

THE PROVINCIAL
**End-of-Life Care
Action Plan**
FOR BRITISH COLUMBIA

*Priorities and Actions
for Health System
and Service Redesign*

Ministry of Health
March 2013



**FAMILIES
FIRST**





Acknowledgements

The *Provincial End-of-Life Care Action Plan for British Columbia* was developed with input from clinical experts, community stakeholders, policy leaders and service providers from across the province under the leadership of the provincial end-of-life care working group. All are thanked for their insight, expertise and time in the development of the action plan.

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Definitions

Palliative Care – Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness – whatever the diagnosis. The goal is to improve quality of life for both the patient and the family and is provided in a variety of locations, including people's homes and community settings, hospices, residential care settings and hospitals. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided together with any beneficial treatment.

End-of-Life Care – End-of-life care is associated with advanced, life-limiting illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological and spiritual concerns.

Life-Limiting Illness – Life-limiting illness is used to describe illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses that are expected to shorten an individual's life.

Population Needs-Based Approach to Palliative Care – A population needs-based approach recognizes that individuals facing a serious illness have different needs, based on their unique health conditions, stage of disease and complexity of symptoms. Health care services and supports should therefore vary in type and intensity to most effectively meet the needs of the individual.

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Executive Summary

The *Provincial End-of-Life Care Action Plan for British Columbia* is a key component of the province's health innovation and change agenda to achieve better health outcomes and experiences for British Columbians through a more efficient, sustainable health care system. The plan outlines key priorities and achievable actions to improve the way health care providers meet the needs of people coping with end of life, including their families and caregivers.

This action plan is intended to guide health authorities, physicians, health care providers, and community organizations in planning integrated primary and community care services. It supports quality hospice, palliative and end-of-life care services across British Columbia with a focus on supporting individuals with life-limiting conditions to remain at home in their community, reducing the need for hospital or emergency department visits, and improving coordination of care across all settings.

Based on leading practices for managing chronic and life-limiting conditions, the action plan incorporates a population needs-based approach to palliative care, which recognizes that the health care needs of individuals vary over the course of a life-limiting illness. With this in mind, end-of-life care is most effective in meeting the needs of a patient with complex needs through an integrated team approach that includes the patient, patient's family, family physician, specialists, nurse practitioners, community health teams and others.

A key element of this approach is the early identification of individuals who would benefit from a care approach that focuses on the individual's quality of life to ensure the patient's symptoms and goals of care are identified and addressed appropriately. This care approach takes into account the individual's beliefs, values, and wishes and represents a significant shift from an eligibility based model that provides access to specific service bundles. Incorporating the individual's journey, including the final stages of life, into discussions and planning for care, requires a shift for patients, families and health care providers who deliver their care.

Through the priorities in this action plan, the Ministry of Health has outlined areas that research evidence and expert stakeholders agree are of high importance in providing quality end-of-life care. Implementing this plan will ensure the diverse health care needs of those requiring hospice palliative and end-of-life care services are met through:

- ▶ Appropriate clinical approaches and ranges of services required to meet end-of-life care needs, including a focus on partnerships and technical innovation;
- ▶ Improved skill mix, expertise and qualifications of health care providers involved in the provision of hospice palliative and end-of-life care services; and
- ▶ Monitoring frameworks to evaluate the access, efficiency, integration and effectiveness of end-of-life care services available across the province.



As hospital staff identify people with palliative and end-of-life care needs more readily, and referrals to appropriate community based services are made, more individuals will receive quality end-of-life care at home. This will support improved quality of life, patient and family engagement in the community, and help to maintain the capacity of hospital resources to respond to those who require hospital care.

This action plan is foundational to the planning and delivery by ministries, health authorities, physicians, nurse practitioners and other health care providers, of quality compassionate care for persons at the end of life and their families. The plan is one part of the Ministry of Health's larger collaborative effort with health authorities and all health care providers to support the shift towards a stronger, more effective and integrated health care system, particularly in the community sector.



