

Engaging People Living with Dementia in Decision-Making

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Today's Presentation

1

KRISTA: Who makes our health care decisions?

2

KRISTA: What is supported decision-making?

3

JESS: What have we learned from community?

4

DISCUSSION: What supports best practices?



Presentation Objectives:

- . Participants will better understand health care decision-making law
- . Participants will learn about supporting respect for decision-making rights of people living with dementia
- . Participants will better understand the rights and responsibilities of family members and substitute decision-makers

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

www.bcli.org/ccel

Our work = Law reform + Consultation
+ Research + Legal education



Current CCEL areas of research

**Elder abuse
and neglect law
and policy
across Canada**

**Decision-making
rights and
dementia**

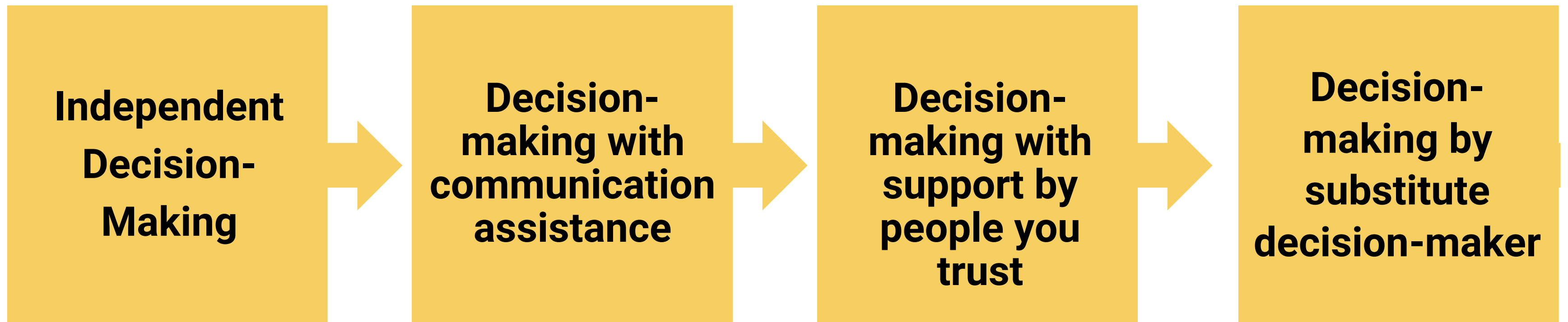
**Criminal court
witnesses with
capacity issues**

**Regulation of
health care
assistant
practice**

Who makes health care decisions for a person who is living with dementia?

- **They can make their own health care decisions** if they understand the information relevant to a decision, and can apply it to their situation
- **They may decline care** their family or physician wants them to accept
- **Their decision-making abilities may vary.** They may be able to understand information on some days, but not others

Decision-making along the dementia journey



Who makes your health care decisions?

1. **YOU** make your health care decision if you have capacity for THAT decision

2. You can appoint a **substitute decision-maker**.
= Advance care planning

3. Someone can go to court to appoint a **guardian** for you.
= rare & expensive

4. Health care provider chooses a **temporary substitute decision-maker**



Human rights and decision-making

Accommodation of disability

Health care providers must communicate with people in a manner appropriate to their skills and abilities



Support with communication

Health care providers 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



Duties of substitute decision-makers

A temporary substitute decision-maker must be willing to comply with the duty to:

- consult with the adult to the greatest extent possible, and
- comply with previously expressed wishes

Who makes your health care decisions?



1. No treatment
without consent



2. Presumption of
capacity



3. Substitute consent
from the right person



4. Consent must be
informed

Consent in Long Term Care

- A person who did not have capacity to consent to admission to long-term care might be capable of consenting to all or some of their treatment.
- Some treatment is agreed to in advance in the care plan, which also requires agreement.
- Physicians must maintain ongoing contact with substitute decision-makers to get consent for medication changes when a resident cannot provide consent for themselves
- Some treatment, like use of chemical restraints, requires agreement in writing for ongoing use

Family = so much more than “visitors”



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

Supported Decision-Making



I listen
when she
needs to
talk

I research
medication

I book language
interpreters

I explain things
in simple
language

I take notes at
appointments



Videos

3 animated videos:

