

KEY PALLIATIVE CARE CONCEPTS AND TERMS

DEFINITION OF HOSPICE PALLIATIVE CARE

The Ontario Palliative Care Network (OPCN) endorses the definition provided by [Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action](#). This document states:

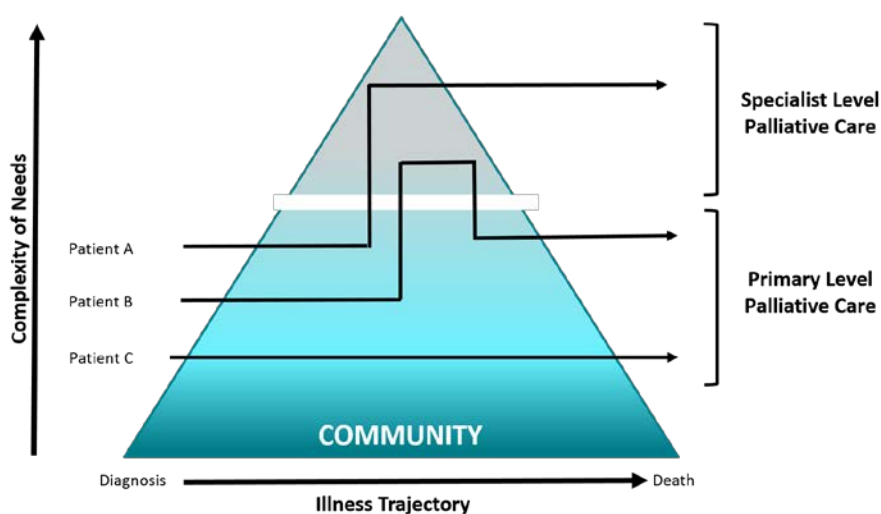
Hospice palliative care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage end-of-life choices and the dying process;
- cope with loss and grief;
- treat all active issues;
- prevent new issues from occurring; and
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth.

Hospice palliative care:

- is appropriate for any individual and/or family living with, or at risk of developing, a life-limiting illness, at any time they are prepared to accept this type of care and support;
- may enhance other types of care – including restorative or rehabilitative care – or may become the total focus of care;
- is most effectively delivered by an inter-professional team of health care providers skilled in all aspects of palliative care – including volunteer staff;
- is most effective when the care is integrated at the clinical, organizational and overall system level;
- is person- and family-centred, respecting people's social, spiritual and cultural practices; and
- includes end-of-life care, but is not limited to the time immediately preceding death.

WHO PROVIDES HOSPICE PALLIATIVE CARE?



Adapted from: [Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action](#) and Pallium Canada

- Complex palliative care needs may require transfer to specialist palliative care teams (Patient A)
- Some palliative care needs may require consultation and clinician to clinician support (shared care) by specialist palliative care teams (Patient B)
- Most palliative care needs can be addressed through primary-level palliative care (a palliative approach to care) (Patient C)
 - Primary care clinicians (i.e. family physicians, nurse practitioners, family health teams, nurse practitioner-led clinics, community nurses, home health care providers, pain and symptom management consultation teams, emergency care, etc.)
 - Non-palliative specialist clinicians (i.e. oncologists, internists, geriatricians, pediatricians, respirologists, cardiologists, nephrologists, neurologists, critical care physicians, surgeons, etc.)

KEY PRINCIPLES

- Hospice palliative care is active, research-based, medical and supportive care.
- A palliative approach to care should be initiated early in the diagnosis of a life-limiting illness by a primary care clinician or other treating clinician.
- Palliative care is not limited to the last days of a person's life.
- Hospice palliative care is applicable to all advanced disease states, including cancer and non-cancer conditions.
- Hospice palliative care is applicable across all age groups, sub-populations, cultures, religions and ethnic affiliations.
- Hospice palliative care can and should be provided concurrently with other disease-modifying treatments (chemotherapy, radiation, inotropes, non-invasive ventilation, hemodialysis, etc.).
- Evidence shows that early integration of hospice palliative care increases the quality and quantity of life for those living with an advanced, life-limiting illness.
- A multidisciplinary team (physician, nurse, nurse practitioner, social worker, dietician, spiritual care provider, physical and occupational therapist, volunteers, and others) is needed to provide comprehensive and quality care, based on patient needs.
- The knowledge, competencies and skills of all health professionals should be utilized to serve the needs of the patient and family.
- Social determinants of health must be considered to deliver effective hospice palliative care.
- Patient wishes, values, goals and beliefs must be established through advance care planning conversations and goals of care discussions. These should be initiated early, and reviewed regularly and as required according to health status, as needs will change over time.