Introduction

The *Provincial End-of-Life Care Action Plan for British Columbia* is a key component of the province's health innovation and change agenda to improve health outcomes for British Columbians, and provides an integrated, proactive approach to community health care services. The action plan outlines important shifts in the way the needs of people with life-limiting health conditions are addressed. It identifies priority actions that build on work in B.C. and other jurisdictions to improve health care outcomes and quality of life for individuals coping with the end of life, and for their families and caregivers.

Access to palliative and end-of-life care services is becoming increasingly important. As people age, the likelihood they will have at least one chronic disease rises dramatically, resulting in more people with complex care needs. With B.C.'s growing and aging population, it is projected that the prevalence of chronic conditions may increase by 58 per cent over the next 25 years.¹

BC Stats estimates that the percentage of seniors aged 80+ in B.C. will grow from 4.4 per cent of the population in 2012 to 7.4 per cent of the population by 2036.² This statistic has significant implications for health service use in British Columbia and access to end-of-life care services in the community.

Health Care Use at the End of Life in British Columbia³

In 2008, the Canadian Institute for Health Information (CIHI) undertook a study of the usage patterns of health care services in the two years prior to death for the 29,456 persons of all ages who died in British Columbia between April 2003 and March 2004. The CIHI study noted that the majority of deaths were attributed to chronic diseases and cancer and that 79 per cent of those who died were aged 65 and over.

CIHI's study of health care use in the last two years of life also revealed two other important factors that have significance in planning for quality end-of-life care in British Columbia. The report notes that despite the fact the majority of deaths were from diseases that are known to be life-limiting, only about 15 per cent of the study group had received palliative care. Identification and receipt of palliative care services tended to be most closely linked to cancer patients, rather than those who died from other diseases such as congestive heart failure, kidney disease or dementia.

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¹ Ministry of Health, Medical Services Division, *Chronic Disease Projection Analysis* (March 2007).

² BC Stats, *British Columbia Population Projections 2012 – 2036* (September 2012), p. 9.

³ Canadian Institute for Health Information, *Health Care Use at the End of Life in British Columbia* (September 2008).

Another finding in CIHI's study was in the pattern of health care use over the last two years of life. While it is often assumed that the use of health care services increases steadily over the final one to two years of life, the data suggested that for many users, health service use peaked in the final three to six months of life. The findings also showed that many people with chronic illness and co-morbid conditions, in addition to people with cancer, had increased need for and received complex bundles of services in the period of time well before the last three to six months of life.

These results suggest a number of important factors to consider in developing priority actions for end-of-life care. First, there is a need to improve the identification of individuals with non-cancerous conditions who may benefit from a palliative approach to care. Second, if, as the CIHI data suggests, the majority of those with life-limiting illnesses manage their health condition for most of its duration with the support of a primary health care team, family and friends, it is important to ensure that end-of-life care strategies strengthen individual capacity for self-management, as well as the connection between the family physician and other members of the health care team.

Population Needs-Based Planning and Quality End-of-Life Care

Individuals with life-limiting conditions can have a wide range of different needs. A population needs-based approach to health care services planning recognizes that as the needs of individuals vary, the health care services they require will vary as well – from working solely with the individual's primary health care provider through to an interdisciplinary care team that works with the patient and their family physician to help assess and manage complex needs.

Australia led the way for many jurisdictions in incorporating a population needs-based approach into end-of-life care using a model they called the palliative approach. This model is based on the principle that palliative care services must be effective, efficient and ethically delivered at the medically appropriate time. It also recognizes the needs of family members and the importance of volunteers and community.

The model (Figure 1) includes all individuals with life-limiting illnesses: those whose needs can be managed with support from their primary care physician or health care provider (Group A), those with complex needs who may occasionally need shared care services (Group B), and those who frequently require specialized services and facilities with highly specialized palliative care physicians and staff (Group C). The model also recognizes that individual needs change over time, and consequently an individual may move both upwards in complexity, as well as down, as their disease progresses.

