Health Care Consent & Advance Care Planning in Ontario

What You Need to Know

Health Care Consent Advance Care Planning Community of Practice
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Welcome

• Introductions

• Webinar Instructions
  • If you have a mute button on your phone, please use it
  • If you don’t, press *6

• Background
Learning Objectives

• At the end of this session, participants will have a better understanding of:
  • What Health Care Consent and Advance Care Planning means in Ontario
  • What all HSPs need to both know and understand about Health Care Consent and Advance Care Planning
  • What Long Term Care Homes must understand about Health Care Consent and Advance Care Planning to support their residents and their role
For a person who lacks the mental capacity to provide consent for treatment plans, ACP conversations can occur with substitute decision makers on behalf of the person.

True or False?
Wishes for treatments should be documented in either an advance directive or a living will.

True or False?
Poll #3

When a person appoints an Attorney for Personal Care only a lawyer has the authority to oversee the process.

True  or  False?
Wishes expressed verbally are less clinically relevant then wishes that are written, signed and witnessed.

True or False?
Outcome evidence indicates that Consent and ACP:

- Improves patient & family satisfaction with EOL care\(^1\)
- Decreases caregiver distress & trauma\(^2\)
- Decreases unwanted investigations, interventions & treatments\(^3\)
- Increases the likelihood of dying in preferred setting\(^3\)
- Decreases hospitalizations & admissions to critical care\(^4\)
- Decreases cost to the health care system\(^5\)

This was not always the case...what changed?
Why does it matter to GET THIS RIGHT?

ADVANCING HIGH QUALITY, HIGH VALUE PALLIATIVE CARE IN ONTARIO

The Declaration of Partnership and Commitment to Action

Why does it matter to GET THIS RIGHT?

Auditor General 2014

Patients First Action Plan

CDN Cancer Society HPC Report: Right to Care

PA FRASER REPORT 2016

Transformation & Improved Quality
Why does it matter to GET THIS RIGHT?

Under Ontario Law, Advance Care Planning is part of the Health Care Consent Act

Health care professionals must always obtain informed consent or refusal before treatment from either the mentally capable patient or their substitute decision maker (SDM)
The Law Commission of Ontario strongly recommends using terminology in the Health Care Consent Act (HCCA): "...terminology used in health care consent and advance care planning forms, tools, and policies track the language in the HCCA, and that these documents should expressly distinguish between consent and the recording of wishes, values, and beliefs."

There is tremendous confusion and incorrect practices about this distinction within Hospitals, LTC Homes and Community HSPs across Ontario.

Many HSPs are currently noncompliant with the Ontario Legal Framework.
Who needs to worry about GETTING THIS RIGHT?

Hospitals

Patient’s Care Wishes

☐ Patient has requested to discuss AD’s

☐ Patient has a written directive and ☐ copy has been requested
   ☐ copy has been obtained and placed in record

☐ Patient has discussed care wishes with SDM(s)

Has the patient / SDM verbally expressed care wishes? ☐ Yes ☐ No
   If “yes” summarize any information provided here, and notify physician:

Has the physician been informed? ☐ Yes ☐ No
(Note, if care wish information is provided physician must be notified.)

Name of Physician:_____________________ Date:________________ Time:_____________

Name of Healthcare professional Completing this form:_________ Date:_____________
Who needs to worry about GETTING THIS RIGHT?

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These are either confusing or incorrect elements

Health Care Consent & Advance Care Planning Community of Practice
Advance Directive for Treatment
Resident’s Name: ____________________________________________
If the Resident is incapable, Substitute Decision-Maker (SDM): ______________________________
Health Practitioner recording consent: ______________________________
Date of consent discussion: _________________________________

Name and Description of Directive
After discussion, the Resident or SDM has decided that in the event of life threatening illness, the Resident is to receive treatment as follows:
☐ COMFORT MEASURES ONLY
☐ COMFORT MEASURES WITH ADDITIONAL TREATMENT AVAILABLE AT THE HOME
☐ TRANSFER TO ACUTE CARE HOSPITAL WITHOUT CARDIOPULMONARY RESUSCITATION
☐ TRANSFER TO ACUTE CARE HOSPITAL WITH CARDIOPULMONARY RESUSCITATION

