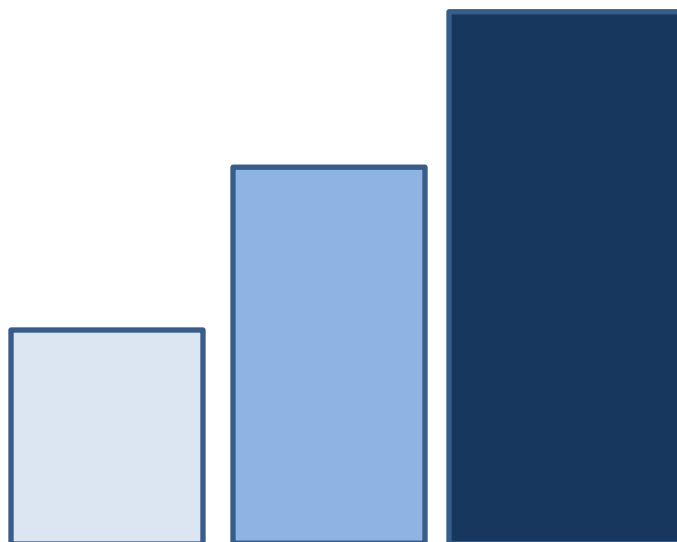




# Creating an Integrated Hospice Palliative Care System in Ontario

**Setting the Stage for Change**

November 2010



“We are a death denying society who refuses to accept that we are all going to die and we should endeavour to make that dying process as comfortable as possible. The evolution of palliative care is being profoundly affected by the increase in chronic diseases. Combined with an aging population, the system is being stretched and tested as never before. There are still at best 70% of Canadians who do not have access to palliative care. And even when there is access, it is not equitable. There are still those who do not understand palliative care and see it as boutique care, rather than as a natural and equally important part of health care as is maternity care. We need a culture of care that recognizes death as a natural part of life and rises to meet the challenges of the new realities of caring for those at end-of-life.

Since 1995 there have been some significant improvements in public policy regarding end-of-life and in the delivery of palliative care services. Yet, we need to raise the bar. Quality palliative care is the right of every Canadian. It is the responsibility of every Canadian to work together at all levels - federal, provincial, territorial and community - to ensure quality care at end-of-life.”

The Honourable Sharon Carstairs, P.C.  
The Senate of Canada

Raising the Bar: Roadmap for the Future of Palliative Care in Canada,  
June 2010

# Implementing an Integrated Hospice Palliative Care System in Ontario

## Recommendations from the Quality Hospice Palliative Care Coalition of Ontario

### Who We Are

The Quality Hospice Palliative Care Coalition of Ontario advocates for quality hospice palliative care for all Ontarians. Current members of the Coalition Steering Committee include:

### Membership of Coalition Steering Committee

#### Provincial Association Members Representing:

##### ***The Ontario College of Family Physicians***

- Ms. Jan Kasperski, Chief Executive Officer. QHPCCO Chair Person
- Dr. Sandy Buchman, Past President and CCO Primary Care Lead for Toronto Central LHIN

##### ***The Provincial Hospice Palliative Care Network***

- Andrea Martin, Chair PEOLCN
- Paul Cavanagh, Vice Chair PEOLCN
- Beth Lambie, Director, Erie St. Clair End-of-Life Network

##### ***The Hospice Association of Ontario***

- Rick Firth, Executive Director

##### ***The Ontario Palliative Care Association***

- Marg Poling, President
- Chris Sherwood, Past President

##### ***Ontario Long Term Care Association***

- Christina Bisanz, Chief Executive Officer

##### ***Cancer Care Ontario***

- Dr. Deborah Dudgeon, Provincial Program Head - Palliative Care
- Esther Green, Provincial Head - Nursing and Psychosocial Oncology

##### ***The Ontario Association of Community Care Access Centres***

- Margaret Mottershead, Chief Executive Officer
- Georgina White, Director, Policy and Research
- Donna Ladouceur, HPC Lead, CCAC Client Services Committee

##### ***The Provincial Palliative Care Consultants Network***

- Cathy Joy, Co-Chair
- Carol Sloan, Co-Chair

##### ***The Quality Hospice Palliative Care Coalition of Canada***

- Dr. Larry Librach, Past President CHPCA

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Dr. Mary Lou Kelley

### ***McMaster University, Division of Palliative Care***

Dr. Denise Marshall

### ***University of Ottawa, Division of Palliative Care***

Dr. Jose Pereira

### ***McMaster University, Department of Oncology***

Dr. Hsien Seow

## **Administrative Support:**

### ***QHPCCO Consultant***

Julie Darnay

## Charter for End-of-Life Care in Ontario

How we treat those who are dying in our community reflects who we are as a society. All

Ontarians have the right to die with dignity, to have access to physical, psychological, bereavement and spiritual care, and to be granted the respect consistent with other phases of life.

As professional, volunteer and family representatives of Ontario's hospice palliative care community, we are committed to providing the best possible quality end-of-life care to Ontario residents and their families. Our goal is to optimize their quality of life and to minimize the physical and emotional suffering associated with this phase of life.

We endorse an integrated approach focused on the individual and their family and caregivers, accessible through hospice palliative care services in the local community and tailored to individual needs.

Our efforts to increase awareness and availability of quality and integrated end-of-life care run parallel to our collaboration with government, social agencies and other decision makers to develop innovative clinical, community and public policy strategies.

On behalf of the residents of Ontario whom we serve, we speak with a unified and cohesive voice, share information and resources and work through a coordinated network of partners from the voluntary, public and professional sectors.

**Note: This Charter was created collaboratively during a 2004 province-wide consultation to develop a provincial strategy for end-of-life care. Organizational supporters include:**

ALS Ontario  
Cancer Care Ontario  
Department of Public Policy, Management and Evaluation, University of Toronto  
Faculty of Medicine, University of Toronto  
Family Caregiver  
GlaxoSmithKline  
Hospice Association of Ontario and its 98 member hospices  
Hospital for Sick Children  
Near North Hospice Palliative Care Network  
Ontario Association of Community Care Access Centres  
Ontario Community Support Association  
Ontario Home Health Care Providers' Association  
Ontario Long-Term Care Association  
Ontario Multifaith Council on Spiritual and Religious Care  
Ontario Palliative Care Association  
Ontario Trillium Foundation  
Ontario's Pain and Symptom Management Consultants  
Order of St. Lazarus (Toronto Commandery)  
Ottawa Consortium of Palliative Care  
The Yee Hong Centre  
Toronto Palliative Care Network  
Toronto Rehabilitation Hospital

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## **Executive Summary**

Hospice Palliative Care is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. One-hundred-percent of people in Ontario will die. Only 10% will die suddenly (Plonk & Arnold, 2005). Ninety-percent of people in Ontario will require assistance and support with end of life care.

The aging population not only creates service demand pressures, but also supply pressures. Seniors make up the fastest-growing age group. In 2003, an estimated 4.6 million Canadians were 65 years of age or older, a number that is expected to double in the next 25 years. By 2041, about one in four Canadians is expected to be 65 or over. By 2031, the number of older seniors (persons aged 80 years and over) will then account for between 6.1 % and 6.5 % of the total Canadian population. In 2004, Statistics Canada projected that the rate of deaths in Canada will increase by 33% by the year 2020 to more than 330,000 deaths per year (CHPCA, 2010). This has serious implications for the hospice palliative care system. There will not be enough specialists in hospice palliative care to provide direct care to everyone in need. Greater engagement by the rest of health care system (primary care, acute care, long term care, etc.) will be crucial.

Family physicians along with other health care professionals in the community can successfully deliver effective care to their palliative home care patients on a full-time basis if supported by a collaborative practice and integrated models of care delivery. Using best practice screening criteria and helping all providers with timely symptom identification to refer patients in need early on in the advanced disease and dying trajectory enhances clinical problem solving and avoids crisis management. High-quality EOL care in Ontario is achievable with this integrated model of hospice palliative care (Marshall, 2008).

This document is an extension to the Policy Brief submission and is presented as advice to the Ministry of Health and Long-Term Care and serves the following purposes:

1. to recognize and acknowledge the MOHLTC's valiant effort in responding to the hospice palliative care needs of Ontarians to date,
2. to reinforce the urgency of a continued response to address the growing hospice palliative care needs in Ontario with the development of an integrated hospice palliative care system,
3. to demonstrate how the priorities of the Ontario Ministry of Health and Long-Term Care can be achieved through the implementation of this system,
4. to describe the key elements of an integrated system of hospice palliative care system, and
5. to provide recommendations and action steps needed to move forward.

The Quality Hospice Palliative Care Coalition of Ontario applauds the MOHLTC for the over 1.9 billion dollars spent on home care through the Community Care Access Centres (CCACs) to serve over 600,000 Ontarians. We also acknowledge the \$115.5 million investment over three years to improve end-of-life care services for 6,000 more Ontarians at home and in the community. Last year's instalment of \$39 million ensured that 4,300 more Ontarians could

receive the care they required through Residential Hospices, Volunteer Home Hospice Visiting and other Community Support Service agencies (Matthews, 2010).

The establishment of the Hospice Palliative Care Networks has also succeeded in developing an initial structural foundation for ongoing local and provincial dialogue, and strategic planning across the entire continuum of care. The Aging at Home Strategy was successful in some areas of the province providing innovative funding for hospice palliative care in such areas as Waterloo Wellington, Erie St. Clair and Central. The MOHLTC has also put money into alternate payment plans for physicians, but unfortunately uptake has been very limited thus far. In fact, physician fee increases have now placed Ontario at the top for compensation for MDs to provide community palliative care.

While these investments represented a major step forward and helped to draw attention to the importance of hospice palliative care services in Ontario, these strategies were less effective than envisioned due to the lack of an integrated system-wide policy. There still remains significant disparity amongst Local Health Integration Networks (LHINs) in adopting hospice palliative care as a component of their regional priorities. This regional inconsistency creates a provincial landscape in which hospice palliative care is a patchwork. We are optimistic that the Integrated Client Care Project initiative for hospice palliative care will also help to enhance health and system outcomes. However it is critical that everyone across the continuum of care is working together to build the future hospice palliative care system and that we continue moving from our current system of sector specific service provision to a cross-sector system that requires:

1. A full continuum of care settings and services is in place;
  2. In each care setting where patients die, there is a clearly defined hospice palliative care program;
  3. Sectors and services are linked by common practice, processes, structures and education;
  4. Adequate numbers of trained professionals are available;
  5. System-level accountability is clearly defined and communicated; *and*
  6. Funding models, guidelines and policy directions support an integrated system
- (Provincial End of Life Care Network, 2010)

These integrated models of hospice palliative care have been successfully adopted in other provinces throughout Canada as well as internationally. While some End-of-Life/Hospice Palliative Care Networks and their partners in Ontario have made noble attempts to create integration (e.g., Champlain, Central East, Erie St. Clair, South East, Hamilton Niagara Haldimand Brant, & Waterloo-Wellington), without formal policies, standards and clear accountability across Ontario, a patchwork of access, outcomes, practices, and services is the best that has been achieved. Therefore it is important that we recognize what is working well and build on those strengths across the province.

An integrated system of hospice palliative care would also assist the Ministry to address the following provincial priorities:

- Right care, right place, right time with an appropriate level-of-care in the right care setting
- Home as first place of care wherever possible
- ER / ALC burden and cost reductions
- Low cost - high impact initiatives
- Evidence-based solutions
- Models that build system capacity
- Ease the pressures on Health care resources
- Measurement of results
- Stewardship of system resources
- Culture shift to one that understands innovation, value, experimentation
- Chronic disease management

To enhance and leverage the work that has been done to date, and to move the province forward in an integrated approach to hospice palliative care, the Quality Hospice Palliative Care Coalition of Ontario (QHPPCO) Steering Committee has identified four primary recommendations along with a number of related implementation actions. These recommendations are unique in that they address the issue of hospice palliative care from a system perspective, including the identification of required care settings and services, programs, integration and linkages, human resources, accountability, as well as policies, guidelines and funding. This system level development requires a simultaneous focus on each of these six realms and is considered a dynamic process in which activity in all six elements is interrelated. This comprehensive approach is vastly different from our current system of sector specific service provision to one that is a cross-sector system. It is also important to note that of the 49 recommended actions 53% can be achieved with no new investments required. The majority of these recommendations also have high outcome impact and can be achieved in the short term.

