Facilitating Advance Care Planning Conversations

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Objectives

• Appreciate the importance of incorporating a values history into professional practice to improve patient centred-care

• Identify information that may be helpful to a patient’s SDM for potential decision-making processes in the future

• Enhance comfort and confidence with integrating ACP conversations into routine care through the use of a conversation guide
ACP: Advancing Knowledge & Skill

• Two levels

• General ACP knowledge and skills
  • Advocate, encourage, clarify myths/misconceptions

• Specific to ACP Conversations - Knowledge and skill to facilitate
  • Advanced communication skills
  • Likely requires experiential learning environment
ACP: Outcome Evidence

• Improves pt & family satisfaction with EOL care\(^1\)
• Decreased caregiver distress & trauma\(^2\)
• Decreased unwanted investigations, interventions & treatments

• Pts more likely to die in preferred setting, with earlier palliative care involvement\(^3,4\)
• Less likely to be hospitalized & admitted to critical care
• Decreased cost\(^5\)
ACP: Process Evidence

- ACP conversations are documented and accessible in an electronic medical record

- Approach is ideally standardized

- Timing of an ACP conversation (i.e. > 1 month prior to dying) is more important than setting

- Having and documenting advance care planning conversations are more predictive of patient outcomes than code status decisions
What ACP elements are critical?

1. SDM...identified AND present

2. Integrate into routine care and standardize appropriate parts

3. Focus of conversation: should NOT be on treatment, it should be on the person’s values
Making Healthcare Decisions

Values

- Are the risk worth the benefits to me?
- Is this plan or treatment consistent with what I want to achieve?

Evidence

- Facts
- Expected outcome
- Side effects and risks

An Interprofessional Approach to ACP

• ACP requires advanced communication skills that are not dependent on a specific profession

• ACP focusing on values and beliefs rather than medical interventions therefore not MD dependent

• Evidence for effectiveness of an interprofessional facilitator model
Step 1 ACP Process

• Outline process for **identify**ing patients
• Assess **capacity** to participate in an ACP conversation
• Introduce topic and assess **readiness**
  – If not ready, assess readiness to discuss SDM
• Provide resources on **choosing SDM**
  – Determine SDM if appropriate
• Provide **ACP workbook** and encourage review prior to next appointment
• **Encourage SDM presence** for next appointment
## Readiness for ACP

<table>
<thead>
<tr>
<th>Stage</th>
<th>What the person thinks about ACP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-contemplation</strong></td>
<td>Patient does not know about or consider ACP</td>
</tr>
<tr>
<td><strong>Contemplation</strong></td>
<td>Patient may be aware of the pros and cons regarding ACP but does not appear ready to take any action</td>
</tr>
<tr>
<td><strong>Preparation</strong></td>
<td>Patient prepares to engage in ACP through review of educational materials or discussions with others</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td>Patient has discussed their wishes with others, chosen a substitute decision maker and may request help or further medical information</td>
</tr>
<tr>
<td><strong>Maintenance</strong></td>
<td>Patient has consistent ACP wishes and may want to revisit these wishes with their substitute decision maker and/or doctor when health circumstances change.</td>
</tr>
</tbody>
</table>
Counseling Based on Readiness

<table>
<thead>
<tr>
<th>Stage</th>
<th>Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-contemplative</td>
<td>Introduce topic of ACP and provide educational material if patient seems receptive. Mention that you can answer questions or address concerns about ACP in a future meeting.</td>
</tr>
<tr>
<td>Contemplative</td>
<td>Ask patient if he/she has any questions or need for further information about ACP as well as their current health circumstances. Offer resources that would assist them in identifying their values or wishes. Talk about the role and importance of a substitute decision maker.</td>
</tr>
<tr>
<td>Planning</td>
<td>Engage patient in discussion regarding the educational materials on ACP. Help him/her talk about their values and wishes. Discuss a possible substitute decision maker and perhaps an alternate in case this person is unwilling or unable to assume these duties.</td>
</tr>
</tbody>
</table>
## Counseling Based on Readiness

<table>
<thead>
<tr>
<th>Action</th>
<th>Provide a workbook or other resources to help the patient record wishes, values etc. Offer to meet with patient and the substitute decision maker to discuss ACP further.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintenance</td>
<td>Provide opportunity to update the ACP with your patient particularly if there has been a change in health status or a long period during which ACP has not been reviewed.</td>
</tr>
</tbody>
</table>
Step 2 of ACP Process: The Conversation

An ideal ACP:

• The SDM will be aware of the person’s values and what he or she views as a meaningful life

• The SDM will begin to understand how the person makes decisions (i.e. how they view benefit and burdens)

• Avoids statements such as “no machines” or “no heroics” or “no feeding tubes” without the context or modifiers that would make these situations bearable or unbearable for the individual

Dr. Jeff Myers - Sept 29, 2015
# Advance Care Planning Conversation

**Patient Name:**

**Today’s Date:**

### 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 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:

#### Alternate SDM:

### This is the first documented ACP Conversation: Yes ☐ No ☐

If “No”: Date of most recent ACP:

- 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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Advance Care Planning Conversation

**Patient Name:** ________________________  **Today’s Date:** ________

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 loves 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 eat, 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:** ___________________________

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ACP Conversation Template

1. What is your **understanding** of your illness? What have you been told?

2. What **information** is important to you?

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 **trade offs** are you willing to make for the possibility of added time?