- Who Makes Your Health Care Decisions?
- Getting Support with Health Care Decisions
- Protecting Your Decision-Making Rights



HEALTH CARE DECISION-MAKING:
**Legal Rights of People
Living with Dementia**



Rights Booklet

Plain language 12-page booklet

Available in 4 languages:

- English
- French
- Chinese
- Punjabi

Downloadable at:

<https://www.bcli.org/project/health-care-decision-making-legal-rights-of-people-living-with-dementia>

The Challenge

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

Ableist and ageist attitudes

Inadequate understanding of dementia and its impact on capacity

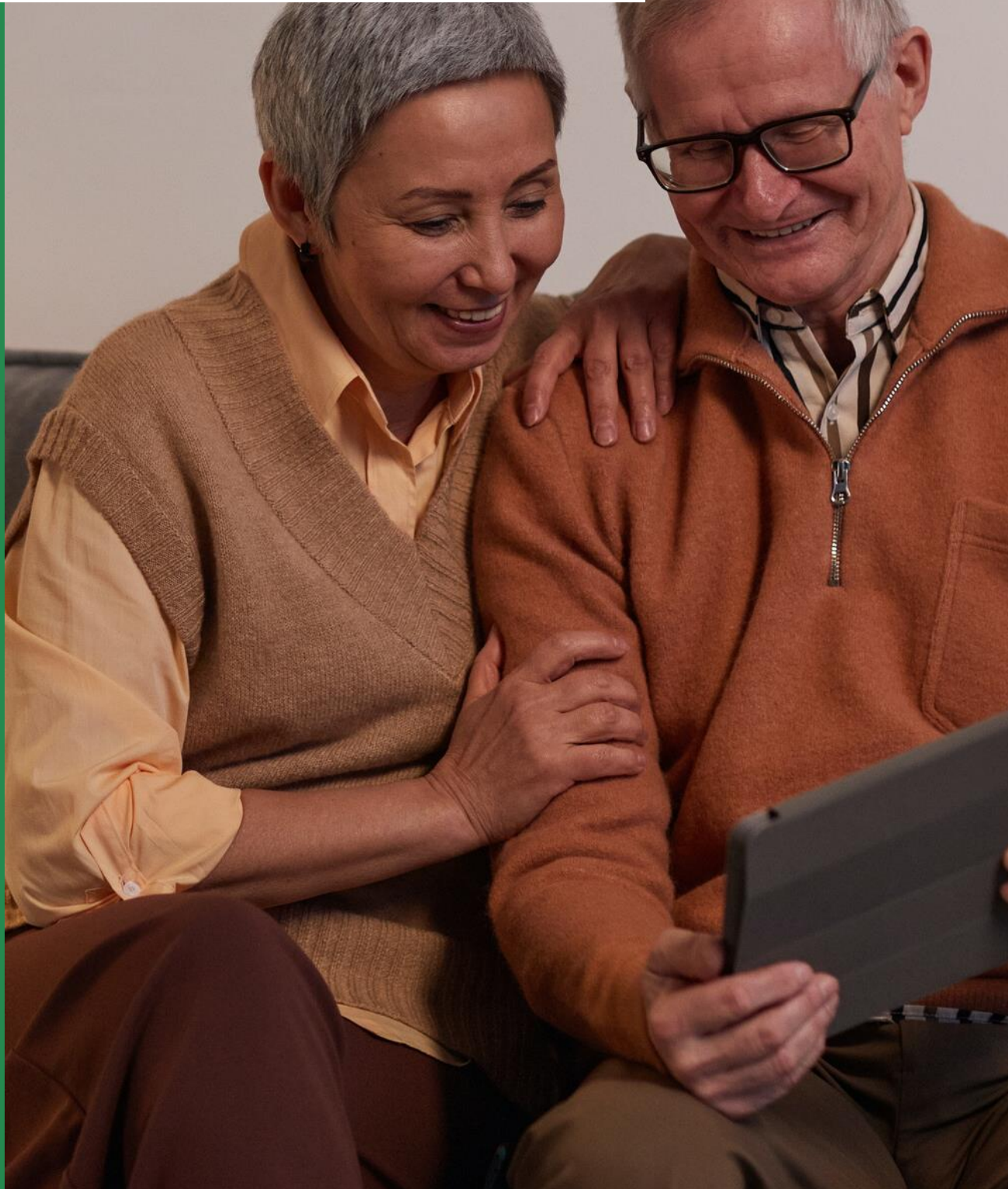
Health institution emphasis on patient outcome over process

Staffing issues that result in lack of time and resources to support people and learn about their abilities

Lack of health care staff knowledge of legal rights and duties

Barriers related to racism, health literacy, colonization, lack of cultural safety/humility, and more

Engaging People Living with Dementia in Decision-Making



PROJECT GOAL

To change how healthcare decision-making is approached so that the rights of people living with dementia are respected and they participate as much as possible in the decisions that matter to them.



