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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**.

Find her writing at www.bcli.org/ccel and on Twitter at [@KristaElan](https://twitter.com/KristaElan).

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



CANADIAN CENTRE FOR
ELDER LAW

Current CCEL areas of research:

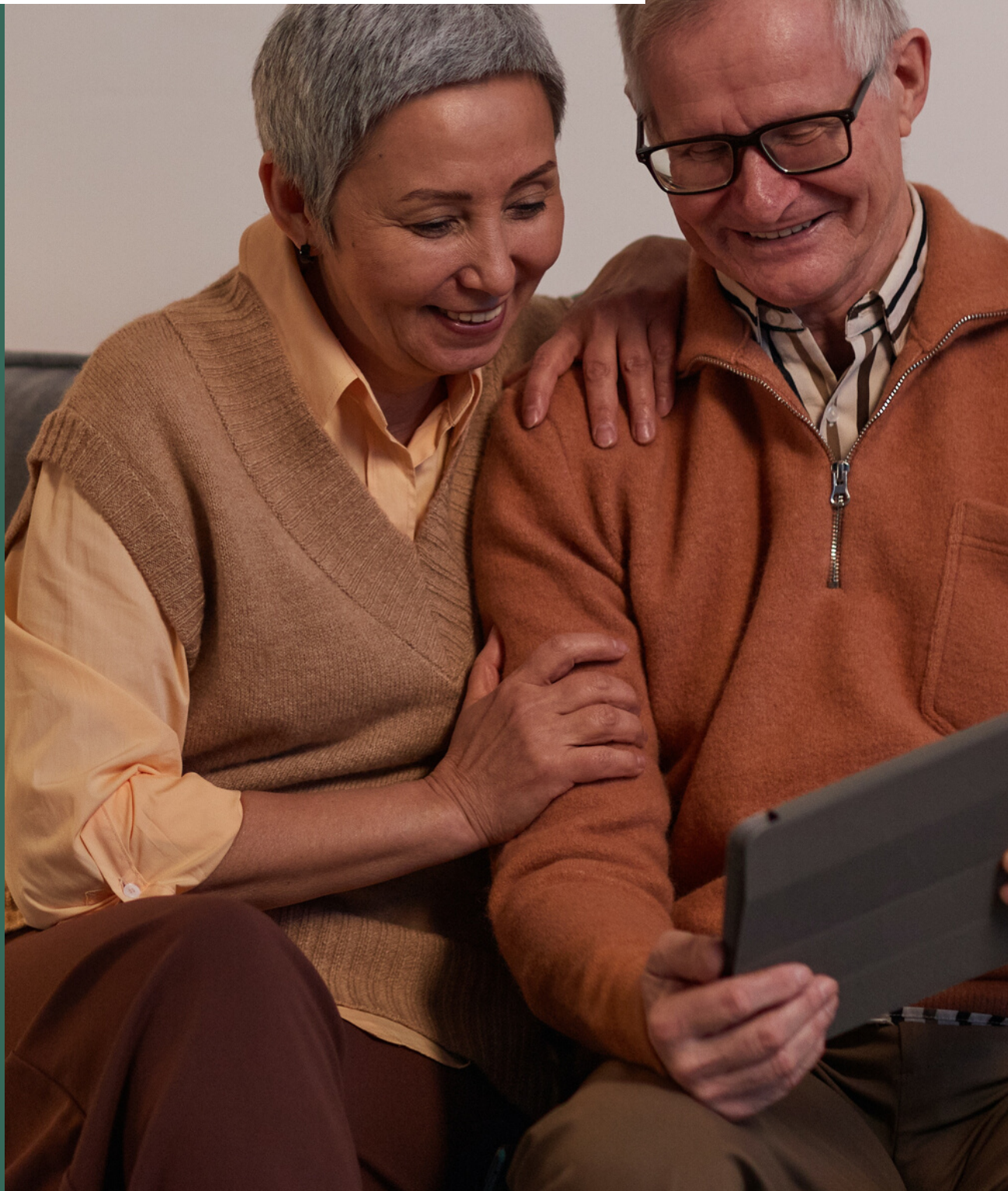
Elder abuse and
neglect — law and
policy across
Canada

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

Lack of health care staff knowledge of legal rights and duties

Poor understanding of dementia and its impact on capacity

Health institution emphasis on patient outcome over process

Staffing issues and institutional capacity

Barriers faced by unique populations—racism, health literacy, colonization, lack of cultural safety and humility, and more

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