Dementia + Decision-Making

Empowering People Living with Dementia and Their Caregivers

A Guide for Caregivers and Care Partners

CANADIAN CENTRE FOR
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BRITISH COLUMBIA LAW INSTITUTE

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- promote improvement of the administration of justice and respect for the rule of law, and
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Overview

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. This Guide is an ongoing resource to understand the law relating to the rights of people living with dementia and how caregivers and care partners can help people living with dementia to participate in decisions regarding their care and well-being. 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. All materials were designed with the direct input of people living with dementia and those who support them. Dementia + Decision-Making project's materials include videos, guides, quick reference materials and decision-making flowcharts and are available here.

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. We understand that every person's journey is different, there is no one size fits all way of supporting people living with dementia. Based on the input we received, the Guide identifies common barriers and provides 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 Guide focuses on decision-making in care settings and is written for those who identify as a caregiver, care partner, or loved one who provides unpaid support and/or care of a person living with dementia. It is based on the premise that all people living with dementia can make decisions for themselves until it is shown that they are no longer able to. It provides insight for caregivers, care partners, support networks, and service providers of people living with dementia when it becomes unclear that the person living with dementia may not be able to fully participate in decision-making. It provides information on how to better support their involvement.

The Guide is divided into the following sections:

Section 1 discusses "Capacity" to help readers understand how capacity is understood in the legal context and how capacity determinations are made. It also considers potential impacts or barriers that caregivers can help a person living with dementia to overcome to support the decision-making rights of the person living with dementia.

> **Summary:** Capacity is a legal term that refers to the ability to make decisions or enter into legal relationships. While some decisions require more capacity than others, what matters most is whether a person understands the decision they need to make, information about the decision, and what the possible outcomes or consequences of the

decision are. For people living with dementia, their capacity to make certain decisions will change over time. Caregivers can help the person living with dementia by understanding things that may impact their capacity. This could include:

- communicating the information in a way that helps the person living with dementia understand better;
- understanding the impact of any medication on the person living with dementia; or
- identifying when a person living with dementia may not be able to fully participate in making a decision.

Section 2 discusses "decision-making" and the different types of decisions that a person living with dementia may need to make. This includes understanding the rights of a person living with dementia to make decisions. This also includes strategies for how a caregiver can help or support the person living with dementia when making decisions.

Summary: There are typically three forms of decision-making that may arise when caregiving:

- Independent decision-making – the person living with dementia can make the decision on their own.
- Supported decision-making – the person living with dementia requires some form of support to make a decision. This support may come from a caregiver, care partner, representative, or someone else the person trusts.
- Substitute decision-making – the person living with dementia can no longer participate in the decision-making process and a substitute decision-maker must step in. There is still consultation with the person living with dementia, where possible, though the decision will be made on the person's behalf.

Caregivers can help a person living with dementia participate in decisions more fully by incorporating different strategies, such as directing the health care provider to speak directly with the person living with dementia or using written information to have follow-up discussions rather than making a decision in the moment.

Section 3 discusses the law related to capacity and decision-making. It is divided into two parts – the first part considers the types of decisions in the health care setting that a person living with dementia may be asked to make. These decisions require consent from a patient, either directly or through an advanced directive, or their substitute decision-maker before moving forward with a particular treatment or decision. The second part addresses the different types of substitute decision-makers in British Columbia that can be appointed to make decisions for a person living with dementia.

Summary: Decisions in health care and long-term care home settings mostly centre on a person's ability to provide consent to a treatment or to a move. Consent is needed before touching someone else's body generally and the health care setting is no different. All patients are presumed capable of giving consent to treatment unless it is proven they no longer can give consent. To give consent, a person must understand the following:

- 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.

If a person is not capable of giving consent even with support, a substitute decision-maker will be asked to consent on the person's behalf. There are different legal tools in the health care setting to identify a substitute decision-maker:

- A person may have an advance directive, which allows them to pre-determine certain health care decisions, and contains the expressed wishes of the person to guide health care providers and any substitute decision-makers. In some cases, a health care provider may have to follow the instructions in the advance directive regardless of what a substitute decision-maker wants.
- A representation agreement appoints a substitute decision-maker for only health or personal care decisions and can be in one of two forms – a section 7 representation agreement or a section 9 representation agreement. A section 7 representation agreement is for people with lower capacity, and who can make some decisions about their care, particularly when supported in doing. Section 7 representation agreements do not permit more major care decisions, such as refusing consent for life-saving treatment. A section 9 representation agreement is for people with more capacity as it can allow a representative to make very major care decisions, such as refusing to consent to life-saving treatments.
- A power of attorney appoints a substitute decision-maker for only legal or financial decisions. A power of attorney does not provide authority to make personal or health care decisions.
- A committee is a legal guardian, appointed by the court, to make decisions for an incapable person. This occurs where there is no representation agreement or power of attorney in place. A committee can be one person or more than one. Appointing a committee is a major step because it means that the court will declare the person incapable of taking care of themselves, their finances, or both.
- A temporary substitute decision-maker will make specific health care decisions at a specific point in time. They are chosen based on a prioritized list in law – spouse, child, parent, sibling, grandparent, grandchild, other relatives by birth or adoption, close friend, then persons immediately related by marriage.

All of the above substitute decision-makers must include the affected person in any decision-making as best they can at the time of the decision. If the substitute decision-maker cannot involve the person, they are to make decisions based on what they know the person would do in similar circumstances. Where this is not known, the substitute decision-maker must still make decisions that are in the best interest of the person.

Section 4 discusses decision-making in long-term care homes and the role of caregivers and care partners where the person living with dementia moves into a long-term care home.

Summary: a person is presumed capable to give consent to their admission to a long-term or community care home after demonstrating they understand:

- the type of care they will receive in the long-term care home;

- the services the long-term care home will provide to the adult; and
- the circumstances under which the adult may leave the long-term care home.

Where a person has moved into a long-term care home, a caregiver or care partner still needs to be involved in decision-making. For many caregivers, their role shifts to advocating for the person living with dementia. This may look like being involved in care and routine planning with health care providers or long-term care staff. It may also be more formal by participating in a Family Council or other approach used by the long-term care home.

