

Health Care Consent in relation to Advance Care Planning

Ontario information session for Health Care Providers
Condensed 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:
***Health Care Consent in relation to Advance Care Planning
Ontario Information Session – Condensed 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. (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 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

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

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 Health Care 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_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>

Key Website resources:

The Advocacy Centre for the Elderly (ACE) : <http://www.ancelaw.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.ancelaw.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.ancelaw.ca/appimages/file/Advance%20Care%20Planning%20&%20End%20of%20oLife%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>

Health Care Consent in relation to Advance Care Planning Ontario Information Session - Condensed Version

Slide 1: Health Care Consent in relation to Advance Care Planning: Ontario Information Session – Condensed 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 in the facilitation guide on page 2.

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.

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 slide deck.

In order to gain knowledge and understanding of the laws that guide Health Care Providers related to consent, we recommend you review all resources and websites listed in the facilitation guide. This condensed version does not have opportunities embedded in it for questions or participant activities to aid in knowledge translation to practice 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: Presentation Goals

Briefly review the goals for the session. We strongly 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.

Slide 3: 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.

Slide 4: When must you obtain consent?

Review slide details.

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

Slide 5: 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 6: Except...

Today's focus is not on how to handle an emergency situation but rather on health care consent.

Slide 7: 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 required for consent to treatment to be valid.

Slide 8: 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 Health Care Consent Act (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 9: 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 10: 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. **Informed consent based on a current condition is a plan of treatment and wishes expressed in the context of a ‘what if’ scenario is “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 11: 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.

Repeated emphasis on the information given can be interpreted as coercion because -

- 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 12: 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 may not be capable of providing informed consent, in and of themselves they do not necessarily indicate incapacity.

Capacity is a legal definition and is not a medical definition. It 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 13: 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.

You determine understanding and appreciation by:

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

Slide 14: 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 15: 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 16: 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 as needed for your audience.

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 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 17: Substitute Decision Maker (continued)

(Notes are a continuation from the previous slide)

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 18: 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 19: 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 well-being 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 not 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 Health Care 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 20: 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 21: 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 22: “Advance Care Planning”

The term “advance care planning” is in quotation marks as it is 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 within 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-board or any other communication means.

Slide 23: “Advance Care Planning”

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

Slide 24: Why is “ACP” important?

These research points are drawn from several studies and the references can be found on slide 42 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 25: Power of Attorney for Personal Care (POAPC)



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

The person(s) named in a POAPC is referred to as either the attorney for personal care or the substitute decision maker. A POAPC is the document itself and this is the only document or way that you may appoint your substitute decision maker(s). If there is no POAPC document then the hierarchy of SDM’s is how the SDM(s) is determined.

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 SDM(s) understand the role as well as what the person’s wishes are.

Slide 26: Expression of Wishes

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

Slide 27: Written Wishes

Review slide details.

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

Slide 28: 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:

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.)

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 29: Levels of Care Forms

A level of care form is a statement of broad wishes or health care preferences obtained at a specific time e.g. on admission to a facility (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)

A level of care form is not consent because it:

- Does not deal with a particular treatment or plan of treatment related to a current health care issue. (lacks detail)
- 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 at the time 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 30: Health Care Provider Role

Review slide details.

Slide 31: Health Care Provider Role in the ACP process

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 32: In Summary: “Advance Care Planning” is:

Review slide details.

Slide 33: Summary (continued)

Review slide details.

Slide 34: Resources

The following slides contain numerous resources.

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

Slide 35 to Slide 37: Resources

Slide 38: Resources

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

Slide 39: Resources

There are also wallet cards available on the site listed here that a person can carry with them. It does 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 40: 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 41: 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. The workbook shown here is Ontario specific in its content.



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 42: ACP References-re: slide 24

These are the references in regard to slide 24 that detailed the research on having an “advance care plan”.

Slide 43: Questions???