

**Provincial Framework for Palliative Care in New Brunswick  
Draft 5**

***“Unfortunately, in end of life care, we do not have a vocal constituency:  
The dead are no longer here to speak, the dying often cannot speak, and  
the bereaved are often too overcome by their loss to speak.”***

Harvey Chochinov, Testimony before the Subcommittee, Feb. 28, 2000

**Developed by the New Brunswick Hospice Palliative Care Association  
L'Association des Soins Palliatifs du Nouveau-Brunswick  
January 2010**

## **Introduction**

Hospice palliative care relieves suffering and improves the quality of living and dying for those individuals with a progressive life-threatening illness/injury throughout the illness and at the end of life and/or who are bereaved.

Currently in New Brunswick there is no provincial approach to palliative care. Hospice palliative care services have developed unevenly across the old regions and continue to do so within the new provincial health care zones. Where you live depends on how well you die.

Based on national standards from the Canadian Hospice Palliative Care Association (CHPCA)<sup>1</sup> and the extensive work of the Nova Scotia Hospice Palliative Care Society<sup>2</sup>, the New Brunswick Hospice Palliative Care Association/L'Association des Soins Palliatifs du Nouveau-Brunswick (NBHPCA/ASPNB)) has developed a framework to help guide the province in improving palliative care for New Brunswickers. We wish to build on our existing resources in the province so that patients may receive expert palliative care regardless where they live.

It is important to realize that palliative care affects both patients in hospital and patients at home, whether their home is a nursing/special care home, residential hospice, or private residence.

The overall objective of this proposal is to ensure that all New Brunswickers who need palliation and end-of-life care have access to appropriate timely and quality hospice palliative care services.

Specific objectives of the framework are:

- Assist with understanding why a model of care based on CHPCA standards is essential for New Brunswick
- Assist with the understanding of existing services in New Brunswick
- Make recommendations for service delivery guidelines
- Provide information for further planning purposes

## Why New Brunswick needs a provincial approach to palliative care

The World Health Organization definition of Palliative Care:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone 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 patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;

is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.” (WHO, 2008)

Hospice palliative care is a combination of active and compassionate therapies that address the physical, psychological, social, spiritual and practical needs of individuals who are dying and their families. Hospice palliative care cuts across care settings and involves a network of health professionals as well as familial caregivers and volunteers. Hospice palliative care is most applicable in those situations where disease modifying interventions are not expected to save or significantly prolong life.

Hospice palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement.

Hospice palliative care aims to:

- treat all active palliative care issues; i.e., management of symptoms, loss, grief, and transitions
- prevent new issues from occurring

- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.<sup>2</sup>

### **The Importance of Palliative Care**

Ninety percent of the population will have a period of illness before they die. Most would be relieved to know that during this time they will still be looked after by the medical system in a way that will ensure the least amount of suffering possible. Palliative Care is aimed at the relief of suffering and improving the quality of life for persons who are in the final stages of advanced illnesses.

It is distinct from other branches of health care in that its focus is on the whole person, including the person's relationship to family, friends and community. Hospice Palliative care is now recognized as a specialty practice of medicine (fellowship level training available) and nursing (specialized certification through the Canadian Nursing Association) due to the extra skills that are required to provide quality end of life care and symptom management that encompasses not only physical but emotional and spiritual support as well. The palliative care approach is reaffirmed through the government reports of Carstairs<sup>3</sup>, Kirby<sup>4</sup>, and Romanow<sup>5</sup>.

### **Advantages of Palliative Care**

Better Patient Care - The dedicated health care professionals who currently care for patients may not have the experience or knowledge required to deal with complex symptom management. This can lead to under treating pain and other symptoms, unnecessarily extending patient stay in hospital, restricting transition to home due to lack of follow up, or not realizing that end of life care can occur at home with proper supports.

At times the goals of care may not be focused on the patient's and their family's wishes, resulting in care that may not be appropriate for the individual who perhaps wishes only to return home with the promise of home support. Due to our aging population these concerns will be ongoing, resulting in an increase in the number of people affected with chronic illnesses. Though these people are not yet actively dying they will still need the help of experienced professionals to assist them with symptom management, discussion of goals of care, and with the transition from curative to end of life care.

There have been no randomized, double blind controlled studies comparing standard of care versus care from a palliative care team; however, there have been various small studies that show patients who receive care from a palliative care team have decreased pain and other symptoms<sup>6</sup>, greater patient and family satisfaction<sup>7,8</sup>, decreased visits to the ER, less hospitalizations, and decrease in length of stay.<sup>9,10,11,12,13,</sup>

Better Education of Health Care Professionals – A provincial palliative care model would encourage more focused opportunities for teaching about palliative

care in the province, help with recruitment and retention of the interprofessional team members including medical staff, nursing, occupational therapy, social work.... Integration of palliative care education into the core curriculum of the inter-professional team would assist with developing the knowledge and basic skills needed to care for people with a life-threatening incurable disease. The benefits of this are many.

