



Advanced Chronic Kidney Disease: Making decisions about your care

"I think that every patient needs to have these conversations...then maybe families would feel better and not force their loved ones to continue with treatment that they do not want to do." - Anne O.

When you have advanced chronic kidney disease (CKD), it is important to think about your wishes, values, and beliefs for your care now and in the future. Having conversations about your care makes it easier for your healthcare providers and your loved ones to understand your wishes.

These conversations are also important to make sure you get the support you need throughout your treatment, which may include 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 CKD. In making decisions, you will need to decide what you would want for your care in the future, what you want for your care right now, and how these preferences fit with your treatment options.

Goals of Care

A conversation about your current care

It is important that you and your healthcare providers have open and honest conversations about your current care when you have a serious illness.

You and your healthcare providers (e.g., nephrologist [kidney doctor], nurse, social worker, family doctor) should talk about:

- The nature of your illness, and
- The values and the goals you have for your care.

The goals you share with your healthcare providers will be used to help you make decisions and provide **consent** (permission) for your treatment. Your **Substitute Decision Maker** should also know your goals. For more information about Substitute Decision Makers, see the Frequently Asked Questions resource.

You can set any goals you want based on what is important to you. It might be things like keeping up with your social life, going to an important family function, or staying independent for as long as possible.

Your healthcare providers will write down your goals and use them when discussing treatment decisions with you. Talk about your goals often. You and your healthcare providers can change your goals at any time. If you would like a copy of your Goals of Care, please talk to your healthcare providers.

Advance Care Planning

A conversation about your future care

Goals of Care

A conversation about your current care

Treatment Decisions & Informed Consent

A conversation about your current treatment

Advance Care Planning

A conversation about your future care

Advance Care Planning is planning for your future care before you need it. It helps you think about what is important to you, and lets others know what kind of care you would want in the future if you were sick and unable to communicate.

Advance Care Planning involves confirming your **Substitute Decision Maker** and discussing your wishes, values, and beliefs with them.

This helps prepare your Substitute Decision Maker to make future care decisions for you if you do not have the **capacity** (ability) to do so yourself.

*A person's **capacity** (ability) to make decisions for themselves can change over time, especially if they get sicker.*

Everyone should confirm their Substitute Decision Maker and should have an Advance Care Planning conversation with them.

For more information on Advance Care Planning and to complete a guided online workbook, please visit speakupontario.ca

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.

Treatment Decisions & Informed Consent

A conversation about your current treatment

In Ontario, anytime a healthcare provider offers you treatment, you or your Substitute Decision Maker must give **informed consent** (permission) for that treatment.

***Informed consent** (permission) may be explicit (verbal or written) or implied.*

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.

You and your healthcare providers should then make the treatment decision together based on your wishes and Goals of Care. This process is called Shared Decision-Making and is considered essential to good patient care.

Your treatment decisions are used to create a **Plan of Treatment**. Not everyone will want or need the same type of treatment. You will decide with your healthcare providers what is right for you.

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

If you have questions about your treatment, or would like a copy of your Plan of Treatment, please talk to your healthcare providers. It is important that you understand every part of your treatment.