family members require a better understanding of their rights and responsibilities as part of the health care consent process. Certainly all focus group participants valued the legal information component of the Health Care Consent Project consultation sessions. Many health care professionals and social workers also expressed concern that substitute decision makers do not understand their role.

Various agencies in BC are engaged in providing public legal education about substitute and supportive decision making, and health care consent. Nidus Personal Planning Resource Centre and Registry has developed fact sheets on health care consent, and delivers information sessions on the topic in community and to professionals. Health care rights materials have also been produced by Seniors First BC, the BC Health Coalition, the PGT, and the Ministry of Health. There appears to be a fairly reasonable amount of accurate written information available online that would be accessible to people with a high level of English literacy who know how to conduct research online, or how to find a referral to an advocacy agency for assistance.

Family caregivers desire strategic guidance on how to exercise their rights and responsibilities, and support when they are struggling to exercise their health care decision making rights and responsibilities, particularly within long-term care. Many caregivers reported great difficulty accessing any information about the person living with dementia's care, or getting staff to address their concerns about care. As a result, we recommend more proactive efforts to ensure long-term care residents, family caregivers, and substitute and supportive decision makers understand their rights and responsibilities with respect to health care consent. We have identified three possible law or policy sites for reform mandating that long-term care facilities provide information with respect to health care consent and substitute and supportive decision making to residents and their families at the time of admission:

1. The care facility admission provisions of the *HCCA* or associated regulations;
2. Section 48 of the *RC Regulation*, which currently requires that licensees provide certain advice to incoming residents or their representative prior to admission, including information on the “the policies of the community care facility respecting expressing concerns, making complaints and resolving disputes” as well as information on the facility’s complaint processes; and
3. With respect to publicly subsidized care facilities, the Ministry of Health develops policies set out in the Home and Community Care Policy Manual on which the health authorities must base their own operational policies and procedures.

We leave it to future discussion to determine the most impactful site of reform on this issue. However, we note that care facilities may require support from the

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*“I think most residential care sites have some kind of welcome packet or intro packet and put lots of different pamphlets and information in there. I think it would be great to have some information on what it means to be a substitute decision maker or temporary substitute decision maker.*

**– Social worker**

## 33

Long-term care facilities should be required to provide written educational information on health care consent rights and substitute and supportive decision making rights and responsibilities to both residents and their substitute or supportive decision makers at the time of admission, or shortly thereafter. Such information should be provided in the language they prefer, or where that is not possible, read to them through the use of a professional interpreter as soon as can be practically arranged.

## 34

The Government of BC should develop a comprehensive public education plan regarding supported and substitute decision making for health care, including representation agreements, and also including additional funding to non-profit agencies to further engage in this work.

Ministry of Health or the provincial health authorities in order to enhance their efforts in this area.

### RECOMMENDATION 33

#### Representation Agreements and Supported Decision Making

*I think there's a lot of misconceptions about what the representative can do. I think there's a lot of confusion about power of attorney versus representative, and what kind of decision-making they can each do, and like I said, I think that confusion is amongst patients, it's amongst health care professionals, [and] I think it's amongst legal counsel.*

– Pharmacist

As discussed throughout this report, in BC supported decision making relationships can be legally recognized by way of representation agreements. Consultation revealed that many people living with dementia and their family caregivers consider health care decision making a collaborative activity, and desire greater inclusion of their supportive decision makers in decision making and care. However, it appears that lack of knowledge of formal supported decision making through representation agreements is pervasive among health care professionals and other staff, people living with dementia, and family caregivers. Key informants indicated that representation agreements are rarely used.

The lack of uptake of supported decision making for health care raises concerns regarding the extent of public legal education with respect to representation agreements. While many non-profit agencies in BC are engaged in teaching people about representation agreements and supported decision making, widespread public education is required, particularly if supported decision making is to be further embedded into the *HCCA*.

### RECOMMENDATION 34



# List of Recommendations

## LAW REFORM

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### Recommendation 1

The *Health Care (Consent) and Care Facility (Admission) Act* should be amended to recognize that capacity can vary in the following manner:

- A person may be incapable with respect to some decisions regarding treatment, and capable with respect to others; and
- A person may be incapable with respect to a treatment at one time, and capable at another.

### Recommendation 2

The *Health Care (Consent) and Care Facility (Admission) Act* should be amended to state that every adult, regardless of capacity, has the right to:

- Receive support in decision making provided by a family member or friend whom they trust, if they choose to do so; and
- Be involved to the greatest degree possible in all case planning and decision making.

### Recommendation 3

The Government of BC should consider amending the *Health Care (Consent) and Care Facility (Admission) Act* such that the right to support, and the right to participate in case planning and decision making, apply to all adults, including adults currently excluded by the combined impact of section 2 and the deemed consent provisions of the *Mental Health Act*.

### Recommendation 4

Section 81 of the *Residential Care Regulation* should be amended to clarify that informed consent of the resident, or the substitute decision maker if the resident does not have capacity to consent, must be obtained prior to finalizing or amending any aspects of the resident's care plan that relate to health care treatment.

### Recommendation 5

The *Residential Care Regulation* should be amended to require that care facilities maintain detailed policies on staff and health care professional obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflect the *Health Care (Consent) Care and Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

### **Recommendation 6**

The *Residents' Bill of Rights* included in the *Community Care and Assisted Living Act* should be amended to include clear language informing people in reasonable detail of their health care consent rights, including a specific reference to the rights to:

- Give, refuse, or withdraw consent to any non-emergency medication and treatment, where they have the capacity to consent to that decision;
- Receive the support of a supportive decision maker, if they choose to do so; and
- Have their substitute decision maker make a decision if they do not have capacity.

### **Recommendation 7**

Reform of guardianship law should be explored in order to bring greater consistency to the statutory duties of all substitute decision makers for health care in British Columbia, and greater compliance with the general principles contained in the United Nations Convention on the Rights of Persons with Disabilities.

### **Recommendation 8**

The *Community Care and Assisted Living Act* (and associated provisions of the *Residential Care Regulation*) should be amended to require that in non-emergency situations, agreement to the use of any form of restraint must be obtained in the same manner as consent to health care under the *Health Care (Consent) and Care Facility (Admissions) Act*. The provisions should include:

- A presumption of capacity;
- A requirement that the consent be informed;
- A hierarchy of substitute decision makers; and
- An independent decision maker as a last resort, such as the Public Guardian and Trustee.

The use of the term “representative” should be avoided unless used to reference a representative under a representation agreement.

### **Recommendation 9**

Section 75(3) of the *Residential Care Regulation* should be amended to:

- Require consent of either the adult, or their substitute decision maker, when emergency use of a restraint continues for more than 24 hours; and
- Recognize the right of the adult, or the substitute decision maker, to revoke their consent to the use of the restraint.

### **Recommendation 10**

Section 73(3) of the *Residential Care Regulation* should be amended to require that the resident's substitute decision maker, if any, be informed of any emergency use of a restraint as soon as possible after its use, including:

- The reasons for its use; and
- The duration of its use.

### **Recommendation 11**

The restraint provisions of the *Residential Care Regulation* should be amended to define chemical restraint as the administration of psychotropic medication to prevent harm to a resident or others in situations where a resident has lost behavioural control, or where there is imminent risk of loss of control in behaviour.

### **Recommendation 12**

Section 85 of the *Residential Care Regulation* should be amended to include a requirement that long-term care facilities have a detailed policy on the use of restraints, in both emergency and non-emergency situations, which outlines:

- The consent process; and
- Requirements for advising substitute decision makers.

## **PRACTICE SUPPORT AND HEALTH CARE PROVIDER EDUCATION**

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### **Recommendation 13**

The College of Physicians and Surgeons of British Columbia should disseminate to all members materials aimed at supporting physicians to better understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflect the *Health Care (Consent) Care and Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

### **Recommendation 14**

The BC Ministry of Health's *Health Care Providers' Guide to Consent to Health Care* should be amended in the following manner:

- Include discussion of the importance of using professional interpreters, and awareness of hearing and speech issues, in determining capacity, and providing information about treatment;
- Add information on supported decision making by way of a representation agreement;

- Clarify that consent to non-psychiatric treatment is still required under the *Health Care (Consent) and Care Facility (Admission) Act* where a patient is involuntarily committed under the *Mental Health Act*; and
- Provide expanded information on the role of the Public Guardian and Trustee with respect to health care consent.

### **Recommendation 15**

The General Practices Services Committee Divisions of Family Practice and the UBC Faculty of Medicine Divisions of Geriatric Medicine and Geriatric Psychiatry should undertake educational work aimed at supporting physicians to better understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflects the *Health Care (Consent) Care and Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

### **Recommendation 16**

The BC College of Nursing Professionals should publish, and widely disseminate to all registrants, material on a nurse's informed consent obligations, with a particular focus on the licensed practical nurse and registered nurse's role with respect to consent to health care treatment prescribed by physicians in long-term care.

### **Recommendation 17**

The British Columbia Ministry of Health and the Ministry of Advanced Education, Skills and Training should review and amend the Health Care Assistant Core Competency Profile (March 2014) and the Health Care Assistant Provincial Curriculum (2015) to ensure that health care assistants receive training on health care consent and substitute decision making, including clarification of the role of health care assistants in facilitating the consent process as a member of an inter-disciplinary team.

### **Recommendation 18**

Working with relevant partners, the Care Aide and Community Health Worker Registry should develop an educational module for health care assistants on health care consent and substitute decision making processes, including the role of Public Guardian and Trustee, which reflects the *Health Care (Consent) Care and Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation. The Registry should make this course easily accessible to its registrants, promote it widely, and consider methods of incentivizing registrants to undertake the course.

### **Recommendation 19**

The BC Health Regulators should work with the appropriate regulatory colleges, the British Columbia Ministry of Health, and key organizations such as Doctors of BC, to develop educational modules on incapability assessment with respect to health care decision making and care facility admission. Content should provide guidance on:

- How to engage the person being assessed in the assessment process?

- What is the appropriate involvement of supportive family and friends in the assessment process, and what emphasis should be placed on their views when they differ from the perception of the person living with dementia?
- What is the appropriate involvement of different health care professionals and various members of the care team in the assessment process?
- How to appropriately document findings?
- What is the impact of hearing, speech and language issues on incapability assessment?
- How can variables such as medication and time of day be reflected in the process so as to support the person living with dementia to present with as much capacity as is possible for them?
- What avenues are available to a person who wishes to challenge a finding that the person is incapable of making a health care treatment or care facility admission decision?

### **Recommendation 20**

The College of Physicians and Surgeons of British Columbia should amend Bylaw 3-5(1)(b) to:

- Require that physicians' clinical records include a clear record of the health care consent process, including:
  - who provided, or refused to provide, informed consent;
  - how consent was provided; and
  - when the informed consent was provided; and
- Clarify how to update the record when the physician is prescribing medication over the telephone, or through another offsite method.

The College should also educate members regarding changes to the bylaw.

### **Recommendation 21**

The provincial health authorities should deliver training on dementia to all staff providing services or care to older people (including nursing professionals, health care assistants, community health workers, social workers, and physicians) with the goal of advancing knowledge, undermining myths, and reducing stigma.

### **Recommendation 22**

In order to better support the practice of all health care professionals and staff, a best practice guideline should be developed which addresses how to:

- Engage people who are living with dementia in health care decision making; and
- Maximize the capacity of people living with dementia to participate in their health care decisions.



### Recommendation 23

The BC Ministry of Health should develop a province-wide policy on whether and under what circumstances, if any, the use of involuntary commitment under the *Mental Health Act* is appropriate for older people living with dementia.

### Recommendation 24

The provincial health authorities, on behalf of the BC Ministry of Health, should develop a system to:

- Collect data regarding the use of the involuntary commitment and extended leave provisions of the *Mental Health Act*; and
- Make its findings publicly available through annual reporting of statistics.

The data collected should enable an analysis of how the *Mental Health Act* is used with older people living with dementia by tracking information on:

- The demographics of people detained, such as age, gender, and diagnoses; and
- What *Mental Health Act* powers are used, such as involuntary admission frequency and duration, frequency and duration of extended leave, location of extended leave placements, and recalls from extended leave.

