Health Care Consent & Advance Care Planning in Ontario

What You Need to Know

Health Care Consent Advance Care Planning Community of Practice

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 LTC homes must understand about Health Care Consent and Advance Care Planning to support their residents and their SDMs

Poll #1

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?

Poll #1 - Answer

- **FALSE**
- SDMs cannot advance care plan for another person. SDMs ONLY give or refuse consent to treatment on behalf of an incapable person.
- Only Patients when capable may do ACP for themselves.

Poll #2

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

True *or* False?

Poll #2 - Answer

- **FALSE**
- There are no such documents called “Advance Directives” or “Living Wills” in Ontario law and this terminology should not be used as its confusing.
- In Ontario the only part of advance care planning that must be done in writing is when a person wants to name someone as their SDM that is not their automatic SDM. That must be done in writing by preparing a POA Personal care .
- Advance Care planning about communication of wishes, values and beliefs to guide the SDM may be done ORALLY , in WRITING, or be communicated by alternative means .

Poll #3

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

True *or* False?

Poll #3 - Answer

- **FALSE**

- A person MAY want to get advice and help from a lawyer to prepare a POA Personal Care but its not necessary to do so.

- For a POA Personal care to be VALID it must have been signed by the person when the person understood what the document is, was mentally capable, and signed the document voluntarily. Also the POA Personal care document must be in proper form – it must NAME someone as SDM, must be signed by the person granting it in front of two witnesses, and signed by the two witnesses in the presence of each other and the person granting it . The witnesses also must not be prohibited by law to act as witnesses.

Poll #4

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

True *or* False?

Poll #4 - Answer

- **FALSE**

As ACP wishes do NOT need to be in writing, a person may express wishes about future care at any time when they are mentally CAPABLE . Later Oral wishes expressed when capable OVERRIDE and replace earlier written wishes.

Why does it matter to GET THIS RIGHT?

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

Auditor General 2014

Patients First Action Plan

CDN Cancer Society HPC Report: Right to Care

PA FRASER REPORT 2016

Transformation & Improved Quality

Role of LTC Compliance

- What is YOUR role as Compliance in ensuring that LTC Homes comply with requirements of HCCA?

- Eg. LTCHA s. 3 Residents Rights (and other relevant sections throughout LTCHA)

11. Every resident has the right to:

i. participate fully in the development, implementation, review and revision of his or her plan of care,

ii. give or refuse consent to any treatment, care or services for which his or her consent is required by law and to be informed of the consequences of giving or refusing consent,..

Role of LTC Compliance

- s. 80 Regulated Documents and Regulation 79/10 , s227(6)

  6) A document containing a consent or directive with respect to "treatment" as defined in the *Health Care Consent Act, 1996*, including a document containing a consent or directive with respect to a "course of treatment" or a "plan of treatment" under that Act,

(a) must meet the requirements of that Act, including the requirement for informed consent to treatment under that Act;..

(c) must contain a statement indicating that the consent may be withdrawn or revoked at any time; and

(d) must set out the text of section 83 of the Act.

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)

Why does it matter to GET THIS RIGHT?

- 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

Who needs to worry about GETTING THIS RIGHT?

Long Term Care

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

Who needs to worry about GETTING THIS RIGHT?

