



**The Hamilton Niagara Haldimand Brant  
Hospice Palliative Care  
System Design**

**PHASE ONE**

**August 2008**



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### ***Background***

Demand for palliative care is increasing world-wide because the population is aging and more people are living longer with a chronic or terminal illness than at any time in history. Most deaths in the developed countries of the world occur in people over the age of 65 years. In Canada, more than 200,000 people die annually and 75% of these deaths are of adults 65 years and older. The three leading causes of death for older Canadians are coronary heart disease, lung cancer, and stroke; typically older people have end-of-life care needs that meet palliative care criteria. Given Canada's aging population and the concurrent rise in age-associated degenerative and chronic illness, the need for access to palliative care services by older people at the end-of-life is expected to rise steadily.<sup>1</sup>

Therefore, for a growing number of people suffering from terminal and chronic illness in today's aging society, there is an obvious need for high quality end-of life care that will relieve suffering and improve their quality of living and dying. Now, more than ever before, it is important to ensure that people in the Hamilton Niagara Haldimand Brant region have access to the best possible system of Hospice Palliative Care. It is estimated that there are 486,597 people aged 50 and over living in the region today and that this number will increase to 595,212 in 2016. Projections, based on the incidence of cancer and other terminal illness in this demographic, show that approximately 3,080 will require hospice palliative care in 2008 and 3,782 will need these services in 2016. This is an extremely conservative estimate based predominately on cancer rates and the assumption (expounded in the Romanow Commission's 2002 report on the Future of Health Care in Canada) that approximately two thirds of those who could need palliative care will actually want it.

### ***But what will it take to ensure quality hospice palliative care for all individuals who require it?***

This is a complex question that crosses many sectors, care settings and disciplines. Hospice palliative care is a term that describes a type of care, sometimes also referred to as end-of-life care that may be delivered in various locations including hospices. People may also receive hospice palliative care in hospitals, their own homes, long-term care facilities or any other setting where they spend their last days. They may also move from one of these locations to another during the course of their illness. The care may be delivered by hospital physicians and staff, and family physicians, as well as other health professionals in institutions or in the community. Care may also be delivered by social workers, home care and other community agencies, family members, friends, spiritual advisors, volunteers and other community members or professionals.

What is lacking in all this is a way of bringing all these disparate aspects of hospice palliative care together to promote collaboration, exchange of information, common standards and a coordinated system of care. Responding to this challenge is the overarching goal of the Hamilton Niagara Haldimand Brant (HNHB) Hospice Palliative Care (HPC) Network (the Network).

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<sup>1</sup> Mary Lou Kelly. (2007) Developing Rural Communities' Capacity for Palliative Care: a Conceptual Model.

The Network has been working diligently over the past two years to design an HNHB hospice palliative care system that will enable people to receive quality end-of life care when and where they need it. This **Phase 1 System Design** is now at a stage where the HNHB HPC Network has reached consensus agreement on the top priority palliative care issues requiring urgent attention within the HNHB LHIN area. The Network has shared this report and their ideas with the broader hospice palliative care community and received positive support regarding this initial direction and proposed approach. Ongoing strategic planning will continue to identify future short range, mid range and long range priorities for the HNHB HPC System Design.

### ***Why invest energy in developing a system design?***

It is envisioned the system design will provide the framework that the Network and its membership can use to help guide development of hospice palliative care services. It will support hospice palliative care organizations in their own decision-making and in the development of their own internal hospice palliative care strategic plans. It will also help inform the LHIN about priority requirements and support a multi-staged implementation plan for hospice palliative/end-of-life care in the HNHB LHIN.

### ***How was the system design developed?***

The system design was developed through the leadership of the HNHB HPC Network Advisory Committee and the deliberations that took place at a planning workshop on May 27 2008, attended by Advisory Committee members and representatives from the three Hospice Palliative Care Community Committees of Hamilton/Burlington, Niagara and Haldimand/Norfolk/Brant.

