

# PALLIATIVE CARE in New Brunswick

A person-centred care and  
Integrated services framework



**Palliative Care in New Brunswick :  
A person-centred care and Integrated services framework**

Published by:

Government of New Brunswick  
P. O. Box 6000  
Fredericton, New Brunswick  
E3B 5H1  
Canada

Printed in New Brunswick

ISBN 978-1- 4605-1402-3 (print edition)  
ISBN 978-1-4605-1403-0 (PDF: English)  
ISBN 978-1-4605-1404-7 (PDF: française)

11045-02-2018

## Message from the Minister



At all ages and stages of life, New Brunswickers expect to have accessible and high-quality health-care services.

New Brunswick has one of Canada's oldest populations. By 2026, it is estimated that 26.3 per cent of the population will be older than 65. In the same time frame, it is estimated that New Brunswick will see an increase of 60 per cent in the number of seniors 75 and older. With an aging population, it is projected that the prevalence of chronic conditions will increase, resulting in more people with complex health-care needs.

An aging population combined with an increase in chronic diseases will stretch our health-care system as never before. We must make changes today to ensure our system is sustainable for the future but, just as important, to also ensure we are offering New Brunswickers high-quality services.

The framework for a provincial palliative care strategy will help enable progress in the care New Brunswickers receive. The framework outlines strategic directions and is intended to guide regional health authorities, health-care providers and community organizations in planning integrated palliative and end-of-life care services. It supports quality palliative and end-of-life care with a focus on supporting individuals with life-limiting illness to remain at home in their community while improving coordination of care across all settings.

Given our demographics, change is critical. But it will take time. It will also take leadership, dedication and commitment from health-care providers, government, community organizations, individuals and families.

I am continuously impressed by the compassionate and talented people involved in palliative and end-of-life care across New Brunswick. Our province has a strong group of dedicated individuals who deliver the care that patients and their families need. Their passion and focus provide a solid foundation for the work still to be done.

I look forward to the future transformation of our system resulting from ongoing and new partnerships that will strengthen palliative and end-of-life care at both a regional and provincial level.

A handwritten signature in black ink that reads "Benoit Bourque". The signature is written in a cursive, flowing style.

Hon. Benoit Bourque  
Minister of Health

## Acknowledgements

The integrated services framework for the New Brunswick Palliative Care Strategy was informed by a number of key stakeholders. The contribution of the members of the Provincial Palliative Care Advisory Committee who participated in the development and recommendations for this framework is graciously acknowledged.

Committee members included:

- Canadian Cancer Society – New Brunswick Division
- New Brunswick Association of Nursing Home
- New Brunswick Home Support Association
- New Brunswick Hospice Palliative Care Association
- New Brunswick Medical Society – Family Medicine
- Regional Health Authorities - Horizon Health Network and Vitalité Health Network representation from – palliative care, oncology, primary health care, home care, as well as patient/family
- Department of Social Development
- Department of Health

Also acknowledged is the work of other organizations and jurisdictions in the field of palliative care. Their work helped the Provincial Palliative Care Advisory Committee develop this framework. This framework was influenced by and adapted content from the following:

- World Health Organization's Palliative Care Fact sheet No 402 (July 2015)
- New Brunswick Hospice Palliative Care Association's Provincial Framework for Palliative Care in New Brunswick (January 2010)
- Canadian Hospice Palliative Care Association's
  - » A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice (2013)
  - » The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care, The Way Forward Initiative (2015).
  - » Valuing Caregiving and Caregivers: Family Caregivers in the Integrated Approach to Palliative Care, The Way Forward Initiative (2013), and
  - » The Palliative Approach: Improving Care for Canadians with Life-Limiting Illnesses, The Way Forward Initiative (2012)
- Supportive Care Framework: A Foundation for Person-Centered Care (2008) by Margaret I. Fitch, Heather B. Porter, and Beverly D. Page
- Integrated Palliative Care: Planning for Action in Nova Scotia (2014)
- A Palliative Care Framework for End-of-Life Care. British Columbia, Ministry of Health (May 2006)



## Preamble

Palliative-care services have been available in the province, in hospitals, nursing homes and in homes through the New Brunswick Extra-Mural Program. Palliative care guidelines for the Extra-Mural Program providers were developed in 2008, while a number of communities have developed hospice volunteers programs and grief and bereavement services.