A synopsis of these recommendations and action steps follows. A complete and detailed discussion starts on page 19 and a summary table begins on page 60.

### **RECOMMENDATION #1**

**Develop a provincial vision and principles for hospice palliative care to enable Local Health Integration Networks, Service Providers and community groups a basis for planning exemplary hospice palliative care services throughout Ontario.**

- A. Articulate the future desire for equitable access to a choice of safe, comprehensive and quality hospice palliative care
- B. Model the National vision that all Canadians have access to quality end-of-life care
- C. Model the Charter for End-of-Life Care in Ontario.

### **RECOMMENDATION #2**

**Develop and implement an integrated hospice palliative care system-wide policy for the province of Ontario that supports the vision and principles.**

- A. Articulate the urgency to develop and maintain equitable access to a choice of safe, comprehensive and quality hospice palliative care.
- B. Endorse the implementation of the provincial Hospice Palliative Care System Design Framework.
- C. Designate within the Ministry of Health and Long-Term Care a Hospice Palliative Care Lead.
- D. Provide immediate direction on the regional prioritization of HPC at the LHIN level.
- E. Formulate central provincial program and service volumes to meet current and future demand for the next 25 years.
- F. Establish clear accountability at the provincial level, which includes a mechanism for monitoring LHIN wide progress.

### **RECOMMENDATION #3**

#### **Adopt and implement a fully Integrated Hospice Palliative Care Service Delivery System for Ontario based on the provincial vision, policy and Hospice Palliative Care System Design Framework.**

- A. The system incorporates the elements as described in the Hospice Palliative Care System Design Framework as soon as possible.
- B. The Ministry designates the Quality Hospice Palliative Care Coalition of Ontario as the provincial expert in HPC.
- C. All LHINs have a local hospice palliative care plan that works towards the provincial Hospice Palliative Care Service Delivery System Design.
- D. The Ministry recognizes the HPC Networks as the local HPC experts and designates them as the official advisory body informing and guiding the LHINs regarding HPC.
- E. The Ministry provides provincial direction for consistent collection of data, system level outcomes and performance indicators that can be uniformly tracked
- F. Organizations and clinical service leadership teams in all settings report to their LHINs on the hospice palliative services provided to their patients / clients / residents according to the standard provincial key indicators.
- G. HPC Networks in each LHIN area are charged with the lead role in analyzing and monitoring local data and submitting monthly statistics to Hospice Palliative Care Lead, the LHIN and others where appropriate.
- H. The Ministry of Health and Long-Term Care Hospice Palliative Care Lead is responsible for:
  - i. Finalizing the integrated service delivery model.
  - ii. Supporting the LHINs and the Networks in overseeing the local hospice palliative care plans.
  - iii. Monitoring the implementation of the provincial hospice palliative care service delivery system.
  - iv. Reviewing hospice palliative care plans and statistics from each LHIN area.
  - v. Bringing together the different parts of government working on related issues.
  - vi. Facilitating the resolution of common provincial issues.

- I. The Quality Hospice Palliative Care Coalition of Ontario is responsible for advising the Hospice Palliative Care Lead and the Networks on a wide range of province-wide projects and initiatives.
- J. Consistent provincial implementation of best practice hospice palliative care standards are used for all care settings across the continuum, based on the work of Accreditation Canada and other recognized standards.
- K. Services are not just for individuals in the final months of life. Extend services to individuals with progressive life-threatening illnesses other than cancer.

#### **RECOMMENDATION #4**

**Provide strategic investments to enhance, build and sustain an integrated system of quality, safe, coordinated and comprehensive hospice palliative care services.**

##### **Program Strategic Investments:**

- A. Fund the creation and expansion of inter-professional teams across the province as a means of building palliative care community capacity within primary care.
- B. Expand the Alternative Payment Plan for the development of additional expert Palliative Care Physicians. Optimize their role by integrating them within inter-professional teams.
- C. Fund 80% of the operating costs of residential hospices.
- D. Review the adequacy of funding for palliative care services in hospitals.
- E. Provide effective and sustained supports for informal caregivers, including more respite and bereavement services.
- F. Expand home care nursing and home support availability over the 24 hour period, seven days a week based on client need.
- G. Embark on a sustained quality improvement program to ensure that hospice palliative care services are working effectively in long-term care homes across Ontario.
- H. Enable access to specialized quality hospice palliative care services and expertise from other care settings within long-term care homes, including interdisciplinary teams.
- I. Build community capacity by protecting, designating, and equitably and adequately funding existing community-based hospice palliative care programs.
- J. Support work with diverse cultural and social communities to develop approaches that are responsive to their unique and distinct traditions for end-of-life care.

##### **Infrastructure Strategic Investments:**

- A. Define clear, consistent accountability relationships between LHINs, the Ministry's designated lead and other Ministry departments with respect to the implementation of hospice palliative care policies.
- B. Define clear, consistent accountability relationships that support integrated systems of quality hospice palliative care services between LHINs and their respective HPC Networks.
- C. Re-establish a funding mechanism for the Hospice Palliative Care Networks that ensures that they are sustainable and able to deliver on their mandate.

- D. Recognize the primary mandate of the Quality Hospice Palliative Care Coalition of Ontario is to act as a provincial advocate body for quality hospice palliative care for all Ontarians.
- E. The provincial Hospice Palliative Care Lead should continue to work with the Quality Hospice Palliative Care Coalition of Ontario to define essential hospice palliative care services based on the System Design.
- F. Recognize the Provincial End-of-Life Care Network as the interim secretariat for the Quality Hospice Palliative Care Coalition of Ontario.
- G. Resource the Seniors Health Research Transfer Network's hospice palliative care Community of Practice and the Community of Practice for Health Care.
- H. Define the accountabilities and communication channels between the Hospice Palliative Care Lead and the:
  - a. Provincial End-of-Life/Hospice Palliative Care Network
  - b. Quality Hospice Palliative Care Coalition of Ontario
  - c. Centralized provincial sponsoring agency (transfer payment organization)

#### **Technological Strategic Investments:**

- A. Evaluate current efforts, such as eShift (South West CCAC), to introduce technology to support the implementation of best practices in the community
- B. Pilot and implement a Shared Electronic Health Record within the HPC system with full interdisciplinary team record access

#### **Health Human Resource Strategic Investments:**

- A. Develop, adopt and implement a human resource and capacity-building strategy for hospice palliative care, based on health human resource needs in three levels of expertise
- B. Establish core competencies in various settings and levels of expertise in conjunction with experts within each profession.
- C. Build capacity by developing a recruitment and retention strategy for all disciplines (regulated and un-regulated) involved in HPC.

#### **Educational Strategic Investments:**

- A. Endorse and implement a provincial hospice palliative care education strategy that is evidence-based and draws on already developed curricula being used in the field.
- B. Expand fellowships, the creation of subspecialties and other educational opportunities for the development of additional Expert Palliative Care Physicians, Community Hospice Palliative Care Resource Physicians and other disciplines.
- C. Heighten public awareness of HPC by providing special grants to the HPC Provincial Association, for example the funding of a provincial Advance Care Planning Campaign.

#### **Research Strategic Investments:**

- A. The *Raising the Bar* report identifies several key elements that would greatly enhanced through further research evidence. Invest in research to advance knowledge in:
  - i. the socio-economic benefits of palliative care;

- ii. quality indicators;
  - iii. common data collection methods;
  - iv. how to best meet the needs of caregivers;
  - v. use of technology in providing care;
  - vi. inter-professional educational curricula; and
  - vii. differing health service configurations and models such as shared care and more comprehensive integrated care delivery models early in the disease trajectory.
- B. Invest in research to evaluate the ability and effectiveness of Hospice Palliative Care Networks as a community capacity builder to increase hospice palliative care integration.
  - C. Ensure knowledge translation is an integral part of all research studies to successfully integrate research into practice.

With the unanimous endorsement of this report and its recommendations by the Quality Hospice Palliative Care Coalition of Ontario Steering Committee, a province-wide foundation for action is now in place. While all stakeholders are poised and ready to move forward, they are also realistic in recognizing that a reasonable planning and implementation approach will need to take place, and that this comprehensive plan cannot be achieved all at once. Setting out a manageable strategic work plan to implement the recommendations is therefore an important next step. Hence a Plan for Action Strategy for transitioning to the integrated hospice palliative care service delivery model has been developed, which rates the recommendations and action steps by those that have the greatest impact with regard to patient and system outcomes; practical and achievable timelines; and those that will not cost the system any additional resource requirements. (*See Page 60*).

The Ministry of Health and Long-Term Care has the opportunity to provide system-wide leadership on the issue of hospice palliative care. “The Ministry is the guarantor of social values and choices. In that role, therefore, there may be some health service areas which require province-level coordination or which may require an all-LHIN approach” (Gow & Tremblay, 2006). With strategies, policies, regulatory support, scientific advice, and evidence-based research, the MOHLTC can ensure system level integration for hospice palliative care so that all people of Ontario can die pain free and with dignity.

## Introduction

How we treat those who are dying in our community reflects who we are as a society. All Ontarians have the right to die with dignity, to have access to physical, psychological, bereavement and spiritual care, and to be granted the respect consistent with other phases of life. Not only is it a moral imperative, but the Excellent Care for All Act (2010) demonstrates that the people of Ontario and the Government:

- Believe the patient experience and the support of patients and their caregivers to realize their best health is a critical element of ensuring the future of our health care system;
- Recognize that a high quality health care system is one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focussed, and safe;
- Committed to ensuring that health care organizations are responsive and accountable to the public, and focused on creating a positive patient experience and delivering high quality health care;
- Believe that quality is the goal of everyone involved in delivering health care in Ontario, and that ultimately, each health care organization should hold its executive team accountable for its achievement;
- Believe that everyone involved in delivering health care in Ontario has a role to play in ensuring the quality of the system;
- Recognize the importance of providing Ontario's health care providers with support to help them plan for and improve the quality of the care that they deliver based on the best available scientific evidence;
- Recognize the value of transparency in the health care system;
- Share a vision for a Province where excellent health care services are available to all Ontarians, where professions work together, and where patients are confident that their health care system is providing them with excellent health care.

One-hundred-percent of people in Ontario will die. Only 10% will die suddenly (Plonk & Arnold, 2005). Ninety-percent of people in Ontario will require assistance and support with end of life care yet Ontario has no consistent vision for hospice palliative care.

The purpose of this paper is to:

1. Reinforce the need for an integrated hospice palliative care system in Ontario.
2. Describe the key elements of an integrated system of hospice palliative care system.
3. Demonstrate how the priorities of the Ontario Ministry of Health and Long-Term Care can be achieved through the implementation of this system.
4. Provide recommendations for action.

**Hospice Palliative Care** is a philosophy of care that aims to relieve suffering and improve the quality of living and dying.

It strives to help patients and families to:

- 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; and
- cope with loss and grief during the illness and bereavement.

It aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

(CHPCA. 2002)

## Background

In November 2004, the Ontario Government announced an investment of \$115.5 million over three years in support of the provincial end-of-life care strategy. Investments were made in volunteer visiting hospice services, residential hospices, and in-home end-of-life care. Funding was also provided to support 14 End-of-Life Care or Hospice Palliative Care Networks (EOLCN/HPCN) across the province.

The provincial strategy represented a major step forward and drew some attention to the importance of end-of-life care services in Ontario. However, the strategy was less effective than envisioned due to the lack of an integrated system-wide policy. There is significant disparity amongst Local Health Integration Networks (LHINs) in adopting hospice palliative care as a component of their regional priorities. This regional inconsistency creates a provincial landscape in which hospice palliative care is patchwork. Furthermore, long-term sustainability was not addressed by the strategy, as it focused on services not systems. The emphasis was on individuals with the advanced stages of a “terminal” disease.

The 14 End-of-Life Care or Hospice Palliative Care Networks (EOLCN/HPCN) were established under the Provincial EOL Care Strategy to coordinate and integrate services at the system level, promote service innovations, and monitor and assess community needs. They were also given responsibility for broad system design. However, this mandate was not supported by provincial policies, standards, authority, or designated hospice palliative care funding. As a result, the development of hospice palliative care services has been inconsistent across the province. In most cases, there has been no clear link with the LHINs’ integrated health service planning processes and accountabilities have remained unclear. Moreover, in some areas, there has been an erosion of local community based hospice palliative care programs. Funding for the EOLCN/HPCN’s has remained insufficient and unchanged at \$70,000 per year. The full potential of the EOLCN/HPCN’s has not been realized.

