Speak Up Ontario

Advance Care Planning Workbook Ontario Edition

Who will speak for you?
Start the conversation.
It's how we care for each other.

HPCO
Hospice Palliative Care Ontario

Speak Up Ontario c/o
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Toronto, Ontario M5B 1J3

www.speakupontario.ca

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Speak Up

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.

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

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The information in this workbook is intended as a public service and for general reference only. Every effort is made to ensure the accuracy of the information. 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 any questions about your or someone else's legal rights, speak with a lawyer or contact a community legal clinic.

What you Have to Say is Important!

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Life Can Change in an Instant. Imagine:

You have been in a serious car accident. You have lost the ability to speak for yourself or direct your care. You do not recognize your family or friends. Do you know who would make health and personal care decisions for you?

Your widowed mom has had a stroke and is unable to speak for herself. Do you know what kind of care she would have wanted if able to speak for herself? Who would be your mother's "substitute decision maker"? Who would make health and personal care decisions on her behalf? You? Your siblings?

You are planning a trip and have taken out travel insurance to prepare in case something goes wrong. Do you know how important it is to also talk to family and friends about the possible emergency health care you would want?

Your health or personal care circumstances can change quickly and without warning. None of us know what tomorrow will bring. We cannot always predict if, or when, we will need to rely on others to make health or personal care decisions for us, or when we will be called on to make these decisions for a family member.

This resource can help you become familiar with advance care planning in Ontario and how it can help you prepare for a time when you may not be able to make health decisions for yourself and when someone else - your substitute decision maker - would have to make decisions for you.

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What is Advance Care Planning?

In Ontario, advance care planning (ACP) is

- Confirming your substitute decision maker(s) (SDMs)

and

- Communicating your wishes, values and beliefs about care to help your SDM(s) make health and personal care decisions for you if you become mentally incapable of doing so for yourself.

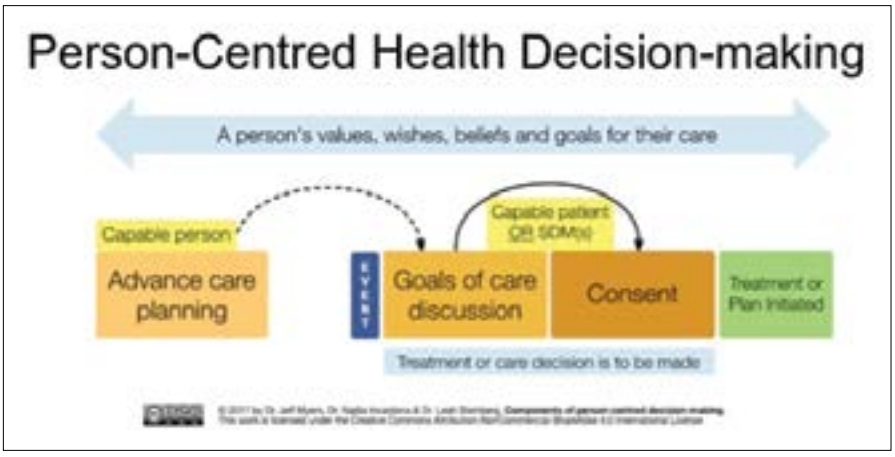
Why is this Important?

In Ontario, the law requires all health care providers to get informed consent, or refusal of consent, before providing a patient with any treatment or care. Health practitioners must tell you about your illness and what may be done to treat you. You then have the right to make a decision and agree to or refuse the treatments offered. **This is called health care consent**: it is a basic patient right to decide what health care to receive.

Only in emergencies, to save a life or to reduce suffering, can people be treated without informed consent. Consent always comes from a person: either the mentally capable person or their substitute decision maker(s).

If you are not mentally capable, the health practitioner will turn to another person, **your substitute decision maker**, who will then speak for you and make the decision about your care. Advance care planning lets you know who would speak for you.

<u>Advance care planning is not about decisions</u>. It is about preparing you, and your future substitute decision maker(s), for a time when you may not be able to make your own health or personal care decisions because of your lack of mental capacity. At that time, your future SDM would step in to give or refuse consent for treatment.



Person-Centred Health Decision-making

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You make your own decisions about any health care as long as you are **mentally capable** – that is, as long as you have the ability to understand and appreciate information relevant to making that decision.