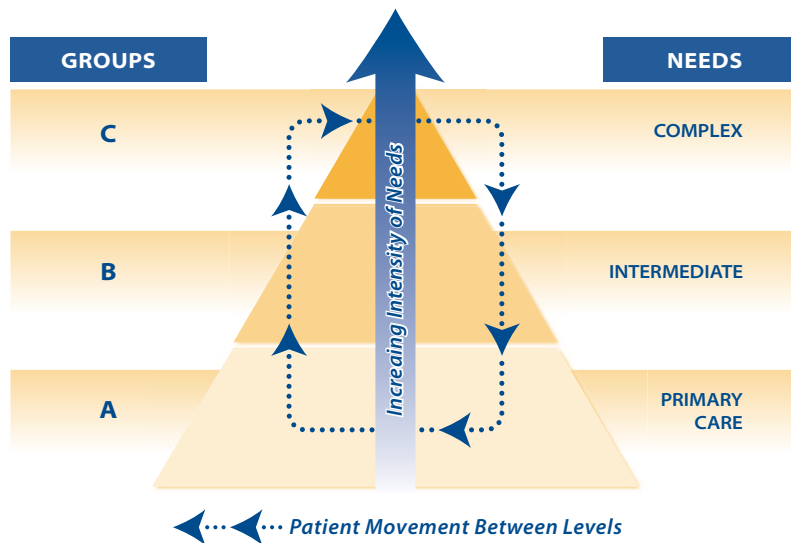


Figure 1: Palliative Approach Population Needs-Based Model of Care.⁴

Australia’s experience with this approach confirmed that the majority of clients can manage their illness in the community, with support from their primary care provider and integrated health services as needed. A smaller number of clients require periodic shared physician care and only a small number need frequent specialized services.

In practice, the population needs-based model promotes the development of networks between primary health care providers and specialist hospice palliative care services in the delivery of hospice palliative care to all individuals with life-limiting illness.

Implementing a Population Needs-Based Approach to End-of-Life Care Services

An important element of implementing a population needs-based approach includes identifying individuals with life-limiting illness earlier, including patients with cancer and non-cancerous conditions, and initiating important discussions regarding advance care planning based on the person’s beliefs, values, and wishes. This includes important conversations with family, friends and family physicians or other health care providers regarding possible future health care treatments and decisions about which treatments the patient wishes to accept or refuse. In planning ahead, it is also important that care providers understand those things that give the individual’s life meaning, and contribute most to their quality of life. A population needs-based approach to end-of-life care services must also include support for the family up to and including bereavement.

Health care providers require resources, skills and support to provide both the clinical care that is needed and the skills to effectively support the individual and their family in managing their own journey. It is also important to publicly report on how end-of-life care services are meeting the needs of British Columbians in terms of quality, safety and accessibility.

⁴ Palliative Care Australia, *A Guide to Palliative Care Service Development: A population based approach* (February 2005), p. 13.

The Provincial Framework for End-of-Life Care in British Columbia⁵

In 2006, British Columbia released the *Provincial Framework for End-of-Life Care in British Columbia*. The framework outlines the province's policy on end-of-life care planning, services and approaches for health authorities and stakeholders, developed in consultation with clinical experts, service organizations, patients and families.

The framework describes an integrated approach to providing hospice palliative and end-of-life care services across sectors, consistent with established leading practice models for chronic disease management. The framework's vision sets out that end of life is a critical phase that must feature high quality services that are competent, compassionate and respectful of all people who are dying and their families.

Many successes and milestones have been achieved since the provincial framework was released.