A palliative care forum organized by the New Brunswick Cancer Network brought key stakeholders together. Working together they helped identify common challenges including timely access to palliative care, meeting needs with increasing demand, and the lack of skilled providers. Subsequently, The Palliative Care Advisory Committee consisting of key stakeholders was established by the Department of Health and led by the New Brunswick Cancer Network and the New Brunswick Extra-Mural Program. The committee made recommendations toward the development of this framework.

This conceptual framework and the strategic directions outlined in it support the development and standardization of palliative care services to meet the needs of persons living with life-limiting illness in New Brunswick.

## Definitions

**Palliative care** is an approach that improves the quality of life of patients (adults and children) and their families facing problems associated with life-threatening illnesses. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. According to the World Health Organization, palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psycho-social or spiritual. It offers a support system to help patients live as actively as possible until death.

**Hospice** refers to palliative care services at the end of life when curative or disease-modifying care is no longer an option. It includes volunteer programs supporting care in the community and may include residential care in a facility or in hospital when appropriate.

**Person** is generally used as it reflects the reality that more than health care is required to provide palliative care. A Person can be the patient in the health-care system and also a client or user of various services in the community.

**Family** is used to include the living environment of the person therefore is used broadly to include anyone designated as “significant other(s)” by the person in need of palliative care and/or services and is not to be limited to the spouse, parents, siblings, children and in-laws.

In pediatric situations, the level of autonomy, self-determination and decision making varies based on developmental stages of a child and is generally age-dependent; the use of **Person** and **Family** is to be referred to as the **Family Unit**.



Mission	Vision
Key stakeholders working together to ensure high quality palliative care services in order to reduce the suffering for persons living with life limiting illness and their families, from diagnosis to death.	All New Brunswick residents in need of palliative care have access to responsive palliative care services that are based on common goals and evolve as required to address the changing needs, regardless of the time of day and location, from diagnosis to death and including bereavement care for significant others.
Values	
<p>Palliative care services are provided based on the following values:</p> <ul style="list-style-type: none"> <li>• The natural process of death as a normal part of life provides for personal growth through experience and self-actualization.</li> <li>• Each person is unique, autonomous and capable of self-determination.</li> <li>• The need to address the person's and family suffering, expectations, needs, hopes and fears.</li> <li>• The person/family's dignity and integrity is supported and maintained.</li> <li>• Care and/or services are provided when the person and/or family accepts them.</li> <li>• Care is guided by quality of life as defined by the person or family unit.</li> <li>• Care and/or services are provided within the parameters of therapeutic relationships</li> <li>• Communities are an essential component of a unified response to relieve suffering.</li> </ul> <p>These values are adapted from the New Brunswick Hospice Palliative Care Association's Provincial Framework for Palliative Care in New Brunswick (2010).</p>	

## Guiding principles

Services, programs, policies and other initiatives related to palliative care in New Brunswick will be developed and implemented based on the following guiding principles. These principles are consistent with the national principles and norms of practice from the Canadian Hospice Palliative Care Association.

### Person and family centred

The person is engaged in and directs his or her care, including deciding how family members will be involved. When care is provided, the person and family are treated as a unit. All aspects of care are provided in a manner sensitive to the person's and family's personal, cultural, religious values, beliefs and practices, their development state and preparedness to deal with the dying process.

### Ethical and high quality

The delivery of services is guided by the ethical principles of autonomy, beneficence, non-maleficence, justice, truth telling and confidentiality. All palliative care activities are guided by accepted principles, norms of practice and standard of professional conduct for each discipline.



## Safe and efficient

All services are conducted in a manner that is interdisciplinary and team-based, collaborative, confidential and private, without coercion, discrimination, harassment or prejudice, safe and secure for all, conducted with continuity and accountability; with minimized unnecessary duplication and repetition and in compliance with laws, regulations and policies.

## Accessible and affordable

All persons and families have equal access to palliative care services in a timely manner as defined by eligibility and assessed needs. The financial, human, informational, physical and community resources are sufficient to provide quality care. These resources are allocated to address the palliative care population needs.

## Clinically sustainable

Services are provided with sufficient human resources to address the palliative care needs of the population. A clinically sustainable service typically requires enough human resources available 24 hours a day, seven days per week, 365 days a year. Adequate volume of services is also necessary for providers to maintain their skills and expertise.

## Collaborative

Collaboration between individual communities and service providers will ensure access to the required level of care and services through the creation of partnerships with organizations interested in meeting the palliative care needs of the population.

