

You've been asked to be a substitute decision maker, now what?

A guide to help you understand the role of a substitute decision maker in making care decisions for another person

Who is this guide for?

This guide is designed to help you understand the role of substitute decision makers in making health-care and personal-care decisions for another person. This document will cover two common types of substitute decision makers in British Columbia: **representatives** and **temporary substitute decision makers**.

It includes information about:

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What is a substitute decision maker?

If an adult needs to make a decision about a health care or personal care option, but isn't capable of decision making, someone close to them will be asked to make the decision for them. This person is called a **substitute decision maker**.

Decision making can include accepting or refusing:

- **Health care options**, which may include treatments, procedures, medications, vaccines, examinations, or tests.
- **Personal care options**, which may include place of living, diet, clothing, personal hygiene, employment, and other daily activities.

Note: this guide doesn't cover decisions about admission to a care facility (eg. assisted living home, long-term care home, hospital). The laws about these decisions are different. You can find more information from the Public Guardian and Trustee of British Columbia: <https://www.trustee.bc.ca/Documents/adult-guardianship/CFA%20and%20the%20Role%20of%20the%20PGT.pdf>

Two common ways you can become a substitute decision maker:

1. Being appointed by someone in a representation agreement.
In this legal document, you are called a **representative**.
2. Being appointed by a health-care provider to act as a **temporary substitute decision maker** according to a list defined by law.

You can be an appointed representative for a person, and be a potential temporary substitute decision maker for other people. [Pages 7 to 9](#) provides more information about representatives and temporary substitute decision makers, including how they're appointed, how they differ from each other, and the kinds of decisions they can make for a person.

A temporary substitute decision maker will be appointed if a person doesn't have any other substitute decision making options in place (e.g., committee, representative, or advance directive). Refer to the [flowchart on page 17](#) for an overview of health-care substitute decision making options.

What does it mean to be capable of making a decision?

Being capable of making a specific health-care decision means that a person:

- understands the information provided to them about a care option, including its purpose, benefits, and potential risks;
- understands that the information applies to them; and
- can communicate their consent to or refusal of the care option voluntarily.

This is also known as being able to give **informed consent** (or refusal) to a proposed health-care option.

Capability isn't determined by how the person communicates. Everyone has a right to receive assistance in understanding and communicating their decisions. For example, if a person speaks a different language, a language interpreter can help them communicate. If a person is non-verbal, they can communicate using head nodding and body language.

A person's capability is decision-specific and may fluctuate from time to time and day to day. For example, a person may not be capable of making a decision about surgery but may be capable of refusing a medication. A person living with dementia may be capable of making a decision in the morning but not in the evening.

Capability can be impacted by:

- | | |
|--|---|
| <ul style="list-style-type: none">• environmental factors:<ul style="list-style-type: none">- time of day- noises and distractions• emotional wellbeing:<ul style="list-style-type: none">- exhaustion- grief or depression- stress and anxiety• a developmental disability | <ul style="list-style-type: none">• physical wellbeing:<ul style="list-style-type: none">- medications- pain or discomfort- accident or injury- surgery- progression of a serious illness (eg. dementia, kidney disease, heart failure) |
|--|---|

Note: another term for “capability” you may have come across in other resources is “capacity”. Both are legal terms and are interchangeable.

How is capability assessed?

A person is presumed to be capable unless proven otherwise.

Capability is decision-specific, meaning it's determined at the time of the decision, and in relation to the decision being made.

An incapability assessment is done only if there are legitimate reasons to believe the adult does not have the ability to make a decision. The assessment can be completed by a health-care provider, social worker, or another professional with expertise in assessing capability.



What is supported decision making?

A person who is capable of making a specific decision doesn't need a substitute decision maker. The person can make the decision independently, or with support from the people they trust. This is known as supported decision making.

Everyone has a right to receive support in their decision making to help them:

- understand the information provided, and
- communicate their wishes.

What is the role of a substitute decision maker?

A person who is assessed to be incapable of making a specific decision, even with support, needs a substitute decision maker to make the decision for them. The person still has the right to be involved in the decision-making process **to the greatest extent possible**.

A good substitute decision maker is someone who:

- knows the person well, and understands their values, beliefs and wishes for health care and personal care;
- honours the person's wishes and instructions when making decisions for them (this is their legal role), even if the person's wishes are different from their own;
- can communicate with health-care providers, advocate for the person, and not be pressured into accepting care options that the person wouldn't want;
- is calm in a crisis;
- can handle conflict or disagreement; and
- is willing and available to take on the role.