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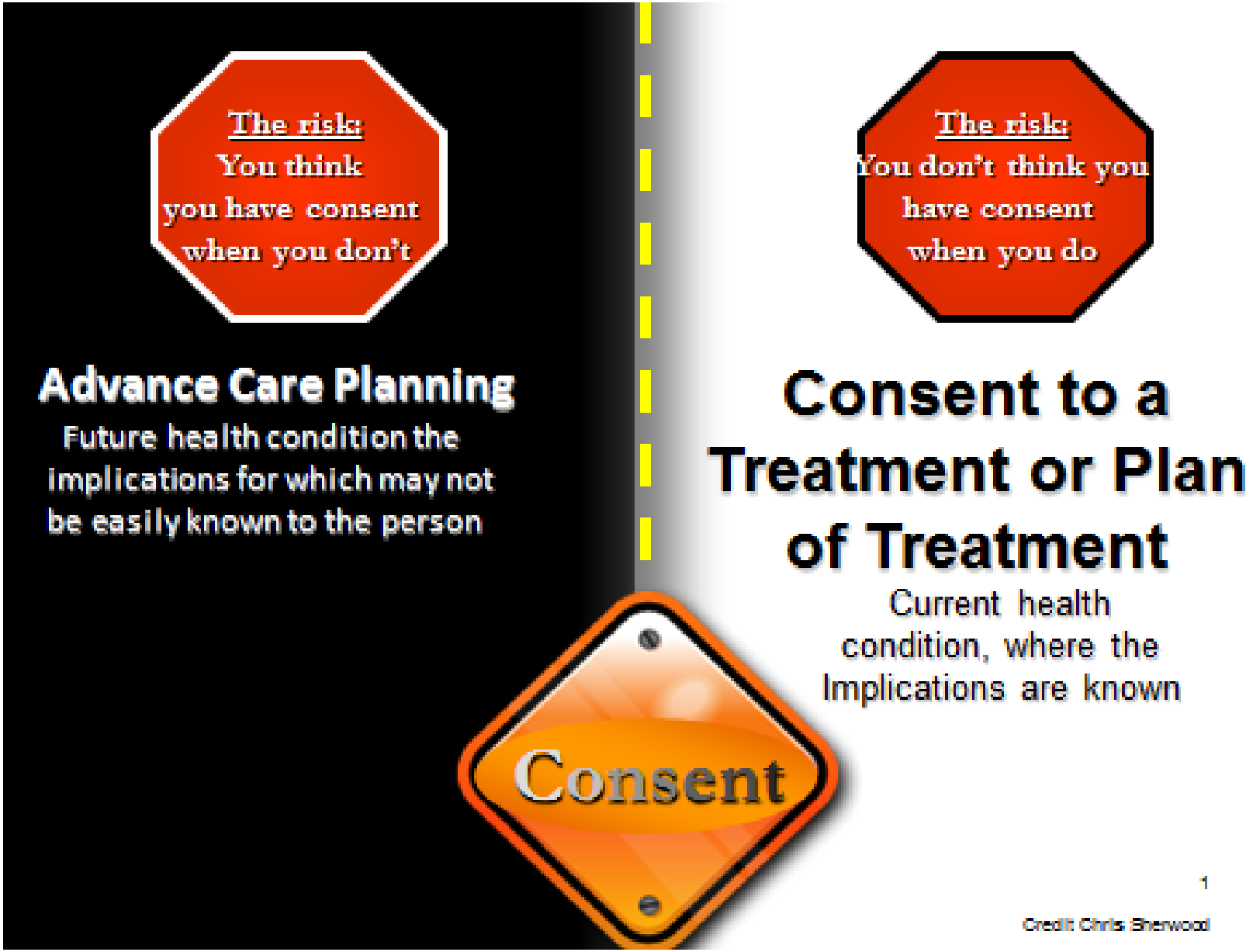

The risk:
You think you have consent when you don't
The risk:
You don't think you have consent when you do
Advance Care Planning
Future health condition the implications for which may not be easily known to the person
Consent to a Treatment or Plan of Treatment
Current health condition, where the Implications are known
Consent
1
Credit Chris Sherwood

Why does it matter to GET THIS RIGHT?

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

Who will be accountable to GET THIS RIGHT?

- 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.

  These forms are REGULATED DOCUMENTS as defined in s.80 Long Term Care Homes Act and are subject to inspection
- 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

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

- 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)

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

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

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

AND

2. Communicating their Wishes, Values and Beliefs about care to help SDM(s) make healthcare decisions for them in the future when they are incapable

Both are core elements of ACP and each could be a deliverable or area of focus for institutions

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

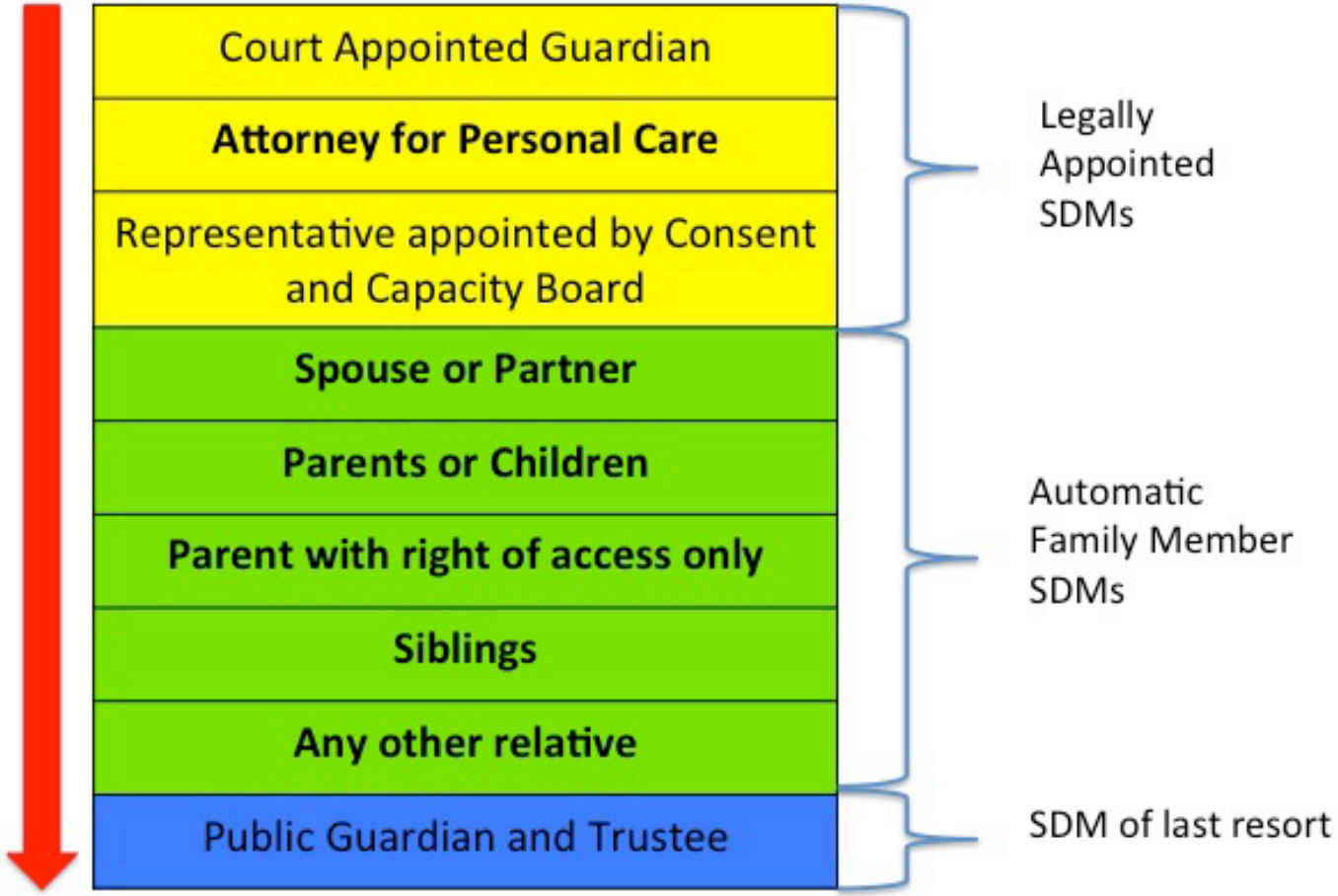
- Understanding of who is the treatment decision maker - Patient or incapable patient's SDM

