



CONVERSATIONS ABOUT CARE:

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

Summary Report



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“
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

About the CCEL

The CCEL conducts legal research and develops legal reports and educational tools on the legal and policy issues that impact us as we age. The CCEL is part of the BC Law Institute, BC’s non-profit independent law reform agency.



About the Alzheimer Society of B.C.

The Society’s vision is a world without Alzheimer’s disease and other dementias. The Society works in communities throughout BC to support, educate, and advocate for people living with dementia. The Society advocates for dementia-friendly communities in which people affected by dementia are acknowledged, supported, and included.

Alzheimer Society
BRITISH COLUMBIA

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INTRODUCTION

Decisions about health care treatment are deeply important and personal. Medication can have a significant impact on what activities we are able to enjoy, how much pain we experience, and how long we live.

Our right to make our own health care decisions is a fundamental right protected by BC laws, the *Canadian Charter of Rights and Freedoms*, and international conventions and treaties. Unfortunately, sometimes health care professionals and family do not respect the rights of people living with dementia. Sometimes others assume that people living with dementia are not able to understand information or make their own decisions.

In 2016 the Canadian Centre for Elder Law and the Alzheimer Society of B.C. worked together to study health care decision-making for people living with dementia in BC. We wanted to better understand:

- What does the law say about the right to make medication and treatment decisions at home, in hospital, and in long-term care?
- Who is entitled to make decisions for people living with dementia if and when

they are not able to make their own decisions?

- Do health care providers adequately understand health care consent law?
- What options do people have when they disagree with decisions others make about their health care?
- How can BC laws be improved to better support the decision-making autonomy and well-being of people living with dementia?
- What can be done to further support best practice in hospitals, physician offices, and long-term care facilities?

This publication explains:

- ✓ **How we did this work;**
- ✓ **What we learned; and**
- ✓ **What we think should be done to improve the health care and legal systems.**

Glossary of Legal Terms

Restraint

A method of controlling or restricting freedom of movement in a community care facility, including through medication.

Consent to Health Care

An informed, voluntary decision to accept or refuse health care treatment.

Health Care

Anything that is done to treat, prevent or diagnose illness or disease, ease suffering, or achieve another purpose related to health.

Long-Term Care

Facilities providing 24-hour professional care to people with complex health care needs who can no longer be cared for in their own homes, or in assisted living. These facilities are sometimes referred to as seniors' homes, nursing homes or residential care.

Representative

A person chosen by another person to make, or help them make, certain decisions through a legal document called a representation agreement.

Representation Agreement

An agreement made under the *Representation Agreement Act* to grant one or more people authority to make, or help a person make, decisions. The agreement should specify the types of decisions the representative may make. Representation agreements can deal personal care, health care, and the routine management of financial affairs.

Substitute Decision Maker

An adult who is authorized to make decisions on behalf of another person. In BC a substitute decision maker for health care can be:

- a court ordered guardian (also called a committee of person);
- a representative appointed through a representation agreement; or
- a temporary substitute decision maker under the *Health Care (Consent) and Care Facility (Admission) Act*.

Supportive Decision Maker

A person who helps another person with decision-making. Supportive decision makers “support” people to:

- Understand the issues involved in a decision;
- Understand the consequences of a decision;
- Access assistance or information to help them make a decision;
- Express their views;
- Help others to understand them, and to respect their needs, rights, values, preferences, and goals.

Supported decision-making can occur with or without a formal agreement. In BC formal supportive decision makers get their authority from a representation agreements.



When I do talk about consent, and the obligation piece around risks and benefits, they say 'my doctor has never done that.'