Resources – The last part of this Guide contains links/references to different resources that can support caregivers.

Glossary of Terms

An **‘Assessment’** is where a health care provider or legal professional meets with an adult to determine if the adult is capable of a certain decision. In the legal setting, a lawyer or notary is assessing whether the adult can enter into a legal relationship or sign a legal document, such as a representation agreement. Criteria may differ, and generally the assessment usually considers if the person:

- can express a choice;
- understands the nature of the decision and relevant information;
- appreciates the decision will have consequences for them and what those consequences may be.

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

‘Caregivers’ or **'Care partners’** are persons who are giving unpaid support and/or care to persons living with dementia or helping to look after them. These persons 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 provide treatment to the person.

‘Decision-making’ refers to a person’s ability to make a decision after receiving necessary information about the decision and understanding the possible consequences of the decision.

‘Health care providers’ refers to persons who are providing paid care and/or prescribed health care to persons living with dementia in health care settings, including in the community and home care settings. In this Guide, health care providers generally include medical practitioners, physicians, 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, and/or health care aides.

‘Person(s) living with dementia’ or **‘People living with dementia’** refers to persons 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 a representation agreement.

‘Public Guardian and Trustee’ is an independent corporation that provides services to adults who may need help managing their affairs, and to their families, legal representatives, the courts and the general public. The role of the Public Guardian and Trustee includes protecting the legal, financial, personal and health care interests of adults who require assistance in

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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>.

decision-making. This means that it may take on a protective role for a person or oversee the actions of a person's committee.

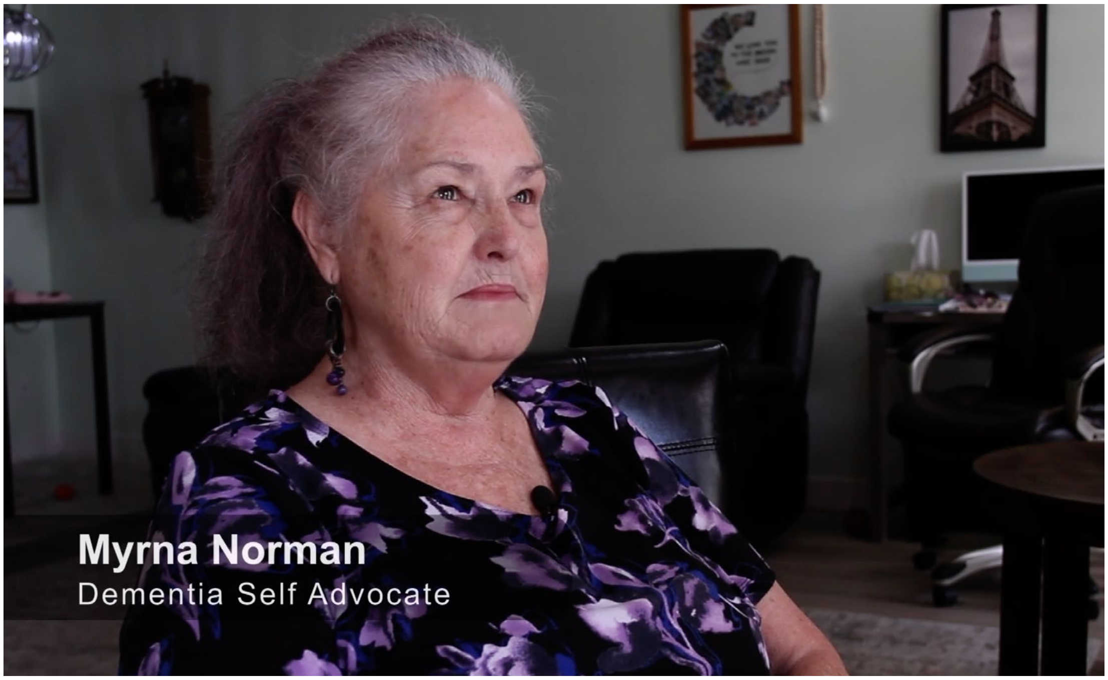
'Substitute decision-maker' refers to a person who has the legal authority to make a decision on behalf of an adult who does not have capacity. There are several types of substitute decision-makers:

> 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). The committee can be one person or more than one person.
>
> An *attorney* is appointed by a person in a **power of attorney** document as a trusted substitute decision-maker on financial and legal affairs. The attorney should be someone the person trusts to make legal and financial decisions for them and should involve the person in decision-making where possible. In BC, an attorney does not have authority to make personal or health care decisions.
>
> A *representative* is appointed by a person as a trusted substitute decision-maker 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. As with an attorney, the representative should be someone the person trusts, and should involve them in decision-making where possible.
>
> A *statutory property guardian* is appointed by the court to make financial decisions for an adult 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 to health care matters for a person when there is no appointed substitute decision-maker. This person is chosen from a prioritized list of persons close to the person who cannot give consent – spouse, child, parent, sibling, grandparent, grandchild, other relatives by birth or adoption, close friend, then persons immediately related by marriage.

'Supported decision-making' is a voluntary relationship that provides an alternative before moving to substitute decision-making where possible. Supportive decision-makers help people to make their own decisions. Supportive decision-makers provide support suitable to a person's unique 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 supportive decision-maker, generally by signing a legal document.

'Undue Influence' refers to the pressure or other form of trickery 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 Guide or by clicking here.

SECTION 1: CAPACITY



1.1 What is Capacity?

Capacity (also known as mental capacity, capability, or competence) is a person's ability to make decisions about their life, with some decisions needing more capacity than others. These decisions may include decisions about personal care, financial and legal matters, and health care or medical treatments. This means that the starting point is that we assume that everyone has capacity to make a decision until it is proven otherwise. If it seems they do not have capacity to make the decision, we should still involve them in the decision-making process as much as possible. Even when someone is not capable of making a decision, it does not mean that they are not capable of other decisions.

