

JOINT POSITION STATEMENT

The palliative approach to care and the role of the nurse

The Canadian Nurses Association (CNA), the Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Hospice Palliative Care Nurses Group (CHPC-NG) support the **palliative approach**¹ to care and its central aim (as outlined in *The Way Forward National Framework*): to help people live well until death, across the lifespan, in all practice settings.² All nurses³ have a fundamental role in a palliative approach to care.

POSITION

CNA, CHPCA and CHPC-NG believe that:

Nurses are essential providers of health care throughout people's lives until death occurs. Their practice within the palliative approach and primary health care framework⁴ is based on CNA's *Code of Ethics for Registered Nurses*.

Person-centred care is the foundation of the palliative approach. It honours people's **values** and health-care wishes by promoting **autonomy**, dignity and control as well as **shared decision-making** (as appropriate) with health-care decisions.

Nurses, as key stakeholders, advocate for high-quality palliative and **end-of-life care** that is accessible to all Canadians and is provided in a setting of choice that best suits their care needs.

Nurses (across practice settings and domains of practice), **interdisciplinary** colleagues, health-care employers and governments all share a responsibility to support accessible, high-quality palliative and end-of-life care:

- Nurses in all clinical practice settings are responsible for providing and advocating for safe, compassionate, competent, ethical and evidence-informed palliative and end-of-life care.⁵
- Nurse educators are responsible for teaching nursing students and nurses (from novice to expert) about palliative and end-of-life care by explaining and modelling related competencies.
- Nursing regulators are responsible for ensuring that professional standards of practice are followed in palliative and end-of-life care across the continuum.
- Nursing policy-makers are responsible for developing, promoting and advocating for proactive policy on palliative and end-of-life issues.

1 Terms in bold text are included in the glossary.

2 CNA, CHPCA and CHPC-NG wish to acknowledge the contributions of the palliative and end-of-life care position statement working group in the development of this statement and glossary.

3 In this document, the term *nurse* refers to a registered nurse, clinical nurse specialist and nurse practitioner.

4 The primary health care framework underpins nursing practice in all settings. It includes the five "principles outlined in the World Health Organization's 1978 *Declaration of Alma-Ata*: (1) accessibility; (2) active public participation; (3) health promotion and **chronic disease** prevention and management; (4) the use of appropriate technology and innovation (including knowledge, skills and information); and (5) intersectoral cooperation and collaboration" (Canadian Nurses Association [CNA], 2012, p. 1).

5 All nurses value the right to life and the importance of a person's choices, dignity and respectful treatment. The CNA code of ethics provides guidelines for nurses when changes in health-care practices challenge a nurse's moral obligations when providing care (p. 43).

- Nurse researchers are responsible for identifying evidence-informed best practices, evaluating outcomes and promoting research on the provision of end-of-life nursing care.
- Nurse leaders, both formal and informal, are responsible for demonstrating, promoting and advocating for a palliative approach to care.
- Interdisciplinary colleagues are responsible for collaborating with the patient and team members to meet the patient's goals of **care**.
- Health-care employers are responsible for creating practice environments that promote access to safe, compassionate, competent, and ethical palliative and end-of-life care and offer related continuing education for health-care providers.
- Governments are responsible for supplying adequate resources (financial and human) to make quality palliative and end-of-life care services accessible for Canadians. This responsibility includes ensuring an appropriate nursing workforce is in place to enable such access.

BACKGROUND

Terminology

The following discussion on the palliative approach to care uses four distinct terms:⁶

Palliative care — seeks to improve a person's quality of life once a chronic, life-limiting condition is diagnosed. It then continues until death and into family **bereavement** and care of the body. Palliative care is provided in all **primary care** settings, including homes, ambulatory clinics and other community settings, and in all tertiary care settings, including hospitals, hospices and long-term care facilities.⁷

The palliative approach — uses **palliative care** principles (i.e., dignity, hope, comfort, **quality of life**, relief of **suffering**) with people facing chronic, life-limiting conditions at all stages, not just at the end of life. It reinforces personal autonomy, the right for persons to be actively involved in their own care and a greater sense of control for individuals and families. The palliative approach “does not link the provision of care too closely with prognosis”; rather, it focuses (more broadly) on “conversations with [people] about their needs and wishes.”⁸

Specialized palliative care — involves a specialist palliative care team or health professional to augment palliative care, usually in one of two ways:

- assessing and treating complex symptoms
- providing “information and advice to staff about complex issues (e.g., ethical challenges, **family** issues, psychological or existential distress)”⁹

End-of-life care — starts in the final stage of dying, then continues until death and into family bereavement and care of the body. It is provided across all settings across the continuum of care to relieve suffering and improve the quality of living until death.

