

"Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers."


- Atul Gawande

A Practical Approach to Integrating Advance Care Planning into Primary Care

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Conflict of Interest Declaration

- ◆ No financial or personal relationships to disclose

Thank you and acknowledgement to Dr. Jeff Myers

Objectives

- ◆ Define and differentiate different elements of end-of-life care planning and care
- ◆ Articulate the role of Advance Care Planning to in the moment decision making and goals of care conversations
- ◆ Identify the emerging evidence addressing patient outcomes and advance care planning (ACP)
- ◆ Describe how values can guide decision-making
- ◆ Outline an interprofessional process for facilitating a values-based ACP conversation

Terminology: Advance Care Planning

- ◆ **A process** of discussing a person's values, beliefs, wishes, trade-offs and approach to decision-making as they pertain to future healthcare
- ◆ Must occur with a **capable** patient
- ◆ Prepare SDM by **outlining helpful information for future decision-making** if the person him/herself lacks the capacity for decision-making
- ◆ An SDM **cannot** make an advance care plan on behalf of a patient

Terminology: Goals of Care Conversations

- ◆ Occur between a capable patient or their SDM and the healthcare provider
- ◆ Start with an articulation of the patient's goals
- ◆ Aligns available treatment options with these patient defined goals
- ◆ The goals, treatment and discussion are focused on current care decisions that must be made.

Conceptualizing ACP as a Process

Identify the substitute decision maker and ensure they want the role

Consider values, beliefs and the way healthcare decisions are made by the individual

This information is shared with the SDM so they can make informed decisions in the future if needed



- Identify or confirm SDM
- Discuss
 - values, beliefs
 - a person's concept of a good life or quality of life
 - perceptions of benefits, burdens
 - acceptable trade-offs

Capable Patient

- What is most important to the person (goals)?
- Are there previous conversations (eg ACP) that help you define the person's goals for care now?
- How do these goals fit with available treatment options?

Capable Patient or their SDM

- Look for prior capable wishes that apply to the decision to be made (e.g. from ACP or POA document)
- Informed consent process
- Incorporates patient values into the decision making process

ACP Evidence

- ◆ Improves patient & caregiver experience¹
- ◆ Decreases caregiver distress & trauma²
- ◆ Decreases unwanted investigations, interventions & treatments^{3,4}
- ◆ Decreases hospitalizations & admissions to critical care^{3,4}
- ◆ Decreases cost⁵

Having and documenting advance care planning conversations are more predictive of patient outcomes than code status decisions

ACP can improve patient outcomes if....

- ◆ Assess and respond to PERSON'S readiness
- ◆ PERSON'S substitute decision maker is identified and present
- ◆ Focus of the conversation is the PERSON'S values NOT on specific treatments

Why readiness?

- ◆ Change Theory

Readiness for ACP

Stage	What the person thinks about ACP
PRE-CONTEMPLATION	Patient does not know about or has not considered ACP
CONTEMPLATION	Patient may be aware of the pros and cons regarding ACP but does not appear ready to take any action
PREPARATION	Patient prepares to engage in ACP through review of educational materials or discussions with others
ACTION	Patient has discussed their wishes with others, identified their substitute decision maker and may request further information
MAINTENANCE	Patient has consistent ACP wishes and may want to revisit these when health circumstances change

Adapted from:

1. Westley C & Briggs L. Using the Stages of Change Model to Improve Communication About Advance Care Planning. *Nursing Forum* 2004, 39(3).
2. Rizzo V et al. Use of the Stages of Change Transtheoretical Model in End-of-Life Planning Conversations. *Palliative Medicine* 2010, 13(3).

Why involve the SDM

- ◆ 70% of decisions made in the last week of a person's life are NOT made by the person him or herself⁷
- ◆ ACP is way for the SDM to learn what is important to the person, and how they make medical decisions.
- ◆ Prepares the SDM for future in the moment decision making

Why Values?

