

# Advance Care Planning Conversation Guide: Clinician Primer

## Read this primer to learn about:

- How to prepare for Advance Care Planning Conversations with patients and substitute decision-maker(s) or SDM(s)
- Practical information on: consent, capacity and decision-making
- How to determine who the automatic SDM(s) are for a patient
- How to prepare SDM(s) for decision-making about healthcare in the future

**NOTE:** *This primer is NOT intended as a patient education resource. Alternate materials and resources are available for patients, SDM(s) and other family members and caregivers.*



## How will this Clinician Primer help you?

- PROVIDES a brief overview of advance care planning (ACP), including distinguishing between ACP and Goals of Care
- DISCUSSES the legal concepts of consent, capacity and SDM(s) as they relate to ACP
- OUTLINES the patients with whom clinicians should consider having ACP conversations
- INTRODUCES a standard *ACP Conversation Guide* for patients and their SDM(s)
- SUGGESTS a process for integrating ACP conversations into practice

## What are ACP Conversations?

- ACP conversations are a way for capable patients to reflect on and express wishes, values and beliefs, what's important to them, and what they value about life and their health.
- ACP is about knowing who the patient's automatic SDM(s) would be if he or she is NOT capable of making a healthcare decision.
- Discussing how a person has made healthcare decisions in the past can help the patient and their SDM(s) understand how values and beliefs have influenced decision-making. This can be helpful information to pass on to SDM(s).
- Information that is shared by a patient can help guide their SDM(s) in the future if the patient loses capacity for healthcare decisions and the SDM(s) must make the decisions.
- The two most important outcomes of ACP conversations are....

Patient knows who SDM(s) will be and this is who is wanted for the role

Patient shares wishes, values and beliefs about healthcare with their SDM(s)

## How are ACP conversations related to future care?

- ACP conversations today can help prepare both the patient and the SDM(s) for decision-making conversations in the future.
- **Important note:** ACP conversations are **NOT** about making decisions or obtaining consent.
- In the future, when a patient becomes ill and decisions need to be made, the healthcare provider will determine if the patient is capable of making the healthcare decision.
- **If a patient is capable** of making healthcare decisions, healthcare providers must speak with and obtain consent from this patient.
- **If a patient is NOT capable** of making healthcare decisions, healthcare providers must speak with and obtain consent from the patient's SDM(s).

## If the patient loses capacity for healthcare decisions...

- The healthcare provider offering care or treatment must obtain consent from the SDM(s).
- This will involve explaining the condition of the patient, all options for care and the risks and benefits of each option, including declining all the options.

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- When SDMs make decisions they must follow certain rules. They must make decisions as the person would have made the decision him/herself. SDM(s) must consider:
  1. Prior capable wishes if they apply to the current situation and are possible to follow.
  2. Best interests of the person if there are no prior capable wishes.
- Some helpful information about either of these may be discussed during ACP conversations.
- Even if ACP conversations or prior capable wishes have been documented, the healthcare provider must seek consent from the SDM(s) prior to providing care in the future.

## Capacity and ACP

- **Only capable patients can participate** in ACP as the information discussed will be considered a patient's *Prior Capable Wishes*, as defined in Ontario's *Health Care Consent Act* (1996).
- A patient is capable of making a specific decision if he or she BOTH:
  - **Understands** the information given about a decision to be made, why a treatment is being recommended, risks and benefits of saying Yes or No and if there are options
- AND**
- **Appreciates** the reasonably foreseeable consequences of saying Yes or No to the treatment
- Capacity is both decision and time specific. Meaning that a patient can **lose capacity** for some decisions yet **retain capacity** for others. In addition, capacity can fluctuate over time.
- Capacity as it relates to ACP conversations is the patient's ability to **understand** and **appreciate** what ACP is and is not.
  - It is important to ensure the patient understands that ACP is **NOT** informed consent, **NOT** about decision-making and will **NOT** affect current care.
  - It may be helpful to reassure patients that discussing care in the future, even end of life care, will not impact being offered disease directed treatment plans in the current context.
  - The patient should also understand that ACP conversations cannot be used as a way to ask for or guarantee specific treatments.
- Even if a patient is incapable of both making treatment decisions and participating in ACP, he or she may still be capable of appointing an Attorney for Personal Care (see below).

## Why should patients have ACP conversations?

- **Respects** an incapable patient's right to self-determination in critical illness and end-of-life
- **Improves** both patient and family members' satisfaction with end-of-life care<sup>1</sup>
- **Decreases** the level of distress experienced by family members<sup>2</sup>
- **Decreases** unwanted investigations, interventions and treatment<sup>3</sup>
- **Decreases** likelihood of being hospitalized or critical care admission if this is not patient's wish<sup>4</sup>
- **Decreases** overall costs to the system by ensuring alignment with each patient's values<sup>5</sup>

