Speak Up

Start the conversation
about end-of-life care

Advance Care Planning Workbook
Ontario Edition

It's about conversations.
It's about decisions.
It's how we care for each other.

www.advancecareplanning.ca

Speak Up, c/o Canadian Hospice Palliative Care Association | Annex D, Saint Vincent Hospital, 60 Cambridge Street North, Ottawa, ON K1R 7A5

For more information about advance care planning, please visit our website at:

www.advancecareplanning.ca

e-mail: info@advancecareplanning.ca

National Advance Care Planning Task Group
c/o Canadian Hospice Palliative Care Association
Annex D, Saint-Vincent Hospital
60 Cambridge Street
Ottawa, ON K1R 7A5

Telephone: 613-241-3363
Fax: 613-241-3986

The National Advance Care Planning Task Group wishes to recognize and thank the following organizations for generously allowing us to adapt components of their publications and information for use in this workbook:

- Canadian Researchers at the End of Life Network (CARENET)
- Fraser Health Authority (British Columbia)

The Ontario Alzheimer Knowledge Exchange HCC-ACP Community of Practice adapted the original version of the Speak Up Workbook to create this Ontario edition.

Speak Up in Ontario is coordinated by Hospice Palliative Care Ontario.

HPCO
Hospice Palliative Care Ontario

Making an Advance Care Plan

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

Advance Care Planning is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let others know what kind of health and personal care you would want in the future if you become incapable of consenting to or refusing treatment or other care.

Advance Care Planning means having discussions with family and friends, especially your future Substitute Decision Maker(s). A Substitute Decision Maker is the person or people who will provide consent or refusal of consent for care and treatments for you if you are not mentally capable to do so for yourself. Advance Care Planning can include choosing a Substitute Decision Maker as well as expressing your wishes about care that you want or may not want.

It can include discussions with your health care providers to ensure that you have accurate medical information on which to make decisions (consents) or to express wishes about future care and treatment. It can also include writing down your wishes, and may even involve talking with legal professionals.

It is a way to give those who will be required to provide consent for your medical treatment and care the confidence to make decisions on your behalf when you are mentally incapable to do that for yourself.

You may never need your advance care plan – but if you do, you will be glad that you have had these conversations. It is a way to make sure that your voice is heard when you cannot speak for yourself.

This workbook contains tips for having conversations with others about your wishes for care at the end of life. It also includes information about making a plan and understanding medical procedures, as well as a sample plan. You can use the workbook to help get the conversation started with a friend or family member or to express your wishes about future care.

Why plan for end-of-life care?

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

Life can take many twists and turns. **Imagine:**

- One day, without any warning, you find yourself in a hospital with a life-threatening illness. You are unable to speak for yourself – you do not recognize your family or friends. Your doctors do not feel that you will leave the hospital alive. Do you want to be kept alive using machines? Does anyone know your wishes? Who will make decisions for you?

  OR

- Your widowed mother has slipped into a coma. Someone needs to make some decisions about her medical care. If you have siblings, who will make those decisions? All of you? One of you? Someone else? How do you know if the decisions are the right choices for your mother?

  OR

- You are at the beginning stages of Alzheimer's and you know that at some point you will not be able to recognize people or make your own decisions. How will you make your wishes known? Who will make decisions about your care and treatment when you are no longer mentally capable of doing so yourself?

An Advance Care Plan is more than a document outlining your wishes for care at the end of life – it is also a conversation that you have with the person or people who will act for you if you cannot speak for yourself. It means thinking about what is important to you and what you value. It means talking to your loved ones about these things. Reflecting on your values and having these conversations will help you, your loved ones and anyone that will act as your Substitute Decision Maker talk to health care professionals about difficult decisions that may have to be made about your care at the end of life.

Having these conversations and making a plan are ways to give your Substitute Decision Maker(s) the confidence to make decisions on your behalf. It is how we care for each other.

Remember, this plan will only be used if you are not capable of speaking for yourself. You can also change it at any time as long as you are mentally capable.

The choices you make at the end of life – for yourself and others – are important. Make sure that your voice is heard and respected. Think about what you would want and start the conversation with others about your end-of-life care.