Sometimes we assume that because someone has a mental health or dementia diagnosis that they are not capable. This is wrong. Decisions about whether someone is capable or not require more considerations than a diagnosis. A dementia diagnosis does not mean an adult immediately becomes unable to make their own decisions. A person living with dementia can still have decision-making capacity after being diagnosed with dementia, especially in the early and middle stages. Even in the late stages, a person living with dementia may have a clear sense of preferences and values and be capable of expressing their views, even if through non-verbal means or with communication support. There may be times where a person living with dementia may not be able to fully participate in a decision, but this does not mean they are not capable. When this happens, remember that adults are first presumed to be capable, and a person living with dementia must be found to be incapable before others can make decisions on their behalf.

1.2 Findings of Incapacity:

It is important to work with the person to have necessary legal tools, such as the power of attorney or representation agreement, in place before the person starts to show signs that their capacity is changing.

A more formal assessment may need to happen when there are concerns that a person is no longer able to fully understand a particular decision or its consequences. You may be one of the first people to notice any changes in the abilities of the person living with dementia and it may be important for you to raise your concerns with a health care provider. Your observations may be important factors in the capacity assessment as they provide more information to whomever is doing the assessment. Capacity determinations are made by health care providers, lawyers, and sometimes by a court.

A finding of incapacity can be done in many ways, ranging from an informal to formal process. There are always informal assessments that all people are going through when making decisions, whether it is at home, the doctor's office, or when meeting with a lawyer. For example, anytime a person meets with a lawyer, the lawyer must consider if the person can give them instructions. In that situation, a lawyer must think about whether the person understands what they are there to do, among other things, regardless of a diagnosis of cognitive impairment. The definition and process of finding someone incapable is different for each decision.[3] A person is typically not found to be incapable of making all decisions. For example, a doctor may evaluate their patient and find they cannot make health care decisions, prompting them to get consent from the person's substitute decision-maker, which may include you as a caregiver. This finding, however, does not necessarily mean the person cannot make personal care decisions. In the most extreme case, a court may make a finding of incapacity and grant a guardianship or committeeship order if a person has not appointed a decision-maker in a power of attorney or representation agreement.[4]

Remember that a finding of incapacity means that a person living with dementia may no longer be able to make their own decisions on a specific matter (whether health-related, personal, financial, or legal) and should be seen as a last resort. It is important that everyone support the person living with dementia and/or impaired cognitive abilities in making their own decisions to the greatest extent possible (explored below in Section 2: Decision-making). Seeking a formal finding of incapacity should come only after attempts to support the person's decision-making capacity has begun to break down and there is a need for decision-making to keep the person and their property safe. As discussed below, this is a process that may take time.

1.3 Assessing Capacity:

In general, an adult is capable of making a decision if they can understand the information, use the information, and appreciate the consequences of the decision. Capacity is a subjective assessment – it is decision, time, and situation specific.[5] It is important to remember that:

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

For most of us there is some fluctuation in our capacity to make decisions. For example, when we are under stress, we may have more difficulty. This is true for people living with dementia, where decision-making capacity can change from day-to-day, and even hour-to-hour. [6]

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[3] CCEL, 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 (pdf): <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 (pdf): West Coast LEAF <www.westcoastleaf.org/roads/> ("**WCL, Roads to Safety**");, *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> ("**BCLI Common Law Capacity**").

[4] Adult Guardianship Act, RSBC 1996, c 6; Patients Property Act, RSBC 1996, c 349.

[5] CCEL Conversations About Care, at 6.

[6] CCEL Conversations About Care, at 6.

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. It is also important to recognize and respect if a person living with dementia has previously made decisions with family support and input. Supported decision-making is discussed more below.[7]

2. 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 certain legal decisions, such as making a will, is greater than the capacity required to make personal care decisions. In the health care context, capacity requirements are higher for major decisions like major surgery or end-of-life decisions and lower for more minor decisions like whether to take a prescription medication.[8] This means that a person living with dementia could be capable of some health care decisions and not others. For example, a person could be capable of personal or health care decisions but not capable of making financial or legal decisions.

3. 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 the person's decision-making process.[9] We must respect that people living with dementia can make decisions that seem irrational or incorrect to others if they are able to go through the decision-making process of understanding the decision, the information needed to make the decision, and the possible consequences of the decision.

This means that people living with dementia:

- **Can choose to live at risk.** Everyone, including people living with dementia, has different levels of comfort when it comes to risk.
- **Do not need to make the "correct" decision.** As a care partner or caregiver, you may not think the decision is right. But if the person living with dementia has the capacity, it is their decision to make.
- **Do not need to make decisions that align with the best interests of others.** Decisions that go against the suggestions of caregivers, family members, and even health care providers can still be valid.
- **Can change their values and preferences but this does not necessarily signal incapacity.** Most of us will develop our values and preferences as a result of our life experiences. People living with dementia are no exception. As a dementia diagnosis can be a life-changing event, some changes in values or preferences can be expected. Determining whether such changes impact the person living with dementia's capacity may require a formal assessment by a health care provider or lawyer that addresses capacity for the specific decision at issue.[10]

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

[8] CCEL Conversations About Care, at 6.