As a result of the significant interest in enhancing hospice palliative care services across the province, in June of 2009 the Ontario College of Family Physicians partnered with Cancer Care Ontario to plan and host a strategy development workshop aimed at improving the quality of care delivered in Ontario for patients with end-of-life conditions. This workshop was done in collaboration with the Provincial End-of-Life Care Network and the Ontario Association of Community Care Access Centre. One hundred and thirty key stakeholders from across the province participated in the workshop. Their input at the workshop, as well as their ongoing

### Hospice palliative care:

- is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to ***any diagnosis, with any prognosis, regardless of age,*** and at any time they have unmet expectations and/or needs, and are prepared to accept care
- may complement and enhance disease-modifying therapy or it may become the total focus of care
- is most effectively delivered by an interdisciplinary team of healthcare providers skilled in all aspects of the caring process related to hospice palliative care.

(CHPCA, 2002)

support towards the overall goal and vision continues to accelerate the movement towards an integrated hospice palliative care service delivery system in Ontario.

The main messages from the workshop were as follows:

- There is consensus that an integrated hospice palliative care (HPC) service delivery system is needed throughout Ontario. The vision and framework for this HPC system needs to be provincial; however, the implementation needs to be regional and locally driven using a grassroots, community development approach.
- Since the primary care sector is key to an integrated hospice palliative care delivery system, the dynamics of how palliative care is planned and delivered needs to change. It will be important to establish the supports needed by family doctors, advance practice nurses, community care case managers and home care nurses and to ensure adequate linkages between family practices, family health teams and community health centres and secondary and tertiary care providers.
- A comprehensive and integrated Hospice Palliative Care Delivery System should include:
  - Seamless linkages between primary, secondary and tertiary care health service providers
  - Easy and timely access to all services in the **Square of Care** in all care settings
  - An inter and intra-professional collaborative care service delivery model (including Intra-professional education)
  - An appropriate system to support patient/family navigation
  - A health human resource strategy
  - Common assessment and communication tools including electronic health record that are easily accessible by the patient, family caregivers, family physician and all other members of the patient's care team.
  - An accountability framework that includes benchmarks/quality indicators and includes a public reporting framework
  - A population based registry
  - Population based funding for health human resources, information technology, physical space, pharmaceuticals, supplies, tools, etc.
  - Accountability structures that are cross sector and diminish the sector specific "silos".

The participants at the event also identified the fact that, as a key priority, there is need to establish provincial leadership to assist the Ministry of Health and Long Term Care to develop and implement a mandated strategic plan for Ontario's Hospice Palliative Care Delivery System. To that end, concrete next steps were identified to continue the positive momentum; namely, to establish a Hospice Palliative Care Coalition and relevant Action Teams to support the planning agenda and to further develop the strategy begun so effectively at the workshop.

In summary, the partners committed to the following actions:

- A. To circulate the report on the results of the Strategy Development Workshop to all participants, as well as to circulate the report to the stakeholders who were invited but unable to attend;
- B. To organize the first meeting of the Hospice Palliative Care Coalition; and, to establish action teams to develop work plans in the following areas:
  - a. system accountability
  - b. funding models, policy development and guidelines
  - c. addressing the full continuum of care
  - d. defining the palliative care program
  - e. linkages through common practices, processes and structures
  - f. health human resource strategy development
- C. To inform the MOHLTC in regards to the recommendations from the workshop and to establish a forum for ongoing discussions regarding a provincial strategy and implementation of an integrated hospice palliative care delivery system throughout the province.

This report represents the collaborative effort among the members of the Quality Hospice Palliative Care Coalition of Ontario, with several working groups led by the Provincial End of Life Care Network. It embodies the growing evolution of provincial teamwork towards a common vision and goal for hospice palliative care in Ontario. The province's HPC community is poised and ready to move forward with the agenda (*See Appendix I*).

Over the course of the last year and a half the details of this plan have been fleshed out in the development of 4 key documents:

1. Improving the Quality of Hospice Palliative Care Across Ontario: A Summary of the Results of the Strategy Development Workshop (July 2009)
2. A Provincial System Design Framework (September 2010)
3. Implementing an Integrated Hospice Palliative Care System in Ontario – Briefing Paper (October 2010), and currently
4. Creating an Integrated Hospice Palliative Care System in Ontario: Setting the Stage for Change (December 2010)

The next section of the report details the four recommendations that have received unanimous endorsement by the Steering Committee members of the Quality Hospice Palliative Care Coalition of Ontario for the creation of an Integrated Hospice Palliative Care System in Ontario.

The outline of the report is as follows:

- Recommendation
- Rationale
- Outcomes
- Recommendation Details
- Enablers
- Leadership
- Evidence and Discussion

## Recommendations

### **Recommendation #1**

**Develop a provincial vision and principles for hospice palliative care to enable Local Health Integration Networks, Service Providers and community groups a basis for planning exemplary hospice palliative care services throughout Ontario.**

#### **Rationale:**

How we treat those who are dying in our community reflects who we are as a society. All Ontarians have the right to die with dignity, to have access to physical, psychological, bereavement and spiritual care, and to be granted the respect consistent with other phases of life. Hospice Palliative Care strives to provide comfort and dignity for anyone who is in facing a life-threatening illness. Palliative care is not about dying, it is about living well until the very end. Ontario needs a formal vision for hospice palliative care to guide us in achieving the best possible hospice palliative care at the right time, and in the right setting, based on individual needs.

#### **Outcomes:**

The Local Health Integration Networks (LHINs) were established as community-based organizations to plan, co-ordinate, integrate and fund health care services at the local level to ensure a well-coordinated system of health services. However, the Ministry maintains funding over critical system components like physicians and drugs that necessitate their continued leadership in matters like hospice palliative care. A provincial vision would provide a concrete strategic direction on the desired and intended future state for hospice palliative care that would guide all levels of government. The vision would outline with explicit and consistent language what the Ministry wants to achieve across Ontario. By providing clear leadership it will serve to inspire all service providers to work in collaboration and alignment towards this common vision and joint responsibility.

#### **It is recommended that the vision and principles:**

- A. Articulate the future desire for equitable access to a choice of safe, comprehensive and quality hospice palliative care services for individuals and families across Ontario
- B. Model the National vision that all Canadians have access to quality end-of-life care (CHPCA, 2010).
- C. Model the Charter for End-of-Life Care in Ontario that was created collaboratively during a 2004 province-wide consultation to develop a provincial strategy for end-of-life care.
- D. Be at a provincial level; with implementation being regional and locally driven using a grassroots, community development approach.

### **Enablers for the implementation of Recommendation #1:**

- a) Work with the Quality Hospice Palliative Care Coalition of Ontario to ensure that the vision reflects the “Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice”
- b) The vision statement receives an all-party endorsement to ensure longevity, successful implementation and sustainability.

### **Leadership for implementation of Recommendation #1:**

Responsibility for communicating the above recommendation:

- Premier of Ontario
- Ministry of Health and Long Term Care

Implementation of this recommendation will be the responsibility of:

- Provincial Government
- Ministry of Health and Long Term Care

Assistance with implementation will be offered by:

- All Political Parties
- Quality Hospice Palliative Care Coalition of Ontario

### **Evidence and Discussion related to Recommendation #1:**

#### **Ontario requires a Hospice Palliative Care Vision**

Palliative care is intensely human and caring. It is not synonymous with death—it is about life, about the proper care of someone who is alive, someone who still has days, months, or years remaining in their life. Palliative care strives to provide comfort and dignity for anyone who is facing a life-threatening illness. This implies that we attend not only to their medical needs, but also to their spiritual and emotional needs. The focus of palliative care is on preserving the quality of the recipient’s life so that their suffering is minimized but their experience of life is not. Palliative care is not about dying, it is about living well until the very end. Canadians at end-of-life and their families need the right interdisciplinary health and social services care, at the right time, and in the right setting, based on their needs. Wherever they live in Canada, they also should expect to receive equitable access to the same quality of care (Carstairs, 2010).

To realize a society where all Canadians have access to quality palliative care services we need five things: a culture of care, to build capacity, support for caregivers, integration of services, and leadership (Carstairs, 2010).

- A culture of care that overcomes the limitations imposed by a death-denying society. A culture of care would recognize and respond to the reality that death trajectories are changing, and that Canadians are living longer and longer with chronic and complex

diseases. To succeed at developing a culture of care, we need to incorporate palliative care services sooner for those who have a life-threatening illness, confront the challenges of defining palliative care, and achieve a common understanding of what constitutes good care for the dying.

- A serious capacity-building exercise, comprising the full spectrum, from significantly increased research activities and knowledge translation, to improved and consistent education and training, to modernizing our health human resources plans to meet the emerging needs.
- To adapt systems and programs to facilitate caregiver support that is a critically important piece of the puzzle. Support includes: providing financial assistance to address lost income due to caregiving; offering training and advice to improve the capacity of caregivers; counseling and support to alleviate the stress of providing care; providing respite; and assisting with the difficult process of bereavement, which begins with diagnosis and carries through well after a death has occurred.
- To get serious about integration of services. This concept is not new, but the reality on the ground is that there is still far too much territoriality and lack of cooperation. We must overcome incompatibilities that make it difficult for patients and caregivers to transition from one care setting to another.
- Leadership on many levels: individual leadership in local settings; champions at various levels of government and within society who help overcome jurisdictional barriers; leadership from community organizations and professional associations; and finally, the restoration of the federal leadership role that is the key to achieving success on a national scale.

*“If we know how to provide integrated hospice palliative care and we know it increases patient quality of life and satisfaction, and reduces costs, why are the practices not more widespread?” (CHPCA 2010)*

## **Recommendation #2**

**Develop and implement an integrated hospice palliative care system-wide policy for the province of Ontario that supports the vision and principles.**

### **Rationale:**

A provincial hospice palliative care policy is needed to help guide a process of making important decisions, including the identification of different alternatives in programs, services and spending priorities, and choosing among them on the basis of the impact they will have. The

lack of a provincial integrated system-wide policy has created significant disparity amongst Local Health Integration Networks (LHINs) in adopting hospice palliative care as a component of their regional priorities. This regional inconsistency creates a provincial landscape in which hospice palliative care is piecemeal. We are facing a tsunami of aging in the next few years and we are not prepared to handle the increase in numbers of those who will require palliative care (Carstairs, 2010). Without provincial leadership there will continue to be a patchwork of services across Ontario. This report provides background information to assist with the production of a provincial policy which enunciates government-wide direction.

### **Outcomes:**

As a result of the aging population, the number of deaths in Ontario is expected to increase substantively. Action must be taken now to prepare for this upcoming wave of urgent need. With the MOHLTC providing leadership and coordination on the issue of hospice palliative care at the provincial level it will ensure an all-LHIN commitment and approach that would provide an enhanced degree of consistent system level integration across the province. The policy would also ensure greater alignment of Hospice Palliative Care with other provincial priorities to maximize success and performance.

### **It is recommended that the policy:**

- A. Articulate the urgency and necessity to develop and maintain equitable access to a choice of safe, comprehensive and quality hospice palliative care services for individuals and families across Ontario who can benefit from them.
- B. The policy endorses the implementation of the provincial Hospice Palliative Care System Design Framework, which outlines an integrated systems approach at the provincial level that will respond to rapidly changing future demand for services and unmet need.
- C. Designate within the Ministry of Health and Long-Term Care a Hospice Palliative Care Lead, with accompanying resources, responsible for supporting and monitoring the implementation of the provincial hospice palliative care policy. This centralized planning of services will ensure seamless and border-free access to quality HPC across Ontario.
- D. Provide immediate direction on the regional prioritization of HPC at the LHIN level.
- E. Formulate central provincial program and service volumes to meet current and future demand in the next 25 years in all hospice palliative care settings (including acute care, complex continuing care, long-term care homes, in-home services through CCAC, and hospice programs).
- F. Establish clear accountability at the provincial level, which includes a mechanism for monitoring LHIN wide progress towards these policy goals.

