

Advance Care Planning (ACP)

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Dementia Caregivers' Appreciation/Information Day
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Outline for today

- Define advance care planning (ACP)
- Review the process of appointing a Substitute Decision Maker (SDM) in Ontario
- Review role and responsibilities of the SDM/POA
- Explore common misconceptions about advance care planning
- Review resources for advance care planning

Recent Headlines

IN THE GLOBE AND MAIL

Early release, published at www.cmaj.ca on July 15, 2013. Subject to revision.

CMAJ

REVIEW

2014

Just ask: discussing goals of care with patients in hospital with serious illness

John J. You MD MSc, Robert A. Fowler MD MS, Daren K. Heyland MD MSc; on behalf of the Canadian Researchers at the End of Life Network (CARENET)

INVITED COMMENTARY

Disregard of Patients' Preferences Is a Medical Error

ACADEMIA AND CLINIC

Annals of Internal Medicine

Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD



COURAGE LIVES HERE

What is Advance Care Planning (ACP)?

A process whereby a capable person may express:

1. Who they trust to act on their wishes and make healthcare decisions if they become incapable.

- Indicated in a Power of Attorney for Personal Care (POA) and becomes the patient's *appointed* Substitute Decision-Maker (SDM).

2. Values and preferences to guide treatment decisions if they become incapable.

- Planning in advance of a treatment or plan of treatment being proposed is documented in an Advance Directive or Living Will.
- Inform and guide the patient's SDM

Substitute Decision Makers in Ontario

- The Ontario Health Care Consent Act includes a hierarchy of substitute decision makers (SDMs)
- The SDM is the highest capable person over age of 16 who is willing and available.
 - Court appointed guardian with authority to give/refuse consent
 - Attorney for Personal Care (signed POA is required)
 - Representative appointed by Consent & Capacity Board
 - Spouse/Partner
 - Children
 - Parents
 - Siblings
 - Other Relative
 - Public Guardian/Trustee

**If there are two or more people at the same level, they will need to make your treatment decisions jointly*

Why a Power of Attorney Instead of SDM?

- The patient may not want to follow the SDM hierarchy outlined in the Health Care Consent Act legislation because:
 - There are two people in the patient’s life at the same level but they only want one of them to make treatment decisions (e.g. two sons)
 - The patient wants to appoint a person on a “lower” level to make the decisions (e.g. you prefer a sibling to make your treatment decisions because it would be far too stressful for your spouse)

Appointing a Power of Attorney in Ontario

- If a capable patient wishes to formally appoint a SDM, they must complete a Power of Attorney for Personal Care and a copy must be placed in their chart. The Ontario POA toolkit can be found at: <http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

Powers of Attorney

This booklet contains forms for
Continuing Power of Attorney for Property
and
Power of Attorney for Personal Care

Myth busters - True or False?

A substitute decision maker (SDM) only has authority once the patient is deemed incapable of making his/her own health care decisions.

True

An SDM only has authority for as long as the patient is incapable and alive.

Myth busters – True or False?



We will diminish patient's hope if we offer them the opportunity for advance care planning and convey a message that the health care team has 'given up' on them.

False

Studies show that patients feel more empowered and more hopeful when they are able to engage in advance care planning. If health care providers tell and show the person that the team is not giving up on their care, the individual should feel more supported.

What is an Advance Directive or 'Living Will'?



- Patients may choose to record their medical treatment preferences in a legal document called an advance directive to 'pre-specify' their treatment wishes in writing.

Alleviates loved ones' burden of responsibility for care decisions

Assists care providers in offering treatments/interventions that align with patients' goals and values as they define them.

Patient-doctor end-of-life care talks happen infrequently in Canada: Study

Patients and families also wanted to be able to talk about their fears, concerns and values, such as how unacceptable would it be for them not to be able to speak, or not recognize their loved ones, or to be dependent on others for toileting, feeding and walking.

“For me personally that would be completely unacceptable,” You said.

“Someone else might say something different. They might say, ‘If I was dependent for feeding, for me, that might still be okay if I could recognize and interact with my family.’”