Making an advance care plan

Advance Care Planning is a process, not just a document. In fact, in Ontario, an Advance Care Plan can be expressed orally, in written form or by any alternative means that you use to communicate, such as a picture board or computer.

Advance Care Planning includes conversations that you have with close family and friends about your values and beliefs as well as the medical procedures that you want and do not want at the end of life. It is also about the experiences and people that you want around you at the end of life.

How to begin:

1. Think about what is right for you

Begin by reflecting on your values, beliefs and understanding about end-of-life care or specific medical procedures, such as drug therapies, cardiopulmonary resuscitation (CPR) or dialysis. Think about any situations that you may have experienced with others and how it made you feel. You should also speak with your health care providers to ensure you have accurate information about your own health condition in order to express wishes about medical procedures that you may or may not want.

Ask yourself:

- If possible, would I prefer to die at home, in a hospice or in the hospital?
- What might change my mind about my choice?
- Do I want or not want certain medical interventions (e.g., resuscitation or feeding tubes) if I am unlikely to survive or live independently?
- Why would I want or not want these procedures?
- Do I have any fears about dying (e.g., I'll be in pain, I won't be able to breathe)?
- Is there someone that I can talk to about these fears, such as my doctor?
- What would be meaningful for me at the time of my death (e.g., family/friends nearby, music playing or pictures)?

2. Learn about end-of-life care options and procedures

Some individuals want to prolong life as long as possible using medical interventions. Others would not want to be hooked up to machines at the end of life if there is no chance of recovery.

We have included a list of Advance Care Planning terms and medical procedures on pages 13 and 14 to help you consider what is right for you.

3. Decide who will make medical decisions on your behalf should you become incapable of doing so

Think carefully about who you feel would understand, honour and follow your wishes, and would be most capable of making medical decisions on your behalf as your Substitute Decision Maker. This may be a spouse, an adult child, a trusted family member or a good friend.

Before you choose someone, you need to understand what the law says about what you must do to appoint someone as your Substitute Decision Maker. You also need to know what happens if you do not appoint someone to act for you through that legal process.

In Ontario, the law provides that even if you do not appoint someone to act on your behalf, you will still always have a Substitute Decision Maker that the health professional must turn to get consent or refusal of consent to any treatments for you.

Legal requirements regarding the appointment of a Substitute Decision Maker vary across the country and from country to country. You need to follow the law that is applicable in the province or territory in which you live when you appoint someone to be your Substitute Decision Maker.

What do you need to know about Ontario law regarding Substitute Decision Makers?

a. Power of Attorney for Personal Care

In Ontario, you can CHOOSE someone (or more than one person) to be your Substitute Decision Maker(s) by preparing a Power of Attorney for Personal Care.

The legal requirements for preparing a Power of Attorney for Personal Care are in the Ontario Substitute Decisions Act.

A Power of Attorney for Personal Care is a document, in writing, in which you name someone to be your "attorney." The word attorney does not mean lawyer. In this case, an attorney is a type of Substitute Decision Maker.

To be valid, the document must:

i. be signed by you voluntarily, of your own free will;
ii. be signed by you in the presence of two witnesses;
iii. be signed by the two witnesses in front of you.

Also, you must be mentally capable of understanding and appreciating what kind of document you are signing and what you are doing by signing such a document.

More information about Ontario Powers of Attorney for Personal Care can be found on the websites of the Advocacy Centre for the Elderly (www.acelaw.ca), Community Legal Education Ontario at (www.cleo.on.ca) and the Ontario Ministry for the Attorney General (http://www.attorneygeneral.jus.gov.on.ca).

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.
2.	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).
8.	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.

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,
3. 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.

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 13 and 14 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.

NOTES

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.

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.

