



The journey of dementia is different for every person, including family and friend caregivers and care partners and the person living with dementia. Just as each person's experience is different, so are the decisions they need to make and the strategies that best support them. There are often words that have special meaning in the law that apply to our rights to make decisions about our lives. This information sheet provides a brief overview of some of the most common words you may hear in relation to decision-making rights with a view to understanding decision making as it relates to dementia.

Words You May Hear from a Health Care or Legal Professional

The Canadian Centre for Elder Law's Dementia + Decision-Making project encompasses a range of resources designed to help caregivers, care partners and health care providers support people living with dementia to participate in decisions regarding their care and well-being. Please see www.bcli.org/ccel-projects/dementia-decision-making-project/ web page for a full list of materials and resources.



The 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** webpage www.bcli.org/ccel-projects/dementia-decision-making-project/

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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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Words You May Hear from a Health Care or Legal Professional



Consent

When you act as a substitute decision-maker for a person in the care setting, you may be asked to give, refuse, or withdraw consent for treatment for that person. Because you are acting for another person, your decision about the treatment is treated as though it is the person making the decision for themselves. Giving consent means you are agreeing to the treatment. You should ask questions and get as much information as possible, so you understand the risks and benefits are for the person if you say yes or no on their behalf.

Supported Decision-Making

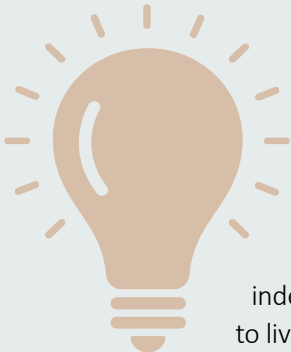
Supported decision-making means giving a person the support they need to make decisions for themselves. Supported decision-making has two key parts – 1) helping the person to understand the decision in a way suited to them, and 2) ensuring that others understand the person and respect their decision. This support may include explaining the roles of other people involved in a decision, researching the decision, or explaining information to them in a way they can understand. You may find you have to speak up for the person when you feel like their voice is not being heard or help explain on their behalf.



Substitute Decision-Making

When a person no longer has capacity to make decisions for themselves, a substitute decision maker can be appointed to make decisions on behalf of that person. Even where a substitute decision maker is appointed, they still must consult with the person living with dementia. A health care provider should be careful to only use the consent of a substitute decision maker where it is clear that the person can no longer make decisions for themselves. The following are different types of substitute decision-makers.

Autonomy



Autonomy is our right to make decisions for ourselves based on our values, beliefs, and information. For a person living with dementia, this includes decisions related to their independence in how they want to live. It also includes making decisions about their care even if they need support in making decisions.

Attorney

An attorney is someone with the legal right to be a substitute decision-maker because the person they act for appointed them in a power of attorney. An attorney can make financial and legal decisions for the person that they represent; they do not have the power to make any personal or health care decisions. If you are an attorney and you need to decide for another person, you must always try to involve the person. If you have tried to engage the person but they are unable to participate, you should think about what they would have wanted if they could make the decision for themselves.



Advance Directive

An advance directive is often referred to as a living will. A person can provide instructions to health care providers and/or their representative about the type of care they are to receive and under what circumstances, such as refusing blood transfusions or whether or not to receive life-saving treatments. It is important that these documents are detailed and provide enough information to make sure everyone engaged in the person’s care understands what the person wants, and in what circumstances.

Committee

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). A committee may be needed if a person does not have an attorney or representative, but decisions must be made on behalf of the person. The application process requires documentation for the court to determine if a person is no longer legally capable and unlikely to regain their capacity. It can be stressful, expensive, and time consuming.

Temporary Substitute Decision Maker

If a person does not have a representative or committee and they are not able to make health care decisions for themselves, a temporary substitute decision maker is selected from a list of possible people defined in BC law. The list, in order of priority, is spouse, child, parent, sibling, grandparent, other relative, close friend, and then in-law. They only decide about the specific treatment in that moment and then their authority ends. To avoid this situation, it is recommended that a person put in place a representation agreement

Assessment

When a health care professional, lawyer or notary meets with a person to determine if they are capable, it is called an assessment. In the legal setting, the legal professional is assessing whether a person can sign a legal document, such as a representation agreement.



Representative

A representative is someone appointed by a capable person in a representation agreement to be a substitute decision-maker for care decisions. There are two types of representation agreements. A section 7 representation agreement can cover health care, personal care, routine financial affairs, and legal decisions. A section 9 representation agreement can cover health care and personal care, but not routine legal or financial decisions. If you are a representative and need to decide for another person, you must always think about what that person would have wanted if they could decide for themselves. When you do not know, you must think about the best interests of the person. Best interests are discussed in our “Things About the Law for a Caregiver to Know” at number 6.