Speak Up Ontario

Advance Care Planning Workbook

Ontario Edition

What's important about your health and wellbeing?
Who will speak for you if you are not capable of making your own healthcare decisions?
Start the conversation.

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Hospice Palliative Care Ontario

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Share what matters to you with others. It's important!

Life can change quickly. Help your Substitute Decision-Maker (SDM) be prepared. Imagine:

Your widowed mom has had a stroke and is unable to speak for herself. Do you know what's important to her (what she values) and how she would want you to approach making decisions for her? Who would make health and personal care decisions on her behalf? Who would be your mother's Substitute Decision-Maker (SDM)? You? Your siblings?

You have been in a serious car accident. You have lost the ability to speak for yourself or make decisions. Have you talked to your SDM(s) about what would be important to you if they have to make decisions for you?

You have early dementia and you want to prepare your family to act as your SDMs in the future. Have you thought about what they should know so they can make the best decisions for you if they need to?

We cannot know what future healthcare decisions we may face, but we do know what quality of life means to us and what values and wishes inform our health care decisions. Your SDM(s) needs to know that too.

Information in this workbook includes:

WHAT is Advance Care Planning (ACP)?
WHY is ACP important?
WHO is your SDM?
WHAT would your SDM do?
WHAT should you talk about with your SDM?

All about Advance Care Planning

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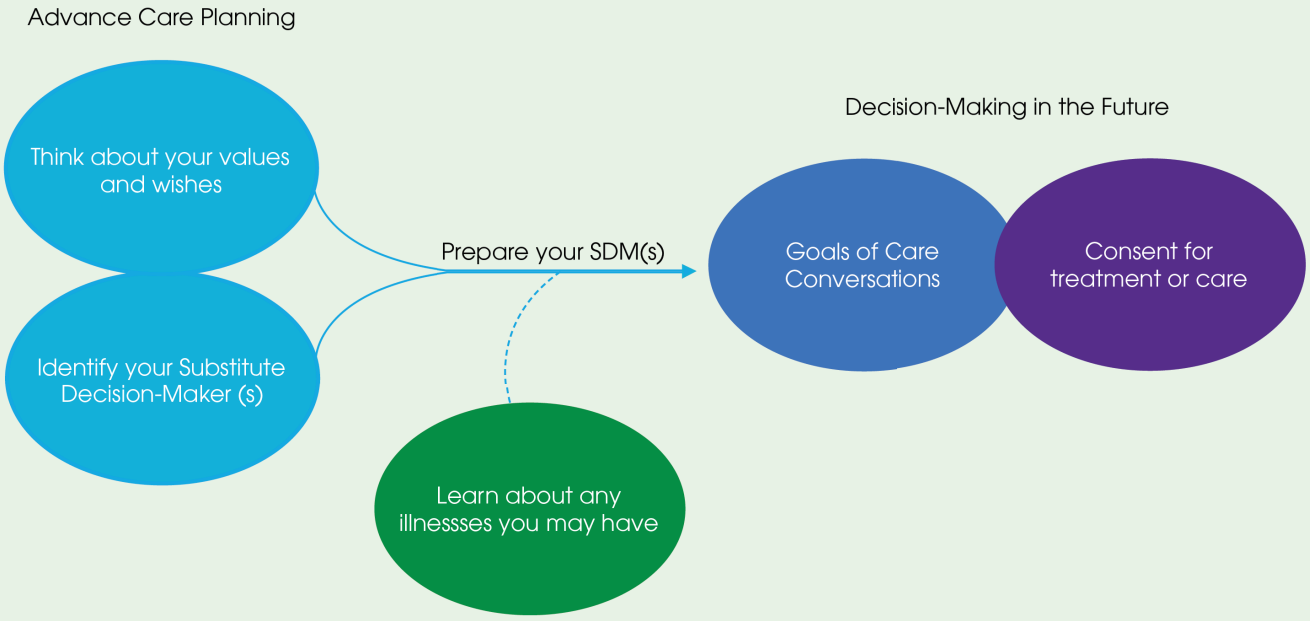
What is Advance Care Planning?