[9] 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*

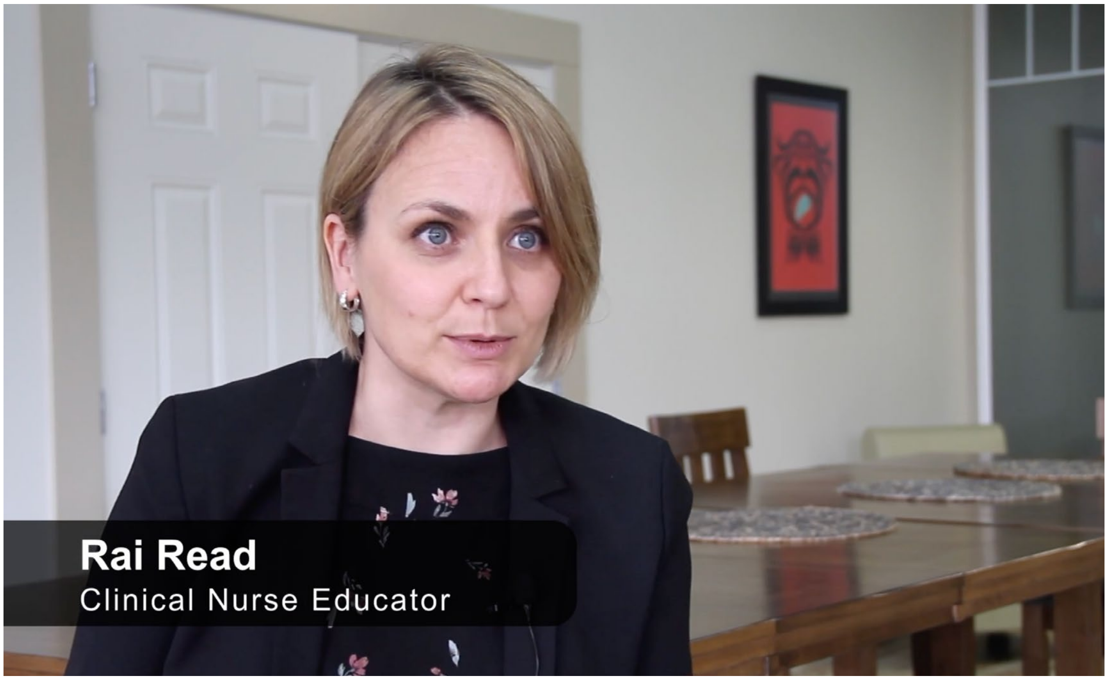
[10] CCEL Conversations about Care at 6.

4. **If a person living with dementia does not appear to have capacity for independent decision-making, consider:**

- Can they make a decision with support from someone they trust, including you as a caregiver?
- Do you need to change the environment you are in, such as shifting to a quieter space, so that they will understand the relevant information?
- Can you change the way you communicate to support their participation decision-making?
- Do they have a substitute decision-maker, possibly you, with authority to provide consent for them?

The next section talks about how to better support the healthcare decision-making capacity of people living with dementia.

SECTION 2: DECISION-MAKING



2.1 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 system challenges.

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, lack of confidence, and negative self-esteem around making the wrong decision.

Interpersonal Barriers

- **Communication barriers:** People living with dementia may have difficulty communicating their wishes and preferences such that you may not hear or understand.
- **Lack of support systems:** Some people living with dementia do not have the support of trusted people to help with decision-making.
- **Risk of undue influence:** Sometimes, family members, friends, or legally appointed representatives may use their relationship with a person to influence decisions that do not respect their wishes or take advantage of the person by accessing money, disposing of property or taking legal actions the person living with dementia would not want.

Systemic Barriers

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

  Because a person lives with dementia, others assume they are incapable of all decision-making, even when no assessment of their abilities has occurred. One person living with dementia gave the following example:

> *"If I could just share what happened to me with [...], 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..."*

In such cases, the presumption that people living with dementia are capable of decision-making is ignored. While in some cases, the capacity of a person living with dementia may be impacted, most people living with dementia can participate in decisions related to their personal, health care, legal and financial matters. A person living with dementia may well be able to make decisions for themself, either independently or with the support of friends, family, and others.

One should be careful to create the space for the person with dementia to make decisions, including advocating on their behalf when health care providers fail to recognize their rights to be involved. When one supports a person living with dementia in decision-making, one must respect their right to make "risky" or "wrong" decisions when they are capable of making them. As a caregiver, you may not always agree with their decision or opinion but allowing them to be heard and respected is essential.

Resource limitations of the health care system

The rushed pace of medical environments does not always allow enough time for inclusive/collaborative decision-making. Beyond that, people living with dementia also face a lack of long-term support options, which may force decisions such as living in a care home.

Language barriers

Non-English speaking and immigrant families can struggle to communicate with health care providers that do not speak a common language. Interpreters are not always available; 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. As a caregiver, you may need to locate an interpreter the person living with dementia trusts to help with certain appointments so that everyone can understand the decisions and possible consequences or outcomes of the decision.

Cultural barriers

Healthcare systems often fail to accommodate cultural differences surrounding dementia and decision-making, sometimes perpetuating medical racism. Notably, Indigenous people face significant barriers in accessing health care and dementia services. As a caregiver, you may find yourself having to stand up for the cultural beliefs of the person living with dementia despite negative responses in the care setting.

2.2 Types of Decision-Making

Decision-making may involve different people in different ways and can be described as a range:

Independent decision-making

> The person living with dementia is capable and makes a decision on their own, with no support.

Decision-making with support from trusted family members, friends, or caregivers

Most people normally make decisions in an interdependent and social way – most people consult with friends or family when making important decisions.[11] Supported decision-making is especially important for people living with a disability, including dementia, because it encourages them to make their own decisions.

Supported decision-making helps protect the decision-making rights of people living with dementia. In BC, Yukon, Alberta, and Saskatchewan, the right to a supporter is recognized by the law.[12] Supported decision-making can be legalized through a standard representation agreement (discussed further below); however, many people living with dementia make decisions with the help of people they trust even if they do not have a written agreement.

Decision-making by substitute decision-maker

If a person living with dementia 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 living with dementia should first be supported to help them make decisions. There are five types of substitute decision-makers in BC:

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

See **"Section 3: The Law"** below for more information on the types of substitute decision makers and their responsibilities.

2.3 Decision-Making Rights

Everyone, including people living with dementia or other health issues that may impact their decision-making, has 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.

In British Columbia, a representative is appointed by a capable person under a representation agreement to support them in making decisions when they are no longer capable.[13] However, while a supported decision-making relationship may be formalized in a representation agreement, caregivers may also be involved more informally in supported decision-making by virtue of being in a relationship of trust with a person living with dementia. 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.*

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[11] CCEL Conversations About Care, at 74-97; WCL, Roads to Safety, *ibid* at 18-29; BCLI Common Law Capacity.