“It’s not super complicated stuff,” You said. “They just want their care team to have honest conversations about the things that matter to them. We need that to happen more.”

National Post, November 3, 2014 - Sharon Kirkey

What is Advanced Care Planning?

- On-going conversations with your care team that focuses on these questions;
 - What brings meaning to your life?
 - What's important to you?
 - What are your core values and beliefs?
 - How do these values and beliefs inform your medical treatment decisions?
 - Do you have medical treatment limits based on those values and beliefs? If so, what are they?
 - Do you have someone in your life that could communicate your treatment preferences on your behalf if you were incapacitated?

What is Advanced Care Planning?

What are my options if my health quickly gets worse?”

- “How will the treatment plan start? Is the treatment meant to *cure* the disease or just make me more comfortable or both?”

“What is the best you can hope for with this treatment?”

- “How will you know if the disease has progressed? Will there be any signs or symptoms?”
- “How do we make decisions about whether I should be in hospital or at home?”
- “What resources are available to support me at home? In the community? In a health care setting?”

Ontario ACP Resources

A Guide to Advance Care Planning

Helping you know and exercise your rights in
preparing for a time when you may be unable
to make decisions about your care.

THIS PUBLICATION IS FREE OF CHARGE.

Communication / Choice / Respect



Speak Up! Workbook

Available at Patient Family Libraries at UHN

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.

Start the Conversation

START THE CONVERSATION CHECKLIST



KNOW YOUR OPTIONS

- I have reflected upon my personal values and priorities and I have thought about what makes life meaningful and important to me.
- I understand the importance of discussing the risks and benefits of medical interventions and treatments specific to my health condition.
- I have considered where and how I would like to be cared for if I were terminally ill.
- I understand the options in my community for palliative care and hospice.
- I know how to access end-of-life care for myself or a loved one.

START THE CONVERSATION

- I have shared my wishes and concerns on end-of-life care with family and close friends.
- I have discussed with my family what role I want them to play in my end-of-life care and in making health care decisions.
- I have discussed my health care wishes, goals, and concerns with my doctor.

MAKE A PLAN

- I have identified who I would like to represent me if I were unable to speak for myself (Health Care Agent).
- I have documented my wishes in an Advance Directive.
- I have recently reviewed my Advance Directive and decided if any changes need to be made.
- My Advance Directive is signed and has been properly witnessed.
- I have shared a copy of my Advance Directive with my Health Care Agent, my doctor, and my family.
- My Advance Directive is filed with the Vermont State Registry.

ABOUT THIS LIST

Lists help us organize our thoughts, keep us on track, and guide us in new processes. This list was developed with input from multiple sources and experts on advance care planning and end-of-life care. It provides some basic steps for you to consider. This process is unique for each person and is influenced by differences in your health condition, age, culture, and values. It is not intended to be a complete list of every step you may take to prepare for the end of life.

START THE CONVERSATION

GET A CONVERSATION STARTER KIT AT
STARTTHECONVERSATIONVT.ORG

START THE CONVERSATION IS A PUBLIC EDUCATION
INITIATIVE OF THE VNAs OF VERMONT, YOUR NONPROFIT
HOME HEALTH AND HOSPICE AGENCIES.

Understanding *the* OPTIONS



Planning care for critically ill patients in the Intensive Care Unit

Understanding the Options

STEP 1: What was your family member's situation before coming to the ICU?

Check how your family member was over the last few weeks before coming to the ICU.

