Engaging People Living with Dementia in Decision-Making

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Krista James is a lawyer.

She is the National Director of the Canadian Centre for Elder Law.

Her work addresses legal and policy issues linked to aging. She has a particular interest in how aging, gender, and other aspects of identity intersect.

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About the CCEL

The CCEL conducts research, and develops reports and educational tools about legal and policy issues related to aging.

The CCEL is part of the BC Law Institute, BC's non-profit independent law reform agency.

Our work = Law reform
Consultation
Research
Legal education
Current CCEL areas of research:

- Elder abuse and neglect — law and policy across Canada
- Unregulated health care assistants — legal models for practice oversight
- Consent to participate in research — laws and ethics for inclusion of people living with dementia
- Decision-making, mental capacity, and disability
Engaging People Living with Dementia in Decision-Making

PROJECT GOAL

We want to change how health and personal care decision-making is approached in homes, physician offices, acute care, and long-term care so that people living with dementia will be robustly supported to participate meaningfully in all the everyday decision-making that matters to them, to the best of their abilities.
Project Objectives

- Consult with people with different kinds of disabilities to identify strategies that support people living with dementia to be meaningfully involved in decision-making.

- 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.
Legal Framework

BC Adult Guardianship Act
BC Representation Agreement Act
BC Health Care Consent and Care Facility Admission Act
BC Patients Property Act
BC Residential Care Regulation
Canadian Charter of Rights and Freedoms
BC Human Rights Code
United Nations, Convention on the Rights of Persons with Disabilities
Summary of the Law in BC

- All adults are presumed capable of decision-making—regardless of age or disability.
- People with disabilities have a right to accommodation of their communication needs and abilities.
- The right to make any decision depends on whether a person is able to understand information relevant to that specific decision.
- The role of supportive decision-makers is protected.
- Substitute decision-makers have a duty to consult with the people they represent.
The Challenge

In spite of robust legal rights, people living with dementia are often excluded from decision-making due to:

- Ableist and ageist attitudes regarding decision-making capacity
- Poor understanding of dementia and its impact on capacity
- Staffing issues and institutional capacity

- Lack of health care staff knowledge of legal rights and duties
- Health institution emphasis on patient outcome over process
- Barriers faced by unique populations—racism, health literacy, colonization, lack of cultural safety and humility, and more

Source: Conversations about Care: the Law and Practice of Health Care Consent for People Living with Dementia in British Columbia (2019)
Project Partners

Alzheimer Society of B.C.
Centre for Research on Personhood in Dementia
Family Caregivers of B.C.
Key methods

• Leadership by a Dementia Advisory Council
• Consultation with diverse disability populations
• Health care sector consultation including family caregivers
• Tools grounded in the experiences of people living with dementia
• Expertise of an Indigenous Facilitator
Would you like to participate?

- Virtual focus groups
- Key informant interviews
- Stakeholder forums

Contact Jess Fehrenbacher at jfehrenbacher@bcli.org to participate in the project.
Thank you to our funder

vancouver foundation
Let's stay in touch!

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PROJECT WEBPAGE:  
www.bcli.org/project/engaging-people-living-with-dementia-in-decision-making