Ontario
Palliative Care
Network

Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent

Frequently Asked Questions (FAQ)

1 Why are Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent conversations important?

Having these conversations will help to prepare your future Substitute Decision Maker(s) (SDMs) to make decisions on your behalf, if you are not able (capable) to make them for yourself. They also help to make sure that your treatment decisions are based on your wishes, values, and beliefs for your care now and in the future.

2 How do Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent conversations differ?

Advance Care Planning is a two-step process that should be completed when healthy. It includes:

- Confirming your Substitute Decision Maker, and
- Discussing your wishes, values, and beliefs with your Substitute Decision Maker.

The information shared with your Substitute Decision Maker is used to help them make future health care decisions if you are not capable (able) to make them yourself.

Goals of Care conversations focus on making sure you understand the nature of your illness, and help healthcare providers (e.g., nurse, doctor, or social worker) understand the goals you have for your care. They help prepare you to make treatment decisions, and provide informed consent.

Anytime a healthcare provider offers you treatment, you or your Substitute Decision Maker (if you are not capable) must give informed consent (permission) for that treatment.

To get your informed consent (permission), healthcare providers must give you information about:

- What is involved in the treatment;
- Expected benefits, risks, and side effects;
- Any different treatment options; and
- What may happen if you refuse the treatment.

Your healthcare provider will then help you (or your SDM) to make a decision based on your wishes, and goals of care.

3 I am not near the end-of-life – why are you telling me about Advance Care Planning?

You can't predict how and when you'll become seriously ill and unable to communicate your wishes. If you are an adult, you should engage in the process of Advance Care Planning. You can change your wishes as often as you like, and as your life changes. You may want to write them down, but the most important thing is to share your wishes with the person or people who will make decisions for you when you can't as they will be asked to give or refuse consent to treatment when you are unable. Please visit the Speak Up Ontario website at speakupontario.ca for additional information and patient resources.

4 Who is my Substitute Decision Maker?

A Substitute Decision Maker is a person who makes treatment decisions on your behalf if and when you are not capable (able) to make these decisions for yourself. Please see pages 2-3 for more information about confirming your Substitute Decision Maker.

Ontario
Local Health Integration
Network

Ontario
Cancer Care Ontario

5 Who can be a Substitute Decision Maker?

To be a Substitute Decision Maker (SDM), the person must:

- be 16 years or older
- be capable of providing consent
- be willing to accept the role as your SDM
- be available when decisions need to be made
- not be prevented from accessing you by a court order or separation agreement

6 I am not comfortable with who my automatic Substitute Decision Maker is, how do I choose a different person?

This is a common concern. For example, some patients may want only one of their children as their Substitute Decision Maker, instead of all of them, or may want to have their child instead of their spouse. This can be done. If you want to choose a different person as your Substitute Decision Maker, you will need to prepare a Power of Attorney for Personal Care free of cost. In this case, an "attorney" does not mean a lawyer. This will let you name someone who will make decisions for you if you are not able to. You can download the form and find more information on the Ministry of the Attorney General website at https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf.

7 Who is supposed to interpret my wishes if I am not able to make decisions myself?

If you are not able (capable) to make a treatment decision, your Substitute Decision Maker will decide whether to give or refuse consent (permission).

While healthcare providers can help with the process when needed, your wishes should be interpreted by your Substitute Decision Maker.

CONFIRMING YOUR SUBSTITUTE DECISION MAKER

A Substitute Decision Maker is the person who will make decisions about your care and treatments if you are too sick and unable (not capable) to make them for yourself

By Ontario law, everyone has an **automatic** Substitute Decision Maker following the order in the list to the right (see lines 4 to 8). People at the same level in the list share decision-making responsibility.

If you do not have a spouse or partner, but have three children, all three are your Substitute Decision Makers, and they would all share responsibility for decision-making. This can sometimes be stressful for families. Any of the children can choose not to act as a Substitute Decision Maker. They should decide together who will be responsible for decision making.