To perform your role, you need to know the person's values, beliefs, and wishes for future health care and personal care. This information can help you make the right decisions for the individual. See [page 10](#) for how to prepare for your role.



What decisions can a substitute decision maker make for another person?

1. Representative

A substitute decision maker legally appointed by a person in a representation agreement to make **health-care** and **personal-care** decisions.

There are two types of representation agreements:

Enhanced (also called Section 9)	Standard (also called Section 7)
Can be made by an adult who can understand the nature and consequences of the agreement. Click here to learn more.	Can be made by an adult even if they have some trouble understanding information. Click here to learn more.
Can be used to appoint one or more substitute decision makers .	Can be used to appoint one or more persons to provide substitute decision making <u>or</u> supported decision making .
Representative can make health-care and personal-care decisions , including decisions to: <ul style="list-style-type: none">• refuse life-supporting care or treatment;• admit the person to a care facility;• physically restrain, move, or manage the person.	Representative can make health-care and personal-care decisions , but cannot make decisions to: <ul style="list-style-type: none">• refuse life-supporting care or treatment;• admit the person to a care facility;• physically restrain, move, or manage the person.
Representative cannot make legal and financial decisions . An enduring power of attorney and/or a standard representation agreement can be used for this.	Representative can make routine legal and financial decisions for the person as outlined in the representation agreement.

A person can limit the decisions they want their representative to make in a representation agreement. For example, in a standard representation agreement, a person can specify that they only want their representative to make personal-care decisions.

A person can also appoint more than one representative. Appointed representatives must act unanimously on all decisions unless the representation agreement states otherwise.

2. Temporary substitute decision maker

A substitute decision maker chosen by a health-care provider to make health-care decisions.

A temporary substitute decision maker will only be appointed if a person doesn't have other substitute decision making options. See the [flowchart on page 17](#) for an overview of the other options (committee, representative, advance directive).

In B.C., there's a legally defined list of potential temporary substitute decision makers. The treating health-care provider will start at the top of this list and work down until they identify someone who qualifies and is willing to accept the role:

1. Spouse, including same sex partners and common-law, (the length of time living together doesn't matter)
2. An adult child (equally ranked)
3. A parent (equally ranked)
4. A sibling (equally ranked)
5. A grandparent (equally ranked)
6. A grandchild (equally ranked)
7. Anyone else related by birth or adoption
8. A close friend
9. A person immediately related by marriage

If you are on this list and meet the qualifications, you may be asked to temporarily make health-care decisions for the person.

To qualify, you must:

- be 19 years of age or older,
- be capable of making decisions,
- have no dispute with the person, and
- have been in contact with the person during the past 12 months.

If you cannot be reached or decline to take on this role, the health-care provider will contact the next available, qualified person on the list.

The health-care provider will contact the Public Guardian and Trustee if:

- no one from the list can be reached or qualifies, or
- there's dispute between two equally ranked people on the list and the health-care provider cannot resolve the conflict.

For more information on the role of the Public Guardian and Trustee, visit:

<https://www.trustee.bc.ca/Documents/adult-guardianship/Consent%20to%20Health%20Care.pdf>.

Health-care providers will repeat this process for every set of decisions that need to be made.



Preparing for your role as a substitute decision maker

1. Talk with the person about their wishes

This is a critical part of your role as a substitute decision maker.

To **the greatest extent possible**, have early and ongoing conversations with the person about their values, beliefs, and wishes for health care and personal care.

This can include topics such as:

- What matters most to the person?
- What's important to the person for their quality of life?
- What likes and dislikes does the person have?
- What life-supporting treatments would the person accept or refuse in emergency situations?

For example:

- Cardiopulmonary resuscitation (CPR) for a person whose heart has stopped beating.
- Breathing tube and machine (ventilator) for a person who cannot breathe on their own.

If the person agrees, other trusted family members and close friends, (especially the person's potential temporary substitute decision makers) may be invited to join the conversation. The more people who know about these wishes, the more support the person can receive when decisions have to be made. These conversations can also help to reduce misunderstandings, conflict, and stress.

Tips for these conversations:

- Pick a time when the person is the most comfortable, relaxed, and alert.
- Pick a location that's free of noise and distractions.
- Be gentle and go slowly. These conversations touch on sensitive topics that can make people feel vulnerable and can be difficult to talk about.
- Be open to having several shorter conversations. It may take a few attempts to get going and get comfortable. Shorter conversations will also allow time for processing and reflection in between.
- Recognize that the person can change their mind at anytime. This is why these conversations should be ongoing and not be a one-time event.