- Understanding of WHO is the RIGHT SDM according to the hierarchy and recording name and contact information properly on forms

Substitute Decision Maker Hierarchy

Confirm automatic SDM(s)

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



Ontario Health Care Consent Act, 1996

Requirements for Person to be an SDM

The person highest in the hierarchy may give or refuse consent only if he or she is:

a) Capable in respect to the treatment;
b) At least 16 years old unless the parent of the incapable person;
c) Not prohibited by a court order or separation agreement from acting as SDM;
d) Available (including via electronic communications); and,
e) Willing to act as SDM.

IT IS THE OBLIGATION OF THE HEALTH PRACTITIONER OBTAINING CONSENT FROM AN SDM TO ENSURE THESE REQUIREMENTS ARE MET.

Remember SDM is not the same as Next of Kin

SDM ≠ Emergency Contact or Next of Kin

- Change terminology to be legally accurate
- Consider who needs to be involved in this process

Remember the POA is just one type of SDM

An Electronic Medical Record Example below helps to illustrate:

Health Care Consent and Advance Care Planning

1. My Substitute Decision Maker (SDM) is/are: *(May require additional space for multiple SDMs)*
    - Name:
    - Contact Information:
    - Relationship:

(Note 1: Confirm that the above noted SDM is the highest ranked in the SDM hierarchy list)

The Hierarchy List (Create as a drop down menu)

The following is the Hierarchy of SDMs in the Health Care Consent Act, s.21:

1. **Guardian of the Person with authority for Health Decisions**
2. **Attorney for personal care with authority for Health Decisions (See Note 2)**
3. **Representative appointed by the Consent and Capacity Board**
4. **Spouse or partner**
5. **Child or Parent or CAS (person with right of custody)**
6. **Parent with right of access**
7. **Brother or sister**
8. **Any other relative**
9. **Office of the Public Guardian and Trustee**

(Note 2: if the above noted SDM is #2 in the hierarchy list: Attorney for personal care with authority for Health Decisions - confirm this information in the patient's POAPC document)

2. I have shared my wishes, values and beliefs with my future Substitute Decision Maker as they relate to my future healthcare?
    - Yes
    - No