LANGUAGE NORMS

Palliative:

- refers to an approach to care, as well as a philosophy of care.
- should not be used as a label for patients, nor as a category of patients. A person may have palliative care needs, or they may receive a palliative approach to care.
- is not a phase or stage in the illness trajectory, nor a diagnosis. A palliative approach to care is appropriate for any individual and/or family living with a life-limiting illness at any time.

Advance Care Planning

In Ontario, advance care planning is an iterative process that involves the mentally capable patient: **IDENTIFYING** their future Substitute Decision Maker by either

- **Confirming** their satisfaction with their default/automatic Substitute Decision Maker in the Substitute Decision Maker hierarchy list in the *Health Care Consent Act* OR
- **Choosing** someone else to act as Substitute Decision Maker by preparing a Power of Attorney for Personal Care (a formal written document).

SHARING their wishes, values, and beliefs through conversations with the SDM and others that clarify their wishes, values and beliefs, and more generally how they would like to be cared for in the event of incapacity to give or refuse consent.

Rather than being a single event, advance care planning is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. It may be initiated at any point in the health care process, and may involve individuals who are currently healthy.

Advance directive, or “living will”

The terms “advance directive” and “living wills” are not contained in the *Health Care Consent Act* and **should not** be used in Ontario as these cause confusion. Healthcare providers may believe they must take “direction” from the document, rather than seeing the document as the expression of a wish to be interpreted by a Substitute Decision Makerⁱ.

Ontario law requires consent even where a patient has engaged in advance care planning or has expressed their wishes in a written document.

Capacity or “mental capacity”

Under the *Health Care Consent Act*, 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 Mental capacity is issue- or task-specific, and would apply to a particular type of decision. A person should not be labelled as globally incapable. In Ontario, where an individual lacks mental capacity and a healthcare decision must be made, the healthcare practitioner must turn to the Substitute Decision Maker(s) to obtain consent or refusal of consent for treatment or withdrawal of treatment.

End-of-life care

End-of-life care refers to care for people in decline who are expected to die in the foreseeable (near) futureⁱⁱⁱ. It constitutes active care aimed at helping patients and families to prepare for death, ensure comfort, and to make care decisions that are consistent with the patient’s prognosis and goals of care.

Frailty

Frailty refers to a non-specific state caused by changes to a number of physiological systems, which may be related to a variety of physical, psychological, cognitive and social factors. Together, these changes lead to reduced function and strength, and affect the person’s resilience and ability to cope with any physiologic stress, such as an infection or disease or personal loss^{iv}.

Goals of care discussion

A goals of care discussion between a patient (or his/her Substitute Decision Maker if the patient lacks capacity) and healthcare provider(s) addresses the patient’s goals for his or her care in the context of healthcare consent and decision-making in advanced illness. The purpose of these discussions is to outline the patient’s values, beliefs, wishes, perception of quality of life and what he or she characterizes as meaningful and important. Other elements include the patient’s understanding of current health conditions, prognosis, and likely course of events if his or her goals of care are applied to potential treatment decisions. The goals of care discussion provides the

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foundation for decision-making and will often include the development of (and obtaining informed consent to) a plan of treatment.

Hospice

The term “hospice” is 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 access to 24-hour care. 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, advance care planning and other issues relevant to the last stages of life.

