Facilitating Effective End of Life Communication—Helping People Decide

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Objectives

At the end of this presentation you will :

- Be aware of the benefits and importance of EOL discussions within Ontario's Advance Care Planning (ACP) process
- Be familiar with legislation in Ontario that shapes Advance Care Planning (ACP)
- Identify some tips and strategies to facilitate ACP conversations

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Things I want to do before I die (Bucket List)

 3

Things I want to do before I die (Bucket List)





But what if you have just a year to live?

With a show of hands:

- Have you had a conversation with a patient about advance care planning in last 3 months?
- Do you feel knowledgeable and comfortable in discussing advance care planning?
- Have you had a personal advance care planning conversation?

Why are EOL Discussions Important?

- Many people are unable to make decisions when they are near death resulting in:
  - uncertainty for families and health care providers about their wishes and end of life choices
  - perceived urgency to make decision about the delivery of treatments
  - Often anxiety and feelings of guilt of surviving family

(Butler-Jones, 2010; CHPCA, 2015)

Why are EOL Discussions Important?

- Lack of EOL conversations often result in the treatments and intervention which individuals may not have wanted
  - higher rates of ventilation (1.6% vs 11.0%;, resuscitation (0.8% vs 6.7%;,ICU admission (4.1% vs 12.4%;, 0.14-0.90), In adjusted analyses,
  - more aggressive medical care was associated with worse patient quality of life and higher risk of major depressive disorder in bereaved caregivers

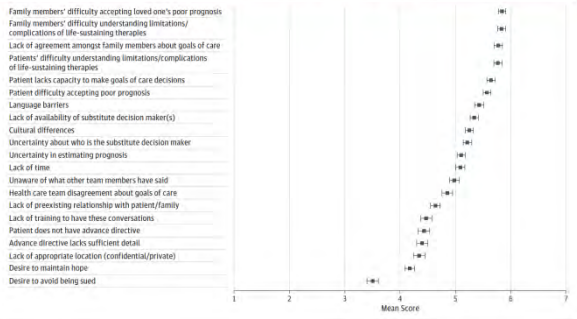
(Wright *JAMA. 2008;300(14):1665-1673*)

Why are EOL Discussions Important?

- Its often not done!
  - Although 95% of Canadians feel its important only 30% have had any EOL discussion and only half of those have recorded ACP/directive (CMA National Dialogue 2014)
  - Only 9% have had EOL discussions with a physician
  - 90% of dialysis patients report having no discussions about prognosis or wishes despite annual mortality rate of 22% (Davison SN. Clin J AmSoc Nephrol. 2010;5(2):195-204)
- Or its delayed
  - Cohort group with metastatic lung and colorectal cancer first conversation took place 33 days before death (Mack JW, et al. J Clin Oncol. 2012;30 (35):4387-4395).
  - 15% of hospice patients are referred in last week of life (Ferrell BR. J Clin Oncol. 2005;23(12):2588-2589).

From: **Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families A Multicenter Survey of Clinicians** JAMA Intern Med. 2015;175(4):549-556.

Figure 1. Importance of Barriers to Goals of Care Discussions as Perceived by Clinicians on Medical Teaching Units



Impact of delayed or inadequate EOL discussions

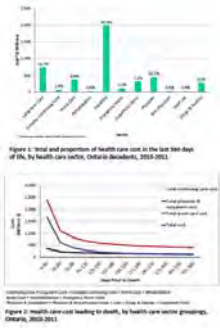
- poor quality of life and anxiety, and family distress (Wright AA, et al JAMA. 2008;300(14):1665-1673).
- prolongation of dying process, undesired hospitalizations, and patient mistrust of the health care system (Mack JW, et al J Clin Oncol. 2010;28 (7):1203-1208)
- physician burnout (Jackson VA, et al. J Palliat Med.2008; 11(6):893-906.
- high costs (Zhang B,Wright AA, et al. Arch Intern Med. 2009; 169(5):480-488).