- Advance Care Planning (ACP) is learning who would be your Substitute Decision-Maker(s) (SDMs) under Ontario law and deciding if this is who you want in the role (more about this on pages 8 and 9).
- ACP helps you reflect on and share your values, beliefs, and wishes for future care.
- ACP is about sharing your values and beliefs with your SDM(s). It is a way to help prepare your SDM(s) to make healthcare decisions for you in the future if ever you were unable to speak for yourself.
- ACP is NOT about making decisions now for treatments in the future.



This is Althea. She is 72 years old. She is healthy other than an occasional cold and arthritis in her left knee. Althea is not married . Her mother is 96 years old and she has two sisters.

This is Bob. He is 76 years old. Bob has been told his trouble breathing is because he has heart failure. Bob's wife died 6 years ago and he has 3 children.

Tran is 48 years old. She recently found a lump in her breast. She has been told that it is early stage breast cancer and is now preparing for surgery. Tran is married and has a son and daughter.

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Why is ACP Important?

ACP is important because it prepares your SDM(s) to give consent for treatments in the future if you are NOT mentally capable. Being mentally capable means that you must have the ability to BOTH:

1. **Understand the information** you are given about the decision to be made: Why is the treatment being recommended? What are the benefits of saying Yes or No? Are there any other options?

   AND

2. **Understand what could happen** if you say Yes or No to the treatment: How might it help or harm you? What will likely happen if you have it (or decide not to)?

Your healthcare provider will determine if you are mentally capable to make your own healthcare decisions. (If you disagree in Ontario you have the right to ask the Consent and Capacity Board to review that decision).

If you are not mentally capable of making your own healthcare decisions, your SDM(s) will need to consent for you. It will help your SDM(s) if they understand the things that are important to you. ACP conversations you have today will make it easier for your SDM(s) in the future so they don't have to guess at your wishes in the middle of a difficult time.

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What Kinds of Decisions do SDMs Make?

If you cannot speak for yourself, your SDM(s) will make decisions for your care. These decisions will be based on the conversations you already had about your wishes, values and beliefs.

These decisions could include things like whether or not to:

- have tests, surgery or other medical care
- stop or start a treatment
- move to a long-term care home

How Will My SDM(s) Use My Wishes to Make Decisions in the Future?

Your SDM(s) will be asked to "step into your shoes" when making care decisions on your behalf. That means they have to try and make decisions the way you would want. Talking with your SDM about your values and wishes could help them with this task in the future. For more information, see page 16.

It is important to note that you and your SDM(s) can only consent or refuse consent to a treatment, you cannot demand a treatment: it is up to the health care provider to determine what treatments will be offered based on your health condition.

What Should I Include in Conversations About my Wishes?

Think about what is important to you when it comes to your health and wellbeing. What should your SDM know about you if they have to make healthcare decisions on your behalf?

For example, for some people, being able to communicate and interact with others is most important. Look at pages 12 and 13 for ideas on what to share with your SDM(s).

It's not always possible to know what kind of future health problems you may have. Give your SDM(s) information to help them make many different decisions.

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All about Advance Care Planning

Talking about treatments such as life support or feeding tubes is not helpful on its own. Make sure you also tell your SDM what situations would be ok (acceptable) and ones that are not. For example, a feeding tube may be ok if you have a fixable problem and you can still communicate with people.

Helping your SDM(s) understand your priorities and how you make decisions can be very helpful to them.

ACP conversations may look different if you are healthy or if you are living with an illness or serious health condition. Examples of serious illnesses include heart disease, lung disease, stroke or dementia.

If you are healthy, engaging in Advance Care Planning is like 'insurance' for unexpected events.

When you have chronic or serious health condition(s), ACP includes learning about those conditions and how they may effect your life over time.

Remember:

Your SDM(s) do not make decisions for you unless you are incapable of making decisions for yourself. You can always change your mind about your wishes. Be sure to keep your SDM(s) updated.

See page 8 for more information on identifying your SDM(s).

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When is the 'Right Time' to have ACP Conversations?

The right time is whenever you say it is. It is important to have these conversations when you feel well and you have time to think about what's important to you.

If you are not ready to have a conversation about your values and wishes that's ok. This workbook also gives you information to help you identify who would be your SDM(s). This is an important first step in the ACP process.

