

***Position Statement***



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# **Palliative and End-of-Life Care**

**A Position Statement**

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Approved by the College and Association of Registered Nurses of Alberta (CARNA) Provincial Council, June 2018.

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Nurses<sup>1</sup> provide palliative and end-of-life care for people with a life limiting and/or life-threatening condition across a wide variety of settings, including primary care, home care, continuing care, hospitals, hospice, corrections, and shelters. Nurses working in these care settings must have the skills and competencies to integrate palliative and end-of-life care into their nursing care.

Often there are difficult and important decisions to be made in these circumstances, and nurses have an important role to play in listening to and encouraging individuals to express their goals and wishes related to end-of-life care and to communicate these wishes to other health-care providers (CNA, CHPCA, & CHPC-NG, 2015).

### **Purpose**

The purpose of this document is to present beliefs and principles to guide the practice of nurses in palliative and end-of-life care.

Nurses' contribution to palliative and end-of-life care is vital as they have the expertise and leadership skills to coordinate and implement palliative and end-of-life care services.

The practice of nurses is grounded in the Canadian Nurses Association (CNA) *Code of Ethics for Registered Nurses* (2017) and the College and Association of Registered Nurses of Alberta (CARNA) *Practice Standards for Regulated Members* (2013). Other key documents provide direction and guide nursing practice; for example:

- *Medical Assistance in Dying: Standards of Practice for Nurse Practitioners* (2016)
- *Medical Assistance in Dying: Guidelines for Nurse Practitioners* (2017)
- *Medical Assistance in Dying: Guidelines for Nurses in Alberta* (2017)
- *Pronouncement of Death: Guidelines for Regulated Members* (2018)
- *Scope of Practice for Nurse Practitioners* (2017)
- *Scope of Practice for Registered Nurses* (2011)

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<sup>1</sup> The term nurse(s) in this document refers to all regulated members of CARNA including registered nurses, graduate nurses, certified graduate nurses, nurse practitioners and graduate nurse practitioners.

## What is Palliative and End-of-Life Care?

The World Health Organization (WHO Definition of Palliative Care, n.d.) defines palliative care as an approach that improves the quality of life of patients and their families facing a life-threatening condition. Palliative care focuses on managing symptoms through the prevention and relief of suffering. Palliative and end-of-life care is both a philosophy and an approach to care that enables all individuals with a life limiting and/or life-threatening condition to receive integrated and coordinated care across the continuum (Alberta Health Services, Palliative and End-of-Life Care Alberta Provincial Framework, 2014).

## Principles Related to Palliative and End-of-Life Care

The goals of palliative and end-of-life care are to:

- provide person centred care
- care for and support the family
- improve the quality of life and death for the person
- provide comfort
- maintain the person's dignity

These goals recognize that the person's priorities, values, and choices are to be respected and considered in every aspect of care.

A palliative approach to care takes the principles of palliative and end-of-life care 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 of life (CNA, CHPCA, & CHPC-NG, 2015). Palliative and end-of-life care is appropriate for any person and their family living with a life limiting condition, regardless of age, and at any time they have unmet expectations and/or needs. Only a small proportion of Canadians will need the kind of complex, intensive, or tertiary hospice palliative and end-of-life care provided by expert palliative care teams. However, everyone who is becoming frail or is faced with a chronic condition could benefit from certain key palliative and end-of-life care services (CHPCA, 2015).

CARNA believes that the following principles are fundamental to palliative and end-of-life care. These principles are grouped in four categories: person and family centred care, quality of life, providing comfort, and maintaining dignity.

## Promoting Person and Family Centred Care

As advances in medical treatment continue, disease trajectories change and people diagnosed with a life limiting or life-threatening condition can live many years. The need for palliative and end-of-life care has never been greater. Canadians need to have access to palliative and end-of-life care services integrated with their care to help them manage symptoms, enhance their lives, give them a greater sense of control, and enable them to make informed decisions about the care they want (CHPCA, 2015). The person and their family are experts in their own experiences and need to be the center of their own care.

- Nursing care is directed towards meeting the physical, psychological, social, and spiritual expectations/needs of the person and their family.
- The person identifies who makes up their family.
- Palliative and end-of-life care is culturally safe, responsive, and has an integrated approach.
- Every person has the right to determine who has access to their personal information and who may participate in care decisions.
- Every person and their family have the right to be informed and to participate in decisions and care to the degree that they wish.
- Every person and their family are encouraged to discuss palliative and end-of-life care with their health-care providers, including the importance of advance care planning (Covenant Health, 2016).
- The needs, strengths, and resources of the person and family are included in the plan of care.
- The setting where care is to be provided and death is to occur is guided whenever possible by the preference of the person and family.
- Palliative and end-of-life care needs to be integrated into existing health-care systems.
- Nurses assess the personal health of families and caregivers for challenges they may be experiencing such as isolation, stress, anxiety, exhaustion and anticipatory grief. They recommend respite care when needed (Covenant Health, 2016).

## Preserving and Improving Quality of Life

The quality of life of persons and their families facing a life-threatening condition are greatly improved by palliative care (WHO, 2017). Work needs to be done to integrate a palliative care approach throughout every aspect of the health-care system (CHPCA, 2015).