- ▶ The Ministry of Health and British Columbia Medical Association have strengthened access to quality end-of-life care by general practitioners and specialists, including collaborative palliative care education with community health teams provincewide.
- ▶ Health authorities are actively engaged in planning and implementing new services, and the number of publicly-subsidized hospice beds has increased.
- ▶ All health authorities have introduced interdisciplinary palliative care consultation teams, and there has been a significant shift away from hospital deaths to planned, expected natural deaths at home. To support this shift, the B.C. Palliative Care Benefits Program, which provides access to the same drugs and palliative supplies and equipment at home as if the person were in hospital, has served increasing numbers of clients in the last six months of life.

Integrated Primary and Community Care in British Columbia

Addressing many of the overall challenges posed by the growth and aging of its population has led government to commit to other innovative approaches to how services are organized and delivered. Through integrated primary and community care strategies, the Ministry of Health and health authorities are working with physicians and other health care providers, community organizations and researchers to redesign and realign services in partnership with patients. An integrated system of primary and community care offers improved patient experience of care in community based settings with timely access to quality hospital services when needed.

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⁵ Ministry of Health, *A Provincial Framework for End-of-Life Care* (British Columbia, May 2006).

Integrated primary and community care strategies specifically targeted to support improved end-of-life care include:

- ▶ End-of-life care training is offered as part of the Practice Support Program, delivered in partnership between the Ministry of Health and the British Columbia Medical Association. The End of Life module is training physicians and their office staff together with health authority staff to improve their knowledge and skills in delivering end-of-life medical care and aims to improve collaborative care for patients and support for families.
- ▶ A palliative care planning fee code was introduced in 2009 to provide general practice physicians with an incentive to do more comprehensive, individualized palliative care planning with their clients. In 2012, a similar fee code was introduced for specialist physicians to work with general practice physicians.
- ▶ The Michael Smith Foundation for Health Research provided \$800,000 to the University of Victoria and Fraser Health to support the project for a palliative approach in nursing: evidence and leadership⁶ (iPANEL).
- ▶ Provincial legislation for advance care planning was updated and resources for the public and health care providers were developed to enable individuals' wishes for end-of-life care to be known, respected and followed.
- ▶ After-hours palliative nursing service was implemented provincewide through an innovative partnership between the home and community care program, health authorities, and HealthLink BC.
- ▶ Stronger working relationships with Provincial Health Services Authority's staff and physicians have been developed to promote advance care planning and the adoption of the palliative approach to care within their specialized services, including BC Cancer Agency and BC Renal Agency.

These strategies provide a foundation of meaningful support for the significant shift in clinical practice and service planning required to implement a proactive, integrated approach to end-of-life care.

Need for System-Wide Innovation and Support for End-of-Life Care

Building on this foundation, further improvements in end-of-life care services across B.C. are needed to improve patient and family experience, while reducing the need for emergency department or hospital care and admissions. The goal of this action plan is to increase individual, community and health care services' capacity and support people at end of life to remain at home and in their communities to the greatest extent possible.

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⁶ K. Stajduhar and C. Tayler, *Initiative for a Palliative Approach in Nursing: Evidence and Leadership*, British Columbia Hospice Palliative Care Association Conference (May 2012).



Action Plan Priorities for End-of-Life Care in British Columbia

Three key priorities were identified in consultation with clinical experts, health authorities, researchers, community organizations and patient representatives to reflect the principles of the provincial end-of-life framework and the shift to integrated health services.

PRIORITY 1: *Redesign Health Services to Deliver Timely Coordinated End-of-Life-Care*

GOAL: Improved access to a range of quality end-of-life care services, delivered in collaboration with physician care, responsive to the needs of individual patients, their families and caregivers and with a focus on supporting end-of-life care in the community.