⁶ More detailed descriptions of these terms can be found in the glossary.

⁷ (Carstairs, 2010)

⁸ (Stajduhar, 2011, p. 10)

⁹ (Kristjanson, 2005, p. 15)

The palliative approach in Canada

Most Canadians would prefer to die at home surrounded by their loved ones. In practice, nearly three-quarters die in hospitals — which are costly in both economic and human terms. While hospitals are responsible for most end-of-life care **costs** in Canada,¹⁰ because hospitals are designed for treatment and recovery,¹¹ the experience of dying there can often mean inappropriate treatments, poorly managed symptoms, prolonged suffering and painful bereavement.¹²

Using the palliative approach to care would reduce these hospitalizations and inappropriate medical treatments, including those not in keeping with the person's end-of-life wishes. Ultimately, a palliative approach offered in the person's setting of choice that best suits care needs is more effective for improving health outcomes (including a peaceful death) and sustaining the health-care system. It would also reduce the significant emotional trauma persons and families may experience at the end of life.

Canada would benefit from having more specialized palliative care services and more accessible palliative approaches for patients approaching the end of life and their families.¹³ Specialized end-of-life care includes **pain and symptom management** as well as bereavement, which are usually provided in designated **hospice palliative care** programs or facilities. Hospice palliative care programs would help Canadians “gain more control over their lives, manage pain and symptoms more effectively, and [support] family **caregivers**.”¹⁴

Despite the growth of specialized palliative care services, high-quality end-of-life care is still inaccessible for far too many patients and families,¹⁵ particularly in non-specialized acute medical-surgical units and in residential, long-term and home care settings.¹⁶ Consequently, Canadian leaders from non-governmental organizations, nursing and governmental sectors are recommending a palliative approach be embedded into primary care and be used with all people who are moving toward or are near the end of life.

Role of the nurse

Over several years, the hospice palliative care movement has been able to promote palliative care as a specialized form of nursing practice and has already “irreversibly improved the standards of care for the dying.”¹⁷ In fact, by addressing care at the end of life, palliative care nursing has emerged as a unique and highly valued specialty.¹⁸ In keeping with its principles, the nurses who work in this area focus on enhancing a person's quality of life, regardless of age, and on supporting family members and significant others.¹⁹

Palliative care nursing practice is closely tied to nursing values more generally. All nurses value the right to life and the importance of a person's choices, dignity and respectful treatment. Access to pain relief and other symptom management practices reflected in the **care plan** are inherent to providing quality care and dignity in life until death.

10 The Canadian Institute for Health information (2007) found that just 16 to 30 per cent of western Canadians have access to and receive palliative or end-of-life care. By contrast, of the 90 per cent of Canadians who can benefit from palliative care, 70 per cent do not receive these services.

11 (CHPCA, 2013a)

12 (Chan, 2014; Heyland, et al., 2006)

13 (Carstairs, 2010; Stajduhar, 2011)

14 (CHPCA, 2013b)

15 (Storch, Starzomski, & Rodney, 2013)

16 (Peter, 2013)

17 (Stajduhar, 2011, p. 8)

18 This specialty includes hospice nurses.

19 (Stajduhar, 2011)

Nurses have a fundamental responsibility to alleviate suffering, and the need for effective nursing support is universal.

The *Code of Ethics for Registered Nurses* is also foundational to nursing practice. With care of the dying, it counsels nurses to “foster comfort, alleviate suffering,²⁰ advocate for adequate relief of discomfort and pain and support a dignified and peaceful death. This includes support for the family during and following the death.”²¹ In addition, the code considers changes in health-care practices that challenge a nurse’s moral obligations when providing such care.²²

Overall, the Canadian health-care system needs nurses to provide a palliative approach to care for the people they interact with, across the lifespan and across the continuum of care and care settings. Today, nurses in all practice settings directly engage with people and their human condition, assessing suffering²³ and survival while supporting them as they progress through death and dying.²⁴ As a result, nurses play a key role in the palliative approach to care by