### **The Population Affected**

Palliative Care assists people with symptoms of pain, dyspnea, cachexia, asthenia, confusion, nausea/vomiting ... While cancer patients comprise approximately 80% of patients who receive care, they are not the only population requiring palliative care. As the population of New Brunswick ages so does the incidence of chronic disease. Patients with Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), renal failure, neurodegenerative diseases, dementias, etc. all benefit from palliative care. Hospice palliative care is a collaboration between health care professionals from all levels of care and areas of specialization.

### **Existing palliative care services in each zone**

The delivery of palliative care and end-of-life care has developed differently based on the resources available across the province.

Each Regional Health Authority (RHA) is responsible for delivery of palliative care. Within each RHA, each zone delivers palliative care differently. Each hospital has some structure for palliative care beds, but not all inpatients have access to palliative care physicians, nurses, or other interdisciplinary staff who have been trained in palliative care. For patients at home, the extra mural program has developed provincial guidelines, but depending on the zone the extra mural may or may not have been able to put these standards into practice. Again, not every home patient has access to health professionals who are skilled in palliative care. As well, home patients have limited access to resources available for the delivery of care in the home.

The following examples highlight some of the differences: Saint John is the only zone in the province with a dedicated full time palliative care physician for home visits. Miramichi has a physician that provides four hours or coverage for palliative care for inpatients only; there is no physician for patients out of hospital. Moncton Driscoll Extra Mural has a full time palliative nurse specialist to help the other nurses care for palliative patients at home. Beausejour Extra Mural Unit does not have this resource. Miramichi has social workers who are consulted on every palliative care patient but this does not happen in Fredericton due to available resources. There is a palliative care pharmacist that sees palliative care patients at the Moncton City Hospital but this does not happen in Campbellton, again due to lack of resources.

As is evident here, where you live depends on the palliative care services that are able to be delivered.

## **Recommended Provincial approach to hospice palliative care**

### **Vision:**

All New Brunswickers who need palliation and end-of-life care have access to appropriate quality hospice palliative care services. This will be fulfilled by establishing a formal palliative care service in each health zone across the province guided by national standards, as outlined below.

### **Values:**

Hospice palliative care is based on and ***continuously supported*** by the following values:

- The intrinsic value of each person as an autonomous and unique individual capable of self-determination of need.
- The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
- The need to address individuals' and families suffering, expectations, needs, hopes and fears.
- Care is only provided when the individual and/or family is prepared to accept it.
- Care is guided by quality of life as defined by the individual.
- Caregivers enter into a therapeutic relationship with individuals and families based on dignity and integrity.
- A unified response to suffering strengthens communities

### **Guiding Principles:**

The following principles are essential to and ***continuously guide*** the development and delivery of hospice palliative care services:

#### **1. Individual and Family Focused**

When care is provided the individual and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the individual and family's personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.

#### **2. High Quality**

All hospice palliative care activities are guided by:

- the ethical principles of autonomy, beneficence, non-maleficence, justice, truth-telling and confidentiality.
- policies, procedures, and care processes that are based on the best available evidence or opinion-based preferred practice guidelines for each discipline
- data collection / documentation guidelines that are based on validated measurement tools.

#### **3. Safe and Effective**

All hospice palliative care activities are conducted in a manner that:

- is interdisciplinary and team-based

- is collaborative
- ensures confidentiality and privacy
- is without coercion, discrimination, harassment or prejudice
- ensures safety and security for all participants
- ensures continuity and accountability
- aims to minimize unnecessary duplication and repetition
- complies with laws, regulations and policies in effect within each RHA

#### **4. Accessible**

All individuals and families have access to hospice palliative care services:

- as they choose and at an easily accessed point of entry
- wherever they live and/or choose to receive services, recognizing that creative efforts are required to overcome geographic isolation.
- in a timely manner as identified by the service delivery organization

#### **5. Adequately Resourced**

The financial, human, information, physical and community resources are sufficient to provide quality care, as determined in each RHA's strategic and business plans. Resources are allocated based on the health zone's capabilities and priorities and may require inter-zone collaboration and sharing of resources.

#### **6. Collaborative**

Each community's needs for hospice palliative care are assessed and addressed through the collaborative efforts of available organizations and services in partnership with the respective Zone and RHAs. This may include, but is not limited to, the extra mural program, home health care organizations, nursing homes, community hospice organizations, and other community volunteer organizations.

