

Information session for Health Care Providers

Facilitator Notes

Created by the Health Care Consent and Advance Care Planning Community of Practice
April 2013

Sponsored by the Alzheimer's Knowledge Exchange

In the pages that follow you will find:

☑ A Facilitator preparation sheet

Facilitation Notes to accompany the PowerPoint Presentation:

Health Care Consent in relation to Advance Care Planning

Presentation Reminders:

- ❖ This presentation material has been designed for maximum readability when presenting in an adequately lit space to ensure participants can easily view the content. (i.e. dark background with light lettering)
- ❖ Provide your contact information to the group you are speaking to as the PowerPoint presentation is protected and you will be <u>unable</u> to add it to the slide deck.
- ❖ Adult learning theory strongly recommends you embed opportunities to interact with the material presented.
- Throughout the presentation participants may raise specific medical and legal questions that may be outside your expertise and experience – please refer them to the appropriate resources.
- ❖ If you have access to an internet connection during your presentation, we recommend you link to the Speak Up website at www.advancecareplanning.ca in order to illustrate for participants where certain materials and resources might be obtained.

Symbols used in the facilitation notes:



Please utilize the questions and activities included within the notes as time affords.



Important to Note

Health Care Consent in relation to Advance Care Planning Information session for Health Care Providers

Facilitator Preparation

To ensure a successful learning event it is essential that you prepare appropriately. We strongly encourage you to access, review and become familiar with the resources and information we have listed below.

Providing handout materials for providers and patients that reflect Ontario specific laws and guidelines would be beneficial for your audience. We recommend you have resources preordered and available for distribution at the event.

If you are affiliated with a particular professional body such as the College of Nurses, the College of Physicians and Surgeons or the Ontario College of Social Work, we encourage you to familiarize yourself with your College specific materials related to health care consent. These resources should be available on your individual professional College website. Links to these can be found within the resource section at the end of the slide presentation.

In order to gain knowledge and understanding of the laws that guide Healthcare Providers related to consent. We recommend you review all resources and websites listed below:

Legislation and Ontario Specific guides:

Link to the Health Care Consent Act: http://www.e-

laws.gov.on.ca/html/statutes/english/elaws statutes 96ho2 e.htm

Link to the Substitute Decision Act: http://www.e-

laws.gov.on.ca/html/statutes/english/elaws statutes 92s30 e.htm

Link to the Consent and Capacity Board: http://www.ccboard.on.ca/scripts/english/index.asp
Link to the Advance Care Planning Workbook the Ontario Edition available for download at: http://www.advancecareplanning.ca/media/73430/acp_ontario_workbook_final-print.pdf
Link to the Ontario Seniors' Secretariat: A Guide to Advance Care Planning: http://www.seniors.gov.on.ca/en/advancedcare/index.php

Key Website resources:

The Advocacy Centre for the Elderly (ACE): http://www.acelaw.ca/
Speak Up: Start the Conversation about end-of-life care —link to Health Care Professional page: http://www.advancecareplanning.ca/health-care-professionals.aspx

Informative articles and pamphlets:



25 Common Misconceptions about the Substitute Decisions Act and Health Care Consent Act available for download at:

http://www.acelaw.ca/appimages/file/25%20Common%20Misconceptions.pdf

Advance Care Planning and End of Life Decision-Making: More than just **Documents** available for download at:

http://www.acelaw.ca/appimages/file/Advance%20Care%20Planning%20&%20End%2 oof%20Life%20Decision%20Making.pdf

Informed Consent to Treatment – A quick guide for healthcare consumer & healthcare providers available for download at:

http://www.stmichaelshospital.com/pdf/ethics/informed consent.pdf

Health Care Consent in relation to Advance Care Planning Information session for Health Care Providers

Slide 1: Health Care Consent in relation to Advance Care Planning: Information session for Health Care Providers AND

Slide 2: Health Care Consent in relation to Advance Care Planning

Note: The content for slides 1 &2 are covered fully in the Facilitators Preparation sheet (pg. 2)

Slide 3: Presentation Goals

Briefly review the goals for the session. We <u>strongly recommend</u> that you paraphrase the information as you share as it is not intended to be read verbatim.

