Dementia + Decision-Making

Empowering People Living with Dementia and Their Caregivers

A Guide for Health Care Providers

CANADIAN CENTRE FOR ELDER LAW
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Overview and Terminology

The Canadian Centre for Elder Law's Dementia + Decision-Making project encompasses a range of resources designed to engage people living with dementia in decision-making. We hope this Guide will be an ongoing resource to understand the law relating to the rights of people living with dementia and how health care providers can help people living with dementia to participate in decisions regarding their care and well-being. All materials were developed following extensive consultation with key informants with lived experience, including health care providers, caregivers, and people living with dementia. The project's materials include videos, guides, quick reference materials and decision-making flowcharts and are available here.

This Guide can be read in its entirety or readers can use the table of contents to access information on specific care and decision-making related issues. This Guide provides an overview of the law and some considerations for caregivers and care partners in how the law works to better help people living with dementia in decision-making. The Guide identifies barriers and provide strategies to overcome those barriers, where possible. By understanding the law surrounding decision-making as it relates to capacity, caregivers and care partners will be in a better position to support the decision-making rights of people living with dementia.

This is a detailed guide for health care providers so they can support people living with dementia navigate the decision-making process. It is meant to work in tandem with the flowcharts developed for specific decision-making scenarios and can be used as a reference tool for specific scenarios.

We are starting with the presumption that all people are capable of making decisions until proven otherwise. It provides insight for health care providers working with people living with dementia when it becomes unclear that the person living with dementia may not be able to fully participate in decision-making and information on how to better support their involvement. Following feedback from health care providers, we recognize the need for resources that can be accessed and reviewed in short timeframes. Therefore, the guide is broken down into overviews of key concepts, legal tools and their applicable tests, and best practices, all aimed at providing greater awareness of how health care providers can better incorporate people living with dementia in decision-making.

Terms

It is important to avoid ageist and ableist language. Words can have a harmful impact on people and contribute to stigma. The language around dementia is often very negative, focusing on loss of memory, identity, and ability. We should acknowledge loss without assuming that everyone living with dementia is "suffering from dementia".

People living with dementia are often reduced to labels. It is important to always respect a person's preference on how they want to be identified. However, as a general guideline, language should be people-first. Choose expressions such as "person living with dementia". Being mindful of the terms you use can help to promote the dignity and autonomy of people living with dementia and reduce stigma. Being alert to terminology can also help reduce confusion, while in turn promoting awareness and communication. For example, in certain contexts, using the term "dementia" might be confusing for the person, and it may be more helpful to speak about dementia in terms of symptoms or experiences.

'Capacity' refers to a person's ability to make decisions about their life. In the legal context, capacity refers to the ability of a person to enter into a legal relationship in an informed manner. This requires that the person is able to understand the nature of the decision and appreciate the consequences of the decision.

'Caregivers' or **'Care partners'** refers to people who are giving unpaid care to a person living with dementia. These people are often a family member or friend.

'Consent' in the health care setting refers to the permission given by a person or patient for a health care provider to perform an activity or give a form of treatment on the person.

'Decision-making' refers to a person's ability to make a decision after receiving all the necessary information to understand what the decision is and the possible consequences or impact of the decision.

'Health care providers' refers to people who are providing paid care and/or prescribed health care to people living with dementia in health care settings, including in the community and home care settings. For the purpose of this booklet, we refer to health care providers generally to include medical practitioners, registered nurses, registered psychiatric nurses, nurse practitioners, registered social workers, registered occupational therapists, registered psychiatrists, health care assistants[1], long-term care facility administrators and managers, or health care aides.

'Person(s) living with dementia' or '**People living with dementia'** refers to people living with a set of symptoms, such as memory loss, changes in mood, and difficulties with thinking, problem solving, and language, caused by damage to the brain by diseases or a series of strokes.[2] The experience of living with dementia varies significantly from person to person.

'Pre-expressed wishes' refer to the wishes, desires, or intentions of a person that have been expressed in the past. Such wishes may have been expressed verbally, through actions, in writing, or formalized in a legal document such as an advance directive or representation agreement.

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[1] Interior Health, "Overview of Health Care Assistant Workers" (last visited August 2023), online: < www.interiorhealth.ca/careers/careers-at-ih/health-care-assistant-careers>. Health care assistants can include community health worker, care aide, long-term care attendant, nurse's aide, assisted living worker, some support worker and personal support worker.

[2] "What is Dementia?" (March 2021), online (pdf): *Alzheimer Society of Canada* <alzheimer.ca/sites/default/files/documents/ASC_What-is-dementia-info-sheet_en.pdf>.

'Substitute decision-maker' refers to a person who has the legal authority to make a decision on behalf of a person who does not have capacity. There are several types of substitute decision-makers:

> A *committee* is a substitute decision-maker appointed by the court. The court can appoint a **committee of estate** (for financial and legal decisions) or a **committee of person** (for personal and health care decisions).
>
> An *attorney* is appointed in a **power of attorney** to act as a substitute decision-maker for a person on financial and legal affairs.
>
> A *representative* is a substitute decision-maker appointed under a representation agreement. A **section 7 representation agreement** can cover major and minor health care, personal care, routine financial affairs, and legal decisions. A **section 9 representation agreement** can cover major and minor health care and personal care, but not routine legal or financial decisions.
>
> A *statutory property guardian* is appointed to make financial decisions for a person who has been deemed incapable. The Public Guardian and Trustee acts as the statutory property guardian, but only as a matter of last resort.
>
> A *temporary substitute decision-maker* is a person who provides consent on health care matters where there is no appointed substitute decision-maker. This person is chosen from a ranked list of people close to the person who cannot give consent.

'Supported decision-making' is a voluntary relationship that provides an alternative to substitute decision-making. Supported decision-makers help people to make their own decisions. Supported decision-makers provide support suitable to a unique person's needs. They can, for example, help people understand information, communicate their needs and wishes, research options, and follow through on their choices. In some provinces and territories a person can formally appoint a supported decision-maker, generally by signing a legal document.

'Undue Influence' refers to the pressure or other form of subterfuge that causes a person to perform a legally significant act, such as making a gift, a will, or granting a power of attorney, that does not reflect the genuine wishes or intentions of that person, but rather those of the influencer. For further information on undue influence, see the BCLI guide in the reference section at the end of this booklet.

Spotlight on Contexts of Care

In developing this resource, ample information was provided by way of focus groups and consultative sessions with key informants with lived experience. These sessions indicated that the context of care can have significant impacts on the decision-making capacities of people living with dementia. The following contexts should be taken into account when considering how to better involve people living with dementia in decision-making.

Long-term care and assisted living

Long-term care and assisted living environments pose barriers to decision-making through their governing care structures, which may give the perception of advancing institutional priorities over the decision-making rights of people living with dementia.[3]

Long-term care facilities may also prevent people living with dementia from participating in research, a systematic exclusion that prevents people living with dementia from making decisions they would otherwise be able to make in a different environment.[4]

Long-term care and assisted living environments may require health care providers to advocate for the decision-making rights of people living with dementia in contradiction to their leadership.

Emergency and acute care

In emergency and acute care, there is often a need for fast and complex decisions. Such a rushed environment is often at odds with the amount of time necessary to establish the decision-making capacities and needs of people living with dementia. As a result, some people living with dementia describe a tendency for health care providers to rely solely on the judgement of caregivers at the expense of patient-centered care for people living with dementia.

As one person with lived experience shared,

> *"the doctor actually said just tell us what her values are and they'll make the decisions which is, goes against kind of the patient centered care or the patient's right for decision-making."*[5]

Advanced care planning through advance care directives or representation agreements can help ensure that the decisions of people living with dementia are respected in emergency and acute care. Moreover, even where there are no advance care planning documents, and a person living with dementia does not have capacity to provide consent, health care providers should have conversations with people living with dementia about their beliefs, wishes and values.

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[3] Discussions with persons with lived experience provided this insight from their experiences.
[4] Discussions with persons with lived experience provided this insight from their experiences.
[5] Discussions with persons with lived experience provided this insight from their experiences.

Rural and remote areas

In rural and remote areas there is a lack of long-term care facilities or community care services, leaving both people living with dementia and their care partners with fewer or no options for support.

The lack of available information in rural areas is also a barrier to decision-making; namely, information on finding the right care home, proper care, and advisory decision-making.[6]

Health care providers should strive to ensure that people living with dementia living in rural areas receive high-quality health care. The use of telecommunications and information technology have been described as one strategy for improving access to health care in remote areas.[7]

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[6] Discussions with persons with lived experience provided this insight from their experiences.

[7] "Improving the Care of Persons with Dementia in Rural and Remote Areas" (last visited 2 August 2023), online: *Rural Dementia Action Research* <cchsa-ccssma.usask.ca/ruraldementiacare/>.

SECTION 1: CAPACITY

1.1 Definition of Capacity – What is Decision-Making Capacity?

Capacity (also known as mental capacity, capability, or competence) is a person's ability to make decisions about their life. Capacity applies to any type of decision a person makes from big legal, financial, or health care decisions, to day-to-day decisions such as what to eat, how to dress, or whether to take an over-the-counter pain medication.[8]

While capacity is a legal term, there is no consistent legal definition of capacity; it can differ from province to province and even for each type of decision at issue. However, for the most part, all persons, including people living with dementia, are presumed to be capable and have the right to make decisions for themselves.[9]

1.2 Rights of Capable Persons

All capable persons must consent to all medical treatment, personal care, financial decisions, and legal matters. In situations of abuse or neglect, an older person who is being abused or neglected must consent to any proposed interventions.[10] This means that any decision being made involving care for a person living with dementia should start with the presumption they are capable to make that decision, let alone participate in the decision-making process.

