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Supporting People Living with Dementia to Participate in Decision-Making



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Over 500,000 Canadians and about 1-in-4 seniors age 85+ live with a diagnosis of dementia. Family members and professionals may not recognize the ability of a person living with dementia to direct their own life choices.

The Canadian Centre for Elder Law (CCEL) is collaborating with people living with dementia, their care partners, and key stakeholders to address barriers to participating in decision-making. In 2021 and 2022, we are consulting with people to identify barriers and strategies. The ultimate goal of this work is to create resources for teaching healthcare stakeholders how to support people living with dementia to participate as much as possible in decisions that impact their lives.

What We are Hearing from People

For the past 3 months, the CCEL has facilitated conversations with people living with dementia and their care partners. Participants, whose names were changed in this article due to confidentiality, emphasized the importance of being included in all decisions. Scott voiced, “I don’t want to just be a rubber stamp on decisions.” These individuals told us that it

matters for them to be involved in decisions such as healthcare decisions, finances, personal and financial planning, everyday decisions, living arrangements, personal care, and funeral arrangements.

Participants shared with us the barriers they face to being involved with decisions including difficulty in navigating the system, attitudes of healthcare professionals, and lack of communication. In navigating the system, individuals often did not know where to find information and checklists to make future decisions.

Many people living with dementia are capable of making their own decisions, particularly if they have support from people they trust.

People living with dementia can be looked over and not consulted. Jean shared, “I found that a common issue with medical staff . . . just talking over [the patient] was a huge problem. I really felt I had to redirect the conversation to pull my mother back in.” People living with dementia and care partners also wished they had talked about

future decisions while they were still able to do so.

To address those barriers, participants shared the importance of having someone they trust help make decisions. The desire for a professional to advise them of timely information related to decision-making came up many times. Participants also wished that professionals would respect their personhood by taking enough time, seeing the person behind the disease, and treating them with dignity. They said professionals need to respect the rights of people living with dementia to be involved in decisions.

Professionals can help by ensuring access to timely information about personal planning and pursuing training on dementia and decision-making. In the words of Alice, “We need folks to understand our diagnosis and to ask all the questions they want.”

The Legal Context

The law in British Columbia says that all adults are presumed to be capable of decision-making. People are not capable if unable to understand the information relevant to a decision and how it applies to their situation. Many people living with dementia are capable of making their own decisions, particularly if they have support

from people they trust. Others can participate in the decision-making process even if they have appointed someone to make decisions for them.

The right to make our own healthcare decisions is protected by multiple levels of legislation. The Supreme Court of Canada has determined that the *Canadian Charter of Rights and Freedoms* protects the right to informed consent. That right is also codified in British Columbia's *Health Care (Consent) and Care Facility (Admission) Act* (the *Health Care Consent Act*), and recognized in international laws, such as the *United Nations Convention on the Rights of Persons with Disabilities*. British Columbia also has robust legislation that supports advance planning and imposes responsibilities on people who have the authority to make decisions for others.

1. The Right to Assistance with Communication

The experience of dementia can meet legal definitions of disability. People with disabilities have a right to assistance with communication. In BC that right is supported by the *Human Rights Code* and the *Health Care Consent Act*. The *Human Rights Code* prohibits discrimination against people with disabilities and requires accommodation of barriers linked to disability. Accommodation means not only building ramps and other mechanisms of physical accessibility but also providing assistance with communication.

BC's *Health Care Consent Act* (section 8) also imposes an obligation on healthcare providers to communicate with people "in a manner appropriate to the adult's skills and abilities." That language means healthcare professionals need to adapt their ways of communicating to suit the needs of a person with disabilities. That provision will sometimes require including in the discussion someone who knows the person with a disability well and understands the individual's unique communication methods.

Question for BC Notaries to consider: How can you adapt the way you communicate to be more dementia-friendly?

2. The Right to Support with Decision-making

Many people with disabilities who cannot make decisions independently can make some or all of their own healthcare decisions if they have support with decision-making from a person they trust.

Other people with disabilities may make better decisions for themselves when they have support. In BC, the *Representation Agreement Act* allows people to appoint a supportive decision-maker for healthcare through a document called a Representation Agreement. (You can also appoint a substitute decision-maker for healthcare.)

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; or
- express their views, acting as interpreter where required.

People with disabilities are entitled to communicate with their supporters when healthcare decision-making is required. The supportive decision-maker can help them demonstrate capacity for decision-making and assist with decision-making.

Question for BC Notaries to consider: How can you work effectively with supportive decision-makers without allowing them to take over the process?

3. The Duty to Consult

Certainly, some people cannot make their own decisions—even with support. In such instances, healthcare staff and others must seek consent to treatment from a substitute decision-maker. In BC, a substitute healthcare decision-maker could be a guardian, a representative, or a temporary substitute decision-maker chosen under the *Health Care Consent Act*.

Healthcare decision-makers cannot make substitute decisions in a vacuum. They have legal obligations to communicate with the person they represent.

For example

- A temporary substitute decision-maker for healthcare is required to consult with the adult to the extent possible, consider the adult’s wishes, and comply with them if reasonable. If a temporary substitute will not fulfil those duties, then the healthcare provider cannot

accept substitute consent from the adult and must choose the next person in the list under section 16 of the *Health Care Consent Act* (section 19).

- A representative must consult with the adult and follow the adult’s wishes to the extent that is reasonable. If the adult is not capable, the representative must make decisions based on pre-expressed wishes of the adult. If the adult has no pre-expressed wishes, the representative must act based on the adult’s known beliefs. If the beliefs are not known, the representative must act in the adult’s best interest (subsections 16, 18).

Most of us consult with people we trust to make the best decisions we can for ourselves. We talk about our concerns with family and close friends. We seek additional expert opinions. For many people with disabilities, however, the support of trusted allies is not just helpful—it may be integral to exercising legally protected decision-making rights.

Question for BC Notaries to consider: How can you help representatives and other substitute decision-makers to understand their legal responsibilities?

How can you Support Respect for the Decision-Making Rights of People Living with Dementia?

1. BC Notaries are critical gatekeepers of information on decision-making rights and advance planning. Notaries can refer folks to reliable information, such as CCEL’s animated videos and brochures on supported decision-making and healthcare rights. Other great sources of information are the Alzheimer’s Society of B.C., Nidus Personal Planning Resource Centre and Registry, and the Public Guardian and Trustee.

2. Notaries can be key allies in supporting people to identify how they can live their best lives across the dementia journey, and develop resources to articulate their needs and wishes. Many people learn about Representation Agreements through their BC Notary.

3. Notaries can role-model strategies for including people living with dementia in conversations about their needs and wishes. The client meeting can be an excellent opportunity to teach by example.

4. Some strategies

- Communicate using clear and simple jargon-free language.
- Speak lowly and clearly.
- Allow time for questions.
- Take breaks or re-schedule when a person living with dementia seems tired or overwhelmed.
- Remember who the client is and get instructions from the person living with dementia—not the potential beneficiary, testator, or representative.

You can access all CCEL resources and learn more about the CCEL project on “Engaging People Living with Dementia in Decision-Making” on the CCEL website www.bcli.org/ccel.

The CCEL is continuing to work to identify strategies and tools for supporting people living with dementia to assert their decision-making autonomy. ▲

Contact Jess Fehrenbacher at jfehrenbacher@bcli.org to participate in the CCEL project.

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