Throughout the presentation participants may raise specific medical and legal questions that may be outside your level of expertise and experience – please refer them to the appropriate resources.

Slide 4: Why talk about Health Care Consent?

Our various regulatory bodies have guidelines and directives based on those laws. i.e. the College of Nurses, the College of Physicians and Surgeons etc.

Client directed care is a norm of practice. Individuals have a right to the information necessary to make an informed decision related to their health care and treatment. In today's environment, personal autonomy is paramount and there is no tolerance for health care providers to unilaterally determine which treatment or care a person will receive.

Education related to healthcare consent has been and continues to be lacking. An understanding of what health care consent **is and is not**, is sorely misunderstood.

The bottom line for all of us is that the law is quite clear with respect to requiring health care consent for all treatments.

We know that Canadians are living longer - we know that 100% of us will die.

The majority of us will have one or more chronic illnesses for years before our decline into death. We have time to learn about and plan for challenges and crises we may face.



Additional statistics you may wish to share if time allows:

- In 2009, Canada had 4.7 million persons aged 65 years or over, twice the number recorded in 1981.
- By 2031, 6.5% of the total population will be older than 80 years.
- Only 9% of Canadians had ever spoken to a healthcare provider about their wishes for care
- Over 80% do not have a written plan
- Only 46% have appointed a specific Substitute Decision Maker

Source: Ipsos Reid Poll, 2012 retrieved on December 17, 2012 from:

www.advancecareplanning.ca/news-room/national-ipsos-reid-poll-indicates-majority-of-canadians-haven't-talked-about-their-wishes-for-care.aspx

Slide 5: Case #1

Read the scenarios to set the stage.

This is a reflective question and **not meant** to be taken up with the group.

Pause for a few seconds after you read each scenario out loud to allow the participants time to consider the scenario.

Slide 6: Case #2

Read the scenarios to set the stage.

This is a reflective question and **not meant** to be taken up with the group.

Pause for a few seconds after you read each scenario out loud to allow the participants time to consider the scenario.

Slide 7: Case #3

Read the scenarios to set the stage.

This is a reflective question and **not meant** to be taken up with the group at this time.

Pause for a few seconds after you read each scenario out loud to allow the participants time to consider the scenario.

Slide 8: Health Care Consent (HCC)

Case law is the basis of the Health Care Consent Act (HCCA) and its related legislation. To a great extent, the HCCA focuses on the communication required in the informed decision making process. The resulting HCCA was derived from cases that came before the courts that dealt with conflicts and challenges in health care.

The very premise of consent is about individual autonomy and respectfully sharing information and communicating with a capable person. We will be defining many of these terms as we proceed (capable, informed etc.)

Consent is only valid if you follow the rules.

Information source: Marcela G. del Carmen & Steven Joffeb (2005). Informed Consent for Medical Treatment and Research: A Review. *The Oncologist*;10, 636–641 www.TheOncologist.com

Slide 9: When must you obtain consent?

Review slide details

Basically you must obtain consent for all situations related to care and treatment

Slide 10: Consent

Consent means a capable person or the SDM(s) is agreeing with the proposed treatment or plan of care.

Consent can be to go ahead with the treatment, to withhold the treatment or to withdraw a treatment.

Slide 11: Except...

Today's focus is not on how to handle an emergency situation but rather on Health Care Consent.

Slide 12: Elements of Consent

Bullet expansion points:

Bullet 1 - Consent must relate to the treatment and consent for one particular treatment does not necessarily imply consent for any other treatment.

Bullet 2 - Consent must be informed (we will describe the elements of "informed" consent as we move forward in the presentation).

Bullet 3 - Consent must be given voluntarily – no coercion or pressure into making a particular decision –Example: daughter trying to influence mother's decisions around CPR because she cannot bear the thought of her mother dying.

Bullet 4 - Consent must not be obtained by giving inaccurate or biased information –Example: Understating, overstating, or omitting the burdens and risks of a particular treatment to steer someone in a particular direction.

These are the elements of consent required for consent to treatment to be valid.

Slide 13: What information needs to be provided

The term **material** refers to significant, relevant, important, pertinent risks or side effects.

For each treatment or plan of treatment proposed as defined in the HCCA - this is the level of information that must be shared with the person or the SDM(s) if the person is not capable in order for the consent to be valid.

Conversations on consent for treatment or a plan of treatment may include discussions on whether the proposed treatment is likely to:

- Improve the person's condition or well-being
- Prevent the person's condition or well-being from deteriorating
- Whether the person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment

Slide 14: The Health Care Practitioner:

Bullet expansion points:

Bullet 1 - Situations differ from person to person but the information must be presented in a way that it is understood i.e. not using jargon, using the services of an interpreter when necessary, ensuring an environment conducive to the discussion. Remember whether speaking to the person or their SDM(s) you must provide them with the same information.

Bullet 2 - What information would a reasonable person require in order to make an informed decision in this circumstance? Example: In order to make an informed decision, a reasonable person would require an understanding of his or her condition and its expected trajectory, the treatment being proposed, its benefits, burdens, risks, side effects, alternative courses of action and the consequences of having or withholding the treatment.

Bullet 3 - The person is entitled to receive a response to any request for additional information related to the proposed treatment or plan of treatment.

Slide 15: Consent must relate to a current illness

Health Care Providers may get mixed up when they think of a plan of treatment that addresses something that will come to play in the future so they may want to call it an advance care plan rather than a plan of treatment. If we stick to **informed consent based on a current condition** <u>is</u> a plan of treatment and wishes expressed in the context of a 'what if' scenario or a known condition <u>is</u> advance care planning.

Example: A person has ALS and is provided with all the information necessary to make an informed decision about ventilation. The person is still able to breathe but it is inevitable that the person will require ventilation sometime in the future due to their current health care condition: ALS. This person can consent to a plan of treatment that either:

- provides ventilation
- withholds ventilation
- withdraws ventilation following a trial period

Slide 16: Can a person say 'no' to a treatment?

Just because a person does not agree with the Health Care Provider's assessment of a situation and declines a treatment being offered does not mean that the person is incapable.

Ensuring that the person understands and appreciates the information should be done each and every time a person needs to make a healthcare decision and not just when the person doesn't want the treatment. We must ensure that the information is understood and appreciated without coercion and badgering by healthcare providers.

If there is no time to engage in the activity as outlined below please share the points outlined in the expected responses.

We will talk more in this next section about understanding and appreciating as they are basic tenets of capacity.

Optional Activity – Large group activity



Ask: How can a repeated emphasis on the information given be interpreted as coercion?

Anticipated responses:

- repetition may be interpreted as pressure
- repetition may convey a blatant disrespect for the person's choice, values, beliefs
- the person may feel as if they don't really know what they want
- the person may feel there is only one right answer
- we can convey a sense that science alone holds the answer

Slide 17: Capacity

Capacity is not dependent on:

- 1) A test result e.g. a mini mental
- 2) A diagnosis e.g. Dementia

Although such tests and diagnoses can alert the Health Care Provider to consider that the person <u>may not</u> be capable of providing informed consent, in and of themselves they do not necessarily indicate incapacity.

Capacity is based on the context and the complexity of the situation being assessed. Capacity is not defined by age. The same concepts apply to children and adults about understanding and appreciating.

Slide 18: Capacity

It is the responsibility of the person offering the treatment or plan of treatment to determine capacity.

A person must be capable of providing informed consent. Unless you have reasonable grounds to believe that a person is incapable, there is a presumption of capacity.

The HCC Act 1996 says that a person is capable with respect to a treatment if the person is: able to understand the information that is relevant to making a decision about the treatment, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

Capacity can fluctuate due to their underlying condition or a treatment. Some people may be lucid and aware in the morning but in late afternoon and evening understanding may be compromised. Some decisions are more complex than others and it may depend on the seriousness or complexity of the decision at hand. One cannot assume lack of capacity based on a diagnosis alone (i.e. person who is developmentally delayed, a person who has a psychiatric disorder or even a person with a dementia related disorder (will depend on stage). Capacity is related to the specific treatment proposed; a person can be incapable with respect to a treatment at one time and capable at another time. A capable person has the right to change his or her mind at any time.



Optional Activity: If time does not allow to do this as an activity then please share this information within your presentation.



Ask: How do you determine understanding and appreciation?

Anticipated answers:

- by having repeat back what they just heard
- by the quality of their responses to the information (i.e. appropriate, demonstrates they understand, it matches the context of the information being shared etc.)

Slide 19: Consent and Capacity

Every person in Ontario has a SDM(s). It is up to the Health Care Provider offering the treatment to determine who the lawful SDM(s) is for the incapable person.

Slide 20: Substitute Decision Maker(s) [SDM(s)]

If a person is deemed incapable of making a treatment or care decision the responsibility for consent is given to the SDM(s).

Slide 21: Who is the SDM for the incapable person?

A person appointed through a document called a **Power Of Attorney for Personal Care** has a higher ranking than a spouse, partner or children.

On the next slide we will review the hierarchical or ranked list that determines who is the SDM(s).

Slide 22: Hierarchy (a ranked list) of Substitute Decision Makers

Review list with participants

These notes are not meant to be read verbatim but it is a resource for you as the facilitator to be able to explain in detail.

Notes for points 4 to 9 are in the notes of the following slide, you will need to move forward to the next slide to be able to access the full terms included.

The hierarchy is embedded in the Health Care Consent Act and is ranked. Health care providers must utilize this when a person is incapable of giving consent. The list is ranked, meaning that the health care provider is required to identify the highest ranked person.

- 1. **Guardian of the person**: This is someone that is appointed by the court to be your Substitute Decision Maker.
- 2. Attorney named in a Power of Attorney for Personal Care: This is the person or persons YOU have chosen to be your Substitute Decision Maker if you prepared this document when you were mentally capable to do so.

3. **Representative appointed by the Ontario Consent and Capacity Board**: One of your family or friends could apply to the tribunal, known as the Consent and Capacity Board, to be named as your "Representative," which is a type of Substitute Decision Maker. However, if you prepared a valid Power of Attorney for Personal Care, the Consent and Capacity Board will not appoint anyone even if they apply because the Substitute Decision Maker YOU chose in the Power of Attorney for Personal Care will rank higher in the hierarchy list.

Slide 23: Substitute Decision Maker (continued from slide 22)

- 4. **Spouse or partner.** Two persons are "spouses" if they are:
 - a) Married to each other; or
 - b) Living in a marriage-like relationship and,
 - i) have lived together for at least one year, or
 - ii) are the parents of a child together, or
- iii) have together signed a Cohabitation Agreement under the Family Law Act. A Cohabitation Agreement is a document that two people who live together, but are not married, can sign in which they agree about their rights and obligations to each other during the time they live together and on separation. The types of things they can include in the agreement are rights to financial support from each other, ownership and division of property, and the education of their children.

Two persons are not spouses if they are living separate and apart as a result of a breakdown of their relationship.

Two people are "partners" if they have lived together for at least one year and have a close personal relationship that is of primary importance in both people's lives. This can include friends who have lived together for at least one year in a non-sexual relationship and have a special personal family-like relationship.

- 5. **Child or parent or Children's Aid Society** or other person lawfully entitled to give or refuse consent to treatment in place of the incapable person: This does not include a parent who only has a right of access. If a Children's Aid Society or other person is entitled to give or refuse consent in place of the parent, this then would not include the parent. *Note that your children have equal ranking as SDMs*.
- 6. A parent who only has a right of access.
- 7. **Brother or sister** (see c. in the Ontario Speak up workbook if you require more explanation if you have more than one brother or sister).
- 8. **Any other relative** (see c. in the Ontario Speak up workbook if you require more explanation if you have more than one relative) People are relatives if they are related by blood, marriage or adoption.
- 9. If no person in your life meets the requirement to be a Substitute Decision Maker, then the Public Guardian and Trustee, a public government organization, is your Substitute Decision Maker.

Slide 24: SDM(s) Criteria

Bullet Expansion points:

- Bullet 1 Same criteria we covered in terms of capacity
- Bullet 2 At least 16 of age unless you are the parent of the incapable person
- Bullet 3 No court order or separation agreement prohibiting you from being the SDM
- Bullet 4 Available within a time that is reasonable and is willing to assume the responsibility of giving and refusing consent

The SDM(s) must receive all the information that the person deemed incapable is entitled to receive before making any decisions. The SDM(s) must provide consent to give, without or withdraw treatment on behalf of the person who is incapable.

Slide 25: Role of the SDM(s)

The SDM(s) must try to make the same personal care choices that **the person if capable** would make in that situation.

Bullet expansion points:

Bullet 1 - A **prior expressed wish** is an instruction or direction that the person gave about the treatment while capable. (written, verbal, POAPC, "living will" etc.) Recently expressed wishes trump any wishes that came earlier. Occasionally, wishes cannot be honored e.g. I never want to go to a nursing home but now the incapable person requires 24/7 care so the wish cannot be honored.

Bullet 2 - If there are no expressed wishes, then the SDM(s) must consider the person's values and beliefs. An important question to ask is "What would the person want if he or she could decide for him or herself?"

Bullet 3 - In determining **best interests**, the SDM(s) must consider:

- any current wishes the incapable person may have
- the values and beliefs the incapable person held while capable
- whether the treatment is likely to:
 - improve the incapable person's condition or well-being
 - prevent the incapable person's condition or well-being from deteriorating
 - reduce the extent to which, or the rate at which, the incapable person's condition or wellbeing is likely to deteriorate
 - the expected benefits of one treatment versus another treatment.

SDMs may have to be reminded of, or educated about, their legal obligation to make decisions based on the person's values and beliefs and <u>not</u> the SDMs values and beliefs.

If concerns arises that the SDMs are not making decisions based on the person's previously expressed wishes or the decision is not in the person's best interest, the Health Care Provider may apply to the Consent and Capacity Board.

If there is disagreement (between SDM(s) and team or SDM's of equal ranking) and after robust attempts to resolve the situation, a healthcare provider has two choices:

- involve the Public Guardian and Trustee to make the decision or
- involve the Consent and Capacity Board to appoint one person to make the decision

Slide 26: Role of the Health Care Provider (HCP)

Review slide details

If the person's goal may not be attainable, consider these aspects:

Whether the proposed treatment is likely to:

- Improve the person's condition or well-being
- Prevent the person's condition or well-being from deteriorating
- Whether the person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment

Slide 27: How does this relate to Advance Care Planning?

It is beneficial for a person to begin a process of Advance Care Planning in the event that a sudden illness or accident renders the person unable to make decisions for him or herself. In addition, reflecting on one's goals, values and beliefs in terms of life and death issues in the absence of a medical emergency can assist the person to make health care decisions based on personal values and beliefs if a crisis arises.

The process of Advance Care Planning also enables discussions with family and others so everyone is aware of the personal values, beliefs and goals that one hopes will be reflected in decision making around health care issues.

Wishes change over time as health status changes and periodic communication and updating of wishes keeps everyone current.

At the time that it becomes appropriate to offer specific treatment interventions, feeding tube, medications, ventilation etc. an informed consent will be required in the development of a plan of treatment. The capable person will make the decision or if the person is incapable the SDM(s) will make the decision about the treatments to be included in the plan.

Slide 28: "Advance Care Planning"

The term "Advance Care Planning" is in quotation marks as it is a not a recognized term in Ontario law or legislation though we do find it embedded in common language and used by many. Be aware that there are also different laws and expectations in each of the provinces with in Canada.

Terms such as "living wills" and "advance care directives" are terms that are not used in Ontario law or legislation and come from other jurisdictions. (i.e. US, other provinces etc.)

Ontario law states that wishes can be communicated in any number of ways - verbal, written, braille, bliss or any other communication means.

Slide 29: "Advance Care Planning"

We will define the two highlighted terms here over the next few slides in this presentation. Capacity and Substitute Decision Maker(s) is the focus moving forward.

When a person is deemed incapable, they are no longer able to make a decision about a plan of treatment for themselves. This may be as a result of:

- a disease process (e.g. Dementia etc.) that affects the ability to understand and process information
- a treatment that may affect the ability to understand and appreciate
- being unresponsive due to a brain injury or an induced coma



You may ask if anyone has questions thus far but remind them that many of the concepts will be explained in greater detail as the presentation moves forward.

Slide 30: Why is "ACP" important?

These research points are drawn from several studies and the references can be found on slide 58 at the end of the PowerPoint.

Bullet four relates to a study where Quality of Life ratings from patients and families indicated that having an advance care plan contributed to higher ratings on Quality of Life index used.

Slide 31: Power of Attorney for Personal Care (POAPC)



A person may complete a POAPC with or without a lawyer.

A person may appoint more than one person to act as SDM(s). In the Power of Attorney Personal Care document you may appoint them to act jointly (together) or severally (separately).

A person can choose an alternate SDM(s) as a backup.

A person should choose someone she or he trusts, can communicate with and believes will carry out his or her wishes.

Conversations about the person's wishes, values, beliefs and goals are an important part of the Advance Care Planning process – it is critical that the Substitute Decision Maker(s) understand the role as well as what the person's wishes are.

Slide 32: Expression of Wishes

You may mention again that in Ontario wishes can be given orally, using braille, in writing etc. They can be communicated by any means and are not required to be written down.

Slide 33: Written Wishes

Review slide points

Reminder: If a person does not appoint an SMD(s) through a POAPC; Health Care Providers refer to the hierarchy to determine who the SDM(s) will be.

Slide 34: Consent vs. Wishes

Facilitator note:

Expansion points on these bullets are offered below:

First Bullet - Share examples of decisions requiring consent (e.g. Arranging admission to a long term home because you are not able to care for yourself; starting or stopping any medical treatment, for example an antibiotic for an infection you have right now.)

Emphasize that consent can include agreeing to, withholding or withdraw pertaining to a particular treatment

Second bullet – Wishes are typically based on speculations or "What if" scenarios

- a) What if scenarios "What if I..." Your wishes might be influenced by things you have seen or experienced. (Example Mom dies of cancer, Uncle in a car accident)
- b) Wishes can relate to a condition you already have (examples Alzheimer's, ALS, CHF, COPD). Knowing an illness path allows one time to prepare and understand what the likely course of the disease will be.
- c) Wishes can be an expression of one's religion, culture, or personal preference.

Slide 35: Levels of Care Forms – Large group activity



Ask: What is a level of care form?

Anticipated response:

 A statement of broad wishes related to health care preferences obtained at a specific time usually on admission to a facility

Provide examples if the participants are not familiar with level of care form (i.e. a form where you choose between 3 or 4 levels of care to be provided example - level one CPR and all interventions, level 2 no CPR but medical interventions, level 3 no CPR, no medical interventions to prolong my life)

Ask: Why is a level of care form not consent?

Anticipated responses:

Does not deal with a particular treatment or plan of treatment related to a current health care issue – Levels are arbitrary.

Does not require the disclosure of the burdens, benefits, risks or side effects related to specific treatment(s) or a plan of treatment

Does not require discussion of the current health status

Potential pitfalls of such documents:

- •Levels of care form are not legal documents and may give the care provider a false assurance that consent has been obtained e.g. DNR
- May falsely assure a health care provider that a particular treatment would not be wanted without asking the person <u>at the time</u> the health care intervention becomes an option due to a current condition e.g. someone who has chosen comfort only as a level of care is not offered treatment for a recently developed pneumonia or other infection.
- May discourage the discussion of appropriate interventions when a new situation arises e.g. treatment for an infection such as pneumonia.
- Levels are not consistent across organizations and each level could hold different meanings.

Slide 36: "Allow natural death"

"Allow natural death" is not a specific treatment but provides us with language that gently reminds that death is the natural and inevitable outcome of life. Using the term "allow natural death" can help care providers discuss the natural end of life as they explain the care and symptom management that will be provided.

Informed consent related to the specific treatment or plan of treatment being offered is still required even if allowing natural death is part of the discussion or the decision. For example, CPR, artificial hydration, antibiotics, management of terminal secretions etc. still require specific informed consent.

Slide 37: Health Care Provider Role

Review slide details

Slide 38: Health Care Provider Role in ACP

Health care Providers can:

- provide motivation and opportunity for reflection
- share tools and resources
- promote education about HCC and ACP
- encourage individuals to engage in communicating their wishes and goals
- encourage individuals to appoint a SDM(s)
- participate in the Speak Up campaign
- clarify understanding of diagnosis, provide information about disease progression, discuss prognosis and provide treatment options.

Slide 39: Health Care Provider Role in ACP - Speak Up!

Review slide details

This National campaign provides information; resources and encouragement for Health Care Providers and the public to participate in Advance Care Planning. The website is www.advancecareplanning.ca.

There is also an annual Advance Care Planning day (April16) that provides an extra opportunity to bring awareness to Advance Care Planning.

Slide 40: Health Care Provider Role in avoiding conflict

Review slide details

Being familiar with what are the requirements for informed consent can assist Health Care Providers in being able to communicate more clearly on health care issues. Healthcare decisions can be difficult for individuals or their Substitute Decision Maker(s) and conflict is a possibility when emotions are high. Allowing opportunities to reflect on the person and their values, in a safe and non-judgmental forum is key to understanding.

We make mention in the power point of a few strategies to aid in difficult situations. Resources to aid in conflict could include the person's spiritual advisor, an ethicist, a neutral second opinion etc.

Slide 41: Most Canadians die of a chronic illness

Healthcare Providers do have opportunity to initiate these conversations earlier in the disease trajectory.

- The "other" category may include conditions such as Alzheimer's and related dementia, Diabetes, end stage renal failure, neurological diseases (i.e. ALS, MS etc.) and others.
- Generally speaking we have time to prepare. We live with chronic conditions for some time and have opportunity to prepare. This does not mean that only those with an illness engage in these discussions; those who are healthy also need to consider what their future might hold.
- The scenario of "slipping away while we sleep" would be the preferred choices for many of us yet the statistics indicate this likely will not happen. Engaging in conversations about your care will help those wishes to be known in the event we aren't able to make our own decisions as we approach the end of our lives from any cause.

Slide 42: In Summary: "Advance Care Planning" is:

Review slide details

Slide 43: In Summary: What "Advance Care Planning" is not:

Review slide details

Slide 44: Summary

Review slide details

Slide 45: Case #1

Read the scenario again.

Pause briefly to allow the participants to begin to think about the question posed.

Slide 46: Case #2

Read the scenario again.

Pause briefly to allow the participants to begin to think about the question posed.

Slide 47: Case #3

Read the scenario again.

Pause briefly to allow the participants to begin to think about the question posed.

Slide 48: Summary Activity - In the interest of time divide learners into 5 small groups – assign one question per group – whip responses as a large group activity.

Please thank the participants at the end of this activity before moving into resources



ASK: Where will you start? Anticipated Responses:

- Gather information materials related to your discussion, organizational forms required e.g. DNR(C)
- Determine who will lead the conversation (s)
- Determine who will be present for the conversation (s)
- Do research (i.e. current understanding of person's health condition, physician determination of risks and benefits of proposed treatment, review treatment being offered etc.)

ASK: What do you need to consider? Anticipated Responses

- Capacity
- Literacy
- Cultural issues —who needs to be present for support i.e. family members, spiritual advisor determine what information is to be shared/not shared with others
- Spiritual issues e.g. Chaplain, Parish nurse, Priest, Rabbi etc.
- Potential language barriers i.e. translator, communication aids (glasses, hearing aids etc.)
- Setting privacy, adequate time etc.

Who will be making decisions?

Anticipated Responses:

- Capable individual
- Ascertain if a POAP C is in place
- If no POAPC next in the Hierarchy

What information do you need to provide for informed consent? Anticipated Responses:

- Nature of the treatment
- Expected Benefits of treatment
- Material Risks of treatment
- Material side effects of treatment
- Alternative course of action
- Likely consequences of not having the treatment
- Having their questions answered

What resources do you have to aid the discussion? Anticipated responses:

• Printed resources i.e. brochure on the role of the SDM(s). Links to 2 examples are listed below: http://www.palliativecareconsultation.ca/resources/Substitute%20Decision%20Making%20-%20English.pdf or

 $\underline{http://www.hamiltonhealthsciences.ca/documents/Patient\%20Education/SubstituteDecisionMak} \\ \underline{er-trh.pdf}$

- Definition of terms such as ventilation, artificial feedings, CPR etc.
- Family conference to share information and support the SDM(s)
- If decision is stop all measures of life support and allow natural death provide printed information such as: What to expect when someone is dying brochure available at:

http://www.palliativecareconsultation.ca/resources/resources/When%20a%20loved%20one%20is%20dying%20in%20LTC.pdf or

http://www.palliativecareconsultation.ca/resources/resources/When%20a%20loved%20one%20is%20dying%20in%20LTC.pdf

• Team members: Ethicist, Spiritual advisor(s) etc.

Slide 49: Take Home Messages

Review slide details

Slide 50: Resources

The following sides contain numerous resources.

Resources that are included are for Health Care Providers as well as patient and family materials.

Slide 51 to Slide 53: Resources

Slide 54: Resources

This pocket tool can be downloaded or you can order a hard copy.

Slide 55: Resources

There are also wallet cards available on the site that can be carried with you, and it would indicate whom you have chosen as your SDM(s) in a POAPC.

The booklet can help you understand the process in greater detail - This book has many of the basics we spoke about today.



We encourage you to have some on hand for your event where possible. They can be ordered from the Ontario government service center and are free.

Slide 56: Resources

We encourage you to have some on hand for your event where possible. They can be ordered from the Ontario Government Service Center and are free.

Slide 57: Resources: National Speak Up Campaign

Remind participants that researching the topic may lead to accessing information from many jurisdictions or countries and please consider the Ontario perspective when vetting information and sites.



If you can connect to the site in your presentation, show participants where to find the Ontario specific materials and information. The Ontario specific workbook is found following the Quick Links to the side on the home page. Click on the Provincial and Territorial resources. Under the Ontario tab on that page you will find the Ontario Speak Up Campaign workbook. You may also use the site search engine to find the document.

Slide 58: ACP References-re: slide 30

These are the references in regard to slide 30 that detailed the research on having an Advance Care Plan.

Slide 59: Questions???