There may be times where a person living with dementia may not be able to be an active participant in a decision; however, it is imperative not to overlook this presumption in a decision involving people living with dementia. A person living with dementia **must** be found to be incapable before others can make decisions on their behalf. Incapacity is discussed further below.

1.3 Impact of Dementia on Capacity

- **People living with dementia can be capable.** A person living with dementia is not incapable simply because they have a disability, illness, or form of dementia. People living with dementia are not a homogenous group, and a dementia diagnosis does not mean a person immediately becomes unable to make their own decisions. A person can still have decision-making capacity after being diagnosed with dementia, especially in the early and middle stages. Even people with late-stage dementia can express wishes, values, or preferences, even if this is through non-verbal means. Despite cognition challenges, people living with dementia may have a clear sense of preferences and values and be capable of expressing their views. Some people living with dementia may need support with communication. For others, communication approaches may need to be adapted to suit different abilities. As one nurse shared

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[8] Canadian Centre for Elder Law, ***Conversations about Care: The Law and Practice of Health Care Consent for People Living with Dementia in British Columbia***, Report 10 (Vancouver: British Columbia Law Institute, 2019) at 74-97, online: <www.bcli.org/project/health-care-consent-aging-and-dementia-mapping-law-and-practice-in-british-columbia> [**CCEL Conversations About Care**]; West Coast LEAF and Canadian Centre for Elder Law, ***Roads to Safety: Legal Information for Older Women in BC*** (Vancouver, BC: West Coast LEAF, March 2017) at 18-29, online: West Coast LEAF <www.westcoastleaf.org/roads/> [**WCL, Roads to Safety**].

[9] *Ibid*; See for example, British Columbia: Adult Guardianship Act, RSBC 1996, c 6 ("**AGA**"), s 3(1); *Representation Agreement Act*, RSBC 1996, c 405 ("**RAA**"), s 3(1); *Health Care (Consent) and Care Facility Admission Act*, RSBC 1996, c 181 ("***HCFA***"), s 3(1); Alberta: *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 2(a); Saskatchewan: Adult Guardianship and Co-decision-making Act, SS 2000, c A-5.3, s 3(b); Manitoba: *Vulnerable Persons Living with a Mental Disability Act*, CCSM c V90, Preamble; The Health Care Directives Act, CCSM c H27, s. 4(2)(a); Ontario: Substitute Decisions Act, 1992, SO 1992, c 30, s 2; Health Care Consent Act, 1996, SO 1996, c 2, Schedule A, s 4(2); Québec: Code civil du Québec, RLRQ c CCQ-1991, art 154; Prince Edward Island: *Consent to Treatment and Health Care Directives Act*, RSPEI 1988, c C-17.2, s 3; Nova Scotia: Hospitals Act, RSNS 1989, c 208, s. 52(1); Northwest Territories: Guardianship and Trusteeship Act, SNWT 1994, c 29, s 1.1; Nunavut: *Guardianship and Trusteeship Act,* SNWT (Nu) 1994, c 29, s. 1.1; Adult Protection and Decision-Making Act, SY 2003, c 21, Sch A, s 3.

[10] *AGA,* s 52-53.

with us, “sometimes we have to honor the non-verbal communication of meaning and desires and wants.”

- **Changing values and preferences do not necessarily signal incapacity.** When interacting with people living with dementia, there may be a temptation to attribute their value changes to brain degeneration. People living with dementia are just as likely as anyone to change values and preferences as a result of life experience. Indeed, as a dementia diagnosis can be a life-changing event, some changes in values or preferences can be expected. Still, changes in values and preferences may present ethical dilemmas for certain medical decisions. Determining whether such changes impact decisional capacity requires a proper incapability assessment addressing capacity for the specific decision at issue.[11]

1.4 Assessing Capacity

In general, a person is capable of making a decision if they can understand the information, evaluate the information, and appreciate the consequences of the decision.

Capacity is a subjective assessment as it is decision, time, and situation specific.[12] The following considerations should be kept in mind when assessing the capacity of a person living with dementia.

Different decisions require different standards of capacity.

Each type of decision (whether it is legal, financial, personal, or health-related) has its own required level of capacity. For example:

- The capacity required to make legal decisions will be greater than the capacity required to make personal care decisions.
- Even within legal or financial decisions, capacity requirements differ within decisions such as making a will, representation agreement, power of attorney, gift of property or money, entering into a contract, retaining and advising legal counsel, and marrying.
- In the health care context, capacity requirements are higher for major decisions like major surgery and end-of-life decisions and lower for more minor decisions like whether to take a prescription medication.[13]

A person living with dementia may be capable of some health care decisions, but not others.

Some people living with dementia may be able to consent to health care, some not. Some may be able to consent to some forms of health care, but not others. Some could be capable of personal or health care decisions despite not being capable of making financial or legal decisions.

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[11] CCEL Conversations About Care, at 6.
[12] CCEL Conversations About Care, at 6.
[13] CCEL Conversations About Care, at 6.

Capacity is not affected by the outcome of the decision.

When assessing capacity, the focus is not on the decision itself or its outcome, but on the person's decision-making process.[14] People living with dementia are entitled to make a decision that seems irrational or incorrect to others, so long as they are functionally able to go through the decision-making process of understanding, evaluation, and appreciation. This means that people living with dementia:

- **can choose to live at risk.** Everyone, including a person living with dementia, has different levels of comfort when it comes to risk.
- **do not need to make the "correct" decision.**
- **do not need to make decisions that align with the best interest of others.** Decisions that go against the suggestions of healthcare workers, family members, and/or care partners can still be valid.

Decision-making capacity fluctuates over time.

A person living with dementia may be better able to take in and process information at a particular time of the day. For people living with dementia, decision-making capacity can change from day to day, and even hour to hour, depending on the type of decision to be made.[15]

Decision-making capacity can be affected by mood, type of dementia, and/or the surrounding environment.

Many factors can impact a person living with dementia's decision-making capacity. For example, if a person living with dementia is experiencing a lot of stress, they may be less able to make a decision. A person living with dementia may be better able to make decisions when they are in a quiet environment compared to a noisy and distracting environment. Some people living with dementia cannot make decisions independently but can make decisions with support or assistance from someone they trust. Supported decision-making is discussed more below in **Section 2.1**.[16]

Be aware that these factors may be unique to each person living with dementia.

1.5 Findings of Incapacity

People living with dementia must be found to be incapable before others can make decisions on their behalf. A finding of incapacity can be done in many ways, ranging from an informal to formal process. This is usually done by a medical professional or a lawyer, and sometimes by a court. A doctor may evaluate their patient and find they cannot make health care decisions and get consent from the person's substitute decision-maker. A lawyer may assess their client and find the client does not have the necessary understanding and appreciation to give instructions.

A person is typically not found to be globally incapable. People living with dementia can be capable of making some decisions but not others. For example, while a person living with dementia may be found to be incapable of making a major financial, legal, or major health care decision, they may still be capable of making other decisions, such as minor health care, personal care, or executing a standard representation agreement.[17] As discussed above with respect to capacity, the definition and process of finding someone incapable differs for each decision.[18]

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[14] BC Adult Abuse and Neglect Prevention Collaborative, ***Provincial Strategy Document: Vulnerable Adults and Capability in BC*** (January 2009) at 17, online (pdf): ***British Columbia Law Institute*** <www.bcli.org/sites/default/files/Vanguard_(16May09).pdf>.

[15] CCEL Conversations About Care, at 82 – 83.

[16] CCEL Conversations About Care, at 82 - 83.

[17] CCEL Conversations About Care at 74; WCL, Roads to Safety, at 18 - 29; British Columbia Law Institute, *Report on Common-Law Tests of Capacity,* Report 73 (Vancouver: British Columbia Law Institute, 2019), online (pdf): <www.bcli.org/publication/report-on-common-law-tests-of-capacity/>.

[18] CCEL Conversations About Care, at 74 - 97; WCL, Roads to Safety, at 18 - 29; *Report on Common-Law Tests of Capacity* Report 73 (Vancouver, BC: British Columbia Law Institute, 2013), online: <www.bcli.org/publication/report-on-common-law-tests-of-capacity>.

SECTION 2: DECISION-MAKING

2.1 Types of Decision-Making

There are several different ways people may be involved in decision-making.

Independent Decision-Making

A person is capable and makes a decision on their own, not requiring support in doing so.

Supported Decision-Making

A trusted person supports the person to make a decision. The person retains their full decision-making capacity, and the trusted supporter assists them. This is based on the idea that most people normally make decisions in an interdependent and social way – most people consult with friends or family when making important decisions.[19]

Supported decision-making is especially important for people living with dementia because supported decision-making can increase a person's decision-making capacity. People living with dementia may be capable of making a decision with help when they may not have been able to on their own. Supported decision-making helps protect the decision-making rights of older persons. In BC, the right to a supporter is recognized in legislation.[20] Supported decision-making can be legally realized through a standard representation agreement (discussed further below); however, many people make decisions with the help of people they trust regardless of a formalized agreement.