Health care consent (consent to treatment)

Health care consent refers to an informed and contextualized decision involving a mentally capable person and a healthcare provider as outlined in the Ontario *Health Care Consent Act*. Healthcare providers proposing treatment must obtain informed consent from either a capable patient or their Substitute Decision Maker if they do not have the mental capacity. This discussion must address present condition (context), available treatment options, risks/benefits/side effects, alternatives to treatment and what would happen without the proposed treatment.

Palliative approach to care

A palliative approach to care focuses on meeting a person’s and his/her family’s full range of needs – physical, psychosocial and spiritual – at all stages of a chronic progressive illness. It reinforces the person’s autonomy and right to be actively involved in his or her own care – and strives to give individuals and families a greater sense of control. It sees palliative care as less of a discrete service offered to dying persons when treatment is no longer effective and more of an approach to care that can enhance their quality of life throughout the course of their illness or the process of aging^v.

Palliative sedation

Based on the Canadian Consensus Framework, palliative sedation is defined as:

- 1) the use of (a) pharmacological agent(s) to reduce consciousness;
- 2) reserved for treatment of intolerable and refractory physical symptoms (rarely for existential distress); and
- 3) only considered in a patient who has been diagnosed with an advanced progressive illness.

Continuous palliative sedation therapy (CPST) is the use of ongoing sedation continued until the patient’s death. There remains concern over the misuse or abuse of sedation in general and continuous palliative sedation therapy in particular^{vi}.

Typically, continuous palliative sedation therapy is intended for the last days or weeks of life.

Palliative sedation is distinct from sedation caused as an unintended side-effect of medications that are given to relieve other symptoms (e.g. opioids administered for analgesia). Palliative sedation is also distinct from sedation given to relieve anxiety or agitation, when the intended effect is to make the patient calm and relaxed (but not necessarily unconscious). There has been some research exploring the practice and documentation of continuing palliative sedation therapy:

<http://www.current-oncology.com/index.php/oncology/article/view/1773/1486>

Power of Attorney for Personal Care

Power of Attorney for Personal Care is a legal document in which one person gives another person the authority to make personal care decisions on his or her behalf if he/she becomes incapable. In the document, the person is referred to as an **attorney for personal care** (this person is the **Substitute Decision Maker**). This is distinct from assigning Continuing Power of Attorney for Property, which gives the authority to make financial decisions on behalf of an incapable person.

Substitute Decision Maker

A Substitute Decision Maker is a person who makes care and treatment decisions on another person's behalf if and when that person becomes incapable of making these decisions. Decisions would be based on the incapable person's prior capable wishes, or, if these are not known, or not applicable, the decision should be consistent with known values and beliefs and in the best interest of that person. The *Health Care Consent Act* provides a hierarchy that lists who the automatic Substitute Decision Maker(s) would be if a patient did not have capacity to provide consent for a plan of treatment. If a patient is not satisfied with the automatic Substitute Decision Maker provided in the list, the patient must prepare a Power of Attorney for Personal Care.

For more terms, please see the Lexicon developed by The Way Forward:

<http://www.hpcintegration.ca/resources/lexicon.aspx>

ⁱ Advocacy Center for the Elderly (February 20, 2015). Comments on Draft Planning for and Providing Quality End-of-Life Care Policy (Approved by Council for Consultation). Email correspondence accessed at the Advocacy Centre for the Elderly

<http://www.advocacycentreelderly.org/appimages/file/FINAL%20ACE%20response%20to%20CPSO%20Planning%20for%20the%20End%20of%20Life%20Policy%20Feb2015.pdf>

ⁱⁱ HCCA, s. 4.

ⁱⁱⁱ Canadian Institute for Health Information, Health care use at the End of Life in Atlantic Canada (Ottawa: CIHI, 2011).

^{iv} Canadian Hospice Palliative Care Association, Lexicon, The Way Forward Initiative: An Integrated Palliative Approach to care, 2014

^v <http://www.hpcintegration.ca/resources/lexicon.aspx?cat=l#sthash.KDe6cS0e.dpuf>

^{vi} Dean, M. M., Cellarius, V., Henry, B., Oneschuk, D., & Librach, S. L. (2012). Framework for continuous palliative sedation therapy in Canada. *Journal of palliative medicine*, 15(8), 870-879.