### Recommendation 25

The provincial health authorities should explore strategies to increase resources, such as social workers, available to all employees, physicians, and contractors who work in long-term care, and home and community care, to ensure they fully understand their obligations with respect to health care consent and substitute decision making processes, including the role of Public Guardian and Trustee in a manner which reflects the *Health Care (Consent) Care and Facility (Admission) Act*, the *Representation Agreement Act*, and other relevant provincial legislation.

## SYSTEMIC BARRIERS AND STRUCTURAL CHANGE

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### Recommendation 26

The provincial health authorities should explore strategies for making social work services more available in order to better support older people living with dementia, their family members, and their supportive and substitute decision makers with health care decision making.

### Recommendation 27

The Doctors of BC and the Ministry of Health should collaborate to develop incentive payments to encourage and support physicians to:

- Engage in robust conversations with patients living with dementia about health care treatment decisions in order to ensure their consent is informed; and
- Undertake incapability assessments of patients living with dementia where capacity for a specific health care decision is at issue.

### Recommendation 28

The First Nations Health Authority, Indigenous Health within the Ministry of Health, and Aboriginal Health leads within each of the other health authorities should engage in discussions with Indigenous communities in order to better understand and address barriers to informed consent to health care experienced by Indigenous people in British Columbia.

### Recommendation 29

The Ministry of Health should develop a plan to:

- Expand access to language interpretation for people living with dementia who reside in affiliated or contracted long-term care facilities, as well as their family members and supportive and substitute decision makers; and
- Improve health care professional and staff awareness of language interpretation services.

## ACCESS TO JUSTICE AND INFORMATION

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### Recommendation 30

The Government of British Columbia should implement an independent non-court review mechanism to enable people to challenge:

- Findings of incapability to consent to health care treatment;
- Choice of temporary substitute decision makers;
- Care facility admission decisions; and
- Decisions made by substitute decision makers with respect to the person's health care, including the use of restraints.

The Provincial Government should engage in robust research and consultation to determine the most appropriate and effective mechanism, and undertake education of health care professionals and staff, and the general public, when the process is implemented.

### Recommendation 31

The structure of legal aid should be amended to include funding for prompt legal advice and representation regarding any legal action or proceeding that could remove or restore health care decision making autonomy, including:

- Applications pursuant to s. 33.4 of the *Health Care (Consent) and Care Facility (Admission) Act*, including capacity to consent to admission to a care facility;
- Challenges to applications for a committee of the person pursuant to the *Patients Property Act*; and
- Involuntary committals, and reviews of involuntary committals, under the *Mental Health Act*.

**Recommendation 32**

The *Representation Agreement Act* should be amended to provide that a person with mental capacity to make a representation agreement with standard provisions under section 7 of the statute also has the mental capacity to retain and instruct counsel for the purpose of advising on drafting the representation agreement.

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Long-term care facilities should be required to provide written educational information on health care consent rights and substitute and supportive decision making rights and responsibilities to both residents and their substitute or supportive decision makers at the time of admission, or shortly thereafter. Such information should be provided in the language they prefer, or where that is not possible, read to them through the use of a professional interpreter as soon as can be practically arranged.

**Recommendation 34**

The Government of BC should develop a comprehensive public education plan regarding supported and substitute decision making for health care, including representation agreements, and also including additional funding to non-profit agencies to further engage in this work.

# Table of Key Informants

Stakeholder	Title/Position/Credentials
<b>Lawyers/ Advocates</b>	
Hugh S McLellan	Barrister and Solicitor
Jaqua Page	Barrister and Solicitor
Kevin R Smith	Elder law lawyer, retired
Emily Clough	Barrister & Solicitor, Clark Wilson LLP
Grace Balbutin	Formerly Director, Seniors Abuse and Information Line, and Program Manager, Community-Based Victim Services, Seniors First BC
<b>Pharmacy</b>	
Ann Johnston	M Pharm, RPh; Manager, Pharmacy Practice Support, BC Pharmacy Association
Glen Schoepp	BCPhA; Community Pharmacist
<b>Medicine/Psychiatry</b>	
Dr. Margaret J McGregor	MD MHSc; Home ViVE Physician, Vancouver General Hospital STAT Centre; Clinical Associate Professor & Director of Community Geriatrics, Faculty of Medicine, Department of Family Practice, University of British Columbia
Dr. Joy Masuhara	MD, CCFP; Physician at Vancouver Coastal Health Community Older Adult Mental Health and Substance Use Services; member of Vancouver Division of Family Practice, Residential and Frail Elder Care Committee; member of Seniors Task Force, S.U.C.C.E.S.S.
Dr. Sue Turgeons	MD, CCFP
Dr. Elisabeth Drance	Geriatric Psychiatrist, Vancouver Coastal Health and Providence Health Care
Dr. Martha Donnelly (deceased)	MD, Retired; Division Head, Geriatric Psychiatry (2002-2012), Community Geriatrics, Department of Family Practice, (1987-2011), Director of the Subspecialty Residency Program for Geriatric Psychiatry (2011 to 2016), UBC
Dr. A Maria Chung	Clinical Associate Professor, Division of Geriatric Medicine, UBC Faculty of Medicine
Dr. Conrad Rusnak	CCFP; Physician Home-Vive Program, Vancouver Coastal Health; Director, UBC Enhanced Skills in Care of the Elderly
Dr. Michael Wilkins-Ho	MD, FRCPC; (former) UBC Clinical Associate Professor Head, Division of Geriatric Psychiatry (UBC); Director Geriatric Psychiatry (UBC); Medical Manager, Older Adult Tertiary Program at Willow
Dr. Leena Jain	Geriatrician, Fraser Health; Clinical Instructor, UBC
Dr. Carol Ward	MD FRCPC; Geriatric Psychiatrist
Dr. Ritesh Parekh	MBBS MPH FACP; Clinical instructor UBC, Internal and Geriatric medicine
Dr. Heidi Oetter	Registrar & CEO, College of Physicians and Surgeons of British Columbia
Dr. Galt Wilson	Senior Deputy Registrar, Complaints and Practice Investigations and Library Services, College of Physicians and Surgeons of British Columbia

<b>Stakeholder</b>	<b>Title/Position/Credentials</b>
Dr. Karin Blouw	MD CCFP FCFP; Year 3 RFP Course Co-Director, UBC Department of Family Practice; Site Lead - Northwest, Northern Medical Program, University of Northern BC; Board Chair, Pacific Northwest Division of Family Practice
<b>Health Authorities</b>	
Leanne Lange	Clinical Specialist, Adult Abuse & Neglect, Fraser Health
Melinda Allison	MSW; Specialist, Adult Abuse & Neglect, Northern Health Regional Office
Matt Scott	Family & Social Support Practitioner, Three Bridges Community Health Centre, Vancouver Coastal Health; previously Clinical Specialist for Vulnerable and Incapable Adults, Vancouver Island Health Authority
Judy Nicol,	RSW; Regional Practice Leader, Interior Health Authority
Gina Gasbard	RN, MN, GNC (c); First Nations Health Authority, BC
Fancy C Poitras,	Senior Policy Analyst, Strategic Policy, Policy, Planning & Quality, First Nations Health Authority
Carmela Vezza	Operations Director, Long Term Care, Island Health
Kirsten Thomson	Regional Director, Risk & Compliance, Northern Health Authority
Chris Rauscher	Community Consultant in Geriatric Medicine, Vancouver, BC
Elizabeth Pearce	RN BSN; Home & Community Care Manager, First Nations Health Authority
Cari Borenko Hoffmann,	BA BSW RSW; Coordinator, Advance Care Planning, Fraser Health; Clinical Instructor, Dept of Medicine, UBC
<b>Directors of Care/ Res Care Admin/Medical Coordinators</b>	
Al Jina,	BCom, LLB; President and Legal Counsel, Park Place Seniors Living
Lynda Foley	RN, MN, GNC (c); Chief Nursing Officer and VP Quality Assurance, Park Place Seniors Living
Dr. Ralph Jones	General Practice, Chilliwack; Board Member, Divisions of Family Practice
Joy Hall	R.N. GNCC; Director of Care, Augustine House, Ladner, BC
<b>Alzheimer's Society</b>	
June Murray	B.Soc.Sci, RN, GNC(C); Director, Programs & Services, Alzheimer Society of B.C.
<b>Public Guardian and Trustee</b>	
Kimberley Azyan,	Executive Director Services to Adults, Public Guardian and Trustee
Goran Todorović,	Manager, Assessment & Investigations Services and Health Care Decisions Services to Adults, Public Guardian and Trustee
Grainne Sheridan	Case Manager, Services to Adults, Public Guardian and Trustee
<b>Nursing</b>	
Anita Dickson	President, Licensed Practical Nurses Association of BC
Jennifer Baumbusch	RN, PhD; Associate Professor, School of Nursing, University of British Columbia
Lillian Hung	RN, PhD; Clinical Nurse Specialist, Vancouver Coastal Health, Clinical Assistant Professor, University of British Columbia
Lori Amdam	RN, MSN; Education Consultant, Gerontology, Vancouver Island
Tansey Ramanzin	Professional Conduct Review Consultant, Regulatory Compliance, British Columbia College of Nursing Professionals
Adrienne Kehl	RN, BScN; Regional Practice Lead – Home Health, Hospitals and Communities Integrated Services, Interior Health Authority

<b>Stakeholder</b>	<b>Title/Position/Credentials</b>
Chris Armeanu	Executive Councillor, Pensions and Seniors' Care, BC Nurses' Union
Marlene Goertzen	LPN; Regional Co-Chair, Central Vancouver, BC Nurses' Union BC
<b>Social Work</b>	
Lynda Lougheed	MSW; Vancouver Acute Social Work Practice Lead
Monica Tarnowsky	Social worker, Vancouver Coastal Health
Chris Whyte	RSW, MSW, MA; Social Work Site Leader – Residential, Providence Health Care, Youville Residence
Tracie Janzen	BSW; Social Worker, Northern Health
<b>Ethicists</b>	
Jenny Young,	Director, Ethics Services, Providence Health Care
<b>Ministry of Health</b>	
Karen Archibald	Karen Archibald, Director, Strategic Initiatives, Seniors Services Branch. Ministry of Health
Sue Bedford	Director, Community Care Facility Licensing and Director, Assisted Living Registry, Ministry of Health
Alix Adams	Alix Adams, Director, Palliative and Dementia Care, Seniors Services, Ministry of Health
Scott Wingrove	Manager, Strategic Policy, Seniors Services, Ministry of Health
Gerrit Van der Leer	Director, Mental Health and Substance Use, Specialized Services Division, Ministry of Health
Brian Westgate	Director Strategic Priorities, Professional Regulation and Oversight, Ministry of Health
<b>Speech &amp; Hearing</b>	
Mardi-Lowe Heistad	Mardi Lowe-Heisted, RSLP, Certified by SAC; Director, Quality Assurance & Professional Practice, College of Speech & Hearing Health Professionals of BC
<b>Other</b>	
Leanne Dospital	Advocate for Service Quality
Jennifer Lyle	Chief Executive Officer, SafeCare BC
Gerritt W Clements	Barrister and Solicitor; Health Law and Ethics Educator and Consultant; Adjunct Professor, Schools of Nursing (University of Victoria and University of Northern British Columbia)
Lara Williams	MA; Consultant, Education Assessment, BC Care Aide & Community Health Worker Registry
<b>Caregiver Organizations</b>	
Barb MacLean	Executive Director, Family Caregivers of British Columbia

# Key Informant Questions

1. Please summarize your professional experience in relation to:
  - a) health care consent for older people, including adults with and without capacity to make their own decisions'; and
  - b) consent to, and use of, restraints for older people living in long-term care, acute care, and extended care settings, particularly in terms of use of anti-psychotics.
2. What kinds of health care settings do you work with older people living with dementia? (eg acute hospital, long-term care, home and community care, mental health).
3. What regulations, policies or guidelines with respect to consent issues in health care and restraint, government or otherwise, do you regularly come across or use in your work?
4. Are the regulations in the *Health Care (Consent and Care Facility (Admission) Act* or the *Residential Care Regulations* frequently cited, referred to, and used to guide your work, respond to cases, and educate and train staff? What other regulations do you apply if your work in relation to health care consent or use of restraints?
5. Is your work guided more by the individual policies or guidelines of care facilities on issues of consent and restraint? If so, which policies do you work with?
6. In your professional experience, what are the main issues that arise on a regular basis with respect to older patients or residents and consent to health care? (Canvas topics such as substitute decision making processes, disagreement resolution, complaint processes, end of life care, role of the health professional, role of the public guardian, as well as issues of consent to admission to care facilities.)
7. Are decision making processes in the event of an adult's incapacity generally well known and clear to facility staff, health care staff, government service departments, advocacy organizations and family members of the older person? What, if any, are some common misconceptions or areas of confusion or vagueness?
8. In your professional experience, what are the main issues that arise on a regular basis with respect to older adults and practices surrounding the use of restraints, in particular chemical restraints and anti-psychotic medications.
  - a. Are staff and health care providers clear on what constitutes restraint, consent requirements for uses of restraint, restraint regulations? Are antipsychotic medications which are used to manage behaviour considered by staff to be the use of a restraint?

