

# Integrated Palliative Care

## Integrated Palliative Care:

Planning for Action in Nova Scotia





*Vision: All Nova Scotians  
can access integrated,  
culturally competent,  
quality palliative care in  
a setting of their choice.*





# Introduction

The way we live matters. So does the way we die. That is why it is so important to have access to quality palliative care when confronted with a life-limiting or life-threatening illness. According to the World Health Organization<sup>1</sup>:

“Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Neither hastens nor prolongs death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and throughout their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counseling.
- Can enhance quality of life, and may also positively influence the course of the illness.
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications.”

Nova Scotia has embraced this definition to look at a more holistic, integrated approach to palliative care services and considers the use of the term *palliative care* as synonymous with *hospice palliative care*. For too long, we have thought of palliative care only when the focus of care has shifted from cure to comfort.

The fact is, Nova Scotia has one of the oldest populations in Canada. Although our aging population is living longer, many do so with chronic conditions that can impact the quality of life, worsening over time. Nearly 75 per cent of all deaths in Nova Scotia are attributed to chronic diseases. By 2025, two-thirds of Canadians who die will have had two or more chronic diseases and will have lived for months or years in a state of fragile health. Only 20 per cent of Canadians will die with an illness that has a recognizable terminal phase.

Changing our attitudes towards palliative care can ensure that everyone who is becoming frail or facing a life-limiting illness can benefit from quality palliative care services. This approach helps ensure we can live well with illness up to the end of life, with an ability to manage symptoms and make informed decisions about the kind of care we want. In essence, this approach recognizes that dying is very much a part of living.

Given our demographics, change is critical and it will take time. It will take dedication and commitment from health professionals, governments, individuals and families to truly understand and accept that it is important to not only manage and maintain our health, but to also prepare for death.

1. World Health Organization (February 6, 2013). Definition of Palliative Care. Retrieved from: <http://www.who.int/cancer/palliative/definition/en/>



# Palliative

## Integrated Palliative Care

Research has shown that an integrated palliative care approach can lead to positive effects on emotional wellness, greater longevity and less suffering<sup>2</sup>. An integrated palliative approach to care is person driven, reinforcing the individual's autonomy and right to be involved in his or her own care. It is focused on meeting the physical, psychosocial and spiritual needs of the individual and the family and providing care at appropriate times during an illness in a setting of one's choice.

We know that only ten percent of people die suddenly, the remaining 90 per cent will need care and support at the end of life. Data from the Canadian Institute of Health Information indicates that almost 60 per cent of Nova Scotians die in hospital, while only 18 per cent die at home. We also know that 67 per cent of patients are hospitalized at least once in their last year of life, staying an average of 25 days according to the Health Associations of Nova Scotia. They are often occupying acute care beds, at the greatest cost, when more appropriate and comfortable care could be provided at home or in a hospice with appropriate supports in place.

This lack of access to palliative care is a service gap that must be addressed as more Canadians age. As we grow older, we have physical, emotional and spiritual needs. Many of us will experience pain, loss of mobility and other functions, mental limitations, or loss of friends and spouses. Given these major events, one should not have to be diagnosed as close to death to receive services that could enhance not only our quality of life, but our death as well. That is why the Department of Health and Wellness has developed a strategy that will move us towards integrated, community-based palliative care programs and services.

It is based on a review of national and international practices, with input from a range of health professionals across the province. We have incorporated best practices from around the globe and tailored our approach to the health care needs of Nova Scotians. As a result, we have created a vision, guiding principles, and priorities for action that will help us achieve our goal.

**Vision:** All Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice.

**Principles:**

- Patient and family-centered
- Respectful
- Equitable
- Effective
- Culturally competent, safe and inclusive

*The way we live  
matters. So does  
the way we die*

2. Bakitas M, Lyons KD, Hegel MT, et al (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized control trial, JAMA 302:741-749.



# The Nova Scotia Solution

Changing the way care is provided begins with an understanding that in a system that has traditionally focused on treatments and cures, there may not be sufficient opportunity to discuss the dying process, or fully understand illness and prognosis. An integrated palliative care approach encourages the discussion of goals of care early and often, ensuring that symptoms are managed in an appropriate care setting with required supports available.

The Nova Scotia strategy embodies the philosophy that care is delivered in a seamless manner by various health care providers and services that function in the community. It is person and family-centered rather than system-centered. There is integration between primary, secondary and tertiary

care with a shared responsibility among all care providers along the continuum. Support to patients and families are available early in the disease process, and adapts as one's condition advances and changes. Support to families continues on during the bereavement stage.

Care can be integrated in all settings including the home, long-term care facilities, hospitals, and in urban, rural and remote communities. Offering these services as close to home as possible means that individuals and caregivers are supported by a variety of health care providers such as primary care physicians, nurses and paramedics, home care nurses, personal support workers, long-term care and hospital staff, all working as a team in a culturally competent and safe manner. Providers in the community can consult with specialists in a timely fashion to tailor care as needed over time.