- 💧 A bit more complicated....
- 💧 1st misconception is that the conversation is about difficult choices
- 💧 It's about **what people want to look forward to** and how they want to live the rest of their life
- 💧 2nd misconception is that we want to arrive at a decision
- 💧 ***It's a process...*** a series of conversations

How a person makes healthcare decisions

Values

- Are the risks worth the possible benefits?
- Is this plan consistent with what the person wants to do?
- What is important to the person?

**Health
Care
Decisions**

Evidence

- Facts
- Expected outcome
- Side effects and risks

Historically ACP Conversations...

Commonly used	Think about it for a moment...
“No heroics and no machines”	Ever? Or when there is no chance of recovery? What about a 90% chance?
“No tubes”	What if the circumstances were short term and reversible... would a “tube” be acceptable?
“Do everything”	What does this mean? What “state of being” is to be achieved? How will the SDM know when everything has been done?

Potentially more helpful for the SDM

	Explore further
“No heroics and no machines”	What experiences have you had that are behind this statement? What is it about “heroics and machines” that is driving the wish to avoid them?
“No tubes”	What situation are you thinking of when you say you don’t want a tube?
“Do everything”	What does it mean to not “do everything”? What are you worried about if we don’t “do everything”? How should we approach reconciling this?

Challenges with ACP

- ◆ “ My clinic is booked every 10 minutes, how do I have time for this?”
- ◆ “What do I even need to talk about?”
- ◆ “The hospital never calls me to ask about an advance care plan so why should I bother?”
- ◆ “I don’t want to take away hope by talking about the end of life”

Addressing the challenges

- ◆ Time
 - ◆ It's a process.....no need to do all at once!
 - ◆ Conversations over time.
 - ◆ Break up SDM conversation and values conversations
 - ◆ Focus on values allows other healthcare providers to be involved not just MDs

ACP Interprofessional Practice

- ◆ Advanced communication skill talking about values
- ◆ Not confined to one profession
- ◆ Respecting Choices model is interprofessional
- ◆ Training for all providers based on having values based conversations.
 - ◆ East Toronto Health Link Online modules
 - ◆ Respecting Choices
 - ◆ Other local programs

Addressing the challenges

- ◆ What do we talk about?
 - ◆ Standardized evidence-based questions
 - ◆ What will be helpful for the SDM to know when they have to make future decisions for the person?
- ◆ Where will the information “live”?
 - ◆ EMR but...
 - ◆ More importantly with the SDM who has to make decisions

How does this fit into practice?

- ◆ Outline process for identifying patients
- ◆ Assess capacity for ACP (these become prior capable wishes)
- ◆ Introduce topic & assess readiness
- ◆ Facilitated ACP conversation with SDM present
- ◆ Document

Process: Identifying Patients

- ◆ To be determined as appropriate for each clinical setting
 - ◆ All patients?
 - ◆ All patients over a certain age?
 - ◆ All patients according to the Surprise Question/Gold Standard Framework?

Process: Readiness and Capacity

- ◆ For what?
 - ◆ ACP vs. Discussing or Appointing a Substitute Decision Maker.
 - ◆ May be capable for ACP but do not lose the opportunity to discuss SDM.
 - ◆ May not be ready to talk about ACP but ready to discuss who their SDM is.
- ◆ Introduce the topic and give relevant “homework” to patient
 - ◆ ACP Pamphlet, SDM Pamphlet
 - ◆ Prepare for your care website or other resource to help patient think about their values if ready to start the conversation

Talking about SDMs

- ◆ Know local legislation for proxy decision makers
- ◆ Help patients understand the kind of decisions a proxy decision maker may be asked to make
- ◆ Help patients understand who their default proxy decision maker would be
- ◆ If there are multiple people at the same level, all will have to agree on a decision