- b. Are policies and regulations consistent and applied consistently across settings? (for instance, between different long-term care providers and extended care settings, between acute care hospital and long-term care settings.)
9. Do you feel that the areas of consent to health care and chemical restraint of older adults is sufficiently regulated? For instance, is your work and that of organizations and people you work with adequately guided by regulation and/or policies? Is this regulation consistent? Are there areas of confusion or common misconception?
10. Can you identify any noteworthy discrepancies that exist between practice in long-term care facilities with respect to health care consent and use of restraint, and the legal regulation of this area?
11. Possible other areas to discuss depending on expertise:
  - a. Likely impact of the new provisions of *Health Care (Consent) and Care Facility (Admissions) Act* regarding admission to a care facility expected to come into force on issues discussed above;
  - b. Intersection of *Mental Health Act* and long-term care admission;
  - c. Any barriers to consent which you have noticed which are specific to particular groups, such as particular ethno-cultural communities, Indigenous communities, women/men, geographic location (eg. rural or remote) etc.
  - d. Levels of training and education of staff and health care providers who work at long-term care and other settings on health care consent law and policies.
12. Other issues identified by the key informant.



# Survey of Family Caregivers

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1.

**The Canadian Centre for Elder Law, in collaboration with the Alzheimer Society of British Columbia, is examining the law, policy and practice of consent to health care in the context of aging and dementia. This 16-month project funded by the Law Foundation of British Columbia involves extensive comparative legal research on informed consent and interrelated areas of the law, as well as community and key stakeholder consultation. The work is informed by an expert interdisciplinary advisory committee and will culminate in a report identifying areas for law and practice reform and at least one plain language educational resource on health care consent rights.**

**This year we have been holding focus groups with people living with dementia and their family caregivers to learn more about your experiences with health care consent. As a final step in consultation we are conducting this online survey of family caregivers of people living with dementia who make health care decisions or assist with health care decisions for the person living with dementia.**

**More on this project: <https://www.bcli.org/project/health-care-consent-aging-and-dementia-mapping-law-and-practice-in-british-columbia>**

1. Do you, or did you in the past, make health care decisions for a person living with dementia, or assist them with health care decisions?

BC law defines health care as anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health. Health care decisions include decisions about medication and treatment, including participation in drug trials, testing and surgery.

Yes

No

2. Does/did the person living with dementia live in British Columbia?

Yes

No

3. Please complete the following statement. The person for whom I made or make health care decisions is my...

- Mother
- Father
- Mother-in-law
- Father-in-law
- Adult child
- Under-age child
- Spouse / husband/ wife/ life partner
- Boyfriend / girlfriend
- Grandmother
- Grandfather
- Sibling
- Friend
- Prefer not to answer
- Other (please specify)

4. For how many years have you been making or assisting with health care decisions for the person living with dementia?

If the person living with dementia has passed away, please select the option that corresponds to the total number of years of assisting with, or making, health care decisions for the person living with dementia.

- less than 1 year
- 1-5 years
- more than 5 years but less than 10 years
- more than 10 years

5. Where does the person living with dementia currently live? Please check all that apply

- Person lives with me
- Person lives alone
- Person lives with someone other than me
- Person resides in assisted living
- Person resides in residential care
- Person is in hospital
- Person is in respite care
- Person has passed away

2.

6. If you are or were a health care decision maker, where do/did you get your authority?

- I am a court-ordered guardian or committee of the person
- I am a substitute decision maker under a representation agreement
- I am a supportive decision maker under a representation agreement. (You have the legal authority to assist with decisions but not the authority to make decisions for the person)
- There is a no legal document. I am recognized by health care providers as a next of kin (also called a temporary substitute decision maker)
- I don't know

Other (please specify)

7. If you are or were a health care decision maker for the person living with dementia, were you ever provided with any information about your rights and responsibilities as a health care decision maker?

- Yes
- No

8. If you answered yes to the above question, who provided information about your rights and responsibilities? Please select all that apply.

- Lawyer
- Notary public
- Hospital social worker
- Community organization, such as the Alzheimer Society of BC
- Physician
- Nurse
- Family member or friend
- Internet source
- Other (please specify)

9. Which statement best describes how you approach making or assisting with health care decisions?

- I make decisions for the person living with dementia
- I help the person living with dementia make decisions
- We make decisions together
- I am there for support—I do not make health care decisions
- Other (please specify)

10. What kinds of assistance do or did you provide? Please check all that apply

- I help the person understand information
- I ask questions about risks, benefits, alternatives and other issues we need to understand
- I take notes
- I help the person remember what was discussed
- I accompany the person for emotional support
- I book medical appointments
- I make sure the person remembers to attend the appointments
- Other (please specify)

11. Do you (or did you) attend medical appointments with the person living with dementia?

- Yes
- No

12. What statement best describes the interaction with the doctor during medical appointments with the person living with dementia?

- Doctor speaks/spoke to the person living with dementia
- Doctor speaks/spoke to me
- Doctor speaks/spoke to both of us
- Doctor meets/met with us separately
- Other (please specify)

13. Does the health care provider speak to you about medication and treatment risks, side effects, benefits and alternatives to help you make informed decisions?

Yes

No

Other (please specify)

14. Which health care or other professionals provide you with the information that assists you and/or the person with dementia with decision making about medication and treatment (if anyone)? Please check all that apply

Family physician

Geriatric psychiatrist

Nurse

Nurse practitioner

Pharmacist

Social worker

No one. I have to do research on my own

Other (please specify)

15. Did you and the person with dementia ever disagree about medication or treatment while the person still had/has mental capacity? Mental capacity refers to the ability to understand and evaluate relevant information, and appreciate the consequences of a decision.

Yes

No

I'm not sure

16. If you answered yes to the above question, what happened in those instances? Who decided about medication and treatment?

17. Do you, or did you, and the person living with dementia ever disagree about medication or treatment after the person no longer had capacity to make the health care decisions involved?

- Yes
- No
- I'm not sure

18. If you answered yes to the above question, what happened in those instances?

19. Were you, or are you, the only person assisting with or making health care decisions for the person living with dementia?

- Yes
- No

20. If you answered yes to the above question, please identify the other categories of people involved in health care decision making. For example, spouse, child or children, sibling, friends.

21. Please comment on how decision making responsibilities are/were shared.

22. Have you or do you experience challenges working together to support the person living with dementia with health care decisions, or with making decisions for the person?

- Yes
- No
- I'm not sure

23. If you answered yes to the above question, please describe the challenges and how you worked through them.

3.

24. If the person lived, or is living, in residential care, which statement best describes your experiences with medication in the residential care facility?

- The care facility discusses all medication changes with me and gets my consent first
- The care facility notifies me of medication changes before they occur
- The care facility notifies me of medication changes immediately or shortly after they occur
- Staff notify me of medication changes at scheduled care conferences
- I find out about medication changes when I see the bill
- I have no experience with care facilities
- Other (please specify)

25. Do you believe you have accurate and up to date knowledge about what medication the person living with dementia is currently taking?

- Yes
- No
- I'm not sure
- I am no longer caring for the person living with dementia
- Other (please specify)

26. Do you feel that you are supported to participate in health care decision making for the person living with dementia?

- Yes
- No
- Other (please specify)

27. Please describe any concerns you have about decision making regarding medication and treatment for people living with dementia



28. Can you identify anything that would have made it easier for you to participate in medication and treatment decisions for the person living with dementia?

29. How do/did you engage the person living with dementia in health care decision making, especially once communication abilities and capacity to understand information become limited?

30. The law requires health care decision makers to make decisions consistent with a person's wishes, beliefs and values, or in the person's best interests if beliefs and values are not known. As a health care decision maker for a person living with dementia, how do you ensure you are making decisions in a manner that is consistent with these responsibilities?

31. Is there anything else you would like to tell us about your experiences with health care decision making?

# Endnotes

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- 2 *Ibid.*
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- 5 *Ibid.*
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- 11 *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 1 [HCCA].
- 12 “Guidelines for Care: Person-centred care of people with dementia living in care homes” (2011), online (pdf): *Alzheimer Society of Canada* <[alzheimer.ca/en/Home/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care/guidelines-for-care](http://alzheimer.ca/en/Home/We-can-help/Resources/For-health-care-professionals/culture-change-towards-person-centred-care/guidelines-for-care)>.
- 13 Joseph C Segen, *McGraw-Hill Concise Dictionary of Modern Medicine* (New York, McGraw-Hill Companies Inc, 2002) *sub verbo* “psychotropic drug”.
- 14 *Residential Care Regulation*, BC Reg 96/2009, s 1 [RC Reg].
- 15 Although the *Representation Agreement Act* does not use the expression “supported decision making” but instead refers to authority “to help the adult make decisions”, this language was incorporated into the Act as a result of advocacy by families who make use of supported decision making. The reference is widely understood, both locally and internationally, to have codified supported decision making in BC.
- 16 See definition at *supra* note 13.
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- 25 Statistics Canada, *A portrait of the population aged 85 and older in 2016 in Canada*, Catalogue No 98-200-X (Ottawa: Statistics Canada, 3 May 2017).
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- 31 *Ibid* at 14.
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- 33 Based on data from 2011, (the 2010/2011 Canadian Community Health Survey, the 2011/2012 Survey of Neurological Conditions in Institutions in Canada, and the 2011 Survey on Living with Neurological Conditions in Canada), Suzy L. Wong, Heather Gilmour and Pamela L. Ramage-Morin characterize the national prevalence in long-term care at 12% of people between the ages of 45 to 64, 42% of people between the ages of 65 to 79, and 56% of people 80 years old, or older. Overall an estimate of 45% of people over 45 and older living in long-term care have a diagnosis of dementia. See Wong, Suzy & Gilmour, Heather & Ramage-Morin, Pamela. (2016). Alzheimer’s disease and other dementias in Canada. Health reports / Statistics Canada, Canadian Centre for Health Information Rapports sur la sante / Statistique Canada, Centre canadien d’information sur la sante. 27. 11-16, at 11, online: <[www150.statcan.gc.ca/n1/pub/82-003-x/2016005/article/14613-eng.htm](#)>
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- 41 BPSD Guideline, *supra* note 1 at 6.
- 42 Jennifer T’jia, Jerry H. Gurwitz & Becky A. Briesacher “The Challenge of Changing Nursing Home Prescribing Culture” (2012) 10:1 *The American Journal of Geriatric Pharmacotherapy* 37.
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- 44 BC Care Providers Association, “Best Practices Guide for Reducing Anti-Psychotic Drug Use in Residential Care: Ensuring Residential Care Homes are Safe Places to Live and Work” (2013), online (pdf): *BC Care Providers Association* <[bccare.ca/2013/06/backgrounder-best-practices-guide-for-safely-reducing-anti-psychotic-drug-use-in-residential-care/](#)>.
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- 52 *Canadian Charter of Rights and Freedoms*, Part 1 of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (UK), 1982, c11 [the *Charter*].
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- 60 *Mary Louise MacLaren, D.C., and Council of Canadians with Disabilities v Attorney General of British Columbia*, amended notice of claim (December 11, 2017), online: *Community Legal Assistance Society* <[www.clasbc.net/current\\_cases](#)>. Toward the end of the Health Care Consent project the British Columbia Supreme Court released a decision ruling that the Council of Canadians with Disabilities (the CCD) did not have public interest standing to bring the action, and dismissed the

claim: *MacLaren v British Columbia (Attorney General)*, 2018 BCSC 1753. The CCD is appealing this decision.