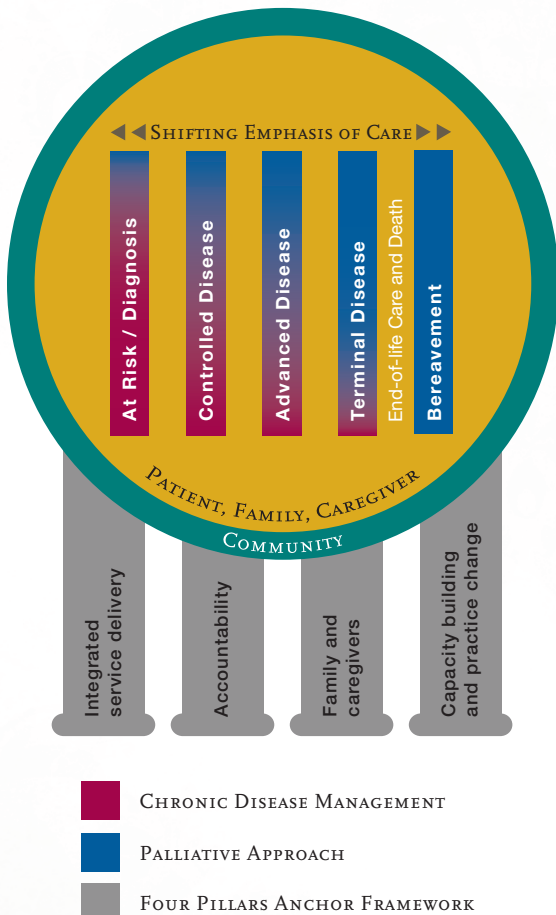
Good communication is key to success. Responsibility is shared among the Department of Health and Wellness, health authorities and partners in the community. We can build capacity in the system through education, training and creating mechanisms for communication and support.

Four pillars anchor the framework, all of which are inter-connected, and of equal importance. They include:

- Integrated service delivery
- Accountability
- Family and caregivers
- Capacity building and practice change

In order to advance in these four areas, several priorities have been identified for action. In some areas, we will move forward quickly. In others, it will take more time and resources to achieve our goals. We are committed to moving forward as we change our areas of practice and attitudes towards dying. Each pillar and its recommended actions are described below.

**Nova Scotia Integrated Palliative Care Framework**





# Service

## Integrated Service Delivery

Our approach will be rooted in primary health care, where a relationship between the patient and their provider is established. Services will cross the continuum of care providing access to a palliative care approach for individuals dealing with various progressive chronic diseases as well as end of life care. Integrated and seamless, this system allows for ease of movement among many sites, including home, long-term and residential care, a hospice setting and/or acute care. Community-based supports need to be readily available, as well as access to a consultation team for advice, assessment and support.

### Access to services 24/7—Recommended Actions

- Strengthen a core palliative care team in each health authority.
- Engage and support primary health care providers to enhance their knowledge about the integrated palliative approach to care through education and training opportunities.
- Develop partnerships and linkages among care providers, building inter-professional teams that use a lens of inclusion, cultural competency, and safety.
- Continue to identify and develop best/promising practices.

### Options for sites of care—Recommended Actions

- Support the concept of four choices for sites of care to include home, long-term and residential care, acute care, and hospice to provide effective and efficient options for individuals and their families.
- Assist health authorities in addressing system planning to determine needs for their respective sites.
- Build capacity for supporting home deaths across the province.
- Build partnerships with community-based hospice organizations.

### Enhancing Continuing Care—Recommended Actions

- Identify additional requirements (equipment, services, financial supports).
- Assign dedicated care coordinators to the palliative care teams.
- Provide direct support to patients and families.
- Consider coverage for nutritional supplies (i.e. medical food) in the home setting.

### Streamlining Services—Recommended Actions

- Standardize processes, teams and roles.
- Establish a single point of entry.
- Work towards meeting Accreditation Canada Standards for Hospice Palliative and End-of-Life Services.
- Reassess the need for additional provincial standards.

*Our approach will be rooted  
in primary health care.*



# Accountability

## Accountability

An accountable system is one that has a well-defined governance structure, with clearly outlined roles and responsibilities. Shared accountability is critical to overall success. To ensure the strategy is implemented and continues to move forward, leaders within the department and the health system will be identified to provide oversight. Key indicators to monitor and evaluate system progress and effectiveness will also be identified. Measuring individual and family satisfaction, cost of care, and cost avoidance are important indicators that can help to demonstrate whether the program is effective and meeting the objectives of person-centered care.

### Shared Accountability—Recommended Actions

- Establish a governance structure within the Department of Health and Wellness and confirm the leadership under which initiatives will be implemented.
- Ensure there is a provincial Palliative Care Coordinator to support and coordinate the strategic and operational requirements within the strategy.
- Establish a Provincial Palliative Care Advisory Committee to ensure ongoing support of and progress towards implementing the strategy.
- Clarify provincial, health authority and community service providers' roles and responsibilities to support an integrated approach to palliative care services.
- Establish an Information and Decision Support Working Group to address the requirements for standardization of data collection and management.
- Create an evaluation framework to guide implementation and ongoing evaluation.
- Develop a provincial palliative care system report card.
- Develop a change management process for effective roll-out.