To name just one person (or to name a person who is not your automatic Substitute Decision Maker), you need to prepare a **Power of Attorney for Personal Care**. The diagram on page 3 can help you decide if this is relevant to you.

List of Substitute Decision Makers

1. Court appointed guardian
2. Attorney named in a Power of Attorney for Personal Care
3. Representative appointed by the Consent and Capacity Board

IF LEGALLY
APPOINTED

4. **Spouse or partner**
5. **A child or parent**
6. **A parent who only has right of access**
7. **A sibling**
8. **Any other relative**

★
AUTOMATIC
Family member Substitute Decision Makers

(9.) If none on the list meets the requirements to be the Substitute Decision Maker, the office of the Public Guardian and Trustee will make healthcare decisions. They will also step in if two or more SDMs at the same level cannot come to an agreement.

8 How Will My Substitute Decision Maker Make a Decision For Me?

To make a decision, the Substitute Decision Maker must follow any wishes about future care that you expressed when you were still able (capable). They should follow the last known wishes, because your wishes can change as your health condition changes. If the wishes do not apply, or are not possible to follow, they will make a decision in your best interest. The wishes, values and beliefs you share with them will help them to understand you, how you make choices, and what you think is important.

9 Who should set my Goals of Care?

You should set your own Goals of Care. You may need assistance from one of your healthcare providers or a family member or friend but it is your goals and values that matter. For example, your goals could be things like: keeping up with your social life, continuing to work, avoiding pain, going to an important family function, passing away at home, avoiding the hospital, not being a burden to friends or family, or living in your own home for as long as possible. If you are not capable (able), your healthcare providers will discuss your Goals of Care with your Substitute Decision Maker.

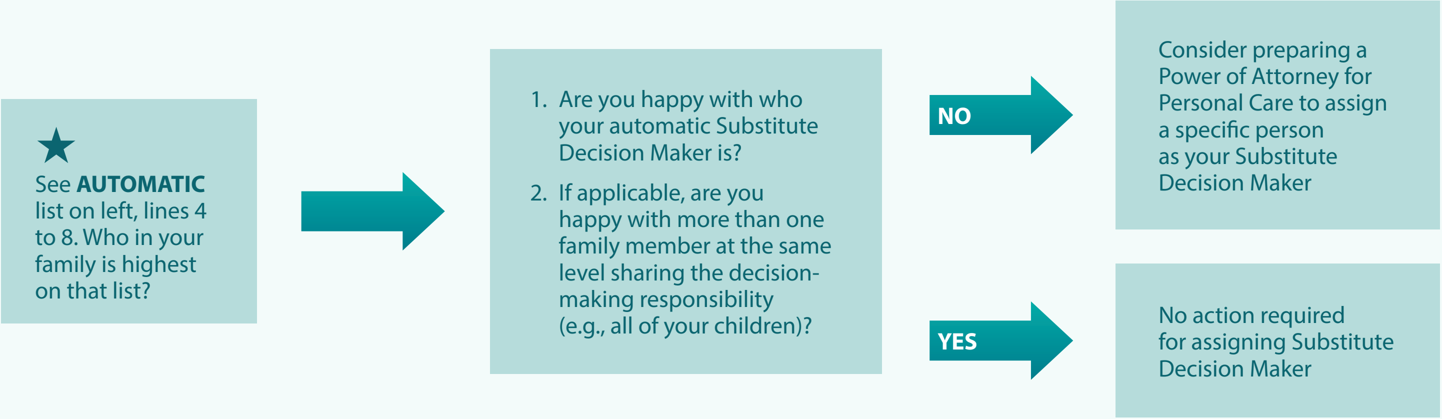
10 What is a Plan of Treatment?

A Plan of Treatment summarizes the treatment decisions you make with your healthcare providers. It includes information about the treatment you may need, and what treatment you would want or not want.

11 How is a Plan of Treatment different from Advance Care Planning?

A Plan of Treatment gives you or your Substitute Decision Maker an opportunity to give permission (consent) to treatment taking place in the future based on your current condition. This is different from you expressing wishes for future care (Advance Care Planning), where you do not have all of the information about your health condition.