1. Heyland DK, et al. Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning. *JAMA Intern Med* 2013;173(9):778-87.

2. Wright AA, Zhang B, Ray A et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300(14):1665-73.

3. Canadian Hospice Palliative Care Association. Speak Up. 2013 Available from: <http://www.advancecareplanning.ca>

4. Detering KM, The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010; 340. doi:10.1136/bmj.c1345

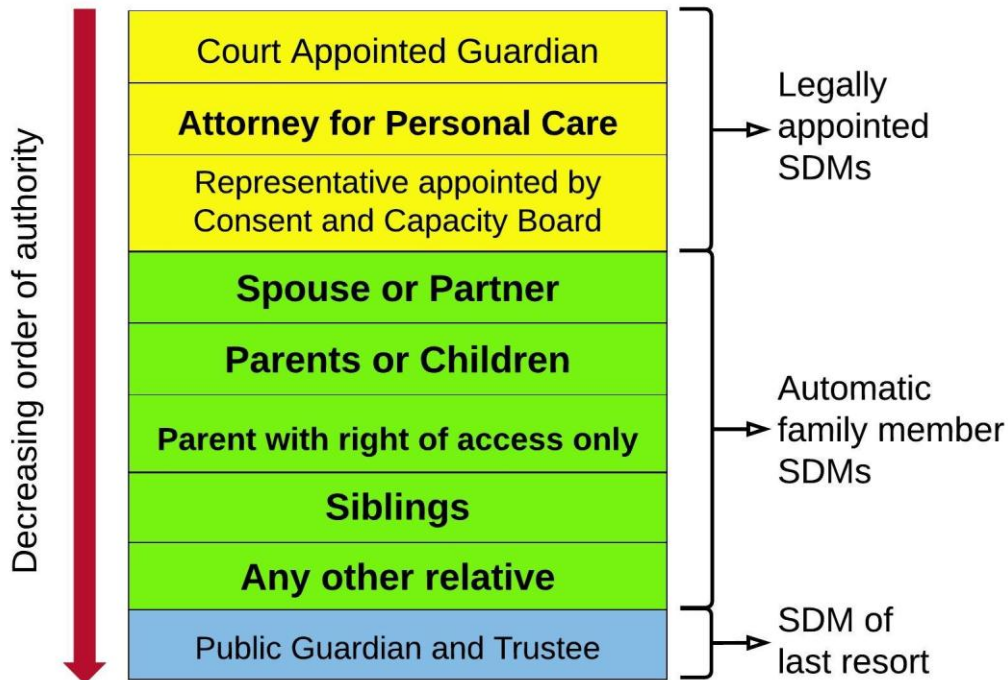
5. Zhang B, et al. Health Care Costs in the Last Week of Life Associations with End-of-Life Conversations. *Arch Intern Med* 2009;169(5):480-8.



## Who is the patient's SDM(s)?

- In Ontario, every patient automatically has SDM(s).
- SDM(s) are the person or persons who will make treatment and personal care decisions if the patient loses the capacity to make these decisions in the future.
- The hierarchy in the Health Care Consent Act outlines the ranking of SDMs (see figure below).
- A patient's automatic SDM(s) is the highest ranking family member(s).

### Substitute Decision Maker Hierarchy



Ontario's Health Care Consent Act, 1996

### NOTE:

- When there are **multiple SDMs at the same level** (e.g. multiple children, multiple siblings or a child and a parent), all names should be listed as SDMs. When future decisions are to be made, all SDMs must be consulted to see if each is willing to act as an SDM.
- When all eligible SDMs are willing, able and available ALL must agree on any decision.
- If the patient is concerned about possible disagreement among SDMs or if the patient prefers a different individual to act as their SDM, ACP conversations are the optimal time to discuss legally appointing an Attorney for Personal Care. (For more info visit [www.attorneygeneral.jus.gov.on.ca](http://www.attorneygeneral.jus.gov.on.ca))
- This can be more than one person but this person or these people would become the patient's SDM(s).
- Two SDM roles are legally appointed: court-appointed Guardian and Representative appointed by the Consent and Capacity Board. These positions are appointed once a person is already incapable of decision-making so they are not as relevant to discuss during ACP conversations.
- If a patient has no living family members and no one has been legally appointed as an SDM(s) (e.g. Attorney for Personal Care), the Public Guardian and Trustee will make decisions for that patient.

## What are important qualities of SDM(s)?

SDM(s) should be:

- Willing to accept the role and make health and personal care decisions for another person in the future
- Willing to talk to and understand the goals, values and beliefs of another person
- Willing to interpret, honour and follow the patient's wishes, values and beliefs as much as possible when they apply
- Able to ask questions and advocate for the patient with the health care team
- Able to make difficult decisions

## How often should ACP conversations take place?

- ACP is an ongoing process of reflection that should be revisited with any change in health or when the patient's wishes, values or beliefs change.
- Revisions and updates must be communicated to the patient's SDM(s).
- Any documentation of ACP conversations must be dated and should contain the most up to date information.

**Remember:** In Ontario, *prior capable wishes* (e.g. what is discussed during an ACP conversation) do not need to be written. The most recent wishes (whether written, verbal or in a video etc.) will take precedent as per the *Health Care Consent Act*.