### **Enablers for the implementation of Recommendation #2:**

- a) The provincial hospice palliative care policy clearly state the types and general magnitude of changes expected across the province over the next 5 years and next 10 years.
- b) The policy is integrated and embedded into other relevant MOHLTC and government priorities such as chronic disease management, wait list management, ER and ALC strategy, as well as the Integrated Client Care Project
- c) The policy conveys the principles of equitable access to a choice of safe, comprehensive and quality, evidence based hospice palliative care services for individuals and families across Ontario who can benefit from them. The policy also conveys accountability based on the provincial HPC System Design Framework.
- d) The policy receives an all-party endorsement to ensure longevity, successful implementation and sustainability.

### **Leadership for implementation of Recommendation #2:**

Responsibility for communicating the above recommendation:

- Ministry of Health and Long Term Care

Implementation of this recommendation will be the responsibility of:

- Ministry of Health and Long Term Care through the provincial Hospice Palliative Care Lead

Assistance with implementation will be offered by:

- The Quality Hospice Palliative Care Coalition of Ontario
- All Political Parties

### **Evidence and Discussion related to Recommendation #2:**

#### **Hospice Palliative Care needs to be an Urgent Priority in Ontario**

An international examination of hospice palliative care shows Canada is currently lagging behind many other countries regarding their progress in hospice palliative care. A recent Quality of Death Index by the Economist Intelligence Unit released July 2010 placed Canada ninth in terms of provision of end-of-life care, including pain management and hospice care, as well as social, legal and spiritual elements. The U.K. was ranked first and was praised for its long-established hospice tradition. The study commissioned by Singapore based The Lien Foundation, the 'Quality of Death' index measures current hospice and palliative care environments across 40 countries in terms of the quality and availability of end-of-life care. The index scores countries across the following four categories:

- Basic end-of-life health care environment;
- Availability of end-of-life care;

- Cost of end-of-life care; and
- Quality of end-of-life care.

“This is the first report to rank end-of-life care on a global scale and it is important for federal/provincial/territorial governments, health care providers and Canadians alike to understand how Canada is doing compared to other countries and what we could do better,” (Sharon Baxter, 2010). Although ranking high in terms of availability to pain medications, Canada rates poorly on the cost of end-of-life care for families. Canadian families frequently shoulder 25% of the total cost of palliative care due to costs associated with home based services such as nursing and personal care services (Palliative Medicine, Dec 2009). Despite our progress over recent years, this report clearly shows that hospice palliative care needs to be an even greater priority across Canada.

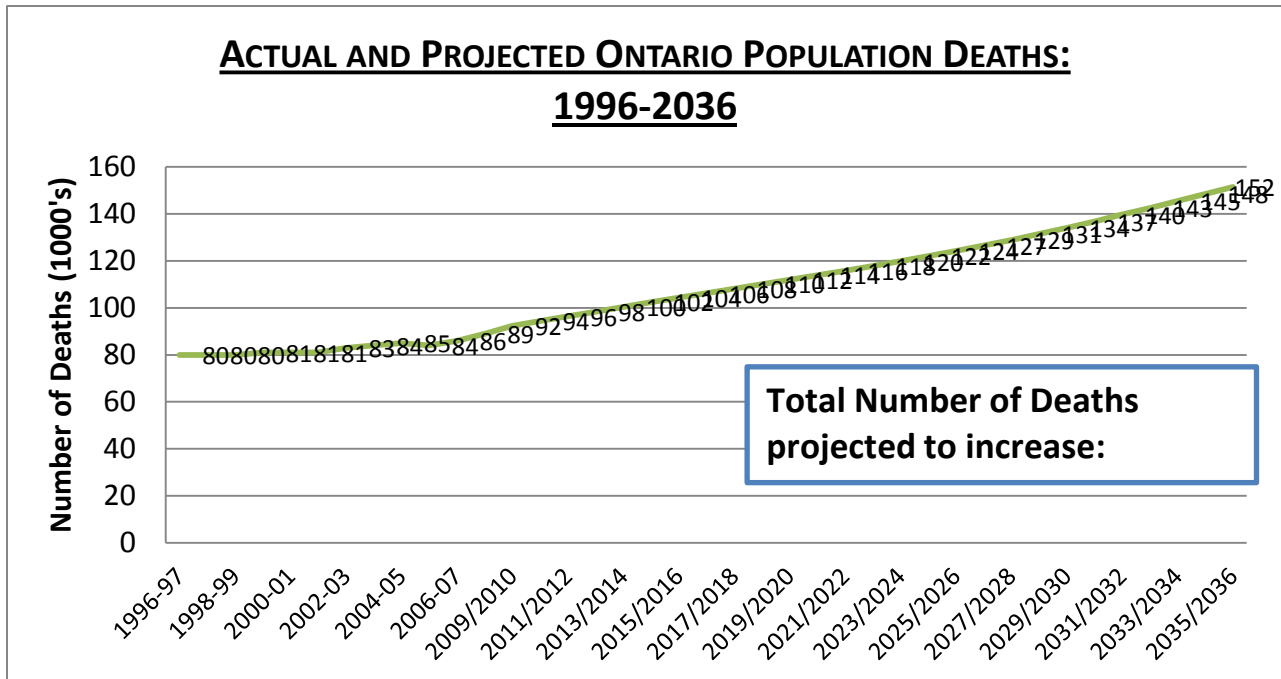
Other provinces in Canada have made hospice palliative care a priority and are now exceeding Ontario in this regard, noteworthy examples are British Columbia, Alberta and Manitoba. In fact, the Ministry of Health in British Columbia considers high quality end-of-life care services to be a critical part of health care services. The Government of British Columbia has made a commitment for providing leadership and setting the overall direction for end-of-life care. This includes setting out policy, making legislative changes, allocating funds to organizations and individuals who provide services and monitoring their performance, as well as the general progress of the system. They also provide direction to their local health authorities to identify more specific expectations and requirements for end-of-life care. Finally, in order to monitor end-of-life care, the British Columbia government articulates a need for quantitative and qualitative means of determining what changes are occurring and the results of these changes for people who need these services (A Provincial Framework for End-of-Life Care, Ministry of Health, 2006).

It is time for Ontario to make a similar commitment to hospice palliative care. As a result of the aging population, the number of deaths in Ontario is expected to increase substantively.

- In 10 years, the number of deaths is expected to increase by 20%
- In 25 years (2036), the number of deaths is expected to increase by 65% (Statistics Canada, 2010).

The following graph illustrates the magnitude of this increase. The number of deaths has been relatively stable until now; however, we are entering the beginning of a steep incline.

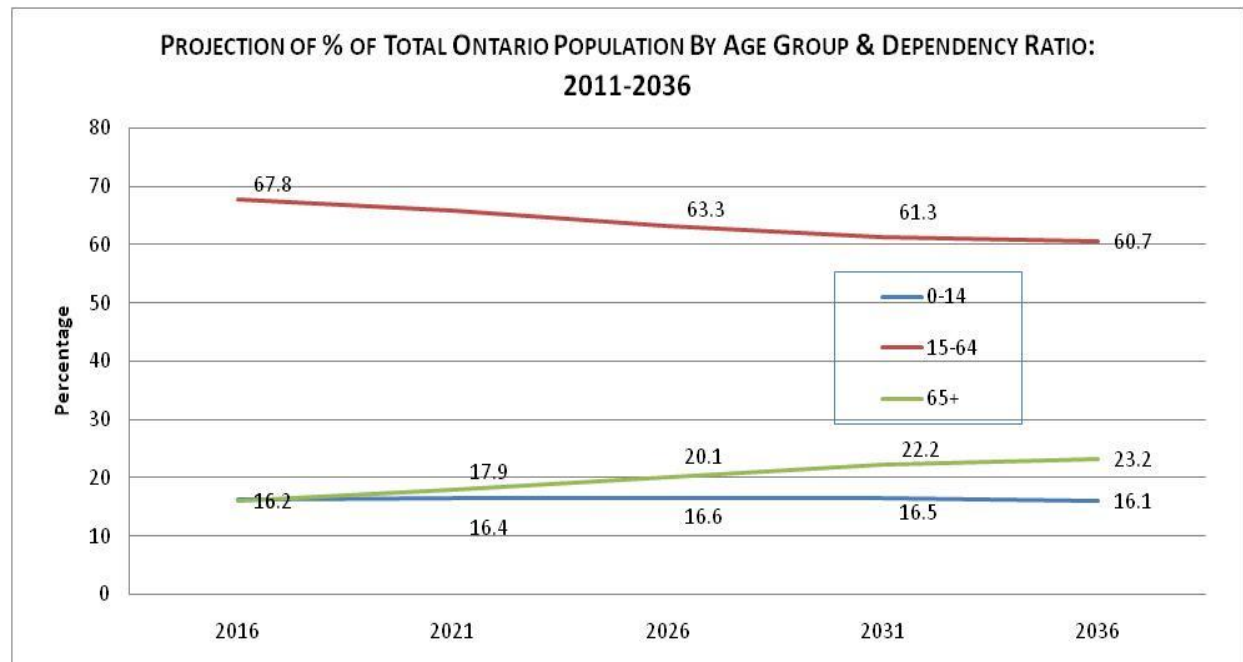
Figure 1: Actual and Projected Ontario Population Deaths: 1996-2036



This mortality trend creates a sense of urgency given the fact that even now the gap between demand for services and supply of quality integrated hospice palliative care services is currently significant.

Over 70% of care-giving (e.g. meal preparation, driving for errands, housework, personal care) is provided by family, friends and other unpaid caregivers (Stobert & Cranswick, 2004). This alone raises great concerns since the number of potential caregivers per care recipient is expected to decline dramatically as we advance into the 21<sup>st</sup> century (Carstairs, 2010). Decreasing fertility rates, pressures on the 'sandwich-generation', definitions of family as a result of marriage/divorce/re-marriage, geographical distance between members, and family complexity/dysfunction are all contributing to the decline in the availability of informal caregivers (Change Ability, 2009). Further, the increasing ethno-cultural diversity of Ontario's population is changing how families care for their dying loved ones (Change Ability, 2009). Greater attention will be needed to adapt systems and programs to facilitate caregiver support, including providing financial assistance to address lost income due to caregiving; offering training and advice to improve the capacity of caregivers; counseling and support to alleviate the stress of providing care; providing respite; and assisting with the difficult process of bereavement (Carstairs, 2010).

Figure 2: Projection of % of Total Ontario Population by Age Group & Dependency Ratio: 2011-2036



The aging population not only creates service demand pressures, but also supply pressures. By 2035, 40% of the population will be under the age of 14 and over the age of 65. This has huge implications for the hospice palliative care system. There will not be enough specialists in hospice palliative care to provide direct care to everyone in need. Greater engagement by the rest of health care system (primary care, acute care, long term care, etc) will be inevitable.

As few as 16-30% of Canadians had some level of access to hospice palliative care (Carstairs, 2010). Access varies greatly by diagnosis. Even though cancer patients represent 28% of Canadian deaths (Statistics Canada, 2005), they make up 80-90% of home-care clients receiving end-of-life care with the Community Care Access Centres in Ontario (Seow et al., 2009). Individuals with diseases of the circulatory system (35% of deaths) and of the respiratory system (about 10% of deaths) are grossly underrepresented (Statistics Canada, 2005). In studies of patients' experience with and without hospice palliative care, the negative impacts of the current system on caregivers' health and the rising costs of our current approach necessitate that we look to the successes of other jurisdictions. Integrated models of hospice palliative care have been successfully adopted in Manitoba, British Columbia, Alberta, and Australia. Some EOLCN/HPCN in Ontario have made valiant attempts to create integration (Central East, Champlain, Erie St. Clair, South East, Hamilton Niagara Haldimand Brant, Wellington). However, without formal policies and standards across Ontario, a patchwork of

access, outcomes, practices, and services is the best that has been achieved. The Canadian Cancer Society states (2010) “there is no comprehensive provincial palliative care program in Ontario”.

### Provincial Leadership and Coordination

The Ministry of Health and Long-Term Care (MOHLTC) has the opportunity to provide system-wide leadership on the issue of hospice palliative care. “The Ministry is the guarantor of social values and choices. In that role, therefore, there may be some health service areas which require province-level coordination or which may require an all-LHIN approach.” (Gow & Tremblay, 2006). With strategies, policies, regulatory support, scientific advice, and evidence-based research, the MOHLTC can ensure system level integration so that the people of Ontario can die pain free and with dignity in the place of their choice.

While there is no universal definition of integration, The Canadian Council on Health Services Accreditation (2006) defines integration as “services, providers, and organizations from across the continuum working together so that services are complementary, coordinated, in a seamless unified system, with continuity for the client”.