Health Costs of Dying in Ontario 2010-11

Table 2: Characteristics of health care users (1+ use) in the last year of life, by health care sector, Ontario decedents, 2010-2011

	Decedents (n)	%	Average Cost ($)
All Decedents	177,817	100%	49,267
Decedents with 1+ Use	175,478	98.7%	49,924
Male	86,514	49.3%	49,325
Female	88,964	50.7%	50,507
Age, yr*			
<19	1,964	1.1%	45,530
19-44	5,229	3.0%	42,687
45-54	9,183	5.2%	49,881
55-64	18,151	10.3%	53,713
65-74	27,833	15.9%	55,237
75-84	48,784	27.8%	51,789
85-94	52,807	30.1%	46,402
95+	11,507	6.6%	43,599

Health Costs of Dying in Ontario 2010-11



What is Advance Care Planning?

Advance Care Planning (ACP) is a process of reflection and communication:

- in which a person lets others know what kind of health and personal care they want in the future if they were to become incapable of giving consent for treatment or care, or for refusing treatment or care
- includes choosing a Substitute Decision Maker (SDM)
- may involve having discussions with Health Care Providers and the SDM to obtain accurate information for making decisions
- is shaped by legislation in Ontario
- Its not the same as a "Directive" or "Living Will"!

(adapted from CHPCA, 2015)

Terminology and Legislation can be Confusing?

- Instructional directives are written document that states what health care decisions should be made when the person is unable to make decisions.
- They have legal status only in Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, Northwest Territories, Prince Edward Island and Saskatchewan.
- Living Will is not part of any Canadian legislation
- Variety of terms used to describe proxy decision maker
  - "Agent" AB, NWT, NB
  - "Proxy" PEI, MB, SK, YT.
  - "Representative" BC, NFL
  - "Mandatory" QB
  - "Substitute decision maker" ON.
  - "Guardian" NS

Health Care Consent Act (HCCA), 1996

- States a health professional must get consent for:
  - any type of treatment
    - Therapeutic
    - Preventive
    - Diagnostic
    - Cosmetic
    - Other health related purpose including course of treatment and plan of treatment
  - accepting/refusing admission to care facilities
  - certain personal assistance services
- Provides a hierarchy of people who will be the SDM, in the event one has not been named

(http://www.ontario.ca/laws/statute/96h02)

Health Care Consent (HCC)

- Development based on case law
- HCC is about principles of respect and individual autonomy
- Only valid if it occurs within the rules that govern it
- In an emergency if the person is not capable or able to give consent and there is no SDM available, the Health Care provider must follow the known wishes or in absence of known wishes act in persons best interest.
- Emergency is defined as experiencing severe suffering or is at risk of serious bodily harm

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Substitute Decisions Act (SDA), 1992

- The SDA outlines the formal process to identify a Substitute Decision Maker in the event that a person is incapable of making decisions and identifies the responsibilities of the Substitute Decision Maker

(http://www.ontario.ca/laws/statute/96h02)

Elements of Consent

For consent to be valid the following elements are required:

- ✓ Must relate to the treatment being offered for person present health condition
- ✓ Must be informed
- ✓ Must be given voluntarily
- ✓ Must not be obtained through misrepresentation or fraud

(HCCA, 1996)

Elements of Consent

Information to be provided:

- ✓ Nature of the treatment
- ✓ Expected benefits
- ✓ Material risks
- ✓ Possible side effects
- ✓ Alternative course of action
- ✓ Likely consequences of not having the treatment
- ✓ Answers to any questions

(HCCA, 1996)

Can the person say "no" to treatment

- Yes even if it doesn't appear to be in his/her best interest providing they are **capable**
- Every effort should be made to ensure the person understands the consequences each and every time a treatment or non-treatment is proposed
- Must apply the "Reasonable Person Standard"

"a reasonable person would require an understanding of his or her condition and its expected trajectory, the treatment being proposed, its benefits, burdens, risks, side effects, alternative courses of action and the consequences of having or withholding the treatment"

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Triggers to Capacity Assessment

- Health Professionals legal requirement for consent to treatment
- Discharge planning issues
- Values/Belief Conflict with staff/family/patient
- Belief patient unable appreciate issues/concerns
- Requirement within Power of Attorney
- Inpatient treatment in a Mental Health Facility

Capacity

- Capacity is not dependent on:
  - 1) A test result e.g. MMSE or MoCA
  - 2) A diagnosis e.g. Dementia
- Capacity is based on the context and the complexity of the situation being assessed
- Capacity can fluctuate due to their underlying condition or a treatment.
- Capacity is related to the specific treatment proposed; a person can be incapable with respect to a treatment at one time and capable at another time.
- A capable person has the right to change his or her mind at any time.

