Health Care Consent and Advance Care Planning Long Term Care and Hospitals:

The BASICS that you NEED to know

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Disclaimer

- This presentation contains legal INFORMATION for educational purposes and not legal advice
- If you need legal advice for a particular situation, please consult your own legal advisor

- The word "resident" is used throughout as reference to the residents living in LTC homes however the same information applies to "patients" when the person is in a hospital receiving treatment

OVERVIEW and Goals for This Workshop

- **To Understand the BASICS about Health Care CONSENT and ADVANCE CARE PLANNING**
  - Who is the decision maker for health care – the resident or the residents' SDM and why? What does Capacity to make a treatment decision mean and who determines if a resident is mentally capable?
  - WHO is the SDM for a resident and why?
  - How are SDMs required to make decisions for incapable residents?

OVERVIEW and Goals for This Workshop

- What is INFORMED CONSENT to a treatment or a Plan of Care/ Plan of Treatment? When is Informed Consent NECESSARY?
- What is Advance Care Planning ? WHO can ACP? Who can't ACP and why?
- How does ACP fit together with the Requirement to get Informed Consent?

OVERVIEW and Goals for This Workshop

- **Myths and Common Misconceptions about Advance Care Planning**
- **The problems with Common forms** such as:
  - Levels of care forms (pick 1 to 4 or 5 and then what happens in practice???)
  - So-called "advance directives" (what are these, how are these used or understood or misunderstood)
  - Various "advance care planning" tools (does the tool reflect Ontario law; dangers of using certain tools)
  - What is the DNR(c) form and how is it supposed to be used?

OVERVIEW and Goals for This Workshop

- Where do we go from here??
  - What are practical "Better" Practices

- WHY should YOU CARE about understanding Health Care Consent and Advance Care Planning and doing it RIGHT???

Some ideas..

- It is Good Practice – Good to do it right – Good to do it consistently in ALL health settings to facilitate care when a resident is transferred to hospital and then returns back to LTC Home
- It's part of Residents' Rights in LTCHA and HCCA
- Its part of basic patients rights in the health system
- It is part of Resident and Patient Centred Care
- It's part of Professional Obligations
- It is part of legislation applicable to any type of regulated health facility
- If you don't do it right there is a risk of complaints and liability

Report for the Law Commission on HCC and ACP

- ACE has recently prepared a report for the Law Commission of Ontario with the law firm of Dykeman Dewhirst O'Brien LLP.
- We reviewed the operationalization of health care consent and advance care planning by health practitioners and organizations in the province of Ontario.
- Our final report can be accessed at: http://lco-cdo.org/en/capacity-guardianship-commissioned-paper-ace-ddo

What we found…

- Under Ontario law, advance care planning is part of health care consent
- Ontario law is different than the other jurisdictions we used as comparators in its emphasis on informed consent even where a resident has engaged in ACP.
- There are persistent misconceptions in Ontario about the relationship between health care consent and advance care planning.

What we found ….

- Many health care organizations were using legally incorrect forms and policies (including using documents from other jurisdictions without adaptation for Ontario law).

  This causes confusion and doesn't help Health practitioners understand the requirement to get an informed consent at the time of treatment from a capable resident or the incapable resident's SDM EVEN IF an Advance Care Plan exists in the chart

How is Ontario law different?

- In some other Canadian provinces, a written "advance directive" is equivalent to informed consent to treatment.
- In some other jurisdictions, "advance directives" are interpreted and applied directly by physicians.
- <u>THIS IS NOT THE LAW IN ONTARIO</u>:
- In Ontario, "advance directives" are equal with all other expressed capable "wishes" and are meant to be interpreted <u>by the SDM</u> in giving or refusing informed consent.

How does Health Care Consent relate to Advance Care Planning?

- Under Ontario law, advance care planning is part of the law of informed consent.
- Resident "wishes" are only relevant where a resident is incapable because otherwise you need to talk to the resident to get an informed consent to a treatment or plan of care.
- Resident "wishes" are **interpreted** by the SDM – not the health practitioner. The SDM uses the wishes to determine whether to give or refuse consent to the offered treatment.