#### **7. Knowledge-Based**

Ongoing education of all individuals, families, caregivers, staff and stakeholders is integral to the provision and advancement of quality hospice palliative care.

#### **8. Advocacy-Based**

Regular interaction with legislators, regulators, policy makers, healthcare funders, other hospice palliative care providers, professional societies and associations, and the public is essential to increase awareness about, and develop, hospice palliative care activities and the resources that support them. All advocacy recognizes the Canadian Hospice Palliative Care Association's *A Model to Guide Hospice Palliative Care*. (Ottawa, 2002)<sup>1</sup>

#### **9. Research-Based**

The development, dissemination, and integration of new knowledge are critical to the advancement of quality hospice palliative care. Where possible, all activities are based on the best available evidence. All research protocols comply with legislation and regulations governing research and the involvement of human

subjects in effect within the jurisdiction.

## **Recommendations for Service Delivery Guidelines for a Provincial Framework to Hospice Palliative Care**

These guidelines are based on evidence of best practice and existing research at the national and provincial levels including standards of practice that have already been referenced above. These guidelines are consistent with the provincial vision, are client-centred, integrated, effective, evidence-based, and uses reasoned resources.

This range of services is delivered by an interprofessional network of providers knowledgeable and skilled in hospice palliative care, to those who are living with or dying from a progressive life-threatening or life-ending illness/injury and to those who are bereaved. The range of services are supported by and offer support to family caregivers and volunteers.

Hospice palliative care services are comprehensive in nature, addressing the physical, psychological, social and spiritual needs of individuals and families in the care setting of choice and by the most appropriate team members at any point in the care experience. The suggested roles and responsibilities of the various members of the palliative care team, are included in Appendix A.

### **Functional Elements/Components:**

To actualize consistent application of the purpose, values and guiding principles, the service delivery guidelines include the following elements or service components:

#### **1. Referral or Access**

To ensure easy and consistent access, each zone needs to have a single entry point for access to the service. This is crucial to allow health professionals to know where to direct a consult and to make sure there is no unnecessary delays in the patient receiving the services needed.

#### **2. Referral Source**

To ensure an individual/family-centred approach, increased access, and a timely response to services, referrals to the service can be made directly by health professionals based upon specific criteria. This would allow consults from not only physicians, but also from other members of the health care team, including nurses and other allied health professionals, as well as nursing homes and residential hospices.

#### **3. Coordination and Continuity of Care**

To ensure that care is integrated across the continuum of care (i.e. across all care settings), a case management approach should be applied and a case

coordinator should be identified. Using the most appropriate or available resource to the case the case coordinator will facilitate care plan development and case review, as needed, to ensure that needs and expectations are managed in a timely manner.

#### **4. Care Planning and Delivery**

The individual and family will be included in all care planning and decision making around care delivery. A standardized palliative care assessment tool (such as the Edmonton Symptom Assessment Scale) will guide assessment and a continuous palliative care plan will be developed to meet the needs and expectations of the individual and family in all settings of care. All information will be entered into the patient's electronic medical record (EMR) if available and utilized by all team members and follow the individual throughout the care experience.

#### **5. Palliative Care Consult Team**

The primary provider team will be supported by an interprofessional palliative care consult team with expertise and skill in the management of complex symptom management, advanced care planning, and bereavement counselling. This core consult team will consist of a palliative care physician, palliative care consult RN, pharmacist, and social worker. As deemed appropriate, spiritual support will also be available. This consult team will provide leadership, advice, guidance and support to individuals, families, and care providers. Patients across all spectrums of care would have access to the palliative care consult team, whether in hospital, at home, in a residential hospice, nursing home, or special care home.

Please see the appendix for more information on the suggested roles and responsibilities of the palliative care consult team.

#### **6. Interprofessional Primary Care Team**

An individual/family-centred care plan will be developed and implemented by a team of knowledgeable and skilled providers who will collaborate to meet the individual and family's physical, psychosocial, and spiritual needs. The team includes, but is not limited to; the family physician or attending physician, case manager, registered nurse/licensed practical nurse, social worker, speech language pathologist, respiratory therapist, occupational therapist, dietician, physiotherapist, homemakers, chaplain/spiritual care and other service providers as available and deemed appropriate to the situation.

#### **7. Timely and Consistent Clinical Review**

Palliative care rounds allow effective primary team and palliative consult team communication, timely referral to needed interventions or resources, progress evaluation, review of individual/family expectations, and ensure that the complex needs of the individual and family are accurately met.

