



Yukon
Health and Social Services

Yukon Palliative Care Framework



Contents

Executive Summary	2
Introduction.....	3
Principles of the Framework.....	6
Continuum of Integrated Services.....	7
Supporting Care Providers.....	8
Best Practice Service Delivery.....	9
Service Evaluation and Accountability.....	10
Conclusion	11

Definitions

Palliative care refers to focused and specialized care that supports the quality of life of those living with a serious or life-limiting illness of any diagnoses. Palliative care occurs as early in the course of the illness as possible.

End-of-life care refers to the last stages of a serious or life-limiting illness (usually weeks to months). The ultimate goal is to ensure the best possible quality of life for dying people and their families, regardless of the setting of care.

Hospice palliative care as defined by the Canadian Hospice Palliative Care Association (CHPCA) is whole-person health care that aims to relieve suffering and improve the quality of living and dying.

Executive Summary

The Yukon Palliative Care Framework outlines the principles that form an integrated palliative care model for the territory. It is intended to be a high-level document that sets the course for current and future development of palliative care services. The framework recognizes the many services and organizations involved in the delivery of quality hospice, palliative and end-of-life care. These organizations include First Nation governments, the three acute care hospitals, continuing care facilities, home care, community nursing and other services provided by the Yukon government, as well as NGOs, such as Hospice Yukon, and other community organizations.

“Individual and community engagement is paramount in supporting integrated, quality palliative care.”

Integrated and coordinated services support individuals with life-limiting conditions to receive palliative care and to remain in their home or community as long as possible. This approach is paramount in reducing the need for and use of acute and long-term care resources. By keeping these individuals at home or in their communities, not only will quality of life improve, it will also lead to greater sustainability of our health care system. The integration of services matches the philosophy and approach of the Clinical Service Plan for Yukon.

The Yukon Palliative Care Framework principles will guide the redesign of existing palliative care service delivery systems, at all levels, as well as support care in all settings. There will be specific actions, strategies and deliverables developed at a later date and these actions will be aligned with all the principles of the document. For the purpose of this framework the terms ‘palliative’ and ‘end-of-life’ are used within the continuum of care, or range of services, provided by all types of care providers. An aging population and the increased presence of multiple chronic and life-limiting diseases are two primary factors that will increase the demands for palliative care service. These added pressures to the system support the need for a redesign of a system that is not only supported by the government and other agencies, but also one that builds the capacity of the community as a whole. Individual and community engagement are paramount in supporting integrated, quality palliative care.

Introduction

Palliative and hospice palliative care are integral parts of the continuum of services offered within the broader health and social care system. The Canadian Hospice Palliative Care Association defines hospice palliative care as “whole person health care that aims to relieve suffering and improve the quality of living and dying.”

It is no secret that Canada’s population is aging. The Yukon’s aging projections from Statistics Canada show an increase in the ‘over 65’ population from 3.5 per cent in 2013 to 8 per cent in 2036. As the number of seniors increases, so does the prevalence of chronic conditions, particularly near end-of-life. The average life expectancy in Yukon in 2007-2009 was 76.7 years, which is lower than the Canadian average. Although the aging population increases the need for palliative care, quality palliative care spans across the lifespan to support people of all ages.

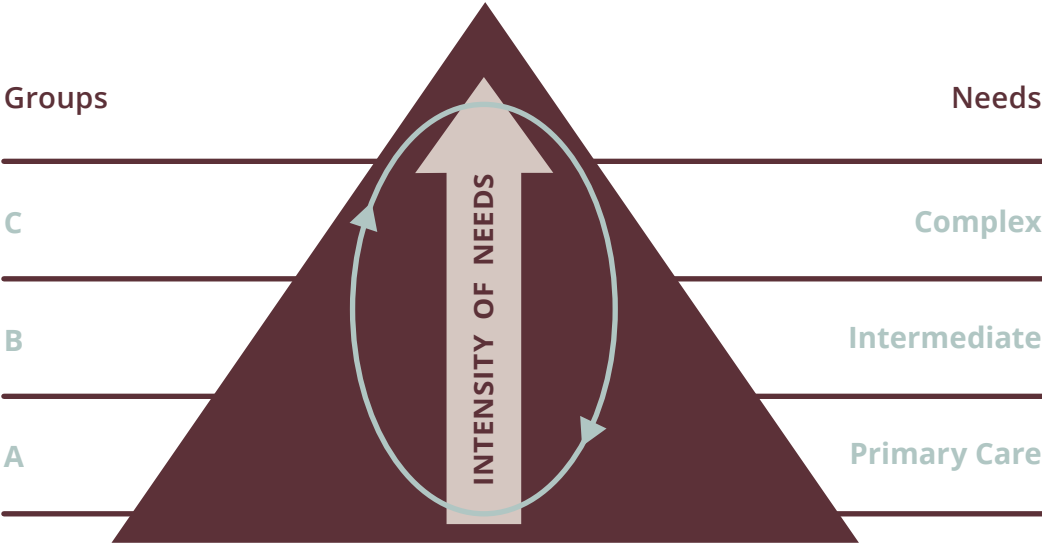
From 2007 to 2012, an average of 196 people died each year in the territory. Yukon also has above-average rates of some chronic conditions, specifically heart and cardiovascular diseases.