The planning process included a thorough literature review of more than 72 best practice articles which identified 63 hospice palliative care system best practice elements and components. An assessment and analysis of these best practices led to the understanding that **the creation of an integrated service model was the most critical first step in laying a solid foundation for a viable and sustainable system of hospice palliative care services. The relevance and importance of the integrated service delivery model was considered and confirmed at the workshop attended by 50 members from throughout the region, who validated the need for an integrated approach and went on to endorse the creation of a shared care model.**

### ***A shared care model is a best practice method for achieving an integrated service delivery approach***

Most people with advanced progressive illness prefer to receive end-of-life care at home. They prefer to die there if adequate supports are available to minimize suffering and burden on family caregivers. Primary caregivers repeatedly express the desire to be able to provide such care if given adequate support. However, family care givers are seldom able to address the multiple domains of care that occur at the end of life. They are often overwhelmed because they not only have to respond to a wide range of disparate needs, but they also find that addressing these needs involves connecting with various different professionals in different agencies and, even in different systems. Furthermore, the caregivers may well have great difficulty finding the information or locating the services that they need. And – when they find all that is needed – they may still face huge challenges in trying to coordinate and manage the various aspects of care that the patient is receiving from different sources.

It is not only patients and their primary caregivers, who risk becoming overwhelmed. Primary care physicians and other professionals are also likely to become overburdened if they take on the task of coordinating a patient's end-of-life care, since services are often fragmented, roles ill-defined and standards sometimes unclear.

A shared care model is a best practice method for achieving an integrated service delivery approach and can provide the type of end-of-life care that most people would prefer. This type of approach fosters inter-professional collaborative practice which is now known to be key to developing a sustainable and effective health care system.

### ***What is a shared care model?***

Shared care involves primary care providers in a team partnership of care with expert clinicians who together share the care of the patient in an integrated and seamless manner. A shared care team typically has an advanced practice nurse (APN) as a system navigator, palliative medicine consultations, a shared 24/7 call set up with access to specialized support, psychosocial and bereavement counselling, volunteer support, a designated CCAC manager and enhanced services (such as 24 hour nursing, drugs and equipment as required).

The model includes primary care providers in a team partnership of care with expert clinicians, who together share the care of the patient in an integrated and seamless way, where:

- Primary care, (which refers to a primary care physician or generally to mean a primary care provider in the community) who ideally provides continuity and integration of health care, acts as the gatekeeper, or as a first point of consultation and referral for all patients.
- Primary care capacity is enhanced through mentorship and point of care coaching, and the pattern of practice is sustainable for the primary care providers;
- Expert clinicians are collaborative consultants to primary care; and
- Care is negotiated patient by patient, with support provided for orphaned patients without a family physician

Components of the Model include:

- Defined population and patient identification
- Standardized assessment and process of care ( mutually agreed upon)
- Education by specialist to primary care, building community capacity
- 24/7 access to specialist clinician support
- Crosses continuum of patient care settings
- Coordinated system navigation and avoids duplication

### ***How could we build shared care models throughout this LHIN area?***

There appear to be four essential building blocks or leverage points that will promote the development of an integrated service delivery model and support the shared care teams throughout the HNHB area. These include coordinated access; common standards of practice; collaborative information systems; and comprehensive education and mentorship. All partners need to be involved in the development of each of these. This includes the hospital sector, the CCAC, the hospices, long-term care homes, primary care providers, shared care teams, and community and volunteer programs.

## Coordinated Access

Coordinated access will ensure that patients and families have access to and can navigate the complex system of health and community services frequently required in end-of-life care.

A coordinated access system involves the development of consistent definitions, a common referral process and assessment protocols, as well as a patient registry. Consideration needs to be given to the “entry points” and the role of the system navigator. The access system will have to be able to work “across boundaries and sectors”, as well as serve orphaned patients.

One of the barriers that impede the development of a coordinated access system is limited capacity to share patient/client information.