- initiating communication that reflects people’s values and health-care wishes;
- honouring the values and health-care wishes of persons and supporting families;
- advocating for and supporting persons in their experience of living and dying;
- providing comprehensive, coordinated, compassionate and holistic care to persons and their families;
- attending to pain and other symptom relief and to psychosocial, grief and bereavement support to maximize a person’s quality of life and death;
- providing a compassionate and therapeutic presence to persons and families, including support for grief and bereavement, throughout the dying process; and
- advocating for resources that support persons and families in choosing their preferred environment for a peaceful and dignified death.²⁵

In terms of quality palliative and end-of-life care, these are “best provided through the collaborative practice of an interdisciplinary team to meet the physical, emotional, [psychosocial, cultural], and spiritual needs of the person and their family.”²⁶ Nurses today work in collaborative, interdisciplinary teams²⁷ while supporting other professionals’ ability to practise with integrity in delivering optimal palliative and end-of-life care.

Interdisciplinary teams are also important for determining whether a person needs specialized palliative care services or a more general palliative approach (an essential and ongoing issue in palliative and end-of-life care). Such teams can address the complex spectrum of needs related to the progression of illness and the end of life. Nurse practitioners, clinical nurse specialists and nurses who are CNA certified in hospice palliative care can provide significant leadership to promote this interprofessional collaboration.

20 Suffering, unlike pain, is intrinsic to a person: it requires that we understand people as individuals.

21 (CNA, 2008, p. 14)

22 See Appendix D in the code of ethics, “Ethical considerations in addressing expectations that are in conflict with one’s conscience,” pp. 43-45.

23 (Chochinov, 2007)

24 (Austin, 2011)

25 (Canadian Hospice Palliative Care Nursing Standards Committee [CHPCNSC], 2014)

26 (CHPCNSC, 2001, p. 9)

27 Interdisciplinary team members include different health-care disciplines that work together in advocating for the person’s health goals to meet assessed and expressed comprehensive health-care needs (Canadian Health Services Research Foundation, 2012).

Advance care planning

The first step in achieving an effective palliative approach and/or palliative care is by starting the conversation about end-of-life care early and periodically revisiting it throughout a person's life. Advance care planning, though often initiated to help guide end-of-life care, can be undertaken at any point. It requires open and ongoing conversations between persons, their families and health-care professionals.

Nurses should encourage all people to reflect on, communicate and document their values (i.e., personal, cultural, religious and those that constitute a legacy for enduring and sustaining life), in addition to health and personal care wishes that include end-of-life care. Such planning means that significant others, **substitute decision-makers** and health-care teams will know about people's values and wishes in circumstances when they are no longer able to direct their care providers. In some jurisdictions, such conversations may result in an **instructional directive**, "a person's formal or informal instructions about their future care and choice of treatment options."²⁸

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28 (Quality End-of-Life Care Coalition of Canada, Canadian Hospice Palliative Care Association, 2014, p. 56)

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Also see:

[Canadian Hospice Palliative Care Nurses Group](#)

[Canadian Virtual Hospice](#)

[iPANEL](#)

[Speak Up: Advance Care Planning in Canada](#)

[The Way Forward: The National Framework](#)

[Worldwide Hospice Palliative Care Alliance](#)

Replaces:

Providing Nursing Care at the End of Life (2008)

GLOSSARY

ADVANCE CARE PLANNING. An ongoing process of reflection, communication and documentation of a person’s values and wishes for future health and personal care in the event that they become incapable of consenting to or refusing treatment or other care. Conversations to inform health-care providers, family and friends — and (especially) a substitute decision-maker — should be regularly reviewed and updated. Such conversations often clarify the wishes for future care and options at the end of life. Attention must also be paid to provincial/territorial legal and health guidelines.¹

AUTONOMY. An ethical principle that refers to respect for persons as unique beings with dignity and a capacity for control over health-care wishes. To honour a person’s autonomy is to acknowledge that person’s right to make choices and take actions, within the law and the context of family, based on their own values and beliefs.

BEREAVEMENT. A broad term that encompasses “the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one.”² Nurses can support family members and friends by being present and allowing them to express feelings of loss and sorrow before and after death.

CARE. “Interventions, treatments and support provided to the person to treat disease, and to enhance health and well-being,”³ across the lifespan until the end of life. Goals for a person’s care, which includes disease treatment and/or symptom management as well as limits on interventions according to the person’s wishes, are supported and informed by the care team.