## Advocacy-based

Regular interaction with legislators, regulators, policy makers, health-care funders, palliative care providers, professional societies and associations and the public is essential to increase awareness as well as develop and enhance palliative care activities and resources that support them.

## Evidence-based and effective

The development, dissemination and integration of new knowledge are critical to the advancement of quality palliative care. Where possible, all activities are based on the best available evidence. Ongoing education of persons, families, caregivers, staff and stakeholders is integral to providing and advancing palliative care.





## Foundational concepts

Palliative care programs are developed using a supportive care framework; programs strive to meet the needs of the palliative care population through the provision of necessary services to support persons living with or affected by life limiting illnesses. The needs include physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnosis, treatment and follow-up phases, encompassing issues of survivorship, palliative care and bereavement. The full range of services does not need to be available in all clinical settings but need to be offered and easily accessible.

Person-centred palliative care services are provided based on assessed needs and are clearly defined; integration, coordination and navigation processes are user friendly to meet the needs of the persons and families along the continuum of care. Care is coordinated within each setting and among agencies involved; transitions from one setting or service to another is fluid and occurs as required to meet the person's or family's assessed needs.

A fundamental requirement is that person's and family members' informational needs are met. Information is available regarding the disease, treatments and available services to support decision-making to meet their evolving needs.



## Responsibility centres

Palliative care services require a coordinated effort. Everyone, from the patient to care providers to family members and community organizations, has a role to play.

### Person and family

The person and family receiving palliative care services guide the care through the identification of care goals and needs. They participate in their care and collaborate by keeping providers informed of changes and decisions relating to care and services required as their needs evolve.

### Care and service providers

The interdisciplinary team comes together with family members, friends and other caregivers to form a circle of care around the person and family. They collaborate and share information to promote continuity and enhance care delivery to the person.

During each therapeutic encounter, the process for providing care involves six essential steps that guide the interaction between caregivers and the person and family: assessment, information-sharing, decision-making, confirmation, care delivery and care planning. While these steps do not need to occur in any specific order, each must be completed during each therapeutic encounter.

Person and family care should address each of the domains/issues commonly faced by persons and families. Domains include: disease management, physical, psychological, social, spiritual, practical, end of life/death management and grief.



## Organizations

To support the process of providing care, organizations must have a management and administrative infrastructure to develop and maintain the resources needed to support its principle activities and functions including: patient and family care, education of primary and expert health-care providers, research and advocacy.

Regional Health Authorities (RHAs) and Extra-Mural/ Ambulance New Brunswick (EM/ANB) are the three main organizations responsible for the delivery of health care services, that include palliative and hospice care in the province.

RHAs plan and organize the delivery of health care at the local and regional levels, in hospitals and residential facilities under their governance. EM/ANB plan and organize the delivery of health care in the community; this includes care in-home and residential facilities. RHAs and EM/ANB access other services such as community based support services that are funded in whole or in part but delivered by separate organizations or individuals. Other community services do not have any formal connection to the RHAs or EM/ ANB but need to be incorporated into the planning and service delivery; partnerships are established. The RHAs or EM/ANB have a critical role in supporting the paradigm shift to care in the home to allow for a higher proportion of persons to die at home. When care in the home does not meet the needs and hospital care is not required, other avenues such as residential facilities and hospices or equivalent alternate services should be explored.

Health-care professional groups and non-governmental groups (various associations, foundations, Accreditation Canada and others) provide support for professional practice to a number of health-care providers involved in palliative care. They provide services to persons and families, professionals, organizations and government. Services may include persons and family information, direct consultation with members or organizations, guidance through position statements, best practice guidelines or standards and active involvement through formal representation on committees to ensure high standard of care for the public.

Non-governmental community-based organizations and groups, available in most parts of the province provide assistance to persons who are dying and their families. These groups generally depend on community support, fundraising and volunteers to offer psycho-social and bereavement support. These organizations have an essential role to play; their efforts need to be integrated with other palliative care services.

## Provincial leadership

The Government of New Brunswick is responsible for providing the leadership and setting the overall direction of the health-care system. These responsibilities include making legislative changes, establishing policy, planning, funding, monitoring and evaluating the overall performance of the health-care system.



## System processes and principal functions

System processes are essential common practices along the continuum of care/services within the palliative care program. Principle functions are defined as essential to actualize a consistent integrated palliative care service delivery across settings.

