



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 make sure that your treatment decisions are aligned with your wishes, values, and beliefs for your care now and in the future. They are also important to make sure that you get the support you need throughout your care, including access to palliative care.

Palliative care is a type of care for people who have a serious illness. It is not only for people that are near the end-of-life. It focuses on helping people live well by relieving their symptoms and providing emotional, social and spiritual support when needed. It can be provided in addition to the treatment for advanced chronic kidney disease (CKD).

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.

These conversations focus on future care. 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 and your healthcare providers for Shared Decision-Making and consent.

Shared Decision-Making involves taking the best scientific evidence available and your values and preferences to make treatment decisions. You, or your Substitute Decision Maker if you are not capable (able), must provide informed consent (give permission) before any treatment can be provided.

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

Palliative care in advanced chronic kidney disease is much more than end-of-life care and is provided in addition to the care to treat the disease. The goal of palliative care is to help people live well by keeping them as comfortable and free of pain or other symptoms as possible.

Chronic kidney disease is often a progressive illness. A patient’s condition can change rapidly or unexpectedly. Advance Care Planning discussions are ideally had well in advance before this change. 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.

5 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>.

6 Who is supposed to interpret my wishes, values, and beliefs if I am not able to make decisions myself?

The wishes, values and beliefs you share with your Substitute Decision Maker while you are capable (able) help them understand you, how you make choices, and what you think is important. While healthcare providers can help with the process when needed, your wishes should be interpreted by your Substitute Decision Maker, who will then decide whether to give or refuse consent (permission) to treatment.

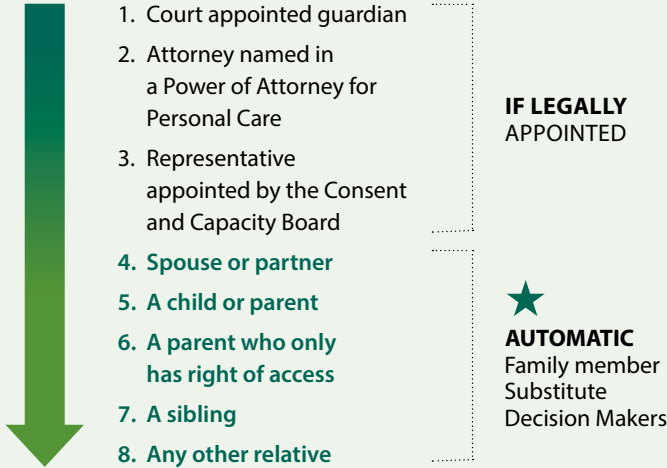
A Substitute Decision Maker is the person who will make decisions about your care and treatments if you are too sick to make them yourself.

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 your automatic Substitute Decision Maker is your child and you have three children, all three children would share the decision-making responsibility. This can sometimes be stressful for families.

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



(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 at the same level disagree.

7 Who should be deciding my Goals of Care?

You should decide 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. If you are not capable (able), your healthcare providers will discuss Goals of Care with your Substitute Decision Maker. 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.

8 What is a Plan of Treatment?

A Plan of Treatment is a summary of all of the treatment decisions you make with your healthcare providers through Shared Decision-Making. It includes information about the treatment you may need, and what treatment you would want or not want.

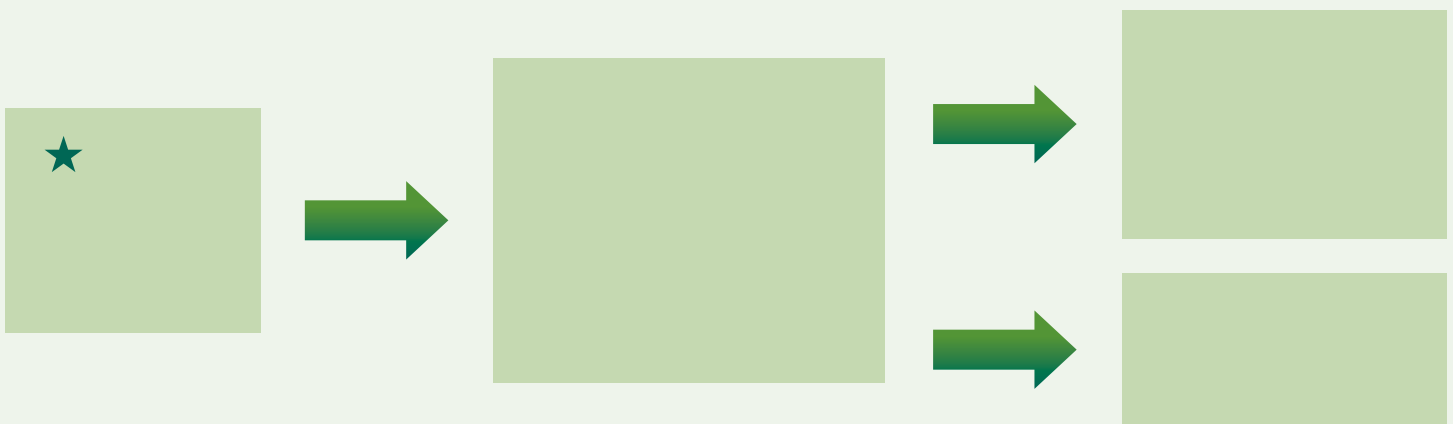
9 How is a Plan of Treatment different from Advance Care Planning?

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.

10 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.

How to confirm your 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.aclelaw.ca/appimages/file/Tip Sheet TWO - Hierarchy of SDMs FINAL Sept 2013.pdf>.

11 I have already talked about my Goals of Care with my family doctor before I came to the kidney clinic, do I need to talk about them again?

Goals of Care should be talked about within the context of your current care. It is important for you to revisit them in the kidney clinic 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.

12 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).

13 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

14 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 to be resuscitated 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. It is important to talk to your healthcare providers about the risks and benefits of resuscitation. Unless you share a different preference, healthcare providers will take aggressive actions to keep you alive. You can change your code status at any time.

For more information about the Ontario Renal Network please visit renalnetwork.on.ca

Need this information in an accessible format?

1-855-460-2647, TTY (416) 217-1815 publicaffairs@cancercare.on.ca.

Version 3 – May 2018 ORN2699