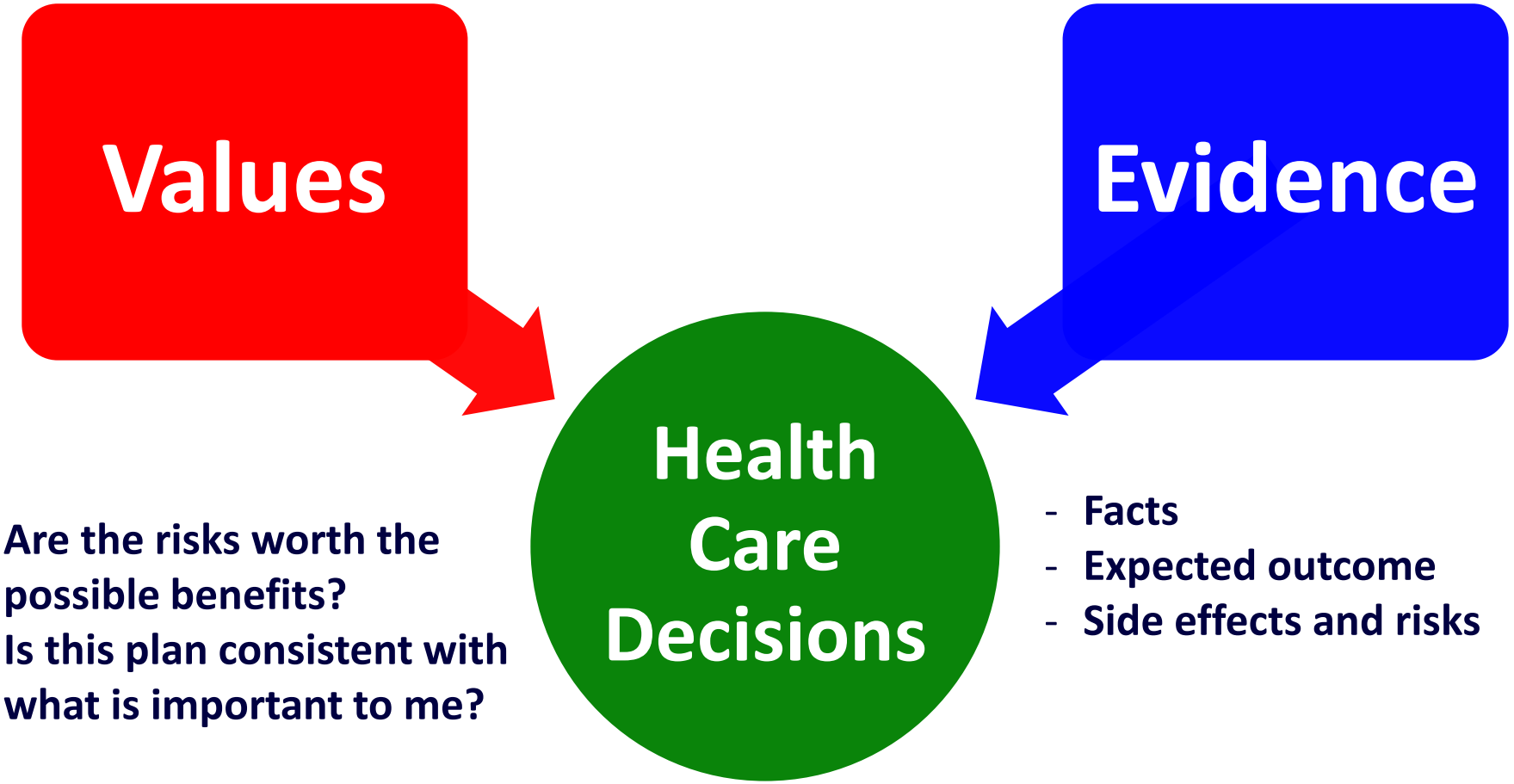
(Note 3: If No, provide ACP provincially approved resources i.e., Speak-Up Ontario ACP Workbook or website information, etc.)

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

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

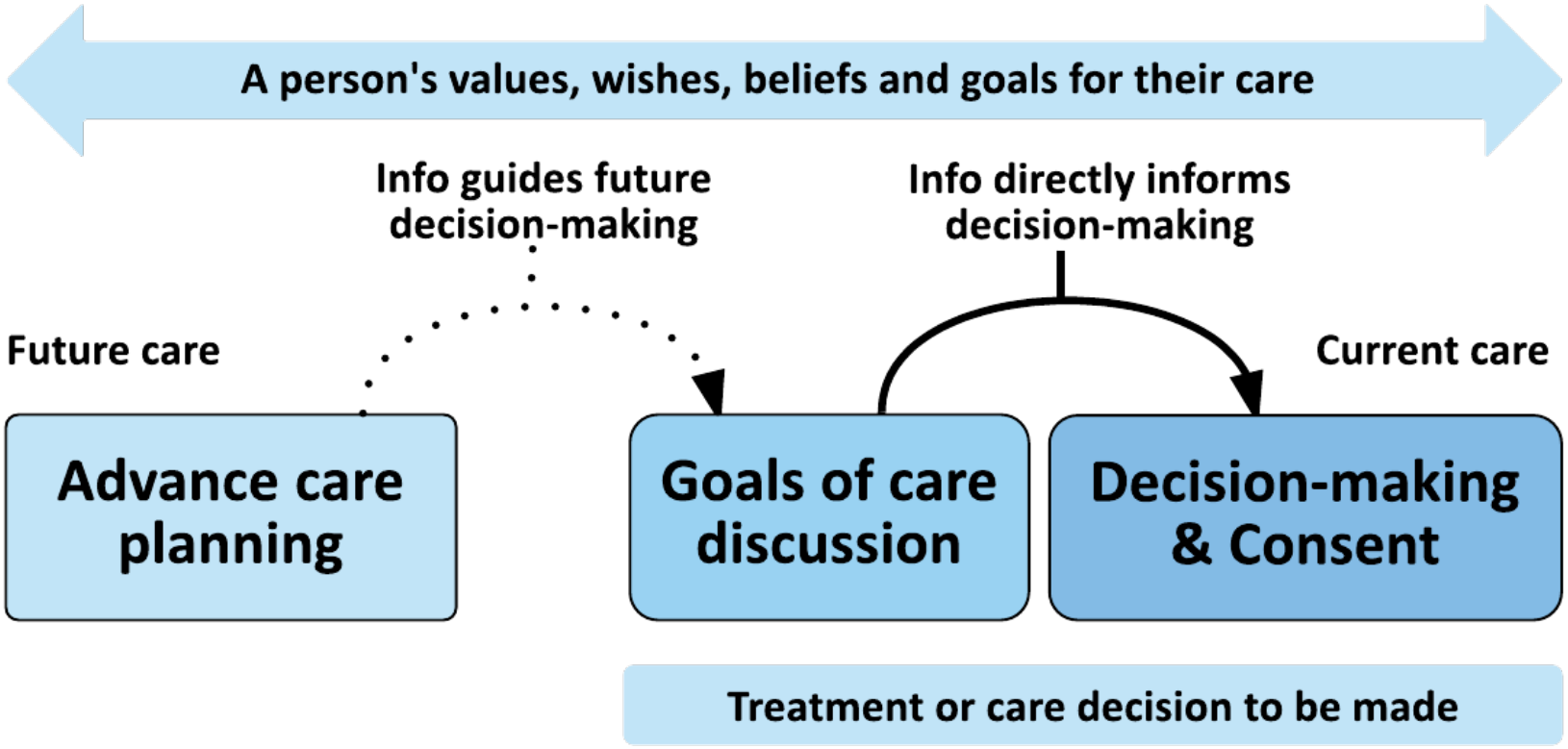
- An understanding the relationship between and differences between advance care planning, goals of care and informed consent