Common Misconceptions / Common "Errors" about Consent and Advance Care Planning

1. That Long Term Care Homes must get an "Advance Directive" or a "level of care" from all residents or their SDMs to be able to know what to do at 3 o'clock in the morning if the resident has a cardiac arrest or other serious incident
2. Thinking that an "advance directive" or advance care plan may be used directly by a physician/nurse/ staff to determine what care to provide to a resident
3. Thinking that DNR / Allow a natural death / No CPR or anything about future treatment is always an "advance directive"
4. Not getting an informed consent by a regulated health professional to a DNR/ Code status. Thinking that the DNR(c) Form is an advance care plan.

Common Misconceptions / Common "Errors" about Consent and Advance Care Planning

5. Thinking that a Plan of Care / Plan of Treatment is an advance care plan
6. Getting consent from the resident's FUTURE SDM or family to a plan of care and not a consent from the Capable Resident – not including the capable resident in the Plan of Care discussion
7. Thinking that "informed consent" is necessary just for major treatments (Like surgery) rather than for ALL treatments
8. Not understanding who would be the Resident's SDM if the resident was not capable to give or refuse consent to treatment

Common Misconceptions / Common "Errors" about Consent and Advance Care Planning

Use of terminology or practice from other jurisdictions in forms and policies instead of terminology or practice in Ontario legislation

Examples

- "Advance Directive" instead of "Advance Care Plan" or "Wishes of the Patient"
- Listing "Next of Kin" or "POA" instead of "Substitute Decision Maker"
- Using Alberta Coding for levels of intervention
- Forms that provide a tick off box to note whether the patient has a "Health Directive"
- Forms that state that the patient "must appoint" an SDM for an SDM to have authority

When I say:

Health Care Consent ?

What does this mean to you?

INFORMED Consent to Health Care/ Treatment

- Health practitioners MUST get an INFORMED CONSENT BEFORE providing treatment to a resident
- CONSENT must come from the resident in the LTC Home, if capable, or from their SUBSTITUTE DECISION MAKER (SDM) if the resident is NOT mentally capable to make the specific treatment decision

Informed Consent to treatment

- Consent must be INFORMED therefore health practitioners must TALK to the right person – the mentally capable resident OR the SDM for the mentally incapable resident EVEN IF they believe the resident previously made an oral or written Advance Care Plan

  INFORMED CONSENT comes from a PERSON not a Paper or Notes on a chart.

  CONSENT is not a written form- it's a conversation. Any written consent forms are just a documentation of the actual consent from the conversation.

Informed Consent to treatment

- Health care consent is an informed and **CONTEXTUALIZED DECISION.**

- When seeking consent, ALL health practitioners have a duty to COMMUNICATE with residents (or the incapable resident's substitute decision-maker) about;
  - the resident's present condition
  - the available Treatment Options
  - Risks and benefits and Side Effects of the treatments
  - Alternatives to the treatment
  - What may happen if he or she does not agree to the treatment

Informed Consent to treatment

- Its NOT good enough for a LTC staff member (RN, RPN ,PSW) to call the SDM and just tell the that the physician ordered X or Y for the resident
- That's NOT "informed consent"

Treatment taking place in the future is NOT necessarily an advance care plan

- A resident **can give an informed consent to a treatment that takes place or is withheld in the future** if that treatment relates to the resident's PRESENT HEALTH CONDITION
- This is not Advance Care Planning, but is **Consent**
- Residents at end of life can CONSENT to No CPR and this is NOT advance care planning

Plan Of Treatment – HCCA s.2(1)

- developed by one or more Health practitioners
- deals with one or more of health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and
- provides for the administration to the person of various treatments or courses of treatment and may, in addition, provides for **withholding or withdrawal** of treatment in light of person's **current health condition.**
- **BOTTOM LINE: PLANS OF TREATMENT MUST BE GROUNDED IN THE Resident's PRESENT HEALTH CONDITION and consent can be provided for the Plan of treatment**
- **Plans of treatment may include Goals for Care**

Requirement for Informed Consent EVEN IF an Advance Care Plan

- Health Practitioner MUST get an Informed Consent or Refusal before treatment from the resident if mentally capable or from the incapable resident's SDM EVEN if the resident had an advance care plan
- EXCEPTION – IN an EMERGENCY – Health practitioners can treat without getting a consent
- IF health practitioners has information that resident when capable did not want a particular treatment then, in emergency ONLY, the health practitioner should follow that direction

WHO assesses capacity for treatment?

- Duty of HEALTH PRACTITIONER offering the treatment to determine if resident capable or not and whether its necessary to turn to the Resident's SDM for consent
- This is NOT done by a “capacity assessor” as defined in the Substitute Decisions Act

How is capacity determined?

- Mental capacity is not a medical determination
- It is not a score on the Mini Mental Test
- It is not a diagnosis
- Mental capacity for decision-making is a legal determination based on an analysis of whether a person has the ability to understand and the ability to appreciate information relevant to making a decision

How is capacity determined?

- Just because a resident was found by the CCAC to be "not capable" to consent to admission to the LTC home, that resident may be capable to make decisions about TREATMENT when living at the LTC home.
- Capacity is decision specific
- People may be capable for some decisions and not capable for others
- Capacity may fluctuate

When I say:

Advance Care Planning

What does this mean to you?

What is Advance Care Planning in Ontario?

1. **IDENTIFYING** the capable resident's future **Substitute Decision-Maker (SDM),** by either
   a) confirming that the resident is satisfied with their default/ automatic Substitute Decision-Maker in the hierarchy list that is in the *Health Care Consent Act*

   OR

   b) resident choosing someone else to act as SDM by preparing a **Power of Attorney for Personal Care** (a formal written document).

2. **WISHES, VALUES, AND BELIEFS** – discussing with the **capable resident** about his/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent.

Everyone has an AUTOMATIC SDM

- EVERYONE has an Automatic SDM for Health care decisions even if they have NEVER planned ahead
- This AUTOMATIC SDM is whoever is HIGHEST in the Hierarchy of SDMs in the Health Care Consent Act that meets the REQUIREMENTS to be the SDM
- The SDM MAY or may NOT be the resident's "Next of Kin"

Hierarchy of SDMs

1. Guardian of person
2. Attorney in POAPC
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

*** See handout for definitions**

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 PRACTITIONER OBTAINING CONSENT FROM AN SDM TO ENSURE THESE REQUIREMENTS ARE MET even if another member of the team is making the inquiries.

SDMs

• Only turn to an SDM for consent when the resident is incapable.

• List is hierarchical (i.e. start at the top and work your way down).

• All persons on same rung rank equally (i.e. all brothers and sisters are equally SDMs). IF multiple SDMs on same rank THEY must decide amongst themselves if they all must participate or that one or more of them are the actual SDMs

• Every person ALWAYS has an SDM if they are incapable.

• **The Ontario Public Guardian and Trustee is the SDM if no one on the hierarchy is available or if there is a conflict between equally ranked SDMs**.

How does the SDM make decisions?

- In making decisions on behalf of an incapable resident, SDMs must:
  - Follow any applicable wishes that were expressed by the resident when capable; or
  - If no applicable wishes were expressed when the resident was capable, make decisions in the resident's best interest (including considering the resident's values, beliefs and any other wishes expressed by the resident)

Best Interests Definition HCCA s.21(2)

SDM to consider:

a) values and beliefs
b) other wishes (i.e. expressed while incapable)
c) whether treatment likely to:
   i) improve condition
   ii) prevent condition from deteriorating
   iii) reduce the extent or rate of deterioration
d) whether condition likely to improve or remain the same or deteriorate without the treatment
e) if benefit outweighs risks
f) whether less restrictive or less intrusive treatment as beneficial as treatment proposed

Obligation to EXPLAIN to SDM

- It is the legal obligation of the Health practitioner to explain to the SDM the criteria for making decisions on behalf of the incapable resident
- Criteria of
  - Following the wishes of the resident expressed when capable and
  - acting in the Best Interests of the resident when no applicable wishes are known

M. (A.) v. Benes, 1999 CanLII 3807 (ON CA)

Wishes

- **Wishes do NOT need to be expressed in writing.**
- **Wishes may be expressed in any form at any time when the resident is mentally capable (Oral, written, communicated by other means)**
- Later wishes, however communicated, expressed while capable prevail over earlier wishes.
- **A recent capable oral wish will trump an older capable written wish.**
- **This is NOT the same in other Canadian Provinces**

ACP "Wishes"

- Advance Care Plans do not need to be about specific treatments that a person would want to not want
- It is very difficult to anticipate what treatments one would want for oneself as people don't know how their health condition will progress or what the effect of particular treatments would be
- ACP Wishes and explanations of a person's values and beliefs **may help the SDM when acting**, make better decisions for the resident as these wishes help the SDM understand who the resident is, how they make choices for themselves, what they think is important to themselves what influences their decision making

Role of the SDM

- **SDM is the "interpreter" of the resident's wishes, values and beliefs and must determine:**
  - whether the wishes of the resident were expressed when the resident was still capable (and were expressed voluntarily);
  - whether the wishes are the last known capable wishes;
  - what the resident meant in that wish;
  - whether the wishes are applicable to the particular decision at hand;

    and,
  - If there are no applicable/capable wishes, how the resident's values, beliefs, and incapable/inapplicable wishes would apply to the resident's best interest.

Rules for Advance Care Planning

- Only capable residents can ACP **(SDMs CANNOT advance care plan).**
- Capable residents can express "wishes," which may or may not be "informed."
- **When a resident has an advance care plan about a potential future health condition:**
  - **Consent has NOT been acquired.**
  - **Consent MUST still be acquired from the resident or the SDM (if the resident is incapable), except in emergencies.**

Who does Advance Care Planning?

- Only the resident when capable can prepare a POA Personal Care
- Only the resident may express his or her own wishes about future care and treatment
- **SDMs cannot Advance Care Plan but do consent or refuse consent to treatment on behalf of a resident incapable for treatment (example- SDM may consent to No CPR if resident is at end of life/ has health conditions where this would be considered as part of the treatment plan)**

What health practitioners need to do ….CONVERSATIONS to get an INFORMED CONSENT

- Need to talk to residents or appropriate SDMs to get INFORMED consent to a treatment or PLAN of treatment
- THESE CONVERSATIONS are fundamental before providing treatment both in law and ethics

Conversations about ACP

- Need to talk to resident about who would be their SDM if resident not mentally capable to make own health decisions
- Explain to resident that he or she should talk to their future SDM about their health needs and what they would want to not want for health cater the future OR about what quality of life means to them OR what's important in their life that would help their SDM make health decisions for them

WHO should have the ACP conversation with a resident?

- No ONE answer – IT DEPENDS what is being discussed
- WHOEVER does it must understand what ACP is and is not and make sure that the resident understands that an advance care plan is NOT a consent and understand how ACP fits together with health care consent
- Advance care planning is NOT just completion of a form
- Some parts of ACP should be integrated into systems – i.e.. STOP asking residents who is their next of kin and instead include the hierarchy of SDMs in forms so that the name and contact information of who would be the resident's future SDM is recorded and available

How to have the Conversation …Which Conversation???

- To get an INFORMED CONSENT to treatment / Plan of Care? …
- To help a resident advance care plan as to WHO they want to be their future SDM?….
- To help a resident express Wishes, Values, believes to help their future SDM make better decisions?....

- Records of Consents and Advance Care Plans

What about "Advance Directives" and "Living Wills"?

- **The terms "advance directive" and "living will" do NOT appear in Ontario Law.**
- The *Health Care Consent Act* only refers to the word "wishes". If a document says it is an 'advance directive" or a "living will", under Ontario law it is just an expression of wishes, to be interpreted by the SDM alongside other oral and written expressions of wishes..
- There is no specific format for creating an "advance directive" and "living will".
- BUT NOTE – Only a formal written Power of Attorney for Personal Care gives authority to name an SDM

Advance Care Plans as part of the Resident's Chart/ file

- Should "advance directives" or "living wills" or other advance care plan forms that the resident brings in be part of the Chart?
- Should the LTC Home have a special Advance Care Plan form as part of the Chart?
- WHY or Why Not?
- Would staff know How or how not these documents should be used when providing care to residents?

Goals of Care

- Are "Goals of Care" advance care planning or part of a Plan of Care / Plan of Treatment that requires an informed consent by the capable resident or the incapable resident's SDM?

How should these be recorded and why?

DNR Confirmation Form used for Transport by EMS services

- The DNR Confirmation Form is NOT an Advance Care Plan but is a Confirmation of a Consent to DNR/ Confirmation of Refusal of Consent to resuscitation treatment
- It is a confirmation of the CONSENT to no resuscitation that resulted from the discussion between the health practitioner and the resident, if capable, or the resident's SDM, if the resident is not capable. In certain circumstances the physician can also decide that CPR will not be proposed, and inform the resident (or SDM) of this choice.

DNR Confirmation form

- The question is whether the physician or nurse at the LTC Home is having the conversation about Resuscitation in enough detail to get an informed consent BEFORE this form is then signed and transferred to EMS or included with any records that may go with the resident to the hospital

Level of Care Form – Can YOU identify the Problems with this form??

ADVANCE DIRECTIVES

- **Level One – Supportive/Comfort Care**

  This includes, but is not limited to, the provision of measures available within the resources of the facility such as: ….

  Diagnostic interventions and transfer to hospital will not normally be utilized for residents who request this level of Advance Directives. No cardiopulmonary resuscitation is requested.

- **Level Two – Limited Therapeutic Care**

  Care measures will include all procedures utilized in Supportive/Comfort Care as well as the administration of antibiotics if indicated. Transfer to hospital may be arranged to provide comfort/treatment measures beyond the capability of the facility upon the direction of and at the discretion of the physician. No cardiopulmonary resuscitation is requested.

- **Level Three – Transfer to Acute Care Hospital**

  If symptoms indicate, the resident would be transferred to an acute care hospital for treatment. Assessment would be made in the acute care hospital emergency department and a decision made whether to admit the resident or return him/her to the … facility. No cardiopulmonary resuscitation is requested and no admission to an acute care intensive care unit.

- **Level Four – Transfer to Acute Care with CPR**

  Transfer to an acute care hospital will be arranged immediately. Cardiopulmonary resuscitation (CPR) will be provided by qualified staff, if available, and by ambulance personnel.

Substitute Decision Maker:_____
Print Name

_____ _____
Resident/Substitute Decision Maker Date

_____ _____
Physician Signature Date

What's the problem with THIS form?

- While this form contains the heading "Advance Directives" it is not clear how this form fits into the legal framework for advance care planning.
- The form is an example of "tick-box" advance care planning, and does not have a space to record the resident's health condition at the time these wishes were expressed.
- The signature line suggests that this form can be completed by an SDM for an incapable resident. However, from a legal standpoint, an SDM can only give informed consent to a plan of treatment. It is also unclear why the physician is signing the form.
- Given the language of 'advance directives' and the absence of standard consent to treatment language (such as an acknowledgement by the resident or SDM of being advised of the risks and benefits of specific treatments) it is doubtful that this form was intended to record a legally valid informed consent to a plan of treatment. The list of interventions suggests that this form was intended to apply beyond emergencies.

- **Why are forms like this used?**
- **Are they of any value?**
- **These forms are NEITHER records of consent nor are these appropriate record of a patient's "wishes" so WHY are they completed?**

Advance Care Planning Tools
Can YOU identify the Problems with this form??

- **Advance Care Plan Review and/or Discussion**[i]
  Purpose of Review:
  - Care Planning *(routine update)*
  - Change in Condition
  - Other*(specify)*_____
  If discussion was held, with whom *(check all that apply)*:
  _____Resident
  _____Resident's surrogate; Name:_____ _____No discussion held
  Was a change in advance care plan or advance directive made? £ No £ Yes
  *(describe)*_____
  _____

  Staff or healthcare provider leading discussion:
  Name_____Title_____
  Signature_____ Date of discussion _____ /_____ /_____

[i] "*©2011 Florida Atlantic University, all rights reserved. This document is available for clinical use, but may not be resold or incorporated in software without permission of Florida Atlantic University*"

What's the Problem with THIS form ?

- This form could inadvertently misdirect health practitioners into making or implementing advance care plans.
- For example, the template Advance Care Planning Tracking Form specifically suggests that an SDM (or "surrogate") can advance care plan (without drawing a distinction between wishes expressed by the resident, ineligible new wishes expressed by the SDM, and consent) and does not contain a place to record if the resident is capable or incapable with respect to treatment.
- This form could be improved by clarifying the difference between the expression of wishes by the resident, and consent by the resident or SDM to treatment.

Transfers between LTC homes and Hospitals

- Forms used in LTC Homes – Have you considered how these will be used in any health facility that the resident is transferred?
- Would the next health facility or next health practitioner have the SAME understanding of the form / record as staff at YOUR facility?
- Why or why not???

How does Health Care Consent relate to Advance Care Planning?

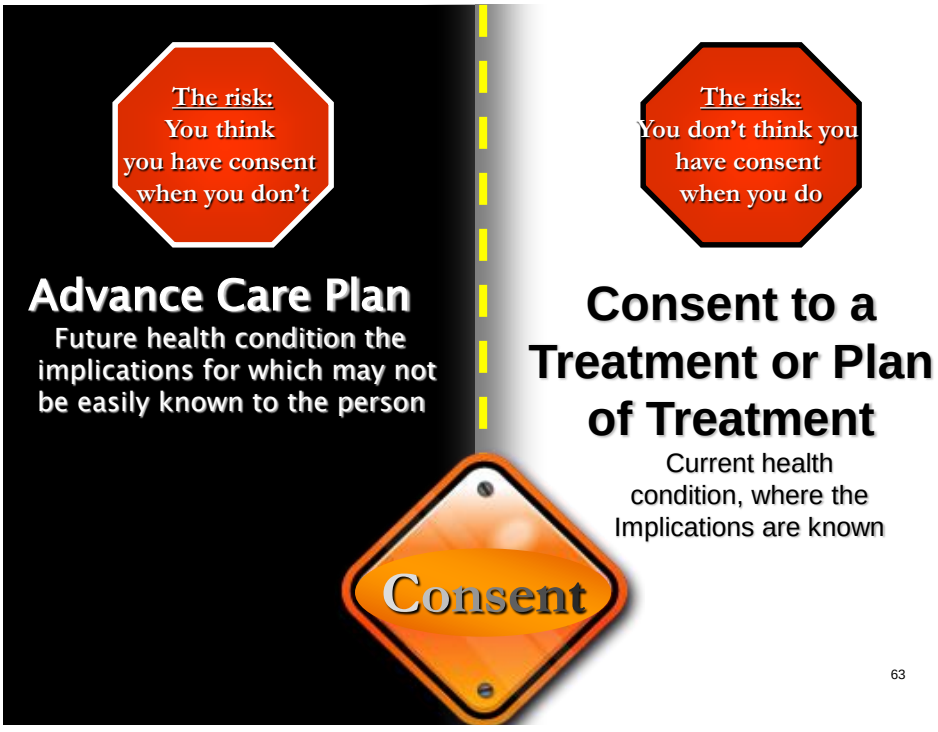
- Under Ontario law, advance care planning is part of the law of informed consent.
- Resident "wishes" are **interpreted** by the SDM – not the health practitioner.
- Advance Care Planning discussions about wishes, values, and beliefs should help the SDM make better decisions for the resident when the resident may be incapable

Can't get out of informed consent....

- The right to informed consent is a requirement that cannot be waived by the resident.
- Even where the resident has completed an "advance directive", the resident or their SDM must still give or refuse informed consent (except in an emergency).

Biggest Problem in Ontario

- Everyone talks about the wishes part of advance care planning, but few talk about consent or about who would be the resident's SDM if the resident becomes incapable!
- Residents are often immediately asked to express future care wishes but residents are rarely told how their statements will be used and WHO will speak for them or HOW the resident can CHOOSE someone to be their SDM.



Where do you go From Here?? Perhaps…….

- Review and Change Forms and documentation
- Get "Regulated Documents" reviewed by LTC facility lawyer
- Training to change practice
- Info sessions for Residents and Resident's present and future SDMs and Families

BEST PRACTICE #1

- Use the language in Ontario's laws.
- Forms, policies and practices at your health care organization should refer to **wishes, values** and **beliefs**.
- Stop using "advance directive" and "living will" – these terms are transplanted from other jurisdictions and cause confusion in Ontario.

BEST PRACTICE #2

- Instead of only asking the resident to express wishes about future treatments in general terms, obtain an informed consent to a plan of treatment (provided the treatments relate to the resident's present health condition).
- Put discussions in context and discuss the risks and benefits of treatment!

BEST PRACTICE #3

- Think about health care consent and advance care planning as part of the same three part process:

1. IDENTIFYING THE CAPABLE RESIDENT'S SDM;

2. DISCUSSING THE CAPABLE RESIDENT'S WISHES VALUES AND BELIEFS; and,

3. OBTAINING INFORMED CONSENT FROM THE RESIDENT (OR THE SDM IF THE RESIDENT IS INCAPABLE).

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