[12] *Adult Protection and Decision Making Act,* SY 2003, c 21, Sch A, s 9 (1); *Adult Guardianship and Trusteeship Act,* SA 2008, c A-42, ss 4 (1) and (3); *Representation Agreement Act,* RSBC 1996, c 405 ("**RAA**"), s 7.

[13] RAA, s 8(2).

As a caregiver in a supported decision-making role, your responsibility is to give the person living with dementia the **support they need to make a decision themself**. This includes helping the person living with dementia understand information, consider a decision and its risks, and supporting the person in communicating their needs, values, and wishes. Alongside the strategies listed in “**Section 2: Strategies to Support Decision-Making**”, supported decision-making may involve:

- explaining the different roles of people in a situation where a decision is to be made;
- explaining information in a variety of different ways;
- doing background research for the person living with dementia so they have the most relevant information (for example, researching different kinds of medication);
- taking notes at appointments or bringing the information in a written format;
- advocating to engage the person living with dementia in decision-making at a different time when the person is less likely to be over-tired or unable to focus;
- requesting language interpreters; and
- being alert to abusive or controlling dynamics.

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

This means involving the person living with dementia in decision-making as much as possible and includes communicating with the person about their wishes and preferences.

People living with dementia should be consulted even after they have lost capacity, and their input should be considered. Even if the person does not have capacity, they can still usually express preferences and wishes.

Decisions made by a substitute decision-maker on behalf of a person living with dementia who is no longer capable must be consistent with the pre-expressed wishes, values, and beliefs of the person.

Substitute decision-makers also have a legal duty to involve the person living with dementia in the decision to the greatest extent possible.[14]

Honour any decisions the person living with dementia may have made when they were capable, or any expression of wishes they have made that can be considered at the time of the decision.

Substitute decision makers can only make decisions in the person’s “best interest” as a last resort – acting as a substitute decision-maker does not mean you can make what you think is the best decision for the person. Where no pre-expressed wishes are known and the person living with dementia can not be consulted for their preferences, a substitute decision-maker, should act in line with the person’s known beliefs. It is only when there are no pre-expressed wishes, values, and beliefs that a decision is to be based solely on the person’s best interests.[15]

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[14] *Health Care (Consent) and Care Facility Admission Act*, RSBC 1996, c 181 (“**HCFA**”), s 19 (1).
[15] *HCFA*, s 19 (2); *RAA*, s 16(4).

Decisions should first be based on what decision the person living with dementia would have made if capable, properly informed, and free from influence.[16] **The decision-making rights of people living with dementia are always paramount,** even when they no longer have capacity. For example, if a person living with dementia has previously expressed a wish not to move to a large urban centre, 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 that a decision is to be based solely on the best interest of the person.[17]

As a caregiver, it is critical that you **learn about the values, wishes, and beliefs of the person living with dementia.** As one informant noted:

> *"…so what is the adult's values, wishes and beliefs? And we can present that if we know them or have good evidence about them…have really solid evidence to say that this is the person who would have wanted this type of treatment…"*

This knowledge will help you support the decision-making capacity and rights of the person living with dementia whether you are helping to facilitate their independent decision-making or acting as a substitute decision-maker.

2.4 Strategies to Support Decision-Making

The following strategies can support in-person communication and decision-making for the person.

Before engaging the person living with dementia in decision-making:

- Ask them how they might be accommodated. Some people have disabilities that are immediately recognizable; others have disabilities that can be invisible. It is important not only to accommodate people's needs and abilities but to ask respectful questions about the unique kinds of support each person needs. An attitude of compassionate curiosity can open the door to help you to better understand a person's communication needs.
- Choose a time of day that works best for the person. 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 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, factor in extra time 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.

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[16] *HCFA*, s 19 (1).
[17] *HCFA*, s 19 (2).

SECTION 3: THE LAW

This section provides an overview of the types of substitute decision-makers and responsibilities of each. It also discusses the concept of consent, which is used in the health care setting to mean agreeing or refusing to certain treatment plans, including more detailed information on the different laws that apply to health care decisions. It is important to remember that the person living with dementia is **presumed capable** to make decisions for themselves unless it is proven they are no longer capable. Once proven, only then does a substitute decision-maker give or refuse consent for the person.

3.1 Overview of Types of Substitute Decision-Makers:

Someone does not have legal authority to provide substitute consent by virtue of being a family member, friend, or caregiver. **You must** be appointed in a legal document, like a representation agreement or power of attorney, or court order. In some emergency situations, you may be appointed temporarily within the hierarchy set-out for temporary substitute decision-makers.

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

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

As a family member, friend, or caregiver, you should avoid encouraging the person living with dementia to appoint you or anyone else as their attorney or representative since it is their decision as to who they want to appoint. This does not mean you should not discuss the decision, but the person needs to decide independently. Do not be surprised if you are asked by a legal professional to not be present during an appointment for executing a power of attorney or representation agreement.

Where there is no power of attorney and/or representation agreement in place, the court can appoint a **committee** (informally referred to as a guardian) for personal or financial matters if the court finds the adult is legally incapable and has not already appointed a substitute decision-maker.

For health care decisions, if a person is not capable, has not appointed a substitute decision-maker, and does not have a committee, a temporary substitute decision-maker is chosen. The Public Guardian and Trustee is the decision-maker of last resort.[18]

3.1.1 Representation Agreements

There are two types of representation agreements – a section 7 representation agreement, or **Standard Representation Agreement**, and a section 9 representation agreement, or **Non-Standard Representation Agreement**.

Standard Representation Agreement

Limited personal or health care decision-making capacity – The person:

- Must be able to express a preference or wish to have someone help them with decision-making,
- Can demonstrate choices or preferences and feelings of approval or disapproval of others;
- Understands the representative will help, make, or stop making decisions that impact them; and
- Has a relationship characterized by trust with the representative.[19]

Non-Standard Representation Agreement

Full personal and health care decision-making capacity – The person:

- Must understand the nature of the proposed representation agreement, meaning what authority they are giving to the representative; and
- Must understand the possible consequences of the proposed representation agreement, meaning that the representative will make decisions that they have authority to make, such as refusing life supporting care.

