



Palliative Approach to Care

Service Delivery Model for the NWT

Table of Contents

Introduction	1
What a Palliative Approach to Care is	3
Patient and Family Centredness	4
Open Communication	5
Cultural Competence and a Palliative Approach to Care	6
Where is a Palliative Approach to Care Available in the Northwest Territories?	7
Who Provides a Palliative Approach to Care?	8
Continuum of Palliative Care	9
Basic Palliative Care	9
Specialized End-of-Life Care	10
Access to Palliative End-of-Life Care Services	10
Continuing Care Services Action Plan	11
Glossary of Terms	12


Introduction

Palliative care has traditionally been viewed as specialized care provided during the last few months, weeks or days of a person's life. In reality, however, most people die unexpectedly, not within a defined timeframe, and often without having been identified as palliative. For these reasons, current best practice is for providing a ***palliative approach to care*** beginning earlier within person's journey with an illness. This approach better meets the individual's health care needs and also supports family and community caregivers throughout the illness, not just at the end of life.

In the Northwest Territories (NWT), as in the rest of Canada, the number of people with life-limiting conditions and illness is growing. While most are elderly, people across the lifespan may be impacted, including children. They all have the right to quality of life for as long as possible. The growing senior population has increased the demand for palliative care services, challenging the health and social services system to respond with innovative approaches appropriate for a diverse, sparsely populated and remote territory.

The GNWT Department of Health and Social Services (Department) is committed to ensuring a quality palliative approach to care is available to all residents of the Northwest Territories when they need it and in the location they wish to receive it.





The Department's strategic framework, *Our Elders, Our Communities*¹ identified palliative care as one service that is needed for elders to be able to age in their community.

In *Caring for Our People: Strategic Plan for the Health and Social Services System 2017 – 2020*², the Health and Social Services system committed to developing and implementing a Continuing Care Action Plan for home and community care; palliative care, and long term care with the following Goal:

- *Reduce gaps and barriers and provide equitable access to safe, culturally respectful programs and services that respond to community wellness needs.*

Caring for Our People, Priority 5 – Seniors' and Elders includes the following priorities related to palliative care services:

- Home care responds to complex care needs and better supports residents in their communities;
- Reduce gaps and barriers to provide equitable services that respond to community wellness needs;
- Communities are involved in making decisions about how services should be delivered and services are culturally respectful; and,
- Patients and families have access to a range of palliative care options to support end-of-life.

The Department has aligned the palliative approach to care service delivery model with the guiding principles and recommendations in *Caring for Our People* and *Our Elders: Our Communities*.

¹ Government of the Northwest Territories Department of Health and Social Services. *Our Elders: Our Communities*. May 2014. <http://www.hss.gov.nt.ca/sites/default/files/our-elders-our-communities.pdf>

² *Caring for Our People: Strategic Plan for the Health and Social Services System 2017-2010*, (May 2017) <http://www.hss.gov.nt.ca/sites/www.hss.gov.nt.ca/files/resources/caring-our-people-strategic-plan-2017-2020.pdf>

What a Palliative Approach to Care is

A palliative approach to care (palliative care) is health services and supports for people who are expected to progress toward death because of a serious illness or medical condition that cannot be cured. End-of-life care is part of palliative care but refers specifically to the care that a person receives in the last days and hours of their life. A person receiving palliative care may be of any age. Most palliative care services are used by elders surviving chronic diseases or cancer, but sometimes palliative care is needed for younger adults or children with terminal illnesses. Palliative care is compassionate care for those whose condition is no longer responsive to treatment aimed at prolonging life.

Palliative care prevents and relieves suffering by planning ahead with the person and their family to decide on goals of care, to anticipate what will be needed, and to meet those needs. It supports self-determination and provides for a high quality of life and death for each person faced with life-limiting illness.³ This advanced care planning is vital to ensuring that persons' care and treatment wishes are known and respected.