How a person makes healthcare decisions



Fulford KWM, Peile E, Carroll H. Essential values-based practice: Clinical stories linking science with people. New York: Cambridge University Press 2012. Adapted by Dr. Nadia Incardona

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



Components of person-centred decision-making

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

	Clinical Context	Outcome is...	Outcome is NOT...	How goals are defined
Advance care planning	Future	values & wishes prepare SDM(s) for future decision-making	code status, POLST, etc.	patient's to define and describe
Goals of care discussion	Current	patient/SDM(s) understands illness team understands pt's values & goals	code status, POLST, etc.	patient's to define and describe
Decision-making discussions	Current	care or treatment decision(s) made e.g. code status, POLST, etc.		treatment oriented e.g. cure, resuscitation, comfort

What's the clinical approach to GET THIS RIGHT?

Not helpful ACP Conversations…

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

What's the clinical approach to GET THIS RIGHT?

Helpful ACP Conversations…

	Explore further…
"No heroics and no machines"	What experiences bring you to this? What is it about "heroics and machines"?
"No tubes"	What is it about a tube?
"Do everything"	What does it mean to not "do everything"? What worries or fears come to mind? How should we approach reconciling this?

Role of Interprofessional Providers in ACP

	Anyone involved in patient/ client/resident care	Trained interprofessional ACP facilitator (SW, Nurse, NP, MD, etc.)	MD/NP
Ask about SDM	✔	✔	✔
Explain what ACP is	✔	✔	✔
Discuss illness understanding		✔ *	✔
Clarify illness understanding			✔
Discuss values, beliefs and quality of life and wishes		✔	✔

*Within the professional scope and comfort level of the individual

HPCO Hospice Palliative Care Ontario

Individuals in any role should ensure that he/she has current accurate Ontario legislation information where applicable and has appropriate skills for the conversation/assessment

Role of Interprofessional Providers in GOC

	Anyone involved in patient/ client/resident care	Trained interprofessional ACP facilitator (SW, Nurse, NP, MD, etc.)	MD/NP
Determine capacity for treatment or treatment plan			**HCP proposing the treatment or plan***
Discuss values, life goals with capable patient or SDM		✔	✔
Discuss treatment plan and options			✔
Consent for treatment or plan			✔

*Exception: HCPs defined as "evaluators" as per the HCCA can determine capacity for admission to long term care. (i.e. audiologist, speech-language pathologist, dietitian, nurse, occupational therapist, physician, physiotherapist, psychologist & social worker

HPCO Hospice Palliative Care Ontario

Individuals in any role should ensure that he/she has current accurate Ontario legislation information where applicable and has appropriate skills for the conversation/assessment

What's the clinical approach to GET THIS RIGHT?

Outcomes of an ideal 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

What's the clinical approach to GET THIS RIGHT?

Outcome evidence of 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]

What changed is incorporating a person's values

Important points to remember about ACP

- Ensure staff and SDMs understand the role of the SDM in **INTERPRETING** and applying any form of the patient's advance care planning (if any)
- Promote understanding that staff **DO NOT** take direction from any form of advance care planning (whether written, oral or communicated by alternative means) except in an emergency
- **DNRC forms are NOT** the same as consent to a DNR status in hospital
  - must confirm through discussion with a capable patient (or their SDM(s) if the patient is no longer capable)