Althea, Bob and Tran are three people who may help guide you through the workbook. They are all at different stages of life and health.

How do I Start the Conversation with my SDM? Here are some suggestions:

Be Straight Forward

"My health is good right now, but I want to talk to you about what I might want if I was sick and needed you to make decisions for me. I have a workbook that will help us both understand how to approach this ... maybe I can show it to you?"

Find an Example from your Family and Friends

"Do you remember my friend Frank who was in a coma for a while? I wonder if that is what he wanted or if his family knew what he wanted ... I would like to talk about this while I'm still well."

Refer to Someone Else or Find an Example from the News

"My doctor wants me to think about who would be my substitute decision maker if I was incapable of making my own decisions about health care and suggested I do 'advance care planning'. Will you help me?"

"That story about the family arguing about their mom's care made me realize that we should talk about these things so the same thing doesn't happen to our family."

Althea had not heard about ACP when her nurse practitioner told her about it at a routine visit. She is going to review this workbook and think about her SDM before the next visit.

Bob's brother was recently admitted to the intensive care unit. Bob visited him daily. Bob was also recently admitted to hospital himself. He is worried about his heart and wants to talk about what to expect in the future.

Tran is optimistic about her cancer treatment. But she is worried that her husband may have trouble making decisions for her in the future if he needs to. She wants to prepare him by talking about ACP today.

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Identifying your Substitute Decision-Maker

Substitute Decision-Maker (SDM) is the term used in Ontario law for the person who would make health and some personal care decisions for you if you are unable to do so.

Did you know that everyone in Ontario has an SDM for healthcare decisions, even if they have never specifically identified someone? The Health Care Consent Act includes a hierarchy (ranked list) of SDMs.

Althea's automatic SDM is her mother.

Bob has three children. They would all share the role of his SDM.

Tran's automatic SDM is her husband.

The hierarchy of SDMs includes:

- People who are appointed through a legal process
- Family members that get authority to **automatically** act as SDMs (you don't have to do anything to appoint them)
- An SDM of last resort

The individual(s) highest on this list who meet the requirements to be a SDM in Ontario is your SDM(s). They have the right to act for you under Ontario law. See Speakupontario.ca for more detailed information on the hierarchy.

Court Appointed Guardian	Legally Appointed SDMs
Attorney for Personal Care	
Representative Appointed by Consent and Capacity Board	
Spouse or Partner	Automatic Family Member SDMs
Parents or Children	
Parent with right of access only	
Siblings	
Any other relatives	
Public Guardian and Trustee	SDM of last resort

Ontario's Health Care Consent Act, 1996

Who is your automatic SDM(s)?

The Substitute Decision Maker Hierarchy in Ontario

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To be a Substitute Decision Maker in Ontario you must:

i) Be mentally capable to understand the proposed treatment and the potential outcomes if you agree to or refuse treatment
ii) Be at least 16 years old (unless you are the parent of the person you are making decisons for)
iii) Not be prevented from acting as an SDM by court order or separation agreement
iv) Be available (e.g. in person, by phone or by e-mail)
v) Be willing to act as SDM

What if More than One Person is Entitled to Act as my SDM?

You may have more than one person on the same level of the hierarchy. If they are highest on the list, they would automatically make decisions for you. They must make decisions together (jointly) or decide among themselves which one will act as your SDM.

For example, if you have three children (#5 on the list), all three are entitled to act as your SDM. They must act jointly and agree on any decisions for your health care or they can agree that only one of them will make decisions for you. The health professionals cannot pick which one of the three should make decisions for you. The three children must decide among themselves whether they will all act together or if only one of them will.

If people who are equally entitled to act as your SDM cannot agree on the decisions about your treatment, the Public Guardian and Trustee is required to act as your SDM. The Public Guardian and Trustee does not choose between the disagreeing decision-makers but makes the decision instead.

What Else is Important to Consider about your SDM(s)?

Your SDM(s) should be someone who you feel would understand and honour your wishes:

- Do I trust this person(s) to make decisions that reflect my wishes even if they disagree with them?
- Can they make decisions under stress?
- Can I talk with this person(s) about my wishes, values and beliefs?
- Can they communicate clearly with my health team in a stressful manner?