Informed Consent
I have been provided the following information by the Home:
Nature of the directive ☐ Yes Expected benefits of the directive ☐ Yes
Material risks of the directive ☐ Yes Material side effects of the directive ☐ Yes
Alternative courses of action ☐ Yes Likely consequences of not having the directive ☐ Yes
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# HealthLinks

<table>
<thead>
<tr>
<th>Future situations</th>
<th>What I will do</th>
<th>What I will <em>not</em> do</th>
<th>Who will help me</th>
<th>Telephone #</th>
<th>Review date</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

I have received information about advance care planning: Choose an item.

I have a completed advance care plan: Choose an item. My ACP is located here:

As I understand it, my advance care plan says:

I have a Power of Attorney (POA) for personal care: Choose an item. My POA document is located here:

Name of POA attorney: Relationship to me: Choose an item. Telephone #: 
Who needs to worry about GETTING THIS RIGHT?

HealthLinks

<table>
<thead>
<tr>
<th>My plan for future situations</th>
<th>Future situations</th>
<th>What I will do</th>
<th>What I will not do</th>
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Advance Care Planning
Future health condition the implications for which may not be easily known to the person

Consent to a Treatment or Plan of Treatment
Current health condition, where the Implications are known

Credit Chris Sherwood
Risk of **legal liability** and **unforeseen negative consequences**, which could include:

- Hospitals and LTC homes cited to their respective reporting and oversight bodies
- LHIN found negligent under the Ministry-LHIN Accountability Agreement
- Detrimental Media coverage locally and provincially
- Civil suits
- Physicians reported to the CPSO
- Nurses Reported to CNO
- Complaints lodged at the Law Society
• LTC Homes are required by the Long Term Care Homes Act to have all such forms/policies “certified” as compliant with the law by legal counsel who has expertise in HCCA or consent law.

• It is a matter of “when” not “if” system performance indicators are implemented at regional level.

• It is a matter of “when” not “if” this will be added to Accreditation Standards.
What is required in all care settings to GET THIS RIGHT?

- Understanding of and proper implementation of the CONSENT process.
- Consent comes from a CAPABLE PERSON not a document or any form of advance care planning.
- Understanding that consent is required for ALL treatments or a Plan of Treatment based on the person’s current health condition.
- Understanding that consent must be informed - risks, benefits, side effects, alternatives, what happens if patient refuses treatment.
There must be proper determination of a person’s CAPACITY for treatment decision-making.

Definition of Capacity:

- **Ability to understand** the information that is relevant to making a decision about the treatment, admission, or personal assistance service as the case may be, AND

- **Ability to appreciate** the reasonable foreseeable consequences of a decision or lack of decision

(HCCA s. 4)
What is required in all care settings to GET THIS RIGHT?

• Mental capacity:
  • Is issue specific – for each type of decision and for each new decision
  • Is not a diagnosis
  • Can fluctuate
  • Does include having INSIGHT
  • Is presumed unless there is REASON to believe otherwise

• If a person is mentally incapable for a particular treatment decision then the HCP must turn to the SDM(s)
Who assesses mental capacity for treatment?

- Duty of **Health Practitioner** offering the treatment to determine if a resident/patient is capable or not and whether its necessary to turn to the patient's SDM(s) for consent

- This is NOT done by a “capacity assessor” as defined in the Substitute Decisions Act
What is required in all care settings to GET THIS RIGHT?

• Understanding of who is the treatment decision maker - Patient or incapable patient’s SDM

• Understanding of WHO is the RIGHT SDM according to the hierarchy and recording name and contact information properly on forms
What is required in all care settings to GET THIS RIGHT?