61 Bill 26, *Health Statutes Amendment Act*, 3<sup>rd</sup> Sess, 38<sup>th</sup> Parl, British Columbia, 2007 (assented to 10 May 2007), RSBC 1996, c 181 [*Health Statutes Amendment Act*].

62 Bill 51, *Health Care (Consent) and Care Facility (Admission) Act*, 2<sup>nd</sup> Sess, 35<sup>th</sup> Parl, British Columbia, 1993.

63 *Supplements Repeal Act*, S.B.C. 2006, c. 33, s 13.

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The CRPD does not create any new rights, but rather consolidates existing human rights as they apply to people with disabilities, including as it does many rights set out in earlier international and regional human rights instruments. For example, the International Covenant on Civil and Political Rights ("ICCPR") and its counter-part, the International Covenant on Economic, Social and Cultural Rights ("ICESCR"), the European Convention on Human Rights ("ECHR") and the European Social Charter ("ESC"), the African Charter on Human and People's Rights ("ACHPR") and the American Charter of Human Rights ("AmCHR"). The rights are also set out in many themed instruments, such as the International Convention on the Elimination of All Forms of Racial Discrimination ("ICERD"), the Convention on the Elimination of All Forms of Discrimination Against Women ("CEDAW"), the Convention Against Torture ("CAT"), European Charter on the Prevention of Torture ("ECPT"), European Convention on Human Rights and Biomedicine ("ECHRb"), Council of Europe Framework Convention for the Protection of National Minorities ("FCNM").

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- 273 *Health Statutes Amendment Act, supra* note 61, cl 6-10, *HCCA*, s 1.
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- 287 *Ibid* at 210.
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- 290 Torrens, *supra* note 288 at 404.
- 291 *Ibid.*

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- 302 *Kern v Forest*, 2010 BCSC 938, citing *Sadlowski v Yeung*, 2008 BCSC 456 at para 1.
- 303 *Lue v St. Michael’s Hospital*, [1997] OJ no 255, 21 OTC 197 at para 114 [*Lue v St Michael’s*].
- 304 *Ibid* at para 116.
- 305 Torrens, *supra* note 288 at 405-406.
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- 311 HCCA, *supra* note 11, s 4.
- 312 The new federal legislation on medically assisted death also references a capacity requirement.
- 313 HCCA, *supra* note 11, s 6.
- 314 *Ibid.*
- 315 *Ibid.*
- 316 *Ibid*, s 8. See also *Adult Guardianship Act*, *supra* note 82, s 3 (2) (“An adult’s way of communicating with others is not grounds for deciding that he or she is incapable of making decisions about [health care]”).
- 317 HCCA, *supra* note 11, s 9(1.1). An advance directive cannot be used to provide consent to health care for which a person chosen under section 16 could not give substitute consent under section 18 (1), which includes, *inter alia*, experimental health care, participation in non-approved medical research and any treatment, procedure or therapy that involves using aversive stimuli to induce a change in behaviour: *HCC Reg*, *supra* note 204, s 5.
- 318 Again, excluding Quebec, which does not set out any elements of consent.
- 319 MHA, *supra* note 55, s 31.
- 320 HCCA, *supra* note 11, s 2.
- 321 HCCA, *supra* note 11, s 1.
- 322 *Ibid.*
- 323 RC Reg, *supra* note 14, s 81(3).
- 324 *Ibid*, s 81(3)(a).
- 325 HCCA, *supra* note 11, s 1.
- 326 RSBC 1996, c 183 [HPA]. This list in this section of the report is not exhaustive.
- 327 Called “medical practitioners” in the Act and Regs: *Medical Practitioners Regulation*, BC Reg 416/2008.
- 328 It should be noted that at this time the BC Government intends to bring the BC Care Aide and Community Health Worker Registry under the new amalgamated single nursing regulatory body, with a view to improving regulation of all Health Care Assistants, including those who work in long-term care. Details of this proposed change are discussed in Chapter 5 of this Report. See Government of BC, “Health Care Assistants Oversight Policy Intentions Paper for Consultation”, (November 2016) online: <[www2.gov.bc.ca/assets/gov/health/practitioner-pro/professional-regulation/hca\\_new.pdf](http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/professional-regulation/hca_new.pdf)>.
- 329 They do, however, have a common law duty to obtain for personal care. Otherwise, their actions may constitute a battery.
- 330 British Columbia Law Institute, *Report on Common-Law Tests of Capacity*, BCLI Report 73 (2013) at 17 [BCLI CL Capacity Report]. The categories of status, outcome and functional approach to mental capability is rooted in the work of the Law Commission for England and Wales, *Consultation Paper on Mentally Incapacitated Adults and Decision-Making: An Overview*, CP 119 (1991) at 50-53 and the Law Reform Commission of Ireland, *Consultation on Vulnerable Adults and the Law: Capacity*, LRC CP 37-2005 (2005) at 41-50.
- 331 BC Adult Abuse and Neglect Prevention Collaborative, *Provincial Strategy Document: Vulnerable Adults and Capability in BC*, at 17.
- 332 Court decisions reinforce the decision-specific nature of capability determination in the health care context. The Court in *Rasouli*, *supra* note 267 at para 79 stated “the common law definition of capacity in the context of making decisions about medical treatment is the ability to understand the nature, the purpose and the consequences of the proposed treatment.” This statement was recently affirmed in the BC Supreme Court decision of *A.A. in the matter of Carter v Canada (Attorney General)*, 2016 SCC 4, 2016 BCSC 570; HCCA, *supra* note 10, s 7.
- 333 BCLI Report on CL Tests, *supra* note 330 at 1.
- 334 *Ibid*; Ontario HCCA, *supra* note 266; *PEI Consent to Treatment Act*, *supra* note 310; *Yukon Care Consent Act*, *supra* note 310; *Civil Code of Quebec*, *supra* note 310, arts 11-25; See also *Law and Mind*, *supra* note 310. It should be noted that all other Canadian jurisdictions are subject to the common law of informed consent to health care.
- 335 HCCA, *supra* note 11, s 5(2).
- 336 *Ibid*, s 17(2).
- 337 *Ibid*, s 17(2.1).
- 338 *Ibid*, s 17(2.2).
- 339 If patient found incapable, may obtain consent from substitute decision maker: HCCA, *supra* note 11, s 11 (personal guardian or representative), s 16 (TSDM).
- 340 Urgent or emergency health care: “in order to preserve the adult’s life, to prevent serious physical or mental harm or to alleviate severe pain,” *Ibid*, s 12.
- 341 To “undertake triage or another kind of preliminary examination, treatment or diagnosis,” *Ibid*, s 13.
- 342 *Ibid*, s 11.

- 343 *Ibid*, s 11.
- 344 A temporary substitute decision maker has authority to consent to major health care under s 14 and to minor health care under s 15.
- 345 *HCCA*, *supra* note 11, s 10.
- 346 *Ibid*, s 12 (i).
- 347 *Ibid*, ss 12 (1)(c), 12(2).
- 348 *Ibid*, s 12(1)(d).
- 349 *Ibid*, s 12.1.
- 350 British Columbia, *Official Report of Debates of the Legislative Assembly (Hansard)*, 37-3, Vol 7, No 14 (14 May 2002) at 3461 (Hon K. Whittred).
- 351 *HCCA*, *supra* note 11, s 12(3). However, where the health care provider believes that the substitute decision maker has not complied with their duties under the *HCCA*, they may go ahead and provide the emergency health care anyway: s 12.2, *HCCA*.
- 352 *Ibid*, s 13.
- 353 SBC 2008, c 28.
- 354 Ontario *HCCA*, *supra* note 266, s 1(b); *PEI Consent to Treatment Act*, *supra* note 310, s 1(ii).
- 355 Ontario *HCCA*, *supra* note 266, s 1(g); *PEI Consent to Treatment Act*, *supra* note 310, s 1(vii).
- 356 *Civil Code of Quebec*, *supra* note 310, art 11.
- 357 *Civil Code of Quebec*, *supra* note 310, art 13.
- 358 “Supported decision-making: An alternative to guardianship” (last visited 12 December 2018) at 3, online (pdf): *Mental Disability Advocacy Center* <[mdac.info/en/resources/supported-decision-making-alternative-guardianship](http://mdac.info/en/resources/supported-decision-making-alternative-guardianship)>.
- 359 *Ibid*.
- 360 RSBC 1996, c 405 [*RAA*].
- 361 *Ibid*, s 7.
- 362 “Routine management of the adult’s financial affairs” is a broad category. Section 7(b) states that it includes: “(i) payment of bills, (ii) receipt and deposit of pension and other income, (iii) purchases of food, accommodation and other services necessary for personal care, and (iv) the making of investments.” The Representation Agreement Regulation provides a lengthy list of activities that are included, such as opening accounts, renewing a mortgage, applying to defer property taxes, making donations (under certain circumstances), completing income tax returns, and redirecting mail. See *Representation Agreement Regulation*, BC Reg 199/2001, s 2(1).
- 363 *Ibid*.
- 364 *Ibid*, s 9.
- 365 The dissimilar statutory drafting of sections 7 and 9 of the Act suggest that only section 7 was intended to capture supported decision making. Comments by Robert Gordon, who was one of the drafters of the statute, confirm this perspective: see Robert Gordon, “The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making” (2000) 23:1, *Intl J L & Psychiatry* 61. Ministry of Health templates for representation agreements also confirm this interpretation: the section 7 template allows a person to indicate whether the agreement is to “help me make decisions” or “make decisions on my behalf”; this option is not available on the section 9 agreement template. See “Incapacity Planning” (last visited 12 December 2018), online: *Government of BC* <[www2.gov.bc.ca/gov/content/health/managing-your-health/incapacity-planning](http://www2.gov.bc.ca/gov/content/health/managing-your-health/incapacity-planning)>.
- 366 The supportive decision maker is called an “associate decision maker” in the Yukon. In the Yukon a representative is a substitute decision maker authorized by agreement. Under the *Adult Guardianship and Trusteeship Act* of Alberta a “supporter” can be empowered via a document called a supported decision making authorization. In Alberta and Saskatchewan a “co-decision maker” can also be authorized via a court process.
- 367 CCEL, *Understanding the Lived Experience of Supported Decision Making*, 2017: online: <[www.bcli.org/project/understanding-lived-experience-supported-decision-making](http://www.bcli.org/project/understanding-lived-experience-supported-decision-making)> [*Understanding the Lived Experience of Supported Decision Making*].
- 368 *Decision-Making Support and Protection to Adults Act*, SY 2003, c 21, s 5(1).
- 369 *HCCA*, *supra* note 11, s 8.
- 370 Hall, *supra* note 162 at 296.
- 371 Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship*, Final Report (2017) at 64. [LCO Report on Capacity].
- 372 Gerald B. Robertson, “Mental Health” in Joly Yann & Bartha M. Knoppers, eds, *Routledge Handbook of Medical Law and Ethics*, (New York: Routledge, 2015) [Routledge]. The common law principle of *parens patriae* gives the court broad jurisdiction to make an order to protect an individual who does not have capacity.
- 373 *Ibid*.
- 374 *MHA*, *supra* note 55, s 31.
- 375 *HCCA*, *supra* note 11, s 11, and *PPA*, *supra* note 383, s 19.
- 376 *RAA*, *supra* note 360, ss 7, 9.
- 377 *Ibid*, s 7(1)(c).
- 378 “Refusing Health Care: What are my Rights?” (2016), online (pdf): *Nidus Personal Planning Resource Centre and Registry* <[www.nidus.ca/?page\\_id=255](http://www.nidus.ca/?page_id=255)>.
- 379 *RAA*, *supra* note 360, s 9(1)(b).
- 380 *Ibid*, s 9(3).
- 381 *HCCA*, *supra* note 11, s 34; *HCC Reg*, *supra* note 260, s 5.
- 382 *RAA*, *supra* note 360, s 8.
- 383 *Patient’s Property Act*, RSBC 1996, c 349, s 6 [*PPA*].
- 384 *Ibid*, s 15.
- 385 *Ibid*, s 16.
- 386 There is some case law that suggests that this reference in the jurisprudence to the benefit of the person’s family only applies with respect to financial decision making, not health care decisions. *Leeming (Re); Mawdsley v. Austin*, [1984] B.C.J. No. 3048 at para 10.
- 387 *PPA*, *supra* note 383, s 18.
- 388 *HCCA*, *supra* note 11, s 11.
- 389 *Ibid*, s 16(1).
- 390 *Ibid*, s 16(2).
- 391 *Ibid*, s 16(3).
- 392 Health care providers are required to complete Form 1 each time for each major health care decision for which substitute consent occurs under section 16: see *HCC Reg*, *supra* note 260, s 6. Although the obligation to notify the adult of the appointment of a TSDM for major health care is clearly laid out in the *HCCA* at s 14(4)(b), this section does not require notice in writing.
- 393 *Ibid*.
- 394 *Ibid*, s 16(4).
- 395 *Ibid*, s 17(1).
- 396 *Ibid*, ss 18(1)–(2). See Duties of a temporary substitute decision maker, *ibid*, s 19(1) and (2).
- 397 *Ibid*, ss 5, 34; *HCC Reg*, *supra* note 260, s 5(1).
- 398 *HCCA*, *supra* note 11, Part 2.1.