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Power of Attorney for Personal Care

Althea chose to appoint her two sisters as joint Attorneys for Personal Care instead of her mother who would be her automatic SDM.

Bob's children do not get along. After reviewing the role of the SDM, he decides to appoint his middle son as Attorney for Personal Care.

Tran is comfortable with her husband as her automatic SDM.

NOTE:
A Power of Attorney for Personal Care does NOT give the individual the ability to make decisions about your property or finances. For property and finances, you must prepare a Power of Attorney for Property.

What if I want to choose someone to be my SDM(s)?

If you don't want your automatic SDM(s) from the hierarchy (page 8) to make decisions for you, you can choose a person, or more than one person, to act as your SDM(s) instead. You would do this by preparing a document called a Power of Attorney for Personal Care (POAPC). The POAPC is one type of SDM and is ranked second in the automatic hierarchy.

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 SDM. In order to sign a POAPC you must be over the age of 16. You must also be mentally capable of understanding the document and any instructions you may include.

To be valid, the document must:

- be signed by you voluntarily, of your own free will
- be signed by you in the presence of two witnesses
- be signed by two witnesses in front of you.

More information about Ontario Power of Attorney for Personal Care can be found at:

- Ontario Ministry for the Attorney General
  https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf
- Advocacy Centre for the Elderly
  http://www.advocacycentreelderly.org/
- Community Legal Education Ontario
  www.cleo.on.ca

Questions About SDMs and Communicating Wishes

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How do SDMs Make Decisions?

Your SDM should not make decisions for you based on their wishes or values. They need to make decisions for you that honour and apply the wishes, values and beliefs that you shared with them when you were mentally capable.

If your wishes are not known, your SDM(s) must act in your "best interests." "Best interests" has a specific meaning in law: your SDM must consider your values and beliefs. They would also consider:

- your health condition
- if you were likely to improve, remain the same or deteriorate without the treatment
- the risks and benefits of the treatment options

SDMs do not have to follow a wish that is impossible to honour. There are many things that can make a wish impossible to honour. Decisions will depend on your health and care needs, finances and the number of people around you who can help care for you. For example, you may tell your SDM that you wish to remain at home but there may be times when a hospital or long-term care home is the best place to receive care based on your needs.

How do I Communicate my Wishes?

In Ontario, you can share your wishes about future health care and treatment any way you would like to communicate them. You could speak to your SDM(s) or write it down. You could make a video or use a picture board. You can make changes to these wishes in any of these same ways.

It is a good idea to also have these conversations with your family and friends. They can help support your SDM(s) make a difficult decision about your care.

What is the difference between an Attorney for Personal Care and an SDM?

An Attorney for Personal Care (POAPC) is one type of SDM. They are the second highest on the list of SDMs.

Remember:

Consent is always given by a person – either you, if mentally capable, or your substitute decision maker – never by a piece of paper.