Palliative care services are a shared responsibility. The inclusion of service delivery, regional coordination, provincial leaders, community partners, non-profit organizations, persons and/or families and other interested parties is a key component of this shared “ownership” and must include developing community capacity.

### Community partners

Key community partners include RHAs, EM/ANB, community service providers and non-profit organizations working together to provide quality palliative care. Each partner is clearly identified; individual service descriptions are clear and guide appropriate referrals and access. As required, partners may vary as services evolve based on the palliative care needs of the population and available resources.

### Primary team

A primary team provides palliative care in an interdisciplinary manner, collaborating to meet the person/family’s agreed upon goals of care that include advance care planning in a defined setting (in-home, residential settings, nursing home, hospital or other setting). The team includes the person/family and, at minimum, providers of medical and nursing services; medical services are provided by family physicians. Other services based on the person’s/family’s assessed needs may include pharmacy, social work, clinical nutrition, occupational therapy, physiotherapy, respiratory therapy, speech language therapy, child life services, pediatric oncology navigators, personal care, home support, spiritual care and others contributing toward the goals of care.

### Palliative care team

The palliative care team is an inter-professional team with expertise and skill in the management of complex symptom management, advanced care planning and bereavement counselling. The core palliative care team consists of a palliative care physician, palliative care nurse, pharmacist, social worker and others as deemed appropriate. The palliative care team supports primary teams by providing consultation, leadership and advice, enhancing capacity to support care and dying in the community. They may participate in the development, implementation and evaluation of clinical protocols, practice guidelines and service delivery.

### Standardized processes and tools

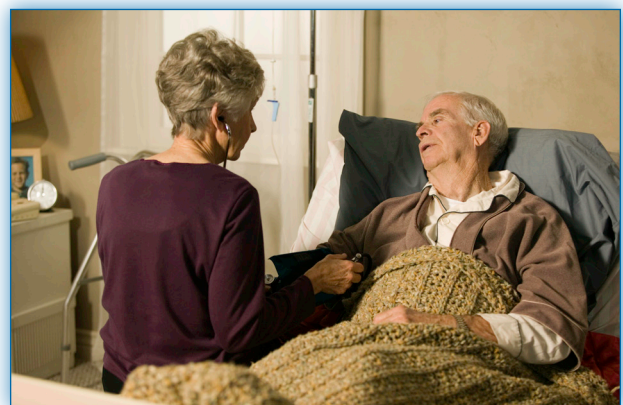
Common processes and tools are used across the system to enhance the provision of palliative care services. Standardized and validated assessment tools are identified and used at minimum, to screen for distress, to guide pain and symptom management and to establish functional status across settings; other standardized tools may be used as appropriate.

### Care coordination and navigation

Care coordination and navigation are responsibilities that shall be assumed by designated professionals on a primary or palliative care team provided the person is under their direct care.

Activities include:

- Maintain an accurate and up to date assessment of



the person's needs.

- Ensure services are provided in a timely manner and reflect the changing needs of the person.
- Organize care and services that are reflective of 24/7 needs.
- Ensure referrals and consultations are made with other professionals or services.
- Ensure effective communication with members of the care team and include case conferences with all parties involved in the care when required.
- Ensure that the services provided respect the person's wishes.
- Organize personal care, home maker and respite services as required.
- Support and plan bereavement care.



### Person and family education

Information provided to the person and family is timely and pertains to the diagnosed illness and treatment options to be considered. Ongoing information is to be provided as the disease evolves and the person's condition and treatment changes. The person and families need to know what to report and to whom; they need the information regarding services to access the community, health and social systems to meet their needs along the journey.

### Provider education

Palliative care education is provided to care

and service providers from all settings. The focus of education is on clinical care, palliative services and to related processes. To ensure the delivery of quality palliative care services, all providers that are part of the integrated palliative care service have access to and benefit from palliative care education.



### Public education

Public education is provided to enhance the public's awareness and knowledge about the natural process of death, what encompasses palliative care services and the importance of advanced care planning and associated directives (e.g., power of attorney).

### Documentation

Documentation guidelines are based on parameters set by health and/or social legislation and applicable professional practices. Documentation parameters are established to support communication between professionals and settings providing palliative care services. The person's care goals are recorded, updated and communicated to partners as required to reflect changes along the continuum and to support the evaluation of palliative care services.

### Data collection

Data collection will occur as established to support the planning and delivery of palliative care services and to monitor outcomes and indicators for the palliative care population.