Ontario law defines capacity as:

Having the ability to understand information that has to do with making a decision about the treatment, admission or personal assistance service

and

Having the ability to appreciate the likely consequences of a decision or lack of decision.

If you become mentally incapable for any particular health decision, then your SDM would be the person who would make health decisions for you.

Health practitioners are required to get your informed consent, or refusal of consent, to treatment or other health care decisions before providing treatment or other health care. If, in the opinion of the health practitioner, you are not mentally capable to make a treatment or other health care decision, then the health practitioner must get the consent or refusal from your substitute decision maker.

Who Determines Mental Capacity?

The health care provider proposing the treatment will determine if you are mentally capable of consenting to or refusing treatment. If you are found incapable, you have the right to ask the Consent and Capacity Board to review that finding. The health care provider who believes you are mentally incapable must tell you about that right of review.

What is Informed Consent?

Informed consent refers to the permission you give health care providers for medical investigations and/or treatments. It is an informed decision made after you have been given information about your current health condition and the treatment options. Health care providers are required to offer you — and you are entitled to receive — detailed explanations of the investigations/treatments including:

- their risks
- their benefits and side effects
- any alternatives to these options
- 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 consent.

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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What is a Substitute Decision Maker?

The term used in Ontario law for the person who would make health and personal care decisions on your behalf when you are unable to do so is "substitute decision maker".

There are two ways to identify who would be your SDM in Ontario:

a. The Health Care Consent Act provides a hierarchy (ranked listing) of your possible automatic SDMs. The individual(s) highest on this list who meets the requirements to be a SDM in Ontario is your automatic SDM. You don't have to do anything to have this automatic SDM make decisions for you when you are mentally incapable of doing so because this SDM has the right to act for you by this law.

OR

b. If you are not satisfied with your automatic SDM then you can choose and name a person, or more than one person, to act as your SDM by preparing a document called a Power of Attorney for Personal Care (POAPC).

Requirements to be a Substitute Decision Maker in Ontario:

i) Being mentally capable of understanding the treatment/care being proposed and appreciating the consequences of consenting or refusing the treatment decision

ii) Be at least 16 years old (unless you are the parent of the incapable person)

iii) Not prohibited by court order or separation agreement from acting as SDM

iv) Available in person, by phone or via electronic communication

v) Willing to act as SDM

The Substitute Decision Maker Hierarchy in Ontario

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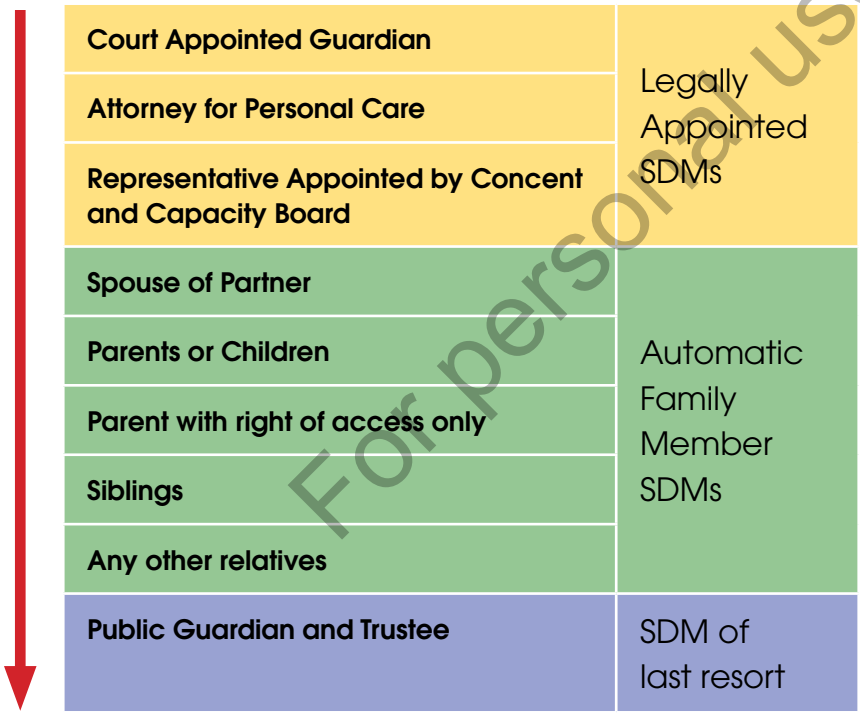
Did you know that everyone in Ontario has a SDM even if he or she has never prepared a Power of Attorney for Personal Care appointing someone to act in that role? The Health Care Consent Act includes a hierarchy of SDMs that includes:

- three different types of SDMs that get authority through different types of legal processes,
- family members that get authority to **automatically** act as SDMs without being appointed – you don't have to do anything, and
- an SDM of last resort.