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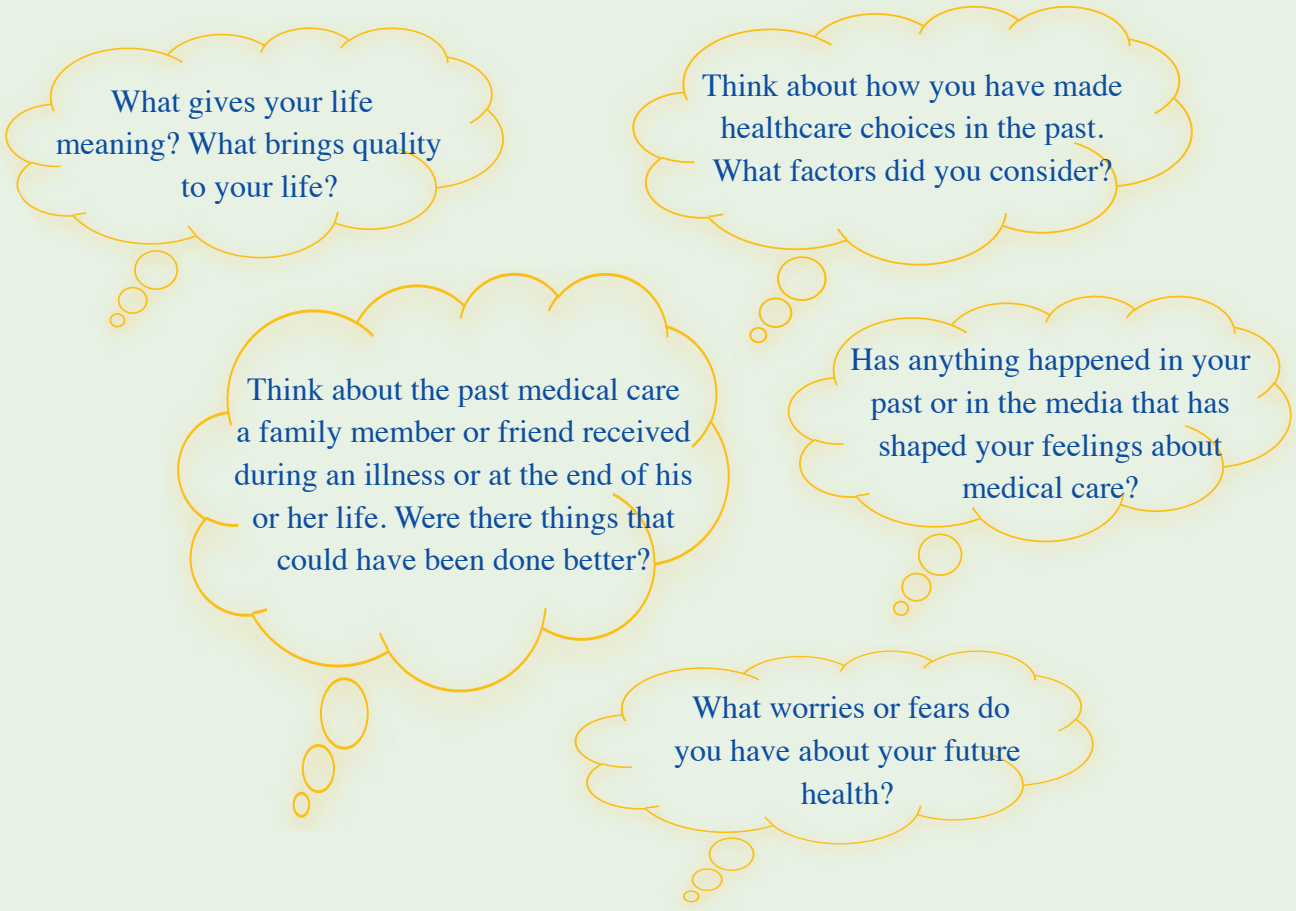
Think about your values & wishes

Think about what is important to you

Who we are, what we believe, and what we value are all shaped by our personal experiences. Our cultural and personal values, family traditions, spiritual beliefs, customs, work, and those close to us affect us deeply. This is important whether you are healthy or if you are living with a health condition.



Think about how to share your thoughts with your SDM(s)

Your SDM(s) may have to make a variety of healthcare decisions for you in the future. It is hard to know what kind of care or treatment decisions they may need to make.

Think about what kind of information would be helpful for them. Involving your SDM(s) in the conversation gives them a chance to ask you questions.

If you are not sure who your SDM(s) will be, it is still important to think about this and share this information with your healthcare provider.

Think About Your Values

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Your values help you make important life decisions including healthcare decisions. Values are very personal and each person may think about them differently.

Most people have an idea of what a 'good life' is.

Take some time to think about the things that are important to you and that make your life meaningful or enjoyable.

Consider this brief list of personal values. Which are the most important to you?

- Dignity
- Independence
- Wellness
- Clear-mindedness
- Other _____
- _____
- Family
- Hard work/dedication
- Strength
- Spirituality
- Not being a burden
- Relationships

Describe what your most important values mean to you

_____

_____

_____

_____

These questions may help you think more about what is important to you:

What does having dignity mean to you?
What comes to mind when you think of losing your dignity?
What does independence mean to you?
What comes to mind when you think about being dependent on others?
If spending time with family is important, what is it about spending time with family that makes it so important?