## Who are the patients that should have ACP conversations?

ACP conversations can be considered for three distinct patient populations:

1. Healthy individuals for which the conversation will be more hypothetical and involve planning for unexpected events (trauma, pre-op for patients with good expected outcome)
2. Individuals living with chronic illness
3. Individuals living with advanced chronic illness, for whom death in a year would not be a surprise

For each of these populations, a slightly different approach is required:

1. **Healthy adult:** hypothetical situations. Certain questions in the *ACP Conversation Guide* may not apply e.g. if no serious conditions, the **Understanding** and **Information** questions may not be completed or the person may have given little thought to **Worries & Fears** about dying.
2. **Early stages of a chronic illness:** ACP conversations will be an opportunity to focus on illness **Understanding** and learning about living with the illness. These patients may or may not be ready to discuss **Worries & Fears** about dying. Questions can be answered when the patient feels ready to address them or as their illness progresses.
3. **Later stages of a chronic illness:** Specific treatments may enter the conversation as patient may have had personal experiences (e.g. ICU admission, intubation, BiPAP etc.). The final question, **Near the End** may become more important at this stage.



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## How do ACP Conversations and Goals of Care Discussions differ?

	ACP Conversations	Goals of Care Discussions
<b>Trigger</b>	Variable (e.g. recent illness, part of routine care, death of family member)	A need for consent on offered treatment or decisions on a general care direction
<b>Time and Context</b>	Planning for potential <b>future</b> care	Because a decision is to be made for <b>current</b> care, preparing to make decision
<b>Who</b>	Only a capable patient	Capable patient or his/her SDM(s)
<b>Outcome</b>	SDM(s) understands how patient would want future care decisions made as well as important factors and values that contribute to decision-making  Prepares a patient and/or their SDM(s) for future decision making	Patient or SDM understands illness and patient's goals of care have been clarified  Decision-making discussions can begin regarding giving or refusing consent for a proposed treatment or treatment plan

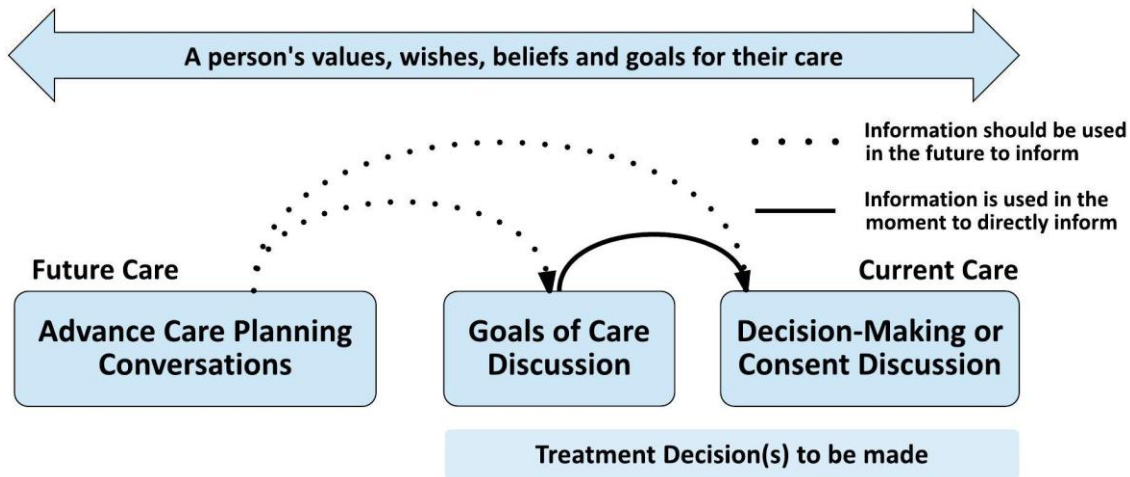


Figure: Relationship between three key discussions contributing to informed consent

## Introducing an ACP Conversation

- Ideally, ACP conversations are integrated into routine care. The process can be adapted based on clinical setting e.g. outpatient clinics, primary care office, patient's home etc.
- Integrating ACP into routine care normalizes the experience for both patients and clinicians.
- **An ACP conversation is entirely voluntary**, and patients should be invited to participate when they are ready and comfortable having the conversation (*see how the stages of change model can be applied to ACP conversations on page 7*). They may also choose to have ACP conversations with their SDM and others without involving a healthcare provider.
- If a person is not ready for a full ACP conversation, some may still be ready to talk about their SDM(s). Take the opportunity to ensure that the person knows their correct automatic SDM(s) and get their contact information recorded accurately.
- When a patient is ready to participate in an ACP conversation, provide further information on ACP (e.g. patient guide, workbook or online resources to help with values clarification) to help start the reflection process before you meet at their next appointment.

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- When the patient is ready to take action, he or she should return with the SDM(s) to proceed with the *ACP Conversation Guide*.

## Discussing SDMs

- Start by reminding the patient that **everyone in Ontario already has an SDM(s)**.
- Ensure they have an accurate understanding of who their SDM(s) will be based on the SDM hierarchy (page 4 of this guide).
- Review the qualities of who makes a good SDM (page 5 of this guide).
- If the patient is concerned that their default SDM(s) might not be right for the role, talk to them about the process of appointing an Attorney for Personal Care.

