The Challenge for System Leaders and Planners

Health Care Consent & Advance Care Planning in Ontario

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
- 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 HSPs need to both know and understand about Health Care Consent and Advance Care Planning
- What system planners, funders and accountability & performance experts must understand about Health Care Consent and Advance Care Planning

Poll #1

For a person who lacks the mental capacity to make decisions, ACP conversations can occur by substitute decision makers on behalf of the person.

True *or* False?

Poll #2

Preferences 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?

Poll #4

Wishes expressed verbally are less "usable" then wishes that are written, signed and witnessed.

True *or* False?

Why does it matter to GET THIS RIGHT?

- Outcome evidence indicates that 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

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:_____

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

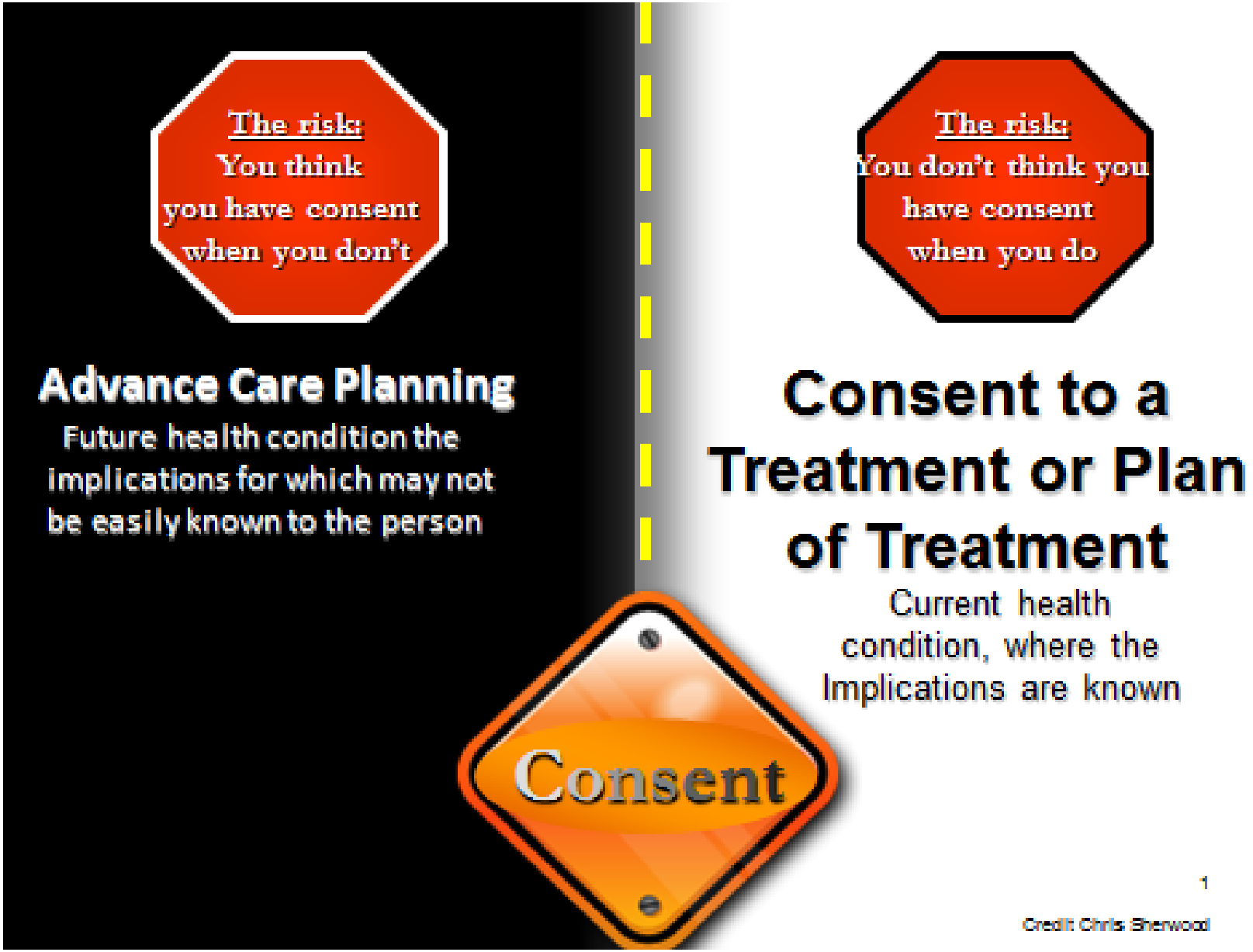
These are either confusing or incorrect elements

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 #:	

These are either confusing or incorrect elements



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" by legal counsel as compliant with the law who has expertise in HCCA or consent law (or something along this line)

- 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 **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?

- Proper assessment of patient's **CAPACITY** for treatment decision-making
- 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

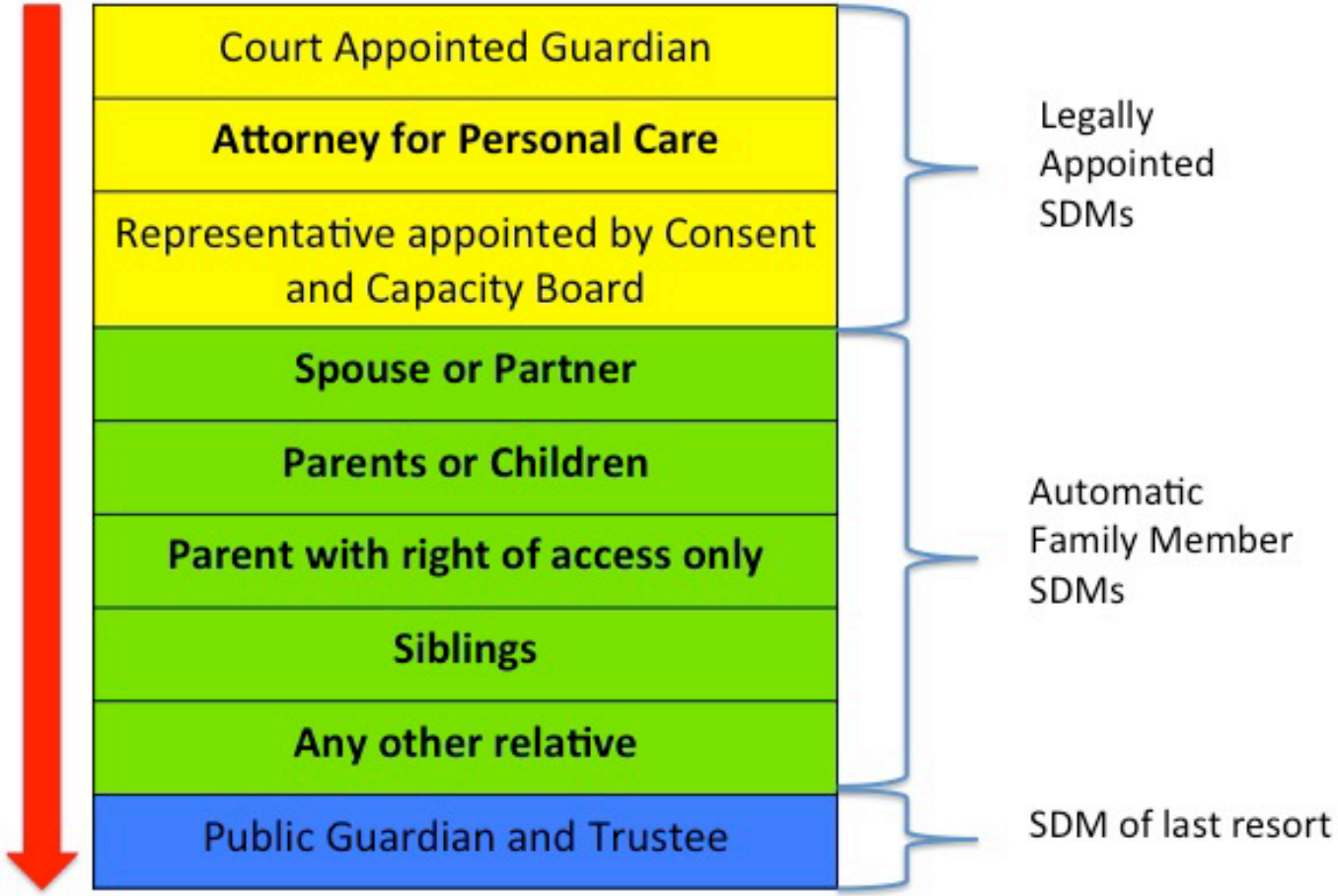
AND

- 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



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?

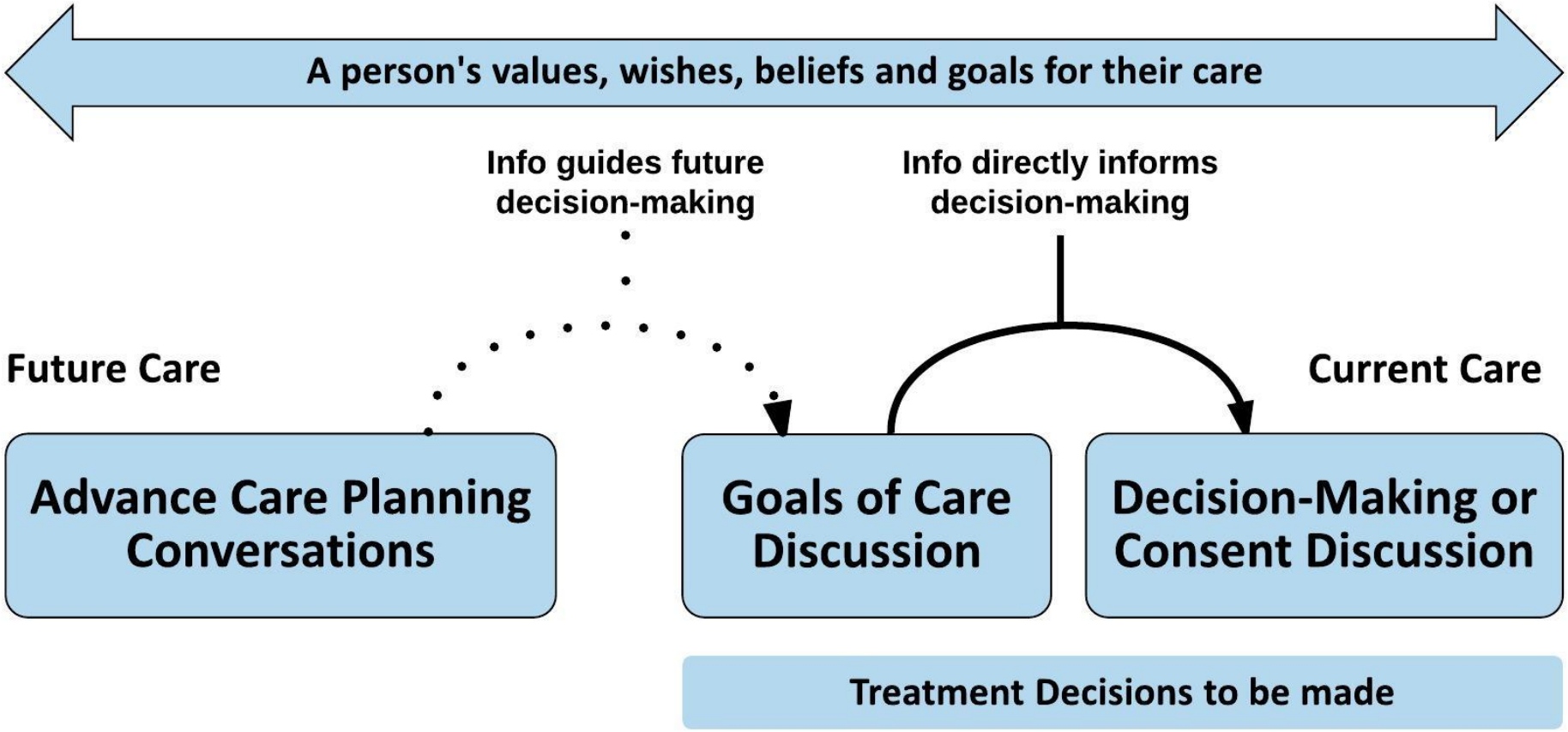


Figure: Relationship between three discussions that contribute to informed consent

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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	SDM is identified & prepared for future decision-making	Code status, POLST, etc.	Patient's to define and describe
Goals of Care Discussion	Current	Different every time - exploring patient's goals assesses readiness and prepares for decision-making	Code status, POLST, etc.	Patient's to define and describe
Decision-making or Consent Discussion	Current	Outcome is always care or treatment decision(s) e.g. code status or POLST		Medically oriented e.g. cure, resuscitative, or comfort

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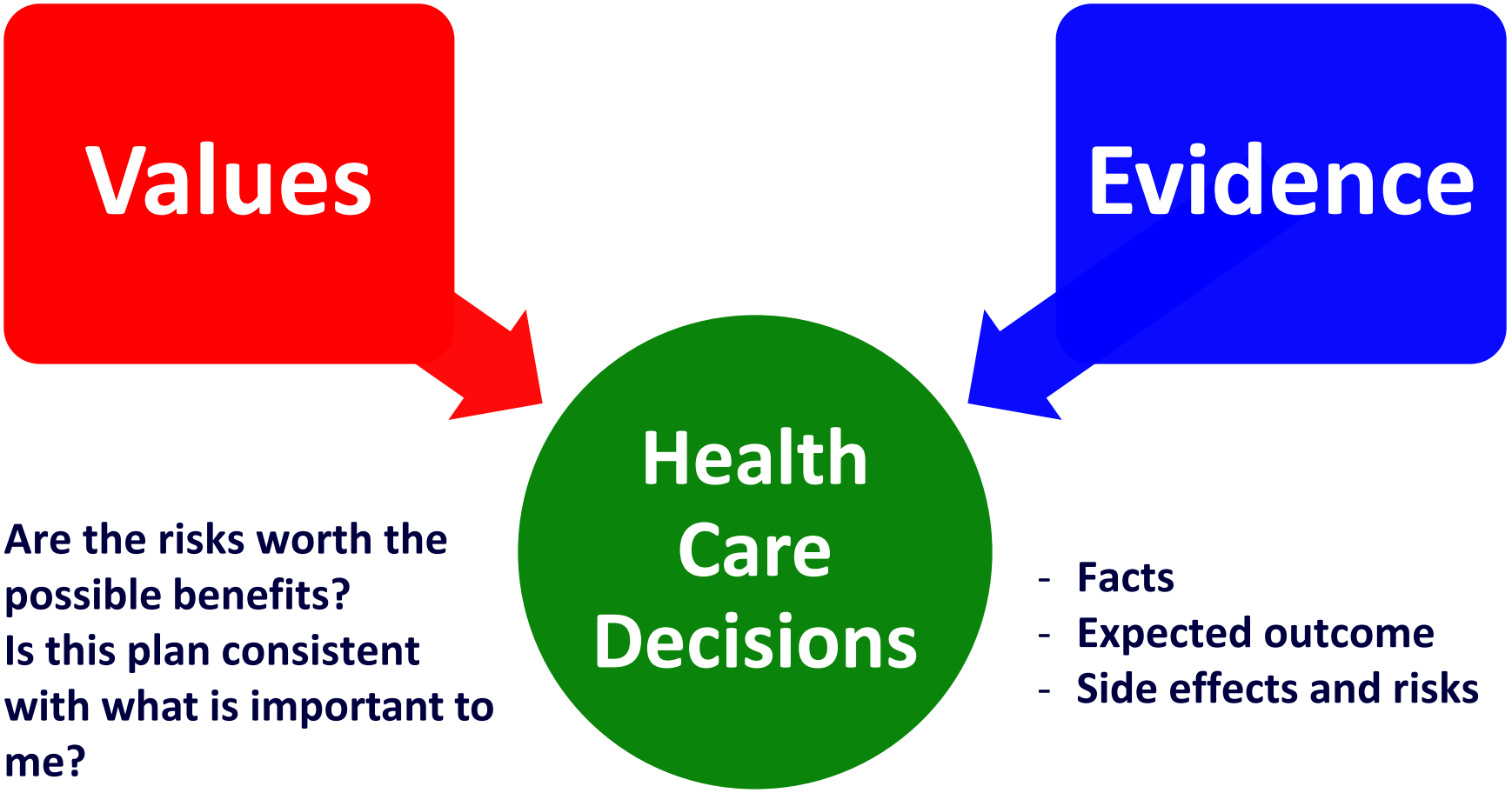
How a person makes healthcare decisions



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's the clinical approach to GET THIS RIGHT?

Not helpful Consent and 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 Consent and ACP Conversations…

	Explore further
"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?

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

System Strategies 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)

System Strategies to GET THIS RIGHT

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

1. **Education:**
   - People & SDMs:
     - Aware
     - Informed
     - Have tools
   - Clinician competence:
     - Attitudes/Aware
     - Knowledge/Information
       - Legal framework
       - Actual conversation
     - Skills
2. **Documentation/EMR**
   - Standardized
   - Accessible
3. **Quality improvement**
4. **System wide planning & coordination**

Next steps for Ontario system leaders & planners?

Assess your organizations and institutions

ACP activities currently underway?	Legal framework compliant? Evidence informed, "Better" Practice?	Suggested Action by System Leaders
Yes	Yes	Ongoing QI
	No	Actively facilitate course corrections
No	N/A	Onboarding; Set clear expectations
In development	Inform/ Educate	Formally assess; Ensure guided well

How we can help you to GET THIS RIGHT?

- HPCO Health Care Consent & Advance Care Planning Community of Practice resources:
  - Ontario specific HCC ACP Tool Kit
  - Resource Review Process
  - Access to Provincial Leaders and Regional Champions
  - Capacity Building through Broad Membership
  - Provincial Inventory of ACP Initiatives
  - Speak Up Ontario – http://www.speakupontario.ca
    - Ontario ACP Workbook (hard copy, download, on-line versions)
    - Educational Presentations – HSP and Public
    - Provincial Best Practices Repository

Who is currently GETTING THIS RIGHT:

- The Waterloo Wellington Advance Care Planning Education Program **"Conversations Worth Having"**
  - 3 year initiative funded by the Waterloo Wellington LHIN
- Uniquely designed to engage general public, community professionals and health care providers to build Consent and ACP understanding and capacity across the region
- Focuses on CHANGE; change in awareness, attitudes, knowledge and behaviours associated with Consent and ACP

Who is currently GETTING THIS RIGHT:

- 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

Key Resource Documents to GET THIS RIGHT

1. Health Care Consent Advance Care Planning Community of Practice Resource Review
2. Health Care Consent Advance Care Planning Common Themes and Errors Tool
3. Leadership in Advance Care Planning in Ontario Tool
4. Leadership Screening Tool
5. Health Care Consent and Advance Care Planning Glossary of Terms for Ontario
6. Ontario Advance Care Planning Workbook
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
10. List of "approved" HCC and ACP resources

Key Reference Sites to GET THIS RIGHT

- Key Reference Documents:
- 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

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

Contact:

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Questions and Discussion