Authorities of Representative, if given

Day-to-day financial decisions	**No** financial decisions
Limited legal decisions	**No** legal decisions
Personal care, such as clothing, getting a haircut or exercise	Personal care, such as clothing, getting a haircut, or exercise
Minor health care, such as dental work	Minor health care, such as dental work
Limited major health care, such as surgery, but does not include, among other major health care decisions, consenting to certain forms of experimental treatment, consent to use restraints, or refusal of life supporting care treatment	Major health care, such as surgery but could also include, among other major health care decisions, certain forms of experimental treatments, consent to use restraints, or refusal of life supporting care treatment

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

[19] *RAA*, s 8.

Both provide for health and personal care decision-making authority, but the Standard Representation Agreement has a lower capacity threshold and permits some legal and financial decision-making.[20] This means that a person who has limited capacity of some decision-making can appoint a representative to support them in their day-to-day activities.

For example, a person whose capacity has diminished but can still express opinions and preferences about their care may appoint a representative in a Standard Representation Agreement. The representative can be given the authority to make routine financial management, tax and banking, or other limited decisions such as personal care, and most health care decisions.[21] A representative in a Standard Representation Agreement cannot give or refuse consent to treatment necessary to preserve life.

The Standard Representation Agreement creates a stop gap for those with limited capacity as it is a compromising of the legal capacity to execute the power of attorney and Non-Standard Representation Agreement. If someone has the capacity to make a power of attorney, they could also likely make a Non-Standard Representation Agreement.

A Non-Standard Representation Agreement can be much more inclusive but requires a higher level of capacity. A Non-Standard Representation Agreement 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 refusing or consenting to care that is necessary to preserve life.[22]

A representative under both types of representation agreement has several duties, including to: [23]

- act in good faith;
- exercise reasonable care, diligence, and skill of a reasonably prudent person;
- act within their authority;
- keep records of actions taken under their authority and produce these when requested by the person, the monitor, or the Public Guardian and Trustee;
- keep their assets separate from the person's assets; and
- consult with the person and follow their wishes to the extent reasonable.

If the person living with dementia is not capable, the representative must make decisions based on pre-expressed wishes of the person. If the person has no pre-expressed wishes, the representative must act based on the person's known beliefs. If these are not known, they must act in the person's best interest based on the information provided by the health care provider and the circumstances of the person they are acting for.

3.1.2 Powers of Attorney

A person can appoint an attorney to be their substitute decision-maker before or during incapacity. A power of attorney covers the person's financial and legal affairs, but **not** health or personal care. Financial affairs include routine banking, managing investments, selling assets including real estate, paying taxes, or making gifts or loans – with conditions[24] – 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 such as in a will.[25]

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[20] *RAA*, ss 7 and 8.
[21] *RAA*, ss7(1) and (2).
[22] *RAA*, s 9(3).
[23] *RAA*, s 16.
[24] *Power of Attorney Act*, RSBC 1996, c 370 ("***POAA***"), s 20(1).
[25] *POAA*, ss 10 and 12(1)(c).

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 ("**EPOA**"). 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. A springing power of attorney only comes into effect when a triggering event occurs, such as the person losing capacity or a particular date.

An EPOA is effective once executed and endures even if the person loses capacity, so long as the EPOA states that the authority of the attorney continues where capacity is lost.[26] EPOAs are the most common of the three options and are a focus of this section.

An attorney acting under any power of attorney has several duties, including to:[27]

- 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.

3.1.3 Committees

In circumstances where there is no power of attorney and/or representation agreement and the person living with dementia is no longer able to make informed decisions about themselves or their legal and financial affairs, you may need to apply for a court-appointed substitute decision-maker (a "**committee**") so that there is someone legally able to make personal, health, legal, and/or financial decisions. One person or multiple people can be appointed as committee. A person can be appointed as a committee of **person** – they are only permitted to make personal or health care decisions, like a representative. The same person could also be appointed as committee of **estate** – they are only permitted to make legal or financial decisions, like an attorney. Sometimes, the court will appoint a different person for each.

This should be considered as a last resort as the court will declare the person legally incapable and is a serious outcome that the court does not take lightly. Going through this court process is not ideal as it can be expensive and time consuming but may be necessary when there are no other options. For example, without any legal documents in place, legal and financial institutions, like the bank, insurance companies, or the government, will not let you or anyone else make decisions for the person living with dementia. Appointing a committee can be an expensive and time-intensive court process.

If a committee is needed, it is recommended that you speak with a lawyer as the process requires multiple court documents. It also often removes people living with dementia from the decision as to who will act for them unless they have executed a nomination of committee document; previously identified who they would like appointed; or can participate in the hearing process in some fashion.

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[26] *POAA*, s 14.
[27] *POAA*, s 19.

The committee can make all decisions the person could if capable, except for making a will.[28] Anyone appointed as a committee has two broad duties when acting for the person living with dementia: first, to act in the best interest of the person, and second, to foster the independence of the person and involve them in any decision-making as much as they can.[29]

3.1.4 Statutory Property Guardians

If a person living with dementia 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 someone looking after their property, then the Public Guardian and Trustee may be appointed as statutory property guardian.[30] Such appointment involves notifying the person and, if applicable, their spouse or nearest relative.[31] 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.[32] However, the person being assessed can ask for a review of their certificate of incapability.

The Public Guardian and Trustee, as statutory property guardian, can make decisions regarding the person's financial affairs that a capable person would be able to make, except make a will.[33] The Public Guardian and Trustee is only appointed as statutory property guardian as a last resort.