Understanding that a patient, when capable, may engage in **ADVANCE CARE PLANNING** which is:

- Confirming that they want their AUTOMATIC SDM(s) OR Choosing an SDM(s) by preparing a POAPC

AND

- Communicating their Wishes, Values and Beliefs about care to help SDM(s) make healthcare decisions for them in the future when they are incapable
Substitute Decision Maker Hierarchy

**Confirm** automatic SDM(s)

**Choose** someone else and **Prepare** a *Power of Attorney for Personal Care* document

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- **Public Guardian and Trustee**
- **Any other relative**
- **Parent with right of access only**
- **Parents or Children**
- **Spouse or Partner**
- **Representative appointed by Consent and Capacity Board**
- **Attorney for Personal Care**
- **Court Appointed Guardian**

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*Ontario Health Care Consent Act, 1996*
What is required in all care settings to GET THIS RIGHT?

• An understanding that SDMs cannot engage in advance care planning for a patient

• An understanding the relationship between and differences between advance care planning, goals of care and informed consent
What is required in all care settings to GET THIS RIGHT?

A person's values, wishes, beliefs and goals for their care

Info guides future decision-making

Info directly informs decision-making

Future Care

Advance Care Planning Conversations

Goals of Care Discussion

Decision-Making or Consent Discussion

Current Care

Treatment Decisions to be made

Figure: Relationship between three discussions that contribute to informed consent
What is required in all care settings to get this right?

The person's values, wishes, and goals for their care

Planning for future care

- Advance Care Planning

Decision-making for current care

- Goals of Care Discussion

  - Decision-Making Discussions

  - Consent for treatment or care

Advance care planning
- A capable patient reflects on wishes and values about health and care
- Information should guide substitute decision maker(s) if the patient becomes incapable in the future

Goals of care discussion
- Ensuring a shared understanding of illness
- The goals a patient or substitute decision maker(s) has for care are identified and facilitate decision-making and consent

Components of person-centred decision-making in serious illness

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What is required in all care settings to GET THIS RIGHT?

<table>
<thead>
<tr>
<th>Clinical Context</th>
<th>Outcome is...</th>
<th>Outcome is NOT...</th>
<th>How goals are defined</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advance Care Planning</strong></td>
<td><strong>Future</strong></td>
<td>Values &amp; wishes prepare SDM(s) for future decision-making</td>
<td>Code Status, POLST, etc.</td>
</tr>
<tr>
<td><strong>Goals of Care Discussion</strong></td>
<td><strong>Current</strong></td>
<td>Patient understands illness Clinician understands patient's values &amp; goals</td>
<td>Code Status, POLST, etc.</td>
</tr>
<tr>
<td><strong>Decision-making Discussions</strong></td>
<td><strong>Current</strong></td>
<td>Care or treatment decision(s) e.g. code status, POLST, etc.</td>
<td></td>
</tr>
</tbody>
</table>
How a person makes healthcare decisions

Values

- Are the risks worth the possible benefits?
- Is this plan consistent with what is important to me?

Evidence

- Facts
- Expected outcome
- Side effects and risks

Health Care Decisions


Health Care Consent & Advance Care Planning Community of Practice
What’s the clinical approach to GET THIS RIGHT?

Not helpful Consent and ACP Conversations...

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

<table>
<thead>
<tr>
<th>Explore further</th>
<th></th>
</tr>
</thead>
</table>
| “No heroics and no machines”                                                    | What experiences have you had to bring you to this?  
What is it about “heroics and machines”?                                         |
| “No tubes”                                                                       | What is it about a tube that makes you not want one?                  |
| “Do everything”                                                                  | What does it mean to not “do everything”?  
What worries or fears come to mind?  
How should we approach reconciling this?                                          |
Outcomes of an ideal Consent and ACP conversation

- SDM is aware of the person’s values and what he or she views as meaningful in life
- SDM begins to understand how the person makes decisions (i.e. how they view benefit and burdens)
- SDM has information that would guide decision making
- Avoids statements such as “no machines” or “no heroics” or “no feeding tubes” without modifiers that would make these situations bearable or unbearable for the person
Outcome evidence of Consent and ACP conversations:

- Improves patient & family satisfaction with EOL care\(^1\)
- Decreases caregiver distress & trauma\(^2\)
- Decreases unwanted investigations, interventions & treatments\(^3\)
- Increases the likelihood of dying in preferred setting\(^3\)
- Decreases hospitalizations & admissions to critical care\(^4\)
- Decreases cost to the health care system\(^5\)

This was not always the case...what changed?
What’s the clinical approach to GET THIS RIGHT?