The person, or persons, in your life ranked highest in the substitute decision maker hierarchy who meet(s) the requirements to act as a substitute decision maker will be your SDM(s) for health care. See next page a detailed description of the hierarchy.



Ontario's Health Care Consent Act, 1996

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(continued)

The Substitute Decision Maker Hierarchy in Ontario

Description of SDM Hierarchy Terms

Possible SDMs	Description
1. Guardian of the person	Someone appointed by the court to be your substitute decision maker.
2. Attorney named in a Power of Attorney for Personal Care	The person or persons YOU have chosen to be your substitute decision maker if you prepared a Power of Attorney for Personal Care when you were mentally capable of doing so.
3. Representative appointed by the Ontario Consent and Capacity Board	A family member or friend who applies 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.
4. Spouse or partner	Two persons are "spouses" if they are: a) Married to each other; or b) Living in a common law 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 because 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. Partners 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	The person who has the legal right to give or refuse consent for treatment. 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, then the parent would not have the legal right to be a substitute decision maker.
6. A parent who only has a right of access	If someone who has the legal right to give or refuse consent for treatment for a child is not available, then a parent who only has a right of access is the substitute decision maker.
7. Siblings	If you have a number of siblings that meet the requirements of an SDM, they are all EQUALLY ranked.
8. Any other relative (see the next page if you have more than one relative)	People are relatives if they are related by blood, marriage or adoption. If you have a number of relatives that meet the requirements of a decision maker, they are all EQUALLY ranked.
9. Public Guardian and Trustee	If no person in your life meets the requirement to be a substitute decision maker, then the Public Guardian and Trustee of Ontario, a public government organization, is your substitute decision maker.

Questions About the Substitute Decision Maker

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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 one level in the hierarchy and they are the highest ranked highest in the hierarchy, they must make decisions together (jointly) or decide among themselves which one will act as your substitute decision maker.

For example, if you have three children (#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 agree that only one of them should make decisions for you, then that one child may 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 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 SDM and they cannot agree on the decisions about your treatment, the Public Guardian and Trustee is required to act as your substitute decision maker. The Public Guardian and Trustee does not choose between the disagreeing decision makers but makes the decision instead.

What Kinds of Decisions do SDMs Make?

Decisions include:

- consenting to tests, surgery, procedures or other medical care
- starting or refusing treatment or withdrawing life prolonging measures
- admission or discharge from a medical facility
- moving into or receiving personal care in a long-term care home.

These decisions should be based on your previously expressed wishes, values and beliefs.

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Questions About the Substitute Decision Maker

(continued)

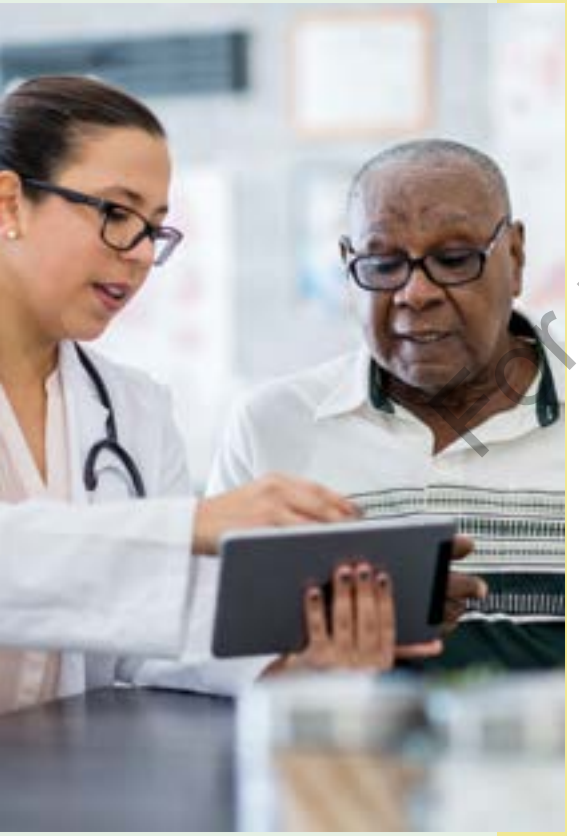
How do SDMs Make Decisions?