Substitute Decision-Making

If the person is not capable of making the decision at hand, a substitute decision-maker must give consent on their behalf. This is a last resort since personal decision-making is fundamental to human rights and people should first be supported to help them make decisions.

Any person can write a document appointing a substitute decision-maker, so long as they are capable at the time of execution. This document can outline the type of decisions the substitute decision-maker is allowed to make, such as health care decisions, personal care decisions, financial decisions, and legal decisions. These documents can include powers of attorney and representation agreements.

The court can appoint a guardian or committee for personal or financial matters if the court finds the person is incapable and has not already appointed a substitute decision-maker. For health care decisions, if a person is not capable, has no guardian, and has not appointed a substitute decision-maker, a temporary substitute decision-maker is chosen. In most jurisdictions, the Public Guardian and Trustee is the decision-maker of last resort.[21] For further discussion of substitute decision-makers, see **section 4.2.**

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[19] CCEL, Conversations About Care, at 74-97; WCL, Roads to Safety, at 18-29; British Columbia Law Institute, ***Report on Common-Law Tests of Capacity*** Report 73.

[20] RAA, s 7.

[21] *HCFA*, s 16 (3). The PGT is the last possible named temporary substitute decision-maker based on a hierarchy outlined in the *HCFA.*

2.2 Decision-Making Rights

As discussed above, people living with dementia are guaranteed certain legal rights. Health care providers must ensure that they work with the person to allow them to effectively exercise their decision-making rights. These rights are outlined below.

People living with dementia have the right to receive and communicate information about a decision they are making in a way they can understand.

People living with dementia have the right to be supported in making their decisions.

The right to be supported in decision-making is outlined through health care legislation, such as the *Health Care (Consent) and Care Facility (Admission) Act* and *Representation Agreement Act.* This involves giving a person living with dementia the support needed to make the decision themselves. This assistance may come in the form of helping the person living with dementia understand information, helping them consider the decision and its consequences, and helping them communicate their needs, values, and wishes. To adequately do so, you may have to reiterate information, bring the information in a written format, explain the information and possible consequences in a variety of ways, or choose a different time or day to come back to the decision.

People living with dementia who require support in making a decision have the right to be included and heard in the decision-making process.

This means involving the person living with dementia in the decision-making to the greatest extent possible. For example, this means communicating with the person living with dementia about their wishes and preferences and how they might want a decision to be made.

People living with dementia should be consulted even after they have lost capacity, and their input should be considered when making the decision. People living with dementia who do not have capacity can still usually express preferences and wishes. Substitute decision-makers also have a legal duty to involve the person living with dementia in the decision to the greatest extent possible in most jurisdictions.[22]

Decisions made by substitute decision-makers for a person living with dementia must be consistent with the known expressed wishes, values, and beliefs of a person living with dementia.

Decisions should first be based on what decision the person living with dementia would have made if capable, properly informed, and free from influence.[23] **The decision-making rights of the person living with dementia are always paramount,** even when the person no longer has capacity to make the decision. For example, if the person has previously expressed a wish not to move to a large urban centre, then this wish should be given weight in the decision about admission to a long-term care facility.

It is only when there are no pre-expressed wishes, values, and beliefs of the person living with dementia that a decision is to be based solely on the best interest of the person living with dementia.[24]

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[22] *HCFA*, s 19 (1).
[23] *HCFA*, s 19 (1).
[24] *HCFA*, s 19 (2).

2.3 Barriers to Decision-Making for People Living with Dementia

People living with dementia face several barriers to engaging in healthcare decision-making, including personal, interpersonal, and systemic challenges. These challenges include the following:

Personal Barriers:

- **Cognitive issues** such as difficulty remembering, understanding, and maintaining concentration.
- **Emotions** such as stress, fear, confusion, and agitation around decisions, as well as doubt and negative self-talk around making the wrong decision.

Interpersonal Barriers:

- **Communication barriers:** People living with dementia may have difficulty communicating their wishes and preferences, or they may be non-verbal.
- **Lack of support systems** and trustworthy people to help with decision-making.
- **Risk of undue influence:** Family members, friends, or legally appointed representatives may use their relationship with the person to make decisions that do not respect the person's wishes or steal money, dispose of property, or take legal actions the person would not want. See section 4.3 on **Misuse of Powers.**

Systemic Barriers:

- **Stigma, paternalism, and assumptions about people living with dementia:**

People living with dementia confront both a general lack of understanding of the condition, and prejudicial assumptions regarding their awareness, intelligence, judgement, and recall. People living with dementia are sometimes presumed to be incapable of all decision-making, even when no assessment of their cognitive abilities has occurred. However, many people living with dementia are capable of participating in health care decision-making for themselves, either independently, or with the support of friends, family, and others.

Moreover, paternalism surrounding decision-making for people living with dementia has resulted in an emphasis on risk management over self-determination. It is important to remember that people with decision-making capacity are entitled to make decisions that others might think are "risky" or "wrong." We must reject stereotypes and challenge negative assumptions about aging, disability, and dementia. Remember that older people contribute meaningfully to their communities, and have a wide range of abilities, roles, and interests.

People living with dementia and caregivers often recounted that health care providers would forego involving the person living with dementia in the decision-making process when a third party, often their caregiver, was present. Disregarding the presumption that people living with dementia are capable can leave some with lowered self-confidence in decision-making or fracture relationships. As one person living with dementia told us,

> *"If I could just share what happened to me with the last, my lady friend that passed away, she always went to...my doctor with me and the two of them talked together as if I wasn't even there and they discussed everything. So I got to the point I wouldn't take her anymore..."*

Resource limitations of the health care system

At the ground level, the rushed pace of medical environments does not allow enough time for inclusive/collaborative decision-making. At a higher level, people living with dementia also face a lack of long-term support options, which may force decisions such as going to live in a care home. For example, the pressure to make a decision to move into a long-term care home can affect the decision-making of people living with dementia and their caregivers and rush them to make a decision because they feel they must. As one informant noted about the decision for their mother to take a bed in a care facility:

> *"Maybe we weren't so ready to give her up to that bed but we had no choice."*

Language barriers

Language issues pose a significant barrier to decision-making for non-English speaking and immigrant families. Interpreters are not always available or sought and non-English speakers often rely on available staff who speak the language, or other family members, to act as interpreters. This approach is not always appropriate: non-professional interpreters may not have adequate knowledge or skills, and family members will sometimes have their own agenda, creating the risk of undue influence.

Cultural barriers

Existing care models often fail to accommodate cultural differences surrounding dementia and decision-making and sometimes perpetuate medical racism. Indigenous people, in particular, face significant barriers in accessing health care, dementia services, and continue to experience racism in all aspects of health care. See section 3 below on developing cultural humility in decision-making and addressing the needs of Indigenous clients.

2.4 Strategies to Support Decision-Making

The following strategies can support in-person communication and decision-making for people living with dementia.

Before engaging someone living with dementia in decision-making:

- Ask them how they may be accommodated. Some people have disabilities that are immediately recognizable; others have disabilities that can be invisible. It is important not only to accommodate older people's needs and abilities but to ask respectful questions about the kinds of support each unique person needs. An attitude of compassionate curiosity can open the door for a disclosure that helps you to better understand an older person's communication needs.

- Choose a time of day that works best for the person living with dementia. Many people living with dementia are better at understanding information at certain times of day. This is often earlier in the day but depends on the person. Medications, the hangover effect, and sleeping patterns are among a variety of time-related factors that could affect a person's ability to engage in decision-making.
- When choosing a time to meet, factor in extra time for the person living with dementia to explain their story, process information, ask questions, and make decisions.
- Be alert to body cues or mood and choose a different time if they seem unable or unwilling to participate.
- Provide plain language written material summarizing the main points you are going to discuss.

While engaging someone living with dementia in decision-making:

- Meet in a room that is calm, quiet, and has few distractions.
- If needed, sit close enough to the person so that it is easy to hear you, subject to their comfort.
- If the person has hearing difficulties, allow the person to see your mouth, in case they use lip-reading to support their hearing.
- Maintain eye contact.
- Put your key points first, limit the number of key points you are making, and break down the information into small, meaningful chunks as needed.
- Give information slowly and use plain language, avoiding jargon, abbreviations, slang, and sarcasm.
- Allow opportunities for follow-up questions.
- Repeat numbers, if needed.
- Be flexible and patient—rushing can create stress, which can undermine people's ability to understand information.
- Ask questions that will help encourage engagement and assess understanding.
- Try different words if it appears a person may not understand the information.
- Include breaks, particularly if the person seems tired.
- Pay attention to non-verbal cues—gestures, body language, and actions can express feelings, priorities, and needs.
- Consider inviting the person to repeat the information to check for understanding.
- Summarize what the person has told you and allow them to correct errors.
- Always inquire whether a follow-up email or letter would be helpful as a standard intake question.
- Provide plain language written material summarizing the main points you discussed.
- Summarize any written material you provide.