- 399 Wahl, *supra* note 278 at 108.
- 400 *HCCA*, *supra* note 11, s 19.7.
- 401 *HCCA* *supra* note 11, s 19.7(1); or in the case of emergency health care, if neither a personal guardian nor representative is reasonably available, *HCCA*, s 12; An exception exists to the priority of a representation agreement over an advance directive where an adult specifies in their representation agreement that a health care provider need not obtain a representative's consent for health care decisions covered in the adult's advance directive: *HCCA*, s 19.3(2).
- 402 *Ibid*, s 19.7(3).
- 403 *Ibid*, s 19.9.
- 404 This is unless the advance directive expressly states that the advance directive is to apply regardless of any change in medical knowledge.
- 405 *HCCA*, *supra* note 11, s 19.8.
- 406 *Ibid*, ss. 9, 19.7–19.8. This is in contrast with Ontario, where the substitute decision maker must interpret the advance directive: See Wahl, *supra* note 278 at 110. Note, a representative who is tasked with making the health care decision will be required to interpret the advance directive for the purpose of complying with expressed known wishes: *HCCA*, *supra* note 11, s 19.3.
- 407 *HCCA*, *supra* note 11, s 19.1.
- 408 *HCC Reg*, *supra* note 260 s 5(1).
- 409 *PPA*, *supra* note 383.
- 410 *RAA*, *supra* note 360.
- 411 *HCCA*, *supra* note 11, Part 2.1.
- 412 *Ibid*, s 16.
- 413 *PPA*, *supra* note 383.
- 414 *HCCA*, *supra* note 11, s 19.3(1)(a).
- 415 *Ibid*, s 19.3(2).
- 416 *Ibid*, s 19.3(1)(b).
- 417 *RAA*, *supra* note 360, s 16 (1).
- 418 *HCCA*, *supra* note 11, s 16(2).
- 419 *RAA*, *supra* note 360, s 16(2.1)
- 420 *Ibid*, ss 9(1)(b)(vii)–(viii).
- 421 *HCCA*, *supra* note 11, s 19(1)(a).
- 422 Section 18 was amended and subsection (2) added by SBC 2014–9–35. The subsection came into force on 1 December 2014.
- 423 *HCCA*, *supra* note 11, s 4(e).
- 424 *RAA*, *supra* note 360, s 16(3); *HCCA*, *supra* note 11, s 19(1)(b).
- 425 *RAA*, *supra* note 360, s 16(3).
- 426 *HCCA*, *supra* note 11, s 19(1)(b).
- 427 When it comes to appointing a committee, a court should consider the known wishes expressed by the adult as to their preference of committee, provided the wishes are rational and reasonable: Palamarek (Re), 2011 BCSC 563, at para 193.
- 428 “Private Committee Handbook” (2014), online (pdf): *Public Guardian and Trustee of British Columbia* <[www.trustee.bc.ca/Documents/PCS/PCS%20Handbook.pdf](http://www.trustee.bc.ca/Documents/PCS/PCS%20Handbook.pdf)> [PGT Handbook].
- 429 *Ibid* at 29.
- 430 *Ibid*.
- 431 *Adult Guardianship Act*, *supra* note 82, as amended by, Part 2 [not in force], s 29(1)–(2), online: <[www.bclaws.ca/civix/document/id/consol9/consol9/sup00600#section%2029](http://www.bclaws.ca/civix/document/id/consol9/consol9/sup00600#section%2029)>.
- 432 *Ibid*, 20(3)(a).
- 433 *HCCA*, *supra* note 11, s 16(2); *RAA*, *supra* note 360, s 16(4).
- 434 *HCCA*, *supra* note 11, s 19(3)(a).
- 435 *Ibid* s 19(3).
- 436 *Leeming*, *supra* note 386.
- 437 See for example, Melinda Munro, “Guardianship of Adults: Good Faith and the Philosophy of Mental Disability in British Columbia”, (1997) 14 Can. J. Fam. L. 217–246.
- 438 DSM-5, *supra* note 78.
- 439 *MHA*, *supra* note 55, ss 1 (definition of “treatment”), 31; See also John F. Gray, Margaret A. Shone & Peter F. Liddle, *Canadian Mental Health Law and Policy* (Ontario: LexisNexis, 2008) [Gray].
- 440 *MHA*, *supra* note 55, s 22.
- 441 *Ibid*, s 1.
- 442 *Mental Health Regulation* B.C. Reg. 233/99, s 11 [*Mental Health Reg*].
- 443 *MHA*, *supra* note 55, ss 22–23.
- 444 *Mental Health Reg*, *supra* note 442, (Form 5 Consent for Treatment (Involuntary Patient)) [Form 5].
- 445 *Ibid*.
- 446 *MHA*, *supra* note 55, s 8.
- 447 Form 5, *supra* note 444.
- 448 Operating in Darkness, *supra* note 59 at 90.
- 449 Section 24 of the *Mental Health Services Act*, SS 1984–85–86, c M-13.1 [*Sask Mental Health Services Act*] sets out the criteria for involuntary commitment: the patient must be mentally disordered, a danger to himself or others, and “as a result of the mental disorder the person is unable to fully understand and to make an informed decision regarding his need for treatment or care and supervision”. According to Luther and Mela, this approach came about as a result of a recommendation of the Saskatchewan Law Reform Commission in 1985: “The Top Ten Issues in Law and Psychiatry” (2006) 69 Sask L Rev 401.
- 450 *Mental Health Care and Treatment Act*, SNL 2006, c M-9.1, s. 17(1)(b)(ii)(B) [*NL Mental Health Care and Treatment Act*].
- 451 *Involuntary Psychiatric Treatment Act*, SNS 2005, c 42, s 17(e) [*Involuntary Psychiatric Act*].
- 452 Routledge, *supra* note 372 at 104.
- 453 *Mental Health Act*, RSA 2000, c M-13, s 29 [*Alberta Mental Health Act*].
- 454 *Mental Health Act*, RSY 2002, c 150, s 23(2) [*Yukon Mental Health Act*]; Gray, *supra* note 439 at 202.
- 455 *Civil Code of Quebec*, *supra* note 310, arts 11, 16; *Mental Health Act*, RSNB 1973, c M-10, s 8.11(3) [*NB Mental Health Act*]; Gray, *supra* note 439. Robertson points out that in Alberta, statistics show that most applications to the Review Panel to override the capable involuntary patient's refusal in the patient's best interests are successful, and as a result, at least in Alberta, the right to refuse treatment is not actually protected in any meaningful way. See Routledge, *supra* note 372, at 105.
- 456 *Ontario HCCA*, *supra* note 266, s 10(1).
- 457 *Mental Health Act*, CCSM c M110, s 29(1)(a) [*Manitoba Mental Health Act*].
- 458 *Mental Health Act*, RSPEI 1988, c M-6.1, s 23(1) [*PEI Mental Health Act*].
- 459 *Mental Health Act*, RSNWT (Nu) 1988, c M-10, s 21 [*NWT Mental Health Act*].
- 460 Routledge, *supra* note 372 at 105.
- 461 Law and Mind, *supra* note 310 at 102.
- 462 Gray, *supra* note 439 at 23–24.

- 463 *Sask Mental Health Services Act*, *supra* note 449, s 25(2); *NL Mental Health Care and Treatment Act*, *supra* note 450, s 35(1); Gray, *supra* note 439 at 23–24.
- 464 *NB Mental Health Act*, *supra* note 455, s 8.11; Gray, *supra* note 439 at 23–24.
- 465 *An Act Respecting the Protection of Persons Whose Mental State Presents a Danger to themselves or to Others*, CQLR c P-38.001, s 9.
- 466 *Ontario HCCA*, *supra* note 266 ss 1 and 10; *Mental Health Act*, RSO 1990, c M.7, ss 1, 15 and 16 [*Ontario Mental Health Act*].
- 467 *Mental Health Act Alberta*, *supra* note 454, s 28(3); Gray, *supra* note 439 at 23–24.
- 468 *Ontario HCCA*, *supra* note 266, s 21(1); *PEI Consent to Treatment Act*, *supra* note 310, s 13(1); Gray, *supra* note 439 at 23–24. In addition, under mental health legislation in PEI, substitute decision makers can only consent to mental health treatment where the treatment is medically necessary and the benefits outweigh the risks: *PEI Mental Health Act*, *supra* note 458, s 23 (9).
- 469 *Care Consent Act*, SY 2003, c 21, Schedule B, s 19; *Yukon Mental Health Act*, *supra* note 454, s 21.
- 470 *Manitoba Mental Health Act*, *supra* note 457, s 28(4)(b); *Involuntary Psychiatric Act*, *supra* note 451, s 39(b); Gray, *supra* note 439 at 23–24.
- 471 *The Best of Care 2*, *supra* note 270 at 267.
- 472 *Ibid.*
- 473 *MHA*, *supra* note 55, ss 25 and 33; Seniors First Advocate’s Manual, *supra* note 263 at 19.
- 474 *Ibid* and *Best of Care 2*, *supra* note 270 at 267. The ombudsperson noted that the Supreme Court procedures were rarely used as they were costly and time-consuming.
- 475 *MHA*, *supra* note 55, s 37.
- 476 Seniors First Advocate’s Manual, *supra* note 263 at 41.
- 477 *HCCA*, *supra* note 11, s 33.4 Section 33.4 was enacted by 2007-34-30 effective September 1, 2011 (BC Reg 14/2011).
- 478 *Ibid*, s 33.4(2).
- 479 *Ibid*, s 33.4(3).
- 480 *Ibid*, s 33.4(1).
- 481 *Ibid*, s 33.4(4); *E (Mrs) v Eve*, [1986] 2 SCR 388 at para 77, 31 DLR (4th) 1: “Simply put, the discretion is to do what is necessary for the protection of the person whose benefit it is exercised ... [t]he discretion is to be exercised for the benefit of that person, not for that of others.” [*E v Eve*].
- 482 *PPA*, *supra* note 383, s 4.
- 483 *Ibid*, s 4(3)(b).
- 484 *MHA*, *supra* note 55, s 25.
- 485 *Mental Health Act Reg*, *supra* note 442, s 6(5).
- 486 *Ibid*, s 6(6).
- 487 *MHA*, *supra* note 55, s 25(1)(c).
- 488 *Ibid*, s 25(2.8).
- 489 Black’s Law Dictionary Online, 2<sup>nd</sup> ed. *sub verbo* “*habeus corpus*”. The *MHA* does not affect the right of *habeus corpus*; see *MHA*, *supra* note 55, 33(3).
- 490 Operating in Darkness, *supra* note 59, at 67.
- 491 *R v Saskatchewan Wheat Pool*, [1983] 1 SCR 205 at paras 226–28, [1983] SCJ No 14.
- 492 *Ibid.*
- 493 *Ibid*; MH Matthews, “Negligence and Breach of Statutory Duty” (1984) 4:3 OJLS 429 at 431.
- 494 *HCCA*, *supra* note 11, s 33.
- 495 Some recent examples of such cases include: *Kemp v Vancouver Coastal Health Authority Ltd*, 2017 BCCA 229 at paras 104–105 [*Kemp v VCH*] (alleged a failure to obtain express or implied informed consent for resuscitation efforts of mother); *Brodeur (Litigation guardian of) v Provincial Health Services Authority (c.o.b. British Columbia Women’s Hospital and Health Center)*, 2016 BCSC 968 (alleged a failure to obtain informed consent in terms of disclosing the material risks of a vaginal delivery instead of elective caesarean section delivery) [*Brodeur*]; *Chen v Ross*, 2014 BCSC 374, affirmed on appeal, *Chen v Ross*, 2015 BCCA 250, (alleged a failure by ophthalmologist to adequately disclose material risks of eye surgery, thereby failing to obtain informed consent) [*Chen v Ross*]; *Ediger (Guardian ad litem of) v Johnston*, 2009 BCSC 386, (alleged a failure to obtain informed consent of mother for use of forceps during birth).
- 496 *Chen v. Ross*, *supra* note 495 at para 302. On appeal, the doctor’s claim that consent was given by plaintiff was successful.
- 497 *Kemp v VCH*, *supra* note 495 at para 104-105.
- 498 *Brodeur*, *supra* note 495 at para 19.
- 499 *Lue v St. Michael’s*, *supra* note 303.
- 500 *Arndt v Smith*, [1997] 2 SCR 539 at para 6, 148 DLR (4th) 48.
- 501 Robertson - 20 Years, *supra* note 279 at 155.
- 502 See case examples at *supra* note 495.
- 503 *Human Rights Code*, *supra* note 68, s 8.
- 504 *Ibid*, s 21.
- 505 *Ibid*, s 8(1)(b).
- 506 *Ibid*, s 37.
- 507 *Patient Care Quality Review Board Act*, SB 2008, c 35, s 2.
- 508 *External Complaint Regulation*, BC Reg 305/2008, s 2(e) [*External Complaint Reg*]: “(A) a licensed hospital within the meaning of section 5 of the Hospital Act, (B) an institution, operated for the reception and treatment of persons referred to in paragraph (b) or (c) of the definition of “hospital” in section 1 of the Hospital Act, that has been designated as a hospital under that Act, or (C) subject to paragraph (a), a licensed community care facility.”
- 509 Provincial Services Health Authority, *Patient Care Quality Office Resource Guide*, (2012) at 5, online (pdf): <[www.phsa.ca/Documents/PCQO/PCQOResourceGuideMoHS\\_PHSA2012.pdf](http://www.phsa.ca/Documents/PCQO/PCQOResourceGuideMoHS_PHSA2012.pdf)>.
- 510 *External Complaint Reg*, *supra* note 508, s 2(e).
- 511 *Ibid.*
- 512 Such complaints should generally be directed to the appropriate regulatory college.
- 513 *External Complaint Reg*, *supra* note 508, s 2(b).
- 514 *Patient Care Quality Review Board Act*, *supra* note 507, s 15(12)(b).
- 515 Patient Care Quality Office, *Resource Guide* (2012) at 8, online (pdf): *Provincial Services Health Authority* <[www.phsa.ca/Documents/PCQO/PCQOResourceGuideMoHS\\_PHSA2012.pdf](http://www.phsa.ca/Documents/PCQO/PCQOResourceGuideMoHS_PHSA2012.pdf)>.
- 516 Patient Care Quality Review Boards, 2016/2017 Annual Report, online (pdf): *Patient Care Quality Review Boards* <[www.patientcarequalityreviewboard.ca/pdf/pcqrb-annual-report-2017-18.pdf](http://www.patientcarequalityreviewboard.ca/pdf/pcqrb-annual-report-2017-18.pdf)> [PCQRB Annual Report].
- 517 *Ibid* at 17.
- 518 *Ibid* at 27.
- 519 *Ibid.*
- 520 *Ibid* at 42.

