Advance Care Planning in relation to Health Care Consent
Ontario Information Session – Condensed Public version

Facilitator Notes

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

Important details about the Facilitator Notes guide:

In the pages that follow you will find:

- ☑ A Facilitator preparation sheet
- ☑ Facilitation Notes to accompany the PowerPoint Presentation: ***Advance Care Planning in relation to Health Care Consent-Ontario Information Session –Condensed Public version***

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.

- Provide your contact information to the group you are speaking to as the PowerPoint presentation is protected and you will be unable to add it to the slide deck.

- 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:

Important to Note

Advance Care Planning in relation to Health Care Consent Ontario Information Session –Condensed Public version

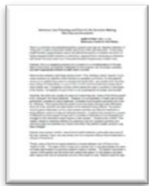
Facilitator Preparation

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 pre-ordered and available for distribution at the event.

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

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

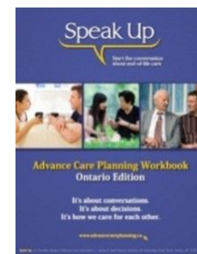
Advance Care Planning and End of Life Decision-Making: More than just Documents available for download at:
http://www.acelaw.ca/appimages/file/Advance%20Care%20Planning%20&%20End%20of%20Life%20Decision%20Making.pdf

Health Care Consent and Advance Care Planning: Fairly Good Law and Good Intent, but Not Always Good Practice available for download at:
http://www.advocacycentreelderly.org/appimages/file/CBA-Health%20Care%20Consent%20&%20Advance%20Care%20Planning-2013.pdf

Key Website resources:

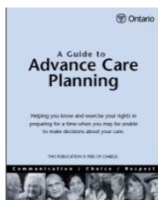
The Advocacy Centre for the Elderly (ACE) - http://www.acelaw.ca/

Speak Up: Start the Conversation about end-of-life care –link to Health Care Professional page:
http://www.advancecareplanning.ca/health-care-professionals.aspx



Legislation and Ontario Specific guides:

Link to the Health Care Consent Act: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_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

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 at the end of the slide presentation.

Advance Care Planning in relation to Health Care Consent Ontario Information Session – Condensed Public version

Slide 1: Advance Care Planning in relation to Health Care Consent – Ontario Information Session – Condensed Public version

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 in the facilitation guide on page 3.

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 pre-ordered and available for distribution at the event.

In order to gain knowledge and understanding of the laws that guide Health Care Providers related to consent please review all resources and websites listed in the facilitation guide on page 3.

This condensed version does not have opportunities embedded in it for questions or participant activities to aid in knowledge translation as does the original or longer version. There are often questions of clarification that participants have and there could be specific medical and legal questions that may be outside your level of expertise and experience – please refer them to the appropriate resources.

Slide 2: Why talk about Advance Care Planning?

The facilitator notes relay information to share - we recommend 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.

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 3: Why is this topic so important?

You may mention to the participants that these research points are drawn from several studies and the references can be found on slide 32 near the end of the PowerPoint. (for yourself as well)

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 indexes used.

Slide 4: Most Canadians die of a chronic illness

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 “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.

The scenario of “slipping away while we sleep” would be the preferred choice for many of us yet the statistics tell us differently and being able to engage in conversations about your care wishes 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 5: What is "Advance Care Planning"?

Review slide details.

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.

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 such as the US or other provinces etc.

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

Slide 6: "Advance Care Planning"

We will define the two highlighted terms capable (capacity) and Substitute Decision Maker as we move forward.

Clarify for the participants that when you are deemed to be incapable you are no longer able to make decisions for yourself about your medical care. This may be as a result of a disease process such as dementia, or late stages in many illnesses affecting ability to understand and process information shared.

Slide 7: Important Concepts and Terms

It is important to share the following information:

Capacity is not defined by age. The same concepts apply to children and adults about understanding and appreciating.

Capacity can fluctuate (share the example- people may be more able to engage in decision making in the morning versus late afternoon).

People can be capable of some decisions and not others (example - may not be able to decide about surgery but may be able to decide what to eat, wear or participate in).

People may be determined to be incapable at some point along an illness trajectory but may regain their ability to understand and appreciate (capable).

Capacity is not determined by diagnosis alone. (example it is only in late stages of Alzheimer's that one may not be able to participate in any decision making).

In assessing a person's capacity what the Health Care Providers weigh in their conversation is - Do you understand? **And** Do you appreciate the consequences of your decision?

The Health Care Providers may ask you to repeat back to them what they just explained to you in your own words. They may also question you to assess your understanding of the consequences of your decision. (Example –If you decide to not to have this treatment what do you expect will happen, if you do decide to take this treatment what will happen).

A formal assessment by an authorized Capacity Assessor may be called for in cases of disagreement or if there are questions as to a person's capacity.

Slide 8: Important Concepts and Terms

Substitute Decision Maker (SDM) is a person(s) who provides consent or refusal of consent for treatment or withdrawal of treatment on behalf of another person when that person is mentally incapable to make decisions about treatment. The SDM(s) is required to make decisions for you following any wishes you expressed about your care when you were mentally capable. If your SDM does not know your wishes applicable to the treatment decision to be made, he or she is required to act in your best interests. If you have not chosen an SDM then one is appointed through the SDM hierarchy which we shall outline in a moment.