The following strategies will help you use **written or email correspondence** in a way that is accessible and easy to understand:

- Do not assume literacy in English or any other language. Watch out for practices that assume literacy and provide a respectful way for people to let you know if they require further explanations of the material. Few people want to admit that they cannot read in English.
- Use active voice.
- If you are drafting instructions, write them simply and clearly, and number the steps.
- Use a larger font, at least 12 point.
- Avoid italics, capitalizing full words, and underlining as much as possible.
- Use headings to break down the material into smaller sections.
- Include white space rather than trying to squish a lot of material into a small space.
- Make paragraphs flush to the left and ragged on the right.
- When creating digital materials, make the text easy to enlarge.
- Use high-contrast colors.
- Make the information available in multiple formats, including text, audio, and visual.
- Choose colours that will produce a high contrast experience for people who are colour-blind.
- Leave a lot of space around clickable targets.

SECTION 3: CULTURALLY SAFE, INCLUSIVE AND PERSON-CENTERED CARE

The below section provides guidance on:

1. Cultural humility and safety;
2. Trauma-informed care;
3. Addressing the needs of Indigenous clients during dementia care; and
4. Gender, sexual orientation, and gender identity lens.

For further information on the below topics, please consult the resources section at the end of this guide.

3.1 Cultural Humility and Safety

Involving people living with dementia in decision-making should be approached with consideration of cultural humility and safety.

The First Nations Health Authority (FNHA) prefers the expression “cultural humility” over "cultural competency”. They define “cultural humility” as follows:

> *Cultural humility is a process of self-reflection to understand personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a life-long learner when it comes to understanding another’s experience.*[25]

Research suggests that “the difference between cultural safety and related approaches (e.g. cultural sensitivity, cultural competence, and cultural appropriateness) is that the former asks us to consider power in our interactions with service users and stresses the need to transfer (more) power to the service user so that the outcome of our intervention is one they consider to be culturally safe.”[26]

Cultural humility and safety emphasize that dementia is not defined solely by ‘individual experience’ and focuses instead on how people living with dementia are shaped by social and cultural realities.[27]

In decision-making contexts, practicing cultural humility and safety might include incorporating the following principles:

- **Understand that culture will impact how a person might understand their own experience of dementia.** When interacting with people who are living with dementia, keep in mind that the term “dementia” is not culturally universal. You will need to learn what term is appropriate for the cultural group you are interacting with to make sure you are using respectful and appropriate language.
- **Understand that the influence of cultural beliefs on family and home settings**

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[25] First Nations Health Authority, *#itstartswithme: FNHA Policy Statement of Cultural Safety and Cultural Humility*, at 11, online (pdf): <www.fnha.ca/documents/fnha-policy-statement-cultural-safety-and-humility.pdf>[#itstartswithme].

[26] Wendy Hulko, “Revolutionising dementia policy and practice: Guidance from ‘the memory girl,’ an accomplice” in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 226.

[27] Wendy Hulko, “Revolutionising dementia policy and practice: Guidance from ‘the memory girl,’ an accomplice” in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 228.

will reflect on the decision-making process of a person living with dementia within such contexts. It is important to take the time to try and understand how the cultural process of decision-making operates in each context. For example, as part of decision-making, it may be necessary to help encourage relevant cultural activities, such as access to certain music or foods.[28]

- What is considered safe care or services **must be defined by the person** accessing supports, not the practitioner.[29]
- Be willing to "**accept and promote all knowledges about dementia**, including Black, Indigenous, minority ethnic, and/or queer ones that may challenge our own and/or dominant understandings of dementia and dementia care."[30]

3.2 Trauma-Informed Care

Trauma-informed care is essential for people living with dementia when making healthcare decisions. As a result of dementia, a person's trauma may manifest in new ways. Experiences of trauma may also impact the ability of people living with dementia to trust health care providers or even their caregivers. There is also a strong link between Post-Traumatic Stress Disorder and dementia, and First Nation Elders have described trauma as a cause of dementia.[31]

To ensure decision-making processes are guided in a trauma-informed manner, health care providers must:[32]

- **Understand what trauma is** and how it impacts a person physically, mentally, and emotionally.
- **Acknowledge the impacts a traumatic experience has had on a person's life.** It is important to be sensitive to how trauma can be experienced differently by people who are immigrants, living with disabilities, Indigenous, youth, or 2SLGBTQIA+, among others. The effects of historical and intergenerational trauma can be triggered by any additional traumas, including a dementia diagnosis. When providing care, connect with the story, history, and background of the person living with dementia. For non-verbal people living with dementia, this approach may require health care providers to search the electronic record of the patient to find their diagnosis history. However, trauma-informed practice does not require the disclosure of a traumatic experience.
- **Recognize the potential for trauma and triggers when they present themselves,** especially when a decision is related to trauma a person has experienced.

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[28] Wendy Hulko et al, "Culturally safe dementia care: Building nursing capacity to care for First Nation Elders with memory loss" (2021) 16:5 Int J Older People Nurs e12395.

[29] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <ccelderlaw.ca/lenses-for-inclusive-practice/>.

[30] Wendy Hulko, "Revolutionising dementia policy and practice: Guidance from 'the memory girl,' an accomplice" in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 231.

[31] Wendy Hulko, Mary Star Mahara, Danielle Wilson & Gwen Campbell-McArthur, "Culturally safe dementia care: Building nursing capacity to care for First Nation Elders with memory loss" (2021) 16:5 Int J Older People Nurs e12395.

[32] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <ccelderlaw.ca/lenses-for-inclusive-practice/>.

- **Deliver services in a way that avoids doing further harm.** In doing so:
    - **Nurture an environment of safety and trust.** Create a physical environment that feels safe and allows for privacy and a social environment where the person feels safe to express their thoughts and feelings. Try to create an environment that reduces power dynamics, for example, by sitting next to the person (instead of across a table) if they are comfortable.
    - **Support opportunities to express choice and collaborate.** This involves giving the person control over their own decisions to the extent possible. Be willing to take the lead from people living with dementia about the best ways to support or care for them.
    - **Create opportunities to build strength and skills.** Support the person living with dementia to identify what strengths they have and develop new skills to help them cope with trauma and gain resiliency skills.

3.3 Addressing the Needs of Indigenous Clients in Dementia Care

The rights of Indigenous peoples to make decisions and draw on their own cultural backgrounds to inform decision-making have been intentionally disturbed by the Canadian health and legal systems. Further, our health system is built on a highly Eurocentric ideal and does not accommodate other modes of care delivery and decision-making. As a result of colonialism, Indigenous people living with dementia face several barriers in decision-making, including:[33]

- racism, discrimination, and sexism;
- cultural differences;
- language and literacy issues;
- reticence of western medicine practitioners to embrace traditional Indigenous healing practices;
- poverty and lack of affordable services;
- lack of health care system attention to spiritual well-being;
- lack of services in rural areas, including access to clean tap water, internet, health and social services, and long-term care facilities (for example, the availability of long-term care facilities on and near reserves);
- lack of culturally appropriate long-term care facilities; and
- jurisdictional barriers relating to health care for Indigenous peoples living off and on reserves.

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[33] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <ccelderlaw.ca/lenses-for-inclusive-practice/>.

Healthcare that supports decision-making for older Indigenous persons must be tailored to the unique cultural contexts and everyday lived realities of Indigenous peoples and communities.[34] Further, there must be understanding that each individual Nation may have a different approach or cultural understanding of health care and decision-making, particularly as it relates to supporting a person living with dementia. Such an approach to decision-making must:

- Recognize colonialism as a key determinant of health for older Indigenous peoples and understand how its impacts may affect decision-making, for example through a lack of access to services or any existing trauma.
- Be conscious of Indigenous perspectives on dementia, on aging well, on health and wellness, and on kinship structures that may inform decision-making processes.[35] Although specific to the individual and community, these factors may impact preferences for caring for loved ones with dementia. Health care providers must "strive to understand, respect and give dignity to Indigenous ways of being and respect Indigenous ways of constructing dementia and cognitive impairment."[36] This involves avoiding pan-Indigenizing, that is, "treating all Indigenous people the same, whether they are Métis, Inuit, or First Nations, and regardless of their specific nation."[37]
- Respect the wishes and values of the Indigenous person living with dementia. Aging well might include a preference for informal care, shared caregiving, and aging within the community. Healthcare decisions and support for decision-making should come from the individual, supported by their family or community, and should not be imposed by the state, which has been an agency of oppression.[38]
- Provide Indigenous persons with opportunities to communicate in their own languages, participate in ceremonies, connect with land, and eat traditional foods, activities which are seen as critical social supports and can promote culturally safe decision-making.[39]
- Combat the ongoing impacts of colonialism, including racism, power imbalances, and the lack of trust in state health care professionals.[40] As an example, this may involve "consulting with Elders or other community members to learn cultural and health status information [as this] can shift the power differential from one in which the health care provider is the "expert" to one in which the Elder teaches or guides the provider about the cultural aspects of their memory loss and care needs."[41]

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[34] Regine Halseth, *Overcoming Barriers to Culturally Safe and Appropriate Dementia Care Services and Supports for Indigenous Peoples in Canada* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2018) at 17, online (pdf) www.nccih.ca/495/Overcoming_barriers_to_culturally_safe_and_appropriate_dementia_care_services_and_supports_for_Indigenous_peoples_in_Canada.nccih?id=243.

[35] Regine Halseth, *Overcoming Barriers to Culturally Safe and Appropriate Dementia Care Services and Supports for Indigenous Peoples in Canada* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2018) at 10, online (pdf) www.nccih.ca/495/Overcoming_barriers_to_culturally_safe_and_appropriate_dementia_care_services_and_supports_for_Indigenous_peoples_in_Canada.nccih?id=243.