Tools you can use to support these conversations:

1) For an adult who is able to make all or some of their own decisions:

- [My Wishes, My Care: Thinking It Through](#): A step-by-step guide to help the person think about and record what matters most to them. If needed, and if the person agrees, you can offer your support to help them complete the booklet.
- [My Wishes, My Care: Starting the Conversation](#): A list of questions you can discuss with the person to learn about their values, beliefs, and wishes. You can each answer the questions from your own perspectives to learn about each other.

2) For an adult who has been assessed to be incapable of making their own decisions:

Have conversations with family members and close friends who know the person well and whom the person trusts. Use the questions at the beginning of this section. Together, you could also complete the [My Wishes, My Care: Thinking It Through](#) guide.

It's important to ask yourself: **how would the person answer these questions?**

2. Talk with the person's health-care provider(s)

If the person agrees, support them in having conversations with their health-care providers to understand:

- the person's health condition(s);
- their health-care treatment options, including the benefits and risks;
- any changes in health that are anticipated;
- any questions you or the person may have about life-supporting treatments;
- any other information that is relevant to the person's health-care needs.

This information will inform the person's wishes, especially about health-care options.

Tips for these conversations:

- Book an appointment and let the health-care provider know the purpose of the visit ahead of time.
- Write down a list of questions ahead of time.
- Take notes during the appointment so there is a helpful record for you both to refer to.

3. Continue the conversations!

It's important to continue having conversations and review the person's wishes regularly (yearly, for example).

More frequent conversations with the person and their health-care providers may be needed if there's:

- a change in the person's health;
- a diagnosis of a serious illness;
- a change in your relationship with the person.

If the person has written or recorded their wishes, make sure you know where the most up-to-date version is.

Accepting your role as a substitute decision maker

You can always decline to take on the role of a temporary substitute decision maker or representative.

If you accept your role as a substitute decision maker, it means that:

1. **You must follow the person's wishes**, including anything they said or wrote down when they were capable. You must also talk to them about their wishes to the greatest extent possible.
2. **You must adhere to the responsibilities of a substitute decision maker** outlined in this document and in B.C. law. You must also act honestly and in good faith.
3. **You are accountable for the decisions you made for the person.** You may be asked to justify your decisions to the person and to organizations responsible to safeguard incapable adults such as the Public Guardian and Trustee, Health Authorities and Community Living B.C.
4. **You must keep records** of the decisions you made and actions you took for the person while acting as a substitute decision maker.
5. **You cannot ask someone else to make decisions for the person.** But you can ask for support from other family members or the health-care team.
6. **You must keep the person's information confidential** except when necessary, such as to carry out your duties or provide information requested by a government official or court.



Your rights as a substitute decision maker

As a substitute decision maker, you have the right to:

- **Communicate with the person you represent.** You have a right to visit them and talk to them about what they want, and how they are doing.
- **Access information.** You have a right to the same information and records the person who chose you has a right to, as long as these are related to your area of authority. This means the person's health-care providers must answer your reasonable questions about health, prognosis and options. This information allows you to make an informed decision.
- **Get help and advice.** You can seek and hire help and advice to carry out your responsibilities.
- **Be protected from liability.** You'll not be legally responsible for errors or damages as long as you follow your duties.
- **Refuse to make a decision if you're not comfortable with doing so.** The health-care provider will follow the [flowchart on page 17](#) to find the most appropriate substitute decision maker.
- **Resign from your role.** A representative can resign through a notice of resignation. You can find more information about resigning as a representative or alternate here:
http://www.nidus.ca/PDFs/Nidus_Info_Resign_Rep-Alt_RA.pdf

If you are appointed as a **representative**, you have the **additional** right to:

- **Be paid for out-of-pocket expenses.** You have a right to be refunded for reasonable expenses resulting from carrying out your duties. Keep a record of expenses and payments.

How to make a decision for another person as their substitute decision maker

Remember, a person's presumed to be capable of making decisions unless proven otherwise, even if they have a representative.

You should only be asked to make a decision on behalf of a person if they have been assessed to be incapable of making the decision independently, or with support. The person continues to have a right to be involved in the decision-making process to the greatest extent possible.