– Social worker



HOW WE DID THIS WORK

This project involved legal research and public consultation. We reviewed:

- BC laws relating to health care decision-making;
- Laws that apply to long-term care in BC;
- Court decisions that comment on health care decision-making rights, the meaning of informed consent, and the duties of health care professionals;
- International conventions that apply to the decision-making rights of people with disabilities;
- Codes of ethics, practice guidelines, and other documents developed by health care professional regulatory bodies and practice associations;
- Education and professional development of health care professionals and staff regarding health care consent;
- Options for people who disagree with health care decisions others make for them, or findings that they are not capable of making their own health care decisions;
- Access to legal aid for people living with dementia; and
- Brochures, factsheets, and other resources published in BC to help people understand their health care decision-making rights

WHO WE SPOKE WITH

In order to better understand practice, we spoke with both professionals who are involved in health care decision-making, and people who have had personal experiences with health care decision-making. We heard from:

- People living with dementia
- Family caregivers
- Physicians
- Psychiatrists
- Nurses
- Managers of care facilities
- Social workers
- Lawyers
- Community agencies

CONSULTATION PROCESS

In 2017 the Alzheimer Society of B.C. hosted a series of meetings with people living with dementia and family caregivers living across BC. At each meeting a CCEL lawyer:

- Gave a presentation about health care decision-making rights;
- Answered questions about health care consent and advance planning; and
- Heard from people about their experiences with health care decision-making.

Inclusion BC also hosted a meeting with the CCEL.

Our consultation included:

- 65 interviews with people whose work involves health care decision-making for older people living with dementia;
- 13 community meetings 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 presentations where we asked health care professionals and staff to identify their concerns about the law and practice of health care consent; and
- An online survey of family caregivers, to which 28 people responded.

“*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



WHAT WE LEARNED

Health care decision-making requires meaningful conversations about care, values, and options. Unfortunately, physicians and other health care staff sometimes do not get informed consent when they should. This is particularly a problem in long-term care.

Here are some of the concerns identified by health care professionals and community:

1. There is not enough time to have these important discussions.

- Physicians have limited time to spend with patients and families. In long-term care physicians often make medication orders over the telephone. Staff have many residents to care for, and feel pressed for time.
- People living with dementia can require more time and support in order to participate in discussions about health care. Rushing creates more stress, which can make it harder for them to express their concerns, ask questions, and make decisions.

2. Some health care providers do not understand the law.

- In long-term care, family caregivers often feel excluded from decision-making. Staff sometimes change medication without the consent of family, or insist that the resident's chart information is confidential.
- Some staff mistakenly believe that admission to long-term care means agreement to all medication recommended by the health care team.
- There are likely a lot of people living with dementia in long-term care who have no health care decision maker because they have no friends or family. For these people, the physician and the health care team sometimes makes decisions, which is against the law.
- Some people living with dementia are being involuntarily committed under mental health law when they do not meet the legal criteria for committal.



It robs me of energy to constantly follow up with things... it is demanding to build relationships with people in care.

– Family caregiver



3. Everyone requires better support with decision-making.

- People living with dementia value the assistance of trusted family and friends when they need to make health care decisions. Spouses often work as a team. Assisting people living with dementia to access this support is important.
- Family members, and substitute and supportive decision makers, need education in order to better understand their rights and responsibilities.
- Health care professionals and staff need practice support when family members disagree about care. It is difficult to get consent when a person does not have capacity to make a health care decision, but does not seem to have family or friends. Often staff do not know what to do, or who to call for assistance. Many do not understand the role of the Public Guardian and Trustee.

4. Some people face unique barriers to health care decision-making.

- Indigenous people often experience racism. Many lack services in their communities, including long-term care.
- People who do not speak or understand English require professional language

interpretation. The service is not always offered, particularly in private long-term care facilities.

- People with hearing and speech issues face false assumptions that they do not have capacity to make their own decisions. Sometimes staff do not know how to address the needs of people with hearing and speech issues, or how to communicate with them.

5. People do not know what to do when they disagree with the actions of health care providers or family.

- Physicians have a lot of power, and can be intimidating, even when they mean well. A lot of people do not know they can make a decision that is not consistent with the physician's recommendation.
- Formally challenging the actions of a substitute decision maker generally requires a person living with dementia to make an application to the court. Legal aid is not available for most health care decision-making and guardianship matters.