Remember:

ACP conversations prepare your SDM(s) for future decision-making. If family is important, help them understand what this means to you. As an example, for some, this means being able to communicate (verbally or nonverbally) and interact.

Explain to your SDM(s) what situations would be acceptable and unacceptable to you.

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Learn about your Health Condition

This section is intended for those who are living with a chronic or serious illness. If you are healthy proceed to page 15.

Think about any illnesses you may have. As part of the ACP process, consider the following:

- What do you already know about your illness?
- What would you like to know about your illness? For example, will it get better or worse? Or how will it impact your life as you get older or as the illness progresses?
- What information would help you plan for the future?

What kind of questions could I ask my healthcare providers?

Ask them whatever you like. It's your health and you have a right to be informed. Here are some suggestions of things you could ask:

- Can my illness be cured?
- What effect will the treatments have on my illness? Can I expect to get better?
- What should I expect in the next 6 months, 1 year, 5 years?
- How will this illness affect my ability to live independently? To walk? My memory?
- What are some possible major changes that my family and I should be prepared for?

Notes and questions to ask my healthcare provider

Putting it all Together

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When you confirm your future SDM(s) and share your wishes, values and beliefs with them, you are engaging in advance care planning. ACP gives those around you the confidence to make decisions on your behalf, helps reduce their anxiety and allows them to better understand and honour your wishes.

By engaging in ACP, your rights as a patient will be respected when you are mentally incapable because your SDM(s) will know what is important to you. Your SDM(s) will be prepared to make decisions for you in the way that you would want.

Below are some questions you can ask yourself to help you start thinking about how to have these conversations.

1. What do I understand about my health or illness? What have I been told about my illnesses?

2. What information would I like to find out?

3. What do I value most? What brings quality or meaning to my life?

4. What concerns or worries do I have about how my health may change in the future?

5. What might I trade for the chance of gaining more of what I value or what's important to me (e.g. more time with family)?

6. Other thoughts:

Thinking about trade-offs:

The side effects of cancer treatment might be ok, if you could get more quality time with family or if you might be able to live until an important life event (graduation, wedding, etc).

But there might come a time when comfort and quality of life become more important, even if it means a little less time.

Let your SDM know what is acceptable to you. And what is unacceptable.

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Other Frequently Asked Questions

Why share your wishes, values and beliefs with your family and friends if only your SDM(s) can make decisions for you?

Your SDM(s) may need help or support with making a healthcare decision for you. If your family and friends know your wishes, values and beliefs, they can help your SDM(s) make a decision. You do not have to share your wishes with anyone other than your future SDM(s), but think about whether it would help your SDM(s) for others to know. It may also help in case your SDM(s) isn't available at the time a decision is needed. In this case, the decision will go to the next person in the hierarchy who meets the requirements to be an SDM(s). It would help them to make a decision if they also know your wishes.

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

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 relieve any pain or suffering or to address any risk of serious harm. If your healthcare providers know of any wishes you have expressed about your care, they must honour those wishes.

Once you are stable, the health care providers will need to determine who your SDM(s) are. They will likely contact them so that they can make ongoing health decisions for you until you are capable of doing so for yourself. You can carry a wallet card* (see page 23) that identifies your SDM(s) and their contact information.

It will also help if you:

- confirm your SDM(s) and speak with them now — while you are well.
- make sure your family and friends know who will act as your SDM(s)
- tell the people who are close to you where you keep any important documents.
- share your wishes, values and beliefs with your family and friends (not just your future SDMs) so they can support your SDM (s).

Other Frequently Asked Questions

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I have a "living will". Is that good enough?

Even if you write your wishes down in a "living will" or "advance directive", your SDM(s) will still be asked for consent before any treatment is started. In Ontario, the law does not use terms such as "living will" or "advance directive". In Ontario, you do not have to write your wishes down in any kind of document. You can share your wishes about your future care in whatever way you want. For example, you can share your wishes in a conversation or in a recording. Your SDM(s) is required to follow your healthcare wishes regardless of how you have shared them. If you do share your wishes in a document, it does not need to be witnessed or signed. If you do write your wishes down, remember to update the document if your wishes change.