## Assessing the patient's readiness for ACP conversations

- If the patient has never heard of ACP or is not interested, the first conversation may focus on explaining ACP, how it may be beneficial and how it can impact future care.
- If a patient is accepting of ACP, a pamphlet explaining the elements can be provided.
- If the patient is not yet ready to consider discussing ACP, it may still be an opportunity to discuss his or her SDM(s).

Stage	What the patient knows or is doing about ACP
<b>Pre-contemplative</b>	Patient does not know about or has considered ACP
<b>Contemplative</b>	Patient may be aware of ACP but not ready to take any action
<b>Planning</b>	Patient reviews ACP educational materials or discusses the topic of ACP
<b>Action</b>	Patient knows who their SDM(s) is, has discussed wishes, values and beliefs with SDM(s) and may request help or further clinical information
<b>Maintenance</b>	Willing to revisit ACP conversations with SDM(s) but not sure when

Stage	Advice to clinician
<b>Pre-contemplative</b>	Introduce ACP and provide educational material if patient seems open Indicate questions or concerns about ACP can addressed in future visits
<b>Contemplative</b>	Ask if they have questions or need further information about ACP as well as their current health circumstances. Offer resources that would assist identifying values or wishes. Talk about the role and importance of SDM.
<b>Planning</b>	Engage in discussion regarding ACP educational materials. Discuss automatic SDM(s), Attorney for Personal Care if necessary and alternate in case SDM(s) unwilling or unable to assume duties.
<b>Action</b>	Meet with patient and the SDM(s) to facilitate ACP conversation
<b>Maintenance</b>	Periodically review and discuss ACP particularly with a change in health status or with critical illness or EOL of family member or friend

Adapted from:

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



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## Components of the *ACP Conversation Guide*

There are six focus areas to address during ACP conversations. Each will be addressed in detail and key questions for the six focus areas are:

1. What do you **understand about** your health or illness if you have any?
  2. What **information** is important for you to know?
  3. What brings **quality** to your life? What do you **value**?
  4. If critically ill or if EOL, what **worries** & **fears** come to mind?
  5. What would you **trade** for the chance of gaining more of what you value or what's important to you?
  6. If you were **near the end** of your life, what would make this time meaningful?
- For some patients it may not be appropriate to address certain questions.
  - The *ACP Conversation Guide* focuses on a person's values and what is considered important rather than preferences or thoughts about specific treatments.
  - Remember: what is discussed during an ACP conversation is **NOT** consent for future care, even if it is documented in writing. Either a capable patient or their SDM(s) must give consent for healthcare decisions in the future.

## Understanding

- **This question is particularly important for patients with early or late chronic illness** and for these patients the focus is on how the patient understands his or her own illness.
- It is helpful to learn how patient perceives the likely impact of illness on their life and function over time as well as what they think illness progression will look like.
- A patient's response may uncover an opportunity to address misconceptions and clarify misunderstandings regarding "what to expect" for their illness.
- **Important:** the response to this item may purely reflect the words clinicians have used with the patient. This does not mean the patient understands the information.

### Addressing potentially unrealistic hope:

- The expression of what seems to be unrealistic hope (or "denial") may or may not mean the patient does not understand the incurable, life limiting and progressive nature of their illness.
- For a small minority, what is perceived as hope by the clinician might be a necessary or invaluable part of the patient's illness experience i.e. an essential coping mechanism.
- It can be challenging to distinguish between **a patient who communicates an unrealistically hopeful** understanding of their illness and **a patient who truly does not understand** the incurable and progressive nature of their illness:
  - A patient in the first group is well informed and understands the nature of their illness but still has a need to express a sense of optimism or hopefulness.
  - A patient in the second group has either not been adequately informed or has not fully understood the information that has been provided. Helpful questions to discern between the two might include:





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*“I hear that 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’ve been told different than this at any time? That a cure may not be possible? If this has been said, what are your thoughts on this? If this has not been said, how would it be for you to hear this?”*

*“Do you not believe what other doctors have told you?”*

*“Is it important for you to maintain hope? Tell me more about this.”*

*“Has your hopefulness influenced any decisions you have made up to this point in your care?”*

- If you assess the patient as needing to communicate a sense of hope, please document this and proceed to the next item in the *ACP Conversation Guide*.
- If, in your assessment, the patient truly has not been provided the necessary information, the **Information** question plays an important additional role (see below).
- Having an inaccurate understanding of illness does not prevent proceeding with the remainder of the *ACP Conversation Guide*.
- Responses to other questions may provide clues as to how illness understanding might be approached at a future visit.

## Information

- Ask what additional information about their illness would be important or meaningful to the patient.
- The information might include: what can be expected in the future or what treatment options are likely to be offered in the future, etc.
- Ask about information preferences:
  - Does the person like to know big picture concepts or many details?
  - How should information be delivered?
- The patient may also tell you that he or she does not want information or ask that you tell someone else the information. Patients have this right and it is important to document this.
- Assessing the patient’s understanding of medical language and probabilities (e.g. CPR survival rate) will help guide how future information will be provided.