Palliative care services in Yukon are broad and multi-faceted as there are a variety of services provided in homes, hospitals, continuing care facilities, by First Nations, through several Health and Social Services branches and other organizations. At present, the Yukon government does not have a data program that integrates data sources from all care service providers throughout Yukon. By not having such a mechanism in place, it is difficult for the government to report the type of or number of services provided to dying people, or to describe the number of people who died in each location. Data would provide information on trends and future needs and assist in identifying gaps in the system to support improved system design and priority setting.

In Yukon, significant investments have been made in palliative and end-of-life care by implementing several nationally-funded projects, needs assessments, and program standards and guidelines, which have provided a foundation for future program development. Thanks to supported training and skill development, as well as public education, the principles of quality palliative care, across all health care sectors, is now an established practice.



Several approaches to palliative care have been adopted around the world. Australia, which shares many geographic and cultural similarities to Canada, developed a population-based approach. By using the same approach, the Yukon government can consider the needs of its population, and how best to design and improve care to meet those needs, while staying in line with cultural, policy and health resource values. By considering all of the resources available throughout the territory, this approach will more effectively meet the clients' needs, while coordinating and integrating existing efforts and resources. An evidence-based reporting system supports the population-based approach to care.



Australian Model of Palliative Care

The model above illustrates that the vast majority of people primarily require services at the **community and primary care level**. Fewer individuals require more **complex care, support and services**, and even fewer individuals require **highly-specialized palliative care services**.

Though few people may need the specialized level of care, there is still a need for quality, integrated palliative care services at all three levels. High quality training and support for the care providers, particularly at the primary and community care level, will lead to greater quality of life and improved outcomes for every client and family. As individual needs change over time, a flexible model like the Australian one allows people to move up and down this scale throughout the course of their illness, receiving the appropriate level of services based on their changing needs.

A palliative approach, applied early in the course of a life-limiting illness, can improve the quality of life of the individual, reduce the strain on acute health care resources, and in certain cases, may increase longevity. This approach puts the client and the client's family at the centre of the care, and in control of health care decisions, while being supported by their care team.

Advanced care planning, not just for palliative clients but for all citizens, is also an important piece of continuum care. Normalizing death as being part of life is a priority in many palliative care strategies and frameworks. This involves a societal approach—encouraging citizens and communities—in having advanced care planning and end of life discussions. As a result, in order to improve access to services and to effectively deliver a supportive, client-centred system, it is important to engage and educate the community as a whole. A population approach to the services, works across multiple ministries and beyond the public sector and requires that all people have a role in developing and supporting quality palliative care. This community-wide approach supports the day-to-day provision of care to those facing a terminal diagnosis.



At a national level, Canada is developing a national framework for the palliative approach to care, led by the Canadian Hospice Palliative Care Association (CHPCA) and the Quality End-of-Life Care Coalition of Canada (QELCCC). The draft national framework, entitled *The Way Forward*, describes six essential principles to guide palliative care in Canada, which are reflected within this territorial framework:

- Dying is a part of living;
- Autonomy and respect;
- Person- and family-driven care;
- Integrated, holistic care;
- Equitable access to health services; and,
- Effective use of health resources.

Principles of the Framework

In its pursuit of integrated palliative care, the Government of Yukon government has identified four key principles or priority statements that direct this framework:

- 1** Providing a holistic **continuum of integrated services** for people living with or dying from a life-limiting illness. These services are clearly linked and based on a model of collaboration.
- 2** **Supporting care providers** with education, resources and partnerships.
- 3** Implementing **best practice service delivery** and care, based on current research.
- 4** Encouraging **service evaluation and accountability**, including use of common definitions and practices.



1 Continuum of Integrated Services

A continuum of service options supports the principles of client-driven care and citizens' cultural needs, autonomy and freedom of choice. These services may be delivered by a variety of providers including physicians and other health care providers, as well as non-government and community agencies, family and friends. Continuum of service speaks to interdisciplinary teams within and between care settings. Holistic care is a fundamental element in palliative care service delivery. Services need to be available in a variety of settings—such as in communities, long-term care facilities and hospitals—to meet varied needs and expressed goals or desires of individuals and their families. This includes considering diverse cultural values, traditions and practices when providing everyday care and then adapting services accordingly. Additionally, the ability to provide care beyond normal service hours is an important consideration in the continuum of care.