- 521 *Community Care and Assisted Living Act*, SBC 2002, c 75, s 5 [*CCAL Act*].
- 522 British Columbia, Ministry of Health *at al*, A Guide to Community Care Facilities, at 8 (last visited 9 February 2019), online (pdf): *Ministry of Health* <[www2.gov.bc.ca/assets/gov/health/accessing-health-care/finding-assisted-living-residential-care-facilities/residential-care-facilities/a\\_guide\\_to\\_community\\_care\\_facility\\_licensing\\_in\\_british\\_columbia\\_spring\\_2016\\_update.pdf](http://www2.gov.bc.ca/assets/gov/health/accessing-health-care/finding-assisted-living-residential-care-facilities/residential-care-facilities/a_guide_to_community_care_facility_licensing_in_british_columbia_spring_2016_update.pdf)>.
- 523 *Ibid* at 54.
- 524 British Columbia, Ministry of Health, “Making Concerns and Complaints”, online: *Ministry of Health* <[www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/concerns-and-complaints](http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/concerns-and-complaints)>.
- 525 *CCAL Act*, *supra* note 521, ss 13 and 33.
- 526 British Columbia, Ministry of Health, “Making a Complaint About an Assisted Living Facility”, online: *Ministry of Health* <[www2.gov.bc.ca/gov/content/health/accessing-health-care/finding-assisted-living-or-residential-care/assisted-living-residences/making-a-complaint-about-an-assisted-living-residence](http://www2.gov.bc.ca/gov/content/health/accessing-health-care/finding-assisted-living-or-residential-care/assisted-living-residences/making-a-complaint-about-an-assisted-living-residence)>.
- 527 *CCAL Act*, *supra* note 521, s 27.
- 528 “About the Health Professions Review Board” (last visited 16 August 2018), online: *Health Professions Review Board* <[www.hprb.gov.bc.ca/about.stm](http://www.hprb.gov.bc.ca/about.stm)>.
- 529 The HPRB also has the power to review registration decisions of the colleges: *Health Professions Act*, RSBC 1996, c 183, s 50.53 [*HPA*].
- 530 *Ibid*, s 50.
- 531 For example: “Decision No. 2015-HPA-182(a)(cataract surgery)”, online (pdf): *Health Professions Review Board* <[www.hprb.gov.bc.ca/decisions/](http://www.hprb.gov.bc.ca/decisions/)>; “Decision No. 2015-HPA-076(a) (cataract surgery)”, online (pdf): *Health Professions Review Board* <[www.hprb.gov.bc.ca/decisions/](http://www.hprb.gov.bc.ca/decisions/)>.
- 532 For example: “HPRB Decision No. 2015-HPA-088(a) (consent regarding a wart removal procedure)”, online (pdf): *Health Professions Review Board* <[www.hprb.gov.bc.ca/decisions/](http://www.hprb.gov.bc.ca/decisions/)>.
- 533 Telephone interview of Dr. Heidi Oetter, Registrar, College of Physicians and Surgeons of British Columbia, by Rachel Kelly, Canadian Centre for Elder Law (22 June 2017).
- 534 “*The Complainant v. the College of Physicians and Surgeons of British Columbia*, Decision No. 2016-HPA-048(a), September 23, 2016”, online (pdf): *Health Professions Review Board* <[www.hprb.gov.bc.ca/decisions/](http://www.hprb.gov.bc.ca/decisions/)>.
- 535 *Complainant v. The College of Physicians and Surgeons of British Columbia*, 2016 CanLII 61757 (BC HPRB).
- 536 *Ibid* at para 35-38.
- 537 *Ibid* at para 83.
- 538 British Columbia, Ministry of Health, “Overview of Complaint, Investigative and Referral Agencies in British Columbia”, online (pdf): *Ministry of Health* <[www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorsbc/seniors-action-plan/concerns-and-complaints](http://www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorsbc/seniors-action-plan/concerns-and-complaints)>.
- 539 “What We Investigate” (last visited 17 August 2018), online: *Office of the Ombudsperson* <[www.bcombudsperson.ca/complaints/what-we-investigate](http://www.bcombudsperson.ca/complaints/what-we-investigate)>.
- 540 *The Best of Care 2*, *supra* note 270.
- 541 *Legal Services Society Act*, SBC 2002, c 30; “Legal Aid Services” (last visited 17 August 2018) online: *Legal Aid Services Society* <[legalaid.bc.ca/legal\\_aid/](http://legalaid.bc.ca/legal_aid/)>.
- 542 “2016/17 Annual Service Plan Report” at 6, online (pdf): *Legal Services Society* <[lss.bc.ca/about/annualReports.php](http://lss.bc.ca/about/annualReports.php)> [2016/17 Annual Service Plan Report].
- 543 “Advice” (last visited 17 August 2018), online: *Legal Services Society* <[www.lss.bc.ca/legal\\_aid/legalAdvice.php](http://www.lss.bc.ca/legal_aid/legalAdvice.php)>; 2016/17 Annual Service Plan Report, *supra* note 542 at 6: Legal aid for criminal matters may also be available to individuals who are unable to represent themselves because of a disability.
- 544 British Columbia Law Institute, *A Comparative Analysis of Adult Guardianship Laws in BC, New Zealand and Ontario*, BCLI Report 46 (2006) at 59 [BCLI AGA Paper].
- 545 “Immigration problems” (last visited 26 November 2018), online: *Legal Services Society* <[lss.bc.ca/legal\\_aid/immigrationProblems.php](http://lss.bc.ca/legal_aid/immigrationProblems.php)>.
- 546 Note, there are numerous other issues which impact the fundamental rights of older people for which legal aid funding is not provided. These include advice and representation in respect of detention pursuant to the *Mental Health Act* and related applications and *Adult Guardianship Act* measures, including support and assistance orders and emergency interventions against an adult’s wishes under Part 3. However, while we recognize these topics as presenting important access to justice issues which require addressing, they fall outside the scope of this project.
- 547 BCLI CL Capacity Report, *supra* note 330 at 160–63.
- 548 *Ibid* at 162.
- 549 *Ibid* at 160 citing *Bank of Nova Scotia v. Kelly* (1973), 41 DLR (3d) 273 at 275.
- 550 *Ibid* at 160.
- 551 Law Society of BC, *Code of Professional Conduct for BC - annotated*, Vancouver: Law Society of BC, 2013), Rule 3.2-9
- 552 *Ibid* at Commentary Note 1.
- 553 *RAA*, *supra* note 360, s 8(1)(a).
- 554 BCLI CL Capacity Report, *supra* note 330 at 172–73.
- 555 Barbara Buchanan, “Acting for a client with dementia”, online: *Law Society of BC* <[www.lawsociety.bc.ca/Website/media/Shared/docs/bulletin/BB\\_2015-01-Spring\\_Part4.pdf](http://www.lawsociety.bc.ca/Website/media/Shared/docs/bulletin/BB_2015-01-Spring_Part4.pdf)> at 15-16 [Buchanan].
- 556 BCLI CL Capacity Report, *supra* note 330 at 173 (Recommendation 27).
- 557 *Health Statutes Amendment Act*, *supra* note 61, cl 26.1.
- 558 *Ibid*.
- 559 H Archibald Kaiser, “Restraint and Seclusion in Canadian Mental Health Facilities: Assessing the Prospects for Improved Access to Justice” (2001) 19 Windsor YB Access Just 391 at 403 [Kaiser].
- 560 British Columbia Law Institute, *A Bill of Rights for Assisted Living Residents*, Memorandum No. 16 (2011) [unpublished, archived at British Columbia Law Institute].
- 561 *Wellesley Hospital v. Lawson*, [1978] 1 SCR 893 at 896, 76 DLR (3d) 688, Laskin CJ (“It was not doubted by counsel for the parties that at common law a hospital, especially one providing treatment for mentally-ill persons, would be under a common law liability if by reason of its failure to provide adequate control and supervision injury occurred to third persons by reason of the conduct or behaviour of a patient”).
- 562 *Conway v Fleming* (1999), 43 OR (3d) 92, 173 DLR (4th) 372 (Div Ct). *R. v Webers* (1999), 95 CCC (3d) 334, 25 WCB (2d) 305 (Ont Gen Div) [*Webers* cited to CCC]; *R v McKenzie*, 2004 ABPC 239; *R v Labrèche*, 2011 ONSC 2828.
- 563 See *Mullins v. Levy*, 2009 BCCA 6 at paras 147-50.
- 564 *Webers*, *supra* note 562 at 349.

