



Health Care Consent Advance Care Planning Community (HCC ACP CoP) of Practice (HCC ACP CoP)

HCC ACP IN ONTARIO – SUMMARY OF KEY THEMES AND COMMON ERRORS

HCCA Ontario <https://www.ontario.ca/laws/statute/96h02>

The Law Commission of Ontario strongly recommends the use of terminology in the Health Care Consent Act (HCCA):

“We recommend that terminology used in health care consent and advance care planning forms, tools, and policies track the language in the HCCA, and that these documents should expressly distinguish between consent and the recording of wishes, values, and beliefs.”¹

Do your ACP materials comply with Ontario Law? You may be surprised! Following these suggestions and recommendations, and avoiding these common pitfalls will result in much stronger resources that are reflective of the Ontario legal landscape.

1. Use **‘Advance Care Planning’** rather than **‘Advance Directive, Directions, Decisions and Living Wills’**

- When engaging in advance care planning, the use of language such as ‘directions,’ ‘decisions’ and ‘living wills’ is discouraged in Ontario. Similarly, the term ‘Advance Directive’ should not be used in Ontario on health care forms, institutional policies, or in discussions with patients. These terms would appear to be transplanted from other jurisdictions (i.e., provinces, countries) where, for example, an advance directive or a living will, are specific documents that ‘direct’ treatment by health practitioners. The use of these terms could lead patients, SDMs and health practitioners to misunderstand Ontario’s legislative system for giving and refusing informed consent.²
- See Appendix A - What is Advance Care Planning?

2. Use **‘Planning’** rather than **‘Plan’**

- The use of the word “plan” contributes to the misunderstanding of the process of advance care planning (expression of wishes, values and beliefs) and its connection to health care consent (decisions). In Ontario we should not utilize the word ‘plan’ when speaking of advance care planning or the process of expressing our wishes for future health or personal care. ‘Plan’ connotes a decision versus a wish, may mistakenly imply consent (it is not informed consent), and may focus on a need to provide information in a written form or may mistakenly steer people to believe that what they share in the process of ACP is a decision and has some legal standing.
- ACP in Ontario (as embedded in the Health Care Consent Act - HCCA) is the expression of wishes and is not about decisions. In Ontario, we get consent from a person and not a piece of paper or document. The expression of wishes (ACP) is a process.

¹ Health Care Consent and Advance Care Planning in Ontario Legal Capacity, Decision-Making and Guardianship, January 2014. Commissioned by the Law Commission of Ontario, pg. 287

² Health Care Consent and Advance Care Planning in Ontario Legal Capacity, Decision-Making and Guardianship, January 2014. Commissioned by the Law Commission of Ontario, pg. 286-287

3. Communicate the link between *'Advance Care Planning'* and *'Health Care Consent Act'* and *'Informed Consent'*.

- Advance Care Planning is the process of thinking about what is important to you and what makes your life meaningful. It is talking about future wishes, values and beliefs that would guide a person's Substitute Decision Maker when they would be called upon to make a treatment decision on your behalf.
- Informed consent must be obtained from a person (when mentally capable) or the Substitute Decision Maker(s) (if mentally incapable). Health care providers are required to get informed consent prior to any care or treatment, as well as withdrawal or withholding of treatment.
- They must explain the benefits, risks, side effects and alternatives to each treatment and what would happen if the patient did not agree to a particular treatment. Any questions about a person's health, care and/or treatment offered must be answered by the Health Care Provider. This process is informed consent.
- Our language, forms, processes should be accurate in their reflection of the differences between ACP and HCC and not contribute to the misconceptions and misrepresentation of either of these distinctly different processes.

4. Clearly distinguish *'Advance Care Planning'*, *'Goals of Care'*, and *'Health Care Consent'* in Ontario.

- Advance Care Planning (ACP) (Future Clinical Context) Outcome is to identify wishes, the SDM and prepare the SDM for future decision-making. ACP is the process of talking about wishes, values and beliefs that would guide the future SDM when they would be called upon to make treatment decisions on a person's behalf.
- Goals of Care Discussion (GoC) (Current Clinical Context) Outcome is different every time – exploring patient's goals assesses readiness and prepares for decision-making. GoC conversations are generally a communication framework that assists in understanding and assessing the person's goals for care. (i.e. personal and clinical goals)
- Health Care Consent (HCC) or Decision-making Discussion (Current Clinical Context) Outcome is always care or treatment decision(s). Health care providers are required to get informed consent from a capable person prior to any care or treatment. HCC conversations are focused on a decision regarding a proposed treatment(s) or care plan based on a person's current condition.
- See Appendix B – Person-Centered Health Decision-Making