Both the **Information** identified by the patient as well as the response to the **Understanding** question, based on your professional role and clinical judgment you may:

- Provide the necessary information to the patient and their SDM(s).
- Help identify the healthcare provider who is best suited to answer outstanding questions.
- Help formulate questions to ask that healthcare provider based on what you have learned is considered to be important.

If providing clinical information is not within your professional scope, consider delaying the remainder of the ACP conversation as a patient can only effectively reflect on wishes, values and beliefs when it is based on having an accurate illness understanding.



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The **Information** item of the *ACP Conversation Guide* can function as a communication tool among clinicians.

## **Illustrative Case Study:**

*A patient on dialysis may truly believe or understand their kidney condition is curable and that the purpose of dialysis is to heal their kidneys. Accurate information may or may not have been provided in the past. Discretion of the clinician should be used to determine if it is appropriate to continue the ACP conversation. If the conversation proceeds, what surfaces when discussing subsequent items may give helpful insights as to how the clinician might structure future ACP conversations. For example, if a patient identifies one of their **Values** as “being well informed”, or identifying certain **Worries & Fears** can be useful to the clinician if revisiting **Understanding**.*

## Values, Beliefs & Quality of Life

- The aim is to facilitate the patient in identifying the essential components of what he or she considers a “good life”.
- It is crucial to maintain focus on the patient’s perspective (not the SDM or anyone else’s) on values, beliefs and quality of life.
- The importance and even the definition of a value may be highly individualized.
- When talking to someone about their values, it’s important to help them express what the value means to them.
- Avoid focusing on specific abilities such as sight, mobility etc. In general, people have a large capacity for adaptation to adverse situations and it is difficult for a patient to accurately predict the impact on their quality of life. For example, rather than “the ability to speak”, an essential component of quality of life could be “communicating one’s thoughts or ideas”. This can be accomplished using means other than verbal.
- If the patient has difficulty answering this question:
  - Ask the patient to think about health decisions they have made in the past
  - Explore how the patient made the decision(s) and how values or beliefs affected the decision-making process
- Examples of personal values related to healthcare may be:

**Independence      Spirituality      Dignity      Courage      Loyalty**  
**Clear-mindedness      Happiness      Wellness      Longevity      Family**

It might be helpful for the patient to consider how the information will be used in the future. E.g. consider an SDM who has to decide if she should consent or refuse the insertion and use of a feeding tube. The purpose is not to arrive at a preference about feeding tubes, but to consider how values can guide future decision-making in different contexts.

**Scenario A:** You have a temporary swallowing problem but converse easily with those around you and take considerable enjoyment from daily life.

**Scenario B:** You have lost the ability to communicate, don’t recognize others and are not very interested in eating.



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- Although the treatment decision is the same, the context and quality of life considerations are very different.
- If a patient places high value on being able to interact and communicate with others, explore how decisions might be made in each of the above two scenarios.
- What if the patient considers staying alive at all costs as the most important value?
- What if dignity is the most important value? How would the way dignity is thought of affect the response?

## Worries and Fears

- These may be related to specific symptom scenarios or emotional / psychosocial fears.
- This information may give SDM(s) guidance on what might be important to avoid, prevent or aggressively manage.
- This item may provide an opportunity to identify worries or fears that can be addressed in the present through reassurance or information exchange.

E.g: a patient may have a fear of suffocating. Reassurance that breathlessness can be well managed may mitigate this fear and impact future decisions about BiPap or other respiratory interventions.

- Based on the wording of the item, it may be the first time that dying or end-of-life enters as a concrete element of the ACP conversation.
- Clinicians may need to manage a patient's curiosity or distress about why end-of-life is being addressed.
- Reiterating the purpose of ACP and normalizing it as something all of us must consider is likely to be the most effective and efficient response to curiosity or distress that might surface.

## Trade offs

- Attempt to clarify what a patient is willing to go through for the possibility of gaining more of what he or she considers to be important (e.g. potentially extending life).
- A patient might say that a greatly diminished quality of life would be acceptable for even a remote chance of extending life.
- A patient might approach this question by listing a number of things they consider essential to their quality of life (things they are unwilling to 'trade off').
- Clinicians may want to remind the patient of the response they gave during the discussion of **Values, Beliefs and Quality of Life**.
- Explore what is valued that the patient might choose to "trade" when the potential for extending life is the alternative.
- SDM(s) may have additional questions at this point to gain a greater understanding of the patient's perspective.