Figure 1 below, shows the role for palliative care across the continuum of care.⁴

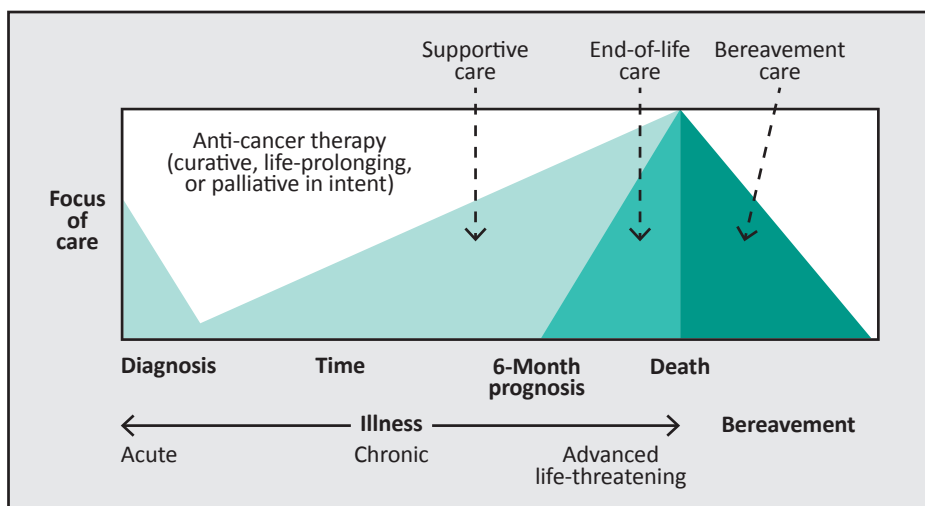


Figure 1: The balance between anti-tumor therapy and palliative care across the continuum of cancer care.

³ Canadian Hospice Palliative Care Association. *A model to guide hospice palliative care: Based on national principles and norms of practice*. 2013. <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>

⁴ Cancer Network, Home of the Journal Oncology. *The Integration of Palliative Care and Oncology: the Evidence*. <http://www.cancernetwork.com/palliative-and-supportive-care/integration-palliative-care-and-oncology-evidence>

Taking a **palliative approach to care** is a way of anticipating the needs of people who have life-limiting conditions, and integrating healthcare with other services and supports to provide quality of life, especially near the end-of-life. This approach has many advantages including better attention to the persons' physical, psychosocial and spiritual needs; it can allow for aging in place and for less reliance on acute care services. Most people with life-limiting conditions and illness do not require specialized palliative care services. They require basic care that improves their quality of life and relieves their suffering.

Patient and Family Centredness

Palliative care is person and family-centred. It is the preferred way to coordinate and deliver the right services, at the right time, to people and their families in the setting of their choosing. Essential components of a palliative approach to care include:

- Relationship building between the healthcare team and the person and family caregivers;
- Understanding the persons' and their caregiver's physical, emotional, psychological, social needs and supports through assessment;
- Attending to the persons' symptoms, distress, and functional status;
- Exploring the person's understanding and knowledge about their illness and prognosis;
- Defining clear goals of treatment that can be adapted as needs and preferences change;
- Determining any spiritual and cultural beliefs or considerations;
- Assisting with medical decision making; and
- Coordinating with other care providers and services when required.



Open Communication

When health care providers are able to speak openly about palliative care with persons who are experiencing terminal illness to explain the likely effect of various treatments and approaches, to provide reassurance, and, take time to explore the person's preferences and goals; these conversations form the basis of true person-centred care. People experience less depression and despair with this approach, undergo fewer unnecessary procedures, and understand better the course of their illness.



Cultural Competence and a Palliative Approach to Care

A palliative approach to care is about health care providers engaging in conversations. This deliberate approach to planning with a person and their family, instead of for them supports relationship building and enables discussions about a person's preferences for their care, where this care should happen and who should be involved in their care.

When care is person-centred health care providers can better understand the persons' beliefs and customs around death and dying and can deliver culturally appropriate care that best aligns with the persons' wishes.

This approach is especially important for northern Indigenous seniors and elders, who wish to remain in their communities where they can be surrounded by their relatives, their language, traditional foods and cultural practices. In the NWT, there is a large culturally diverse immigrant population that also requires health care providers to incorporate and understand cultural practices around death and dying that may be divergent with typical Canadian practices. As the Department continues its commitment to work to ensure all aspects of care are culturally safe and respectful⁵, taking a palliative approach to care is complimentary to this effort.



⁵ Department of Health and Social Services, Government of the Northwest Territories. Building a Culturally Respectful Health and Social Services System. October 2016. <http://www.hss.gov.nt.ca/sites/www.hss.gov.nt.ca/files/resources/building-culturally-respectful-hss-system.pdf>

Where is a Palliative Approach to Care Available in the Northwest Territories?

