Let's get started: Making an advance care plan (continued)



b. What if you have not signed a Power of Attorney for Personal Care? Who is your Substitute Decision Maker?

In Ontario, if you have not signed a Power of Attorney for Personal Care, the law provides that you will always automatically have a Substitute Decision Maker for health care.

The Ontario Health Care Consent Act includes a hierarchy (a ranking list) of Substitute Decision Maker(s). The person or persons in your life that are the highest ranked in this hierarchy and that meet the requirements to act as a Substitute Decision Maker will be your Substitute Decision Maker for health care.

- 1. Guardian of the person: This is someone that is appointed by the court to be your Substitute Decision Maker.
- Attorney named in a Power of Attorney for Personal Care: This is the person or persons YOU have chosen to be your Substitute Decision Maker if you prepared this document when you were mentally capable to do so.
- 3. Representative appointed by the Ontario Consent and Capacity Board: One of your family or friends could apply to the tribunal, known as the Consent and Capacity Board, to be named as your "Representative," which is a type of Substitute Decision Maker. However, if you prepared a valid Power of Attorney for Personal Care, the Consent and Capacity Board will not appoint anyone even if they apply because the Substitute Decision Maker YOU chose in the Power of Attorney for Personal Care will rank higher in the hierarchy list.
- 4. Spouse or partner. Two persons are "spouses" if they are:
 - a) Married to each other; or
 - b) Living in a marriage-like relationship and,
 - i) have lived together for at least one year, or
 - ii) are the parents of a child together, or
 - iii) have together signed a Cohabitation Agreement under the Family Law Act. A Cohabitation Agreement is a document that two people who live together, but are not married, can sign in which they agree about their rights and obligations to each other during the time they live together and on separation. The types of things they can include in the agreement are rights to financial support from each other, ownership and division of property, and the education of their children.

Two persons are not spouses if they are living separate and apart as a result of a breakdown of their relationship.

Two people are "partners" if they have lived together for at least one year and have a close personal relationship that is of primary importance in both people's lives. This can include friends who have lived together for at least one year in a non-sexual relationship and have a special personal family-like relationship.

- 5. Child or parent or Children's Aid Society or other person lawfully entitled to give or refuse consent to treatment in place of the incapable person: This does not include a parent who only has a right of access. If a Children's Aid Society or other person is entitled to give or refuse consent in place of the parent, this then would not include the parent.
- 6. A parent who only has a right of access.
- 7. Brother or sister (see c. on the next page if you have more than one brother or sister).
- Any other relative (see c. below if you have more than one relative)
 People are relatives if they are related by blood, marriage or adoption.

If no person in your life meets the requirement to be a Substitute Decision Maker, then the Public Guardian and Trustee, a public government organization, is your Substitute Decision Maker.

Let's get started: Making an advance care plan (continued)



c. What if more than one person is entitled to act as my Substitute Decision Maker?

If there is more than one person in your life at any one level in the hierarchy, and they are the highest ranking in the hierarchy, they must make decisions together (jointly) or must decide amongst themselves which of them will act as your Substitute Decision Maker.

For example, if you have three children (level 5 on the hierarchy), all three are entitled to act as your Substitute Decision Maker. They must act together and agree on any decisions for your health care. If they together agree that only one of them should make decisions for you, then that one child may make decisions for you alone, without talking to the other two, and the health professionals must take direction from that one child. The health professionals cannot pick which one of the three should make decisions for you. The three children must decide amongst themselves whether they all act together or which one of them will act.

If there is a conflict among people who are equally entitled to act as your Substitute Decision Maker, and they all want to act, and they cannot agree on the decisions about treatment for you, the Public Guardian and Trustee is required to act as your Substitute Decision Maker instead of any of them. The Public Guardian and Trustee does not choose between the disagreeing decision makers but "shall make the decision in their stead."

d. Requirements to be a Substitute Decision Maker

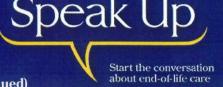
The person (or persons) in your life who is (are) highest ranking on that hierarchy would be entitled to act as Substitute Decision Maker for you only if they meet certain requirements. The requirements that person or persons must meet are that he or she must be:

- 1. mentally capable,
- 2. 16 years of age unless he or she is the parent of the incapable person,
- not prohibited by a court order or separation agreement to have access to you (the incapable person) or to give or refuse consent on your behalf,
- 4. available, and
- 5. willing to assume the responsibility of giving or refusing consent.

For further information you can refer to the booklet "A Guide to Advance Care Planning" on the website for the Ontario Seniors Secretariat at http://www.seniors.gov.on.ca/en/advancedcare/index.php or go to the website for the Advocacy Centre for the Elderly at http://www.acelaw.ca.

For the National Speak Up Campaign materials and for more information about other provincial and territorial guidelines please visit the Speak Up website www.advancecareplanning.ca.

Let's get started: Making an advance care plan (continued)



4. Begin the Conversation

Now it is time to have a conversation with your future Substitute Decision Maker(s), your family and, if needed, appropriate professionals. Your future Substitute Decision Maker(s) may find the conversation difficult, or they may be relieved to know exactly what kind of care you would like to receive. If you write your plan down, make sure that your future Substitute Decision Maker(s) have a copy of your plan and that they can understand it, honour it and feel comfortable making medical decisions on your behalf.

Do not forget to tell others too, such as your doctor, other health care professionals involved in your care, your lawyer, and other family members or friends. Let your doctor know who you have appointed to be your future Substitute Decision Maker(s) and that you have shared your wishes, goals and values with them. You may wish to provide your plan to your doctor or request that the information be noted in your medical record. This is important so that if you become mentally incapable, your doctor can discuss your wishes about health care with your Substitute Decision Maker(s).