- Quality of life is defined by each person and their family, and death is recognized as part of the natural process of life.
- Conversations surrounding quality of life are completed and identify any personal, religious, cultural beliefs, values, and practices that are important in the care of the person.
- Palliative and end-of life care services and access to palliative care expertise needs to be available across Alberta, 24 hours a day, seven days a week.
- Palliative and end-of-life care services must be accessible, equitable, portable, and adequately resourced (Covenant Health, 2016).
- Palliative and end-of-life care services include grief and bereavement support from a cross-cultural perspective throughout the condition and following death of the person.
- Palliative and end-of-life care services include access to current palliative and end-of-life care information, pain and symptom management, and supportive care.
- Organizational support and resources are essential to coordinate, organize, and ensure accountability in palliative and end-of-life care services.
- Quantitative and qualitative research on palliative and end-of-life care needs to collect data that can be used to improve care.

## Providing Comfort

Expert palliative and end-of-life care services can be provided by specialist palliative care teams for people with complex needs. However, most people in need of palliative and end-of-life care are in their homes (WHO, 2017). An integrated palliative care approach requires that palliative and end-of-life care be developed, fostered, and delivered by a competent team of providers throughout a person's terminal condition (CHPCA, 2015).

- Ensure all practice settings and providers aim to relieve a person's pain and suffering, including appropriate and effective symptom management (CNA, 2017).

- Opioids can be an essential palliative care medication and there must be a balance between the prevention of illegal drug use and ensuring accessibility to opioids to relieve moderate and severe pain (WHO, 2017).
- All entry-level nursing education programs should have a core palliative and end-of-life care component that includes pain and symptom management, disease progression, advance care planning, psychosocial support, and grief and bereavement.
- Nurses should establish and have access to continuing competency development and education in palliative and end-of-life care.
- Palliative and end-of life care needs to be integrated into any setting where people can experience a life limiting and/or life-threatening condition (CHPCA, 2015).
- Models of palliative and end-of-life care link home care and care in the community to systems with palliative and end-of-life expertise (WHO, 2017).
- Inter-professional care teams must have the resources and the supportive policies and programs to provide the right care in the right place at the right time.
- Coordination of palliative and end-of-life care services and effective communication among care providers and across settings is fundamental.

## Maintaining Dignity

In palliative and end-of-life care, health-care teams work with persons receiving care and their families to take into account their values, customs and spiritual beliefs without judgement or bias.

- Nurses recognize and respect the intrinsic worth of each person and treat all persons receiving care with respect (CNA, 2017).
- Nurses conserve person and family dignity by facilitating the expression of stories, feelings, needs, and concerns in planning for palliative and end-of-life care.
- Nurses encourage, listen, and document end-of-life goals and wishes (CNA, 2017).
- Nurses support and advocate for resources for family and caregivers in providing care in a person's home.



## The Role of the Registered Nurse

The registered nurse (RN) providing care to a person with a life limiting or life-threatening condition:

- works collaboratively with the person receiving care throughout their journey to identify and put in place the necessary supports;
- aims to maintain and improve quality of life through efforts to alleviate physical, emotional, psychological, and spiritual suffering;
- advocates for and involves the person and family in health-care decision making (CNA, 2017);
- applies a unique body of evidence-informed knowledge, skill, and experience to provide individualized and effective palliative and end-of-life care;
- follows relevant legislation, policies, guidelines, and tools pertaining to assessment, information sharing, decision-making, advance care planning, pronouncement of death, after death care, and grief and bereavement support (CARNA, 2013);
- understands the trajectory of the life limiting condition and the impact, limitations, and care required within these transitions;
- identifies and responds to all the complex and multiple issues that a person and their family may face including discussion of end-of-life issues (CNA, 2017);
- uses an approach to clinical decision-making that provides guidance and support in addressing ethical questions and concerns that registered nurses face in different ways across a variety of practice settings (CARNA, 2010);
- assists the person and their family to access and navigate the health-care system;
- communicates respectfully with the interprofessional team;
- advocates for basic and advanced palliative and end-of-life care education;
- advocates for the development and funding of effective palliative and end-of-life care services;
- strengthens palliative and end-of-life care by encouraging positive societal attitudes toward living with an advanced condition and that death is a natural process;

- advocates for the development and maintenance of health-care environments conducive to ethical practice and to the health and well-being of clients and others in the setting (CNA, 2017);
- recognizes the signs of stress that lead to self-exhaustion and identifies strategies for dealing with stress for themselves and their colleagues when caring for people and families living with life limiting conditions; and
- participates in nursing research in palliative and end-of-life care for the enhancement of nursing practice, and helps people with a life limiting condition to live well and die well.

## The Role of the Nurse Practitioner

The nurse practitioner (NP) role includes the above RN role and in addition, the NP providing care to a person with a life limiting or life-threatening condition:

- applies the principles of a palliative and end-of-life approach from diagnosis through to bereavement;
- uses holistic, palliative, and end-of-life care competencies to conduct comprehensive health assessments and diagnose conditions;
- using a person centred approach, presents care and treatment options and their anticipated benefits and risks in terms that are understandable to the person;
- discusses, establishes, and documents goals of care;
- ensures treatment plans are consistent with the person's goals of care, advance care plan, personal directive, and the trajectory of the life limiting condition;
- prescribes medications and therapeutic interventions to manage pain and suffering and reviews for symptoms and needs as necessary;
- reviews treatment plans as necessary to ensure congruency in goals of care; and
- assumes a leadership role in palliative and end-of-life care for the person and family receiving care and the health-care team.

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