Currently, hospice palliative care in Ontario does not reap the benefits of an integrated system approach for the patients or the providers (see Table 1). Integrated hospice palliative care systems have demonstrated their effectiveness to improve patient experiences, promote the well-being of patients and caregivers, and reduce costs. The current situation of inconsistent hospice palliative care in Ontario and the potential for a truly integrated system presents a significant opportunity for the Government of Ontario to make hospice palliative care a real priority through policy and appropriate funding.

**Table 1: Ontario’s Hospice Palliative Care System – Today and Tomorrow**

	<b>Current Hospice Palliative Care System</b>	<b>Future Hospice Palliative Care System</b>
<b>SYSTEM INTEGRATION</b>	<ul style="list-style-type: none"> <li>• Fragmentation</li> <li>• Inequity across regions, service sectors and within sectors</li> <li>• Poor accountability structure</li> </ul>	<ul style="list-style-type: none"> <li>• Planned, integrated system</li> <li>• Equity across regions, service sectors and within sectors</li> <li>• Transparent accountability structure</li> </ul>
<b>SERVICE INTEGRATION</b>	<ul style="list-style-type: none"> <li>• Sector-based funding streams</li> <li>• Difficult to navigate services</li> <li>• Difficult to access specialists</li> <li>• No standards</li> </ul>	<ul style="list-style-type: none"> <li>• Services offered throughout the entire health continuum</li> <li>• Coordinated access &amp; care</li> <li>• Timely access to specialized, interdisciplinary consultation</li> <li>• Family practitioners integrated with other primary and community care providers</li> <li>• Consistent care according to quality standard</li> </ul>

<b>PALLIATIVE CLIENT AND CAREGIVER EXPERIENCE</b>	<ul style="list-style-type: none"> <li>• Lack of staff skilled in palliative care</li> <li>• Little integration</li> <li>• Caregiver burnout</li> <li>• Hospitals primary place of death</li> <li>• Poor pain and symptom management</li> </ul>	<ul style="list-style-type: none"> <li>• The 'right mix' of workers</li> <li>• The right balance of formal and informal care</li> <li>• Appropriate support for informal caregivers</li> <li>• Shift dying to the most appropriate setting in terms of patient choice and need</li> <li>• Good bereavement and psychosocial support, pain and symptom management</li> <li>• Greater focus on the provision of culturally sensitive services</li> </ul>
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Cancer Care Ontario (2006) - Source: Adapted, with permission.

### **The Alignment of Hospice Palliative Care with other Ontario's Priorities**

Through collaborative governance with the MOHLTC, the LHINs, and the EOLC/HPC Networks, many of the priorities of the MOHLTC can be addressed.

#### ***A Home First Focus***

The medicalization of death over the past hundred years has taken dying from the home to the professional environment of the hospital. The majority of deaths in Ontario take place in a hospital (Cancer Quality Council of Ontario, 2006). While hospital is the appropriate place for some patients, many patients do not need the acute and intensive services that a hospital provides. Eighty percent of Canadians state that they wish to die at home when possible (Ipsos-Reid, 2004). This same survey reported that on average, it would take 54 hours per week to take care of a dying loved one in their homes. Based on this estimate, 64% of those polled indicated that they could not devote the estimated number of hours per week given their current schedule. If appropriate care was provided at home (including owned/rented units, retirement homes, shelters, jails, supportive housing units, and any other place a person may call home) and in Long-Term Care Homes, patients would feel supported and safe to stay where they are most comfortable.

Home care is one of the most effective ways of meeting health care needs that do not require hospital treatment. It is also one of the best ways of increasing the number of people who can die in their own homes. Home care delays hospital admission until it is absolutely necessary.

BC Ministry of Health, 2006.

Several analyses have documented ways in which the utilization of hospital resources by patients at the end-of-life can be reduced. For instance, studies illustrate that palliative home care services have led to fewer ER visits (Seow et. al. 2009; Brumley et al. 2007; Serra-Prat et al. 2001). According to Seow et. al. (2009), the majority of end-of-life homecare patients did not have a hospitalization (57%) or ER visit (77%) in the last month of life; and only about 5% of patients had greater than 1 hospitalization or ER visit. However, of those who had at least one hospitalization in the last month, one-third spent

more than 14 days in the hospital in that last month. It is currently unclear what percentage of Long Term Care Home (LTCH) patients move out of that setting to receive terminal care in hospital or to receive care in the emergency department. With augmented services and education LTCH may be able to increase the number of patients who remain in that setting. Preventing unnecessary ER visits and hospital admissions in the last month of life was deemed as having a positive impact on the length of hospital stays for patients (Seow, 2009).

In 1992, 78% of oncology patients in Edmonton died in acute care hospitals, with an average of 20,000 patient days per year. When Edmonton established their Regional Palliative Care Program in 1995 it saw the number of acute care days drop to 7,639 - a decrease of 14,979 patient care days in 1999/2000. To meet this goal and support the decrease of acute care patient days, services were enhanced in the home, hospice and consultation to allow the transfer of care to other settings (Capital Health Community Care Services, 2000).

The Cancer Quality Council of Ontario - Cancer System Quality Index demonstrated that home care reduced the time spent in out-of-home services (2006). Further, with home care services, patients were more likely to die at home, which is an indicator of quality end-of-life care. Studies undertaken in the U.S. also demonstrated that home care services provided to cancer patients at the end-of-life led to more home deaths (Mor et. al, 1990; Zimmer et. al. 1984). However, even with better home care, some patients may not be able to stay at home or may not wish to die at home.

Currently, such patients are forced to go to the hospital because they have no other option. While they may not need the services of an acute facility, the hospital is often considered as the only alternative. In many situations, residential hospices offer a safe, home-like, less expensive, quality care alternative to hospital.

Approaches aimed at reducing hospital resource utilization have had a positive impact on healthcare costs. Several studies that examined costs of home care interventions suggest they result in lower costs (Brumley et al. 2007; Finlay et al. 2002; Hughes et al. 1992; Mor et. al, 1990; Parkes 1980; Parkes 1985; Serra-Prat et al. 2001; and Zimmer et. al., 1984). Further, the types of home care services provided had an important bearing on cost. Evidence suggests that traditional home care services were more expensive during the last 24 weeks of life than were hospice palliative home care services (Critchley et. al. 1999; Simoens et. al. 2010). The Hospice Association of Ontario (2009) and others (Central East Residential Hospice Working Group, 2009) have also reported that the costs of residential hospice beds are significantly less than hospitalization.

#### **Shared Care Teams**

The model positions experts alongside primary care providers in a way that enables them to have interactions and relationships to attend to what the patient needs. The outcome of this web of interaction is that the patient's care is provided seamlessly. This Team is available and on call 24 hours a day, 7 days per week. When a patient experiences pain or symptom management issues, the team responds, thus diverting a crisis ER visit and potential hospital admission. (Marshall, Howell, Brazil, Howard, & Taniguchi, 2008)

## **Unnecessary ER Usage**

It is well documented that palliative patients with non-urgent needs or whose needs can be addressed in other settings besides hospitals, frequently visit emergency departments (CHPCA, 2010). In 2007-2008 there were 20,023 admissions of palliative patients to acute care beds in Ontario, 80% of whom were via the emergency department. High rates of hospitalizations and emergency room (ER) visits in last weeks of life, and deaths in hospital are indicators of poor quality end-of-life care (Seow et al. 2009). Research shows that patients at the end-of-life make visits to the emergency room for a number of reasons. Cancer patients in Ontario visiting the emergency room at the end-of-life cited abdominal pain, pain, dyspnea, malaise and fatigue, nausea, anemia and back pain among the top ten reasons for their visits (Barbera, Taylor, & Dudgeon, 2010). Descriptions of patients or families no longer coping were captured by diagnoses of malaise and fatigue, need for palliative care and dehydration. Together, these accounted for 5.1% of visits during the final six months; in the final two weeks, this combination surpassed pain in ranking at 8.4% of visits. Avoidable reasons for visits, such as constipation, laboratory exams, attention to dressings or sutures, urinary catheter adjustment or prescription refills, accounted for 2.8% of visits during the final six months and 1.2% of visits during the final two weeks. Barbera, Taylor, and Dudgeon (2010) went on to suggest that with adequate services and supports, either at home or in other care settings besides emergency rooms, the majority of the visits to the emergency room by patients at the end-of-life could have been avoided. ER admissions are dependent on a number of factors, including:

- Caregiver support
- Physician engagement
- Specialists' engagement
- Access to community hospice palliative care services
- Place of residence.

Parkes (1980), Parkes (1985), and Hearn & Higginson (1998) have shown that patients at the end-of-life who were supported by a multi-disciplinary hospice palliative care teams at home reduced the time spent in acute care settings including ER.

## ***Alternative Level of Care (ALC) Burden***

Close to 19 per cent of patients in Ontario spend time in hospital beds while waiting for alternate levels of care. Lack of availability of services for patients at the end-of-life has an impact of hospital resource utilization. An unpublished study that compared end-of-life care for elderly patients with lung cancer in Ontario and the U.S. found that in the U.S., there were fewer hospitalizations than in Ontario, suggesting that comprehensive hospice palliative care services available in the U.S. had a positive impact on hospital resource utilization when compared to Ontario's fragmented approach to hospice palliative care (Krahn, et. al. 2010). Similarly, hospice palliative home care interventions have resulted in fewer hospitalizations (Brumley et al. 2007; McCusker et. al. 1987, Seow et. al. 2009; Serra-Prat et al. 2001; Sessa et al. 1996; Vinciguerra et al. 1986; Zimmer et al. 1985).

Seow et al.'s (2009) research found that the timing of admission into home care and service utilization had an effect on hospital resource utilization. The study, which demonstrated that patients admitted earlier than six months before death had a 35% lower probability of

hospitalization than those admitted three to four weeks before death, and patients using more than seven nursing hours per week and more than seven personal support and homemaking services hours per week had a 50% and 35% lower odds ratio of a hospitalization, respectively, suggests that early home care admission and increased home care services will help alleviate the demand for hospital resources at end-of-life.

### ***Chronic Disease Management***

The Ontario Quality Council (2007) reported that the real story in modern health care is the rise in chronic diseases. Chronic diseases are health conditions that require care over time. Examples of these conditions include heart disease, diabetes, Parkinson's disease, and dementia. Chronic diseases are the leading cause of illness, disability and poor quality of life in Canada. While not all chronic conditions have the same impact on a person's quality of life, they can generate a significant burden to individuals, their families, the health system and communities. Chronic disease presents a particular

challenge to modern health care systems, which have been designed to respond to acute illnesses and often fall short of meeting the needs of people living with chronic diseases. In order to meet the health needs of residents living with chronic health conditions, Ontario is moving from its existing 'find it and cure it' approach for health care delivery, which was designed for acute illnesses, to one that aims to 'prevent, find and manage' chronic conditions. In managing chronic diseases, and avoiding crisis in the later phases of their illness, hospice palliative care can play a major role in addressing unmet expectations and/or needs. It may complement and enhance disease-modifying therapy or it may become the total focus of care (CHPCA, 2002).

Effective primary care and chronic disease management services are widely regarded as necessary for the health system. With appropriate backup, primary care providers (family physicians and other health professionals familiar with the patient) could play a greater role in end-of-life care.

BC Ministry of Health. 2006.

Chronic disease prevention and management (CDPM) has been recognized as a priority health issue by the MOHLTC. As the population ages, prevalence of chronic illnesses will increase. 70% of people will die as a result of two or more chronic illnesses (Rachlis, 2006). As individuals adjust to their diagnoses and learn to manage their illnesses, primary care providers will supervise the vast majority of their care. While the focus of hospice palliative care to date has been largely on patients with cancer, there is increasing need to broaden the scope of hospice palliative care to include persons with other life limiting chronic illnesses. The populations are distinct. Yet there is considerable overlap in the needs of all of the patients and their caregivers. Hospice palliative care needs to be an integral part of this care, from diagnosis to death (CHPCA, 2002; SE Ontario Palliative & End-of-Life Care Network, 2009).