Having trouble talking? Our website has some great tips for starting the conversation. Visit www.advancecareplanning.ca to learn more.

5. Document your wishes

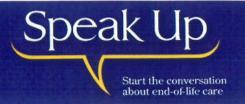
Write down or record what you would want when you are at the end of life and are not expected to survive. Do you want the doctor to use machines that will keep you alive (e.g., breathing machines or dialysis), a trial period of that procedure or no medical interventions at all except to relieve pain or other discomfort? You can learn more about various medical procedures on pages 11 and 12 of this workbook.

It is important to know that when you are in pain or experiencing unpleasant symptoms such as dizziness or nausea, health care providers will always offer you medicine and treatment to relieve those symptoms. There are other medical procedures, however, that you may or may not want at the end of life.

You should also consider documenting any other wishes for your care at the end of life (e.g., dying at home, receiving hospice/palliative care, having music playing, or specific religious rituals).

We have included a form in this workbook to help you document your wishes, but you may also choose to create your own plan or use a form provided by a legal or health professional. You could also make a recording or video of your wishes.

Questions you may have



When is an Advance Care Plan used?

Your plan is only used if you are mentally incapable of making your own health care decisions (e.g., you are in a coma or your illness has impaired your ability to communicate your decisions). Your Substitute Decision Maker(s) can use it to guide your care, advocate for your wishes, and consent or refuse consent to treatment on your behalf.

What if I change my mind?

Our lives – and the people around us – change over time. You will want to review your advance care plan regularly to be sure it still reflects your wishes and that you are comfortable with your choice of Substitute Decision Maker(s). Remember, it will only be used if you cannot speak for yourself.

In Ontario, you can express wishes about future health care and treatment orally as well as in written documents. You can also communicate your wishes using any means that you use to communicate, such as through a computer or picture board. You can make changes to these wishes the same way – orally, in writing or through alternative means of communication. Even if you have prepared a written Advance Care Plan, you can direct changes to be made to your wishes orally and the oral directions will override the written document.

The one thing you can **ONLY** do in writing is **appoint** someone to be your Substitute Decision Maker. This can **ONLY** be done through a written Power of Attorney for Personal Care. Any changes to such a document must also be made in writing (in a document known as a Revocation) and/or by preparing a new Power of Attorney for Personal Care with the changes.

What happens in an emergency if I cannot communicate and the hospital does not know who my Substitute Decision Maker is?

Make sure that your Substitute Decision Maker and your doctor have a copy of your plan and that family or friends know who will act as your Substitute Decision Maker – this person will likely be contacted if an emergency occurs. Carry a wallet card that identifies your Substitute Decision Maker(s) and their contact information. Communicate to those concerned where you have stored the documents.

In Ontario, you always have a Substitute Decision Maker. If the hospital/health provider cannot locate anyone that may know who your Substitute Decision Maker would be or locate anyone else in your life on the hierarchy of Substitute Decision Makers in the Health Care Consent Act that could step in to act as your Substitute Decision Maker, then the Ontario Public Guardian and Trustee would step in temporarily as your Substitute Decision Maker until the appropriate person can be located.

In an emergency, there may be no time to get consent from anyone. In that case, health providers have the authority to treat you without consent if it is necessary to do so to relieve any pain or suffering you may have or to address any risk of experiencing serious bodily harm. If your health providers know of any wishes you have expressed about your care or wishes to refuse consent to particular care, the health providers must honour those wishes.

NOTES

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Speak Up Start the conversation about end-of-life care

Questions you may have (continued)

What if my Substitute Decision Maker is not able or willing to make decisions for me?

In Ontario, a Substitute Decision Maker has to be willing and able to take on this role. If the person you have appointed as Substitute Decision Maker in a Power of Attorney for Personal Care is not able to act or refuses to act for you, then the health care provider will use the hierarchy list of Substitute Decision Makers that appears in the Health Care Consent Act (see pages 6 and 7 of this workbook to see that hierarchy), going down that list in order, to then find someone in your life that is willing, available, and able to consent or refuse consent to the proposed care for you.

I have a "Living Will." Is that not good enough?

In Ontario, the law does not mention any document called a Living Will, although it is commonly thought of as any document in writing in which you list your wishes about medical treatments you may or may not want. The Living Will has no particular "form" in Ontario and does not need to be witnessed or signed.

The law does state that a person can express wishes about their future care orally, in writing or by any alternative means. You can therefore set out your wishes in a Living Will. Anyone that acts as your Substitute Decision Maker is required to follow your wishes about treatment, if known, however expressed, even if described in a Living Will.

The one thing you **cannot** do in a Living Will is appoint someone to act as your Substitute Decision Maker. In Ontario, that can **only** be done through a Power of Attorney for Personal Care.

A Living Will is a type of Advance Care Planning, but it is also important that you have a conversation with those who will be asked to give or refuse consent to treatment when you are mentally incapable because they may have questions about your wishes. You should also review your Advance Care Plan regularly to be sure that it still reflects your feelings, beliefs and values about end-of-life care.





Questions you may have (continued)

My family will know what to do. Why do I have to write it down?

Writing down your wishes helps to ensure your wishes are clear for everyone. You may believe that they know what to do, but they may not. For example, you may have said something like "pull the plug if I'm a vegetable," but you need to be clear about what that really means to **you**. Your family may also have questions about the wishes that you have made. Writing down those wishes may help the conversation.

However you do not need to write down your wishes for those wishes to be followed by your Substitute Decision Maker because in Ontario you can choose to provide wishes only orally.

These types of documents are only for old people, right?

You cannot predict how and when you will die. If you are an adult, you should have an Advance Care Plan. You can change your plan as often as you like and as your life changes. But do not just write it down. The most important thing to do is to have a conversation with the person or people who will be asked to give or refuse consent to treatment when you are unable.

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