Project Objectives

1. Partner with people with different kinds of disabilities, including dementia, their family care partners and health care professionals to identify strategies and barriers to decision-making
2. Identify ways to support families and healthcare professionals' capacities to engage people living with dementia in decision-making.

Project Partners



**Alzheimer
Society of B.C.**



**Centre for Research on
Personhood in Dementia**



**Family Caregivers
of B.C.**



CCEL Dementia Advisory Council

Consultations

23 people living with dementia

34 people living with other disabilities

13 people in mental health housing

60 family care partners

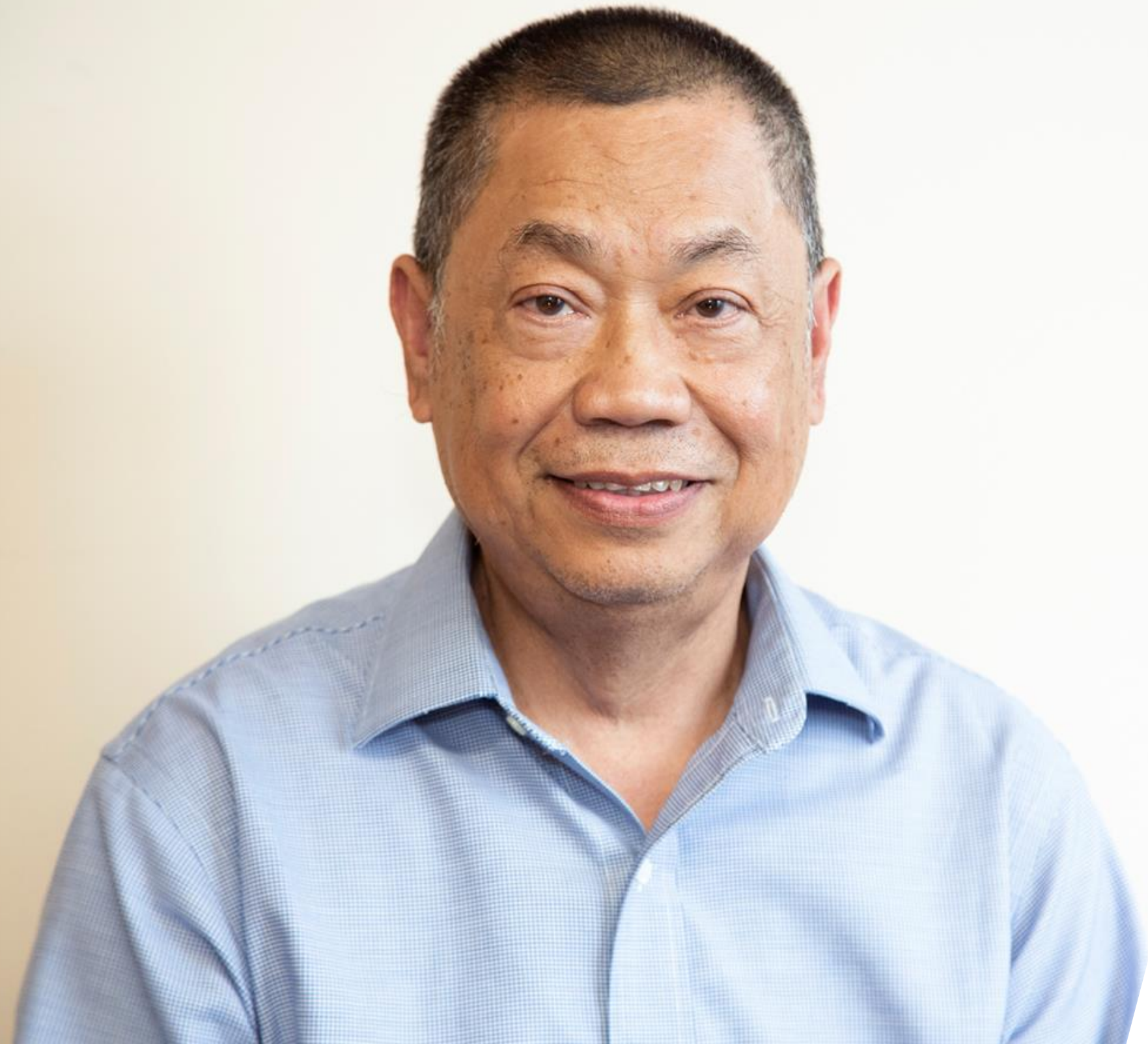
13 English language group consults

3 consults in other languages

8 individual interviews with community members

60 health care interviews

Key takeaways from people living with dementia:



- I am still here.
- Respect my rights to make decisions.
- Talk to me directly.
- Sometimes I need help from people I trust.

Care partner strategies



- Advocate & translator
- Simplifying options
- Prioritizing input
- Enough time
- Emotional level
- Visuals
- Reframing
- Third person

Tips from people living with dementia

- Communication
- Recording
- Advance decisions
- Enough time
- Visuals
- Positive self talk
- Self-advocacy
- Prioritizing
- Involving others

Supported decision-making includes:

Communication

Practical support

Empowerment

Approach

Learning

Relationship

Read more at our blog post: <https://www.bcli.org/project-update-engaging-people-living-with-dementia-in-decision-making-3/>

HOW TO SUPPORT US IN MAKING DECISIONS



Feedback from health care providers

“It’s really nothing magical. It comes down to understanding the individual and the risk and what type of illness they have.”

“As long as they are still capable, focusing on them as the centre point of decision-making. If they want to involve family, that’s up to them.”

- Geriatric psychiatrist



Tips from health care providers

- No one size fits all approach
- Maximize capacity (ie. glasses, time of day)
- Patient-first, then family
- Collaborative approach
- Check assumptions and be curious
- Right to live at risk



Tips continued

- Time, trust, relationship, safety