Several CDPM initiatives have begun to address the need for greater connections with hospice palliative care. In February 2010, the Heart and Stroke Foundation of Ontario issued a report entitled *End of Life Planning and Care for Heart Failure Patients* that recommends the creation of collaborative working relationships between "heart failure champions" and end-of-life care networks in each LHIN. With a five-year mortality rate (approximately 50%), there is a great

need to ensure that heart failure patients receive the benefits of hospice palliative care as needed throughout their journey. Similarly, the Alzheimer Society of Canada noted the rise in the number of people living with dementia will cause a 10-fold increase in demand for long-term care and an increase burden on caregivers (2010). A hospice palliative care system integrated with chronic, life-limiting disease management would help patients move through the trajectory of a chronic disease by enabling their changing goals of care to be met at all stages based on an inter-disciplinary approach to care that attends to psychosocial issues, advance care planning, and symptom management.

In the CE LHIN, the Self-Management Program provides workshops for individuals with chronic illnesses, including one section on advance care planning. This module provides information about the full range of needs they may encounter (psychosocial and practical, as well as health-related) and the choices they may need to make (Central East CCAC, 2010). CDPM initiatives need to partner with hospice palliative care to honestly discuss the likely course of the disease and the client's wishes (BC Ministry of Health, 2007). Cancer Care Ontario (2006) supports the need to change the current focus from providing hospice palliative care only to 'terminally' ill cancer patients to one that emphasizes the importance of providing a more 'simultaneous' approach to care regardless of an individual's prognosis.

*“If we know how to provide integrated hospice palliative care and we know it increases patient quality of life and satisfaction, and reduces costs, why are the practices not more widespread?” (CHPCA 2010)*

### **Recommendation #3**

**Adopt and implement a fully Integrated Hospice Palliative Care Service Delivery System for Ontario based on the provincial vision, policy and Hospice Palliative Care System Design Framework.**

#### **Rationale:**

A fully integrated hospice palliative care delivery system plan is needed to clearly spell out what needs to be done in the province of Ontario. This provincial plan would provide consistent best practice guidance on the 'what', the 'how', the 'where', and the 'when' for hospice palliative care, while allowing for local flexibility to accommodate community readiness and capacity. It would provide a map for each of the 14 LHINs to follow. Currently the development of hospice palliative care services has been inconsistent and fragmented across the province. In most cases, there has been no clear link with the LHINs' integrated health service planning processes and accountabilities have remained unclear. Moreover, in some areas, there has been an erosion of local community based hospice palliative care programs. A direction from the province to work towards a common provincial system design framework for HPC is required.

**Outcomes:**

A fully integrated hospice palliative care service delivery system that is informed by innovative evidence-based principles would ensure a higher level of quality standards and service delivery across the province. The common plan would align program activities and performance measurement and increase the achievement of targets, goals and contract deliverables. Service providers and caregivers would have access to the appropriate systems, skills and resources to match their role enabling greater efficiencies and effectiveness. The integrated system would offer organisations and health care providers' common tools and access to shared information to eliminate duplication and improve the realisation of quality care. The plan would create effective partnerships and structures at all levels (community, LHIN, provincially and nationally) that would be capable of linking and collaborating to achieve common goals.

Significant system-wide savings could be realized as individuals at the end of life are now provided appropriate care at the right place and at the right time. The detailed system design plan would enable a short and long range financial plan to be developed and establish an economic rationale for investment in quality hospice palliative care at the end of life.

**To achieve an integrated and comprehensive HPC service delivery system it is recommended that:**

- A. The system urgently incorporates the elements as described in the Hospice Palliative Care System Design Framework.
- B. The Ministry designates the Quality Hospice Palliative Care Coalition of Ontario as the provincial expert in HPC responsible for working in conjunction with the Hospice Palliative Care Lead to identify and obtain the required expertise to finalize the integrated HPC service delivery model.
- C. All LHINs have a local hospice palliative care plan that works towards the provincial Hospice Palliative Care Service Delivery System Design. Accountability is defined on a system basis rather than a sector basis in each LHIN area. Set province-wide requirements that all LHINs must meet in their plans. Based on local readiness and capacity, the provincial Hospice Palliative Care Lead works with each LHIN to negotiate minimum deliverables and timelines that each must meet in their plans. The LHINs are a necessary and required partner in the local HPC Network.
- D. The Ministry recognizes the HPC Networks as the local HPC experts with representation from across the continuum of care and designates them as the official advisory body informing and guiding the LHINs on a wide range of projects, programs and services related to HPC. The Networks are deemed as a regional resource to the Hospice Palliative Care Lead and the Coalition. As a collaborative governance structure, they take the lead on developing the local HPC plans with the LHINs, as well as facilitating and monitoring their implementation.

- E. Based on expert advice in hospice palliative care and performance measurement (from the Quality Hospice Palliative Care Coalition of Ontario and the Ontario Health Quality Council), provide provincial direction for consistent collection of data, system level outcomes and performance indicators that can be uniformly tracked (consistent with the Ontario Health Reporting Standards), and analysis of information about services, which will support rigorous system-level reporting on the provision of hospice palliative care in Ontario.
- F. Organizations and clinical service leadership teams in all settings report to their LHINs on the hospice palliative services provided to their patients / clients / residents according to the standard provincial key indicators. Review accountability agreements at each LHIN to ensure a consistent and optimum approach to system relationships regarding effective service provision.
- G. HPC Networks in each LHIN area are charged with the lead role in analyzing and monitoring local data and submitting monthly statistics to Hospice Palliative Care Lead, the LHIN and others where appropriate. Facilitate Network's access to existing provincial databases.
- H. The Ministry of Health and Long-Term Care Hospice Palliative Care Lead is responsible for:
  - i. Supporting and monitoring the implementation of the provincial hospice palliative care service delivery system.
  - ii. Reviewing hospice palliative care plans and statistics from each LHIN area, and periodically monitoring their progress towards the provincial system design, and ensuring that quality, integrated services are more evenly and equitably available across the province.
  - iii. Bringing together the different parts of government working on related issues to ensure their coordination and consistency throughout the province.
  - iv. Supporting the LHINs and the Networks in overseeing the implementation of their local hospice palliative care plans
  - v. Facilitating the resolution of common provincial issues to maximize continuity and avoid duplication.
- I. Designate the Quality Hospice Palliative Care Coalition of Ontario as the provincial expert in HPC to inform and advise the Hospice Palliative Care Lead and the Networks on a wide range of province-wide projects and initiatives regarding HPC, such as the Integrated Client Care Project.
  - i. Commission the Quality Hospice Palliative Care Coalition of Ontario to produce a public report on hospice palliative care resources using a population-based approach on a LHIN-by-LHIN basis.
  - ii. Charge the Coalition with updating the provincial system design as new and innovative evidence based practices are developed.
  - iii. Fund a Coalition Coordinator to manage the work of the Coalition.

- J. Consistent provincial implementation of best practice hospice palliative care standards are used for hospitals, long-term care facilities, home care programs, shared care teams, specialist palliative care consultation services, residential hospices, and community volunteer programs based on the work of Accreditation Canada, the Hospice Association of Ontario's accreditation for community volunteer programs and community residential hospices, the Pan-Canadian Standard for Palliative Home Care (Canadian Healthcare Association, 2006), the New Directions for Facility-Based Long-Term-Care (Canadian Healthcare Association, 2009), Canadian Hospice Palliative Care Association Norms of Practice (CHPCA, 2002), and the Canadian Hospice Palliative Care Association's Paediatric Standards (CHPCA, 2006) to ensure consistent, safe, and appropriate care at all times.
- K. Services are not just for individuals in the final months of life. Emphasize the need for better, coordinated care planning along the entire disease trajectory. Integrate hospice palliative care strategies with chronic disease management strategies. Extend services to individuals with progressive life-threatening illnesses other than cancer for whom hospice palliative care is not easily accessible, with the understanding that doing so will contain costs and improve quality of care in the long-run.

### **Enablers for the implementation of Recommendation #3**

- a) LHIN HPC plans should be consistent in working towards the achievement of the provincial system design however provincial performance standards with the recognition of the need for local flexibility in how they are achieved should also be adopted.
- b) System level outcomes and provincial performance indicators are centrally monitored and regularly reported on a LHIN by LHIN basis.
- c) Each LHIN regularly receive distinct reports on their local HPC resources to ensure its protection and alignment with their local hospice palliative care plan.
- d) Affirm the Networks' central role in the partnership and implementation of provincial hospice palliative care initiatives at the LHIN level such as the Integrated Client Care Project.
- e) Hospice palliative care programs have access to local LHIN innovation funding initiatives, such as Aging at Home funding, as well as pay-for-performance initiatives.

### **Leadership for implementation of Recommendation #3:**

Responsibility for communicating the above recommendation:

- Ministry of Health and Long-Term Care

Implementation of this recommendation will be the responsibility of:

- The Provincial Hospice Palliative Care Lead
- LHINS
- HPC Networks
- The Quality Hospice Palliative Care Coalition of Ontario
- OACCAC - Integrated Client Care Project

Assistance with implementation will be offered by:

- The membership of the Quality Hospice Palliative Care Coalition of Ontario

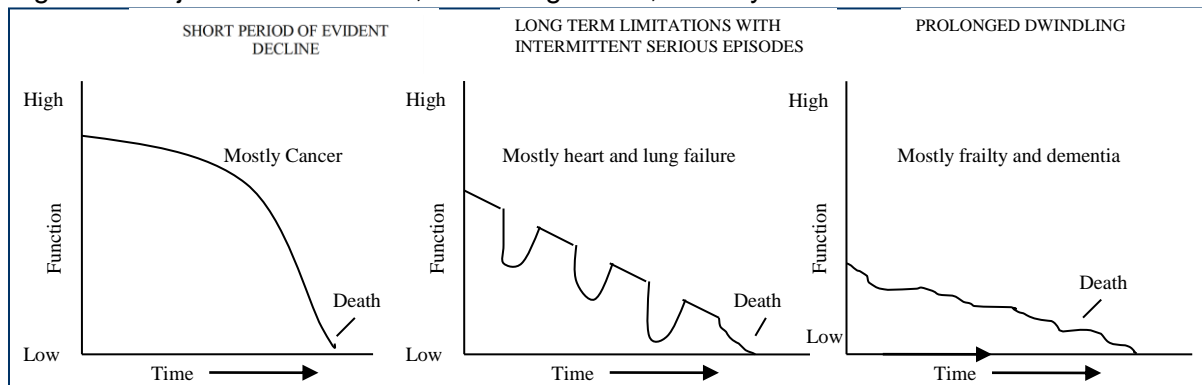
### Evidence and Discussion related to Recommendation #3:

#### System-Based Approach

While the 2004 Provincial EOL Care Strategy was successful in many ways, the strategy focused on services not systems. The emphasis was on individuals with the advanced stages of a “terminal” disease. There are inherent difficulties in taking this approach. It assumed that estimating how long a person has to live is by and large a reliable process. This is not always the case. Even for individuals with what might be considered a relatively “predictable” illness trajectory, such as cancer, estimates sometimes miss the mark. Individuals given months to live may live on for years (see Figure 3).

For individuals with less predictable trajectories, it became even more problematic. The health of persons with heart failure, for instance, may remain relatively stable until they experience an acute episode. Any one of these episodes might end in the person’s death. If they survive, it’s likely that their health will not fully return to what it was before the episode. For these patients, prognostication is more difficult. In its report entitled, *End-of-Life Planning and Care for Heart Failure Patients*, the Heart and Stroke Foundation of Ontario (2010) states that the prognostic uncertainty created by the uneven pattern of decline and improvement can make it difficult for patients and healthcare providers to know or accept when long-term planning or end-of-life care discussions are appropriate.

Figure 3: Trajectories of cancer, heart/lung failure, & frailty/dementia.



(Canadian Institute for Health Information, 2007)

As a result, heart failure patients (as well as patients with other life-threatening illnesses such as chronic pulmonary disease and progressive neurological diseases) are often deprived of hospice palliative care services and the physical, social, and spiritual support they offer. The same is true for patients with dementia, even though their illness trajectory can be described as a slow, steady decline. The focus with all these conditions remains on managing the condition. Lynn, Schuster, and Kabcenell (2000) suggest that “categorizing the ‘dying’ and the ‘living’ prevents us from developing adequate systems of care for seriously ill patients.”

### **A System Design Framework for Ontario**

The System Design Framework summarized below provides a way to organize and depict the basic requirements of an integrated hospice palliative care system for Ontario. This framework was originally developed by the Erie St. Clair End of Life Care Network (2009) and has been advanced, adopted, and endorsed by the Provincial End of Life Care Network and the Quality Hospice Palliative Care Coalition of Ontario. This framework has been used as the foundation to complete a preliminary inventory/review of hospice palliative care in Ontario (Provincial End of Life Care Network, 2009) and has been used as a template to review hospice palliative care systems in several LHIN areas.