How to confirm your Substitute Decision Maker



★ See **AUTOMATIC** list on left, lines 4 to 8. Who in your family is highest on that list?

1. Are you happy with who your automatic Substitute Decision Maker is?
2. If applicable, are you happy with more than one family member at the same level sharing the decision-making responsibility (e.g., all of your children)?

NO Consider preparing a Power of Attorney for Personal Care to assign a specific person as your Substitute Decision Maker

YES No action required for assigning Substitute Decision Maker

You can prepare a Power of Attorney for Personal Care for free through the following website:
https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf

Your healthcare providers can help you complete it. Through this website you can get a wallet-sized card that says who your Power of Attorney for Personal Care is. Carry this with you at all times, including during healthcare visits.

---

1. *Health Care Consent Act, 1996, SO 1992; c 2, s.20.*
2. *Reference: Advocacy Centre for the Elderly (ACE). Tip Sheet #2—HIERARCHY of Substitute Decision Makers (SDMs) in the Health Care Consent Act. 2013 Sept [cited 2017 Apr 18]. Available from: http://www.acelaw.ca/appimages/file/Tip Sheet TWO - Hierarchy of SDMs FINAL Sept 2013.pdf.*

⑫ How should I prepare for a Goals of Care conversation?

Think about your past experiences, hopes, values and priorities, what you would define as quality of life, and what you consider important. Consider talking to your healthcare providers about who else should be part of this conversation. For example, you may want to include your Substitute Decision Maker.

⑬ I have already talked about my Goals of Care with my family doctor, do I need to talk about them again?

Goals of Care should be talked about within the context of your current care to help make sure your treatment decisions reflect your values. It is important for you to revisit them because there could have been changes since the last time you discussed them with your healthcare providers.

Your Goals of Care may also change when new treatments are being considered.

⑭ I have talked about advance directives or living wills with my healthcare providers. Is this the same as Advance Care Planning and Goals of Care?

There are no such documents called "advance directives" or "living wills" in Ontario law and these terms should not be used. In Ontario, the only part of Advance Care Planning that must be written down is the preparation of a Power of Attorney for Personal Care, and this is only needed if someone is not satisfied with who their automatic Substitute Decision Maker is and wants to name someone else (see pages 2-3). The actual communication of wishes, values, and beliefs to the Substitute Decision Maker can be done verbally, in writing, or in another way.

Goals of Care conversations happen in the context of your current condition when information about the illness is known.

This is not a consent discussion by itself, it is a first step to decision-making and consent (permission).

⑮ I see my healthcare providers often and I think they already understand my Goals of Care. Do I still need to talk about Goals of Care with them?

Goals of Care conversations should be ongoing and should always happen before any treatment decisions are made. These conversations allow your healthcare providers to learn about who you are, how your values are reflected in your Goals of Care, and how these goals align with the treatment you are considering

⑯ What is code status and why are my healthcare providers going to ask me about it?

Code status tells healthcare providers whether or not you want them to attempt resuscitation if you stop breathing or if your heart stops working (sometimes known as a do not resuscitate [DNR] order). Resuscitation may mean restarting your heart using electric shock and chest compressions, or using a ventilator if you are unable to breathe on your own. It is an important treatment decision that must be made by you or your Substitute Decision Maker if you are not capable (able) before an emergency situation. Your healthcare providers must talk to you about the risks and benefits of resuscitation before they get your consent. If you do not consent to a DNR order, your healthcare provider may take aggressive actions to keep you alive. You can change your code status at any time.

For more information and resources about Advance Care Planning and Informed Consent, please visit ***speakupontario.ca***

For more information about the Ontario Palliative Care Network please visit ***ontariopalliativecarenetwork.ca***

Need this information in an accessible format?
1-855-460-2647, TTY (416) 217-1815, publicaffairs@cancercare.on.ca OPC4047