You cannot appoint someone to act as your SDM in a "living will" or any other written document. In Ontario, you can only appoint SDM(s) through a documebt called a Power of Attorney for Personal Care.

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Notes

My Substitute Decision Maker(s)

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I have discussed/or will discuss my wishes for future healthcare with my SDM(s) named below. Based on the hierarchy of SDM in Ontario Law, I belive that at the time of completion:

My substitute decision maker(s) are:

There is more than one person at the same level of the heirarchy
No ☐ Yes ☐ How many ☐

First and last name:

Relationship of this substitute decision maker to me:

Phone number:

Alternative phone number:

Address:

E-mail address:

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):

Complete this section if there is more than one person at the same level of the hierarchy

First and last name:

Relationship of this substitute decision maker to me:

Phone number:

Alternative phone number:

Address:

E-mail address:

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):

Just because you have listed the names of people to be your substitute decision maker in this workbook that does NOT mean that these people have the right to be your SDM(s) in the future. The SDM(s) will need to be:

- The highest-ranking people in your life on the hierarchy list of SDM(s) AND
- Meeting the requirements of being an SDM.

This workbook is NOT a Power of Attorney for Personal Care

Additional notes about my SDM(s):

Your SDM will only make decisions for you if you are not mentally capable. It is a good idea to also have ACP conversations with your family, friends and healthcare providers so that they can support your SDM(s) to make decisions if they have to. Unless it is an emergency, your healthcare provider must get consent for treatment (from you, or your SDM if you are incapable), even if they know your wishes.

I have also discussed my wishes with the following people:

Name	Relationship to me	Contact Information

Congratulations on Beginning the Process!

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You have already taken an important step by taking the time to work through this guide and talk with others.

If you have done this in preparation for meeting with your healthcare provider, it may be helpful to write a few things down. He or she may ask the same questions that you have gone through using this guide.You may also have questions for your healthcare provider.

Make sure to share your wishes and values with your SDM(s). Keep them updated, as health and life circumstances change and may impact your wishes for future health care decisions.

Talk to your family members, friends, your doctor and healthcare team. Sharing your wishes, values and beliefs also helps them support your SDM, who may have to make difficult decisions during a stressful time.

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First and last name:

Your date of birth:

Your health card number:

Your address:

Your phone number:

Your e-mail address:

Remember:

In Ontario you can express wishes about future healthcare by talking to your SDM, as well as in written documents. If you choose to record your information and thoughts on your wishes, you may use the space provided in this section. Share this information with your SDM(s), family and friends.

Date:

Additional thoughts:

Speak Up Campaign

Speak Up Ontario, a partnership between Hospice Palliative Care Ontario (HPCO) and the Canadian Hospice Palliative Care Association (CHPCA), began in February 2012. The Ontario Speak Up Campaign is coordinated by Hospice Palliative Care Ontario and provides education and Ontario-based tools and resources that comply with Ontario laws.

About this Workbook

The Ontario Alzheimer Knowledge Exchange Health Care Consent Advance Care Planning Community of Practice adapted the original version of the National Speak Up Workbook to create an Ontario edition and supported the work until the spring of 2013. The responsibility then moved to Hospice Palliative Care Ontario (HPCO) where it is led by a dedicated group of Health Care Consent (HCC) Advance Care Planning (ACP) expert leaders through a HCC ACP Community of Practice. The second edition, the 2018 version of the Ontario workbook, is intended for everyone at any age who is ready to start advance care planning conversations.

WHEN A HEALTH CARE DECISION IS NEEDED:

My Subsitute Decision Maker

Relationship to me:

Tel:

Alt Tel:

Name.

Date:

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Acknowledgements

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- The GlaxoSmithKline Foundation (CHPCA)
- The Ontario Ministry of Health and Long-Term Care (HPCO)

For more information about Health Care Consent & Advance Care Planning in Ontario, please visit:
www.speakupontario.ca

or contact:

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www.hpco.ca
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WHEN A HEALTH CARE DECISION IS NEEDED

I have a Substitute Decision Maker who understands my wishes and can make health care decisions for me if I am mentally incapable of making decisions for myself.

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