• Promote understanding the role of the SDM in **INTERPRETING** and applying any form of the patient's advance care planning (if any)

• Promote understanding that HSPs **DO NOT** take direction from any form of advance care planning (whether written, oral or communicated by alternative means) except in an emergency

• Promote understanding that code status (e.g. DNR) is **NOT** an advance care planning wish but requires an INFORMED CONSENT
System Strategies to GET THIS RIGHT

• Clarify confusions, dispel misconceptions and correct incorrect information

• Provide accurate knowledge about the **Ontario** legal framework

• Encourage consistent practices

• Expect accurate language which promotes clear communication

• Discover and utilize Ontario specific tools, supports and resources (paper & people)
How we can help you to GET THIS RIGHT?

• In response to the need for provincial resources on HCC ACP that utilizes an Ontario legal framework, Hospice Palliative Care Ontario hosts a Health Care Consent Advance Care Planning Community of Practice (HCC ACP CoP)

• The CoP supports Ontario clinicians, administrators, caregivers, policymakers, researchers, educators and leaders who are committed to the promotion of HCC ACP in Ontario.
How we can help you to GET THIS RIGHT?

Ad Hoc Working Groups determined by the membership and advised by the Leadership Team

The Broad Membership is comprised of anyone interested in coming together to better understand and promote HCC ACP in Ontario; and to encourage the recommended Ontario tools and resources, and build capacity and awareness.

The Regional Champions Group is comprised of 1-2 leads from each LHIN area that have a primary role in promoting and implementing HCC ACP within their geography.

The Leadership Advisory Team is comprised of a diverse group of experts in the legal, policy, clinical, operational, knowledge translation and implementation domains of HCC ACP in Ontario.
How we can help you to GET THIS RIGHT?

• To become a member of the CoP simply register at:
  http://fluidsurveys.com/s/hpco-hcc-acp-cop/

• Your participation would:
  • Provide you with direct access to all HCC ACP CoP Tools, Resources and Updates
  • Increase Sector Performance Compliance
  • Increase Patient Centred Care
  • Increase System Capacity & Consistency
• Across the province considerable time and effort is spent by associations, organizations and projects to develop HCC ACP related documents and processes.

• In an effort to support this work, the HCC ACP CoP Leadership Advisory Team offers to review HCC ACP related resources (i.e. content, policies, procedures, materials, presentations etc.,) to ensure the language and intent complies with the Ontario Legal Framework.

• The Resource Review process emerged out a strong desire to support colleagues and address the specific nature of HCC ACP in Ontario.
HCC ACP CoP Tool Kit to GET THIS RIGHT?

1. Health Care Consent Advance Care Planning Common Themes and Errors Tool
2. Leadership in Advance Care Planning in Ontario Tool
3. Leadership Screening Tool
4. Health Care Consent and Advance Care Planning Glossary of Terms for Ontario
5. Physician Assisted Dying (PAD) and Advance Care Planning (ACP)
6. National Consent Legislation Summary Chart
7. ACE Tip Sheet #1: Health Care Consent and Advance Care Planning the Basics
8. ACE Tip Sheet #2: HIERARCHY of Substitute Decision Makers (SDMs) in the Health Care Consent Act
9. ACE: Advance Care Planning – ONTARIO – SUMMARY – Health Care Consent Act List of “approved” HCC and ACP resources
Benefits of GETTING THIS RIGHT

Along with ensuring the right information is given to the right person, at the right time, the resource review process can help:

• Ensure compliance
• Facilitate the use of information
• Enhance clarity and understanding
• Meet legislated professional obligations
• Honour the basic rights of patients
• Reduce the risk of legal liability