# Caregivers

## Family/Caregivers

Watching a loved one pass away is an exceptionally difficult experience. Having the supports, including physical, emotional and spiritual can make the journey easier for both the individual and those who care for them. These supports can include anticipatory grief and bereavement support, and an opportunity to understand and participate meaningfully in the dying process.

According to the Canadian Hospice Palliative Care Association, when someone is becoming frail or is diagnosed with a life-limiting illness, it is estimated that at least five other people are affected. We also know that attitudes towards death are often strongly rooted in culture. Taking a more holistic approach recognizes that caregivers must maintain their own health in order to continue to provide quality care to their loved one. Providing training, creating an inclusive process, and opportunities for respite can help to ensure that care is available so patients can die in the setting of their choice.

### Person Centered Care—Recommended Actions

- Establish a consistent process to ensure patients/family members are involved in the care planning and all relevant decisions.
- Examine how equitable access to bereavement supports and services can be established.
- Develop a caregiver assessment tool to assess the unique needs and capacity of each caregiver.
- Develop an education and training program for caregivers.





# Capacity Building and Practice Change

In many ways, this approach is a return to past practice. After all, in the first half of the 20th century, most deaths occurred at home and were managed by family physicians. We now need to build system capacity to pave the way for the future.

As our demographics change, so do our trends in providing care. More collaborative practices are being established, and more health professionals are becoming involved in the management of chronic diseases. If we are to successfully integrate a palliative approach, we need to examine best practices and tailor them to our unique needs. For example, New Zealand has incorporated a specialist nurse educator and advisor to increase the capacity of primary care providers and break down silos between services. Their model aims to have most end-of-life care provided by primary care providers with specialist palliative care services taking on complex cases<sup>3</sup>.

Here in Nova Scotia, we need to enhance capacity in all settings if we are to integrate palliative care services with other care. Education, ongoing training and support for staff in all sectors of the health care system, including home support workers, first responders, primary, acute and tertiary care is pivotal to begin a culture shift. Education for individuals and families is also critical.

It's also important to recognize the role of the volunteer. Hospice palliative care volunteers are an integral member of the team and can play a significant role in patient/family support. They help meet respite needs, and provide grief and bereavement support.

## Education—Recommended Actions

- Establish a working group to recommend standardized training modules for health care teams.
- Identify qualified individuals/teams to assist in providing training.
- Consider education and implementation of palliative care pathways across all settings.
- Enhance volunteer coordination and support including standardized volunteer job descriptions, identify opportunities to enhance the role of the volunteer, and adopt national training modules for volunteers.
- Examine education requirements for family/caregivers and optimal methods to provide access to information.
- Create an education program for family/caregivers relating to the care required for a loved one at all stages of disease.
- Develop materials for public education to build awareness and understanding.
- Develop advanced care planning awareness and educational resources for providers and the public.
- Continue to support cultural competency guidelines and provide cultural safety training.

*More collaborative practices  
are being established.*

3. McKinley, E, McBain, L. (12 October, 2007). Evaluation of the Palliative Care Partnership: a New Zealand solution to the provision of integrated palliative care. The New Zealand Medical Journal. Vol 120 No 1263 ISSN 1175 8716. URL:<http://www.nzma.org.nz/journal/120-1263/2745/>



# Conclusion

Putting in place a seamless, integrated approach to palliative care is an ambitious goal. It is also an achievable one, with the potential for many benefits. Individuals could enjoy improved quality of life, while taking an active role in decisions surrounding their care. Resources can be more efficiently used, contributing to a more sustainable system. Perhaps most importantly though, we can ensure those requiring palliative care receive compassionate, caring services in a setting of their choice.


Work is already under way. Changes have been made to support palliative care patients and their families with the addition of the Palliative Care Home Drug Coverage Program, the Caregiver Benefit, and some enhancements to palliative care team resources to address care gaps in high need areas. Providing technology to promote communication and improve seamless care between community-based care providers is also underway.

We are also providing better access to more hospital bed systems for the home, including bariatric beds for the Community Bed Loan Program, and working with the Red Cross to implement a rapid response for hospital beds for palliative care clients. We have purchased more computerized ambulatory drug delivery (CADD) pumps for use across the province. Additional funding has been provided to Caregivers Nova Scotia to support more family and friend caregivers. We are piloting a caregiver assessment tool and will look at expanding this tool province wide. We are also working with the Nova Scotia Hospice Palliative Care Society to enhance awareness for both the public and health care providers about the importance of advanced care planning.

Over the next year, we will continue to refine our work and begin a phased approach to the recommended actions from our guiding framework. Changing the way we deliver services will take time. It will also take careful planning, collaboration and a great deal of communication. Today, we begin the conversation.







*“While I thought that  
I was learning how to live,  
I have been learning  
how to die.”*

*— Leonardo da Vinci*



# Integrated Palliative Care:

Planning for Action in Nova Scotia