When your substitute decision maker has to step in and make decisions for you, he or she is required to honour and apply the wishes, values and beliefs that you communicated when you were still mentally capable.

If your wishes are not known, your SDM is required to act in your "**best interests**". "Best interests" has a specific meaning in law. It involves your SDM considering the values and beliefs you had when capable. In addition, the SDM would 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. For example, you may communicate to your future SDM that you want to receive treatment in your home and not a hospital. These types of wishes may be impossible to honour depending on many factors, including your actual state of health, your care needs, the availability of public or private home care, financial resources and the availability of family and others to help care for you in your own home.



What Else is Important to Consider about your SDM?

Your SDM should be someone who you feel would understand and honour your wishes: someone who would be able to make health or personal care decisions on your behalf.

Consider:

- 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 engage the person(s) in conversations about my wishes, values and beliefs as they relate to future health or personal care?
- Can they communicate clearly with my health team in a stressful situation?
- Is this person willing and available to speak for me if I cannot speak for myself?

Power of Attorney for Personal Care

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What if I Want to Choose Someone to be my SDM?

Everyone in Ontario has an automatic substitute decision maker. However, if you are not satisfied with your automatic SDM then you can choose and name a person(s) to act as your SDM 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 substitute decision maker.

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.

You must also be mentally capable of understanding and appreciating the 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 at:

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

Notes

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.

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Questions about Communicating your Wishes

Why Share my Wishes?

The purpose of sharing your wishes, values and beliefs is to help your SDM(s) "step into your shoes" when making care decisions on your behalf. In other words, you are trying to help your SDM become aware of your values and what is meaningful in life for you, understand **how** you make decisions and give them information that will help guide their decision-making about your care.

What Should I Include in my Wishes?

You do not have to make specific statements about treatments you would want or not want. It is often not possible to give directions about specific treatments because it is hard to predict your future health problems. It is important to note that, by sharing your wishes, values and beliefs, you **are not** giving consent to treatment.

How do I Communicate my Wishes?

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 using a computer or picture board. You can make changes to these wishes in the same way- orally, in writing or through alternative means of communication.

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

Who should have Advance Care Planning (ACP) Conversations?

Everyone at any age! Advance care planning is not just about end of life care. Any adult (age 16 or older) needs to understand who would be their SDM if they were not able to provide their own consents to health care.

Advance care planning is important for:

- Healthy individuals
- Individuals at early stages of a serious illness
- Individuals at later stages of a serious illness

How do I Start the Conversation?

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There are many ways to get the conversation started! Remember, it may take a few attempts. Don't feel that you must have the entire conversation at once. These conversations may seem natural or it may take a few conversations to feel comfortable.

If you are having difficulty getting the conversation started, try these strategies:

Be Straight Forward

Examples:
"I have just filled out a workbook and learned about how important it is to share my wishes for future health care and I want to share it with you."

"My health is good right now, but I want to talk to you about what I'd might want if I was sick and needed you to make decisions for me."

Find an Example from your Family and Friends

Examples:
"Does anyone know how Jason's sister died? No one ever talked about it. I wonder if she died at home or in a hospital?"

"Do you remember my friend Frank who was in a coma for a while? I wonder if there was any argument about keeping him on that ventilator?"

Blame Someone Else

Examples:
"Pastor Jones was talking about what our wishes for health care would be if something happened, and I realized that I haven't told you about my own wishes. We should talk about that."

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

Find an Example from the News

Examples:
"Remember the man who was in a coma for years? I would never want that to happen to me."

"That story about the family fighting 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."

It is important to keep in mind that circumstances change. Your health condition may change and your beliefs, values and wishes can change, so you should keep having these important conversations with your SDM, family and friends.

