

Health Care Consent and Advance Care Planning Glossary (Common Language) April 2016

Stakeholders (i.e. public, social, healthcare sectors) have identified the lack of common language and understanding of both Health Care Consent (HCC) and Advance Care Planning (ACP) in Ontario. This Ontario Glossary is a compilation of common terms, and phrases related to HCC and ACP to improve understanding and consistency in the correct application.

Advance Care Planning:

The *Substitute Decisions Act, 1992* (SDA) and *Health Care Consent Act, 1996* (HCCA) govern ACP in Ontario. ACP is a process that involves the **mentally capable patient**:

1. **IDENTIFYING** his/her future Substitute Decision-Maker (SDM), by either
 - a) **Confirming** his/her satisfaction with their default/ automatic Substitute Decision-Maker in the SDM hierarchy list in the Health Care Consent Act

OR

 - b) **Choosing** someone else to act as SDM by preparing a Power of Attorney for Personal Care (a formal written document).
2. **SHARING HIS/HER WISHES, VALUES, AND BELIEFS** through conversations with the SDM and others that clarify his/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent (i.e. what is quality of life to that patient? What is important to that patient with respect to his or her health?)

ACP does not constitute consent to treatment. Except in emergencies, health care providers must always obtain consent from an individual or SDMs prior to administering treatment, even if the individual has engaged in ACP. Obtaining consent is a continuous process that must precede every treatment. When substitute consent is required, known wishes, values and beliefs serve to guide the SDMs' decision-making process. Because a person's wishes, values and beliefs may change over time, later wishes expressed while mentally capable prevail over earlier wishes.ⁱ

ACP can be initiated and reviewed at any time, not just at end-of-life.

Advance Care Plan, Living Will, Advance Directive

These terms are not legally defined in Ontario law. While heard in common language, these terms have been borrowed from other jurisdictions, countries or provinces. Use of this terminology may cause confusion and misrepresentation of HCC or ACP. It is suggested that these terms should not be used when referring to advance care planning to avoid this confusion. Ontario law requires health care providers to obtain consent even where a patient has engaged in the process of ACP or has documented wishes.

Allow Natural Death:

This phrase may be heard in connection with “Do Not Resuscitate.”

Using “allow natural death” may imply that rather than engaging in attempts at resuscitation, efforts are directed at being present with the person and supporting the family at the time of death.

“Allow natural death” is not a specific treatment but provides language that gently reminds that death is the natural and inevitable outcome of life. Using the term “allow natural death” can assist care providers in discussing 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 decision. For example CPR, artificial hydration, antibiotics, management of terminal secretions etc. still require specific informed consent.

Best Interests:

If no applicable wishes were expressed while a person was mentally capable then the SDM(s) must consider making decisions in the person’s ‘best interest’. As outlined in the HCCA the SDM(s) would consider:

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

Capacity or “Mental Capacity”

Under the HCCA, a person is capable with respect to a health care decision if he or she is able to **understand** information that is relevant to making a decision and able to **appreciate** the reasonably foreseeable consequences of a decision or lack of decision.ⁱⁱ In Ontario, where an individual lacks mental capacity and a health care decision must be made, the health care practitioner must turn to the SDM(s) to obtain consent or refusal of consent for treatment or withdrawal of treatment.

Caregiver:

Caregivers are individuals who provide care to family, friends, neighbours and community members with health conditions, disabilities or aging needs. For the purposes of this glossary the term “caregiver” includes those who provide care informally and on a voluntary basis and does not include professional providers.

End-of-life Care:

Refers to the type of health care provided at the end of a person's life. This type of care focuses on the person living the way they choose during their last days or weeks and providing comfort measures until the time of death. Death is likely imminentⁱⁱⁱ and persons are typically in the advanced stages of a life-limiting condition. The terms "end-of-life care" and "palliative care" are often used synonymously in the literature; however, they are distinguishable. End-of-life care is only one aspect of palliative care (see definition of palliative care provided below).

Frailty:

Frailty is a syndrome that some older adults experience when they are particularly vulnerable to adverse health outcomes. Frailty is associated with the presence of multiple physical or cognitive conditions that put older adults at risk when they face additional stressors. Even seemingly minor stressors can trigger major changes in frail persons' health and social functioning, potentially resulting in disability, death and hospitalization.^{iv}

Goals of Care:

Discussions about goals of care may take place between persons receiving care, SDMs, health care providers and family members and are intended to support goal-oriented and person-centred decision-making.^v Examples of goals are: seeing the birth of a grandchild, maintaining independence or climbing a flight of stairs, being among others.^{vi} The goals a person has for their care are their values in the form of actions and clarifying goals of care this allows for a more meaningful exploration of the available treatment and care options.^{vii} In Ontario, the articulation of goals of care may inform decision-making through legal frameworks for informed consent and plans of treatment.