Early identification of individuals who may benefit from a palliative approach to care, including people with chronic conditions, in all areas of service delivery is vital to ensuring quality of life and the prevention and relief of suffering.

Communication, collaboration and linking services for clients—patients and families—are essential when working in a larger integrated system. The primary goal of service providers is to share information and create smooth transitions, between care providers and agencies, in order to deliver quality care.

Essential elements of a continuum of integrated services:

- Identifying individuals who would benefit from early palliative care, including those with chronic diseases such as dementia or chronic obstructive pulmonary disease (COPD).
- Promoting advanced care discussions with clients and families to ensure wishes, values and goals of care are supported.
- Enhancing safe, quality care and improving transitions between service and care providers by communicating and sharing relevant information in a timely manner.
- Ensuring all care providers have access to and use specialized consultative services, such as tele-health virtual consultations and other technologies for rural and remote care services.
- Providing a variety of care options for various settings such as home, hospital, and short- or long-term residential care.

2 Supporting Care Providers

An important aspect of quality care is the use of qualified and highly-skilled care providers. Paid caregivers are one vital part of this, but equally important are family, friends and volunteer care providers. All care providers—direct care providers as well as specialized consultation team(s)—require the necessary support, skills and training to deliver quality care at all levels of care. Support involves human resources planning to ensure the right types of care providers are included in interdisciplinary teams, and resources are in place to sustain the services. Exploring technology use, such as virtual consultation between specialty teams and primary providers, needs to be considered with the geographic challenges of Yukon.

Providing information and support to clients, families and friends are vital for clients and making informed health care decisions. Public education regarding palliative care and for making end-of-life services is an important element in supporting individuals involved in caring for people living with a life-limiting illness.

Essential elements of supporting care providers:

- Educating about palliative and end-of-life care: This includes a focus on: normalizing death and dying; information about and promotion of advanced care planning; public information on issues of death and dying; and how to access available services and supports. Inevitably, palliative care is becoming a growing concern for citizens as well as for care providers.
- Promoting a palliative approach to care: This includes early intervention and access to palliative care services for people with chronic conditions or other life-limiting illnesses, regardless of prognosis, while also ensuring that their wishes and goals of care are supported.
- Accessing specialized consultation team(s) and information when dealing with complex situations and symptom management.
- Educating and supporting care providers: This includes helping unpaid care providers and volunteers, primary and community care providers, as well as specialized teams to learn how to use assessment tools and documents.
- Creating flexible, innovative methods of supporting education and skill development to meet the geographic and demographic challenges of Yukon.

3 Best Practice Service Delivery

Palliative care can be delivered in a variety of settings. Though many people requiring palliative care do not require specialized services, some do. It is essential to have services at the primary and community health levels, as well as specialized services for those with complex medical and/or psychosocial needs. Use of consistent clinical tools, such as standardized assessment tools and use of common definitions, establishes a common language within the larger system.

A growing volume of research is emerging on best practices in palliative and end-of-life care. In order for services to be appropriate and effective, they must be supported by current research and evidence-based practices. It is important that defined and standardized assessment tools be used across all sectors. Developing and revising policies and standards that support best practices should meet or exceed the standards within the industry, such as those of Accreditation Canada and CHPCA.

Essential elements of best practice service delivery:

- Promoting care delivery excellence in all sectors and supporting care providers, at all levels, to learn and use innovative tools and models for palliative and end-of-life care.
- Establishing clear paths of communication and a common set of clinical assessment tools and documents to be used in all care sectors.
- Streamlining and standardizing access to services, supplies and funding to ensure needs are met in a timely manner.
- Offering a range and blend of services through a team-based approach, where the needs of the client and family are honoured; a holistic approach to care is essential to a palliative care approach.