[36] Louise Racine et al, "An integrative review of Indigenous informal caregiving in the context of dementia care" (2022) 78:4 J Adv Nurs 913.

[37] Wendy Hulko, "Revolutionising dementia policy and practice: Guidance from 'the memory girl,' an accomplice" in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 226.

[38] Cindy Holmes & Sarah Hunt, *Indigenous communities and family violence: Changing the conversation* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2017), online: www.nccih.ca/495/Indigenous_Communities_and_Family_Violence__Changing_the_conversation.nccih?id=202 [NCCAH Family Violence].

[39] Regine Halseth, *Overcoming Barriers to Culturally Safe and Appropriate Dementia Care Services and Supports for Indigenous Peoples in Canada* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2018) at 7, online (pdf) www.nccih.ca/495/Overcoming_barriers_to_culturally_safe_and_appropriate_dementia_care_services_and_supports_for_Indigenous_peoples_in_Canada.nccih?id=243.

[40] Cindy Holmes & Sarah Hunt, *Indigenous communities and family violence: Changing the conversation* (Prince George, BC: National Collaborating Centre for Aboriginal Health, 2017), online: www.nccih.ca/495/Indigenous_Communities_and_Family_Violence__Changing_the_conversation.nccih?id=202 [NCCAH Family Violence].

[41] Wendy Hulko, "Revolutionising dementia policy and practice: Guidance from 'the memory girl,' an accomplice" in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 226.

3.4 Gender, Sexual Orientation and Gender Identity Lens

Facilitating decision-making surrounding health care for people living with dementia should both be informed by a gender lens, as well as consider the perspectives and needs of 2SLGTBQIA+ people living with dementia.

Bringing a gender lens means addressing the unique experiences of women and gender-diverse people while recognizing and working to challenge systemic factors.[42] Consider how a person living with dementia's gender may pose barriers to decision-making. This can include considering, among others:[43]

- Access to health care and sexism within health care.
- Access to and control over resources. Women are more likely to have reduced income and savings, which may impact decision-making.
- Abuse and violence. Women and gender-diverse people are more likely to experience abuse and violence. This can impact decision-making in several ways. For example, speaking out may raise fears of loss of decision-making autonomy, and leaving an abusive situation may pose a risk to the ability to live independently.
- Roles and responsibilities. Caregiving has a significant impact on the lives of many older women, and decision-making process should be attentive to any caregiving responsibilities and valued relationships. For example, resisting abusive family dynamics can put at risk important relationships, such as contact with children and grandchildren.

2SLGBTQIA+ people living with dementia also face many barriers that may impact decision-making in health care contexts. These include:

- Increased discrimination, abuse, and neglect from residents, staff, and health care providers. These barriers are significant in long-term care, where there is a lack of privacy, and most care homes are heteronormative and not accepting of the needs of a diverse range of residents.
- Where the person living with dementia is no longer capable of making health care or personal decisions, caregivers or substitute decision makers may not respect the person's sexual orientation or gender identity. This can create conflict in situations where a 2SLGBTQIA+ person living with dementia does not have an appointed substitute decision-maker and a temporary substitute decision-maker is not respectful of the sexual orientation or gender identity of the person. This conflict is discussed in greater detail in Section 4.2.6 **Temporary Substitute Decision Makers.** Transgender people living with dementia face particular challenges, as they are often not allowed to wear the clothing that matches their gender identity, use the correct washrooms, or be identified by the pronouns or names they use.

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[42] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <cceIderlaw.ca/lenses-for-inclusive-practice/>.

[43] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <cceIderlaw.ca/lenses-for-inclusive-practice/>.

In ensuring that decision-making is affirmative of a person living with dementia's sexual orientation and gender identity:

- Have an awareness of the diversity and fluidity of both sexual and gender identity.[44]
- Respect people's boundaries about disclosure of gender identity and sexual orientation. Take your lead from them and avoid outing anyone.[45]
- Refrain from imposing a gender identity on a person. Instead, allow the person to self-determine their gender. This can include "providing a diversity of pins/badges that the person could wear to indicate the pronouns they prefer, and having masculine, feminine, and 'neutral' clothing items in the closet for the person to decide."[46]
- Work to affirm gender identity by using a person's pronouns and chosen name, support the person's intimacy desires/needs, and include partners/chosen family in decision-making where the person wants.[47]

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[44] Wendy Hulko, "Revolutionising dementia policy and practice: Guidance from 'the memory girl,' an accomplice" in Richard Ward & Linn J Sandberg, eds, *Critical Dementia Studies: An Introduction* (New York: Routledge, 15 March 2023) at 226.

[45] Canadian Centre for Elder Law, *Practical Guide to Elder Abuse and Neglect Law in Canada: Lenses for Inclusive Practice* (Vancouver: British Columbia Law Institute, 2022), online: <ccelderlaw.ca/lenses-for-inclusive-practice/>.

[46] Alexander Baril & Marjorie Silverman, "Forgotten lives: Trans older adults living with dementia at the intersection of cisgenderism, ableism/cogniticism and ageism" (2022) 25:1-2 Sexualities 126.

[47] Wendy Hulko, "LGBT* individuals and dementia: An intersectional approach" in Sue Westwood & Elizabeth Price, eds, *Lesbian, Gay, Bisexual and Trans* Individuals Living with Dementia* (New York: Routledge, 28 April 2016).

SECTION 4: THE LAW

This section contains an overview of consent laws, decision-making laws, and the misuse of powers.

4.1 Consent Laws

Consent laws speak to the ability to permit someone else to interfere with their person. This need for consent developed out of the unlawful act of violation of the body, which would find a person liable for injury for touching someone without their consent.[48] This is common within the health care context as health care providers are often having to interfere with a patient's bodily autonomy, making the need for consent integral to respect for the patient's decision-making while also protecting health care providers from liability. The emphasis on patient consent is outlined in both legislation and case law.

Giving consent in the health care setting requires a certain level of capacity. Establishing that a patient can provide informed consent to a particular course of action includes an assessment of their capacity to make the decision. Such decision-making may include the person consulting with a support person.

Consent to Health Care

General Consent

Consent to health care is legislated by the *HCFA*.[49] The *HCFA* begins with the presumption that a patient has capacity unless otherwise determined.[50] The role of the healthcare provider in obtaining consent is to give sufficient information on both the proposed treatment and possible consequences. A healthcare provider must work with the patient in the manner the patient needs to provide informed consent, including by accommodating a method of communication and providing a support person.[51]

Establishing consent to health care requires you first provide sufficient information about:

- the condition for which the proposed care is meant to treat;
- the nature of the proposed care;
- risks and benefits of the proposed care that a reasonable person would expect to be told about; and
- any alternatives to the proposed care.[52]

The reasonable person is a legal standard used to assess behaviour in the circumstances. In the context of consent to health care, we are looking for the patient to demonstrate, regardless of communication method, that they understand the above four points and can make the decision based on the information provided. As discussed in **Section 2.4,** this may require re-phrasing the information in different ways, providing a written summary of the information needed, or coming back at a different time of day. It may also require taking the time to understand the adult and their unique personality, as their mood may dictate their ability to make an informed decision.

It is also important to remember that a decision does not have to conform to what is exter-

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[48] *Reibl v Hughes, [1980] 2 SCR 880, at 899; Arndt v Smith,* [1997] 2 SCR 539, at para 6, 8, 9, and 17.

[49] *HCFA*

[50] *HCFA*, s 3.

[51] *HCFA*, s 8.

[52] *HCFA*, s 6.

nally viewed as a “good decision”. People have the autonomy to make perceived “bad decisions” so long as they are provided sufficient and accurate information to do so. This exercise of personal autonomy must be respected.

Advance Directives

Under the *HCFA*, people may give or refuse consent to health care in an advance directive, except for health care decisions that are beyond the authority of substitute decision-makers.[53] An advance directive must have been made by a capable person, must be in writing, and signed in the presence of witnesses.[54]

Health care providers may provide health care if the person has given consent in an advance directive and must not provide care if the person has refused consent in an advance directive.[55] Health care providers are not required to make more than a reasonable effort to determine whether the person has an advance directive.[56]

Advance directives do not apply if:[57]

- the advance directive does not address the health care decision;
- the instructions in the advance directive are not clear as to whether the person is giving or refusing consent;
- the person’s wishes, values, or beliefs have changed significantly since the advance directive was made (and these changes are not reflected in the advance directive); and/or
- there have been significant changes in medical practice or technology that might substantially benefit the person regarding the health care.

In these circumstances, the health care provider must obtain substitute consent, despite any wishes set out in the advance directive (unless the advance directive expressly states that the instructions apply regardless of any change in medical knowledge, practice, or technology.[58] Substitute consent is set out below under **Section 4.2 Decision-Making Laws.**

4.1.1 Consent to Long-Term Care Admission

Admission to long-term care is a difficult decision at the best of times. Much like consent to health care, the involvement of the person in the decision to transition to long-term care may have varying levels of success depending on their capacity to make that decision. The starting point is that a person is presumed to have the capacity to make the decision to move to long-term care.[59]

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[53] *HCFA*, s 9 (1.1).
[54] *HCFA*, ss 19.1, 19.4.
[55] *HCFA*, ss 19.7 (2).
[56] *HCFA*, ss 19.7 (3).
[57] *HCFA*, ss 19.8.
[58] *HCFA*, ss 19.8 (2)-(3).
[59] *HCFA*, s 3.