Moving about	Activity	Self care	Eating & drinking	Alertness
<input type="checkbox"/> Able to move about as usual	<input type="checkbox"/> Able to do their usual activities such as job, hobbies, housework	<input type="checkbox"/> Able to do all their personal care such as washing, dressing, going to the bathroom	<input type="checkbox"/> Able to eat and drink as usual	<input type="checkbox"/> Alert as usual
<input type="checkbox"/> Moving about less than usual	<input type="checkbox"/> Able to do their usual activities <i>with effort</i>	<input type="checkbox"/> Needed occasional help with their care	<input type="checkbox"/> Ate and drank less than usual	<input type="checkbox"/> Less alert than usual
<input type="checkbox"/> Mainly sitting	<input type="checkbox"/> Unable to do their usual job	<input type="checkbox"/> Needed a lot of help with their care	<input type="checkbox"/> Ate small amounts of food and sips of fluids	<input type="checkbox"/> Drowsy most of the time
<input type="checkbox"/> Mainly in bed	<input type="checkbox"/> Unable to do their usual hobbies or housework	<input type="checkbox"/> Someone else provided most of their care	<input type="checkbox"/> Not able to eat or drink	<input type="checkbox"/> Slept all of the time
<input type="checkbox"/> In bed all of the time	<input type="checkbox"/> Unable to do any work	<input type="checkbox"/> Someone else provided all of their care		
	<input type="checkbox"/> Unable to do most activities			
	<input type="checkbox"/> Unable to do any activities			

How would you rate your family member's overall quality of life over the last few weeks before coming to the ICU? Worst possible Poor Fair Good Best possible

Understanding the Options

Yes No

Knowledge

Do you know enough about your family member's health situation right now?

Do you know enough about how your family member is expected to recover?

Do you know enough about the benefits and risks of each option (comfort care or life support)?

Values

Are you clear about what matters most to your family member?

Support

Do you have enough support to participate in decision making?

Do you have enough advice to participate in decision making?

Certainty

Do you feel sure about the best decision for your family member?

Vermont Advance Directive for Health Care

Prepared by the Vermont Ethics Network

You can decide what kind of treatment you want or do not want at the end of your life. These wishes can apply to all situations or to situations that you specify. Regardless of the treatment limitations stated you have the right to adequate management for pain and other symptoms (nausea, fatigue, shortness of breath) related to your illness. Unless treatment limitations are stated, the medical teams are required and expected to do everything possible to save your life.

1. If my heart stops: (choose one)

- I DO want CPR done to try to restart my heart. I DON'T want CPR done to try to restart my heart.

CPR means cardio (heart)-pulmonary (lung) resuscitation, including vigorous compressions of the chest, use of electrical stimulation, medications to support or restore heart function, and rescue breaths (forcing air into your lungs).

2. If I am unable to breathe on my own: (choose one)

- I DO want a breathing machine without any time limit. I want to have a breathing machine for a short time to see if I will survive or get better. I DO NOT want a breathing machine for ANY length of time.

“Breathing machine” refers to a device that mechanically moves air into and out of your lungs such as a ventilator.

3. If I am unable to swallow enough food or water to stay alive: (choose one)

- I DO want a feeding tube without any time limits I want to have a feeding tube for a short time to see if I will survive or get better. I DO NOT want a feeding tube for any length of time.

NOTE: If you are being treated in another state your agent may not automatically have the authority to withhold or withdraw a feeding tube. If you wish to have your agent decide about feeding tubes please check the box below.

- I authorize my agent to make decisions about feeding tubes.

4. If I am terminally ill or so ill that I am unlikely to get better: (choose one)

- I DO want antibiotics or other medication to fight infection. I DON'T want antibiotics or other medication to fight infection.

U of T Joint centre for Bioethics – Living Will

	CPR	VENTILATOR	DIALYSIS	LIFE-SAVING SURGERY	BLOOD TRANSFUSION	LIFE-SAVING ANTIBIOTICS	TUBE FEEDING
CURRENT HEALTH							
MILD STROKE							
MODERATE STROKE							
SEVERE STROKE							
MILD DEMENTIA							
MODERATE DEMENTIA							
SEVERE DEMENTIA							
PERMANENT COMA							
TERMINAL ILLNESS							

In Light of Brittany Maynard's Death, Go Where You Need to Go - Nancy Sharp, Huffington Post, November 4, 2014

“My own experience has taught me that we have to be brave enough to face uncertainty and adversity, and to hold all the dualities of joy and sorrow, health and illness, past and present and life and death together. Anyone who has faced loss -- which is everyone -- understands that all these paradoxes co-mingle.

We have to be brave enough to have tough conversations and no matter what, to put ourselves on the path of living every day.”