

Speak Up

Start the conversation
about end-of-life care



Advance Care Planning Workbook

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

www.advancecareplanning.ca



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GlaxoSmithKline for their unrestricted funding
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For more information about advance care planning, please visit our website at:
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The information provided within this workbook is included as a public service and for general reference only. Every effort is made to ensure the accuracy of the information found here. However, this information is not considered legal, medical or financial advice and does not replace the specific medical, legal or financial advice that you might receive or the need for such advice. If you have questions about your health or about medical issues, speak with a health care professional. If you have questions about your or someone else's legal rights, speak with a lawyer or contact a community legal clinic.

Advance care planning is a process of reflection and communication, 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 Substitute Decision Maker(s) – the person or people who will speak for you when you cannot. It includes discussions with your healthcare providers to ensure that you have accurate medical information on which to make decisions. It can also include writing down your wishes, and may even involve talking with financial and legal professionals.

It's a way to give your loved ones the confidence to make decisions for you during a difficult time.

You may never need your advance care plan – but if you do, you'll be glad that you have had these conversations, 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, understanding medical procedures and a sample plan. You can use the workbook to help get the conversation started.

Why plan for 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?
- Your mother has slipped into a coma - and you and your siblings need to make some decisions about her medical care. Which one of you will make those decisions? How do you know if they are the right choices for your mother?
- 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 for you?

An advance care plan is more than a document outlining your wishes for care at the end of life. It's a conversation that you have with the person or people who will represent 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.

Having these conversations and making a plan are ways to give your loved ones the confidence to make decisions during a difficult time. It's how we care for each other.

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

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'd want – and start the conversation with others about your end-of-life care.

Let's get started: Making an advance care plan

Advance care planning is a process, not just a document. It's conversations that you have with close family and friends about your values and beliefs as well as the medical procedures that you want and don't want at the end of life. It's also about the experiences and people that you want around you at the end of life.

How to begin:

1. Think about what's 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 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 healthcare providers to ensure you have accurate information to make decisions about medical procedures.

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 (for example, 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 (such as family/friends nearby, music playing, etc.)?



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

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

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

We've included a list of advance care planning terms and medical procedures on pages 9 and 10 to help you decide what's 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 honour and follow your wishes, and would be most capable of making medical decisions on your behalf. This may be a spouse, an adult child, trusted family member or a good friend. This person(s) will be your Substitute Decision Maker.

Legal requirements regarding the appointment of a Substitute Decision Maker vary across the country. Visit www.advancereplanning.ca and click on 'Resources in your Province/Territory' in Quick Links to find more information about provincial and territorial guidelines.

4. Start the Conversation

Now it's time to have a conversation with your Substitute Decision Maker(s), your family and if needed, appropriate professionals. Your Substitute Decision Maker(s) may find the conversation difficult, or 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 Substitute Decision Maker(s) have a copy of your plan, and that they can honour and feel comfortable making medical decisions on your behalf.

Don't 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. It's a good idea to provide your doctor with a copy of your plan if it is written down. If not, have him/her record the conversation in your medical record.

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

5. Document your wishes

Write down or record what you would want if you are at the end of life and are not expected to survive – such as the use of machines that will keep you alive (for example, 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 9 and 10 of this workbook.

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Let's get started:

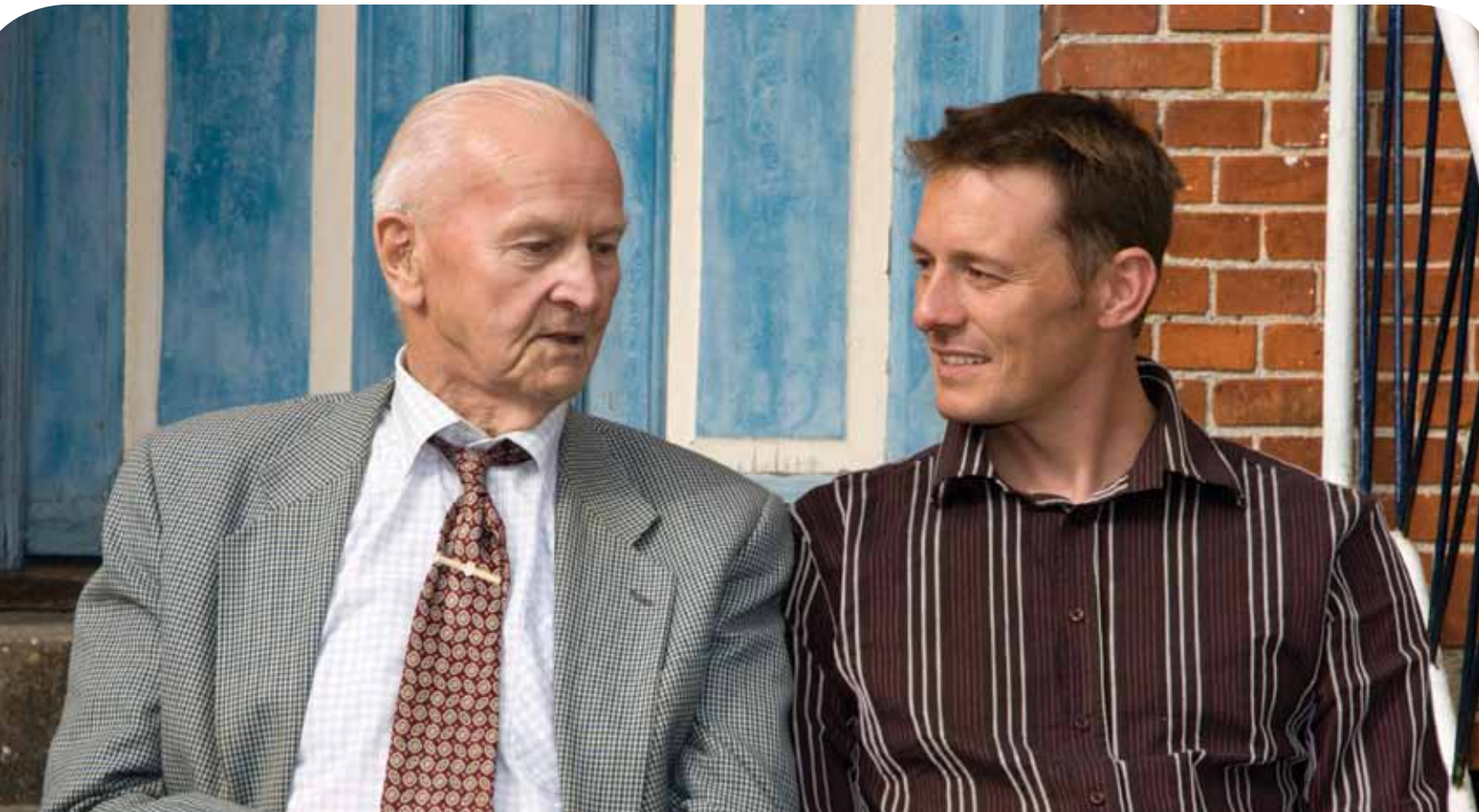
Making an advance care plan (continued)

Start the conversation about end-of-life care

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 give 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 (for example, dying at home, receiving hospice/palliative care, having music playing, specific religious rituals).

We've 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 unable to make your own health care decisions (for example, you are in a coma or your illness has impaired your ability to make decisions). Your representative can use it to guide your care and advocate for your wishes.

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 Substitute Decision Maker. Remember, it will only be used if you cannot speak for yourself.

What happens if I have an emergency, I can't communicate and the emergency room staff don't know about my Substitute Decision Maker?

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 – they will likely be contacted if an emergency occurs. You can also use a wallet card to name your Substitute Decision Maker and contact information (visit: www.advancecareplanning.ca to get a copy of our wallet card).

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

Health care professionals will approach family members as directed in provincial or territorial legislations. Visit www.advancecareplanning.ca and click on 'Resources in your Province/Territory' in Quick Links for more information.