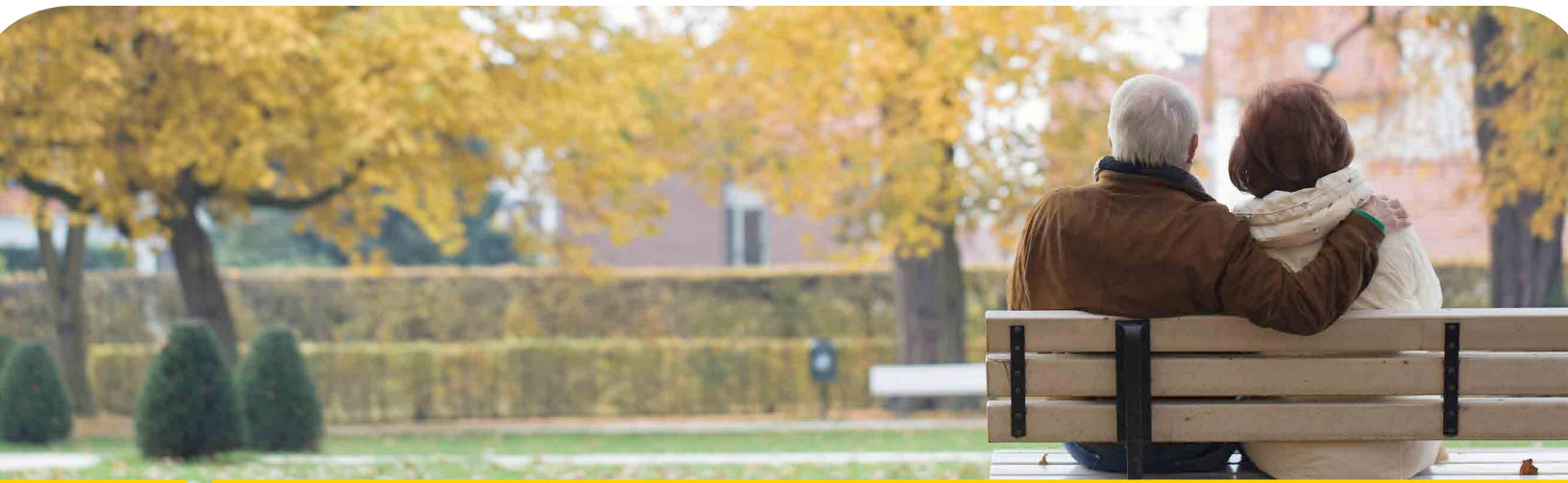
I have a "Living Will." Is that not good enough?

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.

NOTES

Word List

By learning more about common end-of-life terms and treatments, you can develop an Advance Care Plan that truly reflects your wishes. You may also wish to include some of these terms in your Advance Care Plan:

Allow natural death refers to decisions NOT to have any treatment or procedure that will delay the moment of death. It applies only when death is about to happen from natural causes.

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that may restart the heart and machines that breathe for the individual.

Comfort measures are treatments to keep you comfortable (e.g., pain relievers, psychological support, physical care and oxygen).

Dialysis is a medical procedure that cleans your blood when your kidneys can no longer do so.

End-of-life care refers to health care provided at the end of a person's life. This type of care focuses on you living the way you choose during your last days or weeks and providing comfort measures until the time of death.

A ***feeding tube*** is a way to feed someone who can no longer swallow food.

Health care professional is a person licensed, certified or registered in their province/territory to provide health care (e.g., a doctor, nurse or social worker).

Informed consent refers to the permission you give to health care providers that allows medical investigations and/or treatments. Health care providers are required to offer you, and you are entitled to receive, detailed explanations of the investigations/treatments and their risks, benefits and side effects; alternatives to these options; and what would likely happen if you refuse the options. Health care providers must also answer any questions you have about the treatments and the information must be provided before you give verbal consent or sign a consent form.

Intravenous (IV) is a way to give you fluids or medicine through a vein in your hand or another part of your body.

Life support with medical interventions refers to medical or surgical procedures such as tube feeding, breathing machines, kidney dialysis, some medications and CPR. All of these use artificial means to restore and/or continue life. Without them, you would die.

Life limiting illness refers to an incurable medical condition caused by injury or disease.

Palliative care is the way we care for people who have a life limiting illness. It focuses on providing good quality of life. In other words, keeping you as comfortable and free of pain or other symptoms as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for you and for those who are helping to care for you. Palliative care can be provided anywhere, at any stage of any illness along with care and treatment aimed at cure or prolonging life.