In providing sufficient information to help the person decide whether to enter long-term care, a manager must discuss with the person:

- the type of care they receive in the long-term care facility;
- the services the long-term care facility will provide to the person; and
- the circumstances under which the person may leave the long-term care facility.[60]

Understanding the weight of the decision is imperative to supporting a person in how and when that decision is made. This is a particularly difficult decision for a person living with dementia as it will mark a drastic change in their lifestyle. It is also imperative to listen to the concerns of the person as the concerns are valid from their perspective, even if they seem out of context. As a person is presumed to have capacity, their participation in the consent-seeking process requires the health care provider to engage in a capacity assessment of the person. Much like consent to care, facilitating communication must be accommodated to the extent possible.[61] To ensure full involvement in decision-making regarding the move into long-term care, health care providers may need to facilitate a visit or tour to such a facility.

If there is concern that the person cannot provide informed consent, the manager is not responsible for determining the person's capacity; rather, a medical practitioner or prescribed health care provider, such as a registered nurse, registered psychiatric nurse, nurse practitioner, registered social worker, registered occupational therapist, or registered psychiatrist, will conduct a capacity assessment.[62] The conduct of the capacity assessment is prescribed in the *HCCR.*[63] The assessor must advise the person that they are being assessed for their ability to participate in the decision to move to long-term care and that if the assessor thinks that the person cannot provide consent, a substitute decision-maker may step in to provide consent.[64]

There are also special provisions relating to licensed care facilities under the *Residential Care Regulation.*[65] The Regulation specifies that if an incapable person in care expresses a desire to leave a community care facility, the health care providers must have the person assessed if there is reason to believe they may be capable of consenting to leave or obtain substitute consent.[66] However, health care providers are not required to do this if substitute consent to the continued accommodation of the person in care in the care facility has been obtained in the last 90 days.[67]

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[60] *HCFA*, s 21(1)(d).
[61] *HCFA*, ss 21(2) and (3).
[62] *HCFA*, s 26(1); Health Care Consent Regulation, BC Reg 20/2000 ("HCCR"), at s 16.
[63] *HCCR*, ss 17 – 21.
[64] *HCCR*, s 17.
[65] *Residential Care Regulations,* BC Reg 96/2009 ("***RCR***"), s 50.
[66] *RCR*, s 50(2).
[67] *RCR*, s 50(4)(b).

4.1.2 Consent to Restraint Use

Use of restraints can occur either by physical or prescribed means.[68] Prescribed means constitute restraining a person either by chemical, electronic, mechanical, or other means, or by placing the person in a secure unit.[69] The manager bears the responsibility of ensuring that restraints are not used as a means of punishment or discipline, nor for long-term care staff convenience, and by accommodating the person in a secure unit.[70] Consent to the use of restraints may be given by an appointed representative named in a section 9 representation agreement that permits such decision-making.[71]

Further, *Residential Care Regulations* are engaged depending on the licensing of the long-term care facility.[72] If applicable, a licensee may use restraints on a person in care if such use is needed to protect the person or others from serious and imminent physical harm.[73] Alternatively, restraints may be used if the person or their representative or relative who is closest and active in their care, and the medical or nurse practitioner agree in writing to the use of restraints on the person.[74]

4.2 Decision-Making Laws

4.2.1 Types of Decision-Makers

There are five key types of substitute decision-makers in BC:

- a representative under a representation agreement;
- an attorney under a power of attorney;
- a statutory property guardian;
- a committee of the estate or person; or
- a temporary substitute decision-maker for health care.

4.2.2 Representation Agreements

If a person living with dementia cares about who makes care decisions for them when they are unable to make a decision, they need to appoint a person through a representation agreement. Health care providers should include the importance of choice in appointing a substitute decision-maker when discussing care planning with a person living with dementia. This is important in the health care setting because if there is no appointed substitute decision-maker for the person living with dementia, the law clearly outlines who will make decisions for them regardless of who they would have preferred.

There are two types of representation agreements – a section 7 representation agreement (or "**Standard RA 7**"), and a section 9 representation agreement (or **"Non-Standard RA 9"**). Both provide for health and personal care decision-making authority, but the Standard RA 7 has a lower capacity threshold and permits some legal and financial decision-making, allowing for more supported decision-making when a person has more limited capacity to make decisions.[75]

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[68] *HCFA*, s 26. 1(1).
[69] *HCCR*, s 23.
[70] *HCFA*, ss 26.1(2) and (3); HCCR s 23.[71] *RAA*, s 9(1)(b)(viii).
[72] *Community Care and Assisted Living Act*, SBC 2002, c 75; RCR, at s 2(2)(c).
[73] *RCR*, s 74(1)a).
[74] *RCR*, s 74(1)(b).
[75] *RAA*, ss 7 and 8.

A Standard RA 7 can give the following authority to a representative:

1. financial affairs:
    a. routine banking;
    b. investments;
    c. RRSPs or pensions;
    d. income tax filing;
    e. buying insurance; or
    f. purchasing personal care items & services;
2. legal affairs:
    a. hiring a lawyer; or
    b. starting, defending, or settling an action;
3. personal care:
    a. includes admission to a family care home, group home, or mental health boarding home;
4. health care:
    a. minor health care; and
    b. major health care.[76]

A Standard RA7 does not give authority to a representative over the following:

1. financial affairs:
    a. obtaining credit cards;
    b. obtaining or discharging mortgages;
    c. buying or selling real estate; or
    d. giving away property;
2. legal affairs:
    a. pursuing a divorce;
3. personal care:
    a. long-term care admission; or
    b. interfering with religious beliefs;
4. health care:
    a. refusing health care necessary to preserve life; and
    b. restraints.[77]

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[76] *RAA*, s ss7(1) and (2).
[77] *RAA*, s 7(1).

The requisite capacity to execute a Standard RA 7 is that the person can demonstrate:

- they want a representative to help make, make, or stop making decisions on their behalf;
- a choice and preference, along with an expression of approval or disapproval of another;
- awareness that making or changing the representation agreement or any of its provisions means the representative may make or stop making decisions or choices affecting them; and
- if the relationship they have with the representative is characterised by trust.[78]

A Non-Standard RA 9 may give very broad authority – depending on the specific authority chosen to be conferred on the representative by the person – on a wide range of decisions such as:

1. personal care:
   a. living arrangements;
   b. clothing;
   c. food;
   d. employment;
   e. education;
   f. social activities; or
   g. who talk to or see;
2. health care:
   a. includes refusing or consenting to care that is necessary to preserve life;[79] or
   b. use of restraints.[80]

A Non-Standard RA 9 must explicitly authorise a representative to:

1. provide temporary care/education of minor children or a person the person is a guardian for; or
2. interfering with religious practices.[81]

The capacity required for the execution of a Non-Standard RA 9 is that the person must be able to understand and appreciate the nature and consequences of the representation agreement.[82]

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[78] *RAA*, s 8(2).
[79] *RAA*, s 9(3).
[80] *RAA*, s 9(1).
[81] *RAA*, s 9(2).
[82] *RAA*, s 10.

A representative acting under any representation agreement has several duties, including to:

1. act in good faith;
2. exercise reasonable care, diligence, and skill of a reasonably prudent person;
3. act within their authority;
4. keep records of actions taken under their authority and produce these when requested by the person, the monitor, or the PGT;
5. keep their assets separate from the person's assets; and
6. consult with the person and follow their wishes to the extent reasonable.[83]

If the person is not capable, the substitute decision-maker must make decisions based on the known wishes of the person. If the person has not expressed their wishes, the substitute decision-maker must act based on the person's known beliefs. If these are not known, the substitute decision-maker can only base their decision on what in the person's best interest.

Advance directives and representation agreements

Sometimes a person will have made both an advance directive and a representation agreement. Instructions in an advance directive should be treated as the pre-expressed wishes of the person.[84] A person may also state in an RA that a health care provider can act on instruction in an advance directive without consent from their representative.[85]

4.2.3 Powers of Attorney

A power of attorney grants an attorney the authority to make financial and legal decisions on behalf of the person.[86] Financial affairs include routine banking, managing investments, selling assets including real estate, paying taxes, or making gifts or loans – with conditions[87] on behalf of the person. Legal affairs include hiring a lawyer, starting or defending legal action, or executing legal documents on behalf of the person except for beneficiary designations – unless under explicit circumstances.[88]

A power of attorney does not grant any authority over personal or health care. This is because a person who is capable of executing a power of attorney is ostensibly capable of executing a Non-Standard RA 9, which grants personal and health care authority.

There are three different kinds of power of attorneys: a general power of attorney, a springing power of attorney, and an enduring power of attorney.

- A general power of attorney is typically used when there is a specific timeframe or purpose for the power of attorney, such as travelling for an extended period or conducting certain aspects of business operations. A general power of attorney ends if the person loses capacity.[89]
- A springing power of attorney only comes into effect when a triggering event occurs, such as the person losing capacity or on a particular date.
- An enduring power of attorney is effective once executed and endures even if the person loses capacity, so long as the enduring power of attorney states that the authority of the attorney continues even if the person loses capacity.