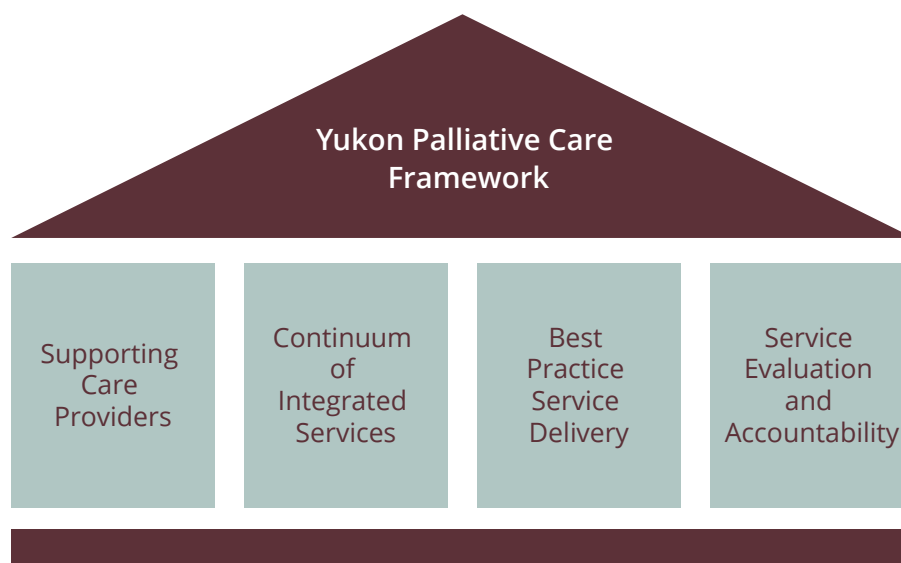
4 Service Evaluation and Accountability

Clear definitions and commonly understood criteria for palliative care are essential. This allows for consistent resource use for Yukon citizens and supports data quality when reviewing system information on access to care.

Clear governance of services and effective leadership within care sectors are also vital to support accountability and a culture of continuous quality improvement. Providers are accountable for service outcomes and evaluating their program delivery goals. Indicators are developed and tracked at the service delivery level, which supports the collection of quality information for larger systems and evaluation. Common data sets, baseline data collection and palliative care registry are all elements of monitoring and evaluating service use. Indicators are linked to national databases whenever possible and tie into adopted minimum data sets, as they are developed.

Essential elements of service evaluation and accountability:

- Developing a territorial reporting system for palliative care service usage and costs, accessibility of services, death statistics, and other performance measures. Outcomes and indicators from aggregate data should also be collected at a systems/territorial level.
- Implementing and evaluating clinical guideline protocols and standards within health care settings to guide future service provisions.
- Working with national organizations to develop and support minimum data sets for palliative care, ensuring common definitions and language match national standards.



Conclusion

Integrated palliative and end-of-life care are essential elements of the broader health care system. With an aging population and an increased prevalence of chronic diseases, a palliative approach to care supports quality living and dying. The Yukon Palliative Care Framework is intended to support effective and responsive delivery of services to meet current and future palliative care needs. Specific actions and recommendations for growth will be aligned with the four principles of this document.

By using a population-based approach, the Yukon government can meet its needs and those of Yukon citizens living with a life-limiting illness, no matter their age; it requires available, accessible and quality services in a variety of care settings. Planning, developing and delivering palliative, hospice and end-of-life services will be guided by the four principles of:

- Supporting care providers;
- Providing a continuum of integrated services;
- Implementing best practice service delivery and care; and,
- Encouraging service evaluation and accountability.

By using these framework principles, Yukon will have improved access to quality palliative and end-of-life services for its citizens, further supporting and honouring the wishes, values and choices of individuals and their families.



References

Government of British Columbia, Ministry of Health. 2013. *The Provincial End of Life Care Action Plan for British Columbia: Priorities and Actions for health system and service redesign*. Available from www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf

Government of British Columbia, Ministry of Health. 2006. *A Provincial Framework for End-of-Life Care*. Available from www.health.gov.bc.ca/library/publications/year/2006/framework.pdf.

Canadian Hospice Palliative Care Association. 2013. The Way Forward National Framework [Internet], reports and discussion papers including *Palliative Care in the Community: An environmental scan of frameworks and indicators*; and, *Innovative Models of Care, The Way Forward Initiative: an Integrated Palliative Approach to Care*. Available from www.hpcintegration.ca.

Australian Government, Department of Health. 2010. *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy 2010*. Available from www.health.gov.au.

Gold Standards Framework [Internet]. Retrieved from www.goldstandardsframework.org.uk October 9, 2013.

Ontario's Provincial End of Life Care Network. 2010. *A Provincial System Design Framework: A Primer on Possible Components of Ontario's Hospice Palliative Care System*. Available from http://hpco.ca/qhpcco/System_Design_Framework_-_Oct_2010.pdf.

Statistics Canada. 2012. *Population projections for Canada, Provinces and Territories: 2009-2036*. Retrieved from www.statcan.gc.ca/pub/91-520-x/91-520-x2010001-eng.htm November 15, 2013.

Best Practice Advocacy Centre New Zealand [Internet]. *Treatment for the dying patient: The Liverpool Care Pathway* (2011). Retrieved from www.bpac.org.nz/BPJ/2011/june/lcp.aspx October 9, 2013.

Government of Yukon, Department of Health and Social Services. 2012. *Yukon 2012 Health Status Report: Focus on Children and Youth*. Available from www.hss.gov.yk.ca/pdf/health_status_report_2012.pdf.