565 Verdun-Jones, *supra* note 281 at 520-21.

566 *RC Reg*, *supra* note 14, ss 73-75.

567 *CCAL Act*, *supra* note 521.

568 *Hospital Act*, RSBC 1996, c 200 [*Hospital Act*].

569 Telephone interview of Ministry of Health staff by Kathleen Cunningham, Krista James and Rachel Kelly (2 May 2017).

570 *RC Reg*, *supra* note 14, s 1.

571 *Ibid*, ss 74(1)(b)(i)-(ii).

572 *Ibid*, s 1.

573 *Ibid*.

574 *Ibid*, s 74(1)(b).

575 *Ibid*, s 74(1)(b)(ii).

576 *HCCA*, *supra* note 11, s 16.

577 *RC Reg*, *supra* note 14, s 74(a) (emphasis added).

578 *Ibid*, s 1.

579 *Ibid*, s 74(3).

580 *Ibid*, Schedule D, s 1.

581 *Ibid*, s 77(2).

582 *Ibid*, s 75(3).

583 *Ibid*, s 73(2); It should be noted that the Ministry of Health has recommended, upon its review of anti-psychotic medications in long term-care, a review of s 73(2) to determine whether it provides appropriate protections: *Best of Care 2*, *supra* note 270 at 288.

584 *RC Reg*, *supra* note 14, ss 74(1) and 75(2).

585 *Ibid*, s 84; see also ss 81 (3)(a)(iii) and 73(2)(c).

586 *Ibid*, s 75(1).

587 *Black's Law Dictionary*, 10th ed, *sub verbo* "Consent, noun".

588 *Ibid*, *sub verbo* "Agreement".

589 *R v Conception*, 2014 SCC 60 at para 88.

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592 *Ibid*, s 88.

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601 *Manitoba Mental Health Act*, *supra* note 457, s 1.

602 *An Act respecting health services and social services*, RSQ, c S-4.2, as amended by s 49, *An Act respecting the protection of persons whose mental state presents a danger to themselves or to others*, SQ 1997, c 75, s 118.1: "Force, isolation, mechanical means or chemicals may not be used to place a person under control in an installation maintained by an institution except

to prevent the person from inflicting harm upon himself or others. The use of such means must be minimal and resorted to only exceptionally, and must be appropriate having regard to the person's physical and mental state."; see also Kaiser, *supra* note 559.

603 *NB Mental Health Act*, *supra* note 455, s 7.1(4) (An "examination certificate... is sufficient authority ... for the attending psychiatrist, without consent ... to administer such restraint as, in the attending psychiatrist's opinion, is necessary.")

604 *Ibid*.

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606 *NL Mental Health Act*, *supra* note 408, s 3 simply provides that one of the purposes of the Act is "to provide for the apprehension, detention, custody, restraint, observation, assessment, treatment and care and supervision of a person with a mental disorder by means that are the least restrictive and intrusive for the achievement of the purpose[s] [of the Act]."

607 See for example, *Homes for Special Care Regulations*, NS Reg 127/77, ss 5A(1) and 7; *Facility Designation Regulations*, RRS c R-8.2 Reg 6, s 17(2) [*SK Facility Designation Regulations*] and *The Provincial Health Authority Act*, SS 2017, c P-30.3, s 9-5(1)(ff).

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- 659 *Ibid*, 7.70.020 (2)-(3).
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- 776 *Nurses Regulation*, *supra* note 774; BC College of Nursing Professionals, “Scope of Practice for Registered Nurses” (2018), online: *BC College of Nursing Professionals* <[www.bccnp.ca/Standards/RN\\_NP/Pages/Default.aspx](http://www.bccnp.ca/Standards/RN_NP/Pages/Default.aspx)> [Scope of Practice for Registered Nurses].
- 777 “Registered Nurse Roles in Long Term Care” (2013) at 5, online (pdf): *Association of Registered Nurses in Newfoundland and Labrador* <[www.arntl.ca/document-type/position-statements](http://www.arntl.ca/document-type/position-statements)> [Registered Nurse Roles].
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- 787 *Nurses Regulation*, *supra* note 774, s 9(1).
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- 791 *Ibid*; *Nurses Regulation*, *supra* note 774, s 8.
- 792 “Practice Standard: Medication Administration” (last visited 4 October 2018), online: *BC College of Nursing Professionals* <[www.bccnp.ca/Standards/RN\\_NP/PracticeStandards/Pages/Default.aspx](http://www.bccnp.ca/Standards/RN_NP/PracticeStandards/Pages/Default.aspx)> [Medical Administration Practice Standard]; “Practice Standard: Dispensing Medications” (last visited 4 October 2018), online: *BC College of Nursing Professionals* <[www.bccnp.ca/Standards/RN\\_NP/PracticeStandards/Pages/Default.aspx](http://www.bccnp.ca/Standards/RN_NP/PracticeStandards/Pages/Default.aspx)>.
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- 796 *Ibid*, Principle 3.
- 797 *Ibid*, Principle 4.
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- 799 Consent Practice Standard, *supra* note 794, Principle 4.
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- 804 *Ibid*.
- 805 *Nurses (Licensed Practical) Regulation*, BC Reg 224/2015 [*LPN Regulation*]; See also “Scope of Practice” (last modified 9 February 2018) at 9-26, online: *BC College of Nursing Professionals* <[www.bccnp.ca/Standards/LPN/LPN\\_ScopePractice/Pages/Default.aspx](http://www.bccnp.ca/Standards/LPN/LPN_ScopePractice/Pages/Default.aspx)> [LPN Scope of Practice].
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- 854** Note, two stakeholders advised of their involvement in a new joint project to address issues around access to information and resources on topics relevant to palliative care, including substitute decision making, in languages other than English.
- 855** CRPD, *supra* note 65.
- 856** HCCA, *supra* note 11, s 3.
- 857** *Ibid*, s 7.
- 858** *Ibid*, s 6.
- 859** *Ibid*, s 6(e).
- 860** *Ibid*, s 17.
- 861** PEI *Consent to Treatment Act*, *supra* note 310, s 7(3)-(4) (bolding to titles added by us).
- 862** Ontario HCCA, *supra* note 266, s 15.
- 863** Manitoba Law Reform Commission, *Substitute Consent to Health Care*, Report 110 (2004) at 27 [Manitoba Law Reform Commission].
- 864** *Understanding the Lived Experience of Supported Decision Making*, *supra* note 367.
- 865** Although the *Representation Agreement Act* does not use the expression “supported decision making” but instead refers to authority “to help the adult make decisions”, this language was incorporated into the Act as a result of advocacy by families who make use of supported decision making, and the reference is widely understood, both locally and internationally, to have codified supported decision making in BC.
- 866** CRPD, *supra* note 65.
- 867** Department of Economic and Social Affairs, Division for Inclusive Social Development, Handbook for Parliamentarians, 2007, No 14, at Chapter Six: From provisions to practice: implementing the Convention – Legal capacity and supported decision-making, online: [United Nations—Disability <www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html>](http://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html). Canada has entered a reservation with respect to Article 12 in order to preserve its ability to retain substitute decision making, where appropriate.
- 868** HCCA, *supra* note 11, ss 11, 12(3).
- 869** *Ibid*, s 4.
- 870** *Ibid*, s 2.
- 871** MHA, *supra* note 55, s 31.
- 872** PRN is the term commonly used in medical practice to describe a physician order to administer medication as needed, or as circumstances require, as opposed to on an ongoing basis, such as to manage pain. The abbreviation comes from the Latin, *pro re nata*. See Merriam-Webster, *sub verbo* “prn”.
- 873** RC Reg, *supra* note 14, s 81.
- 874** HCCA, *supra* note 11, s 1, definition of “health care”.
- 875** *Ibid*, ss 4, 12.
- 876** RC Reg, *supra* note 14, s 81(2).
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- 881** Washington State Health Law Manual, *supra* note 660 at 2A-4.
- 882** *Residents’ Bill of Rights*, s 1, being Schedule to the *CCAL Act*, *supra* note 521.
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- 884** *Hospital Act*, *supra* note 568, s 4(4); *CCAL Act*, *supra* note 521, s 7(1)(c.1).
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- 897** *Ibid*, s 20(1) – (3), not yet in force; see *Adult Guardianship and Planning Statutes Amendment Act*, SBC 2007 c 34, s 4.
- 898** Private hospitals providing long-term care and extended care hospitals are not governed by these regulations, and instead by the *Hospital Act*, *supra* note 511, which does not regulate the use of restraints. It is anticipated that the new regulations associated with Part 3 of the *Health Care (Consent) and Care Facility (Admissions) Act*, which are expected to come into force in 2019, will widen the application of the restraint provisions in the RC Regulation to a broader range of facilities, private hospitals under Part 2 of the *Hospital Act* and institutions designated as hospitals under (b) and (c) of the definition of “hospital” in the *Hospital Act* (rehabilitation or extended care hospitals).
- 899** *RC Reg*, *supra* note 14, at s 1.
- 900** *Ibid*, ss 74(1)(b)(i)–(ii).
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- 922 The CMPA is a membership-based, not-for-profit organization that provides legal defense, liability protection, and risk management education for physicians practicing in Canada.
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- 926 *Ibid.*
- 927 Consent Practice Standard, *supra* note 794; Consent Practice Standard Licensed Practical Nurses, *supra* note 808.
- 928 In spite of the title, the exam is largely focused on statutory law, not case law.
- 929 HCA Core Competency Profile, *supra* note 827.
- 930 HCA Curriculum, *supra* note 828 at 6.
- 931 *Ibid* at 8.
- 932 BC Care Aide Internationally Educated Health Care Professional, *supra* note 830.
- 933 BC Care Aide Role and Mandate, *supra* note 831.
- 934 HCCA, *supra* note 11, s 3.
- 935 HCCA, *supra* note 11, ss 6(e) and 7. This is not an exact quotation of s 7. The section has been edited to include elements of s 6 in order to avoid cross-referencing.
- 936 O’Connor, *supra* note 156 at 1.
- 937 *Ibid*, at 3.
- 938 British Columbia, Public Guardian and Trustee, Practice Guidelines for Incapability Assessments for the Purposes of the *Adult Guardianship Act* Part 3: Support and Assistance for Abused and Neglected Adults and the *Adult Guardianship (Abuse and Neglect) Regulation* (revised draft Sept 1, 2011).
- 939 O’Connor, *supra* note 156 at 3.
- 940 *Ibid*, at 7.
- 941 *Ibid*, at 3.
- 942 *Ibid*, at 33.
- 943 *Ibid*, at 34.
- 944 *Ibid*, at 33.
- 945 Where a TSDM is chosen to make a decision under s 16 of the HCCA with respect to major health care, the health care provider is required to notify the adult and spouse or family member that a TSDM has been chosen, who the TSDM is, and whether the TSDM has consented to or refused consent for health care recommended by the physician: HCCA, *supra* note 11, s 14(4)(b) and HCC Reg, *supra* note 260, s 6: Form 1: Notice of Incapability and Substitute Consent (Major Health Care).
- 946 *Best of Care 2*, *supra* note 270 at 291.
- 947 *Ibid* at 292.
- 948 *Ibid*.
- 949 *Ibid* at 291.
- 950 *Ibid*; Consent Practice Standard, *supra* note 794.
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- 953 *LTCH Reg*, *supra* note 609, s 29.
- 954 CCR, *supra* note 674, tit 22, § 72528(c).
- 955 WAC, *supra* note 656, 388-97-0260 (1).
- 956 CFR, *supra* note 656, tit 42, § 482.24(c)(4)(v); Washington Health Law Manual, *supra* note 660 at 2A-6.
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- 961 See discussion in *supra* note 945.
- 962 British Columbia, Ministry of Health, “A Health Care Providers Guide to Consent to Health Care” (2011) at 6, online (pdf): *College of Physical Therapists of British Columbia* <[cptbc.org/resources/health-care-providers-guide-consent-health-care-ministry-health-2011/](http://cptbc.org/resources/health-care-providers-guide-consent-health-care-ministry-health-2011/)> [Health Care Providers Guide to Consent].
- 963 Dementia in Canada, *supra* note 22 at 41.
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- 969 Provincial Guide to Dementia, *supra* note 28 at 14.
- 970 *Ibid*.
- 971 BPSD Guideline, *supra* note 1 at 3, 13.
- 972 LCO Report on Capacity, *supra* note 371 at 92.
- 973 *Ibid* at 94.
- 974 MHA, *supra* note 55, ss 31, 1 (definition of “treatment”); See also Gray, *supra* note 401.
- 975 *Ibid* at s 22.
- 976 *Ibid* at s 1.
- 977 The DSM-5 uses the equivalent term “major neurocognitive impairment”: see DSM-5, *supra* note 78.
- 978 *Adult Guardianship Act*, *supra* note 82 at 59.
- 979 MHA, *supra* note 55, s 22(3)(c). In addition to being of the opinion that the person has a “mental disorder” the physician must be of the view that the person (i) requires treatment in or through a designated facility, (ii) requires care,

supervision and control in or through a designated facility to prevent the person's or patient's substantial mental or physical deterioration or for the protection of the person or patient or the protection of others, and(iii) cannot suitably be admitted as a voluntary patient.