- ▶ **Action:** Implement a population needs-based approach to planning quality end-of-life care services that identifies individuals earlier, including those with cancer and non-cancerous conditions, who would benefit from a palliative approach and who would receive quality care in the most appropriate settings based on their beliefs, values, and wishes.
- ▶ **Action:** Integrate quality end-of-life care into service planning for all life-limiting chronic diseases that includes information and planning for the end of life as a component of the patient's journey.
- ▶ **Action:** Leverage opportunities to expand telehealth and telemonitoring technologies to improve the ability of individuals and care providers to effectively manage health conditions at a distance, including pain and other symptoms.
- ▶ **Action:** Improve the capacity to provide quality end-of-life care in residential care facilities and other housing and care settings, focusing on an individual's quality of life and access to appropriate supportive care and services for their complex needs.



PRIORITY 2: *Provide Individuals, Caregivers and Health Care Providers with Palliative Care Information, Education, Tools and Resources*

GOAL: Individuals and families are provided with information and resources to effectively manage their own care journey, and health care providers are supported to provide quality, integrated care that is respectful and responsive to the expressed wishes of patients coping with the end of life.

- ▶ **Action:** Increase public knowledge and awareness of palliative care as an approach to care that improves the quality of life for both the patient and the family at any stage in a serious illness.
- ▶ **Action:** Provide information and resources to support advance care planning, including an understanding of the available options for ensuring values, wishes and instructions for health care treatments and choices for end-of-life care are respected by health care providers.
- ▶ **Action:** Provide awareness and education on the unique end-of-life care needs of specialized populations, including Aboriginal peoples, children, and individuals with dementia, kidney disease, or chronic mental health and substance use issues who may require special consideration for planning and care delivery to improve health outcomes.
- ▶ **Action:** Promote excellence in end-of-life care and quality, consistent end-of-life care practice, including promotion of innovation and best practices in end-of-life care, and support for end-of-life care education for family physicians, specialists and health care professionals.



PRIORITY 3: *Strengthen Health System Accountability and Efficiency*

GOAL: End-of-life care services reflect evidence based, clinically appropriate practices, and the public has timely information on the accessibility and outcomes achieved through publicly subsidized care.

- ▶ **Action:** Develop and report on provincial end-of-life care service information and performance measures, including the ability to report publicly on service delivery, observance of advance care plans, and death statistics for children, youth, adults and Aboriginal peoples.
- ▶ **Action:** Implement provincial end-of-life care clinical guidelines, protocols and standards with a focus on clinical transitions and interdisciplinary care, and with a clear priority of improving pain and symptom management.
- ▶ **Action:** Provide equitable access to the B.C. Palliative Care Benefits Program and promote its' sustainability, ensuring residents of residential care facilities have access to the same medications they would have if in hospital, in a hospice or being cared for at home.
- ▶ **Action:** Streamline policies and administrative processes used to access services to improve access to services and supplies in a timely manner.





Summary and Conclusions

Creating a high quality, sustainable system for end-of-life care provincewide is increasingly important as B.C.'s population grows and ages, and as more individuals live with long-term illnesses.

Although much progress has been achieved in recent years, opportunities for improvement remain. This provincial end-of-life care action plan will help enable innovative advancements in the end-of-life care British Columbians receive. By strengthening and integrating our health care system, particularly in the community sector, we hope to realize our vision of high quality, compassionate, respectful and competent care for all people who are dying and their families.

This plan will foster the spread of a population needs-based palliative approach to end-of-life care throughout the system.

With its emphasis on primary and community care services that meet patients' varying needs, this approach will ensure the province's palliative care services are effective, efficient and delivered at the medically appropriate time.

This action plan will help to improve access to quality end-of-life care for patients and families, while fostering the sustainability of B.C.'s publicly funded health care system, through service redesign and enhanced planning of services, provision of information, tools and resources, and strengthened health system accountability and efficiency.

Achievement of the actions in this plan will help physicians and health care providers, community partners, and the health care system itself, to honour and respect the beliefs, values, wishes, and needs of dying patients, to assist them to remain at home and in their communities to the greatest extent possible, and to care for them and their families at one of the most important times in their lives.





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