CARE PLAN. A documented plan that “describes the person’s assessed [and expressed] health needs and goals [i.e., physical, emotional, mental, et al.] and the care that will be provided to meet those needs and goals.”⁴

Family input is considered. A person-centred care plan should be developed to accompany a formalized instructional directive, and this care plan should evolve as the person’s condition changes.

CAREGIVER. “Anyone who provides care.” Health-care organization caregivers are “accountable to defined norms and professional standards of practice.”⁵ Caregivers may be paid health-care professionals or unregulated care providers; family caregivers are family members and significant others who are often unpaid. Family caregivers may have no formal education related to health care.⁶

CHRONIC DISEASE. A disease that “may develop slowly, last a long time, be incurable, and be progressive and/or life-limiting. . . . The disease and its treatment may cause symptoms . . . that can also limit people’s activities, cause them psychological distress and have a negative effect on their quality of life.”⁷ A chronic disease may have uncertain, complex and sometimes a prolonged trajectory toward death. It “cannot be cured but its symptoms can be managed.”⁸

COST. Costs associated with end of life are financial, including health human resources. There are also significant human costs (quality of life, quality of death and bereavement) that ought to be attended to in palliative and end-of-life care.

END-OF-LIFE CARE. Begins when a person is actively dying, then continues until death and into family bereavement and care of the body.⁹ It is care provided to relieve suffering and improve the quality of living until death in all settings across the continuum of care.

FAMILY. The person defines the family members, which “may include the relations through biology, acquisition, or choice.”¹⁰

1 (Storch, Rodney, & Starzomski, 2013)

2 (Canadian Hospice Palliative Care Nursing Standards Committee [CHPCNSC], 2014, p. 16)

3 (Canadian Hospice Palliative Care Association [CHPCA], 2014, p. 1)

4 Ibid., p. 2.

5 Ibid., p. 1.

6 (CHPCA, 2014)

7 (CHPCA, 2014, p. 1)

8 Ibid.

9 (Carstairs, 2010)

10 (CHPCNSC, 2014, p. 17)

HOSPICE PALLIATIVE CARE. Hospice palliative care is specialized end-of-life care that “aims to relieve suffering and improve the quality of life”¹¹ and death. It is “provided by health professionals and volunteers, [who] give medical, psychological and spiritual support. The goal of the care is to help people who are dying [and their families to] have [as much] peace, comfort and dignity [as possible]. The caregivers try to [minimize suffering as well as] control pain and other symptoms so a person can remain as alert and comfortable as [the person wishes]. Hospice palliative programmes also provide services to support a patient’s family.”¹²

INSTRUCTIONAL DIRECTIVE. A written document that specifies which treatments an individual does and does not want, in case that individual becomes unable to make decisions about his or her care. This is one component of an advance directive (see substitute decision-maker).

INTERDISCIPLINARY. Interdisciplinary team members include different health-care disciplines that work together in advocating for a person’s health goals to meet assessed and expressed comprehensive health-care needs.¹³ Team members have different education, competencies and skills to implement a person’s care plan. The services required to address the person’s identified issues, expectations and needs will determine the members of the person’s health-care team. An interdisciplinary team may include but is not limited to any of the following: nurses (including registered nurses, nurse practitioners and clinical nurse specialists), licensed/registered practical nurses and registered psychiatric nurses, allied health workers, dietitians, naturopaths, pharmacists, physicians, psychologists, speech/language pathologists, social workers, spiritual advisors, unpaid caregivers, unregulated care providers and volunteers.

PAIN AND SYMPTOM MANAGEMENT.

Management of pain and other symptoms that cause discomfort and reduce one’s quality of life.¹⁴ It is a key component of palliative care and “addresses one of the

common concerns expressed by dying individuals: a fear that they will experience pain and suffering. Although increasing doses of pain medication may, in very limited instances, have the secondary and unintended effect of hastening death, this action is ethically justifiable if the dosage of pain medication is adjusted appropriately and the primary intent is to relieve pain.”¹⁵ The more pressing concern is the under-treatment of pain.¹⁶

PALLIATIVE APPROACH. Takes the principles of palliative care (such as dignity, hope, comfort, quality of life, and relief of suffering) and applies them to the care of people with chronic, life-limiting conditions by meeting their full range of physical, psychosocial and spiritual needs at all stages of life, not just the end. It does not link the provision of care too closely with prognosis but more broadly focuses on conversations with people about their needs and wishes.¹⁷ This approach “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.”¹⁸