- 980** *MHA, ibid*, s 23; Seniors First Advocate's Manual, *supra* note 473.
- 981** *MHA, ibid*, s 24.
- 982** *Ibid*, s 37.
- 983** *Ibid*, s 39(1)
- 984** *Best of Care 2, supra* note 270, at 267.
- 985** *Ibid* at 270 – Recommendation 130.
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- 990** Daniel Fontaine, "The Case for Minimum Direct Care Hours Per Site" (28 February 2017) online: *BC Care Providers Association* <[bccare.ca/2017/02/the-case-for-minimum-direct-care-hours-per-site/](http://bccare.ca/2017/02/the-case-for-minimum-direct-care-hours-per-site/)> citing Home and Community Care Program, "Costing Assumptions #3 for the Proposed Staffing Framework for Residential Care Facilities," 11 August 2009, at note iv. The reference to care "per resident day" denotes an averaging across all residents within the health authority, that is to say, a recognition that some residents would require more, or less, than the minimum recommended. This number does not include non-medical services such as housekeeping, laundry and meals.
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- 993** British Columbia, Ministry of Health, "Action Plan to Strengthen Home and Community Care for Seniors" (2017), online (pdf): *Ministry of Health* <[www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care](http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care)>.
- 994** *Ibid* at 9.
- 995** *Ibid* at 10.
- 996** "Promising Practices in Long Term Care: Ideas Worth Sharing" (2015) at 74, online (pdf): *Canadian Centre for Policy Alternatives* <[www.policyalternatives.ca/publications/reports/promising-practices-long-term-care](http://www.policyalternatives.ca/publications/reports/promising-practices-long-term-care)>.
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- 1000** NP Streams of Practice, *supra* note 745.
- 1001** Lesley Charles et al, "Care of the Elderly Program at the University of Alberta" (2014) 60:11 *Canadian Family Physician* November e521, online: *Canadian Family Physician* <[www.cfp.ca/content/60/11/e521.full](http://www.cfp.ca/content/60/11/e521.full)>.

**1002** Auditor General BC Physician Funding Models, *supra* note 832.

**1003** *Ibid*.

**1004** *Medicare Protection Act, supra* note 835.

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**1007** CMA, *supra* note 838 at 4.

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**1009** *Ibid*.

**1010** *Ibid* at 3.

**1011** *Ibid* at 7.

**1012** "Mental Health Billing Guide" (last modified January 2018), online (pdf): *General Practice Services Committee* <[www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides](http://www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides)>.

**1013** The GP Frailty Complex Care Planning and Management Fee is payment for the creation of a care plan and advance payment for the complex work of caring for eligible patients. The Complex Care Planning and Management Fee is payment for the creation of a care plan and advance payment for the complex work of caring for patients with eligible conditions.

**1014** "Complex Care Billing Guide" (last modified January 2018), online (pdf): *General Practice Services Committee* <[www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides](http://www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides)>.

**1015** "Palliative Care Billing Guide" (last modified January 2018), online (pdf): *General Practice Services Committee* <[www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides](http://www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides)>.

**1016** "Residential Care Billing Guide" (last modified January 2018), online (pdf): *General Practice Services Committee* <[www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides](http://www.gpscbc.ca/what-we-do/longitudinal-care/billing-guides)>.

**1017** Truth and Reconciliation Commission of Canada, Call to Action (Winnipeg: Truth and Reconciliation Commission of Canada) at 23–24.

**1018** Deepthi Jayatilaka, "Dancing in Both Worlds: A Review of the Aboriginal Patient Liaison/ Navigator Program in British Columbia" (July 2015) at 21, online (pdf): *Vancouver Provincial Health Services Authority* <[www.phsa.ca/Documents/DancinginBothWorldsFINALJuly2015.pdf](http://www.phsa.ca/Documents/DancinginBothWorldsFINALJuly2015.pdf)>.

**1019** *Ibid* at 5–6.

**1020** The PHSA also provides sign-language interpreting services through the Western Institute for the Deaf and Hard of Hearing (WIDHH), for which there is no charge to the patient or the relevant department of the health authority. Sign-language interpreting must be booked directly through the WIDHH.

**1021** "Spoken Language Interpreting Services", online: *Provincial Health Services Authority* <[www.phsa.ca/health-professionals/professional-resources/interpreting-services](http://www.phsa.ca/health-professionals/professional-resources/interpreting-services)> [Provincial Health Services Authority].

**1022** *Ibid*.

**1023** *Ibid*.

**1024** *Ibid*.

**1025** Telephone call between Rachel Kelly, CCEL and a representative of the Provincial Language Service on October 25, 2018.

**1026** *Ibid*.

**1027** *Charter, supra* note 52.

**1028** *Carter v Canada* (Attorney General), 2015 SCC 5 at 67.

**1029** We have noted some of the matters covered by s. 33.4 are being brought in other ways. For example, an application to rescind the appointment of a committee when other family members did not like the treatment decisions being made for the adult or a petition seeking an injunction preventing

- a committee from ever making a decision to withdraw life support (*Ng. v. Ng*, 2013 BCSC 1997) or a petition seeking a declaration that an adult not be given nourishment that she allegedly did not consent to (*Bentley*, *supra* note 262).
- 1030** British Columbia, Office of the Ombudsperson, “No longer your decision: British Columbia’s process for appointing the public guardian and trustee to manage the financial affairs of incapable adults” (6 February 2013) at 110, online: *Office of the Ombudsperson* <[www.bcombudsperson.ca/documents/no-longer-your-decision-british-columbias-process-appointing-public-guardian-and-trustee](http://www.bcombudsperson.ca/documents/no-longer-your-decision-british-columbias-process-appointing-public-guardian-and-trustee)> [Ombudsperson].
- 1031** *Ibid.*
- 1032** *Ibid.*
- 1033** *Ibid.*
- 1034** *Ibid.*
- 1035** SBC 2003 c 96, ss 28-36.
- 1036** Ombudsperson, *supra* note 1030 at 110.
- 1037** BCLI AGA Paper *supra* note 544, at 25.
- 1038** *Ibid.*
- 1039** *Ontario HCCA*, *supra* note 266, Schedule A at s 32(1).
- 1040** LCO Report on Capacity, *supra* note 371 at 105 (Recommendation 7), 108 (Recommendation 8).
- 1041** *Ibid* at 229 (Recommendation 29).
- 1042** *Ibid* at 248.
- 1043** *Yukon Care Consent Act*, *supra* note 310, s 37.
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- 1046** *Ibid*, s 40.
- 1047** Manitoba Law Reform Commission, *supra* note 863 at 50.
- 1048** “Administrative Tribunals and the Courts: an Evolutionary Relationship” (last visited 11 February 2019), online: *Supreme Court of Canada* <[www.scc-csc.ca/judges-juges/spe-dis/bm-2013-05-27-eng.aspx](http://www.scc-csc.ca/judges-juges/spe-dis/bm-2013-05-27-eng.aspx)>.
- 1049** HCCA, *supra* note 11, s 33.4 Section 33.4 was enacted by 2007-34-30 effective September 1, 2011 (BC Reg 14/2011).
- 1050** *Ibid*, s 33.4(2).
- 1051** *PPA*, *supra* note 383 at s 4.
- 1052** *Ibid*, s 6.
- 1053** *MHA*, *supra* note 55, s 25.
- 1054** *Ibid*, s 24(2).
- 1055** *Ibid*, s 33(2).
- 1056** “Legal representation by a lawyer” (last visited 28 August 2018), online: Legal Services Society <[lss.bc.ca/legal\\_aid/legalRepresentation.php](http://lss.bc.ca/legal_aid/legalRepresentation.php)>.
- 1057** Note, there are numerous other issues which impact the fundamental rights of older people for which legal aid funding is not provided. These include advice and representation in respect of detention pursuant to the *Mental Health Act* and related applications and *Adult Guardianship Act* measures, including support and assistance orders and emergency interventions against an adult’s wishes under Part 3. However, while we recognize these topics as presenting important access to justice issues which require addressing, they fall outside the scope of this project.
- 1058** BCLI AGA Paper, *supra* note 544 at 59–60.
- 1059** *Ibid.*
- 1060** *Ibid* at 60.
- 1061** *Ibid* at 61.
- 1062** BC Civil Liberties Association, Community Legal Assistance Society, West Coast Leaf & Pivot, “Justice Reform for BC: Priorities for the Attorney General and Solicitor General of BC” (Fall 2017) at 1, online (pdf): *Community Legal Assistance Society* <[www.clasbc.net/justice\\_reform\\_bc\\_priorities\\_for\\_the\\_provincial\\_government](http://www.clasbc.net/justice_reform_bc_priorities_for_the_provincial_government)>.
- 1063** Operating in Darkness, *supra* note 59 at 61-62.
- 1064** *Ibid* at 60.
- 1065** *Ibid* at 68.
- 1066** “CBABC Statement supporting CLAS report” (December 5, 2017), online: *Canadian Bar Association British Columbia Branch* <[www.cbabc.org/News-Media/Media-Releases/2017/CBABC-statement-of-support-for-CLAS-Operating-in-D](http://www.cbabc.org/News-Media/Media-Releases/2017/CBABC-statement-of-support-for-CLAS-Operating-in-D)>.
- 1067** “An Agenda for Justice” (February 2017), online: *Canadian Bar Association BC Branch* <[www.cbabc.org/Our-Work/Advocacy/An-Agenda-for-Justice](http://www.cbabc.org/Our-Work/Advocacy/An-Agenda-for-Justice)>.
- 1068** *Ibid* at 4.
- 1069** Clare Henning, “Legal aid funding in B.C. budget doesn’t cover demand for services, CBA says” (21 February 2018), online: *CBC News* <[www.cbc.ca/news/canada/british-columbia/2018-budget-falls-short-on-legal-aid-1.4545805](http://www.cbc.ca/news/canada/british-columbia/2018-budget-falls-short-on-legal-aid-1.4545805)>; Ian Burns “B.C. budget boosts legal aid funding but it’s still ‘woefully underfunded,’ women’s equality group says” (26 February 2018), online: *LexisNexis Canada The Lawyer’s Daily* <[www.thelawyersdaily.ca/articles/5971/b-c-budget-boosts-legal-aid-funding-but-it-s-still-woefully-underfunded-women-s-equality-group-says](http://www.thelawyersdaily.ca/articles/5971/b-c-budget-boosts-legal-aid-funding-but-it-s-still-woefully-underfunded-women-s-equality-group-says)>.
- 1070** BCLI CL Capacity Report, *supra* note 330, at 160–163.
- 1071** *Ibid* at 162.
- 1072** *Ibid* at 160 citing *Bank of Nova Scotia v. Kelly* (1973), 41 DLR (3d) 273 at 275.
- 1073** *Ibid* at 160.
- 1074** *RAA*, *supra* note 360, s 8.
- 1075** *RAA*, *supra* note 360, s 8(1)(a).
- 1076** *Ibid*, s 8(2).
- 1077** Code of Professional Conduct, *supra* note 551 at Rule 3.2-9.
- 1078** *Ibid* at Commentary Note 1.
- 1079** Buchanan, *supra* note 555 at 15.
- 1080** *Ibid*, at 15-16.
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