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[83] *RAA*, s 16.
[84] *HCFA*, ss 19.3(1) (b).
[85] *HCFA*, s 19.3(2).
[86] *Power of Attorney Act*, RSBC 1996, c 370 ("***POAA***"), ss 10 and 12(1)(c).
[87] *POAA*, s 20(1).
[88] *POAA*, s 20(5).
[89] *POAA*, s 14.

An enduring power of authority is the most common of the three options. A person is presumed capable of executing an enduring power of attorney, but may be found incapable if they are unable to demonstrate that they understand all of the following:

- the property they have and its approximate value;
- any obligations they owe to their dependants;
- that their attorney can do anything that they could if capable (except making a will) subject to any restrictions in the power of attorney;
- the attorney, unless acting prudently, could cause their assets' value to decline;
- the attorney could misuse their authority;
- if capable, they can revoke the power of attorney; and
- any other prescribed manner.[90]

An attorney acting under any power of attorney has several duties, including to:

- act in good faith;
- exercise reasonable care, diligence, and skill;
- act within their authority;
- keep records of actions taken under their authority and produce these records when requested by the person;
- act in the person's best interest, taking into account the person's wishes, beliefs, and values;
- encourage the person to be involved in decision-making; and
- keep their assets separate from the person's assets.[91]

People should choose their attorneys carefully and with thought as to how responsible the possible attorney is and whether there is a strong relationship of trust. It is sadly not uncommon for POAs to be misused, whether intentionally or not, and so when discussing who a person should appoint as their attorney, trust should be the number one characteristic considered.

4.2.4 Committees

In circumstances where a power of attorney and/or representation agreement have not been executed and a person is no longer able to make informed decisions about themselves or their legal and financial affairs, a court-appointed substitute decision-maker (a committee) may be needed. This can be an expensive and time-intensive process. Further, appointing a committee often removes the person from the decision as to who will act for them unless they have executed a nomination of committee, previously discussed who they would like appointed, or can participate in the hearing process in some fashion.

Going through this process is not ideal but may be necessary. To have a committee appointed, a person files a petition to British Columbia Supreme Court, along with two affidavits from two doctors in which they tell the court what their medical assessment of the person

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[89] *POAA*, s 14.
[90] *POAA*, s 12.
[91] *POAA*, s 19.

is and the likelihood they will regain their abilities to care for themselves and/or their estate, but they do not provide an opinion of the applicant becoming the committee.[92] The applicant must also file a notice of hearing, notice of application for appointment of committee, affidavit of kindred and fortune, and any consents of kin.[93]

Before the hearing, a copy of the petition and supporting materials must be served on the person and the Public Guardian and Trustee.[94] The Public Guardian and Trustee will provide any requirements for the order, such as whether the committee should be bonded or if any sale of real estate is to be approved by their office first, but they will not take a position on the applicant.

If the petition is not opposed, a master or justice will make the order that declares the person incapable of managing themselves and/or the estate and the person applying as the committee of the person. The committee can make all decisions the person could if capable, except for making a will.[95]

A committee of estate or person has two broad duties in acting for the person: first, to act in the best interest of the person, and second, to foster the independence of the person and involve the person in any decision-making, as much as is reasonable.[96]

4.2.5 Statutory Property Guardians

If the person is not capable of managing their financial affairs, they have not previously appointed a substitute decision-maker, there is no willing person to apply to become committee, and the person needs or would benefit from a statutory property guardian, the Public Guardian and Trustee may be appointed as statutory property guardian following an incapability assessment.[97] This appointment is done under the authority of the *Adult Guardianship Act* ("**AGA**").

The appointment of the Public Guardian and Trustee occurs when a certificate of incapability is signed by the health authority designate and does not require a court application.[98] As statutory property guardian, the Public Guardian Trustee can make decisions regarding the person's financial affairs that a capable person would be able to make, except make a will.[99] The Public Guardian and Trustee is only appointed as a statutory property guardian as a last resort option.

Where appointed as a statutory property guardian, the Public Guardian and Trustee must meet the same two duties outlined for a committee. This is because, as statutory property guardian under the AGA, the Public Guardian and Trustee manages the person's financial affairs as a committee.[100] This means the Public Guardian and Trustee should consult with the spouse or a near relative of the person and should involve the person throughout the decision-making process.[101] Further, a person may request a review of their certificate of incapability.

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[92] *Patients Property Act*, RSBC 1996, c 349 ("***PPA***"), s 3.
[93] *Patients Property Act Rules*, BC Reg 311/76 ("***PPAR***"), r 2.
[94] *PPA*, ss 2 and 7; *PPAR*, r 2.
[95] *PPA*, s 15.
[96] *PPA*, s 18
[97] *AGA*, s 32.
[98] *AGA*, s 32.
[99] *AGA*, ss 1, 17, and 32.
[100] *PPA*, s 1.
[101] *PPA*, s 18.

4.2.6 Temporary Substitute Decision-Makers

In health care contexts, temporary substitute decision-makers can be appointed to make specific health care decisions where a person does not have a personal guardian or representative. Their authority is limited to the specific health care decision at hand. These include both “major” health care decisions (such as surgery, major diagnostic/investigatory procedures, radiation, chemotherapy, kidney dialysis, and laser surgery) and “minor” health care decisions (such as routine medical tests and dental treatments).[102]

However, temporary substitute decision-makers do not have the authority to make decisions on experimental care (i.e., where foreseeable risks are not outweighed by any expected benefits), tissue removal/transplants, psychosurgery, or research that has not been approved by designated research ethics committees.[103] Temporary substitute decision-makers are also prevented from refusing care necessary to preserve life unless health care providers agree that the decision is medically appropriate.[104]

If a person living with dementia does not have a representation agreement or committee appointed, who makes decisions about their care is restricted to those permitted by the *HCFA*. Temporary substitute decision-makers are selected from a ranked list of the person’s family members and friends (e.g., spouse, child, parent, sibling, grandparent, grandchild, other relatives by birth or adoption, close friend, or people immediately related by marriage).[105] They must be 19 years old, have been in contact with the person in the past 12 months, have no dispute with the person, and be capable of giving substitute consent.[106]

This means that a person living with dementia loses their voice as to preference of substitute decision-maker as who they prefer may not be the person the *HCFA* places as the temporary substitute decision-maker. This can be difficult in situations where there is conflict between a person classified as the temporary substitute decision-maker according to the *HCFA* but a caregiver or care partner, family member, friend, or significant other disputes the selection as temporary substitute decision-maker. This can be difficult for 2SLGBTQIA+ people living with dementia who may not have a person who is recognized under the HCFA or is lower on the hierarchy than a family member but is the person living with dementia’s preferred substitute decision-maker.

Temporary substitute decision-makers must consult with the person to the greatest extent possible and comply with any previously expressed wishes.[107] Where any previously expressed wishes are not known, temporary substitute decision-makers must decide in the person’s best interests, considering:

- the person’s current wishes, known beliefs, and values;
- if their condition or well-being is likely to be improved by the proposed care;
- if their condition or well-being is likely to improve without the proposed care;
- if the proposed benefit from the treatment outweighs the risk of harm; and
- if there is a less restrictive or less intrusive option that would be as beneficial.[108]

Temporary substitute decision-makers may also consent to a person’s admission into a care facility where no representative or personal guardian is available.[109]

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[102] *HCFA*, s 1; HCCR, s 4.
[103] *HCCR*, s 5.
[104] *HCFA*, s 18 (2).
[105] *HCFA*, s 16 (1).
[106] *HCFA*, 17 (3).
[107] *HCFA*, s 19 (1).
[108] *HCFA*, s 19 (2)-(3).
[109] ***HCFA***, s 22.

4.2.7 Medical Order for Scope of Treatment

Completing a medical order for scope of treatment designation form (the "**MOST**") is completed between a health care provider and the person regarding the scope of treatment and interventions as part of the care planning process with a person. It is meant to record the person's care preferences and goals with respect to the medically appropriate care in the circumstances.

Health care providers who complete a MOST with a person living with dementia should start with the presumption that the person is capable of discussing and giving or refusing consent to the scope of treatment in the MOST (or renewal of it, as applicable). If a person living with dementia is unable to provide consent to the MOST, the health care provider should take steps to determine if the person had an advance directive that provides direction on the particular decision to be addressed in the MOST. If there is no advance directive, the health care provider should then turn to a substitute decision-maker for substitute consent.

4.3 Misuse of Powers

Substitute decision-makers (i.e., attorneys under a power of attorney, representatives, and guardians) may abuse their powers by stealing money, disposing of property, or taking legal actions that do not align with the person's wishes. Financial abuse includes the misuse of powers of attorney, representation agreements, trusts, or guardianship/committeeship. The relevant pieces of legislation designate how an attorney, representative, or guardian can be removed if they are being abusive.

There are also several civil remedies available in most jurisdictions for misuse of these powers, such as breach of fiduciary duty or the equitable remedy of resulting trust.[110] Further, the Criminal Code of Canada has a provision relating to misuse of their authority as an attorney under a power of attorney, with such action being classified as "theft".[111] The abuser may have to prove how they spent the money. The abuser may have to repay the money. Financial or legal transactions may be set aside.[112] The difficulty with pursuing any of the remedies available, the abuser has often absconded with the stolen or misappropriated funds, making any order of repayment or punitive damages incredibly difficult to realize.