Power of Attorney for Personal Care is a document in Ontario that you prepare when you are mentally capable to name a person or persons to be your Substitute Decision Maker for health and other personal care decisions. That person or persons would make decisions about treatment and health care on your behalf if you become mentally incapable. (See page 6 of this workbook for more information about Powers of Attorney for Personal Care.)

Substitute Decision Maker (SDM) is a person(s) who provides consent or refusal of consent for treatment or withdrawal of treatment on behalf of another person when that person is mentally incapable to make decisions about treatment. The Substitute Decision Maker(s) is required to make decisions for you following any wishes you expressed about your care when you were mentally capable. If your Substitute Decision Maker does not know your wishes applicable to the treatment decision to be made, he or she is required to act in your best interests. (See pages 6 and 7 of this workbook for more information about Substitute Decision Makers.)

Symptoms are signs that you are unwell (e.g., pain, vomiting, loss of appetite or high fever).

Terminal illness means an incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

A ventilator is a machine that helps people breathe when they cannot breathe on their own.

What health care always provides

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.

If the doctor finds that you have a condition that is incurable, and you reach the point where you no longer want treatment or care that will prolong your life, there is medical treatment and nursing care available to you to provide comfort. For example, if you choose you may receive:

- Surgery to control pain (such as the repair of a broken hip)
- Antibiotics as needed to relieve symptoms of infection
- Pain-relieving medicine
- Medication to ease breathing difficulties

NOTES

My Advance Care Plan

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

After you have filled out this plan, make sure to give a copy of it to your future Substitute Decision Maker(s), family members, doctor, and any other health or legal professionals.

Most importantly, have conversations with your future Substitute Decision Maker(s) about your plan. They may have questions about your wishes.

Your First name: Your Middle initial:

Your Last name:

Date of birth: Heath Care Number:

Address:

Phone number: Mobile number:

E-mail address:

The following people have copies of this Advance Care Plan:
(List all people who have copies, their relationship to you and their contact information.)

Name	Relationship to me	Contact Information

My Substitute Decision Maker(s)

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

(See pages 7 and 8 of this workbook for information on Powers of Attorney for Personal Care and on the hierarchy of Substitute Decision Makers in Ontario law)

I have discussed my wishes for future health care with the person(s) named below.
My Substitute Decision Maker(s) is:

1. Name:

This person was appointed through a Power of Attorney for Personal Care: ☐ Yes ☐ No

Location of the current Power of Attorney for Personal Care (original document)

OR If no Power of Attorney for Personal Care: Substitute Decision Maker who is highest ranking person in my life on the hierarchy. See page 7.

Relationship of this Substitute Decision Maker to me:

Phone number: Mobile number:

Address:

E-mail address:

2. Name:

This person was appointed through a Power of Attorney for Personal Care: ☐ Yes ☐ No

Location of the current Power of Attorney for Personal Care (original document)

OR If no Power of Attorney for Personal Care: Substitute Decision Maker who is highest ranking person in my life on the hierarchy. See page 7.

Relationship of this Substitute Decision Maker to me:

Phone number:

Address:

E-mail address:

My Substitute Decision Maker(s)

I have also discussed my wishes with the following people:

Name	Relationship to me	Contact Information

In Ontario, if you want to name a particular person or persons as your Substitute Decision Maker, you can only do this by preparing a Power of Attorney for Personal Care. You may want to discuss preparation of such a document with your lawyer because a Power of Attorney for Personal Care is a legal document and must be in a particular form for it to be valid. There are other resources about Power of Attorneys for Personal Care on the websites for the Ontario Ministry of the Ontario General (http://www.attorneygeneral.jus.gov.on.ca), Community Legal Education Ontario (www.cleo.on.ca) and the Advocacy Centre for the Elderly (www.acelaw.ca).

PLEASE NOTE: If you do not prepare a Power of Attorney for Personal Care, your Substitute Decision Maker will automatically be the person highest ranked in the hierarchy of Substitute Decision Makers in the Health Care Consent Act (as listed on pages 6 and 7 of this workbook) that meets the qualifications to be a Substitute Decision Maker.