Palliative care is available to all residents of the NWT, based on need and preference. The location of end-of-life care is based on a person's needs and preferences, and can occur in private homes, long term care (LTC) facilities, and hospitals. There are no independent (private or for-profit) hospice facilities in the NWT.

Home Care provides palliative and end-of-life care in a person's home in every region in the NWT. The health care providers are usually community health nurses, licensed practical nurses or home care nurses. Some of these providers have obtained specialized palliative care training. Home Support Workers and Community Health Representatives are available to help with non-medical supports. Physician and nurse practitioner support for home-based palliation is often provided by phone, where there are no resident physicians or nurse practitioners. In larger communities with resident physicians and/or nurse practitioners the clinician may be able to make a home visit.



- The four largest NWT communities (Fort Smith, Hay River, Inuvik and Yellowknife) provide end-of-life care in the home through their Home Care Services, and with the involvement of nurse practitioners or community family physicians.
- Regional Centres provide basic end-of-life care through the Health Centre, with service delivered by Community Health Nurses on an as needed basis, but they may not have the capacity to deliver specialized end-of-life care (e.g. for clients with pain that is difficult to treat).
- The smallest communities do not have nurses residing in the community and therefore, have no home-based end-of-life nursing services. Where basic end-of-life care is required, Home Support Workers are able to assist clients and their families according to their wishes; the supports are within their scope of services and provided with remote support from nurses.



Hospitals:

End-of-life care is available in all acute care settings across the territory. Inpatient facilities in Yellowknife, Inuvik, Fort Smith and Hay River provide varying levels of specialized inpatient end-of-life care as needed.

Long Term Care facilities:

End-of-life care is also available in long term care (LTC) facilities for residents as needed; and, for clients in the community or Region who request a LTC facility for their end-of-life care. At present, the NWT has 13 beds located in LTC facilities where end-of-life care can be provided. New LTC facilities being built in the NWT will have designated beds for community use for palliative and/or respite care.

Who Provides a Palliative Approach to Care?

In the NWT, palliative and end-of-life care services and supports grow out of continuing care services and primary community health care services a person is already receiving. Palliative care services are provided as a component of Continuing Care Services, in accordance with the NWT Continuing Care Standards (2015). Continuing Care Services provides palliative care services across a continuum in collaboration with community health, and primary and acute care services. Primary care is the day-to-day healthcare given by nurses, doctors and other health professionals. It is the first point of contact. It is where services are pulled together and coordinated to provide clients and families with assessment and diagnosis; treatment and management of health problems; prevention and health promotion; and ongoing support, with family and community intervention where needed.

Continuum of Palliative Care

Depending on the setting, a number of primary care providers can be involved in palliative care. When applying a palliative approach to care, professional care providers regularly assess persons with life-limiting conditions and illness. Persons who can benefit from palliative care have fluctuating and complex needs which change over time. At times, multiple providers, e.g., nurses and home support workers and family care givers, may work together to meet their needs. Providers work with the person and their family to identify services and supports required as they approach end-of-life so they are able to live well until they die comfortably in the setting of their choosing. As mentioned earlier, small communities are limited in capacity to provide more than basic home support and nursing support through remote means.

Basic Palliative Care

Basic palliative care is the standard care provided by all healthcare professionals, in primary or secondary care, within their normal duties for clients with life-limiting conditions. Basic palliative care is available in all NWT communities that have resident nurses. Basic palliative care is considered to be a non-specialized practice, and includes:

- Personalized care planning that reflects the person's preferences;
- Collaborative care planning and decision-making approaches and treatments recommended by care team members and/or case manager or requested by the person;
- Pain and symptom management;
- Psychosocial, cultural, and spiritual support;
- Education, training, and support for the person and family caregivers; and
- Linking with community resources to support the family before and after death and throughout bereavement as needed.

These services can be provided in any setting that the person calls 'home' including in their home or in a long-term care facility. Service providers involved in basic palliative care usually include: home support workers, community health nurses, home care nurses, Licensed practical nurses, community health representatives, nurse practitioners, physicians, occupational therapists, physiotherapists, dietitians, pharmacists, social workers, spiritual and cultural supports, and community based organizations.