As statutory property guardian, the Public Guardian and Trustee must meet the same two duties outlined for a committee because the office manages the person's financial affairs as a committee.[34] This means the Public Guardian and Trustee should be consulting with a spouse or a near relative, and involve the person they act for in respect of decisions.[35]

3.1.5 Temporary Substitute Decision-Makers

In health care contexts, a temporary substitute decision-maker ("**TSDM**") can be appointed to make specific health care decisions where a person living with dementia does not have a personal guardian or representative. Their authority is limited to the health care decision at hand. These include both "major" health care decisions (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).[36]

A TSDM does not have authority to make decisions on experimental care (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.[37] TSDMs are also prevented from refusing care necessary to preserve life unless health care providers agree that the decision is medically appropriate.[38]

A TSDM is selected from a ranked list of the person's family members and friends (spouse, child, parent, sibling, grandparent, grandchild, other relatives by birth or adoption, close friend, or persons immediately related by marriage).[39] This can include caregivers but not necessarily. They must be 19 years old, have been in contact with the person in the past 12 months, have no disputes with the person, and be capable of giving substitute consent.[40]

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[28] *PPA*, s 15.
[29] *PPA*, s 18.
[30] *Adult Guardianship Act*, RSBC 1996, c 6 ("***AGA***"), s 32.
[31] *AGA*, 32(3.1)(b)
[32] *AGA*, s 32.
[33] *AGA*, ss 1, 17, and 32.
[34] *PPA*, s 1.
[35] *PPA*, s 18.
[36] *HCFA*, s 1; *HCCR*, s 4.
[37] *HCCR*, s 5.
[38] *HCFA*, s 18 (2).
[39] *HCFA*, s 16 (1).
[40] *HCFA*, s 17 (3).

Since a TSDM is only called upon in situations where a person is unable to give consent and has no appointed representative or committee, it is important to understand that the ranked list is followed strictly. This can create conflict if a caregiver is lower on the ranked list than another person. Being a caregiver does not automatically place a person as the TSDM.

A TSDM must consult with the person living with dementia to the greatest extent possible and comply with any previously expressed wishes.[41] Where previously expressed wishes are not known, a TSDM must decide in the person's best interests, considering:[42]

- their 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.

A TSDM may also consent to a person living with dementia's admission into a long-term care home when there is no representative or personal guardian available.[43]

3.2 Overview of Consent Laws

Giving consent in the health or personal care setting requires a certain level of capacity to make the decision to give consent. Establishing that a person living with dementia can provide informed consent to a particular course of action might include an assessment of their capacity to make the decision. Such decision-making may include the person consulting with a support person (who might be a caregiver), **so long as the person wants a support person present**. Consent to health care and consent to long-term care admission are both explored below.

3.2.1 General Consent

Consent to health care is legislated by the *HCFA*. The *HCFA* begins with the presumption that every person has capacity unless otherwise determined.[44] Health care providers must obtain consent by giving sufficient information on both the proposed treatment and possible consequences, including by ensuring an appropriate method of communication and including a support person, as needed.[45]

Health care providers are required to provide information regarding:

- 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.[46]

In the context of consent, the person should demonstrate, regardless of communication method, that they understand the above four points and can make the decision based on the information provided. This may require re-phrasing the information in different ways, providing a written summary of the information, or coming back at a different time of day. If time permits, you may encourage a health care provider to take the time to understand the person living with dementia and their unique personality, values, and beliefs.

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[41] *HCFA*, s 19 (1).
[42] *HCFA*, s 19 (2)-(3).
[43] *HCFA*, s 22.
[44] *HCFA*, s 3.
[45] *HCFA*, s 8.
[46] *HCFA*, s 6.

It is also important to remember that a decision does not have to conform to what is externally viewed as a "good decision". All people have the right to make what we may see as "bad decisions" so long as they have enough information to understand the decision and the possible consequences before making the decision. This exercise of personal autonomy must be respected. As a caregiver or care partner, it is important to advocate for the person you are supporting by ensuring their decision-making rights are respected – even when you do not agree with them.

Advance Directives

As a caregiver or care partner, it is important to be aware of any advance directives and bring them to the attention of health care providers. A person may give or refuse consent to a range of health care treatments in an advance directive, except for a very specific group of treatment options, such as experimental treatment where the risk is greater than the benefit.[47] An advance directive must have been made by a capable person, must be in writing, and signed in the presence of witnesses.[48]

Health care providers may provide care if the person has given consent in an advance directive. However, they must not provide care if the person has refused consent in an advance directive.[49] Health care providers are not required to make more than a reasonable effort to determine whether the person has an advance directive.[50]

Advance directives do not apply if:[51]

- 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 consent from a substitute decision-maker, 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.[52]

3.2.2 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.[53] A person may also state in a representation agreement that a health care provider can act on an instruction in an advance directive without consent from their representative.[54]

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[47] *HCFA*, s 9 (1.1).
[48] *HCFA*, ss 19.1, 19.4
[49] *HCFA*, ss 19.7 (2).
[50] *HCFA*, ss 19.7 (3).
[51] *HCFA*, ss 19.8.
[52] *HCFA*, ss 19.8 (2)-(3).
[53] *HCFA*, ss 19.3 (1) (b).
[54] *HCFA*, ss 19.3 (2).

3.2.3 Consent to Restraint Use

As a caregiver or care partner, you may also be called upon to provide substitute consent to the use of restraints. Use of restraints is guided by the HCFA and can occur either by physical or prescribed means.[55] Prescribed means include restraining a person either by chemical, electronic, mechanical, or other means, or by placing the person in a secure unit.[56] The manager of a long-term care home 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.[57] 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.[58]

Further, *Residential Care Regulations* are often engaged depending on the licensing of the long-term care home.[59] 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.[60] 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.[61]

3.2.4 Medical Orders for Scope of Treatment

A person living with dementia and a health care provider may discuss the different goals and preferences for their care plan, including whether they would like to be resuscitated and in which situations. This conversation is then recorded on what is called a “medical orders for scope of treatment" designation form, or a **MOST**. The MOST is then saved on a system that other health care providers can access if the person living with dementia receives care from a different health care provider. As a caregiver, it is important to know if the person living with dementia has completed a MOST with their health care provider.

As with other forms of consent, a person living with dementia gives consent to different types of treatment and in different scenarios when completing the MOST with their health care provider. Health care providers should presume that a person living with dementia is capable of giving or refusing consent to the treatment discussed in the MOST. If a person living with dementia cannot reliably consent to complete the MOST, the health care provider will see if the person has an advance directive. If the person does not have an advance directive or it does not address the particular treatment, the health care provider will talk to the substitute decision-maker to determine the scope of treatment for the MOST.