If you do not want the highest ranking person in the hierarchy list from your life to be your Substitute Decision Maker, you **must** prepare a Power of Attorney for Personal Care.

Just because you have listed names of people to be your Substitute Decision Maker in this workbook does NOT mean that these people have the right to act as your Substitute Decision Maker unless you ALSO name them in a Power of Attorney for Personal Care OR they are otherwise the highest ranking people in your life on the hierarchy list of Substitute Decision Makers. This workbook is NOT a Power of Attorney for Personal Care.

The Government of Ontario Seniors' Secretariat has a booklet on advance care planning. Go to **www.seniors.gov.on.ca** and search for advance care planning.

My Advance Care Plan:
My wishes for care at the end of Life

There are some circumstances when an injury or illness cannot be reversed or cured. In some cases medical procedures, called **interventions**, will only prolong life and delay death. These procedures could include mechanical ventilation, tube feeding, intravenous fluids or other treatments (see our Word List on pages 11 and 12 of this workbook for more information). It is important to think about your wishes should you have a life limiting condition that cannot be reversed or cured. Would you want to be treated with these types of medical procedures?

You may also have other wishes related to your care at the end of life – such as specific spiritual rituals you may want to have performed or to have music playing. You can use the questions below to document your wishes for care.

Consider answering the following questions to help guide you and your Substitute Decision Maker(s) in discussions. Remember that you can change your mind at any time – just be sure that you communicate any changes to your Substitute Decision Maker(s).

1. What do I value most in terms of my mental and physical health? (For example, being able to live independently, being able to recognize others, being able to communicate with others.)

2. What would make prolonging life **unacceptable** for me? (For example, not being able to communicate with those around me, being kept alive with machines but with no chance of recovery, not having control of my bodily functions.)

3. When I think about death, I worry about certain things happening. (For example, struggling to breathe, being in pain, being alone, losing my dignity.)

4. If I were nearing death, what would I want to make the end more peaceful for me?
(For example, family and friends nearby, dying at home, having spiritual rituals performed.)

5. Do I have any spiritual or religious beliefs that would affect my care at the end of life?
(For example, certain beliefs about the use of certain medical procedures.)

6. Other wishes and thoughts. (Write down anything that would help others understand and support you at the end of life.)

Note: You might also consider using the following tools to help you better understand your wishes:

Ottawa Hospital Research Institute Patient Decision Aids: features an A-Z directory of decision aids or a range of illnesses and treatments.
http://decisionaid.ohri.ca/index.html

CANHELP is a tool that measures both what is important to an individual at the end of life and how satisfied they are with that aspect of care. When the questionnaire is completed (by the patient nearing the end of life, the caregiver or a health professional), a customized report is produced that provides guidance for communicating wishes to the health care team.
You can find the CANHELP tool at www.thecarenet.ca

My other planning documents:

In addition to this Advance Care Plan, I have also completed the following documents:
(check all that apply, and note the location of each document)

- ☐ Written statement of my wishes about health care (e.g., Living Will, hand written note) — Location:
- ☐ Power of Attorney for Personal Care — Location:
- ☐ Power of Attorney for Property — Location:
- ☐ Will — Location:
- ☐ Other (e.g., organ donation, specific bequests)

Name of Document: Location:

Name of Document: Location:

Now that you've made your plan...

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

Congratulations on beginning the process!

Now that you've made your plan, it's time to tell others about it.

Continue the conversation about end-of-life care.

Talk to your future Substitute Decision Maker(s) about your plan and your wishes. They may have questions about your wishes about future care or want more details about what you have written in your plan. That conversation can give them the information and confidence to make decisions about your care during a difficult time.

Talk to your family members and friends – they need to know your wishes if you cannot communicate for yourself. Share your conversation and wishes with your doctor and health care providers as you see fit. Talking now will help reduce any anxiety and will help them better understand and honour your wishes at the end of life.

The choices you make at the end of life – for yourself and others – are important. Make sure that your voice is heard.

For more information about advance care planning, please visit:

www.advancecareplanning.ca

NOTES

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