## Addressing specific treatments

- Some treatments (e.g. intensive care unit admission, feeding tubes, ventilators etc.) may naturally enter the ACP conversation.
- When they do, efforts should focus on the patient's values and the context in which they might find a specific treatment acceptable or not.
- A reminder that it will be the SDM(s) who will be asked to consent to the treatment in the future. The ACP conversation is to provide the SDM(s) with as much information as possible to make that future decision.
- Clinicians are encouraged to explore why the patient has a wish/preference regarding a specific treatment, as this is likely to uncover the underlying value e.g. have they recently had an experience with this treatment? Seen someone else have it? etc.
- For patients who are in the latter stages of illness, they may have already experienced specific treatments (e.g. intubation, BiPAP, admission to the intensive care unit). In this case, the treatments as well as their benefits and burdens become less hypothetical.
- Patients with chronic progressive conditions will likely face similar situations with future deteriorations and ACP conversations can become more focused. Having certain experiences, the patient may be able to better articulate their values-based preferences for treatment. Again even when treatments are recorded in these sections, it will be helpful for the future SDM(s) to understand the values and reasoning behind the preferences.

## Near the End

- This question is more relevant for patients with advanced serious illness.
- Those who have no illness or at the early stages of illness may not be able to discuss.
- The patient may express wishes related to care setting or treatments, religious ceremonies, specific music, having books read to them etc.
- If appropriate for your professional scope, this might also be an opportunity to explore with the patient and their SDM(s) what to expect in the last stages of life.

## Additional persons for the SDM(s) to know about

- List any other persons the patient would want the SDM(s) to talk with. E.g. non-SDM family members, Spiritual Leaders, close friends etc.
- It is equally important to identify those who the patient would not want the SDM(s) to involve.
- The SDM(s) will still be the one asked to provide consent in the future, but other individuals can help support the SDM(s) through the decision-making process.

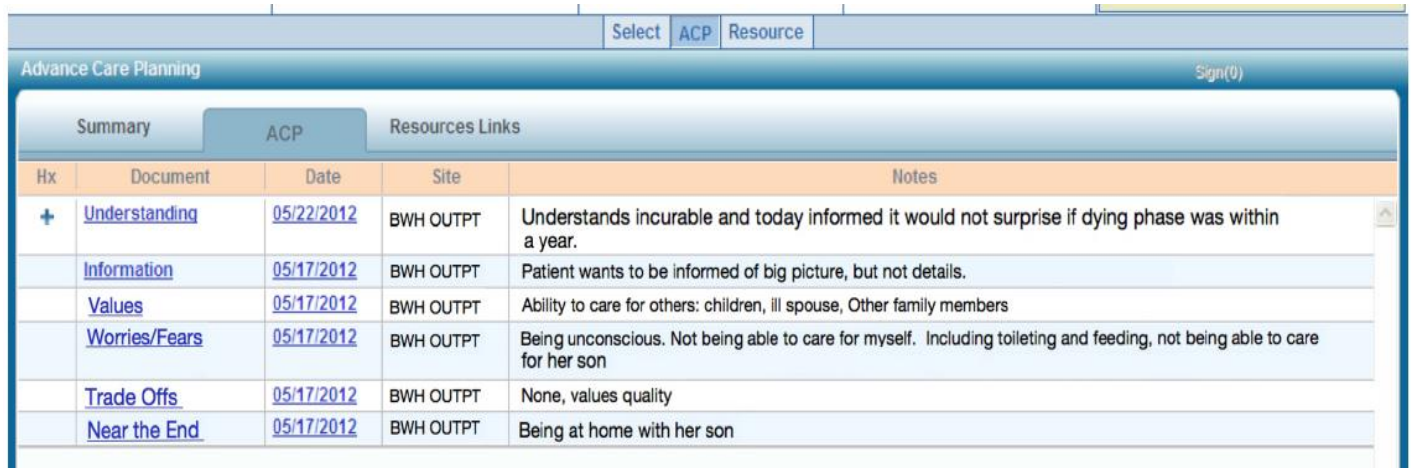
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## Signing the form

- Under Ontario law, **there is no requirement for either advance care planning conversations or *prior capable wishes* to be documented.** The most recent wishes (regardless if they are written, verbal, on video etc.) guide SDM(s) in future decision-making.
- **The purpose of a signature on the *ACP Conversation Guide*** is to remind clinicians that this form **MUST** be completed in the presence of the patient who **MUST** review what is documented **BEFORE** it becomes part of their medical record.
- ACP conversations are a way for capable people to have their wishes, values and beliefs known in the event they lose capacity for decision-making in the future.
- Since this documentation will be an expression of *prior capable wishes*, the patient to whom it applies must review this form to ensure they agree with what is documented.
- This is also why it is essential that any documentation is in the patient's own words.
- If the documentation is done on paper, the patient can sign it himself or herself.