- Get context and learn values
- Mentorship & practice
- Adapt communication & address limitations
- Observe behaviour & give choice
- Recognize cultural considerations



Towards Change



“What we also must have is a change in attitude. That is done one on one at an individual level and also at an institutional level. [We] also need a greater understanding of different communication needs and styles and not to stereotype people as a result of that.”

- Person living with a disability

Thank you to our funder

vancouver
foundation

Additional thanks

- [Inclusion Langley](#)
- [Inclusion BC](#)
- [DIVERSEcity Community Resources Society](#)
- [Richmond Society for Community Living](#)
- [Burnaby Access Advocacy Committee](#)
- [Plan BC](#)
- [PosAbilities](#)
- [The Disability Alliance](#)
- [The Bloom Group](#)
- [Dementia Advocacy Canada](#)
- [Burnaby Seniors Outreach Society](#)
- [Alzheimer's Café: BC Chapter](#)
- [Council of Senior Citizens Organizations of BC \(COSCO\)](#)
- [Canadian Hard of Hearing Association \(Chha-BC\)](#)
- And more!

CALL FOR HEALTH CARE KEY INFORMANTS

For CCEL's Engaging People Living with
Dementia in Decision-Making Project



Are you a health care provider in BC who
works with people living with Dementia?

You are invited to share your feedback in an interview
to inform tool development for health care providers.



We want to hear from:

- Physicians
- Nurses
- Health care assistants
- and others

on their needs and perspectives for tool development to support
decision making involvement for people living with dementia.

Interviews will be recorded on the phone or zoom and last 30 - 60 minutes.

**If you are interested or know someone who would be a good fit, contact
Jess Fehrenbacher at jfehrenbacher@bcli.org or 778-548-9996**

Participants will be entered into a \$200 cash draw.

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.

Resources

- Health care decision-making rights of people living with dementia: [CCEL video and booklet](#)
- CCEL [Engaging People Living with Dementia in Decision Making Project Page](#)
- Advance Care Planning: [BC Centre for Palliative Care](#)
- Learn about dementia stigma: [Flippingstigma.com](#)



Let's stay in touch!

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