Health Care Consent:

An informed and contextualized decision involving a mentally capable person and a health care provider as outlined in the Ontario HCCA. Health care providers proposing treatment must obtain informed consent from either a capable patient or the mentally incapable patient's SDM(s). This discussion must include an explanation of the persons' present condition (context), available treatment options, risks/benefits/side effects, alternatives to treatment and what would happen without the proposed treatment.

Health Care Provider or Service Provider:

Regulated Health Care Provider or Service Provider:

This is a person licensed, certified or registered in Ontario to provide health care (e.g., a doctor, nurse or social worker). Their work is governed by the Regulated Health Professionals Act.

Unregulated Health Care Provider:

This is a person whose work is not governed by a particular legislation in Ontario. An unregulated worker performs a variety of tasks, some of which may traditionally have been performed by regulated health care professionals (e.g. a Personal Support Worker)

Health Service or Health Care Sector:

Any service aimed at contributing to improved health or to the diagnosis, treatment and rehabilitation of sick people. In Ontario we refer to several health care sectors typically when talking about stakeholders and organizations related to these goals. Hospital, Long Term Care and Community Care are commonly identified sectors providing health care for Ontarians.

Hierarchy of Substitute Decision Makers for Health Decisions

The Ontario Health Care Consent Act, includes a hierarchy that provides you with an automatic SDM. The person or persons in your life that are the highest ranked in this hierarchy and that meet the requirements to act as a SDM(s) will be your SDM for health care. If a person is determined to be mentally incapable for a particular health decision, then the health practitioner must turn to the highest ranked SDM to obtain consent or refusal of consent for treatment or withdrawal of treatment.

1. Guardian of person – someone appointed by the court to be a person’s SDM
2. Attorney named in Power of Attorney for Personal Care (attorney here refers to the person(s) named in document)
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner – two persons are **spouses** if they are married to each other OR living in a marriage-like relationship (for at least 1 year or are parents of a child together or have signed a Cohabitation Agreement as defined under the Family Law Act) Two persons 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 persons’ lives.
5. Child or parent or Children’s Aid Society (person with right of custody)
6. Parent with right of access
7. Brother or sister
8. Any other relative (by blood, marriage, or adoption)
9. Office of the Public Guardian and Trustee (if no person meets the requirement to be a SDM- see definition of SDM for health care below for SDM requirements)

Hospice:

The term “hospice” is also used to describe a variety of specific services and supports, and care settings. Residential hospices create a home-like environment for patients who are at the end of their lives and need constant, sometimes intensive care.^{viii} In contrast, visiting hospices offer care through out-patient facilities or by travelling to a patient’s home. Finally, virtual hospices offer online resources to members of the public on palliative care, ACP and other issues relevant to the last stages of life.^{ix}

Informed Consent:

Under the HCCA, health care providers must obtain consent from a mentally capable individual or their SDM(s) prior to administering treatment, except in emergencies.^x Consent must relate to a specific treatment, be informed and voluntary, and must not be obtained through misrepresentation or fraud. Informed consent requires that information is provided on the nature, expected benefits, material risks and material side effects of the treatment as well as on alternative courses of action and the likely consequences of not having the treatment. Informed consent also requires that the person receives responses to his or her requests for additional information about those matters.^{xi}

Levels of Care:

A statement of broad wishes or health care preferences (where a person chooses between 3 or 4 levels of care to be provided) that is inconsistently defined across Ontario by long-term care homes and other healthcare facilities. These levels lack the specificity required for informed consent (i.e. lacks specific treatment details, discussion of current health context) and falsely assures health care providers that they have obtained consent. **Use of level of care forms do not comply with the HCCA and they should not be interpreted as consent or refusal to treatment, nor should they direct care on transfer to hospital.**

Palliative Care or Hospice Palliative Care:

The terms palliative care, hospice care and hospice palliative care (HPC) are often used interchangeably. By understanding this philosophical and clinical approach to care health service providers and the public will find that this care can be provided at any stage of the illness following diagnosis. This approach to care can enhance the quality of care for anyone living with a complex and/or chronic illness diagnosis, and is most beneficial if it is introduced early thorough an interdisciplinary team.