6. If you were **near the end** of your life, what would make this time meaningful?
Why these six domains?

- **Illness understanding**: evidence that this is VERY poor (e.g. cancer, CHF and incurable & progressive nature)

- **Information**: meaningfully meet individual information needs:
  - Pts right not to know information
  - Assess health literacy
  - Preferences re: information delivery
  - Learning style
Why these six domains?

• **Values**: the information that can be applied to various healthcare contexts

• **Worries & Fears**: a different way of expressing values

• **Trade Offs**: facilitates exploration of the conditions under which a person would want quality vs quantity

• **Near the end**: a different way of expressing values
ACP Conversation Template

• Not all questions need to be completed in one encounter

• Quite possible many will be uncomfortable with “Nearing the End” however many will be relieved

• The way the template is used reflects both where the patient is and the HCP comfort/confidence
  – This is one element that makes this an advanced communication skill set
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?)

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Understanding

• If you assess the person as needing to communicate a sense of hope, document and proceed to the next item in the template

• If in your assessment the person truly has not been provided the necessary information, the Information item in the template plays a particularly important additional role

• Having an inaccurate understanding of illness does not preclude the person from proceeding with the remainder of ACP

• It does, however, suggest that for certain individuals, timely follow up and revisiting may be important
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?
Information

Based on the Information identified by the person as well as the response to the Understanding items, you as the facilitator may:

- Provide the necessary information to the person and their SDM
- Help to clarify which information is considered important and meaningful
- Explore and document the meaning certain information has to the person and preferences for how information would ideally be shared
Information

• This item might highlight a patient’s right to not know their healthcare information
• Facilitators should explore which elements of the ACP conversation the patient wants to discuss, identify with whom the patient would like healthcare information shared and who will be making care decisions for them
• Three other components of this item may also include:
  • Assessment of health literacy
  • Preferences for how information is delivered
  • Preferred learning style
Understanding & Information

• First two questions may be as far as the first formal ACP conversation goes
• These two are essential to the ACP process
• E.g. A person on dialysis may truly believe or understand their kidney condition to be curable and that the purpose of dialysis is to heal their kidneys
• Accurate information may have been provided in the past and the patient may not have fully understood this information, for any number of reasons
• Continuing the conversation based on an inaccurate illness understanding can be tricky
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 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? (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 life support 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

- Pt may specifically address certain treatments (e.g. intensive care unit admission, feeding tubes, ventilators etc.)
- Efforts should 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 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
- Facilitators are encouraged to explore what has brought the person to have a wish/preference regarding a specific treatment, as this is likely to uncover the underlying value
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.)
Troubleshooting & Useful Tips

WHAT IF A PATIENT IS PRE-CONTEMPLATIVE?

• If the person is not ready to participate in an ACP conversation, they may still be ready and willing to discuss their chosen decision maker

• Having the discussion around choosing an SDM may or may not lead to further conversations

• Nonetheless, the act of choosing an SDM remains an essential component of ACP
Troubleshooting & Useful Tips

HOW DO WE FACTOR IN CULTURAL OR LANGUAGE CHALLENGES? Cultural Humility

- Explore what a person’s spiritual beliefs mean to them and how it plays a role in their decision making
- Assess preferences for decision making (individual vs. group)
- Explore if death and dying are appropriate topics to discuss
Standardized Documentation

• At minimum documentation of correct SDM

• Attempt to collect information to help SDM make a range of future decisions by documenting values, beliefs and trade-offs rather than specific treatment options

• Does not replace the need for informed consent from the SDM for a treatment plan
<table>
<thead>
<tr>
<th>Hx</th>
<th>Document</th>
<th>Date</th>
<th>Site</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Understanding</td>
<td>05/22/2012</td>
<td>BWH OUTPT</td>
<td>Understands incurable and today informed it would not surprise if dying phase was within a year.</td>
</tr>
<tr>
<td></td>
<td>Information</td>
<td>05/17/2012</td>
<td>BWH OUTPT</td>
<td>Patient wants to be informed of big picture, but not details.</td>
</tr>
<tr>
<td></td>
<td>Values</td>
<td>05/17/2012</td>
<td>BWH OUTPT</td>
<td>Ability to care for others: children, ill spouse, Other family members</td>
</tr>
<tr>
<td></td>
<td>Worries/Fears</td>
<td>05/17/2012</td>
<td>BWH OUTPT</td>
<td>Being unconscious. Not being able to care for myself. Including toileting and feeding, not being able to care for her son</td>
</tr>
<tr>
<td></td>
<td>Trade Offs</td>
<td>05/17/2012</td>
<td>BWH OUTPT</td>
<td>None, values quality</td>
</tr>
<tr>
<td></td>
<td>Near the End</td>
<td>05/17/2012</td>
<td>BWH OUTPT</td>
<td>Being at home with her son</td>
</tr>
</tbody>
</table>
Follow Up

• ACP should be revisited with any change in health or when preferences change

• Reflecting on any incomplete questions or if answers evolve, this should be communicated to SDM and previously documented ACP updated

• Ideally, what is documented will be most up to date

• If not, information expressed to the SDM verbally or in any other format still takes precedent under the Health Care Consent Act
Next Steps

• What are the professional development needs among members of your team?
• How can these needs best be met?
• How can we ensure information is available and accessible?
• How can we evaluate elements of the process as well as the process overall?
COMMENTS?

QUESTIONS?