## Documenting ACP Conversations

Below is a sample entry for an ACP conversation in to an EMR that has 6 free text fields:



Hx	Document	Date	Site	Notes
+	<a href="#">Understanding</a>	<a href="#">05/22/2012</a>	BWH OUTPT	Understands incurable and today informed it would not surprise if dying phase was within a year.
	<a href="#">Information</a>	<a href="#">05/17/2012</a>	BWH OUTPT	Patient wants to be informed of big picture, but not details.
	<a href="#">Values</a>	<a href="#">05/17/2012</a>	BWH OUTPT	Ability to care for others: children, ill spouse, Other family members
	<a href="#">Worries/Fears</a>	<a href="#">05/17/2012</a>	BWH OUTPT	Being unconscious. Not being able to care for myself. Including toileting and feeding, not being able to care for her son
	<a href="#">Trade Offs</a>	<a href="#">05/17/2012</a>	BWH OUTPT	None, values quality
	<a href="#">Near the End</a>	<a href="#">05/17/2012</a>	BWH OUTPT	Being at home with her son

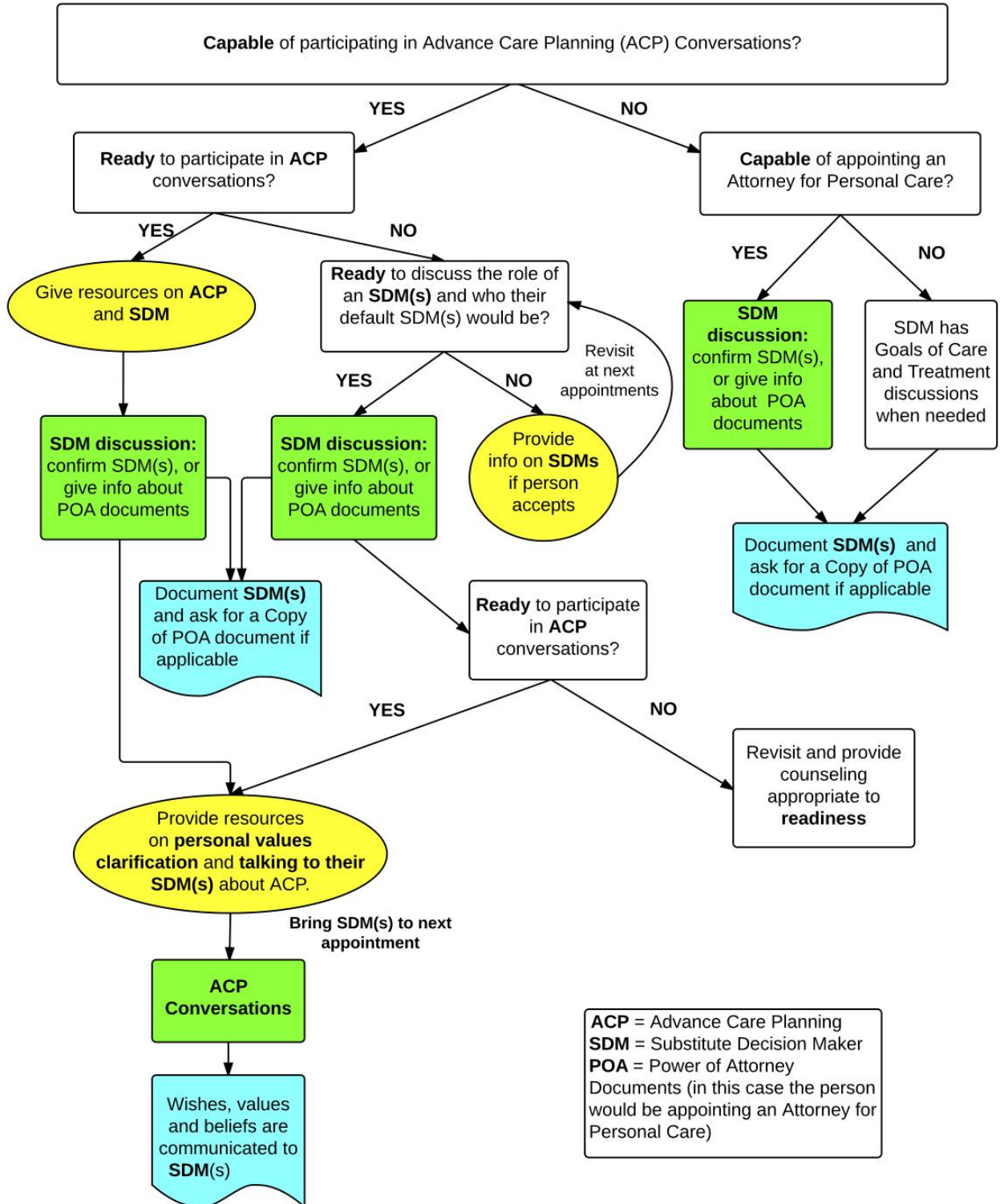


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## Integrating ACP Conversations into Practice

Adaptations of the ACP Conversation process may be required for each clinical environment.

Specifics around clinical implementation may be determined by the availability and training of interprofessional healthcare providers in your clinical setting. The following is a suggested process for clinical implementation that can be broken down over multiple patient interactions.