Slide 9: **Substitute Decision Maker(s) [SDM(s)]**

In addition to the points on the slide add the following details for further clarification

These points regarding SDM's are for those appointed by you or if appointed through the hierarchy.

SDM(s) may have to be reminded of their legal obligation to making decisions based on the persons values and beliefs and not their own values and beliefs.

The Substitute Decision Maker(s) must try to make the same personal care choices that **you** would have made in that situation.

If there are no expressed wishes – then the Substitute Decision Maker(s) must consider your values and beliefs and operate in your best interests in the decision making.

In deciding what those **best interests** are, the SDM(s) must consider:

- any current wishes the incapable person may have;
- the values and beliefs the incapable person held while they were 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 or
  - reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate and
- the expected benefits of one treatment versus another treatment.

Slide 10: **Substitute Decision Maker(s) [SDM(s)]**

Share these points with the participants.

Your Substitute Decision Maker(s):

- Cannot be a person outside the family whom is being paid to provide care or services to you. (examples - your nurse, your PSW, your doctor, landlord etc.)
- Must be available within a time that is reasonable
- Must be willing to assume the responsibility of giving and refusing consent
- Cannot be prohibited through court order

A SDM(s) may be under the age of 16 if they are the parent of the "incapable" child where decisions are needed.

The same tenets of capacity apply to the SDM (s) - **Understand and Appreciate**

Reassure participants that there is still more information to come about SDM(s) before questions are taken.

Slide 11: **Substitute Decision Maker(s) [SDM(s)]**

Review slide details.

Slide 12: **Hierarchy (a ranked list) of Substitute Decision Makers**

***Definitions of terms 4 to 9 are found within the notes for Slide 13**

Below are definitions for each of these terms. These are not meant to be read verbatim but it is a resource for you as the facilitator to be able to share and explain in more detail.

Notes for points 4 to 9 are in the notes of the following slide or found in the accompanying facilitation guide.

The hierarchy is embedded in the Health Care Consent Act and is a ranked list that Health Care Providers must utilize when a person is incapable of giving consent and an SDM is needed. 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 13: What is a Power of Attorney (POA)?

Explain to the participants that we are going to discuss the POA for Personal Care only.

(Notes below are a continuation from slide 12)

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 an SDM*
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 14: **POA for Personal Care**

It would be beneficial to order POAPC kits for your event. At the end of the presentation we have shared the site where you can download a POA document.

Important points of clarification to share: One may complete a POAPC with or without a lawyer.

You may appoint more than one person. In the power of attorney document you may appoint them to act jointly or severally. This means either making decisions together or separately. There are much more fulsome definitions related to this in the POAPC document.

You can choose an alternate SDM as a backup. You should choose someone you trust and you feel will be comfortable communicating and carrying out your wishes.

It is important to have the conversations about your wishes, values, beliefs and goals with all those important to you – it is critical that your Substitute Decision Maker(s) know what their role is and what your wishes are.

Slide 15: Substitute Decision Maker(s) [SDM(s)]

In an emergency situation Health Care Providers will act in your best interest or will take direction from a person available to communicate your wishes or make a decision on your behalf.

In Ontario there are only two ways in which a Substitute Decision Maker is appointed and that is either in a Power of Attorney for Personal Care document or through determining the highest ranked person(s) on the hierarchy of Substitute Decision Makers.

A Health Care Provider will turn to the highest ranked person in the hierarchy for consent when you are no longer capable of making health care decisions.

If you are comfortable with the highest ranked person in the hierarchy then a POAPC is not necessary. If that person is not available then the Health Care Provider refers to the next highest ranked person in the hierarchy. You will note that if you have a person named in a POAPC then that person ranks higher on the list than your spouse or children.

Slide 16: How does all this fit together?

Review slide details. Wishes is the term used in Ontario law. Terms such as "living wills", "advance directives" though commonly heard, are not terms found in Ontario law.

Be aware that there are also different laws and expectations in each of the provinces within Canada.

Slide 17: Health Care Consent

The conversation with the Health Care Provider must relate to a specific treatment or treatment plan being proposed. Consent must be informed, given voluntarily, and must not be obtained through misrepresentation or fraud. (no coercion)

Disagreement with the decision a person makes does not mean that a person is incapable. **We have the right to make poor decisions**. When the terms of informed consent are met, it does rest with the person to make their decision without pressure or coercion on the part of the Health Care Provider. Other considerations may be brought to the table (e.g. ethics consults, second opinion etc.) to assist in the informed decision making process.

Slide 18: **Consent vs. Wishes**

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

Expansion points on these bullets are offered below:

Consent 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.)

Wishes information – Wishes typically are speculations are the "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 19: **The Process**

It will be helpful to have copies of the workbook for the audience or at least some samples that you've downloaded.

Brief review the steps on this slide as the following 6 slides will provide more detail.

Slide20: Step 1 – Think about what is right for you

Read the power point slide.

Potential Examples to share:

Values
Dignity – example: being clean, tidy, odor free, respecting others and being respected, non-aggressive

Independence –example: mobility, able to make choices, able to care for myself

Ability – example: being able to communicate with family, seeing, hearing enjoying a good meal

Quality of life – example: privacy upheld, being pain or any other symptom free, having abilities, not being a burden

Beliefs

Life is sacred - so describe what life support means to you – interventions or not, death is a natural process etc.

I should be able to determine my own fate

No blood transfusions in some religions is a belief

Being specific can help your SDM. Research shows that we may not be able to anticipate the specific scenario we face when an SDM may be needed but knowing and communicating your specific values, beliefs and wishes enables your SDM to make decisions based on your values.

Slide 21: **Step 2 –Learn about health care options and medical procedures**

Examples of where can you learn about healthcare and medical options: Doctor, Nurse, Pamphlets, specific disease societies (i.e. Cancer society, ALS, Huntington's group, Alzheimer's etc.) the internet, libraries, asking others for recommend websites. (**remind that there is considerable information out there so your source is important and recognized sites are recommended – like Cancer Care Ontario, Alzheimer Society etc.)

Considerations that may influence your wishes include:

- Whether you do or do not want food and water supplied by a medical device (tube feeding)
- Whether or not you want cardiopulmonary resuscitation (CPR); major surgery; dialysis; blood transfusions; and anything else to keep you alive
- If I am close to death and I am likely to die within a short period of time and life support would only delay my death, I do not want CPR or any life prolonging measures.
- If I am in a coma and not expected to wake up or recover, I ....
- If I have permanent and severe brain damage and am not expected to recover, I ....
- If I have any other condition where life support is a question I ....
- I do not want to be in pain
- I want my doctor to give me enough medicine to relieve my pain, even if I will be drowsy, sleepy or dependant
- I want music, prayers, rituals that are important to me

Slide 22: **Step3 – Determine your Substitute Decision Maker(s)**

Review slide details.

Slide 23: Step 4 – Have the conversation

Conversations may be difficult for some or it may be a relief to know exactly what your wishes are and what kind of care you would like

In Ontario one can express those wishes verbally, recorded (audio or video), written or by any other means of communication (e.g. braille)

Slide 24: **Step 5 – Communicate Your Wishes**

In Ontario you can convey your wishes verbally, written, bliss-board, braille etc. It is important to share those wishes; this is not meant to be a secret.

You may write down your wishes in a tool such as the Advance Care Planning Workbook – Ontario Edition and that there is some space in the POAPC document to record your wishes.

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 25: **Step 6 – Review Your Wishes/Plan Regularly**

Important point to emphasize: Saying no to one kind of treatment (example CPR) does not mean that other care or treatment will not be provided. Care and treatment will be provided even if one does not want CPR.

Slide 26: In Summary: “Advance Care Planning” is:

Review slide details.

Slide 27: **In Summary: What “Advance Care Planning” is <u>not</u>:**

Bullet expansion points:

- Bullet 1 – This process can be several conversations, it should allow for time to think process and consider options. This process should allow time for the gathering and understanding of information etc.
- Bullet 2 - Consent for or refusal of treatment has to come from the individual in Ontario so your Substitute Decision Maker interprets your wishes to guide decisions being made.
- Bullet 3 – Your expressed wished can and should include what you do want as well. (music, treatment, your values basically)
- Bullet 4 –These are conversations and processes. Levels of care forms are not consent to or refusal of treatment and should not be used or interpreted as such. Levels of care forms if you should come across one is where you may be asked to pick levels of care 1, 2, 3 or 1, 2, 3, 4. They may say level one is no CPR and comfort care only, level 2 is no CPR and other treatments as needed and level 3 is CPR and everything else on offer. These forms do not comply with health care consent and should not be considered consent to treatment or a treatment plan.
- Bullet 5 – “Advance Care Planning” is not a secret. The process is the communication of wishes.

Slide 28: 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 in a POAPC. (Facilitator – print out this resource to be able to share a sample to read from)

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

Facilitator -Have some on hand for your event where possible. They can be ordered from the Ontario government service center and are free.

Slide 29: Resources

This resource is also available for free from the Ontario Government.

Slide 30: Resources

Remind participants that the national initiative is not specific to Ontario though this version of the workbook is. There are different laws, terms and processes throughout Canada. 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, please do so and show participants where to find the Ontario specific materials and information.

Slide 31: Resources

Review slide details.

Slide 32: Research References –re: Slide 3

These are the references in regard to the slide 3 that detailed the research on having an "advance care plan".

Slide 33: **Questions???**

Slide 34: Additional resources for HCP's: College of Nurses of Ontario information

These resources are specific to Health Care Professionals who may be attending a public presentation**.**

Slide 35: Resources: Social Workers and Social Service Workers information

These resources are specific to Health Care Professionals who may be attending a public presentation.

Slide 36: Resources: College of Physicians and Surgeons information

These resources are specific to Health Care Professionals who may be attending a public presentation.