Specialized End-of-Life Care

Specialized end-of-life care is a more complex range of supports for persons with unusually-challenging, rapidly-changing, painful or extremely uncomfortable symptoms. It is provided by or in consultation with an experienced multi-professional team to manage complex symptoms and provide educational and practical resources to members of the primary care or Home Care teams. A palliative care specialist in Alberta may be consulted.

Service providers involved in specialized end-of-life care usually augment the basic services provided in the home, long-term care facility or hospital and can include consultation with physician specialists at Stanton Territorial Hospital, palliative medicine specialists from Alberta, and specialized grief and therapeutic supports from within the NWT or Alberta.

Access to Palliative End-of-Life Care Services

Presently, there are inequities in accessing in-facility end-of-life care services. For example, if a person is transferred to a health care facility for end-of-life care, the transfer is considered an “insured health service” and medical travel policy covers the costs of their travel and the care is considered an insured service. Presently, this not the case if a person is transferred to a long term care (LTC) facility for end-of-life care because LTC facilities are considered to be “uninsured” facilities. We will be examining options for providing NWT residents with equitable access to palliative end-of-life care services.

Continuing Care Services Action Plan

Supporting elders to live in their own homes for as long as possible is a goal identified in the Priorities of the 18th Legislative Assembly⁶. Actions for expanded palliative and end-of-life care services falls within the mandate assigned to the Minister of Health and Social Services⁷ and are integrated into the Continuing Care Services Action Plan.

Improving palliative and end-of-life care services in the NWT will be achieved by taking a person-centred approach; enhancing expert support and consultation, including mental health supports; providing access to training and education; ensuring supplies and equipment are available; and supporting family caregivers.



⁶ Government of the Northwest Territories, Legislative Assembly. *Priorities of the 18th Legislative Assembly*. December 2015. http://www.assembly.gov.nt.ca/sites/default/files/priorities_of_the_18th_legislative_assembly.pdf

⁷ Government of the Northwest Territories, Department of Executive. *Ministerial Mandate Letter*. <http://www.gov.nt.ca/sites/default/files/documents/Minister%20Abernethy%20-%20Mandate%20of%20the%20Government%20of%20the%20Northwest%20Territories.pdf>



Glossary of Terms

Basic Palliative Care

Basic palliative care is the standard of palliative care which is provided by all healthcare providers and caregivers, in primary or secondary care, within their normal duties for people with life-limiting conditions.

Continuing Care

Continuing Care Services provide individuals with health care, personal care, and other supports they need to maintain or improve their physical, social and psychological health when for various reasons, they may not be able to fully care for themselves.

End-of-Life Care

A range of clinical and support services with a focus of care on relieving suffering, ensuring respect, maximizing quality of the life for the patient who is dying, their family and loved ones.

Family Caregiver

A family member, friend, or any other person who provides care without pay.

Healthcare Provider

Healthcare providers consist of two categories of care providers: regulated and unregulated providers who are employed by organizations to provide care.

- Regulated health care providers are registered or licensed by a regulatory body and have a legally defined scope of practice.
- Unregulated health care providers are not registered or licensed by a regulatory body and do not have a legally defined scope of practice.

Hospice (Palliative) Care

Hospice care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness. It is often used interchangeably with Palliative Care. Hospice used as a noun refers to a specialized facility where people spend the last days or weeks of their lives receiving hospice care.

Palliative Approach to Care

A palliative approach to care improves the quality of life of individuals with life-limiting conditions and illness and their families. It focuses on the prevention and relief of suffering by means of early identification, assessment and treatment of pain, and by addressing physical, psychosocial and spiritual needs. It includes, but is not limited to, the care that is provided at end-of-life (the last days or weeks of a person's life).

Specialized Palliative Care

Specialized palliative care is a higher standard of palliative care provided at the expert level, by a trained multi-professional team for clients with complex, rapidly changing symptoms. When provided by primary and secondary healthcare professionals, it may require consultation with palliative care specialists.

Quality of Care

Quality of Care is measured by many dimensions. High-quality care is evidence based (appropriate), focused on the patient (patient-centred), safe and timely. Canadian Institute for Health Information, (2017) <https://www.cihi.ca/en/health-system-performance/quality-of-care-and-outcomes/quality-of-care>

1-855-846-9601