Talking about SDMs

- ✓ Willing to make future medical decisions for the patient
- ✓ Willing to talk to the patient to understand his/her goals, values and beliefs
- ✓ Able to ask questions and advocate for your patient with doctors and nurses
- ✓ Understands that they will only make decisions when the patient incapable of a specific decision
- ✓ Willing to witness care and appreciate the daily lived experiences of the person to be able to make better informed decisions based on the whole person
- ✓ Willing to interpret, honour and follow capable wishes as much as possible when they apply
- ✓ Able to make hard choices

Standardized ACP Conversation

1. What is your **understanding** of your illness? What have you been told? What do you expect to happen?
2. What **information** would be helpful or important to know?
3. What do you **value**, what's **important** & what brings **quality** to your life?
4. If critically ill or if EOL, what **worries** & **fears** come to mind?
5. What **trade offs** are you willing to make for the possibility of more of what's important to you?
6. If you were **near the end** of your life, what might make this time meaningful for you?



ACP Conversation Guide

Advance Care Planning Conversation

Patient Name: _____ Today's Date: _____
MM DD YYYY

This document serves to record wishes, values and beliefs for future healthcare. It is NOT consent for treatment. It will be viewed as a representation of a person's capable thoughts and reflections therefore please use their own words:

1. Understanding

Based on previous discussions with healthcare providers, what is your understanding of your illness? Tell me what you have been told about your illness. What do you expect to happen in the future?

(E.g. Do you expect to get better, be cured, or is your illness expected to get worse over time? Do you think you may develop difficulty with memory, swallowing, walking or other things that are important to you?)

2. Information

What information about your illness that you don't know would be helpful or important for you to know?

Is there information about your illness that you don't want to know?

3. Values, Beliefs & Quality of Life

Quality of life means something different to everyone. As you reflect on the questions below and your answers to them, it may help to think of activities you enjoy and then think about how they impact your quality of life. For example, if you enjoy family gatherings, quality of life might mean being able to communicate with others, share a meal with loved ones, be aware of yourself and your environment, read stories to your children or grandchildren etc. What would it look like if you felt to be a burden on your family or loved ones? What would make you feel undignified? Consider how you have made health related decisions in the past and what beliefs or values may have guided you.

What brings quality to your life? What do you value, or what is important in your life that gives it meaning?

(E.g. being able to live independently, being able to recognize important people in your life, being able to communicate, being able to eat and taste food, spending time with friends and family etc.)

4. Worries & Fears

Think about the care you might need if you have a critical illness or if you are near the end of your life.

What worries or fears come to your mind? (E.g. struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others or being a burden to your family and friends etc.)

5. Trade Offs

If you have a critical illness, life support or life extending treatments might be offered to you with the chance of gaining more time. Think about what brings quality to your life and what you value:

- What would you be willing to trade for the chance of gaining more time or more of what's important to you? (E.g. if you were unable to communicate, unable to interact with others, had lost control of your bodily functions)
- Or are the burdens of these treatments acceptable to you if there is even a slight chance of gaining more time?
- Do your thoughts or feelings change if your condition was permanent or if there was little or no chance of recovery?

6. Near the End

If you were near the end of your life, what might make the end more meaningful or peaceful for you?

(E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music etc.)

Is there anyone who would provide valuable information to your SDM to help them make future care decisions? _____

Is there anyone you would not want to provide information to your SDM? _____

Note to Healthcare Providers:

In the event that this person lacks the capacity to make healthcare decisions in the future, this conversation will be used to guide the SDM to provide informed consent. It may provide information for the SDM to consider prior capable wishes and best interests of the patient. Therefore, this form must not include health care provider interpretations. The patient to whom this applies has reviewed this document and is in agreement with its contents. I have provided copies to the patient and their SDM(s).

I agree with the above statement

Health Care Provider Name: _____ Health Care Provider Signature: _____



Two parts:

Part 1

- Capacity for ACP
- Identification of SDM (Ontario SDM Hierarchy)

Part 2

- 6 Question Areas
- Not intended to complete all at once
- Some questions may not be addressed until years later (e.g. near the end)

Why these areas?

