



ADVANCE CARE PLANNING



Advance care planning



National advance care planning day

April 16th is national advance care planning day in Canada: a day to reflect on what gives your life meaning, your values, and your wishes for your care at the end of life; a day to share these reflections with friends and family; a day to think about what you want, talk about your wishes, write them down and review your plan every year.



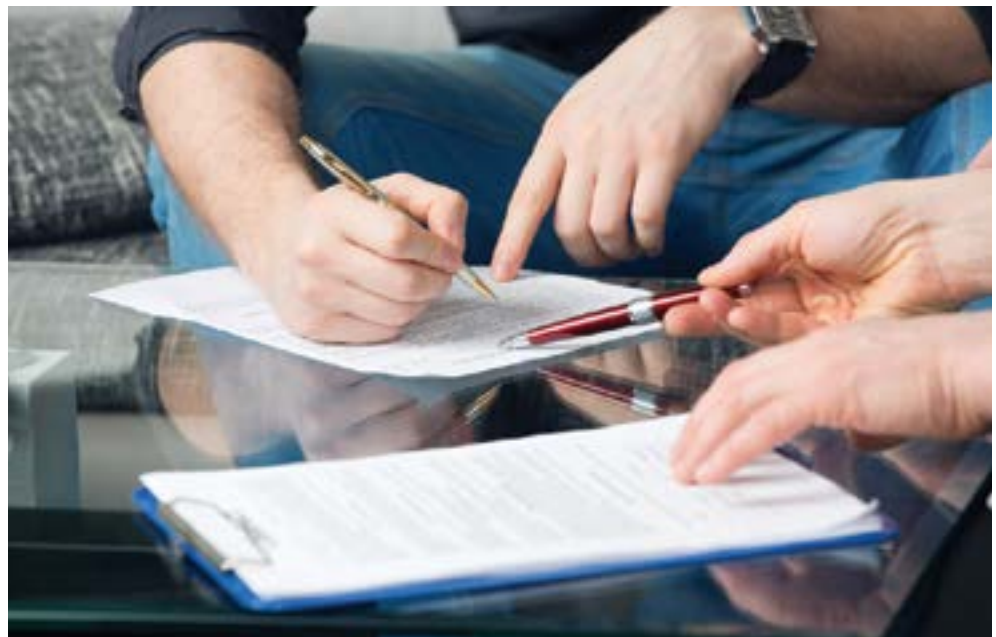
Advance care planning ensures your voice is heard, even when you can't speak for yourself.

Regardless of treatment choice, advance care planning is important, especially if you are living with a chronic disease. Many Canadian adults have a will and some may have a power of attorney. However, very few Canadians know about advance care planning and less than half the Canadian population has ever had a conversation with a family member or friend about what healthcare treatments they would want, or not want, if they were to become ill and unable to communicate their wishes.

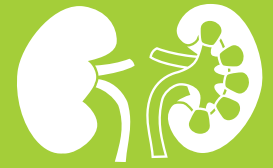
No one really likes to think about the end of life because many of us are uncomfortable thinking about our death. Nevertheless, since death comes to us all, it is a good idea to make some plans for this eventuality. And increasingly, advance care planning is becoming part of routine healthcare.

What is advance care planning?

Advance care planning is a *process* in which you think about what you would like to happen to you, or not happen to you, if you become unable to make decisions about your healthcare treatment or if you are unable to communicate your wishes.



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It's also about *making decisions* before this happens, *writing them down* (or recording them by voice or video), and *talking about your wishes* with your family, friends and healthcare team (so your wishes can be put on your medical record). One of your decisions will be to name a **Substitute Decision Maker**, someone you know well and trust, whom you would want to make decisions on your behalf if you were unable to.

You may have to get more information about what kinds of healthcare treatments and support might be available and needed in the future before you decide what you want to include in your advance care plan.

Some facts about advance care planning

- Your plan will only be used when, or if, you become unable to make decisions for yourself or to communicate your wishes.
- Your advance care plan might never be used. For example, you may always have the capacity to make your own decisions and to communicate them. Or you may pass away in your sleep and never need the plan.
- You can change your mind and change your plan at any time. In fact, it's a good idea to review your advance care plan regularly as you move through life's stages, or if there are changes to your family status through births, deaths, divorce, etc. Also, your health may change over time or new medical treatments may become available.
- No one can do advance care planning for another person. You have the right to do it for yourself and to have your wishes respected.
- Everyone, regardless of his or her current health or age, should probably have an advance care plan.

HELPFUL TIP

It's a good idea to have a small wallet-size card that states who your Substitute Decision Maker is and their telephone number. Keep this card in your wallet with your healthcare and hospital cards.

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- You can provide copies of this chapter or other documents about advance care planning to give others some background information on the process.
- You can also let them know that you can get together with your doctor or other members of the healthcare team at a later date to get answers to any questions they may have. Sometimes people prefer to have their doctor present when they discuss their plan with their family.
- Allow time for reflection – for you and for your family. You may want to get together again at a later date to continue the discussion.
- Be prepared to listen, too, so that you can understand others' concerns.
- Make sure to give a copy of your plan to your doctor, your kidney healthcare team and/or others involved in your care (i.e. home care).
- You should review and re-evaluate your plan as changes in treatment or changes in your personal life occur.

Other documents and suggestions to help put your affairs in order

Here are some suggestions about the kinds of documents you should have and how to put your affairs in order. Ideally, we should all do this kind of planning and organization on a regular basis and review it every few years.

- **Will:** This is a legal document, usually prepared by a notary or lawyer, which explains how you would like your assets to be distributed after your death. It can also include any special wishes or bequests (gifts) that you would like to make to specific people.
- **Power of Attorney:** This is a legal document in which you appoint one or more people to make decisions for you about money, property and other financial issues so that they can act on your behalf.

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NOTE

Each province/territory may have different laws about the topics and documents mentioned here and the documents may have different names. Look into your provincial/territorial regulations. There are many sample documents available and many of them are free. You can ask your kidney healthcare team and/or social worker if you would like more information about this.

- **Power of Attorney for Personal Care:** This document is similar to a regular *power of attorney* but in this case you identify a Substitute Decision Maker who you authorize to make personal and healthcare decisions for you if you become unable to make these decisions yourself or are unable to communicate your wishes. *A power of attorney for personal care* is part of advance care planning. Depending on your province/territory, it may be called a *living will*, *advance directive*, *personal directive*, *mandate* or some other name.
- Organize your financial records, bank accounts, safety deposit boxes and keys, insurance policies, real estate, deeds of sale and all other important papers.
- Make a list of all your usernames and passwords for all your devices like mobile or cell phones, computers, tablets or other devices, all your online social media sites, specific web sites, bank machines/ATMS, etc.



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Summary

- Advance care planning is a process in which you think about what you would like to happen to you, or not happen to you, if you're unable to make decisions about your healthcare treatment or if you're unable to communicate your wishes.
- You reflect on what you want in life, write down your thoughts and wishes and share these reflections with your family and your healthcare team.
- Many people feel a sense of relief, knowing that their family and doctors have the right information to make good healthcare decisions on their behalf, if they become unable to communicate their wishes.
- Several other documents can help you organize your personal affairs including a will, power of attorney, power of attorney for personal care and others.