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

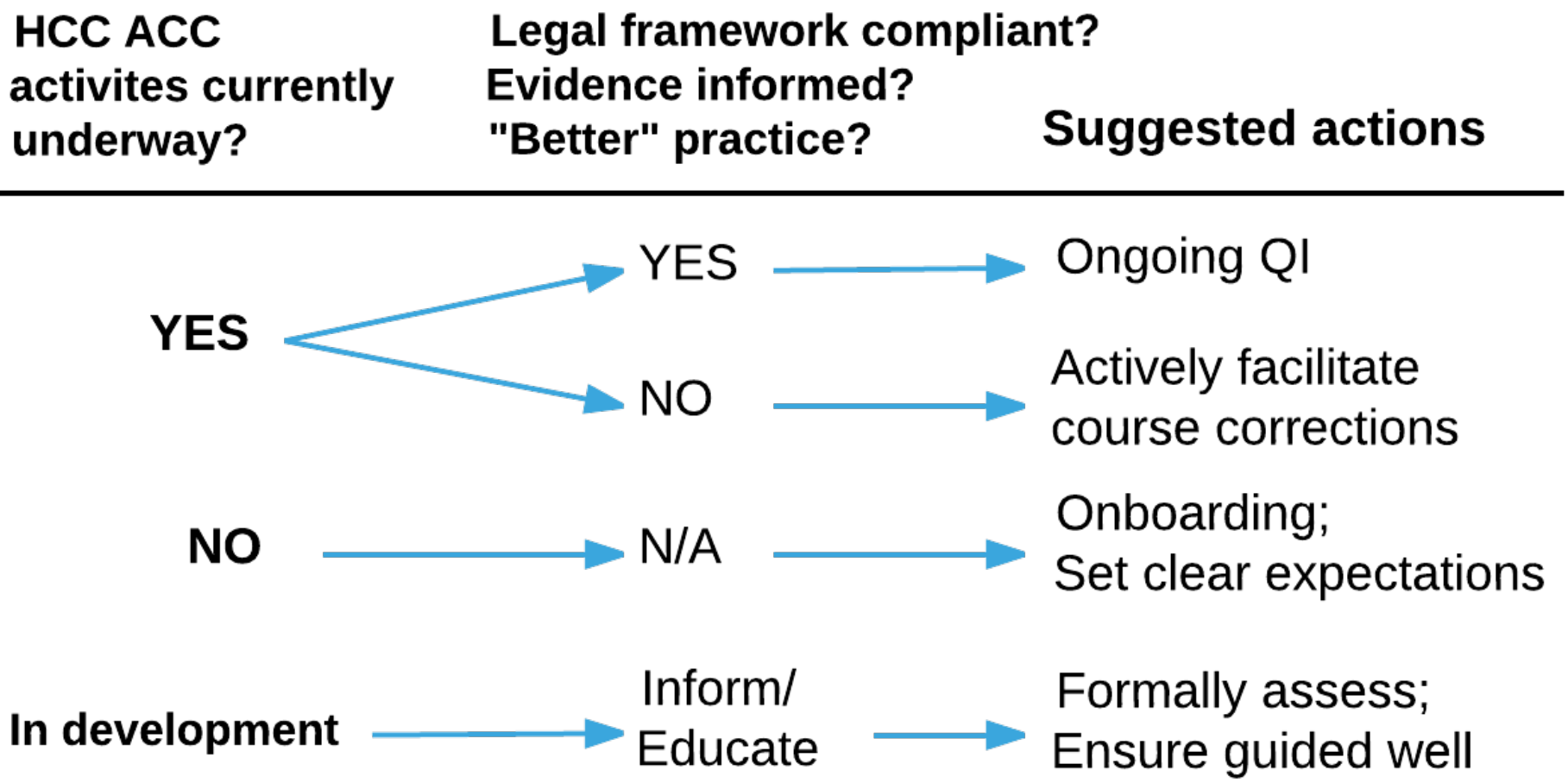
2. **Documentation/EMR**
   - Standardized
   - Accessible