RECOMMENDATIONS

The following are highlights from the 34 recommendations made in the report.

The report makes recommendations which aim to:

1. Improve the law;
2. Support the best practice of health care providers;
3. Address barriers to informed consent; and
4. Enhance access to legal information and assistance for people living with dementia and their families.

1. Improve Health Care Decision-making Laws in BC

Health care decision-making rights are set out in a BC law called the *Health Care (Consent) and Care Facility (Admission) Act*. This law has many strengths. For example, the law confirms that every adult in BC is presumed to be mentally capable of making

their own health care decisions, regardless of illness or disability. The law states that people have the right to ask questions, and receive answers about proposed health care before they make a decision.

However, there are some gaps in the law. We recommend adding language to:

- A. *Recognize that people's capacity to make health care decisions can vary, from day to day, and decision to decision.*
- B. *Affirm the right of every adult, regardless of capacity, 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.

The *Residential Care Regulation* contains rules that apply to long-term care. Some of the rules are not consistent with the rights protected in the *Health Care (Consent) and Care Facility (Admission) Act*.

We make a number of recommendations aimed at bringing the Regulation in line with the Act, particularly regarding use of anti-psychotics used as a form of restraint.

2. Support the best practice of health care providers

The majority of health care professionals and staff work hard to provide excellent care to people living with dementia under challenging circumstances. However, everyone we spoke with said that their workplace or profession would benefit from greater knowledge and education about health care decision-making law. We noticed confusion about the following four topics:

- When are health care providers required to obtain informed consent?
- How and when should they obtain consent from substitute decision makers?
- When should they contact the Public Guardian and Trustee, and how can the PGT get involved or assist?
- When (if ever) can mental health law be used to involuntarily commit a person living with dementia?

We also found that staff require:

- Basic education on dementia; and
- Practice guidance on how to support people living with dementia to be involved in their own health care decisions, even when they have some challenges with understanding and communication.

The report makes recommendations aimed at supporting the best practice of physicians, nurses, health care assistants, and others working in community, hospital, and long-term care. We look forward to working with stakeholders to support health care provider understanding of health care decision-making law, including the College of Physicians and Surgeons, Doctors of BC, the newly formed BC College of Nursing Professionals, the Care Aide and Community Health Worker Registry, the Ministry of Health, and other agencies.

“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

More Information

To learn more about your health care decision-making rights, and planning tools such as representation agreements, see educational factsheets developed by Nidus Personal Planning Resource Centre and Registry www.nidus.ca

Starting in April 2019 you will be able to read the CCEL and Alzheimer Society of B.C. dementia factsheet: *Decision-making about Health Care: Legal Rights for People Living with Dementia.*

3. Address barriers to informed consent

Some people living with dementia experience unique barriers to participating in health care decision-making. We make recommendations aimed at addressing:

- Barriers experienced by Indigenous people in BC; and
- Access to language interpretation.

We also recommend:

- Staff be available to support people living with dementia, their family members, and their supportive and substitute decision makers with health care decision-making; and
- Incentive payments be available to physicians to support them to have adequate time to discuss health care treatment options with patients and their families.

4. Enhance access to legal information and assistance

We recommend the Government of BC:

- Create a review tribunal which allows people living with dementia and others

to seek a review of decisions by substitute decision makers for health care;

- Enhance access to legal aid for matters related to health care decision-making and guardianship; and
- Develop a plan for educating British Columbians about representation agreements and supported decision-making.

For a full list of recommendations, see Appendix A of the report: www.bcli.org/ccel

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

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“*It is a struggle. You have to speak up, ask questions and challenge. But it is overwhelming.*”

– Family caregiver

You can download this Summary Report and the Full Report from the website of the Canadian Centre for Elder Law at www.bcli.org/ccel