How do I start Advance Care Planning?

There are five steps you can take if you would like to start thinking about advance care planning:

THINK about what is 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(s)** (SDMs) are. 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. See the ETHel pamphlet (My Substitute Decision-Maker) to learn more.

TALK about your values, beliefs, and what is important to you with your SDM(s), your family and your healthcare providers.

RECORD or COMMUNICATE your wishes and what is important to you.**You should talk to your SDM(s) 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.

Other ETHeL resources in this series:

2 My Substitute Decision-Maker (SDM)

3 Advance Care Planning Workbook

Related ETHeL resources:

Cardiopulmonary Resuscitation (CPR) Decision Aid for patients and their SDM(s)

Other resources on Advance Care Planning and healthcare decision-making:

Speak up

Canada's national campaign for Advance Care Planning. (Look at the Ontario specific resources.)

http://www.advancecareplanning.ca

Advocacy Centre for the Elderly

http://www.acelaw.ca

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My Health, My Wishes.

Advance Care Planning Information Guide

A gift for you, your family, friends and your substitute decision-makers (SDMs)

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TORONTO EAST HEALTH NETWORK

HealthLink
East Toronto Health Link
Let's Make Healthy Change Happen

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Alice D'Souza has a history of strokes in her family. She has strong opinions about how she would like to be cared for if she were to experience a serious stroke.

Sean O'Reilly has lived a fiercely independent life. Although he is 90 years old and has recently been diagnosed with Alzheimer's disease, he lives in his own home and wants to continue to do so, despite concerns raised by his children.

Lilly Palma has strong religious views and believes that "*where there is life, there is hope.*" If she were to become unconscious, she would want to continue receiving all treatments to live as long as possible.

In all these situations, each person has stated in general terms their wishes for future care. These are helpful but only a beginning.

This guide provides general information to help you start thinking about advance care planning.

"*Advance Care Planning is like retirement planning, important to start early, even if you don't need it for many years to come.*" - Healthcare Provider

What is advance care planning?

Advance care planning is talking about your wishes, values, and beliefs as they relate to your **future healthcare**. It is also about knowing who your future substitute decision-maker(s) (SDMs) will be. If decisions need to be made about your care in the future and you are **not capable of making them yourself**, healthcare providers will ask your SDM(s) for consent.

What does it mean to be capable of making healthcare decisions?

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).

Why is advance care planning important?

If there is a time in the future when you are not capable of telling your doctors what care you want, your SDM(s) will be asked to consent for you. The information that you share with them during the advance care planning process will help them make these decisions for you in the future.

Some examples of when this could happen are:

- serious illness when you can't communicate
- being unconscious during surgery
- advanced dementia

Research shows that when your wishes are known, you are more likely to get the care you want, your family will feel at peace and worry less.

How can I communicate my wishes?

Talk with your future SDM(s) to make sure he/she understands your wishes, values, and beliefs. You may choose to write your wishes down or record them in a video.

Can you change your mind about wishes?

YES

Your thoughts about your health and healthcare wishes may change over time and as your health changes. **It is important that you keep your SDM(s) up to date about your thoughts, wishes, values, and beliefs.**

How can advance care planning help with decisions about your future care?

If your SDM(s) has to make a healthcare decision for you when you are **not capable,** conversations you have now can provide helpful information.

1. A healthcare provider must get consent before treatment. If you are not capable, they will ask your SDM(s) for consent.
2. Your SDM(s) will consider your capable wishes, your values, and your beliefs.
3. Your SDM(s) will also look at anything else you told them that will help them make the decision for you.
4. Your SDM(s) will talk with your healthcare providers about which option for care is the best fit with your wishes, values, and beliefs.
5. **Your SDM(s) will be asked for consent for this option.**