This framework acknowledges the reality that in creating an integrated hospice palliative care system in Ontario, this system will cross sectors within a set of already established systems.

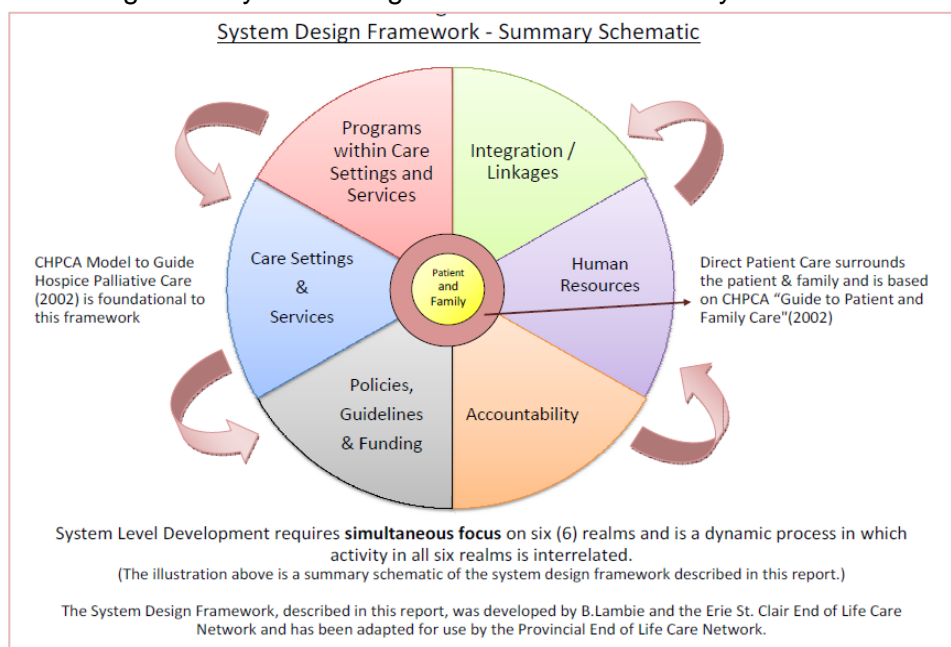
Each ‘regional system’ of hospice palliative care in Ontario is really a ‘system of systems’. Health care in Ontario is delivered by sectors and by independent service providers, each with its own Board of Directors, individual mandate, operational imperatives and strategic directions. For most providers, hospice palliative care is but one of many services they deliver. (Erie St. Clair End of Life Care Network, 2009)

To move from our current system of sector specific service provision to a cross sector system requires that:

1. A full continuum of care settings and services is in place;
  2. In each care setting where patients die, there is a clearly defined hospice palliative care program;
  3. Sectors and services are linked by common practice, processes, structures and education;
  4. Adequate numbers of trained professionals are available;
  5. System level accountability is clearly defined and communicated; *and*
  6. Funding models, guidelines and policy directions support an integrated system
- (Provincial End of Life Care Network, 2010)

These six requirements are the foundational pillars around which the system design framework is constructed. Figure 4 illustrates the six realms within which these requirements are considered.

Figure 4: System Design Framework – Summary Schematic



**Care Settings and Services:** Component parts of an integrated hospice palliative care system include:

- 24/7 Care Settings (and the specialist consultation services serving those settings)
- Ambulatory Care / Day Programs
- Community Support Services / Programs

**Programs within Care Settings and Services:** Basic elements indicating that a hospice palliative care program exists within a specific care setting include:

- Clearly articulated model of care
- Clear processes to access specialist level expertise
- Key organizational contact
- Admission criteria

**Integration / Linkages/Education:** Transitions between sectors are important to patients and families. The patients' and families' perspective of the coordination, seamlessness and integration of the system, is directly proportional to the integration and linkages between sectors. Fundamental integration essentials include:

- Common practice and processes
- Collaborative structures
- Common understanding of service delivery models
- System level data collection and evaluation
- Connections with broad system of health care
- Common education

**Human Capital:** Compassionate, skilled people are at the core of hospice palliative care. Shortages of hospice palliative care personnel are reportedly endemic across Ontario. Key considerations, related to human capital, include:

- Team composition
- Delineation of education and training at primary and specialist levels for various professional categories
- Development of population based guidelines
- Enhancement of innovative care models

**System Accountability:** An integrated hospice palliative care system requires system level accountability that supports and advances the care of patients across sectors while aligning with operational accountabilities within each sector/service. Key considerations related to system accountability include defining:

- Key functions of system level accountability
- Key mechanisms/venues that would facilitate system level accountability
- Fundamental principles that advance system level accountability.

**Policies, Guidelines and Funding:** Policies, guidelines and funding directly impact patient care as well as the development of system-wide integration. The LHINs are an essential driver in this integration process.

The System Design Framework for the development of an integrated hospice palliative care system is consistent with Cancer Care Ontario's recommendations for organizing and delivering palliative cancer care in Ontario (2009):

- Each region should have three levels of palliative cancer care available: Primary, Secondary and Tertiary.
- Each region should have a mix of services that are patient focused, based on the patient's needs, as opposed to prognosis, and optimizes outcomes for patients. All regional cancer programs should offer a tertiary level of expertise to maximize access to specialist palliative care services throughout the cancer centre, hospital and the region.
- Common screening, assessment tools and guides to practice should be implemented in all levels of care in each region (e.g., ESAS, Palliative Performance Scale, Collaborative Care Plans and Symptom Management Guides to Practice)
- Standardized education, training and health human resource planning should be implemented.
- The Regional Palliative Care Program should continue to work with the End-of-Life Care Networks to establish formal linkages amongst palliative care providers in different settings of care.
- Each Regional Cancer Program should address inter-professional and intra-professional collaboration within the integrated cancer program and regional cancer program, as collaborative practice is essential for the effective delivery of palliative care in any care setting and between settings of care.

- A mixture of structure, process, and outcome indicators should be established for palliative care services to identify if symptoms are improving, whether services are accessible and whether there is equitable distribution of services across the province.
- An appropriate number of designated palliative care beds within the acute care and non-acute care sector including complex continuing care, residential hospice and LTC should be established based on current benchmarks and projected need.

Additionally, the System Design Framework is well aligned with recent work of non-cancer proponents of hospice palliative care (Alzheimer Society, 2010; Heart & Stroke Foundation, 2010).

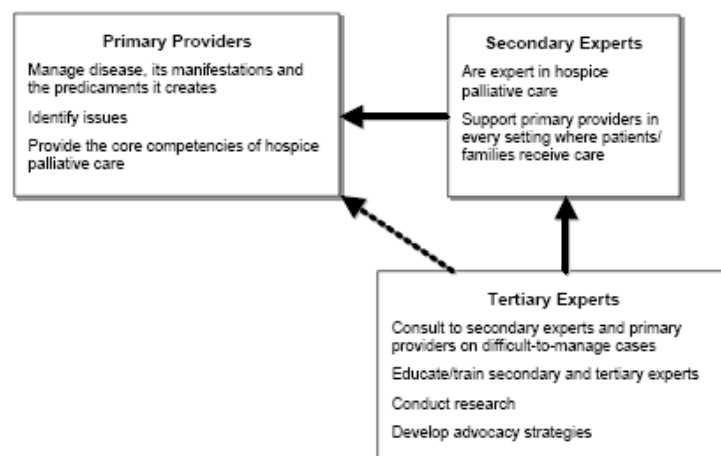
### Required Elements of Hospice Palliative Care

Because hospice palliative care issues occur throughout the illness and bereavement experiences, all clinicians (i.e., formal caregivers including volunteers) must be (CHPCA, 2002):

- competent at identifying the full range of issues that patients and families commonly face
- skilled at providing the core competencies of hospice palliative care using approaches that are based on widely-accepted preferred practice guidelines
- effective at assessing their outcomes, and
- appropriate with their documentation.

As in any other healthcare situation, when primary providers encounter care challenges and situations beyond their level of confidence and expertise, or when their practice outcomes are not consistent with accepted norms of practice (i.e., those in this model), they must be able to seek help and support from hospice palliative care experts. For this to be possible, interdisciplinary teams of secondary hospice palliative care experts must be readily accessible in every setting where patients and families receive care. In addition, these secondary hospice palliative care experts require access to tertiary experts in every major academic/population centre (CHPCA, 2002). (See Appendix B– Conceptual Model)

Figure 5: Primary, Secondary & Tertiary Hospice Palliative Care



### **Required Domains of Hospice Palliative Care**

As illness disrupts people's anticipation of the future, they seek help from the healthcare system to assist them to restore their capacity to live to as close to "normal" as possible. Ultimately, with a combination of appropriate therapeutic interventions aimed at fighting their disease, relieving their suffering and improving the quality of their lives, a patient's and family's experience of illness and bereavement may be different, and their future may be closer to what they anticipated (CHPCA, 2002). (See Appendix C – Domains of Care)

### **Required Processes of Providing Hospice Palliative Care**

Providing care is a process for creating "wanted" change that is based on:

- the development of a therapeutic relationship between those who provide the care (caregivers) and those who receive it (the patient and family as a unit). The relationship evolves with time as familiarity, trust and confidence are established
- a therapeutic process that evolves through a series of therapeutic encounters between the caregivers and the patient and family
- the understanding that only therapies with a potential for benefit and acceptable risk or burden will be offered
- change strategies
- the continued affirmation of the patient's and family's values and choices

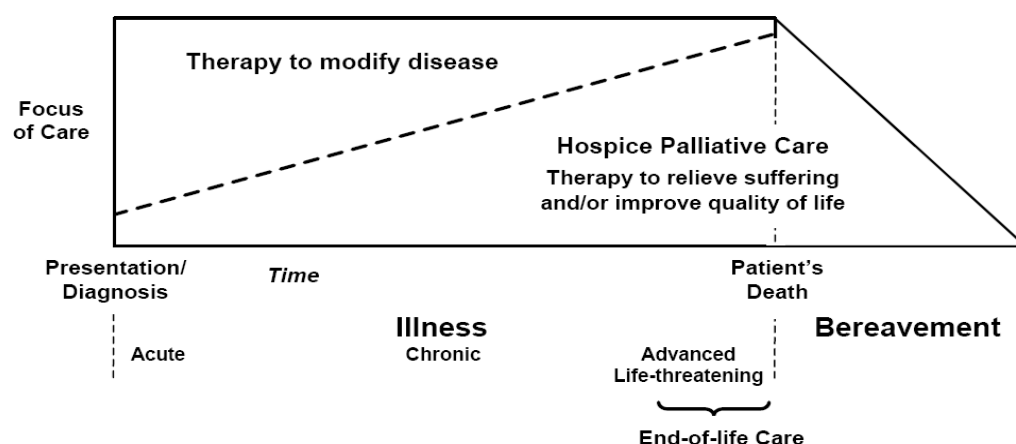
During each therapeutic encounter, the process for providing care involves six essential and several basic steps that guide the interaction between caregivers, and the patient and family. While these steps do not need to occur in any specific order, each one must be completed during each encounter (CHPCA, 2002). (See Appendix D – Processes for Providing Care)

### **Required Processes of Identifying Individuals that could benefit from Hospice Palliative Care**

Hospice palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care. It may complement and enhance disease-modifying therapy or it may become the total focus of care (CHPCA, 2002).

While hospice palliative care has grown out of and includes care for patients at the end of life, today it should be available to patients and families throughout the illness and bereavement experiences (CHPCA, 2002).

Figure 6: Hospice Palliative Care & Treatments to Modify Disease



The top line represents the total 'quantity' of concurrent therapies. The dashed line distinguishes therapies intended to modify disease from therapies intended to relieve suffering and/or improve quality of life (labelled hospice palliative care). The lines are straight for simplicity. In reality, the total 'quantity' of therapy and the mix of concurrent therapies will fluctuate based on the patient's and family's issues, their goals for care and treatment priorities. At times, there may not be any therapy in use at all. As you can see in the CHPCA model hospice palliative care is distinguished from that of end-of-life care, which specifically refers to services provided to dying patients and their families (CHPCA, 2002).