3. **Quality improvement**

4. **System wide planning & coordination**

System Strategies to GET THIS RIGHT

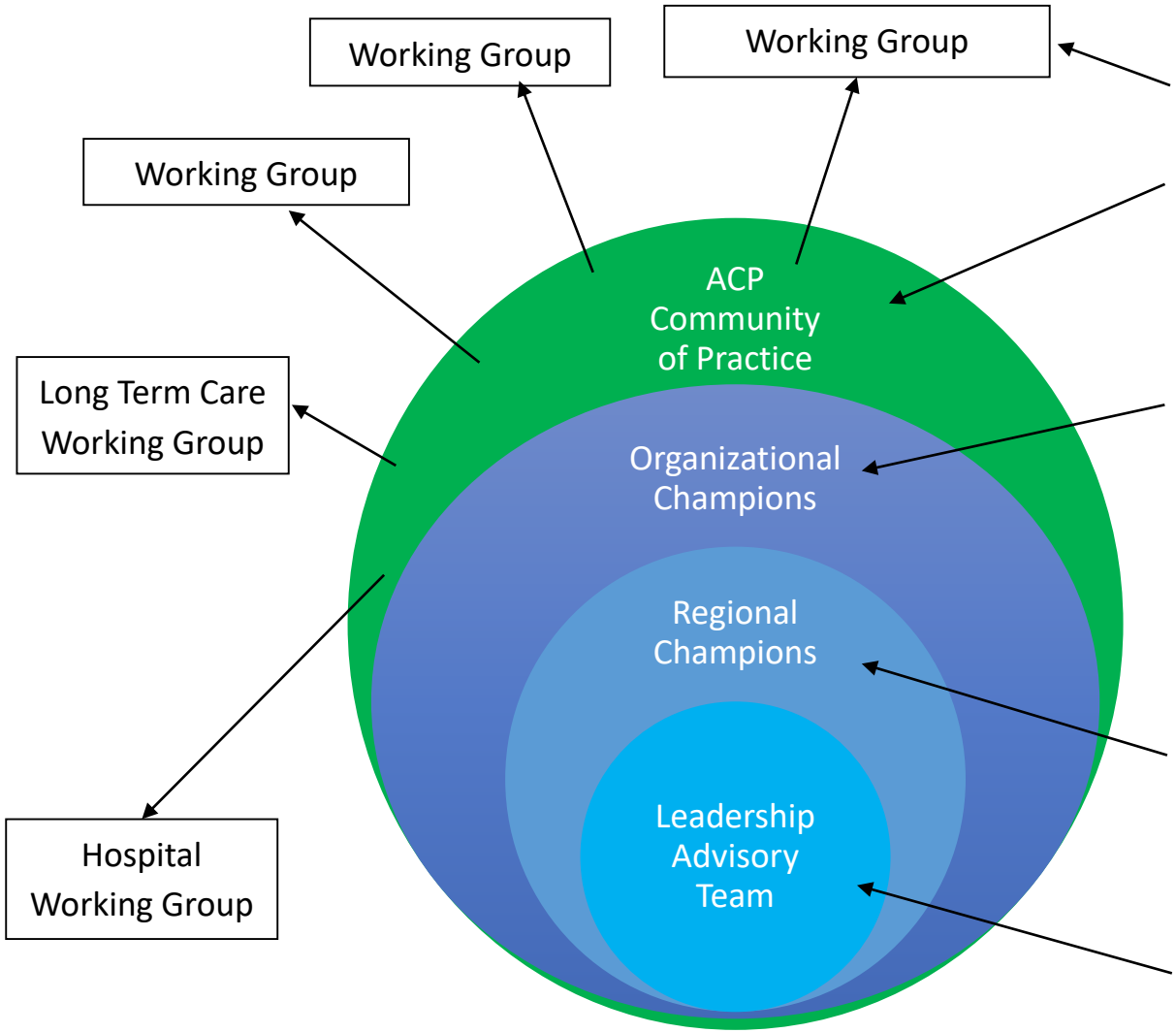
Process for assessing organizations and institutions



HPCO HCC ACP CoP

- Creation of CoP's to respond to the need for a resource for HCC and ACP utilizing an Ontario legal framework.
- The CoP supports Ontario clinicians, administrators, caregivers, policymakers, researchers, educators and leaders who are committed to the promotion of HCC ACP in Ontario.
- Goal of the CoP are to reinforce the link between HCC and ACP to health care providers.
- Hospice Palliative Care Ontario (HPCO) hosts and supports the work of the CoP

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 **Organizational Champions Group** is comprised of individuals, who want to expand into a lead role for promoting and/or implementing HCC ACP within their organization/facility/sector etc. Broad representation from all disciplines and sectors are sought (clinical, legal, social, financial etc.).

The **Regional Champions Group** is comprised of 1-2 leads from each LHIN area that have a lead role for promoting and/or implementing HCC ACP ideally across their regional 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