## Referrals

To strengthen the person/family centred approach and to support timely access and minimize delays in service provision, health-care professionals should refer a person/family for community services and to other professionals when the needs exceed their competencies and/or scope of practice.

## Programs and services performance

Each palliative care service or program is clearly defined and includes eligibility and discharge criteria that can be used to guide access and evaluation of services. The monitoring and evaluation of palliative care programs and services are guided by established outcomes and indicators.

## Strategic directions

To support palliative care services in New Brunswick, strategic pillars were developed under five themes: person-centred care, family support network inclusion, professional capacity, community capacity and regional health authority and provincial leadership. Goals established under each theme are the directions deemed to be priorities for palliative care and service delivery based on today's needs for New Brunswick.

### Person-centred care

Access to coordinated care and navigation in all settings

- Care is holistic and person-centred. At minimum, care includes medical and nursing services, providing psycho-social support as indicated by distress assessment.

Ensure the person:

- Has received the information to have a good understanding of the evolution of the disease and care plan for the journey of the illness.
- Participates in the development and agrees with the documented goals of care which are to be supported by advanced care directives whenever possible.
- Knows what palliative care services are offered and what other services are available, from personal coverage, social, legal and community programs or services.
- The person and/or family know how to access the services and programs if and when needed.

Access to competent home health care and home support services.

### Family support network inclusion

Access to competent home health care and home support services

- Increase direct care and support services to relieve the family caregiver's burden in end-of-life care.
- Support services include personal care, housekeeping, respite/relief, support with instrumental activities of daily living and someone to help with forms (insurance, applications for equipment/supplies/services, compassionate care benefits).





### Access to coordinated care and navigation in all settings

- Care includes regular communication/visits that consists of emotional support for family caregivers by providing reassurance on the care provided, teaching required skills and knowledge on the evolution of the disease and includes planning and preparing for the changing needs of the person.
- Family caregivers know what services are available from insurance, social services, community services, and how to access when needed. Providers have access to technology to support and maintain communication with family who lives away.

### Access to bereavement services

- For the family and including children services when the death of a family member is to occur.

## Professional capacity

### Develop and maintain provider competency

- Palliative care education for family physicians, frontline providers working in hospitals, extra-mural, nursing homes and home support services.
- Provider competency includes self-care for providers.
- Access to palliative care resources and/or peer consultation when required 24/7 to meet patients' needs in their current setting (community may require more access to meet the needs).

### Deliver coordinated care

- Use standardized care tools and best practices across care settings.
- Support effective communication – one patient one record.
- Use rounds/meetings to support the integration of services and competency development.

### Deliver integrated palliative care services

## Community capacity

### Enhance access to in-home services

- Develop skilled home support workers to deliver personal care, respite and relief.
- Improve access to equipment, including transportation/assembly and installation (drop off and pick up) to adapt the home environment to meet in-home palliative care needs.
- Augment transportation services for diagnostics, appointments, treatments and transportation of items required to support clinical decisions and interventions required for the provision of care in the home.

### Enhance hospice services

- Expand accessibility to volunteer programs throughout the province.
- Increase accessibility to residential hospice services where appropriate.

### Enhance the provision of bereavement care

- Develop and provide bereavement programs through Hospice programs, faith communities and funeral homes.



## Enhance social/community navigation

- Better communicate information relating to available community services and process to access them.

## Regional Health Authorities, Extra-Mural/Ambulance New Brunswick and provincial leadership

- Support a paradigm shift toward care and dying in the home.
- Fund equitable resources to meet the needs of palliative care programs, including physicians involved in palliative care.
- Ensure equitable access to palliative care services throughout the province.
- Define and monitor palliative care indicators.

## Moving forward

The way we live matters, and so does the way we die. That is why it is critical to have access to quality palliative and end-of-life care services.

This framework will guide the development of action plans, policies, programs and services, under the Provincial Palliative Care Strategy, to help ensure we can live well with illness up to the end of life, with the ability to manage symptoms and make informed decisions about the kind of care we, as individuals, choose. Oversight of the New Brunswick Palliative Care Strategy will be provided by the Department of Health.

Changing the way we deliver services will take collaboration and careful planning from all partners. Working together, we will develop a sustainable system where individuals and families across New Brunswick benefit from equitable access to a choice of safe, comprehensive and quality palliative and end-of-life care services.