💧 Illness understanding:

- 💧 Patients who retain or develop an accurate understanding of their illness are significantly **less likely to receive systemic Tx** in last 2 weeks of life
- 💧 **EITHER** patients do not fully appreciate the information provided to them **OR** clinicians are not effective in providing info re: intent of therapy and outcomes **OR BOTH**
- 💧 Strong evidence that an inaccurate illness understanding alone significantly impacts patient outcomes i.e. QOL, LOS, ICU

Why these areas?

- ◆ **Information:** helps us meaningfully meet individual information needs
 - ◆ Patients right not to know information
 - ◆ Assess health literacy and numeracy
 - ◆ Preferences re: information delivery
- ◆ The rest are different ways of asking about values and what is important to the person

Understanding

- ◆ Based on previous discussions with healthcare providers, what is your understanding of your illness?
- ◆ Tell me what you have been told about your illness.
- ◆ What do you expect to happen in the future?

(E.g. Do you expect to get better, be cured, or is your illness expected to get worse over time?)

Do you think you may develop difficulty with memory, swallowing, walking or other things that are important to you?)

Understanding

- ◆ Expressing “unrealistic” hope vs. true lack of understanding
- ◆ Therapeutic doublethink
- ◆ Seemingly “unrealistic” hope does not preclude realistic planning

Hopefulness vs. Misunderstanding

- ◆ “I appreciate you are hopeful that your kidney disease will be cured. I’m hopeful for this as well. I’m wondering if in the past you may have been told something different: that a cure may not be possible. If this was said, how did you feel hearing that? If this hasn’t been said, how would it be for you to hear this?”
- ◆ “Do you not believe what has been said?”
- ◆ “Maintaining hope is important to you. Tell me more about this”
- ◆ “Has your hopefulness influenced any decisions you have made up to this point in your care?”

Information

- 💧 What information about your illness that you don't know would be helpful or important for you to know?
- 💧 Is there information about your illness that you don't want to know?

Values, Beliefs and Quality of Life

- ◆ What brings quality to your life?
- ◆ What do you value?
- ◆ What is important in your life and gives it meaning?

(E.g. being able to live independently, being able to recognize important people in your life, being able to communicate, being able to eat and taste food, spending time with friends and family etc.)

Values, Beliefs and Quality of Life

- ◆ Help the person identify the essential components of what they consider a “good life”
- ◆ Be cautious not to overly focus on specific abilities such as sight, mobility etc.
- ◆ In general, people have a large capacity for adaptation to adverse situations and it is difficult to predict how these will impact our quality of life
- ◆ E.g. rather than the ability to speak, an essential component of quality of life could be communication (which in times of disability may be accomplished through non-verbal means)

Worries and Fears

- 💧 Think about the care you might need if you have a critical illness or if you are near the end of your life. What worries or fears come to your mind?

(E.g. struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others or being a burden to your family and friends etc.)

Worries and Fears

- ◆ Could focus on symptoms, emotional or psychosocial fears.
- ◆ Gives future SDMs a further picture of what is important to the person and things to pay particular attention to as the person enters the final stages of his or her life
- ◆ The other opportunity is to identify worries or fears that can be addressed with simple information exchange

Trade-Offs

If you have a critical illness, life support or life extending treatments might be offered to you with the chance of gaining more time. Think about what brings quality to your life and what you value:

- ◆ What would you be willing to trade for the chance of gaining more time or more of what's important to you?
(E.g. if you were unable to communicate, unable to interact with others, had lost control of your bodily functions)
- ◆ Or are the burdens of these treatments acceptable to you if there is even a slight chance of gaining more time?
- ◆ Do your thoughts or feelings change if your condition was permanent or if there was little or no chance of recovery?