Given the difficulty in tracing the misappropriated or stolen funds of an older person, health care providers, caregivers, and other service providers play an important role in identifying misuse of authority earlier on. As you gain an understanding of the rights and responsibilities of both the older person and their appointees, the ability to spot red flags in different contexts becomes stronger. It is vital to ask further questions of the older person independent from the appointee to confirm their instructions. Supported decision-making is important but it is equally important to ensure the older person is deciding with independent thought rather than merely going along with what their attorney, representative, or guardian is suggesting.

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[110] *Kask Estate v Welsh,* 2000 BCSC 791; *Taylor v. Sinclair,* 2017 BCSC 10.

[111] *Criminal Code,* RSC 1985, c C-46, s 331.

[112] British Columbia Government, "Understanding and Responding to Elder Abuse" at 4-5, 17-19, online: https://www2.gov.bc.ca/assets/gov/law-crime-and-justice/criminal-justice/victims-of-crime/vs-info-for-professionals/info-resources/elder-abuse.pdf; WEL Partners, "Whaley Estate Litigation Partners on Elder Law" (2020),at 52-79, 135-141, online: https://welpartners.com/resources/WEL-on-elder-law.pdf.

Health care providers in a variety of settings are in greater proximity to the person, giving them a unique opportunity to identify instances of abuse, neglect, and exploitation. In general, interactions with health care providers occur more frequently than a member of the legal community and a person living with dementia may feel more comfortable disclosing an instance of abuse, threats, or coercion with their health care provider.[113] It may be as simple as one sentence where there is reference to care being a quid pro quo with a family member that may prompt a health care provider to ask more detailed questions.

For a person living with dementia, the disclosure of harm may be difficult for them to articulate but it bears repeating that it may be necessary to ask follow-up questions in a variety of ways to gather sufficient information. This will help ensure they feel supported in making such a disclosure while also providing sufficient information regarding the possible harm.

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[113] Beardon S, Woodhead C, Cooper S, Ingram E, Genn H and Raine R, "International Evidence on the Impact of Health-Justice Partnerships: A Systematic Scoping Review" (Frontiers: 2021), Public Health Rev 42:1603976, at 5.

RESOURCES

Undue Influence Recognition and Prevention: A Guide for Legal Practitioners
BCLI has updated and re-issued its Guide on practices recommended for legal practitioners to follow in the interests of ensuring that the wills and other personal planning documents they prepare represent the genuine independent wishes of their clients and can withstand challenge on the basis of undue influence.

https://www.bcli.org/project/undue-influence-recognition-prevention-guide-update-project/

Trauma-informed care
Guiding Principles for Best Practice
This guide is meant to help people working with older people to respond to the rights of older people who are abused, neglected, or at risk in a manner that is effective and reflects best practices.

https://ccelderlaw.ca/guiding-principles-for-best-practice/

Trauma-Informed Practice Guide
This guide was written for professionals working with people living with mental health illnesses and substance use. This guide outlines what trauma is, what trauma-informed practice is, and how to implement it.

https://cewh.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf

Healing Families, Helping Systems: A Trauma-Informed Practice Guide for Working with Children, Youth, and Families
This guide was written for people working with children, youth, and families. It outlines the general principles of trauma-informed practice, and how it can be implemented in working with families, and within an organization.

https://www2.gov.bc.ca/assets/gov/health/child-teen-mental-health/trauma-informed_practice_guide.pdf

Indigenous perspectives on dementia care
National Collaboration Centre for Indigenous Health
This organization provides information, resources, and tools for improving the health of Indigenous peoples in Canada. They have many publications on cultural safety in health care.
www.nccih.ca/en/

Provincial Health Services Authority in BC: San'yas Indigenous Cultural Safety Training
These courses, provided by the PHSA, cover cultural safety training for anyone working with Indigenous peoples. There are specific modules for people working in health care, mental health, and child welfare.
www.sanyas.ca/

Communicating Effectively with Indigenous Clients by Lorna Fadden
This guide explains how Aboriginal English differs from Standard English, and how Aboriginal English can be misinterpreted by police and the legal system. It describes the biases and prejudices that are associated with speaking Aboriginal English. The guide provides practice suggestions on how lawyers can work with the legal system and their client to reduce prejudice and better represent their clients.
www.aboriginallegal.ca/assets/als-communicating-w-indigenous-clients.pdf

First Nations Health Authority, "Our History, Our Health"
Provides information on the history of Indigenous peoples and colonialization.
www.fnha.ca/wellness/our-history-our-health

Gender, sexual orientation, and gender identity lens
Gender-Based Analysis Plus course
https://women-gender-equality.canada.ca/en/gender-based-analysis-plus/take-course.html

Atira
Promising Practices Across Canada For Housing Women Who Are Older And Fleeing Abuse (2015)
https://atira.bc.ca/wp-content/uploads/Promising-Practices-for-Housing-Women-who-are-Older.pdf

L Greaves et al.
Integrating Sex and Gender Informed Evidence into Your Practices: Ten Key Questions on Sex, Gender & Substance Use

https://cewh.ca/recent-work/sex-and-gender-based-analysis/integrating-and-measuring-the-effect-of-sex-gender-and-gender-transformative-approaches-to-substance-use/

Referral Agencies
Alzheimer Society of B.C. - https://alzheimer.ca/bc/en
Family Caregivers of BC - https://www.familycaregiversbc.ca/get-help
Flipping Stigma - https://www.flippingstigma.com/
Native Women's Association of Canada - Supporting a Circle of Care: Creating A Circle of Care for Caregivers- https://nwac.ca/assets-knowledge-centre/30-March-CIRCLE_OF_CARE_TOOLKIT.pdf
Nidus - https://www.nidus.ca/
People's Law School - https://www.peopleslawschool.ca/

Sample Capacity Assessment Questions

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These are sample questions and not intended as legal or medical advice or determining questions for capacity. They are meant to demonstrate the types of questions for different types of decisions that you may consider asking. As every person, decision, and situation is different, some of these questions may not be applicable.

Prior to undertaking an assessment:

Personal values check – prior to connecting with the client think about the following:

- Is the choice they are making harming themselves or others?
- Does it go against some of your personal values that might interfere with the assessment?

Health

- Would you describe yourself as healthy?
- Do you have any health conditions? What are they and how to they impact your life?
- Thinking top to toe? Pain, aches etc.
- Are you taking any medications? Pills, tablets, injections? Are they prescribed or do you buy them OTC? Do you know what your medications are for? What would happen if you stopped taking them?
- When was the last time you saw a doctor? What was it for?
- If it has been a while, how would you seek medical advice or renew medications?
- Do you understand the treatment/procedure that is being offered? Can you tell me why it is being offered? What is entailed? What could happen if you chose not to have the procedure? Do you have any questions about it or the recovery time?
- If you needed help making health care decisions, who would you ask?

Financial

- Do you currently manage your own finances? Do you find it easy to do this on your own? If not, can you tell me more about this? (Is it a transportation issue, inexperience handling finances rather incapability)
- Do you know how much income you have each month and where it comes from?
- Can you tell me about your bills? What do you have bills for and how do you pay them?If possible, try and have the person show you either on a copy of their own bills what they owe or use a template.
- Do you have any debts or owe anyone money?
- Do you have people who rely on you for money?

- Do you pay your bills online or use online banking?
- How do you protect yourself from online scams?
- Do you feel pressured to pay for things?
- Do people ask you for money or personal items?

Placement (HCCCFAA)

- Can you tell me about your current health conditions and any care that you think you need? Can you describe what that care is and who provides it?
- (alternative) Do you feel you have been able to care for yourself as well as you have liked?
- Do you think that [LTC facility] will help you with your care needs?
- How do you feel about moving into this facility? What would be the pros and cons of doing so?
- What would happen if you chose not to moving?
- Do you have any worries or concerns about moving into the facility?

General judgment questions

- The following questions are to assess the person's ability to problem solve and assess their ability to understand potential risks and what decisions they would make in resolving them.
- You are going to make yourself a meal, how do you know if the food you have is spoiled?
- As you are getting out of the shower you slip and fall, what do you do?
- What would you do if your faucet was leaking and there was a large puddle of water on the floor?
- What would you do noticed smoke coming from your stove?
- If you want to go to a store some distance away to buy a large number of groceries, how would you arrange this?
- If you went out for a walk and became lost, what would you do?
- If you alone in your home at night and felt frightened, what do you do to keep yourself safe?

Charting ideas

Domain assessing:

Date/time/location of assessment:

Assessor details:

Support person present:

Reason for assessment:

Assessment details (including any tools used):

Determining Understanding:

Findings:

Dementia + Decision-Making

Empowering People Living with Dementia and Their Caregivers

These resources were developed with perspectives from caregivers, care partners, health care providers and people living with dementia. The full package of resources can be found on the [CCEL Dementia + Decision-Making Project webpage (www.bcli.org/ccel-projects/dementia-decision-making-project/).](www.bcli.org/ccel-projects/dementia-decision-making-project/)

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About the BCLI www.bcli.org

The BCLI is BC's independent law reform agency. We have been bringing collaborators together to clarify and improve the law, develop just and innovative solutions, and increase access to justice for over 25 years. The CCEL is a division of the BCLI and carries out scholarly research, writing, analysis, and community outreach for the purposes of furthering law reform that is focused on issues of interest to older adults.

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To access **Dementia + Decision-Making**, use the QR code, or visit www.bcli.org/ccel-projects/dementia-decision-making-project/

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