Health Care Consent & Advance Care Planning in Ontario

What Everyone Needs to Know

Health Care Consent Advance Care Planning Community of Practice
February 10, 2017

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 Regional HPC Networks and Programs must understand about Health Care Consent and Advance Care Planning to support Health Service Providers in your LHIN areas

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 TRUMP 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

Why does it matter to GET THIS RIGHT?

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

ACP ≠ **Consent to Treatment**

Health care professionals must always obtain informed consent or refusal before treatment from either the mentally capable patient or their substitute decision maker (SDM)

Requirements to get CONSENT

- You need to be very aware of the difference between “wishes” and “decisions”
- You need to be careful to ensure that you get DECISIONS from clients or incapable client's SDMs and not take direction from any “wishes”
- ALSO the wishes expressed by people when CAPABLE are what is KEY to guide the incapable client’ SDMs in THEIR decision making

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:_____

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Name of Healthcare professional Completing this form:_____ Date:_____

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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Who needs to worry about GETTING THIS RIGHT?

HealthLinks

My plan for future situations					
Future situations	What I will do	What I will *not* do	Who will help me	Telephone #	Review date
					YYYY-MM-DD
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

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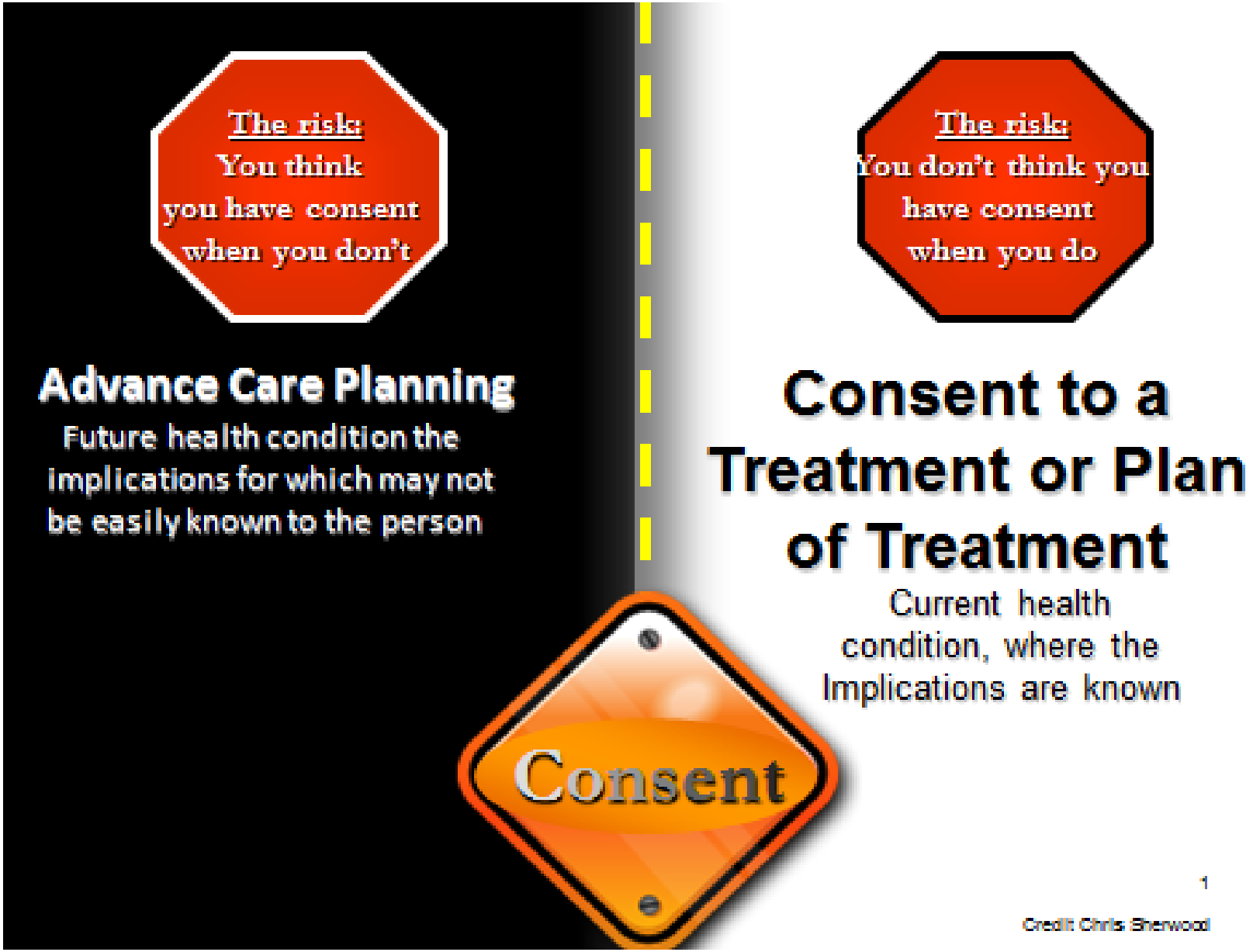

The risk:
You think you have consent when you don't
The risk:
You don't think you have consent when you do
Advance Care Planning
Future health condition the implications for which may not be easily known to the person
Consent to a Treatment or Plan of Treatment
Current health condition, where the Implications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

Long Term Care Homes:

- 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

Who will be accountable to GET THIS RIGHT?

CCAC:

- CCACs MUST comply with the Health Care Consent Act
- CCACs should review their policies and practices about the REQUIREMENT to obtain Informed consent before any treatments are delivered.
- CCACs should review any forms that are used to record:
  - Information about the patient's capacity to make treatment decisions,
  - Who would be the patient's future SDM if the patient became incapable,
  - Information about if and when informed consent has been obtained
  - Information about advance care planning to ensure that ACP wishes are NOT used as consents

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 decision making?

- 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:

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 organizations.

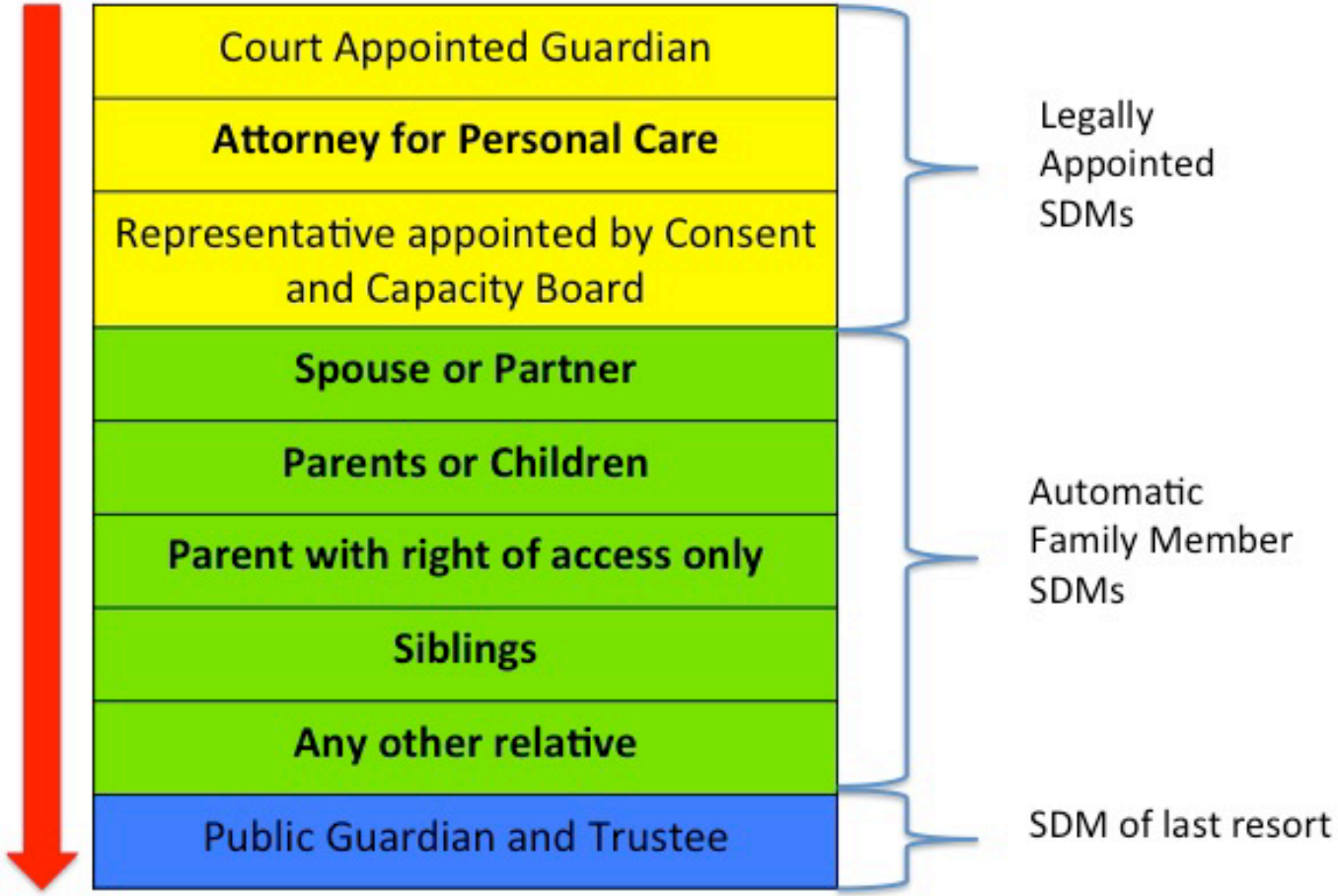
For whom is advance care planning important?

- ACP is important to EVERY PERSON in ONTARIO.
- ACP is often misperceived as being a conversation about end of life.
- Engaging in ACP conversations is for ALL mentally capable adults.
  - Sharing wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of ***becoming incapable*** to give or refuse consent
- EVERY DAY, EVERY PERSON in ONTARIO is at risk of ***becoming incapable*** to give or refuse consent.
  - might be unexpected e.g. car accident or stroke
  - might also be somewhat expected e.g. progressive, life-limiting illness
- ACP is still important to a person diagnosed with a life-limiting illness
- Capacity and consent are fundamental components when treatment or care decisions are to be made
  - This can be informed by past ACP

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.

- **Bottom Line: It Is the obligation of the health care provider obtaining consent from an SDM to ensure these requirements are met.**

Remember the POA is just one type of SDM

An Electronic Medical Record (EMR) 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 person's POA for Personal Care 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

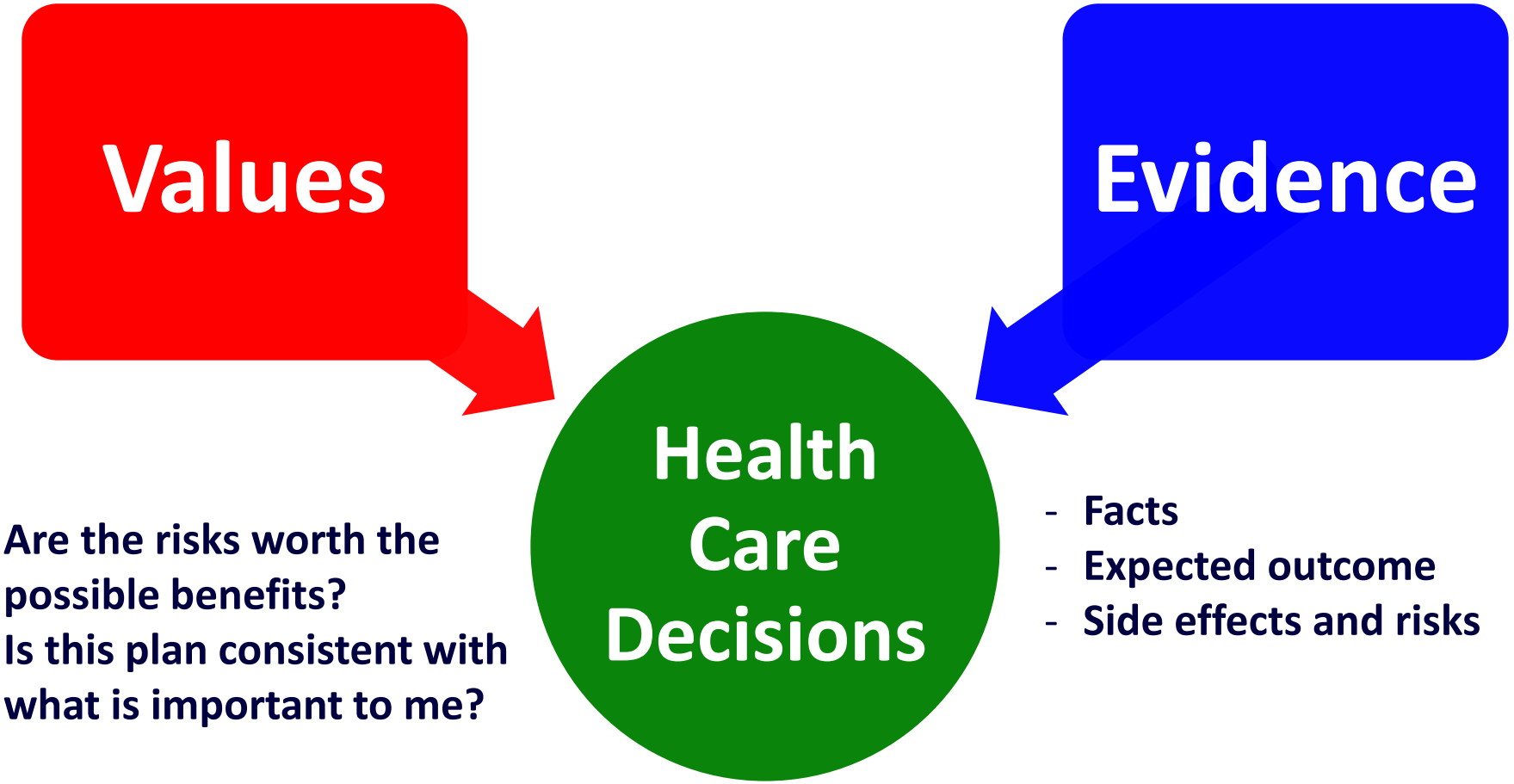
(Note 3: If No, provide ACP provincially approved resources i.e., Speak-Up Ontario ACP Workbook or website information, etc.)

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

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

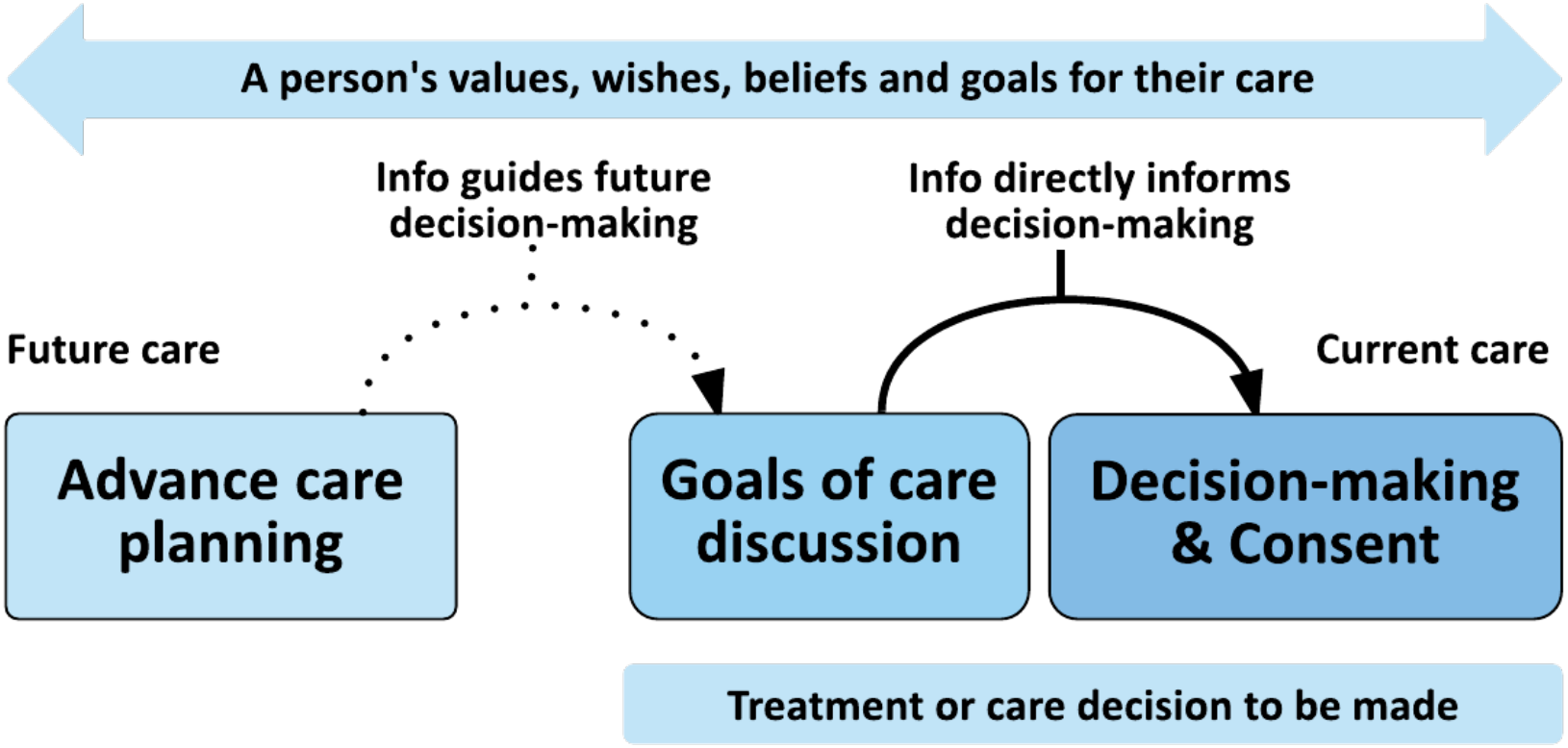
- Understand the relationship between and differences between advance care planning, goals of care and informed consent

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?

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

- 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)

System Strategies to GET THIS RIGHT

improve the quality and effectiveness of HCC ACP in Ontario.
Culture change requires:

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

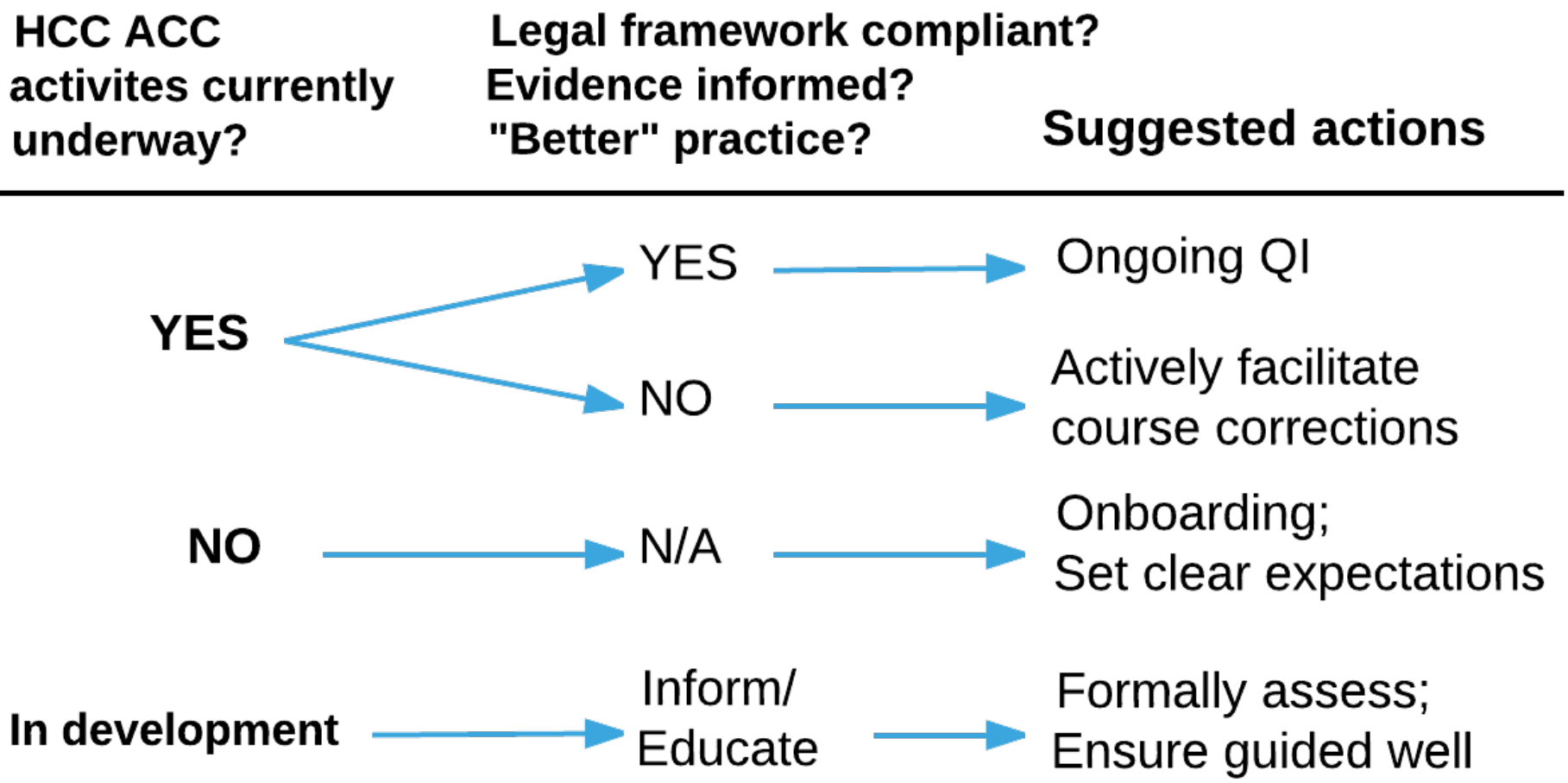
2. **Documentation/EMR**
   - Standardized
   - Accessible

3. **Quality improvement**

4. **System wide planning & coordination**

System Strategies to GET THIS RIGHT

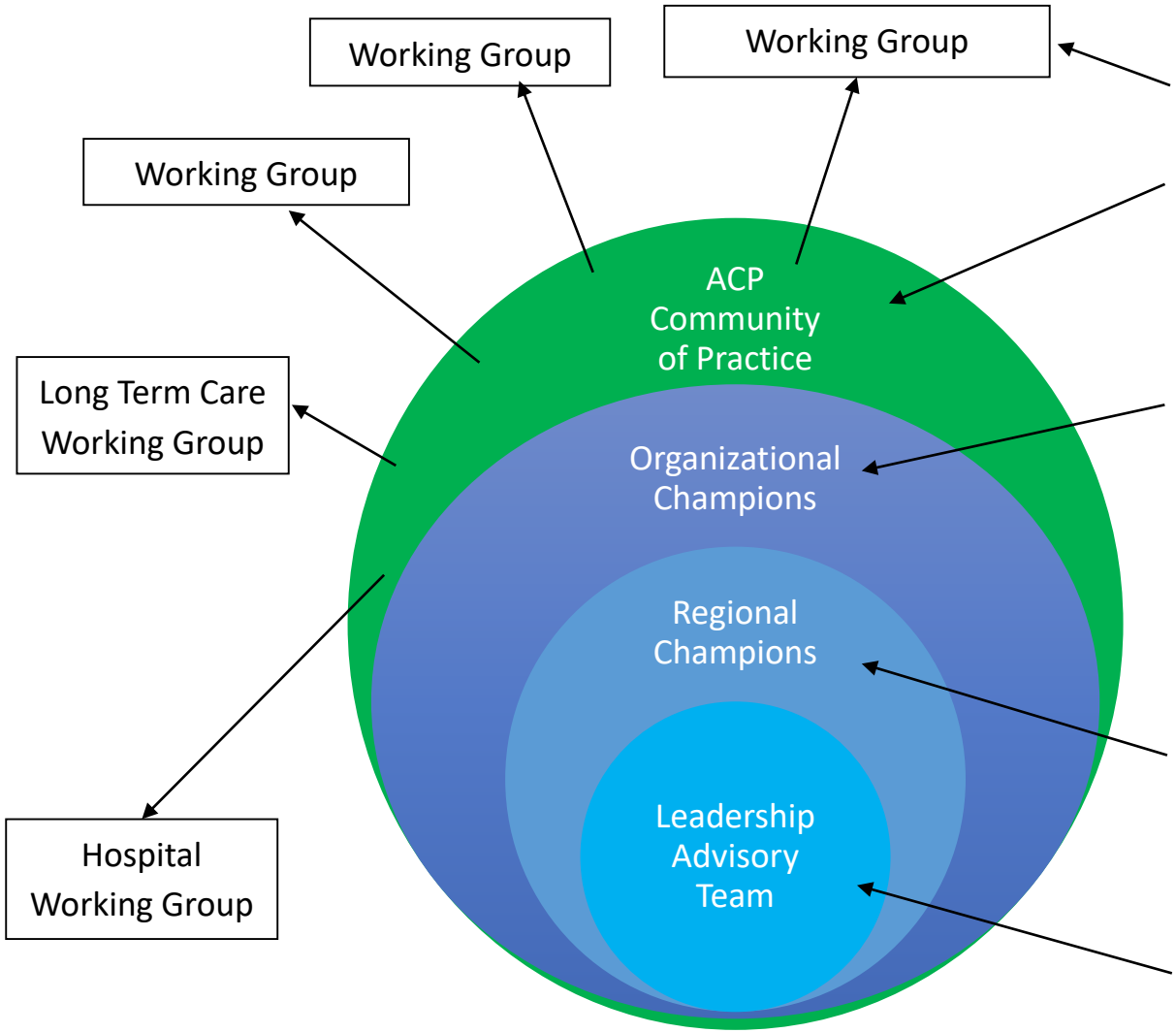
Process for assessing organizations and institutions



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 **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

How we can help you to GET THIS RIGHT?

- Your participation in the CoP would provide you with:
  - An ongoing forum for continued education and sustainability
  - Direct access to all HCC ACP CoP Tools, Resources and Updates
- To become a member of the CoP register at: http://fluidsurveys.com/s/hpco-hcc-acp-cop/

Resource Review Process to GET THIS RIGHT

- Considerable time and effort is spent by associations, organizations and projects to develop HCC ACP related documents and processes.
- **But unfortunately many HSPs continue to be noncompliant with the Ontario Legal Framework**
- The HPCO HCC ACP CoP Resource Review Process
- To schedule a resources review simply go to: http://www.speakupontario.ca/resource/ontario-guides/

HCC ACP CoP Ontario 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

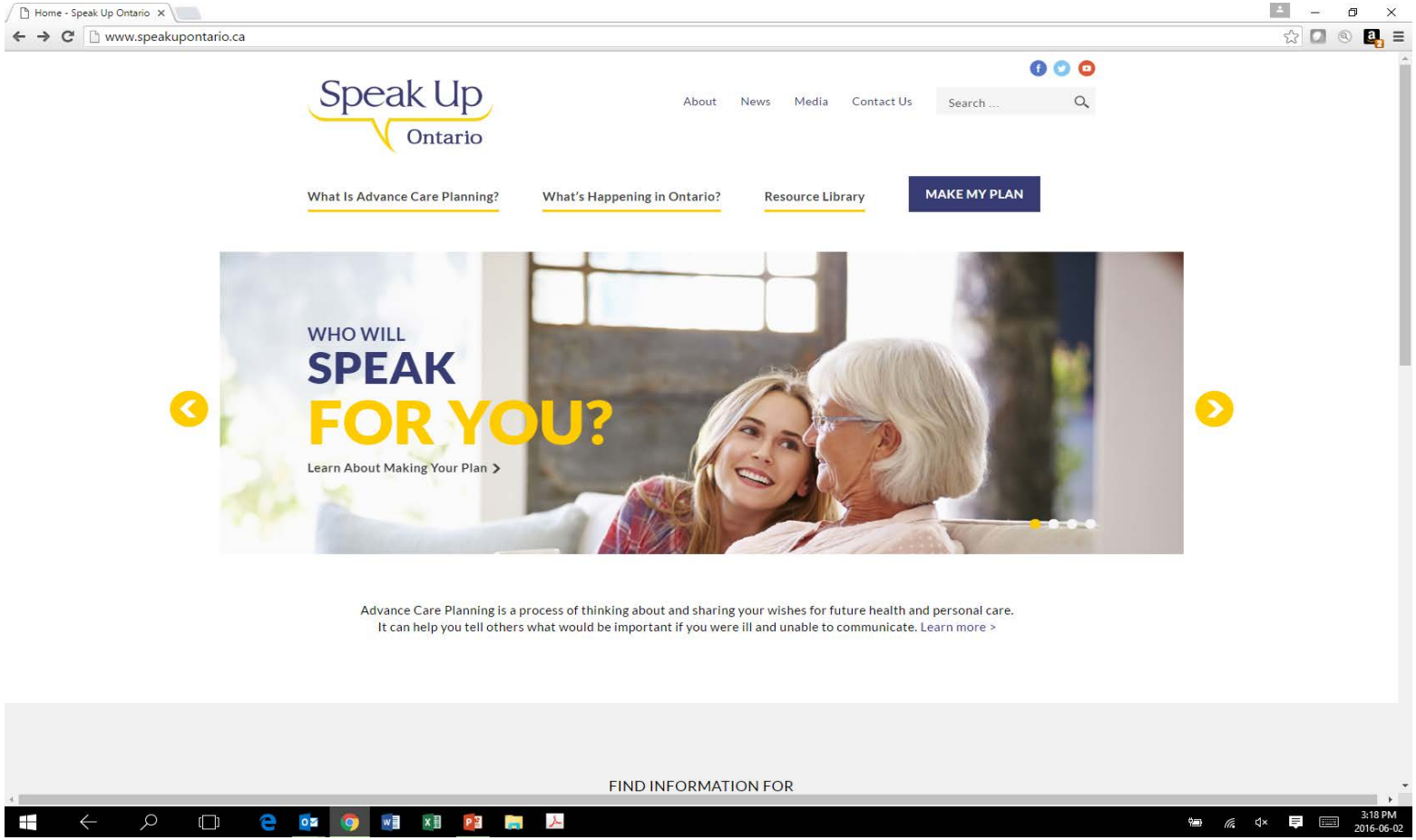
Key Reference Sites to GET THIS RIGHT

- 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

Speak Up Ontario to GET THIS RIGHT

www.speakupontario.ca

Ontario Advance Care Planning Workbook



What you can do…

Work with your local Health Service Providers to:

- Promote the use of compliant materials, resources, tools and policies.
- Enhance awareness of HPCO's HCC ACP CoP for education, support, tools and examples.
- Identify and work with HPCO HCC ACP CoP Regional Champions in your LHIN area
- Consider who needs to be involved in this change process
    - Identify and support key stakeholders and sectors currently interested/engaged in HCC ACP compliance

What you can do…

- Ensure their processes to record the SDM is correct
  - **Do NOT confuse with emergency contact or next of kin -** Change terminology to be legally accurate
- Promote conversation templates that can standardize certain components of the ACP conversation
  - The Speak Up Ontario Website has some great examples to draw from
- Support EMR development (paper or electronic) where ideally **ALL** ACP information can be easily accessed and is legally compliant
  - to be used as a starting point for the next conversation NOT as consent for treatments

What you can do…

Utilize LHIN accountability agreements:

1. Champlain (current):
   - Added to LSAA and HSAA: "The HSP agrees to leverage materials developed by Champlain Hospice Palliative Care Program and Hospice Palliative Care Ontario to provide education for staff, volunteers and service recipients on advance care planning/health care consent and to incorporate regionally developed tools to support standardized documentation of patient/resident goals of care."
     - *Suggestion: "incorporate regionally and/or provincially developed tools (i.e., HPCO HCC ACP CoP) that align with the Ontario legal framework….to support"*
2. HNHB (2012):
   - Developed a Health Care Consent Advance Care Planning E-Learning Module in partnership with ACE
   - LSAA – Mandatory participation by all LTC Home Administrators, Medical Directors/Directors of Care within 1 year, and for all new hires within 6 months. Pass module quiz with minimum of 80%.

Benefits of GETTING THIS RIGHT

Along with ensuring the right information is given to the right person, at the right time, getting this right can help:

- Facilitate the use of correct information
- Enhance clarity and understanding
- Ensure sector performance compliance
- Meet legislated professional obligations
- Increase Person Centred Care and honour the basic rights of patients
- Increase System Capacity & Consistency
- Reduce the risk of legal liability

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