Here are some steps to follow when you're making a specific decision for another person:

1. Talk with health-care provider(s)

Talk with the person's health-care provider(s) to understand the decision that needs to be made, including:

- the person's current health situation;
- the nature of the proposed care option;
- the benefits and risks of the care option;
- alternative courses of health care (or other care options).

Involve the person in these conversations to **the greatest extent possible**.

2. Talk with the person about their current wishes

To the greatest extent possible, talk with the person about the decision that needs to be made to:

- help them determine their **current wishes**, which can be expressed orally, in writing, or may be inferred from body language (e.g., head nodding); and
- comply with their expressed wishes if it's reasonable to do so.

3. Review the person's expressed wishes

If you cannot determine the person's current wishes, think about previous conversations you have had with the person, and review any records.

If their wishes for the decision are known, you must follow those wishes.

A capable person's wishes remain valid even if they become incapable later on.

4. Consider what's in the person's best interests

If the person's wishes for the decision are not known, you must consider whether the proposed care option is in the person's best interests.

To do so, you should consider:

- the person's known beliefs and values,
- whether the person's health or well-being is likely to be improved by the proposed care,
- whether the person's health or well-being is likely to improve without the proposed care,
- whether the benefit of the proposed care is greater than the risk of harm, and
- whether a less restrictive or less intrusive form of care would be as beneficial to the person.

Remember, you always have the option to talk to other people who know the person's wishes. Reach out to the person's support network for help.

You don't have to do this alone!

Health-Care Decision Making in British Columbia*

This flowchart shows how substitute decision makers fit into a person's health-care decision-making process. Note that the word "you" in the flowchart refers to the person.



Are you capable of giving informed consent independently, or with support** from the people you trust?

If you are capable, your health-care provider must directly ask **YOU** for consent.



If you are **incapable** of giving informed consent, your health-care provider will first ask your...



Committee

A person or body appointed by the B.C. Supreme Court to make personal, medical, legal, or financial decisions for you, if you become incapable of making these decisions on your own.



If you **don't** have a Committee



Representative

A person appointed by you, in a Representation Agreement, to make health-care and personal-care decisions for you if you cannot make these decisions on your own.

If you also have an Advance Directive, your Representative will be asked to make the decision, but they must consider the instructions in your Advance Directive.



If you **don't** have a Representative or if your Representative is unable to make the decision



Advance Directive

This is not a person but is a legal document that includes instructions from you to your health-care providers about specific health-care treatments that you accept or refuse. Your Advance Directive must be clear and relevant to the situation to be used.



If you **don't** have a Representative or an Advance Directive that applies to the decision being made



Temporary Substitute Decision Maker

A person identified by your health-care provider from a list defined by law as the first person to qualify as your temporary decision maker for health care.

*This information doesn't apply to a person who is receiving care and treatment at a designated facility under the [Mental Health Act](#).

**The person has the right to receive support in their decision making to help them understand the information and communicate their wishes. Needing support doesn't mean that the person is incapable.

The above was adapted from People's Law School:
www.peopleslawschool.ca/temporary-substitute-decision-makers/.

Things to Remember

- Have early and ongoing conversations with the person about their values, beliefs, and wishes for health care and personal care.
- Making decisions is never easy, and it can be difficult to know if you've made the right choice. What can help in this process:
 - Stay calm.
 - Think about the conversations you've had with the person, and consider what matters most to them for their quality of life.
 - Ask for help from other family members or friends
 - **you don't have to do this alone!**

Resources

- Conversation starter guides:
 - *My Wishes, My Care: Thinking It Through:*
<https://bc-cpc.ca/wp-content/uploads/2021/03/My-Wishes-My-Care-Thinking-it-Through.pdf>
 - *My Wishes, My Care: Starting the Conversation:*
<https://bc-cpc.ca/wp-content/uploads/2021/10/Questions-Worksheet-V2-Full-List-of-Questions.pdf>
- Guides about representation agreements:
 - About the standard representation agreement (section 7):
https://bc-cpc.ca/wp-content/uploads/2021/11/RA7-Guide_SPREAD.pdf
 - About the enhanced representation agreement (section 9):
<https://bc-cpc.ca/wp-content/uploads/2021/03/RA9Doc1-General.pdf>
- **For more information and resources, visit: bc-cpc.ca/acpresources**

Please note: the information presented in this booklet is specific to adults living in British Columbia, Canada. It does not constitute legal advice.

This document was developed by the BC Centre for Palliative Care, a non-profit organization in British Columbia. Contact us at office@bc-cpc.ca.

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