HPCO Hospice Palliative Care Ontario

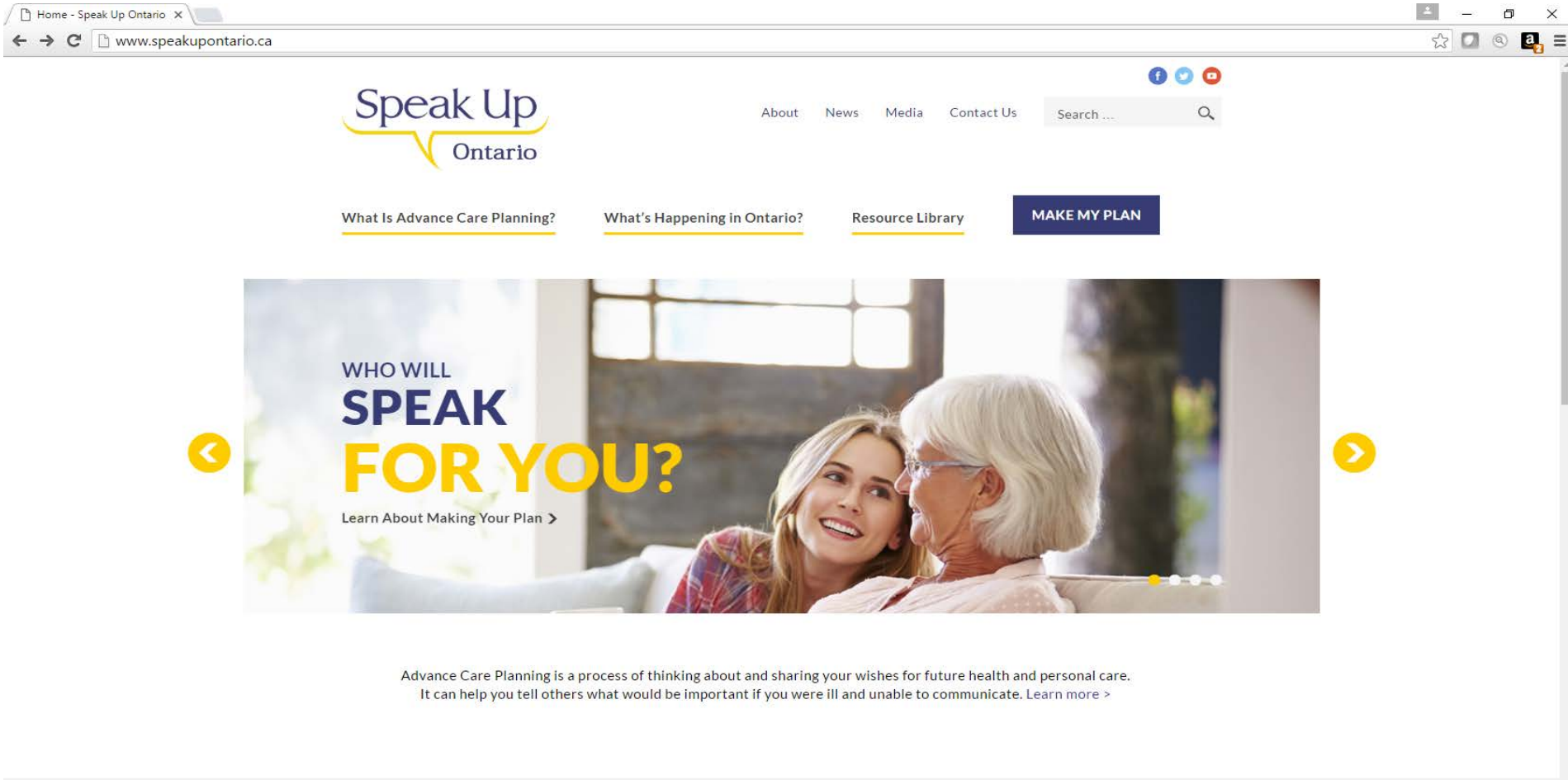
CoP LTC Working Group

- Scope:
  - To develop Ontario based best practice HCC ACP LTC resources
  - To support positive change with HCC ACP practices across LTC Homes in Ontario
  - To incorporate a knowledge translation approach in all of the project activities to ensure that best practice theory is translated to practice and is sustainable.
- Work Plan:
  - Environmental Scan of Current State, Issues and Challenges
  - Repository of innovative/compliant HCC ACP Hospital initiatives
  - Alignment with Law Commission of Ontario Paper Recommendations
  - Develop principles, guidelines and templates
  - Support Education/Knowledge Translation
  - Capacity Building
- Partnership with OLTCA, OLTCC, OANHSS

Speak Up Ontario Resources

www.speakupontario.ca

Ontario Advance Care Planning Workbook



HCC ACP CoP Ontario Tool Kit

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. Medical Assistance in Dying (MAiD) (Previously 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

Key Ontario Reference Sites

- Ontario Health Care Consent Act, 1996 - https://www.ontario.ca/laws/statute/96h02
- Ontario Substitute Decisions Act, 1992 - https://www.ontario.ca/laws/statute/92s30
- Consent and Capacity Board - http://www.ccboard.on.ca/scripts/english/aboutus/index.asp
- 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

Repository of Examples of Resources that meet the Ontario Legal Framework

- **ACP CONVERSATION GUIDE,** *Produced by Dr. Nadia Incardona and Dr. Jeff Myers, 2016, includes:*
  - ACP Conversation Guide template, Clinical Primer
- The Waterloo Wellington ACP Education Program **"CONVERSATIONS WORTH HAVING"**
  - General Public Fact Sheet, Health Care Fact Sheet, Wallet Card
- East Toronto Health Link's **ONTARIO ACP TOOLKIT FOR PATIENTS WITH CHRONIC DISEASES AND THE HEALTHCARE PROVIDERS WHO CARE FOR THEM**
  - ACP Brochure, ACP Workbook, cpr Brochure, sdm Brochure, Wallet Card

Provincial Webinars on "HCC ACP in Ontario"

2016 Education Series:

- LHIN Staff - June 1, 2016,
- Provincial Associations - July 19, 2016
- Health Links and Community Partners - September 28, 2016
- Long Term Care Homes - October 7, 2016
- Hospitals - November 18, 2016
- Community Care Access Centres - December 9, 2016

2017 Education Series:

- General Session – January 13th, 2017
- Regional HPC Networks – February 10th, 2017
- LTC Corporations and Compliance Officers – March 10th, 2017 (AM)
- Primary Care – March 10th, 2017 (PM)
- Lawyers and Legal Clinics – May 12th, 2017
- Clinical Ethicists and Social Workers – June 9th, 2017

How we can help you to GET THIS RIGHT?

To become a member of the Community of Practice simply register at:

http://fluidsurveys.com/s/hpco-hcc-acp-cop/

To schedule a resources review or to request additional support or assistance from the CoP simply go to:
http://www.speakupontario.ca/resource/ontario-guides/

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)

Ontario needs to GET THIS RIGHT

- 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

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Questions and Discussion