Trade-Offs

- ◆ In short, this question seeks to clarify what a person willing to withstand for the possibility of having life extended
- ◆ While someone may list a number of things they consider essential to their quality of life in the question that addresses values, that same person might still chose to “trade” some of those things when the potential for time is the other option.

Trade-Offs

- ◆ Specific treatment may arise (e.g. intensive care unit admission, feeding tubes, ventilators etc.)
- ◆ Explore the drivers of the request for or against a specific treatment. (e.g. past experiences, envisioning specific circumstance such as PVS, unrealistic perception of interventions)
- ◆ Focus on documenting the person's values as they relate to specific treatments including what values they would consider "trading off" and what is perceived to be the benefit/burden ratio of specific treatments
- ◆ If a person communicates a wish/preference regarding a specific treatment, it is important to document the details

Near the End

If you were near the end of your life, what might make this time meaningful or peaceful for you?

(E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music etc.)

In the works

- 🟢 Health Care Provider Companion Guide
- 🟢 Patient work-book

Resources

- ◆ Speak Up
- ◆ East Toronto Health Link
- ◆ Prepare for your Care (for patient values only, not legal information since US resource)
- ◆ Advocacy Centre for the Elderly (specific to Ontario legislation)

Questions?

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Advance Care Planning Conversation

Patient Name: _____

Today's Date: _____
MM DD YYYY

Choosing your Substitute Decision Maker (SDM)

Think about the person(s) who will make healthcare decisions on your behalf if you are unable to. Ask yourself if the person(s) are:

- Willing to make future healthcare decisions for you
- Willing to talk with you to understand your goals, values and beliefs
- Willing to be present and understand your care needs and your condition when decisions need to be made
- Willing to honour and follow your wishes to the extent possible when they apply
- Able to ask questions and advocate for you with doctors
- Able to make hard decisions

Substitute Decision Maker(s)

In Ontario, a substitute decision maker may be appointed through a formal process. You may choose your decision maker by appointing an Attorney for Personal Care. The other two categories are appointed by the legal system. If an SDM has been appointed please indicate below and fill in the contact information of the Guardian, Attorney for personal care or representative as the **Primary SDM**.

- A court appointed Guardian
- My Attorney(s) for Personal Care (POA)
- A representative appointed by Consent and Capacity Board

If you do not appoint a Power of Attorney for Personal Care, in Ontario the following list outlines the rank order of who your automatic Substitute Decision Maker(s) will be:

1. Spouse or partner
2. Children or Parents
3. Parent with right of access only
4. Siblings
5. Any relative
6. Public Guardian and Trustee

Your primary Substitute Decision Maker (SDM) is either the person you have appointed as your POA for personal care or the person(s) who are highest on the list above. Alternate SDMs will either be people you have appointed or the next people from the list above. Please enter contact information for your primary Substitute Decision Maker as well as Alternates:

Primary SDM: _____

Alt SDM: _____

Alt SDM: _____

This is the first documented ACP Conversation: Yes No If "No": Date of most recent ACP: _____
MM DD YYYY

Today's documentation: Affirms a previous version Reflects changes and replaces the previous version

Where is the previous version documented? Within POA PC document Paper record Another institution's chart

Capacity to participate in an Advance Care Planning Conversation:

The person understands and appreciates that:

- These responses are to provide guidance for the SDM who will give consent for future, not current, health care decisions in the event that the person is not capable of speaking for himself or herself
- Their SDM will be required to interpret these wishes to determine if they: (1) are the most recent (2) expressed when the patient was capable (3) are applicable to the decision that needs to be made. Finally, the SDM must interpret what the wishes mean in the context of the healthcare decision that needs to be made
- As long as the patient remains capable, he or she will be asked to make his or her own decisions
- These responses can be updated or changed at any time as long as the patient retains capacity for advance care planning

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Health Care Provider Name: _____

Health Care Provider Signature: _____

