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My Health, My Wishes.

Advance Care Planning Workbook

Most people will develop a chronic illness during their lifetime. It's important to plan ahead, for a time when you may not be capable of making your own healthcare decisions.

This workbook can help you start thinking about what's important to you about your health and your healthcare. It can help you start conversations with your substitute decision-maker (SDM), family, close friends, and healthcare providers.

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HealthLink
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Let's Make Healthy Change Happen

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What is Advance Care Planning?

- When decisions need to be made about your care in the future, your healthcare providers will need to explain things and answer your questions.
- They will need to get your permission (consent) before they treat you.
- If you are **not capable** of making your own healthcare decisions, your substitute decision-maker(s) (SDM) will need to consent for you.

- Advance Care Planning is an opportunity to reflect on your values, beliefs, and wishes for future care.
- It is a way to help prepare your SDM(s) to make decisions for you in the future.
- It is learning about who your automatic SDM(s) are and deciding if this is who you would like in this role.
- It is a way to give your SDM(s) peace of mind if they must make decisions about your healthcare at difficult times.

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 tell your SDM(s) about any changes.

Your SDM(s) may never need to make a decision for you. However, if they are asked to provide consent for your care in the future, it will be helpful for them to know what's important to you.

What does it mean to be capable of making a healthcare decision?

It means you are able to **BOTH:**

1. **Understand the information you are given about the decision to be made.**
   - Why a treatment is being recommended, the risks and benefits of saying Yes or No, and if there are other options;

AND

2. **Appreciate the reasonably foreseeable consequences of saying Yes or No to the treatment.**
   - How it might help or harm you, and what will likely happen if you have it (or decide not to have it).

Advance Care Planning

Think about what's important to you and how your values help you make healthcare decisions.

Learn about your health and any medical conditions you have.

Decide if you are happy with who your substitute decision-maker (SDM) is. This is the person who will make healthcare decisions for you in the future if you are no longer capable of making them for yourself. **In Ontario, everyone automatically has an SDM.** To learn more see Page 5 of this workbook.

Talk about your values, beliefs, and what is important to you with your SDM, your family, and your healthcare providers.

Record or Communicate your wishes and what's important to you. **You should talk to your SDM about your wishes.** You may also put them in writing, on video, or in any form you choose. Your SDM(s) will be asked to give consent for your care in the future if you are incapable.

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.

What gives your life meaning? What brings quality to your life?

Think about how you have made healthcare choices in the past. What factors did you consider?

Think about the past medical care a family member or friend received during an illness or at the end of his or her life. Were there things that could have been done better?

What fears or worries do you have about your condition?

How do your decisions about your condition, your care, and your treatments affect your loved ones?

Has anything happened in your past that has shaped your feelings about medical care?

To help you think more about what's important to you, see the values exercise on page 6 of this workbook.

LEARN about your present health

"Advance care planning is like retirement planning — it is important to start early, even if you don't need it for many years to come." – Healthcare Provider

You might have a number of questions about your health and your medical condition(s). Or even about possible treatments.

Learning about your medical condition(s) and what you can expect can help you decide what is most important to you.

In addition to any condition(s) you may have, a more immediate situation might arise because of a serious illness or injury, such as a car accident or a stroke.

Here are a few general questions to help you learn more about your health and condition(s).

What effect will this disease (e.g. heart disease, lung disease, kidney disease, diabetes, dementia, cancer) have on your life?

What are your options when your health gets worse?

Are the treatment and medication meant to cure your condition or just make you more comfortable or both?

Think about what your spirituality means to you:

How do your spiritual values affect the way you make healthcare decisions?

Talk with your spiritual leaders if this will help you.

What I need to ask my doctor and healthcare providers about my health:

Is my illness curable?

Can you tell me how this disease progresses?

Can you tell me what I can expect from this illness? What will my life likely look like 6 months from now, 1 year from now, and 5 years from now?

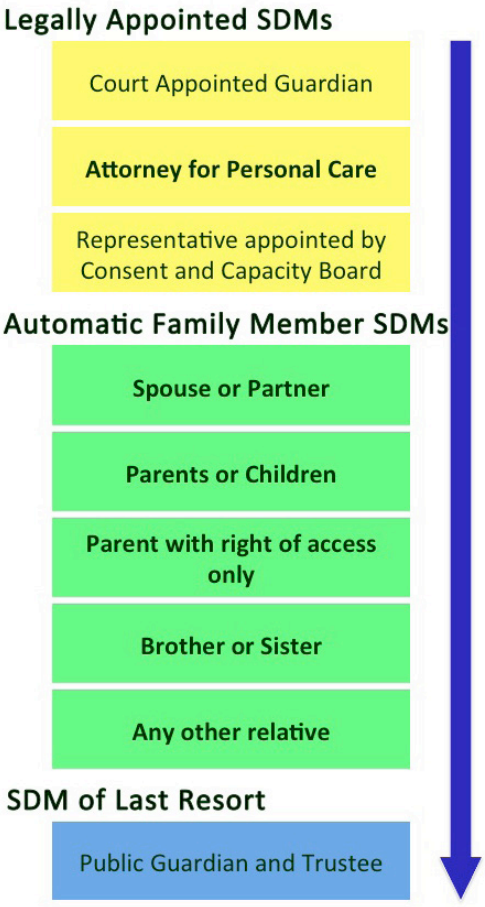
How will this condition affect my ability to function independently?

What are some possible major changes in my health that my family and I should be prepared for?

In what way can I expect my health to improve (or not improve) if I choose this course of treatment, or another course of treatment?