I have a Living Will – isn't that good enough?

A living will is a type of advance care planning – but it's also important that you have a conversation with those who will make decisions about your care – 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.

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 perhaps they don't. 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 choices that you've made.

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

You can't predict how and when you'll die. If you are an adult, you should have a plan. You can change your plan as often as you like, and as your life changes. But don't just write it down - the most important thing to do is to have a conversation with the person or people who will make decisions for you when you can't.

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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 restart the heart and machines that breathe for the individual.

Comfort Measures: treatments to keep you comfortable (for example, pain relievers, psychological support, physical care, oxygen, etc.) but not to keep you artificially alive or cure any illnesses.

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 would include comfort measures until the time of death.

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

Health care provider / Health care professional describes a person licensed, certified, or registered in their province/territory to provide health care. For example: 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 give detailed explanations of the investigations/treatments and their risks and benefits before you give verbal consent or sign a consent form.

An **intravenous (IV)** is a way to give you fluids or medicine, i.e. through a vein in your hand or another part of your body.

Word List (continued)

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.

Palliative Care is care provided for people who have a terminal illness that focuses on providing good quality of life – in other words, keeping you as comfortable and free of pain 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.

Power of Attorney / Power of Personal Care are terms that typically indicate someone who is legally appointed to speak on your behalf. Typically, you would have a witnessed document naming your Power of Attorney / Power of Personal Care and outlining their responsibilities.

If you are incapacitated and have not designated a Substitute Decision Maker or if family members disagree about your care, a provincial or territorial **Public Guardian and Trustee** may be assigned to make decisions about your care.

A **Substitute Decision Maker** is a person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person when they are incapable of communicating their wishes on their own. This person might also be known as a medical proxy, a health representative or agent or a Power of Attorney for Personal Care.

Symptoms are signs that you are unwell - for example, pain, vomiting, loss of appetite, or high fever.

A **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.

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What health care always provides

When you are in pain or experiencing unpleasant symptoms such as dizziness or feeling sick, health care providers will always give you medicine and treatment to relieve those symptoms.

If you reach the point where you no longer want care that prolongs your life, medical treatment and nursing care will always be given to keep you comfortable. For example, you may receive:

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

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My Advance Care Plan

After you've filled out this plan, make sure to give it to your Substitute Decision Maker, family members, your doctor and any other health or legal professionals.

Most importantly – have conversations with your Substitute Decision Maker about your plan. They may have questions about your wishes.

First name: _____ Middle Initial: _____

Last name: _____

Date of birth: _____

Address: _____

Telephone 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 Advance Care Plan: My Substitute Decision Maker



I have discussed my wishes for future healthcare with the person named below.
My Substitute Decision Maker is:

Name: _____ Relationship: _____

Telephone: _____ Mobile number: _____

e-mail: _____

I have also discussed my wishes with the following people:

Name	Relationship to me	Contact Information

***note:** some provinces and territories require you to complete certain legal forms to identify your Substitute Decision Maker – you should discuss any requirements with your lawyer. Find out more by visiting www.advancecareplanning.ca and clicking on 'Resources in your Province/Territory' in Quick Links.

In case of a serious illness or injury, there are a number of medical procedures called interventions, which can prolong life and delay death. These could include mechanical ventilation, tube feeding, intravenous fluids or other treatments (see our Word List on pages 9 and 10 for more information). It is important to think about your wishes for 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 having 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 survival, 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, etc.):

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, etc.)

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 – The CANHELP tool 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 (either by the patient nearing the end of life, their caregiver or a health professional), a customized report is produced providing 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)

Living Will Location: _____

Power of Attorney Location: _____

Will Location: _____

Other (e.g. organ donation, specific bequests, etc.)

Name of document: _____

Location: _____

Congratulations on taking the first step!

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

Start the conversation about end-of-life care.

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

Talk to your family members, friends and health care team too. They need to know your wishes if you cannot communicate for yourself. Talking now will help to 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.

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