ACP = Advance Care Planning  
 SDM = Substitute Decision Maker  
 POA = Power of Attorney Documents (in this case the person would be appointing an Attorney for Personal Care)

# Advance Care Planning Conversation Guide

Patient Name: \_\_\_\_\_

Today's Date: \_\_\_\_\_ (MM/DD/YYYY)

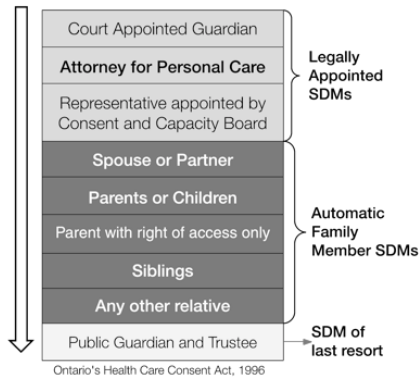
## PART 1. CLARIFYING THE SUBSTITUTE DECISION-MAKER (SDM)

A Substitute Decision Maker is the person or people who will make healthcare decisions on behalf of a person if he/she lacks the capacity to make them for themselves. In Ontario, a person's SDM is automatically determined by following the below list:

Confirm automatic SDM(s)

Or

Choose SDM(s) and Complete a Power of Attorney for Personal Care document



Most people will rely on their automatic SDM. If there are **multiple people at the same level**, they **ALL have the authority** to make decisions. If there are multiples, be sure to record this information. If someone other than the automatic SDM is preferred, the person should legally appoint an Attorney for Personal Care.

## ARE SDMs RIGHT FOR THE ROLE?

Ask if the future SDM(s) are:

- Willing to make future healthcare decisions for the patient
- Willing to talk with patient to understand his/her wishes, values & beliefs
- Willing to understand care needs and patient's condition when consent needs to be provided
- Willing to honour and follow patient's wishes to the extent possible when they apply
- Able to ask questions and advocate for patient
- Able to make hard decisions

## Highest equal ranking SDM(s)

Name	Contact Number

## Next highest ranking SDM(s)

Name	Contact Number

Is this the initial ACP conversation?  Yes  No

Have any previous wishes been communicated to the SDM?  Yes  No  Unsure

## PART 2. DETERMINE CAPACITY TO PARTICIPATE IN ACP CONVERSATION

A person understands and appreciates that:

- These responses provide guidance for the SDM(s). The SDM may need to provide consent for future (not current) health care decisions if the person is not capable of decision-making for him or herself.
- Their SDM(s) will be required to interpret all wishes they express to determine (1) which are the most recent (2) if the person was capable when they expressed the wishes (3) if they apply to the decision that needs to be made. Finally, the SDM(s) must interpret what the wishes mean in the context of the person's health status and healthcare decision that needs to be made
- As long as the person 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 person has capacity for advance care planning at the time of updating or changing
- Healthcare wishes expressed by the capable person at a future date will take precedent over relevant wishes that are documented here, regardless of how wishes are expressed i.e. verbal, written, in a video etc.



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**NOTE:** The structure and organization of the six domains of ACP Conversation Guide questions were influenced by several sources and resources. Among these include the FIFE communication model and the Serious Illness Conversation Guide by Ariadne Labs.

# Advance Care Planning Conversation Guide

Patient Name: \_\_\_\_\_

Today's Date: \_\_\_\_\_  
MM DD YYYY

**PART 3:** 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.

## Understanding

**What do you understand about your current health or if you have any illnesses what have you been told by your healthcare providers? What do you expect to happen over time?**

(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?)

## Information

**If you have illnesses and are unsure about what might happen over time, what information about the illness and treatments would be helpful to you? Is there information that you don't want to know?**

## Values, Beliefs & Quality of life

**What brings quality to your life? What is important to you and gives your life meaning?** (E.g. being able to live independently, being able to recognize important people in your life, being able to communicate, being able to enjoy food, spending time with friends & family etc.)

**For clinicians:** How might this influence the person's healthcare decision making? How would an SDM use this information to make healthcare decisions in the future?

*The remainder of the questions require the person to consider future hypothetical situations. They are meant for the person to consider what might be important in the event of a sudden critical illness (e.g. accident) or as they are nearing the end of their life from a serious illness. This is a chance for the person to tell SDMs what is important and how the person would like SDMs to make decisions.*

## 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 might you worry about or what fears come to mind?**

(E.g. struggling to breathe, being in pain, being alone, losing your dignity, depending entirely on others, being a burden to your family/friends, being given up on too soon etc.)

## Trade - offs

**If you became critically ill, life support or life extending treatments might be offered. Describe for your SDM the state you consider unacceptable to keep living in.**

**For clinicians:**

- What would the person be willing to tolerate? To possibly gain more time? (E.g. would you trade the ability to communicate, the ability to interact with others, the ability to control of your bodily functions)
- Does this change for the person if the condition is permanent or if there is little or no chance of recovery?

## Near the end

**If you were near the end of your life, what would be important you?** (E.g. family and friends nearby, dying at home, having spiritual rituals performed, listening to music etc.)

**For clinicians:** What might make the end more meaningful or peaceful for the person?

## Note to Healthcare Providers:

If this patient lacks capacity to make healthcare decisions in the future, this conversation may be used to guide SDM(s) in providing informed consent. It may outline information about prior capable wishes and best interests of the patient. Therefore, **this form must not include healthcare 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 this statement**

Health Care Provider Name: \_\_\_\_\_ Health Care Provider Signature: \_\_\_\_\_



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