5. Use *'Decide who will speak on your behalf'* rather than *'Choosing a Decision Maker'*

- The use of the wording 'Choose' your Substitute Decision Maker (SDM) may mislead people in believing they are required to 'choose' when in actual fact Ontario legislation provides a ranked list (hierarchy of SDM) that allows for an automatic SDM for all. If the person does not feel that the automatic Substitute Decision Maker is the right individual to act on their behalf, if they should become mentally incapable, then they could decide to name a specific person(s) in a Power of Attorney for Personal Care (POAPC) document.
- To be a Substitute Decision Maker, the person(s) must be:
 - willing to act as your Substitute Decision Maker
 - mentally capable of making health decisions for you

- available -- in person or by phone or by some other means -- when a decision needs to be made
- not prohibited by a court order from acting as your substitute decision maker and
- at least 16 years of age.

If the person in your life that ranks highest in the list of Substitute Decision Makers in the Health Care Consent Act does not meet these requirements, then the health care professional will move down the hierarchy to the next person on the list. The hierarchy order functions from the top of the list to the bottom.

- In Ontario it is important to ensure that patients and health care providers understand the hierarchy, how to use it, and when it would be appropriate to support or encourage someone to complete a Power of Attorney for Personal Care (POAPC) document. Note the POA is a document, not a person.
- See Appendix C - The Ranked List (Hierarchy) of Substitute Decision Makers in the Health Care Consent Act

6. Use *'Recording your Substitute Decision Maker and Communicate your Wishes'* rather than *'Recording of Wishes'*

- In Ontario the law indicates that wishes can be expressed using any communication means such as orally, written, Bliss, Braille etc. Therefore, it is important to ensure that patients and health care providers understand the important distinction of not having to record wishes. It is recommended that all materials reinforce the broad communication ability in the sharing of wishes (ACP) and intentionally seek to not place an overemphasis on written wishes. The focus on written wishes contributes to the misconception that a written record holds legal power, that it is a 'directive' for the healthcare provider and that informed consent is not required. The communication of wishes is a guide for the future SDM.

7. Clearly distinguish the role of the *'Substitute Decision Maker'* versus the *'Health Practitioner'*

- The Ontario legal model is different and health providers do not take directions from some sort of statement of future wishes expressed by the patient. Ontario does not have "living wills" or "advance directives" as in some other provinces. When a patient is deemed mentally incapable, it is up to the Substitute Decision Maker (SDM) to consider the wishes, values and beliefs of the patient, apply it to the treatment decision to be made after being informed of the patients' present health condition and treatment options. The SDM is required to interpret those wishes, values, beliefs and what the patient meant by them. The health practitioners should never be screening out treatment options based on the health practitioners' interpretations of the wishes, values and beliefs. The obligation is placed on the SDM to make the decisions about what treatments to consent to, not the health practitioner.
- The health practitioner should be advising the SDM of their obligations to follow the patient's wishes, values and beliefs when making treatment decisions for the patient. But ultimately it is the SDM that makes the decisions. If the health practitioners believe that the SDM is not acting in accordance with the patient's wishes, values, beliefs, the health practitioner may apply to the Consent and Capacity Board on a form G application.
- Use the correct term of "Substitute Decision Maker" not references to Decision-maker, Substitute, Surrogate, Proxy or Agent. (Spacing can be saved by introducing the word Substitute Decision Maker early in each document and include (SDM) in brackets so one can reference SDM after that introduction)

8. Use *'Mentally Capable Person'* rather than *'Capable Person'*

- Using “mentally capable person” is preferred because a person may be mentally capable yet physically incapacitated. This explicitly emphasizes that even if a person is physically incapacitated there are a variety of means available to communicate Bliss, Braille etc. While a person is mentally capable they are always the decision maker. The Ontario Capacity office defines mental capacity as the ability to understand the information that is relevant to a decision or to appreciate the consequences of a decision. Therefore, the use of the correct concept and term of “mentally capable” to replace all reference to “capable” person throughout all materials is recommended for clarity.
- Where you use the words "capable person" only in your materials as an adaptation for specific users ensure that you are providing a definition to set the context when referring to capable or capacity. For example, define 'capable' outlining the concepts of understanding the information one needs to make a decision and appreciating the likely results of making that decision. This would help to ensure the understanding of mental capacity and health care decision making.

9. Use *'Family and Friends'* rather than *'Loved Ones'*

- Given that family and friends may not always be loved ones, for accuracy it is recommended that the term family and friend be used in all materials.

10. Focus on *'Future Health and Personal Care'* rather than *'End of Life'*

- Engaging in the process of advance care planning is an opportunity for all mentally capable adults to share what is important to them for future health and personal care wishes. The link to end of life only can contribute to the misconception this engagement is for people facing that situation only. If we encourage all to engage in the expression of what is important for them in future health and personal care decisions this speaks to the broader intent of the legal framework in Ontario and is an excellent opportunity to make these conversations normal and part of what we should all consider as a great opportunity to share with family, friends, future SDM's and health care providers.
- It is important to recognize that people at end of life are not advance care planning but are indicating a consent to a treatment or plan of treatment based on their current context.

11. Clearly distinguish the *'Process of Advance Care Planning'* Versus *'CPR Decisions'*

- The process of Advance Care Planning is thinking about what is important to you and what makes your life meaningful. It is talking about your future wishes, values and beliefs. Whereas, CPR information or resources are a support to an informed consent conversation. Therefore, CPR materials are typically about health care consent and not Advance Care Planning even if this particular treatment decision is about 'future' care. Informed consent (decision) to have or not have CPR included in a person's plan of treatment is based on their current health condition. Linking health care decisions and consent to the process of Advance Care Planning is incorrect.

12. Always use Resources and Links aligned with the Ontario legal framework

- All associations, organizations etc. should exercise rigor in their choice of references and resources that accurately reflect the Ontario legal framework. All references, resources and links in these materials should be accurate to Ontario law (Health Care Consent Act and Substitute Decision Act). Vetting for and only including up to date Ontario resources are essential.

- Please remember the laws about ACP vary in each province. It is for this reason that the National Speak Up Campaign provides access to individual provincial links to ensure that you are using appropriate materials that are compliant to the legislation within your local jurisdiction.

13. Other Suggestions

- We encourage the dating of all materials so users can be assured that they are current and updated.
- Establish your next review opportunity now to adjust for a change in law, links and resource rechecks and to continually improve clarity and accuracy.
- We recommend that you develop a dissemination plan to communicate broadly to you stakeholders that these materials have been updated, and to ensure that moving forward, only the most recent tools are being used.
- While it is difficult given the complexity of this information, it is advised that you try to use plain language as much as possible. This is on par with health literacy standards and patient education guidelines as the ideal aim is a Grade 5-6 reading level. If plain language cannot be used, then include a glossary of terms.

HPCO's HCC ACP CoP is interested in being able to support, post and endorse materials to assist in broader provincial awareness and access to accurate, up to date materials. If you are interested in participating in a review by the Leadership Advisory Team of your HCC ACP resources for use within Ontario or if you have any further questions, please contact Julie Darnay at jdarnay@hpcoco.ca, or 1-800-349-311 or 416-304-1477, ext. 30.

Final May 12, 2016

This resource is considered a living document and will be updated as required to ensure ongoing compliance with the Ontario Legal Framework

Revised June 14, 2017

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Appendix A

What is Advance Care Planning?

In Ontario, advance care planning (ACP) is:

- Confirming your substitute decision maker(s) (SDMs)
AND
- Communicating your wishes, values and beliefs about care to help your SDM(s) make health and personal care decisions for you if you become mentally incapable of doing so for yourself.

Why is this Important?

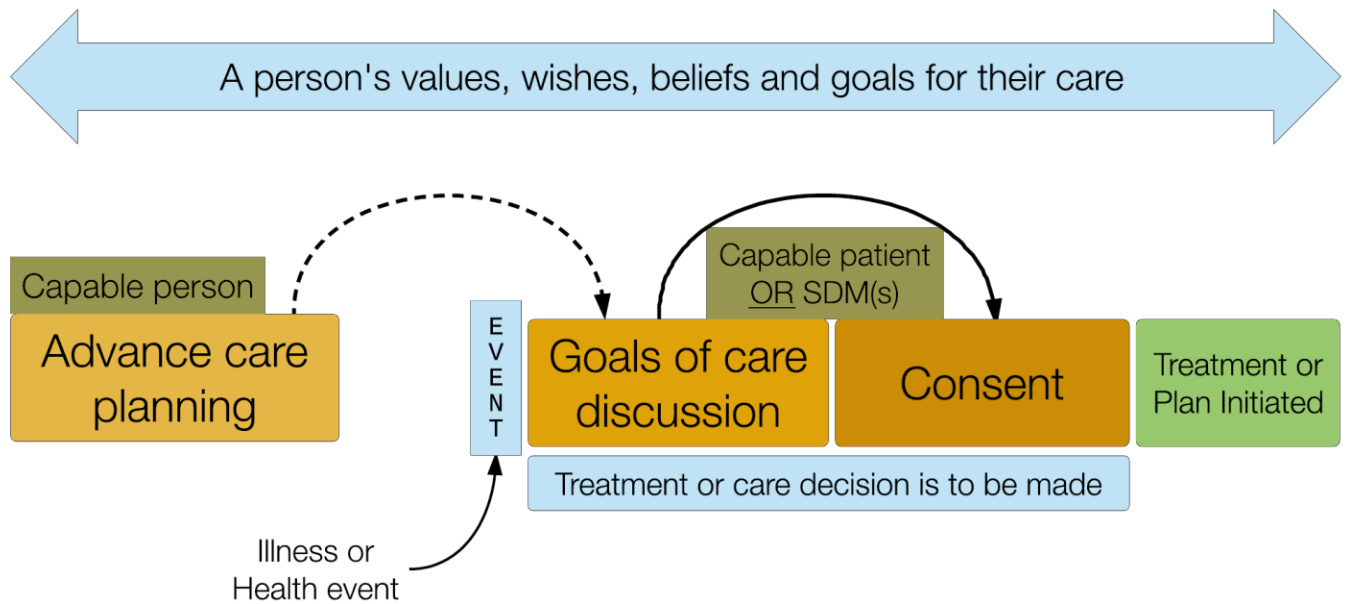
In Ontario the law requires all health care providers to get informed consent or refusal of consent before providing a patient with any treatment or care. Health practitioners must tell you about your illness and what may be done to treat you. You then have the right to make a decision and agree to or refuse the treatments offered. This is called health care consent: it is a basic patient right to decide what health care to receive. Only in emergencies to save a life or to reduce suffering can people be treated without informed consent. Consent always comes from a person: either the mentally capable person or their substitute decision maker(s).

If you are not mentally capable, the health practitioner will turn to another person, your **substitute decision maker**, who will then speak for you and make the decision about your care. Advance care planning lets you know who would speak for you.

Advance care planning is not about decisions. It is about preparing you and your future substitute decision maker(s) for a time when you may not be able to make your own health or personal care decisions because of lack of mental capacity. At that time, your future SDM would step in to give or refuse consent for treatment.

Appendix B

Components of Person Centered Decision-Making



© 2017 by Dr. Jeff Myers, Dr. Nadia Incardona & Dr. Leah Steinberg. **Components of person-centred decision-making.**
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What is Required in all Care Settings to GET THIS RIGHT?

	Clinical Context	Outcome is...	Outcome is NOT...	How goals are defined
Advance care planning	Future	SDM(s) confirmed and prepared with information to guide decision-making	Code status, POLST, etc.	Patient's to define and describe
Goals of care discussion	Current	Patient/SDM(s) understands illness AND Team understands pt's values & goals	Code status, POLST, etc.	Patient's to define and describe
Decision-making & consent discussions	Current	Outcome is always care or treatment decision(s) e.g. Code status, POLST, etc.		May be medically oriented e.g. cure, restore function, address low Hgb

Appendix C

The Substitute Decision Maker Hierarchy

Possible SDMs	Description
1. Guardian of the person	Someone appointed by the court to be your substitute decision maker.
2. Attorney named in a Power of Attorney for Personal Care	The person or persons YOU have chosen to be your substitute decision maker if you prepared a Power of Attorney for Personal Care when you were mentally capable of doing so.
3. Representative appointed by the Ontario Consent and Capacity Board	A family member or friend who applies 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.
4. Spouse or partner	<p>Two persons are "spouses" if they are:</p> <ul style="list-style-type: none"> a) Married to each other; or b) Living in a common law marriage-like relationship and, <ul style="list-style-type: none"> i) have lived together for at least one year or ii) are the parents of a child together <u>or</u> 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. <p>Two persons are not spouses if they are living separate and apart because of a breakdown of their relationship.</p> <p>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. Partners include friends who have lived together for at least one year in a non-sexual relationship and have a special personal family-like relationship.</p>
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	The person who has the legal right to give or refuse consent for treatment. 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, then the parent would not have the legal right to be a substitute decision maker.
6. A parent who only has a right of access	If someone who has the legal right to give or refuse consent for treatment for a child is not available, then a parent who only has a right of access is the substitute decision maker.
7. Siblings	If you have a number of siblings that meet the requirements of an SDM, they are all EQUALLY ranked.
8. Any other relative (see the next page if you have more than one relative)	People are relatives if they are related by blood, marriage or adoption. If you have a number of relatives that meet the requirements of a decision maker, they are all EQUALLY ranked.
9. Public Guardian and Trustee	If no person in your life meets the requirement to be a substitute decision maker, then the Public Guardian and Trustee of Ontario, a public government organization, is your substitute decision maker.