How do you assess their understanding and appreciation of consequences?

- Having them repeat back what they just heard
- Determine the quality of their responses to the information
  - Appropriateness
  - Demonstrates that they understand consequences
  - Matches the context of the information being shared
- If deemed not capable or unable to consent at the time of treatment being offered we turn to their substitute decision maker

Substitute Decision Maker

In Ontario, a Substitute Decision Maker is selected in 2 ways:

1. Is chosen by a person when capable and identified in the Power of Attorney for Personal Care document

(ON Government, 2000; HCCA, 1996; .)

Power of Attorney for Personal Care

A **Power of Attorney for Personal Care (POAPC)** is a **legal document** (piece of paper) by which a capable individual appoints a SDM and gives them the authority to make personal care decisions on their behalf in the event they are unable to communicate their wishes

People who decide to complete a Power of Attorney for Personal Care document may do so by:

- Using a form from the Ontario Power of Attorney for Personal Care booklet
- Making their own form
- Consulting a lawyer and completing a POAPC document

All POAPC documents are required to meet the legal requirements of the Substitute Decisions Act (SDA), 1992

(ON Government, 2014; SDA, 1992)

Substitute Decision Maker

In Ontario, a Substitute Decision Maker is selected in 2 ways:

1. Is chosen by a person when capable and identified in the Power of Attorney for Personal Care document

OR

2. If there is no legally appointed SDM and the person is found to be unable to give consent, the Health Care Consent Act provides a hierarchy of persons who may be asked to fulfill the role of the SDM

(ON Government, 2000; HCCA, 1996; .)

Health Care Consent Act Hierarchy

The following is the hierarchy list of SDMs in the HCCA, s.21 :

1. Guardian of the Person
   - The person's guardian (appointed by the Superior court)
2. Attorney named in a Power of Attorney for Personal Care
   - The person chosen to be the SDM (when the person was capable)
3. Representative appointed by the Consent and Capacity Board (CCB)
   - This may be a friend or family member who has applied to the CCB tribunal to be the guardian.
4. Spouse or partner
5. Child or Parent (person with right of custody)
6. Parent with right of access
7. Brother or sister
8. Any other relative
   - Related by blood, marriage or adoption
9. If no person meets the requirement to be the SDM then the Office of the Public Guardian and Trustee is the SDM

(HCCA, 1996 http://www.ontario.ca/laws/statute/96h02)

Requirements for the SDM

- is mentally capable
- 16 years of age unless they are the parent of the incapable person
- not prohibited by a court order or separation agreement to have access to the incapable person or to give or refuse consent on their behalf
- be available
- is willing to assume the responsibility of giving or refusing consent.

(HCCA s. 20)

Role of the Substitute Decision Maker

The SDM:

- "speaks" for the individual when the person is incapable
- gives informed consent or refuses consent for a treatment
- considers and follows any prior wishes expressed
- if a circumstance arises and the incapable person's wishes are unknown, the SDM must consider the incapable person's values and beliefs when they were capable and respond accordingly and make decisions in their "best interests"

(ON Government, 2000; HCCA, 1996, c. 2, Sched. A, s. 21 (1))

Ontario ACP Workbook & Guide

Available at

http://www.seniors.gov.on.ca/en/advancedcare/

http://www.advancecareplanning.ca/wp-content/uploads/2015/09/acp_ontario_workbook_-_03.2015_colour_final-web-form.pdf

Goals of Care and Treatment Orders

- Goals of Care discussions are the decisional process around specific, time-limited treatment options.
- This includes management of medical issues such as during a period of hospitalization or acute illness which may also be termed a Treatment Plan.
- There are similarities between Goals of Care and ACP, but they should be viewed as intertwined entities.
- ACP does not require a physician to initiate or be part of the conversation.

What's the Difference?