Those working in the field of hospice palliative care have embraced the definition of HPC as outlined by the Canadian Hospice Palliative Care Association (CHPCA) – A Model to Guide Hospice Palliative Care^{xii}.

“Hospice palliative care aims to relieve suffering and improve the quality of living and dying. Hospice palliative care strives to help patients and families address physical, psychological, social, spiritual and practical issues and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to treat all active issues; prevent new issues from occurring; promote opportunities for meaningful and valuable experiences, person and spiritual growth, and self-actualization.

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and /or needs, and are prepared to accept care.

Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

While hospice palliative care has grown out of and includes care for patients at the end of life, today it should be available to patients and families throughout the illness and bereavement experiences.”

Plan of Treatment:

Under the HCCA, a plan of treatment is defined as a plan that is developed by one or more health care practitioners to deal with health problems that are present or likely in the future given the person’s current health condition.^{xiii} Plans of treatment provide for the administration of various treatments or courses of treatment, including withdrawal and withholding of life-sustaining or life-prolonging treatment, in light of the person’s current health condition.^{xiv}

Power of Attorney:

A power of attorney is a legal document that an individual can use to authorize another person to make decisions on her or his behalf for property management (POAP) or personal care (POAPC). There are specific formal requirements in the SDA that must be met for a POA of either type to be valid. The person signing it (the grantor) must be mentally capable to grant a POA at the time they sign it. The POA must name someone (or more than one person) to be the “attorney(s)” which is the formal term for this kind of SDM. The POA must be in writing, must be signed by the person granting it, and must be witnessed by two witnesses. All three people – the grantor and the two witnesses- must be together and see each other sign the POA document at the time the document is signed. All these requirements must be met for the document to be valid.

Power of Attorney for Personal Care (POAPC):

A document in Ontario that a mentally capable person can prepare to name a person (or persons) to be their SDM(s) for future health and other personal care decisions. This document is used to name someone referred to as the “attorney” who would make future health and other personal decisions (decisions about nutrition, shelter, safety, clothing and hygiene) on behalf of that person if they were to become mentally incapable. The word “attorney” does not mean a lawyer but is anyone you name in that document. The Attorney for Personal Care is a type of SDM. Powers of attorney for personal care come into effect only when a person has been found to be mentally incapable under the SDA or HCCA. See definition of POA above for the requirements that must be met for a POAPC to be valid.

Psychosocial Care:

Refers to the emotional, intellectual, spiritual, interpersonal and cultural aspects of care. It essentially means everything except the physical care when used in palliative care. This includes providing communication and care that enhances opportunities to direct care, maintain relationships, and explore grief associated with the illness, the many transitions and dying.

Spirituality:

Refers to the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.

Substitute Decision Maker for Health Care:

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 law in Ontario automatically provides each person with a SDM for health decisions listed in the hierarchy of SDMs (see definition above).

The SDM(s) is required to make decisions on a person's behalf following any wishes expressed about care when mentally capable. If the SDM does not know any wishes applicable to the treatment decision to be made, he or she is required to act in the person's best interests.

To be a SDM, the person must meet the following requirements:

- Willing to act as the SDM
- Mentally capable to make the needed health decisions
- Available (in person, by phone or by some other means) when a decision needs to be made
- Not prohibited by a court order or separation agreement from acting as the SDM and
- At least 16 years of age

If more than one person is entitled to act as the SDM (e.g. three adult children of the incapable person) they must decide together or decide amongst themselves which ones of them will act as SDM. All three may act as SDM but they may decide that only one or two of them will act.

If there is more than one SDM acting, they must agree on any health decisions for the incapable person. If they disagree then the doctor would turn to the Public Guardian and Trustee to make the healthcare decision.

Terminal Illness:

Incurable medical conditions caused by injury or disease that affects health and quality of life. Sometimes referred to as life limiting or life threatening illness. This would include the diagnosis of any chronic illness which will progressively worsen throughout a person's lifetime, such as multiple

sclerosis, amyotrophic lateral sclerosis (ALS), stroke, heart/lung/kidney disease, and some cancer types.

Treatment:

The HCCA defines treatment as “anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose” with some exceptions set out in the legislation.^{xv}

Wishes, Values and Beliefs:

Wishes and explanations of a person’s values and beliefs guide the SDM(s) to understand who the person is, how they would make choices for themselves, what they think is important and what would have influenced their decision making. The SDM(s), and not the health care provider, interpret the wishes that were expressed by the capable person, when decisions for treatment are being sought. The SDM(s) must determine:

- whether the wishes of the patient were expressed when the patient was still capable (and were expressed voluntarily);
- whether the wishes are the last known capable wishes;
- whether the wishes are POSSIBLE to follow
- what the patient meant in that wish;
- whether the wishes are applicable to the particular decision at hand; and
- if there are no applicable/capable wishes, how the patient’s values, beliefs, and incapable/inapplicable wishes would apply to the patient’s best interest.