DECIDE about your Substitute Decision-Maker (SDM)

In Ontario, **everyone automatically has a Substitute Decision-Maker (SDM)**.Your SDM(s) will make healthcare decisions for you if you are not capable of making them yourself. Most often, this will be your closest living family member(s). **Healthcare providers must get consent from the person highest on this list.** You may have multiple SDMs at the same level on this list. To learn more see ETHeL's My Substitute Decision-Maker (SDM) pamphlet.



Ontario's *Health Care Consent Act*, 1996

Think about your SDM(s). Is this person:

- Willing to talk to you to understand your goals, values, and beliefs?
- Willing to learn about and understand your care needs and what it's like to live with your condition?
- Willing to interpret, honour, and follow your wishes as much as possible when they apply?
- Able to ask questions and talk to your doctors/healthcare team?
- Able to make hard decisions?

Your SDM(s) must be:

- **willing** to accept the role as your SDM
- **available** when decisions need to be made
- **capable** of providing consent
- 16 years or older
- not prevented by court order or separation agreement from acting as your SDM

If you prefer to have someone other than your closest family member(s) act as your SDM(s), you may appoint someone as your Attorney for Personal Care.

You can choose a family member, close friend, or anyone you trust to make your healthcare decisions.

Your SDM(s) role in future healthcare decision-making

- If you are **not capable of making a healthcare decision,** a healthcare provider will ask your SDM(s) to make these decisions for you.
- Your SDM(s) will think about **your prior capable wishes, your values, and your beliefs.** This may include things that you discussed during Advance Care Planning conversations, regular conversations, or things you recorded in some way.
- What you have said is just as important as what you may have recorded. Your SDM(s) will consider your most recent wishes.
- **Even if you have written or signed a document that states your wishes, healthcare providers must speak to your SDM(s) to get consent for any treatment or plan.**
- Your SDM(s) will talk to your healthcare providers about which option is the best fit with your wishes, values, and beliefs.
- Your SDM(s) will provide consent for that option.

TALK about your wishes, values & beliefs

Talk with your SDM(s) to let them know your wishes, values, beliefs, and what is important to you.

Share your worries and fears about your condition. Talking about this with your SDM(s) and healthcare providers may allow you to work together to come up with a plan to increase your quality of life and decrease your suffering.

Your SDM(s) may have to make decisions for you in a number of different situations. It can be helpful to talk about some of these.

Some say: "*If I'm going to live like that, let me go*" or "*No heroics*" or "*Don't keep me alive on machines.*" While these remarks are a beginning, they are too vague to help your SDM(s) make a decision for you.

Think about why you feel this way and help your SDM(s) understand your thoughts and feelings. **Giving your SDM(s) more details about this will help them make better decisions for you in the future**.

RECORD or COMMUNICATE your wishes, values & beliefs

It is most important that your SDM(s) knows your wishes since they are the ones who might have to make decisions for you.

Some people do find it helpful to write things down as a reminder for their SDM(s).

If you choose to record your wishes (in writing, video, etc.) **show this to your SDM(s) and give them a copy to make sure they understand what you have recorded.**

Your values help you make healthcare choices

Your values help you make important life decisions including healthcare decisions.

Values are very personal and each person may think about them differently.

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

- Dignity
- Independence
- Wellness
- Family
- Hard work/dedication
- Spirituality

What does having dignity look like 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?

What about family or spending time with family is the most important to you?

What brings quality to my life? What do I value, or what is important in my life that gives it meaning? (E.g. being able to live independently, being able to recognize important people in my life, being able to communicate, being able to eat and taste food, spending time with friends and family, etc.)

When thinking about my care in critical illness or near the end of my life, what do I worry about? What fears do I have? (E.g. struggling to breathe, being in pain, being alone, losing my dignity, being given up on too soon, depending entirely on others or being a burden to my family and friends, etc.)

What would make keeping me on life support or continuing life-saving treatment unacceptable for me? (For example, being unable to communicate or interact with those around me, not having control of my bodily functions, little hope of ever getting better or I would always want to continue life support.)

If possible, nearing the end of my life, I would prefer to spend the last days and hours of my life at _____with the following people at my bedside. (E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music, etc.)

NOTES

Date: _____

Your Advance Care Planning Checklist

- ☐ I have thought about my life, what's important to me, what I value about being alive.
- ☐ I have spoken to my healthcare provider(s) about my current health and what future healthcare decisions I might need to make.
- ☐ I know that if I am capable in the future I will be the one to provide consent for my healthcare. If I am not capable, my SDM(s) will consent for me.
- ☐ I have determined who my SDM(s) are and know they understand and can support my wishes in the future if I am not capable of making my own healthcare decisions.
- ☐ If I have completed a Power of Attorney Document. It can be found here: _____
- ☐ I have had Advance Care Planning conversations and have shared my wishes with:
  - ☐ My Substitute Decision-Maker(s)
  - ☐ My Family
  - ☐ Hospital _____
  - ☐ My Primary Care Provider
  - ☐ The CCAC
  - ☐ Other _____

More Information:

ETHeL Advance Care Planning Resources:

1. ACP Information Pamphlet
2. My Substitute Decision-Maker

Advance Care Planning:

Speak Up: http://www.advancecareplanning.ca/

Canada's Speak Up campaign encourages all Canadians to think about Advance Care Planning. Please make sure you are looking at the information for Ontario.

Advance Care Planning, Informed Consent and more:

Advocacy Centre for the Elderly: http://www.acelaw.ca

The Ministry of the Attorney General of Ontario:

They have a booklet that will help you complete a Power of Attorney for Personal Care and a separate Power of Attorney for Property (finance). You can also ask a lawyer to assist you with this.

Phone: 416-314-2800 Toll-free: 1-800-366-0335 TTY: 416-314-2687

Direct link to the forms:

https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf