Advance care planning:
Challenges and cases in Long-Term Care

OLTCC
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Objectives

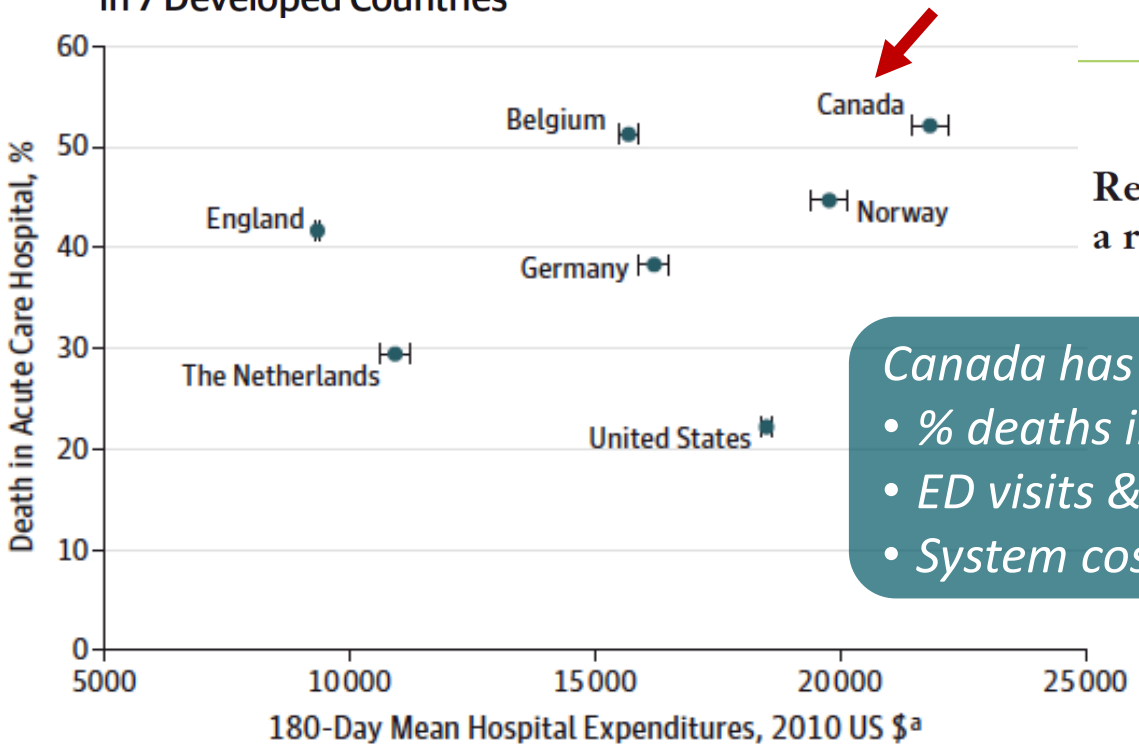
1. Describe how advance care planning informs and directs care
2. Address issues of consent and capacity
3. Present and discuss cases of advance care planning

Why this matters

Research | JAMA, 2016

Original Investigation

Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries



Canada has highest…
- *% deaths in acute care*
- *ED visits & hosp in last 30d*
- *System costs in last 6 mos*

cmajOPEN

2019 Research

Regional variations of care in home care and long-term care: a retrospective cohort study

Ontario LTC = 3 X more likely transfer to acute care than Alta & BC

Outline

- Welcome, Objectives & Why this matters
- Your experiences
- Connect the dots & Revisit decision-making
- How values shape decisions
- Gain SDM experience
- Connect LTC dots

Your experiences

- Think of an ACP conversation or GOC discussion that went well
- Think of an ACP conversation or GOC discussion that did **not** go well
    - As the clinician, as a colleague or as a patient/family member

        - HOW was the discussion conducted?
        - WHAT was said?
        - WHAT was done?
        - WHY did it go well/not go well?
- Report back: common elements

Experiences

Think of an ACP conversation or GOC discussion that **went well**

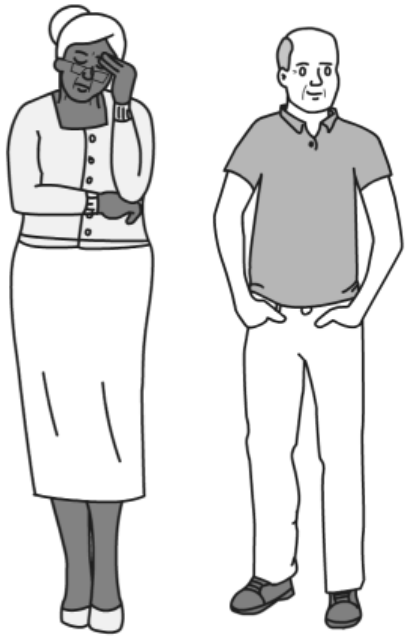
- Taking the time (uninterrupted)
- Focus was on patient's values
- Patients and families understood disease and trajectory
- Conversations occurred over time to allow patients and family times to digest
- Room was read i.e. readiness to have the conversation was recognized
- Gauge of the pts reception of the information served to guide the discussion
- More listening less talking
- Accounted for different personalities
- The right people were in the room

Experiences

Think of an ACP conversation or GOC discussion that did **not** go well

- SDM role was not understood by all
- Diagnosis, current condition & what to expect were not understood
- Only included pt i.e. SDM not present
- Inconsistent messaging among team members
- Location i.e. conversations in shared rooms/hallways
- Checklist followed in an inflexible way
- Clinician clearly had an agenda
- Language barrier not addressed
- Cultural beliefs and values not considered

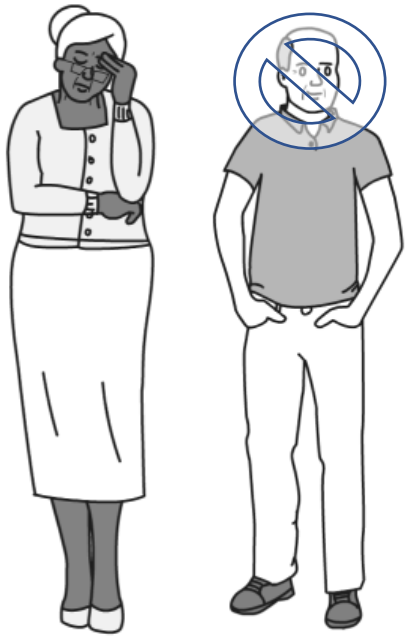
This is Joe and his wife Sandi.
Sandi is Joe’s future substitute decision-maker (SDM).



Joe was recently diagnosed with bacterial pneumonia and to treat this he is offered a course of antibiotics.

The treatment plan of initiating antibiotics requires consent.

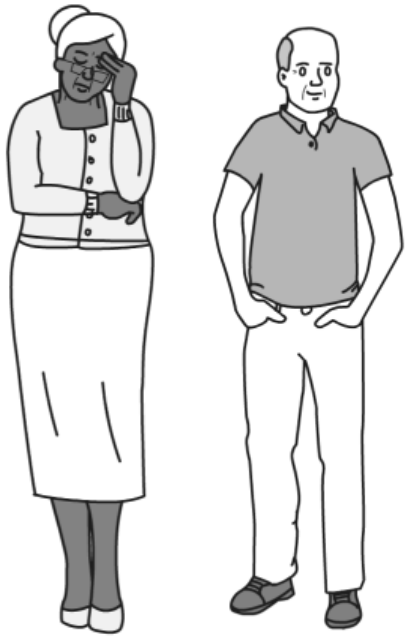
Consent to initiate antibiotics must come from a capable person.



The person must either be Joe **OR**

Sandi (if Joe is incapable of making this decision)

Being capable = ABILITY to understand and ABILITY to appreciate the information related to an illness & treatment or plan



If Joe has a delirium and cannot understand information about treating pneumonia he is NOT capable and Sandi would need to give consent.

What ACP is

ADVANCE CARE PLANNING

=

Preparing SDMs for…

CONSENT

decisions if a person has become incapable

What ACP is not

ADVANCE CARE PLANNING

≠

CONSENT

ACP is NOT consent

It is not about a person making health decisions “in advance”

A **common misunderstanding** is that ACP is to *make decisions* today about *treatments that are wanted or not wanted in the future*

Instead…

ACP is about *preparing SDMs* today so they are able to make well informed *decisions in the future* on behalf of incapable patients

What is Advance Care Planning?

Original Article

Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel

Feb 2017

"Should start with overall personal life goals and values and then these values should be translated by clinicians into more specific discussions concerning medical treatments over time"

- Prepares people in varying health states for decision making, not just at end of life
- Elicit values and personal life goals, which can guide future care considerations

What are goals of care discussions?

Health Quality Ontario
Let's make our health system healthier

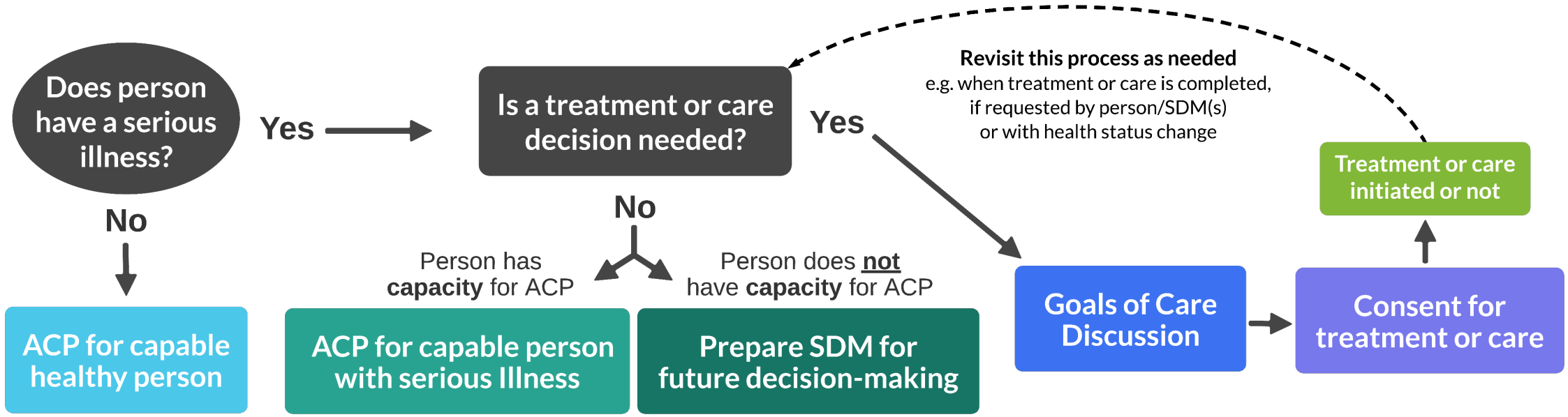
PALLIATIVE CARE QUALITY STATEMENT

Goals of Care Discussions and Consent

For a person with serious illness and a treatment or care decision is to be made, the GOC discussion enables the **goals the person has for their care** to **guide the decision-making process**

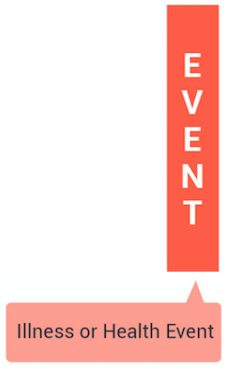
"I can only tell you what my goals are if I understand my condition and what is known about what to expect" i.e. to extent possible, ensure an **understanding of both the illness and care options**

Person-Centred Decision-Making



Connecting the dots

When a person develops an **illness** or has a **health event** different treatment options will be available.

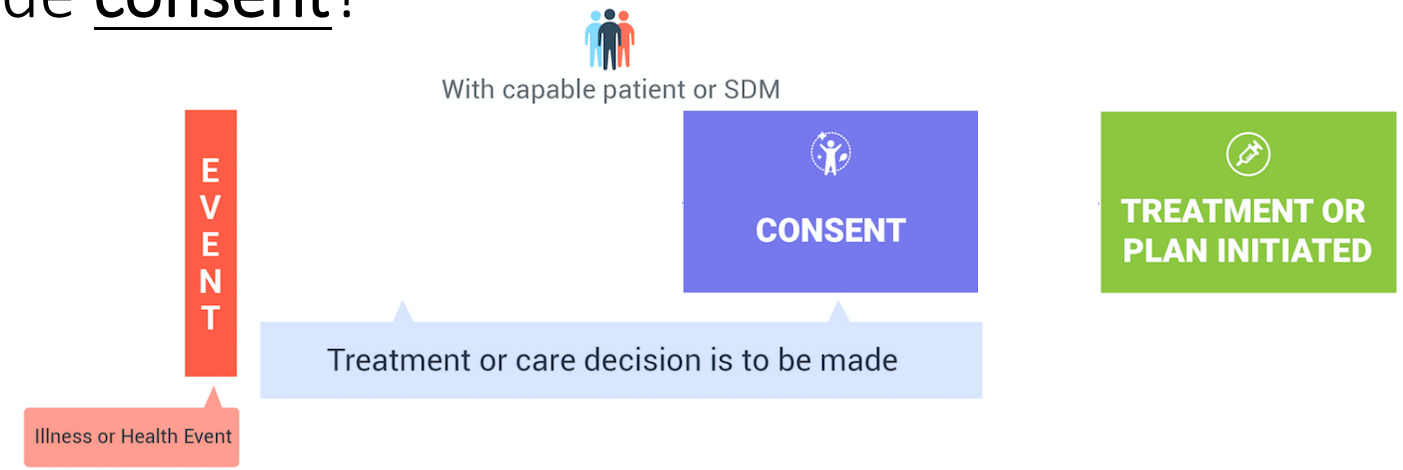


e.g. diuresis for heart failure, antibiotics for pneumonia, blood transfusion in a trauma, surgery etc.

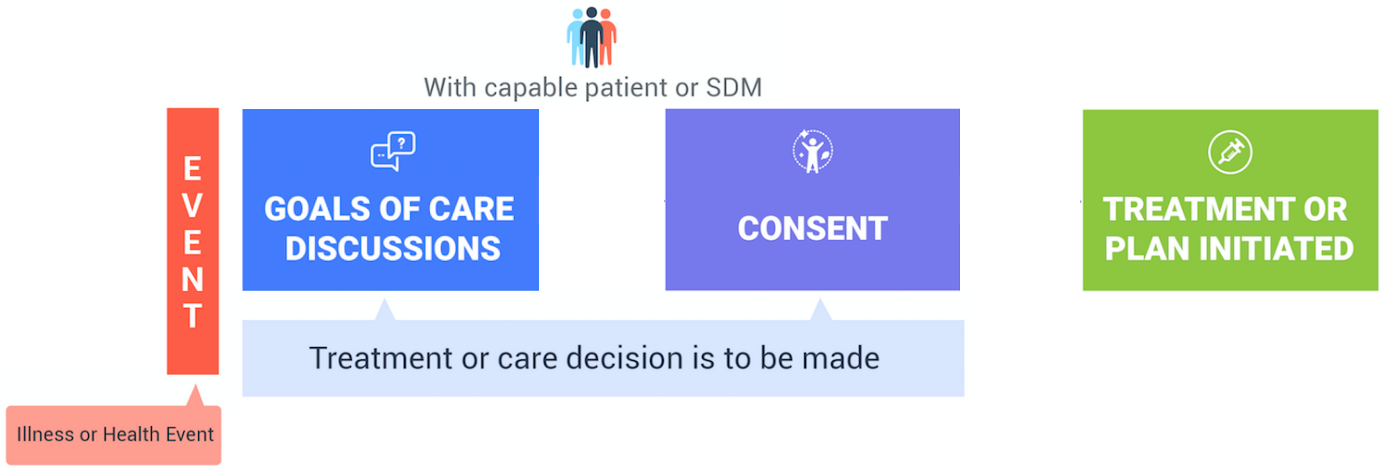
Connecting the dots

A decision needs to be made…

Who will provide **consent**?

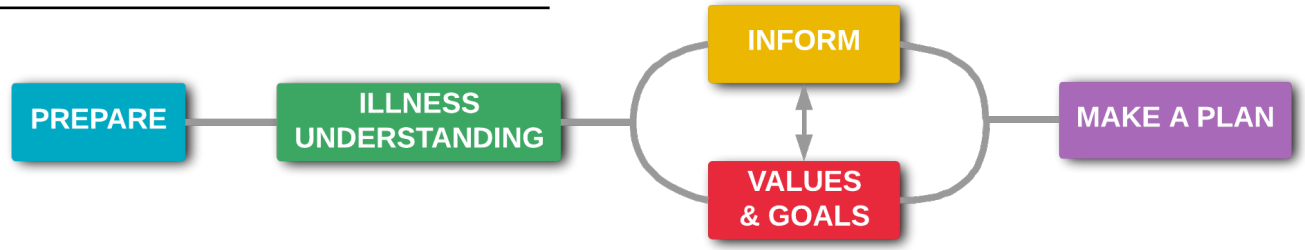


Connecting the dots



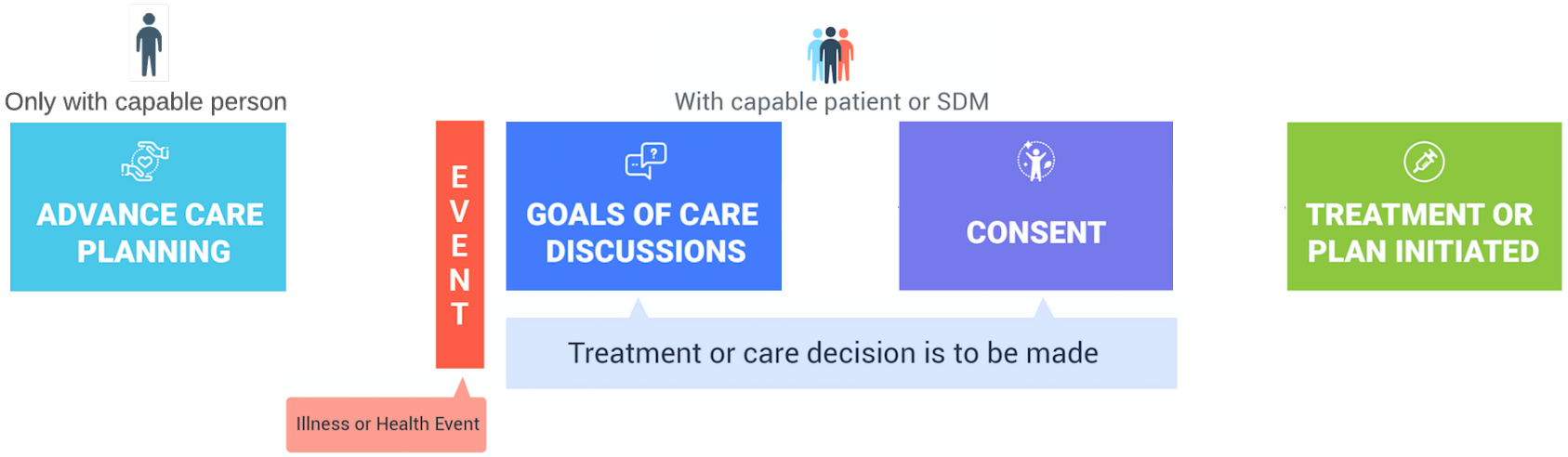
- ensure illness or event is understood
- provide information
- determine patient's goals
- address emotional responses
- together make a plan

What is a goals of care discussion?



Connecting the dots

How do ACP conversations help?

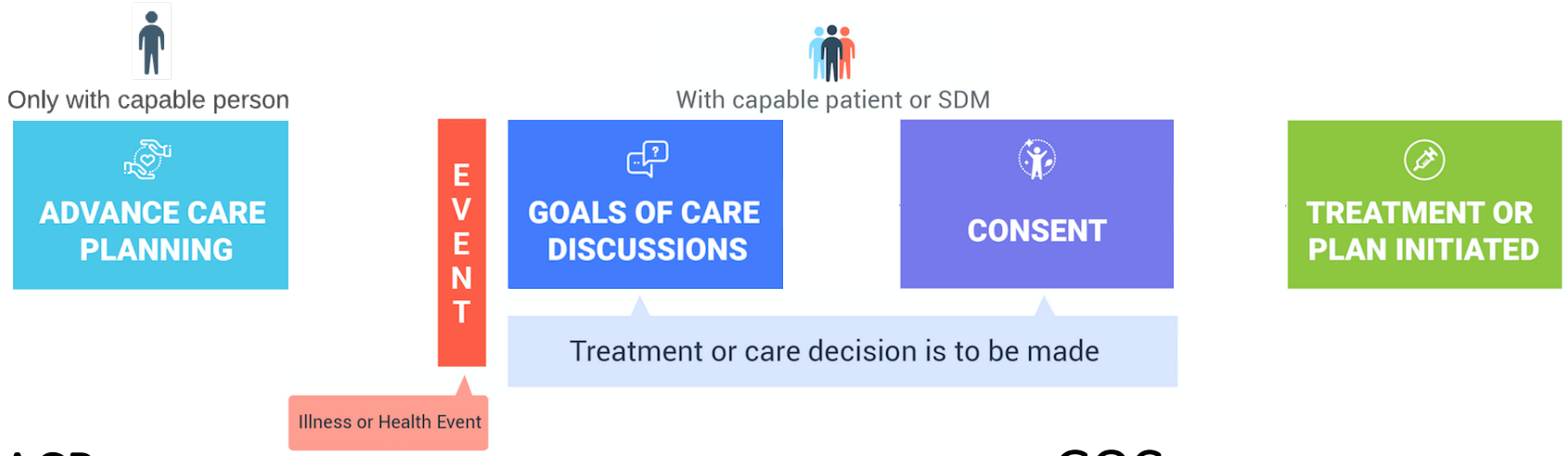


To guide decision-making, SDMs draw from ACP conversations when the person was capable

Contemplating values prior to acute illness also helps prepare the patient for decision-making

Connecting the dots

What are the differences between ACP and GOC discussions?



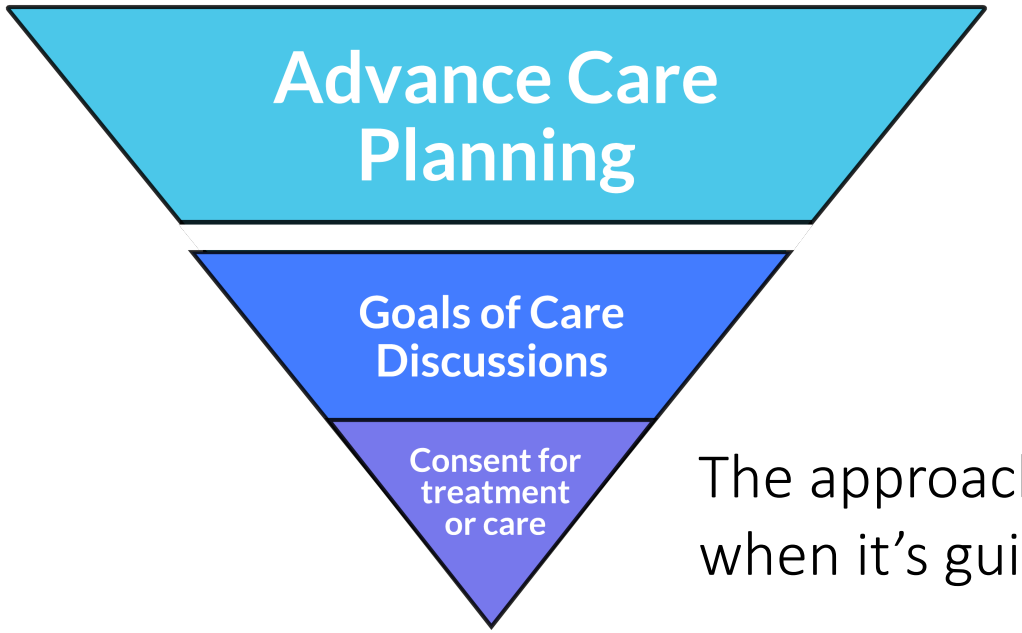
ACP

- Future hypothetical contexts are considered
- Only a capable person can express wishes about future care

GOC

- Decision is to be made that involves a current illness or health event
- A patient **or** SDM can outline patient goals

Connecting the dots



The approach for this entire process is person-centred when it’s guided by a person’s values and goals.

Person-Centred Decision-Making

Universal Barriers:

- Time
- Confidence in skills
- Desire to maintain hope
- Inadequate documentation systems
- Uncertainty around prognosis

Patients/Families:

- Assume we will raise
- Contradictory information
- Turn to google

- Risk of info overload

What would you do?

You suffer a life-threatening injury and offered a surgery that could save your life. However, with the surgery there is 80% chance of paralysis (upper and lower limbs).

Would you have the surgery?

What would you do?

You have a debilitating motor condition and offered a medication that allows most patients to function independently. However most patients also experience a 30% reduction in cognitive function.

Would you take the medication?

What would you do?

You are in the hospital for heart failure and your kidney function has become very poor.

Would you want dialysis?

What would you do?

Paralysis

30% reduction in cognition

How did you arrive at these decisions?

It depends for dialysis

What's different about this decision?

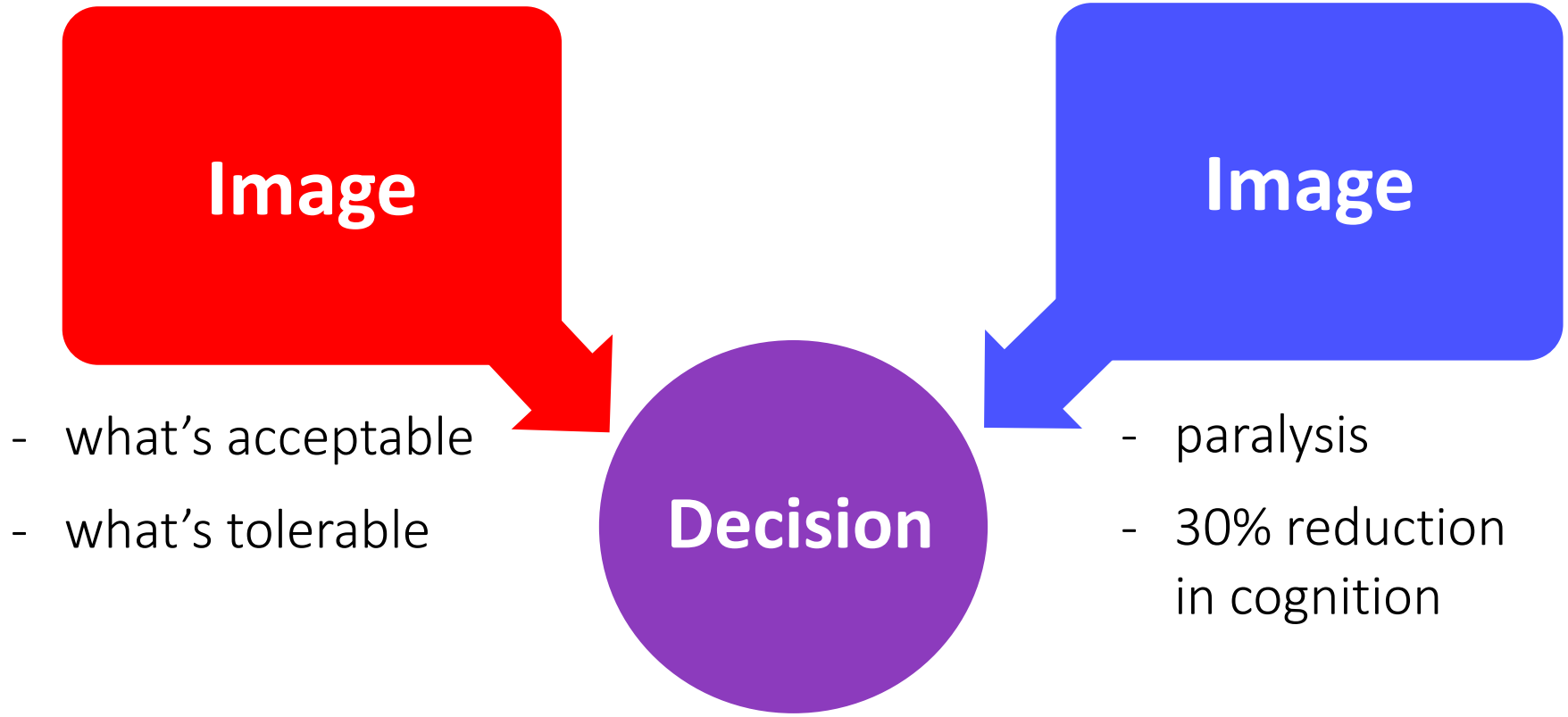
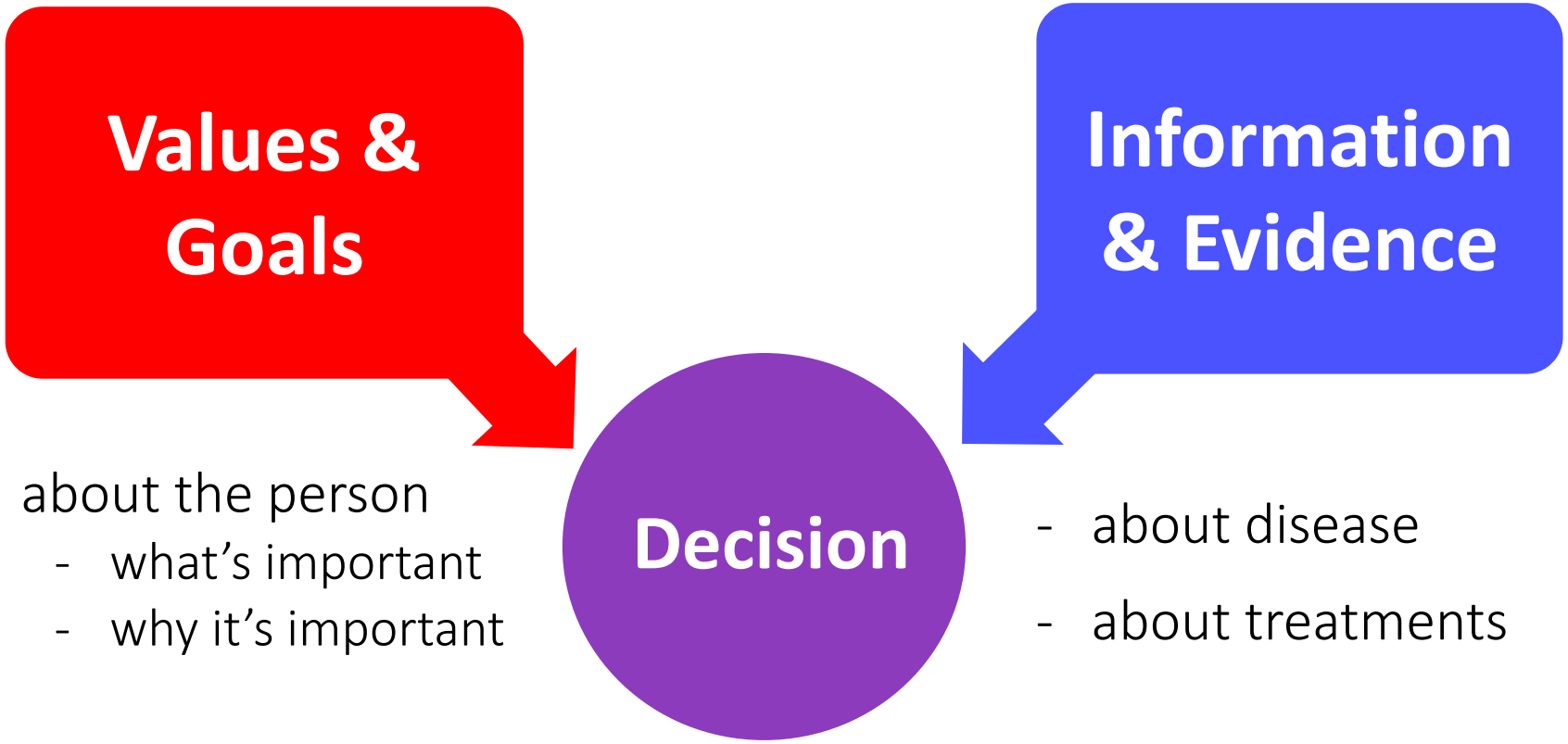


Image
- what's acceptable
- what's tolerable
Decision
Image
- paralysis
- 30% reduction in cognition

Effective decision-making



- about the person
  - what's important
  - why it's important

- about disease
- about treatments

<u>BOTH</u> sources of information are needed for decisions to be effective

What would you do?

Repeat ER visits with multiple tests

- Healthcare workers have a sense of paralysis and loss of cognition
- We have a general idea of the impact of illness & treatments

Spending more time with healthcare providers than family and friends

- Most patients do not have the benefit of knowing what outcomes might look like or mean

Feeling sick from medications that **MAY** prolong life

- Envisioning outcomes like these help patients think about their own priorities, goals and values

Unable to communicate with friends and family

What patients consider

People do not envision their future health in terms of treatments or FEV1 or % tumour burden or kidney function

They think about the **outcomes of treatments**…

What they imagine life to look like and how it will be affected by illness and treatments

Our challenge

The **purpose of ACP** is to help **prepare future SDMs** to make a variety of care and treatment decisions if a person has become mentally incapable

Think:

Is information going to help the SDM in the future?

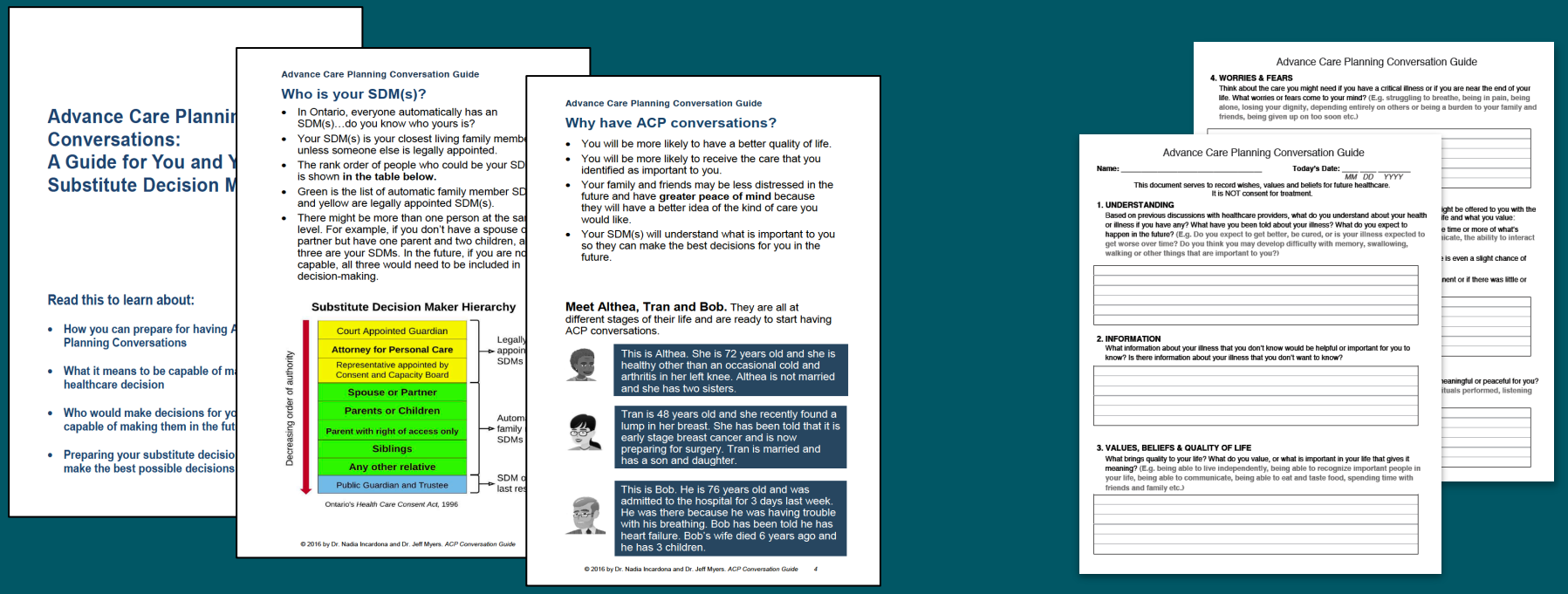
Our task

Identify helpful information

- The following is a series of video clips from real ACP conversations
- Facilitated with two healthy people, Bernie & Frances
- Frances is Bernie's SDM
- Bernie and their daughter Rachael are Frances SDMs (she completed a Power of Attorney for Personal Care and named them both)

The Halligans

- Because both are well, their perspectives are shaped through experiences of family and friends
- Bernie & Frances were provided the **ACP Conversation Guide** ahead of time



Summary

Most people value the ***potential outcome*** of a treatment…not the treatment itself.

Helpful information was identified for Bernie only when Rachael paints a picture of the outcome.

For some, the outcome of losing physical independence is unacceptable or intolerable

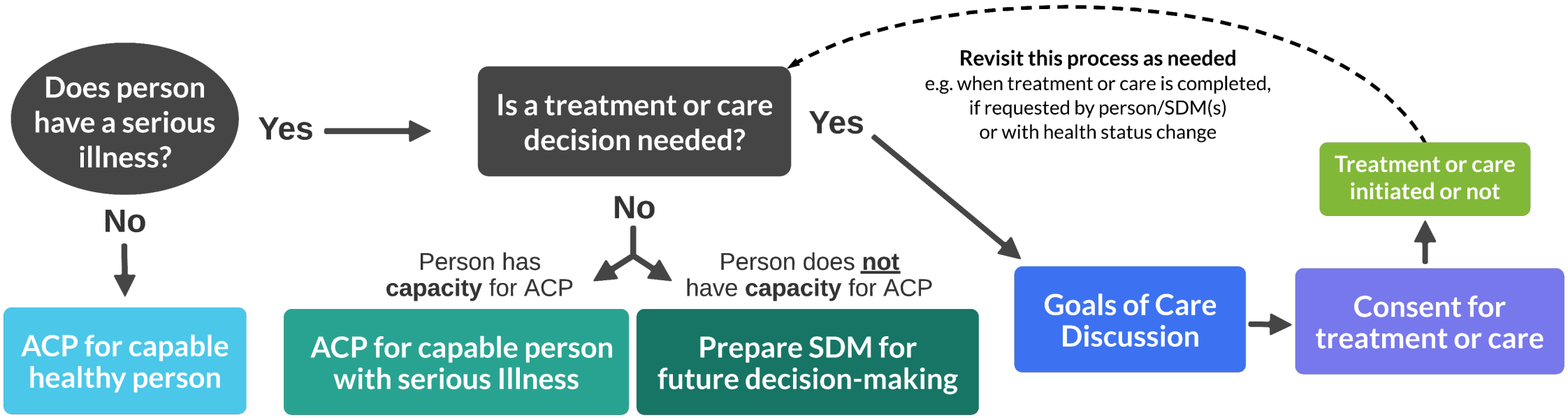
For others, the outcome of losing mental independence (i.e. cognitive ability) is unacceptable or intolerable

Connect LTC dots

- Capacity
- Preparing and engaging SDMs
- ACP & GOC discussions: How to
- Utilizing team members
- ACP or preparing SDMs can be interprofessional
- Discussion & Cases

Connect LTC dots

If a person has lost capacity…

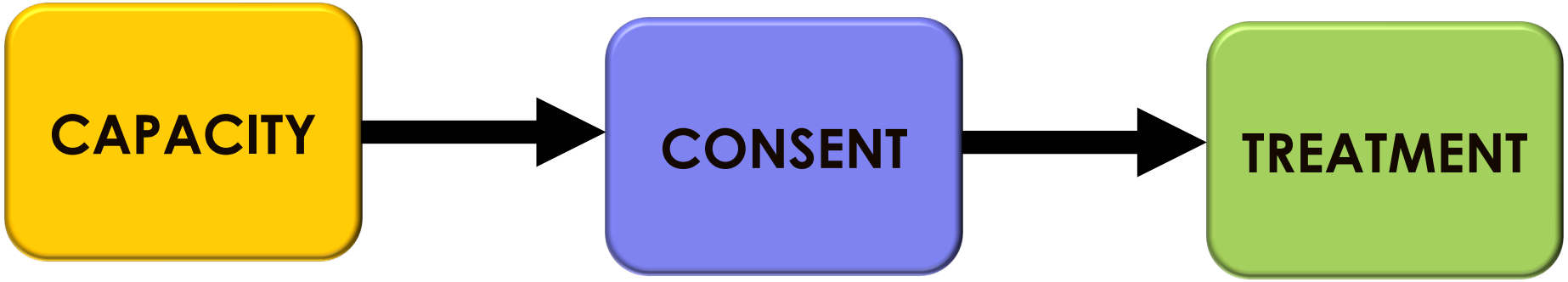


- *Do they understand & appreciate what ACP is all about?*
  - Preparing their SDM for the future NOT consenting to treatments today.
  - Can they talk about or imagine hypothetical situations?
- *Do they understand & appreciate their SDM may have to make future decisions*

Assessing capacity

- Capacity is both decision and time specific.
- A patient can have capacity for some decisions and not have capacity for others.
- Capacity can fluctuate over time.
- Capacity as it relates to ACP conversations is the patient's ability to understand and appreciate what ACP is and is not.

Assessing capacity



No treatment without consent

No consent without capacity

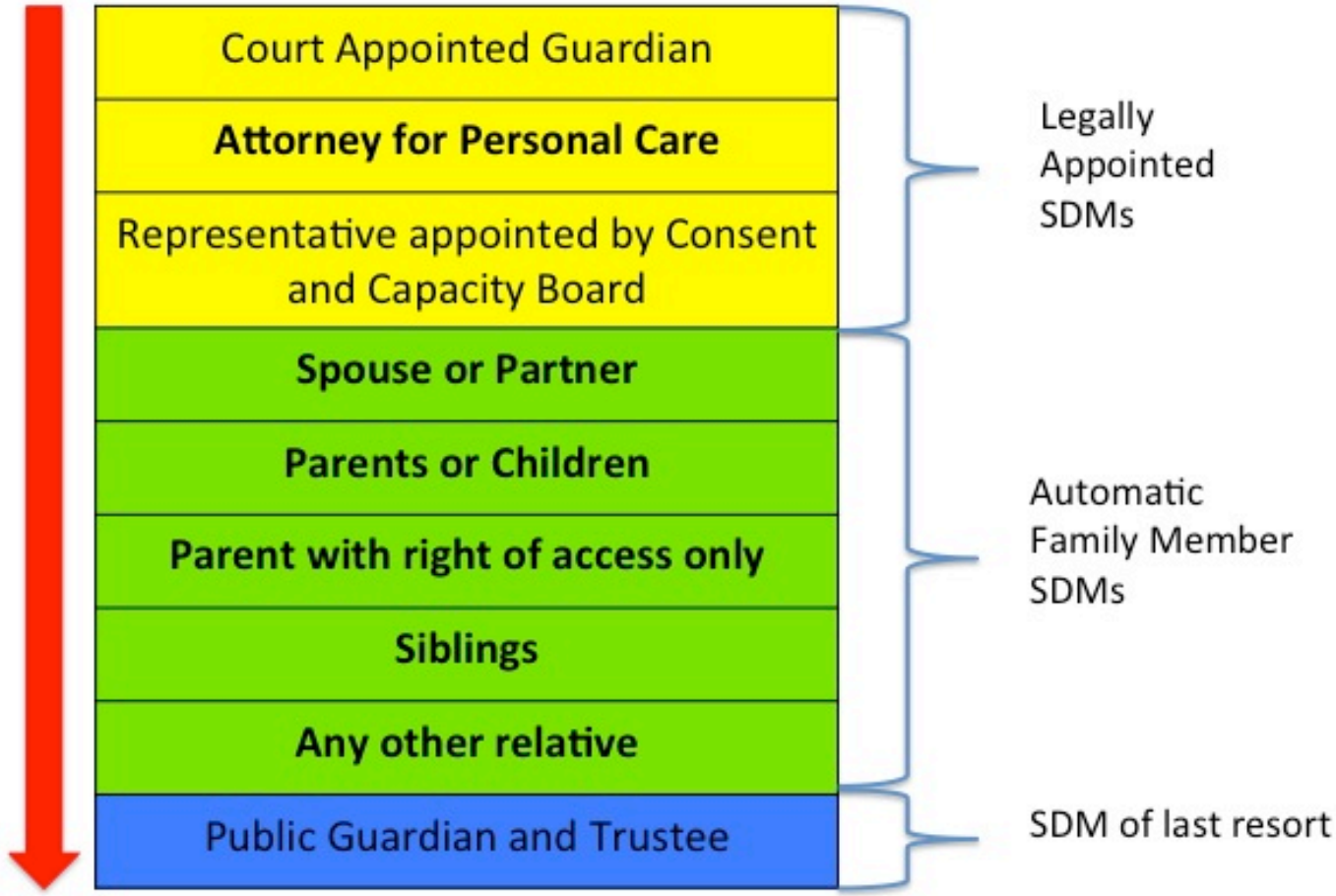
When the patient is incapable → Substitute Decision-Maker

Who is the legal SDM?

Confirm automatic SDM(s)

Or

Choose SDM(s) and **Complete** a *Power of Attorney for Personal Care* document



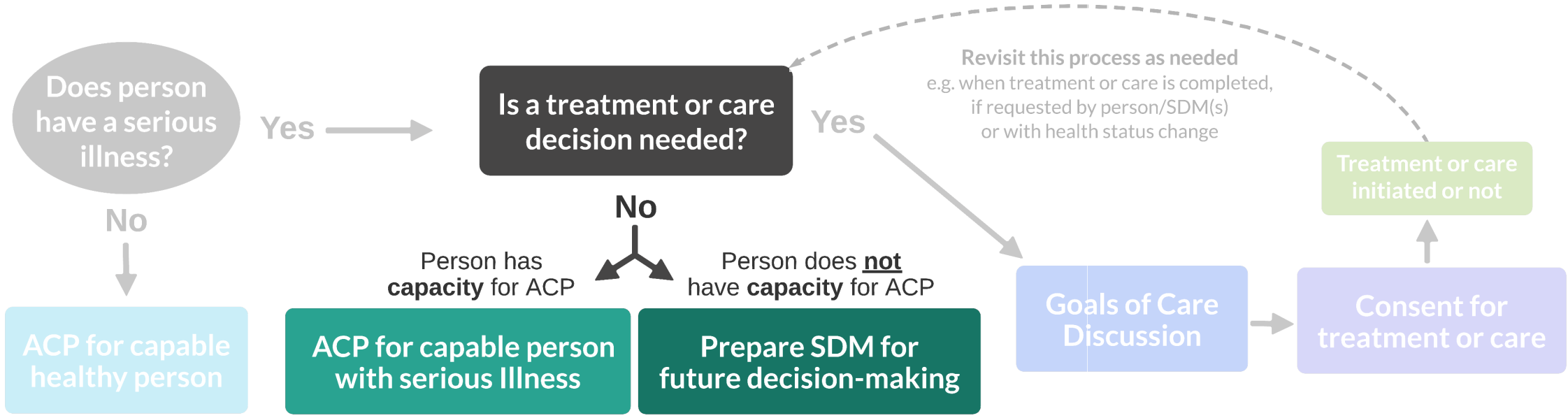
Ontario Health Care Consent Act, 1996

A word about *Advance Directives* & *Living Wills*…

- Do NOT appear in Ontario Law although patients and health records systems often use these terms
- **Terminology should NOT be used**
- If a document says it is an ***advance directive*** or a ***living will***:

- Just an expression of wishes
- Must be interpreted by the SDM alongside other oral and written expressions of wishes

Preparing and Engaging SDMs



ACP & GOC Discussions: How To

Conversation Guides

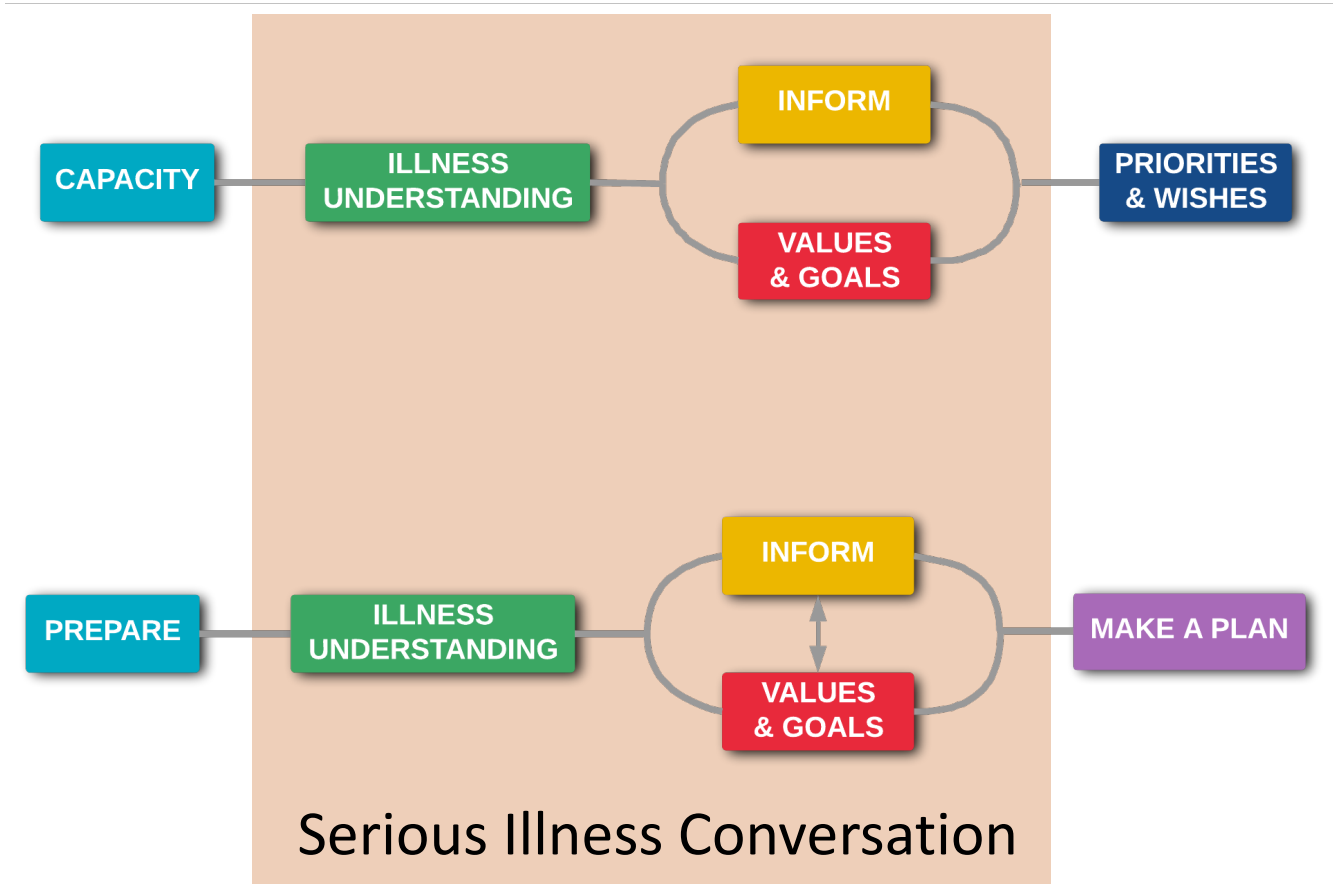
- Improve clinician comfort with the conversation
- People become familiar with the questions and language
- Ensures important Ontario legal information is considered
  - Trigger for correct SDM and Capacity

Which guide?

ACP & GOC Discussions: How To

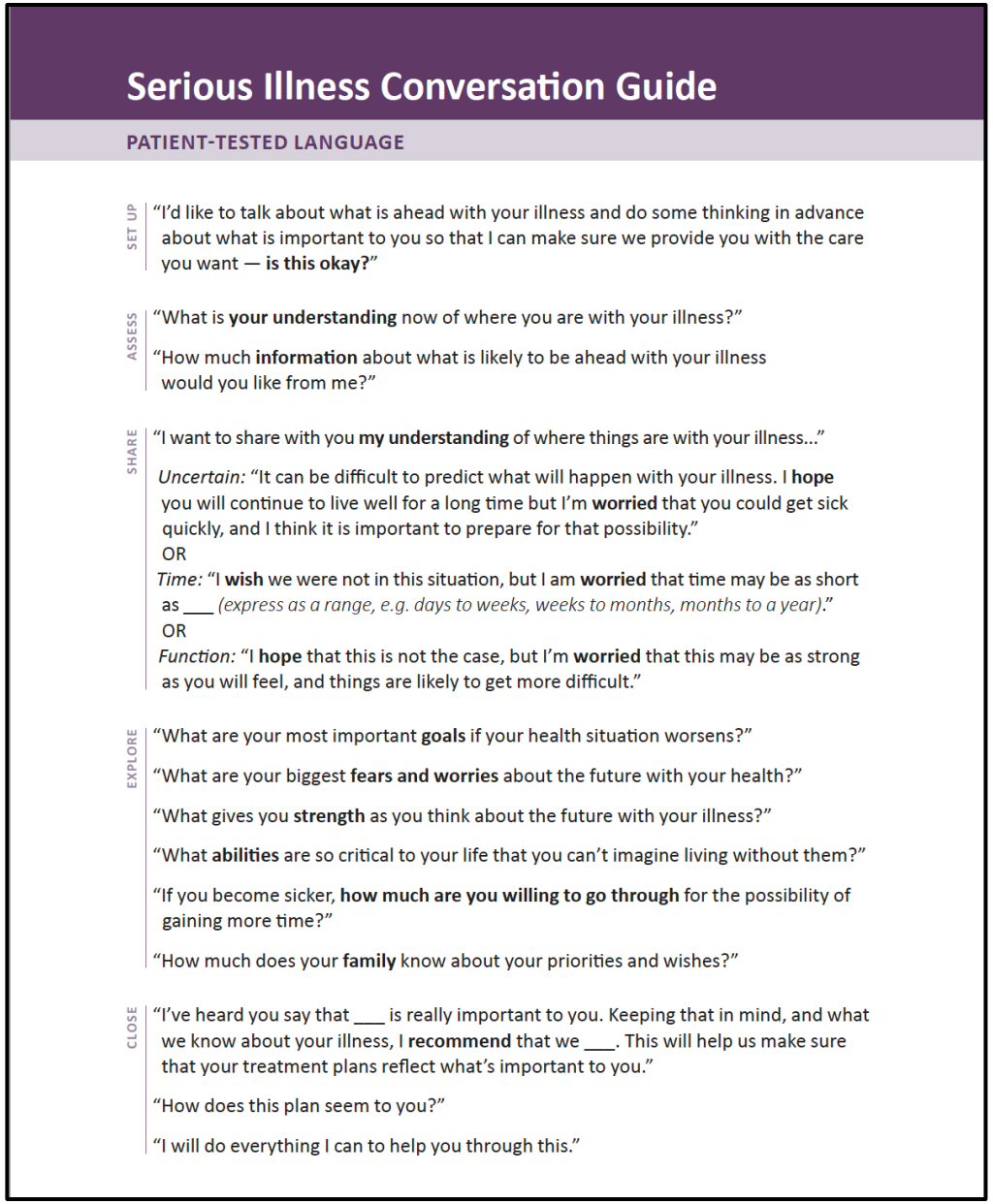
ADVANCE CARE PLANNING

GOALS OF CARE DISCUSSIONS



An approach to preparing SDMs

1. What do you understand about your loved one's health, or illness?
   What do you expect to happen over time?
2. If you are unsure what might happen over time, what information about the illness and treatments would be helpful to you?
3. What has brought quality to their life?
   What has been important and has given their life meaning?
4. Think about the care they might need with a critical illness or if they are near end of their life.
   What worries for them or fears come to mind?
5. If they became critically ill, life extending treatments might be offered. Describe the state they are likely to consider unacceptable to live in.
6. If they were near the end of their life, what would be important?



Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"

ASSESS

"What is **your understanding** now of where you are with your illness?"

"How much **information** about what is likely to be ahead with your illness would you like from me?"

SHARE

"I want to share with you **my understanding** of where things are with your illness..."

Uncertain: "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."
OR
Time: "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*."
OR
Function: "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."

EXPLORE

"What are your most important **goals** if your health situation worsens?"

"What are your biggest **fears and worries** about the future with your health?"

"What gives you **strength** as you think about the future with your illness?"

"What **abilities** are so critical to your life that you can't imagine living without them?"

"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?"

"How much does your **family** know about your priorities and wishes?"

CLOSE

"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you."

"How does this plan seem to you?"

"I will do everything I can to help you through this."

- Example of a tool to help guide person-centred decision-making
- Standardized, patient-tested & clinician-tested language
- Can be person-centred part of goals of care discussions/decision-making
- Many similar components (focusing on a person's values)
- Consider that it can be modified for use as ACP for persons with serious illnesses
- BUT…if a decision needs to be made it can also be adapted into a Goals of care conversation.

What you say

A word about illness understanding…

What the patient hears

Your CT shows your cancer has spread. This means its incurable but I hope to control it with chemo.

Even though cancer has spread, a new medication goes in my veins to get rid of all my cancer cells.

Dialysis should stabilize your kidney function. We will wait and see about a transplant.

Dialysis helps heal my kidneys until my transplant

Dementia is progressive but we will optimize your function.

Dementia will affect my memory, but I will still be myself

ACP or preparing SDMs can be interprofessional

- Because decisions are not being made, appropriate for some components of the conversation to be shared by interprofessional team members
- The most important information exchanges aren't necessarily during a formal case conference or review, but seemingly insignificant informal conversations
- Education begins with addressing misconceptions and bringing awareness to when and how helpful information might be raised

ACP or preparing SDMs can be interprofessional

	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

Discussion, Questions, Cases & Resources…

- Ideas for incorporating into current work flow?
- Unique challenges to your setting?
- Experiences to date?

Case

- 78M with dementia and severe COPD (FEV1/FVC 25%)
- Resides at LTC for 16 mos
- Dysphagia, recurrent aspiration pneumonia
- 4 admissions in 3 months despite modified diet
- Most recent discharge summary states “G tube consideration discussed with wife; concerns about operative risk/code status”
- Wife (SDM) wants “everything done”
- When nursing asked about G tube, wife responds angrily:

  “I don’t understand why people keep asking me this. I’ve already made my decision. I want everything done!”

Case

- Asked wife if there was someone else who could hear the information and help with decision making
- Discussion with daughter:
  - *“I know they’re both terrified of death. My mom is worried that refusing resuscitation will mean he’ll be given up on. He doesn’t want to suffer and can’t stand the hospital”*
  - *“I can’t make the decision between life and death for him”*

Case

- Reflect on the individualized risks and benefits of interventions before presenting options
  - Is there really a decision to be made?
  - What's medically possible? What's appropriate?
  - What's socially feasible?
- Often there is no decision to be made and there is no burden to bear.
- The conversation needs to be reframed to clarify that the patient's disease has already made the decision
- Litigation is more common when clinicians pursue aggressive treatments, not when they limit options

Roeland et al., J Pall Med 2014;17:415-420
Milani AAA. Wash Lee Law Rev 1997;54: 148-228

Resources

speakupontario.ca

jeff.myers@sinaihealthsystem.ca

rachael.halligan@grhosp.on.ca

Provincial Initiatives

The Core Team will collaborate with the patient (or the SDM) and their family/caregivers to regularly assess their needs, and to develop and document a care plan that is based on the patient's wishes, values, and beliefs, and their identified goals of care, and to obtain consent for that plan.

Implementation Resources

*Resources currently in development – Contact Nav Dhillon at ndhillon@hpco.ca for more information

Consistent Definitions (Ontario Law Compliant)

- Framework and Definitions
- Material Review Service and Tool-Kit
- On-Line Resource Guide
- Quick Reference Guide for clinicians

Improve Knowledge

- Orientation Tool-Kit
- Webinars
- E-Learning Modules
- Clinical Algorithm

Improve Skills

- Interprofessional Skills Building Workshop (clinicians & administrators) *
- Implementation Guide (clinicians & administrators)

Educate Public

- Speak Up Ontario Workbook
- Posters, Postcards, Wallet Cards, Videos
- Goals of Care Resources
- Public education: train the trainer workshop *

HPCO
Hospice Palliative Care Ontario