Key Reference Documents:

Ontario Health Care Consent Act, 1996 - <https://www.ontario.ca/laws/statute/96h02>

Ontario Substitute Decisions Act, 1992 - <https://www.ontario.ca/laws/statute/92s30>

Consent and Capacity Board - <http://www.ccboard.on.ca/scripts/english/aboutus/index.asp>

Public Guardian and Trustee Office - <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/>

ACE Advocacy Centre for the Elderly - http://www.ancelaw.ca/advance_care_planning_publications.php

Hospice Palliative Care Ontario - <http://www.hpco.ca>

Speak Up Ontario – <http://www.speakupontario.ca>

ⁱ HCCA, note 1, ss. 5(3), 10, 21, 25; Wahl *et al.*, note 1, 18-19.

ⁱⁱ HCCA, s. 4.

ⁱⁱⁱ See for instance: Government of Ontario, Local Health Integration Networks, Quality Hospice Palliative Care Coalition of Ontario, *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (December 2011) (“Declaration of Partnership”), 3, 12, 57.

^{iv} For definitions of frailty, see: Leocradio Rodriguez-Manas & Linda Fried, “Frailty in the Clinical Scenario” (2015) 385:9968 *The Lancet* 7; Jeremy D. Walston & Karen Bandeen-Roche, “Frailty: a Tale of Two Concepts” (2015) 13 *BMC Med* 185; Allan Gustavo Brigola, Estefani Serafim Rossetti, Bruna Rodrigues dos Santos, Anita Liberalesso Neri, Marisa Silvana Zazzetta, Keika Inouye & Sofia Christina lost Pavarini, “Relationship between Cognition and Frailty in the Elderly: A Systematic Review (2015) 9:2 *Dementia & Neuropsychology* 110.

^v See for instance: Rachele E. Bernacki & Susan D. Block, “Communication about Serious Illness Care Goals: A Review and Synthesis of Best Practices” (2014) 174:12 *JAMA Internal Medicine* 1994; Lauris C. Kaldjian, Ann E. Curtis, Laura A. Shinkunas & Katrina T. Cannon, “Goals of Care Toward the End of Life: A Structured Literature Review” (2009) 25:6 *American Journal of Hospice & Palliative Medicine* 501; John J. You; James Downar; Robert Fowler; Francois Lamontagne; Irene Ma; Dev Jayaraman; Jennifer Kryworuchko; Patricia Strachan; Roy Ilan; Aman Nijjar; John Neary; John Shik; Keven Brazil; Amen Patel; Kim Wiebe; Martin Albert; Anita Palepu; Elysee Nouvet; Amanda Roze des Ordon; Nishan Sharma; Amane Abdul-Razzak; Xuran Jiang; Andrew Day & Daren Heyland, “Barriers to Goals of Care Discussions with Seriously Ill Hospitalized Patients and their Families: A Multicenter Survey of Clinicians (2015) 175:4 *JAMA Internal Medicine* 549.

^{vi} Lauris C. Kaldjian, Ann E. Curtis, Laura A. Shinkunas & Katrina T. Cannon, “Goals of Care Toward the End of Life: A Structured Literature Review” (2009) 25:6 *American Journal of Hospice & Palliative Medicine* 501-511

^{vii} *Ibid.*

^{viii} Residential Hospice Working Group of the Hospice Palliative Care Provincial Steering Committee, *Environmental Scan for Strengthening Residential Hospice Care in Ontario: Evidence and Practice* (March 2015), 2; Ministry of Health and Long-Term Care, *Community Care Access Centres: Client Services Policy Manual* (January 2007), 7.7.

^{ix} See for instance, the Canadian Virtual Hospice, online: www.virtualhospice.ca (last accessed, 7 March 2016).

^x HCCA, note 1, ss. 10, 25.

^{xi} HCCA, ss. 11, 25.

^{xii} Ferris, Frank D., et al. A model to guide hospice palliative care: Based on national principles and norms of practice. 2002 p6.

^{xiii} Wahl *et al.*, note 1, 20, 49-50. CHECK

^{xiv} HCCA, note 1, s.2.

^{xv} HCCA, note 1, s.2.