## **8. Community Support**

Volunteers, family caregivers, and other supports available in the community are instrumental to the plan of care and added as deemed appropriate by the individual and family. The goal of these supports is to assist the interdisciplinary and consult teams in appropriately meeting the needs of the individual and family as well as the patient's support services needs for learning and support.

## **9. Bereavement Support**

Grief counselling may be needed for the family/loved ones once the patient has died. It should be provided by those skilled in this area with spiritual support available as requested or deemed appropriate. Bereavement support will be part of the care plan for the surviving family and caregivers, and as such should be coordinated and managed by the case manager in consultation with the primary care team and, as required, with the palliative care consult team.

## **10. Evaluation**

A provincial database should be established to capture consistent program indicators of performance and clinical outcomes. Each zone would collect standardized data that would be submitted regularly to the Department of Health. An evaluation plan would be developed and implemented.

## **Further Planning – The Next Step**

In conclusion, it is recommended that:

- The Department of Health approve the Service Delivery Guidelines as a framework for program development to be used by each zone in both RHAs
- a common assessment tool that is evidence-based be adopted;
- a partnership be developed with New Brunswick Cancer Network to help train and educate health professionals and volunteers throughout the province;
- consistent program indicators of performance be adopted to support service delivery, evaluation, and research;
- a palliative care advisory committee be established in each zone to further develop the framework and evidence-based processes for program planning throughout the health zones. These advisory committees would report to a RHA palliative care committee ;
- priorities from a provincial perspective be identified, particularly in view of potential federal cost-sharing opportunities; and
- an implementation plan for a province-wide integrated, community-based palliative care approach be developed.

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## **Appendix A: Suggested Roles and Responsibilities of the Palliative Care Team**

To protect or insure the integrity of palliative care services, as a minimum, the following resources are needed to provide direction to the service.

### **The Palliative Care Consultant Team**

#### **1. Palliative Care Resource Physician**

- Provides a palliative care medical assessment for individuals
- Supports family physicians and other attending physicians in the care of palliative care individuals and families
- Provides education to physicians in the care of palliative care individuals and families
- Participates in palliative care rounds
- Provides consultation to palliative care team members
- Participates in the development, implementation, and evaluation of clinical protocols and practice guidelines
- Contributes to the palliative care knowledge of the team

#### **2. Palliative Care Consult Nurse**

- Provides palliative care leadership to the team
- Collaborates in the assessment of all palliative care individuals and families
- Collaborates in the development of the palliative care plan
- Coordinates educational programs in collaboration with the team
- Provides clinical advice and recommendations to providers and individuals and families with complex pain and symptom management issues
- Develops nursing care plan with primary nurses for individuals and families with complex pain and symptom management issues
- Collaborates with the interdisciplinary team to facilitate meeting the individual and family needs and expectations
- Provides clinical support to primary nurses in all care settings
- Provides leadership in the evaluation of individual and family outcomes
- Collaborates with the team in the delivery of bereavement follow-up services for families
- Provides educational resources for individuals and families
- Contributes to the knowledge of the team by keeping current with the palliative literature
- Advocates on behalf of the patient and family

#### **3. Palliative Care Resource Pharmacist**

- Participates in palliative care rounds
- Provides drug information and contributes to the drug knowledge of the team
- Provides pharmaceutical care to ensure the drug-related needs of the individual is met and drug related problems are identified, prevented and resolved
- Educates individual and family
- Ensures palliative care medications and supplies are available 24 hours/day

- Provides support and education to pharmacy colleagues in all care settings concerning the safe and efficient dispensing of palliative related medications
- Provides recommendations to the team and to the New Brunswick Prescription Drug Program regarding medication entitlements

#### **4. Palliative Care Consult Social Worker**

- Participates in rounds
- Facilitates linkages to their social work colleagues throughout the zone to follow up on specified individual and family counselling
- Provides counselling to individuals and families
- Provides assistance with securing financial benefits
- Provides adjustment, grief support and resource counselling to individuals and families who are faced with complicated grief issues
- Provides consultation to individual, family and to team members
- Receives referrals to follow families with complicated grief issues
- Links with Mental Health Services and other community resources as appropriate

#### **5. Palliative Care Case Manager**

- Facilitates the development, implementation, and evaluation of the palliative care plan with the individual, family and team
- Provides continuity to the plan of care
- Acts as a liaison between and among the palliative care service, direct providers, and the individual and family
- Coordinates services in the care setting (hospital or home)
- Communicates changes to team
- Attends rounds
- Coordinates referrals for specialized services
- Coordinates medications and equipment
- Facilitates individual/family conferences
- Coordinates transfers between care settings
- Educates individual and family