To schedule a resources review simply go to: [http://www.speakupontario.ca/resource/ontario-guides/](http://www.speakupontario.ca/resource/ontario-guides/)
Speak Up Ontario to GET THIS RIGHT

www.speakupontario.ca
Ontario Advance Care Planning Workbook

Advance Care Planning is a process of thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate.
Key Reference Sites to GET THIS RIGHT

• Key Reference Documents:
  • Ontario Health Care Consent Act, 1996 - https://www.ontario.ca/laws/statute/96h02
  • Public Guardian and Trustee Office - https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/
  • ACE Advocacy Centre for the Elderly - http://www.acelaw.ca/advance_care_planning_-_publications.php
  • Hospice Palliative Care Ontario - http://www.hpco.ca
  • Speak Up Ontario – http://www.speakupontario.ca
  • Community Legal Education Ontario (CLEO) - http://www.cleo.on.ca/en/publications/power
    http://www.cleo.on.ca/en/publications/continuing
Who is currently GETTING THIS RIGHT:

• ACP Conversation Guides – Produced by Dr. Nadia Incardona and Dr. Jeff Myers, 2016

• Clinical Primer - How to prepare for Advance Care Planning Conversations with patients and substitute decision-maker(s) or SDM(s)

• ACP Conversation Guide - This document serves to record wishes, values and beliefs for future healthcare. It is NOT consent for treatment but is as a representation of a person’s capable thoughts and reflections.

• Advance Care Planning Conversations: A Guide for You and Your Substitute Decision Maker - How you can prepare for having Advance Care Planning Conversations
• East Toronto Health Link developed an Ontario ACP toolkit for patients with chronic diseases and the healthcare providers who care for them.
  • Initiative funded by the Toronto Central LHIN

• Using the Ontario Speak Up campaign as a framework, tools were created to help patients with chronic progressive disease as part of a coordinated care plan, discuss their future care wishes with their family and members of their health team.

• An e-learning module was also created which is an ACP Primer and Practical Approaches for healthcare providers in Ontario
System Strategies to GET THIS RIGHT

To improve the quality and effectiveness of HCC ACP in Ontario, culture must be changed. Culture change requires:

1. **Education:**
   - People & SDMs:
     - Aware
     - Informed
     - Self management strategies
   - Clinician competence:
     - Attitudes/Aware
     - Knowledge/Information
     - Legal framework
     - Actual conversation
     - Skills

2. **Documentation/EMR**
   - Standardized
   - Accessible

3. **Quality improvement**

4. **System wide planning & coordination**
## System Strategies to GET THIS RIGHT

**Process for assessing organizations and institutions**

<table>
<thead>
<tr>
<th>HCC ACC activities currently underway?</th>
<th>Legal framework compliant?</th>
<th>&quot;Better&quot; practice?</th>
<th>Suggested actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>YES</td>
<td>Ongoing QI</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NO</td>
<td>Actively facilitate course corrections</td>
<td></td>
</tr>
<tr>
<td>NO</td>
<td>N/A</td>
<td>Onboarding; Set clear expectations</td>
<td></td>
</tr>
<tr>
<td>In development</td>
<td>Inform/Educate</td>
<td>Formally assess; Ensure guided well</td>
<td></td>
</tr>
</tbody>
</table>
100% of people in Ontario will die

CONSENT and ACP is relevant to 100% of Ontarians

It is NOT a matter of IF we get this right, it is now about HOW and WHEN we get this right

Effectiveness requires a system wide approach

Ideally a coordinated effort at provincial, regional and community levels is required for success
Contact:

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Manager, Partnerships and Communities of Practice

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2 Carlton Street, Suite 707
Toronto, ON M5B 1J3
1-800-349-3111 ext. 30
jdarnay@hpco.ca
www.hpco.ca

To join the HCC ACP CoP simply register at:
http://fluidsurveys.com/s/hpco-hcc-acp-cop/
Questions and Discussion