The following key action steps should be taken to develop a coordinated approach to improve access:

- i. Provide an opportunity for all partners to come together to determine key access points and clearly define the role of the system navigator. This includes the development of common definitions, criteria and referral processes.
- ii. Develop a central registry and tracking system to capture what resources are available in the system at any given time. This could be based on the Criti-call Model currently in place. It could be accessed through a web portal linking resources to needs.

## Common Standards of Practice

The development of common standards of practice in shared care teams will go far in advancing the goal that each person in the HNHB LHIN has access to quality of hospice palliative care.

Many partnerships already exist that could support the development of common standards. Furthermore, there are many existing tools and resources available that can be utilized or modified to meet the unique needs in this area. A starting point in the development of common standards of practice would be to map the hospice palliative care clinical pathways. Once this is complete, standards for inclusive care planning could be developed and implemented.

It is important to acknowledge some of the potential barriers that could prevent LHIN-wide standards being implemented. These include geographic barriers that have limited access to experts, the cost of equipment, and the lack of the human resources required to build new teams in some areas.

The following key action steps should be taken to develop common standards of practice.

- i. Establish a minimum of nine shared care teams for the HNHB area (as previously recommended in the HNHB Hospice Palliative Care Network Collaborative Proposal, December 2007) by enhancing the four existing teams in Hamilton, Burlington, Niagara West and Brantford to the new model, and

establishing five new teams for HNHB within each of the designated communities.

- ii. Investments in end-of-life care and supports should be considered in the context of current assets, equity of access to services and supports, capacity of the system to recruit and retain providers, and the role of the CCAC, in the planning and provision of services and supports.
- iii. Link and share the knowledge and experience from the existing four teams with the new teams.
- iv. Create ongoing opportunities for the teams to come together to delineate the care pathways and review and share existing standards and tools.

### **Collaborative Information Systems**

The creation of a common electronic information system will enable team members to share relevant real time information. Fundamental to the establishment of this common access information system is the development of a minimum data set, a common patient chart and communications protocols. This information derived from this system can be used for monitoring system performance as well as client care.

There are several barriers that need to be overcome with regard to creating a collaborative information system. These include: differing interpretations of privacy standards; in some cases a hesitancy or an unwillingness to share data; and prohibitive costs.

The following key action step should be taken to develop a collaborative information system

- i. The HNHB HPC Network should establish a working group to develop the model and protocols for information sharing.

### **Comprehensive Education and Mentorship**

A comprehensive approach to education and point of care consultation will support the mentoring of family physicians, build capacity in the LTC homes and provide support and education to families, volunteers and caregivers. A curriculum should be developed to support both formal and informal training and mentoring opportunities. This curriculum should focus on all aspects of the shared care model within the context of an overall training and mentoring strategic plan for the shared care model.

The following key action steps should be taken to develop a comprehensive approach to education and mentorship.

- i. Develop a strategic plan for education and mentoring related to the shared care model.
- ii. Create a curriculum outlining what courses are available when targeting specific groups such as physicians, volunteers, LTC homes.

- iii. Create a directory of people who are mentoring.
- iv. Create opportunities for inter professional learning throughout the area.
- iv. Provide informal opportunities for teams and caregivers to get together.
- vi. Hold peer mentoring sessions among professional groups and among teams.

### **Next Steps**

The HNHB HPC Network Advisory Committee and the three Community Committees have received very positive feedback regarding these priorities and recommendations from HNHB HPC Stakeholders to now collectively investigate and act on opportunities, and build partnerships to move forward with the further development of the shared care model and supporting system components as quickly as possible.

As a result of this consensus direction, innovative partnerships with the HNHB HPC Network are continually forming among new organizations and community members both internal and external to the Network's more traditional focus (i.e., specialized geriatrics/dementia, developmental disabilities, congestive heart failure, etc.), with a view to enable the basis principles of hospice palliative care to be afforded to all patient populations at the end-of-life. Avenues for integration opportunities and/or new funding sources to support these system design goals and objectives are frequently being negotiated and explored.

For further information about the HNHB HPC System Design project process, findings and recommendations, please contact the HNHB HPC Network at 1-800-263-5480, ext 432.