Advance Care Planning	Goals of Care	Treatment Plan
Are initiated by the individual at any time.	Are often initiated by the patient's physician or health care team and are developed in consultation with the patient or the SDM.	Are initiated by the patient's physician or health care team and are developed in consultation with the patient or the SDM.
Are designed for patients who want to put a plan in place in event of a future illness, injury, or accident occurring	Are designed for patients with a progressive, life-limiting disease; a critical trauma or injury; multiple complex medical conditions, cognitive impairment, and/or complications resulting from frailty	Are designed for patients requiring specific treatments during an episode of care
Express the individual's wishes, goals, values, and/or beliefs for care in the event of a future illness, disease or accident	Express the individual's wishes, goals, values, and/or beliefs for care within the specific circumstance they are in.	Clearly state the specific treatments a patient consents to or refuses, and may include the conditions under which they would want treatment withheld or withdrawn.
Often broad and non-specific and based on the patient's anticipated health conditions.	Address issues of preferences and priorities concerning future treatments and places of care in the near future based on current health conditions.	Must be for specific treatments designed to address the health conditions the patient currently has, or is likely to have in the future.
Provide guidance to the substitute decision maker and/or care team regarding preferences for future general treatments but consent is still required.	Provide guidance to the substitute decision maker and/or care team regarding preferences for future general treatments but consent is still required.	The physician is required to obtain consent from either the patient if he/she is capable, or from the patient's substitute decision maker in developing the treatment plan.
Durable across treatment settings.	May apply across multiple treatment sites.	Relates only to the circumstances or period of time of that particular treatment setting eg. hospitalization

Treatment Plans or Orders

- The Health Care Consent Act, 1996 (HCCA), defines a treatment plan as follows: A plan of treatment: "(a) is developed by one or more health practitioners, (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition" (HCCA, section 2.(1)).

Code Status Discussions

- In October 2013 the Supreme Court of Canada decision in Cuthbertson v. Rasouli determined that treatment "includes the withdrawal of life support that is effective in keeping the patient alive and forestalling death; therefore, the withdrawal of life-sustaining treatment requires consent."
- This means that orders such as "No CPR" or "Do Not Resuscitate" are separate and discrete treatments that should be discussed with the patient or their substitute decision-maker when completing a specific treatment plan.
- They cannot be considered an ongoing consent and need to be reviewed as part of an ongoing process

Careful what you wish for!

Things to ask Yourself

Who's responsibility is it to have ACP conversations?

When should you start having ACP conversations with patients?

When to start an ACP Conversation

- During an annual examination of "frail" older adult with Chronic Disease
- Change in health status especially if associated with
  - mild cognitive impairment or early dementia
  - when a new functional impairment is identified
  - when increased caregiver involvement is evident
- post-hospitalization, post–subacute rehabilitation, or other care transition (assisted living facility or nursing home)
- changes in family or social situation, including death of a loved one
- High risk of death within next year

(Lum, Sudore & Bekelman, 2015)

End of life care in Cancer and other conditions

Cancer	Chronic Disease	Frailty
• Discontinue curative/life-prolonging Rx when focus changes to palliation • Commonly a unidirectional trajectory with steady progression • Early awareness that disease is life limiting • Often younger and less commonly dealing with multiple co-morbidities	• Often continuation of curative/life-prolonging Rx despite change of focus to palliation • Exacerbations, or slow progression • Delayed perception that disease is life limiting • Interactions with co-morbidities and need to modify treatment goals	• Treatment primarily supportive and symptomatic • Slow progression with sudden change and atypical presentations • Contribution of chronic disease or new illness may not be recognized • Older patients with co-morbidities and older caregivers

In one study of 9 diverse FP's in Scotland likelihood of death in next 6 months was better identified in cancer patients (74%) than frail patients (66%) or organ failure patients (41%).
(Tapsfield et al BMJ Support Palliat Care 2016 Apr. 13)

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High Risk of Death within Next year

- **Age > 55 years and 1 or more of the following**
  - COPD (2 of the following: baseline arterial partial pressure of carbon dioxide > 45 mm Hg, cor pulmonale, episode of respiratory failure within the preceding year, forced expiratory volume in 1 s < 0.5 L)
  - Congestive heart failure (New York Heart Association class IV symptoms and left ventricular ejection fraction < 25%)
  - Cirrhosis (confirmed by imaging studies or documentation of esophageal varices) and 1 of the following: hepatic coma, Child class C liver disease, Child class B liver disease with gastrointestinal bleeding
  - Cancer (metastatic cancer or stage IV lymphoma)
  - End-stage dementia
- **Any patient ≥ 80 years of age with multiple co-morbidities and recent functional decline/cognitive impairment admitted to hospital**
- **You answer "no" to the following question: Would I be surprised if this patient died within the next year?**

Not Sure how to Start?