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Other Frequently Asked Questions

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

Your SDM may need help or support with making a decision on your behalf. If your family and friends know your wishes, values and beliefs, they can help your SDM make a decision. You are not required to share your wishes with anyone other than your future SDM, but think about whether it would help your SDM for others to know. In addition, your SDM may not be available to make a decision at the time it is needed, in which case the decision will go to the next person in the hierarchy who meets the requirements of an SDM. That person will need to make a decision for you and will need to 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 bodily harm. If your health 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 is (automatic or person named in POAPC) so your SDM can make ongoing health decisions for you until you are capable of doing so for yourself.

It is important to confirm your SDM and engage in those conversations now — while you are well.

Make sure your family and friends know who will act as your substitute decision maker. Your SDM will likely be contacted if an emergency occurs. You can carry a wallet card* (see page 19) that identifies your substitute decision maker(s) and their contact information. Communicate to those close to you where you have stored any important documents. It is also important to share your wishes, values and beliefs with your family and friends (not just your future SDM) so they can support your SDM.

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

In Ontario, the law does not use terms such as "living will" or "advance directive" and there is no requirement to record your wishes. A "living will" is commonly thought of as a document in which you list your wishes about medical treatments. However, the law does state that a person can express wishes about their future care orally, in writing or by any alternative means. You can set out your wishes in a written document or "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 "living will" has no particular "form" in Ontario and does not need to be witnessed or signed.

You cannot appoint someone to act as your substitute decision maker in a "living will" or any other written document. In Ontario, you can only appoint a substitute decision maker through a Power of Attorney for Personal Care.

Putting it All Together

When you confirm your SDM(s) and share your wishes, values and beliefs with them, you are engaging in advance care planning. Advance care planning 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 advance care planning, your rights as a patient will be respected when you are mentally incapable because your SDM will know what's important to you. Your SDM 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 need to think about or do before I feel ready to have the conversation?

2. What makes my life meaningful? (e.g. time with family or friends, faith, love for garden, music, art, work, hobbies, pet)

3. What do I value most? Being able to _____ (e.g. live independently, make my own decisions, enjoy a good meal, have my privacy upheld, recognize or talk with others)

4. What are the three most important things that I want my SDM, family, friends and/or health care providers to understand about my future personal or health care wishes?

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

6. Other thoughts:

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Preparing for the Conversation

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 health care orally 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.

My Substitute Decision Maker(s)

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I have discussed/or will discuss my wishes for future health care with my SDM(s) named below.
Based on the hierarchy of SDM in Ontario Law:

1. My substitute decision maker is:

   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):

   If more than one person is equally ranked in the hierarchy:

2. My substitute decision maker is:

   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 act as your SDM unless:

They are the highest-ranking people in your life on the hierarchy list of SDM(s) and meet the requirements of being an SDM, OR

You name them in a Power of Attorney for Personal Care and they met the requirements of being an SDM.

This workbook is NOT a Power of Attorney for Personal Care

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Share Your Wishes

Some notes that share my wishes

It is also important to share your wishes, values and beliefs with your family, friends, doctor and health care team so they can support your SDM. Even if your doctor and health team know your wishes, they still must turn to you, if capable, or to your SDM if you are incapable to get consent before they provide you with treatment or any other health care, subject to the emergency exception.

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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Now that you understand advance care planning in Ontario and have begun to think about your wishes and who will speak for you if you are unable to speak for yourself - start the conversation!

Talk to your future SDM(s) about your wishes. Your SDM(s) may have questions or may want to discuss more details about your values and beliefs or how you make decisions for yourself.

Talk to your family members, friends, your doctor and health care team. Talking now will reduce anxiety and help everyone understand and honour your wishes. Sharing your wishes, values and beliefs also helps them support your SDM who may have to make difficult decisions during a stressful time.

The choices you make for yourself and others are important. Make sure your voice is heard!

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

Your Substitute Decision Maker Wallet Card

You can carry a wallet card that identifies your substitute decision maker(s) and their contact information.

WHEN A HEALTH CARE DECISION IS NEEDED:

My Subsitute Decision Maker

Relationship to me:

Tel:

Alt Tel:

Name.

Date:

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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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