[55] *HCFA*, s 26. 1(1).
[56] *HCCR*, s 23.
[57] *HCFA*, ss 26.1(2) and (3); HCCR s 23.
[58] *RAA*, s 9(1)(b)(viii).
[59] *Community Care and Assisted Living Act*, SBC 2002, c 75 (“***CCALA***”); *RCR* at s 2(2)(c).
[60] *RCR*, s 74(1)a).
[61] *RCR*, s 74(1)(b).

Consent to Long-Term Care Admission

Admission to long-term care is a difficult decision at the best of times. It is also governed by the *HCFA*. Much like consent to health care, the involvement of the person living with dementia in the decision to transition to long-term care depends on their capacity. A person is presumed to have the capacity to make the decision to move to long-term care.[62]

To start the transition to a long-term care home, an application is made by the person living with dementia or someone else on their behalf to a manager or board of the proposed home. In helping the person living with dementia 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 home;
- the services the long-term care home will provide to the person; and
- the circumstances under which the person may leave the long-term care home.[63]

Understanding the weight of the decision is essential 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 significant change in their lifestyle. It is also necessary to listen to the concerns of the person – these concerns are valid, even if they seem out of context to you as caregiver. As a person is presumed to have capacity, their participation in the process requires the health care provider to engage in a capacity assessment of the person.

Much like consent to care, communication must be accommodated to the extent possible.[64] To ensure full involvement in decision-making regarding the move into long-term care, health

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[62] *HCFA*, s 3.
[63] *HCFA*, s 21(1)(d).
[64] *HCFA*, ss 21(2) and (3).

care providers may need to facilitate a visit or tour of the long-term care home. As a caregiver, it is important that you advocate for these opportunities to support making an informed decision.

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.[65]

The conduct of the capacity assessment is prescribed in the *Health Care Consent Regulation*.[66] 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 the person cannot provide consent, a substitute decision-maker (which may include a caregiver) may step in to provide consent.[67]

There are also special provisions relating to licensed care homes under the *Residential Care Regulation*.[68] The Residential Care Regulation specifies that if an incapable person in care expresses a desire to leave a community care home, 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.[69] However, health care providers are not required to do this if substitute consent to the continued accommodation of the person in care has been obtained in the last 90 days.[70]

4.1 Decision-Making in Long-Term Care

Long-term care and assisted living environments have been described as having a governing care structure that poses barriers to the decision-making of people living with dementia.

This may be due to some long-term care homes facing resource shortages or competing priorities over the decision-making rights of the person living with dementia.[71] However, such a shift in priorities prevents people living with dementia from making decisions they would otherwise be able to make in a different environment.[72] For example, if a long-term care home is understaffed on a particular day, they may not be able to fully engage supported decision-making strategies when assisting a person get ready for the day. Alternatively, the long-term care home may recognize a fall risk, but the person does not appreciate the risk of walking unassisted or may simply refuse to use a walking aid. In that scenario, some long-term care homes may prioritize the safety of the person over the decision to walk at risk.

As a caregiver, you may be required to advocate for the decision-making rights of the person living with dementia in long-term care environments, sometimes in contradiction to the leadership of the long-term care home. This may sometimes require you to interact more with the health care providers than you normally would – one way to advocate is by joining a family council.

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[65] *HCFA*, s 26(1); *Health Care Consent Regulation*, BC Reg 20/2000 (“***HCCR***”), at s 16.

[66] *HCCR*, ss 17 – 21.

[67] *HCCR*, s 17.

[68] *Residential Care Regulation*, BC Reg 96/2009 (“***RCR***”), s 50

[69] *RCR*, s 50 (2)

[70] *RCR*, s 50 (4) (b).

[71] CCEL, 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 (pdf): <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 (pdf): West Coast LEAF <www.westcoastleaf.org/roads/> (“**WCL, Roads to Safety**”);, ***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> (“**BCLI Common Law Capacity**”).

[72] Adult Guardianship Act, RSBC 1996, c 6; Patients Property Act, RSBC 1996, c 349.

4.2 Family Councils

As a caregiver, you might also become a member of a family council, which is a group of persons (including residents who are living with dementia, their family members or caregivers, and their representatives) who meet regularly to represent the collective needs and interests of residents to long-term care staff and management.[73]

Becoming involved in a family council is an important avenue to advocate for the decision-making rights of people living with dementia living in long-term care homes. This can include advocating for:

- **Greater collaboration** between long-term care staff, people living with dementia, and their caregivers;
- **Promoting different communication approaches** to facilitate involvement of people living with dementia in decision-making;
- **Recommended decision-making training for health care providers in long-term care homes** on issues such as cultural humility and safety and trauma-informed care, among others.

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[73] "Resident and Family Councils" (last visited 09 August 2023), online: *British Columbia* < www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/family-and-resident-councils>.

RESOURCES

Alzheimer Society of B.C.

https://alzheimer.ca/en/help-support/im-caring-person-living-dementia

https://alzheimer.ca/bc/en/help-support/programs-services/support-groups/family-caregiver-support-groups

https://alzheimer.ca/en/help-support/im-living-dementia/living-well-dementia/helping-others-live-well-dementia

Family Caregivers of BC

https://www.familycaregiversbc.ca/get-help

Flipping Stigma

https://www.flippingstigma.com/

Government of BC

https://www2.gov.bc.ca/assets/gov/people/seniors/health-safety/pdf/myvoice-advancecare-planningguide.pdf

Government of Canada

https://www.canada.ca/en/employment-social-development/corporate/seniors/forum.html

HealthLink BC

https://www.healthlinkbc.ca/health-topics/caregiver-tips

https://www.healthlinkbc.ca/illnesses-conditions/dementia/dementia-support-caregivers

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/

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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Alzheimer Society
BRITISH COLUMBIA

Family Caregivers
of British Columbia

CRPiD
CENTRE FOR RESEARCH ON PERSONHOOD IN DEMENTIA

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.

Our Funders

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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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