PALLIATIVE CARE. Care given to improve quality of life for people facing challenges associated with chronic, life-threatening illnesses. Through the prevention and relief of suffering, palliative care promotes early identification and comprehensive assessment and treatment of pain and other challenges including, physical, psychosocial and spiritual issues.¹⁹ Palliative care is provided in all care settings including homes, communities, institutions (e.g., hospitals, hospices, long-term care facilities). It is care that starts at diagnosis of a chronic, life-threatening condition, carries through until death and continues into bereavement and care of the body.²⁰ According to people’s specific and individualized needs, palliative care can be delivered at three levels:

- Through a palliative approach to care adopted by all health-care professionals

11 (CHPCA, 2014, p. 1)

12 (Worldwide Palliative Care Alliance [WPCA] & World Health Organization [WHO], 2014, p. 6)

13 (Canadian Health Services Research Foundation, 2012)

14 (CHPCA, 2014)

15 (CNA, 2000, p. 3)

16 (Portenory et al., 2006)

17 (Stajduhar, 2011)

18 (CHPCA, 2014, p. 2)

19 (WHO, 2015b)

20 (Carstairs, 2010)

- General palliative care for people with life threatening diseases, provided by health-care professionals and others who have knowledge of the palliative approach
- Specialist palliative care for people with complex conditions (complex care), provided by specialized individuals or teams of professionals²¹

PERSON-CENTRED CARE. Care that is respectful of and responsive to individual needs and values. It is an approach to care delivery that ensures these values guide clinical decision-making. “All aspects of care are provided in a manner that is sensitive to the person’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.”²² It is founded upon “healing relationships grounded in strong communication and trust.”²³

PRIMARY CARE. Clinical health-care services at the initial point of care, which can be provided in a variety of settings, such as family practice, emergency departments, ambulance, et al.²⁴

QUALITY OF LIFE. Well-being as defined by the person living with advanced illness. It “relates both to experiences that are meaningful and valuable to the person, and his/her capacity to have such experiences.”²⁵ It relates to a state of “physical, mental, and social well-being, not merely the absence of disease.”²⁶ The “quality of living and dying is the goal of hospice palliative care.”²⁷

SHARED DECISION-MAKING. Shared decision-making is the collaboration between the health-care provider and the patient, through two-way communication and information exchange, to come to an agreement about a treatment decision. It is used primarily in cases where

there are several treatment alternatives with no single “best” option.

SPECIALIZED PALLIATIVE CARE. Involves “referral to a specialist palliative care team or health professional. It does not replace a palliative approach but, rather, augments it with focused, specific input as required, usually in one of two ways: assessment and treatment of complex symptoms, or provision of information and advice to staff about complex issues (e.g., ethical dilemmas, family issues, or psychological or existential distress).”²⁸

SUFFERING. A state of real or perceived distress (i.e., physical or emotional pain) that occurs when a person’s quality of life is threatened. It may be accompanied by a real or perceived lack of options for coping, which may create great anxiety.

SUBSTITUTE DECISION-MAKER. A capable person with the legal authority to make health-care treatment decisions on behalf of an incapable person. A capable person is someone who has the legal authority to provide consent for health-care treatment or withdrawal of treatment on behalf of another person who is incapable of communicating their own wishes. Since provincial and territorial legislation is not uniform across Canada, each jurisdiction has its own guidelines related to substitute decision-making and instructional directives for treatment and care. Terms also differ across the provinces/territories.²⁹ Nurses need to become familiar with the terms used in their own jurisdictions (see instructional directive).

VALUE. A standard or quality that is “esteemed, desired, considered important or [has] worth or merit (Fry and Johnstone, 2002).”³⁰ Values include “the core beliefs we hold regarding what is right and fair in terms of our actions and our interactions with others. Another way to characterize values is that they are what an individual believes to be of worth and importance to their life (valuable). (From *What is the Difference Between Ethics, Morals and Values?* Frank Navran).”³¹

21 (WPCA & WHO, 2014)

22 (CHPCA, 2013, p. 8)

23 (Epstein, Fiscella, Lesser, & Stange, 2010, p. 1)

24 (CNA, 2012)

25 (CHPCA, 2014, p. 2)

26 (WHO, 2015a, para. 1)

27 (CHPCNSC, 2014, p. 18)

28 (Kristjanson, 2005, pp. 14-15)

29 (“Substitute decision-maker”)

30 (CNA, 2008, p. 28)

31 (“Values”)

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