You're not alone. Depending on the patient, the following phrases may be helpful:

- "When you think of the future, what do you hope for or worry about ?"
- "What fears or worries do you have about your illness or medical care?"
- "Have you given any thought to what kinds of treatment you would want (and not want) if you became unable to speak for yourself?"
- "What do you consider your quality of life to be like now?"

Common Pitfalls to Avoid

- Not providing enough time or information
- Not eliciting the patient's understanding of the situation
- Not aligning to the patient's pace or allowing time for responses
- False reassurance about the future
- Allowing denial to continue
- Removing all hope
- Omitting key participants

Factors influencing Communication:

Patient Factors:
- Anxiety: present 25-50% patients with advanced cancer when initiated during hospitalization
- Denial of terminal illness and misconceptions about efficacy of treatment

Physician Factors
- Time constraints
- Lack of preparation:
- Uncertainty about prognosis
- Ambiguity about who is responsible

Consider using a "handling difficult conversation strategy"
- SPIKES

Strategies for Difficult Conversation(s)

- **S**et up and Staging of Conversation
  - Set aside adequate time for discussions
  - Ensure privacy and minimize noise
  - Consider need for hearing aids, pocket talkers and/or glasses
  - Be prepared and familiar with the person's health condition(s)
- **P**erception
  - Clarify individuals state of mind using open ended questions
    - *"What do you understand about your illness"*
    - *"Tell me what worries you if anything?"*
- **I**nvite Participation
  - *Can we talk for a few minutes about your illness?*
  - *Would you like me to go through your results?*
- **K**nowledge
- **E**mpathy
- **S**ummarize and record

Advance Care Planning: The Process

ACP is not a linear process, it usually involves the following 5 steps:

1. Focusing on values, wishes and beliefs
   - Ask the individual to consider what makes their life meaningful, to consider their quality of life, and to identify what is important to them
   - Have the person disclose important aspects related to end of life care eg. being pain free, dying at home
2. Considering personal care choices
   - Provide information so that the individual can determine when the burden of possible treatment outweighs the benefit
   - Explain different care and treatment options for the individual to consider including life-sustaining measures

Advance Care Planning: The Process

3. Choosing a substitute decision maker (SDM)

   Explain that:

   - the SDM's role is to make health care decisions when the person can no longer do so
   - in Ontario, if an individual wishes to name a SDM, they must be appointed in writing through a Power of Attorney for Personal Care (POAPC) document (the piece of paper)

4. Discussing wishes and future treatment choices
   - Maximize opportunities during current and future discussions to express their wishes and future treatment choices
   - Advise the individual that although legal advice is not necessary, it may assist individuals and families to understand their rights, issues of capacity and the role of the SDM

Advance Care Planning: The Process

5. Record choices
   - Whenever possible, obtain a copy of the POAPC for the individuals health record
   - When discussions are held in a health care setting:
     - the care provider will document conversations in the health care record or agency form(s)
     - regular periodic reviews and updates of the individual's wishes and treatment decisions need to be documented in their health care record following the agency policy

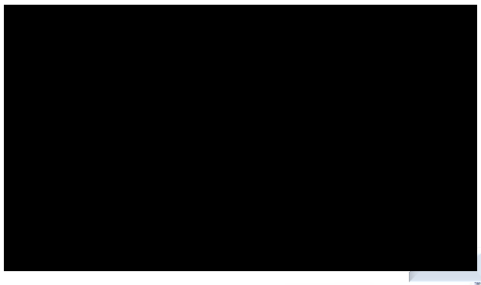
ACP – 5 Steps Advance Care Plans

http://www.advancecareplanning.ca/resource/videos/

What are the benefits of ACP?

- Improved Clinical Outcomes
  - Improved quality of life (QOL), mood and longer survival (Temel JS, et al. N Engl J Med. 2010;363 (8):733-742)
  - More likely to have wishes known and followed (86% vs 30%) (Detering KM et al BMJ. 2010;340:c1345)
- Reduced Substitute Decision Maker distress
- Reduced costs
  - 36% reduced costs of care in patients who had end-of-life discussions (Zhang B, et al. Arch Intern Med. 2009; 169(5):480-488)
  - In RCT of lung cancer patients with randomization to early palliative care referral there was fewer interventions and 29% less time spent in hospital (Temel JS, et al. N Engl J Med. 2010;363 (8):733-742)

Why is ACP Important?



http://www.sagelink.ca

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Discussion / Comments

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