### When to Introduce a Hospice Palliative Care Approach

Within the cancer population, the vast majority of people currently seen by hospice palliative care teams are in the terminal phase of their illness with an estimated prognosis of only weeks to months. The belief that hospice palliative care begins when the disease becomes 'terminal' has often delayed the appropriate entry to formal hospice palliative care. Providing care only for the imminently dying has been described as a potential indicator of poor quality of care (Higginson, 1999). In fact, many hospice palliative care providers believe that referrals are often made "too late" to be able to optimize the care received by patients and their families.

Even though many cancer trajectories are somewhat predictable, variations in referral to hospice palliative care vary considerably across the province.

For example:

- The percentage of cancer patients receiving a palliative care physician visit in their home in the last two weeks of life varies across the province from 10%-32%.
- Outpatient palliative care physician assessments in the last two weeks of life varies from 4% to 33%
- Inpatient palliative care physician assessments in the last two weeks of life varies from 14% to 26% (Barbera, 2005).

Some variations in care patterns may be attributed to regional differences in care protocols and available resources. Other differences are attributed to the fact that palliative patients often receive care throughout the course of their illness in a variety of settings across the care continuum including primary, acute, chronic, home, and long-term care. The factors contributing to variation are further complicated by the fact that palliative care is delivered in different ways based on the training and expertise of the broad range of care providers involved. Current variation in practices by different providers along the care continuum, coupled with fragmentation and an overall lack of coordination and integration of palliative care services across the continuum are major obstacles to achieving high quality care (Barbera, 2005).

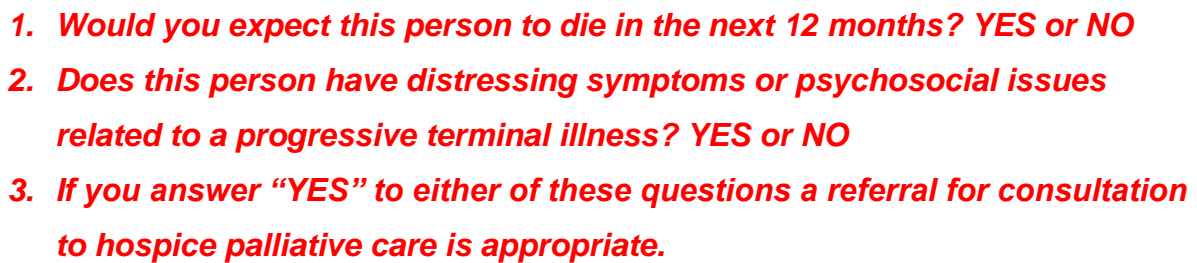
Preliminary studies looking at the advantages of a “simultaneous care” (SC) model (compared to “usual care” (UC) model) have demonstrated improved quality of life for the SC group with diminished quality of life in the UC group (Ferrell, 2005; Meyers, Linder, Beckett, Blais, Enders, et al, 2002). A SC approach focuses on helping patients move through the trajectory of a progressive, life threatening disease by enabling their changing goals of care to be met at all stages based on an inter-disciplinary approach to care that attends to psychosocial issues, advance care planning, and symptom management – the essence of palliative care (Gillick, 2005). Consequently, a key objective in enhancing the quality of hospice palliative care is to ensure earlier identification of patients with advancing illness to allow them to receive appropriate hospice palliative care earlier in the illness trajectory (See Figure 1). Achieving this, would provide opportunities for case managers and other health professionals to educate the client and caregiver on resources available to support them through their illness, allow for potential enhancements to quality of life and care planning, and avoid crisis management and hospitalization (OACCAC, 2003). Key outcomes of earlier identification would also contribute to earlier prevention and detection of symptoms, improved quality of life, and ultimately enhanced ability of patients and families to receive and provide the necessary supports to remain in the home environment longer.

Research also shows that chronic nonmalignant illnesses have specific indicators of advanced illness suggesting the illness is transitioning to the final phase. Generally:

- Medical management maximized,
- Functional decline in performance despite best medical management,
- Symptom issues despite medical management of underlying disease,
- More frequent ER visits, hospitalizations,
- Patient’s expressed wishes for comfort measures.

(Penderell & Winemaker, 2010)

Objective criteria exists within many disease trajectories to assist in identifying the end stages of life. (See Appendix E). Therefore, strong collaboration and alignment of the work between chronic disease management and hospice palliative care is essential. A consistent, standardized, best practice approach in helping to identify when it is essential to introduce a hospice palliative care approach is to ask the following questions as adopted from Joanne Lynn:

- 
1. *Would you expect this person to die in the next 12 months? YES or NO*
  2. *Does this person have distressing symptoms or psychosocial issues related to a progressive terminal illness? YES or NO*
  3. *If you answer “YES” to either of these questions a referral for consultation to hospice palliative care is appropriate.*

*“If we know how to provide integrated hospice palliative care and we know it increases patient quality of life and satisfaction, and reduces costs, why are the practices not more widespread?” (CHPCA 2010)*

#### **Recommendation #4**

**Provide strategic investments to enhance, build and sustain an integrated system of quality, safe, coordinated and comprehensive hospice palliative care services.**

#### **Rationale:**

When today's health system was created it was mainly designed with an acute care focus to respond to the greatest needs of that day. Given the changing aging population a new kind of health care system is now required. To meet today's challenges we need a coordinated approach to public policy and planning. We need to drive systemic change to respond to current and future needs through adequate data collection, human resource planning, education, research, and funding. Therefore, considering the cost of shifting and replacing the current system with best practices, such as hospice palliative care, that better responds to the growing needs of today, makes a very strong case for the appropriate use of limited resources.

In fact, a key finding by the LHIN Support Unity, Inpatient Palliative Care Activity (2009), (where records were studied among patients with a diagnosis of palliative care (Z51.5)<sup>1</sup> within any of the diagnostic fields coded in the discharge abstract database for the 2007/08 fiscal year) showed that there were 25, 958 acute separations from Ontario hospitals for palliative care accounting for 345,327 acute care days. In addition, 5,935 of the acute palliative care separations had alternate level of care days associated with the stay, accounting for 95,018 days. These cited numbers are likely an underestimate due to inconsistent application of Z51.5 coding. Therefore, what these numbers indicate is that the current system is

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<sup>1</sup> The HSMR was developed in the United Kingdom in the mid-1990s and has been used in the Netherlands and the United States. When tracked over time, the ratio can be a motivator for change by indicating how successful hospitals and health regions have been in reducing inpatient deaths—leading to improved patient care. CIHI has led the effort in calculating HSMRs for Canada and publishes results for eligible facilities and regions in all provinces outside Quebec.

spending far too much money actively treating people at the end-of-life when HPC may be more appropriate and desired. When the right patient, right place, right time, right resources approach is the focus of care, system wide resources are used in the most efficient and effective way possible. (See Appendix G). Utilizing an appropriate level of care, particularly for this patient population also supports resolving the ER and ALC issues, which are currently bogging down the system and causing many families unnecessary grief during an already stressful time in their lives.

The recommended strategic investments that are required to shift the current system are presented under several key elements including: programs, infrastructure, technology, human resources, education and research. Many of the recommendations contained within these components can be implemented with little or no additional resource requirements and mainly involve a restructuring or reformation in order to strengthen the system's ability to perform. However, in order to fulfill the system design plan for hospice palliative care in Ontario additional strategic investments will be required in certain areas to enhance current and build new infrastructure. Even when new investments are required evidence suggests that utilizing a hospice palliative care approach is far less expensive for the system and ultimately provides options that save money.

### **Outcomes:**

Strategic investments in hospice palliative care would move the system towards acknowledging and meeting today's growing health care needs. These changes would support a system that provides individuals and their families with the options and dignity that they deserve at life's end. Suter, Oelke, Adair and Armitage (2009) offer 10 benefits of health system integration that help to demonstrate the outcomes that the recommended strategic investments would create in an integrated hospice palliative care service delivery system, including:

- Comprehensive HPC services offered across the continuum of care which is capable of coordinating all core services;
- Patient focused care that places the patient/client at the centre to meet their needs in the most effective and efficient way possible;
- Equitable geographic coverage to maximize patient accessibility to needed services and programs wherever they live;
- Standardized best practice care delivery through inter-professional teams using protocols that are evidence based;
- A performance management and monitoring system including indicators to measure appropriate outcomes;
- Suitable information technology and communication mechanisms which effectively tracks utilization and outcomes;
- A systems-wide culture shift with strong leadership across the continuum of care with a shared vision and common values working in collaboration and partnership;
- Physician integration that effectively involves them in a key leadership role in the design, implementation and operation of the system.
- Strong governance structures comprised of knowledgeable and experienced representatives that are diversified to include the variety of stakeholder groups across the system of HPC; and

- Sound financial management where initial integration strategies may result in increased cost before it provides realistic savings.

**It is recommended that:**

### **Program Strategic Investments**

- A. Fund the creation and expansion of inter-professional teams across the province as a means of building palliative care community capacity within primary care. When generalist practitioners in the community are adequately supported by coordinated systems of care, access to expert advice in palliative care, and mentorship opportunities the outcome is better care coordination across treatment settings, and the alleviation of crisis interventions thus reducing emergency department visits and hospital admissions.
- B. Expand the Alternative Payment Plan for the development of additional expert Palliative Care Physicians. Optimize their role by integrating them within inter-professional teams. This approach is also recommended by the Ontario College of Family Physicians as a means to facilitate, engage, support and expand primary care physicians' roles in HPC. Ensure provincial consistency and access to these important HPC resources.
- C. Fund 80% of the operating costs of residential hospices.
- D. Review the adequacy of funding for palliative care services in hospitals.
- E. Provide effective and sustained supports for informal caregivers, including more respite and bereavement services.
- F. Expand home care nursing and home support availability over the 24 hour period, seven days a week based on client need.
- G. Embark on a sustained quality improvement program, supported by dedicated funding, to ensure that hospice palliative care services are working effectively in long-term care homes across Ontario.
- H. Enable access to specialized quality hospice palliative care services and expertise from other care settings within long-term care homes, including interdisciplinary teams. This would build core competencies among long-term care home staff.
- I. Build community capacity by protecting, designating, and equitably and adequately funding existing community-based hospice palliative care programs, such as
  - a. Palliative Pain & Symptom Management Consultation Service
  - b. Facility and Community Interdisciplinary HPC Education Service
  - c. Physician Education
  - d. Hospice Volunteer Services
- J. Support work with diverse cultural and social communities to develop approaches that are responsive to their needs, particularly French Language Services and Aboriginal

communities with unique and distinct traditions for end-of-life care. Ensure that local Networks include and engage these communities in the development of their local LHIN area Hospice Palliative Care plans.

### **Infrastructure Strategic Investments:**

- A. Define clear, consistent accountability relationships between LHINs, the Ministry's designated lead and other Ministry departments with respect to the implementation of hospice palliative care policies.
- B. Define clear, consistent accountability relationships that support integrated systems of quality hospice palliative care services between LHINs and their respective Hospice Palliative Care Networks.
- C. Re-establish a funding mechanism for the Hospice Palliative Care Networks that ensures that they are sustainable and able to deliver on their mandate of helping to ensure the delivery of quality HPC across the continuum of care, in keeping with the new provincial HPC policy and system design framework.
- D. Recognize the primary mandate of the Quality Hospice Palliative Care Coalition of Ontario is to act as a provincial advocacy body for quality hospice palliative care for all Ontarians, working in alignment with The Canadian Hospice Palliative Care Association, the Quality End-of-Life Care Coalition of Canada, and other provincial hospice palliative care coalitions across Canada.
- E. As a well-connected expert provincial resource in HPC, the provincial Hospice Palliative Care Lead should continue to work with the Quality Hospice Palliative Care Coalition of Ontario to define essential hospice palliative care services based on the System Design Framework, and the work of the Canadian Hospice Palliative Care Association.
- F. Recognize the Provincial End-of-Life Care Network as the interim secretariat for the Quality Hospice Palliative Care Coalition of Ontario until such time as the Hospice Association of Ontario and the Ontario Palliative Care Association take on this role as a single merged organization.
- G. Resource the Seniors Health Research Transfer Network's Hospice Palliative Care Community of Practice and the Community of Practice for Health Care Consent to broaden its membership and agree on provincial best practices in health care consent and advance care planning. Support projects to introduce these practices into a variety of care settings across the province.
- H. Define the accountabilities and communication channels between the Hospice Palliative Care Lead and the:
  - a) Provincial End-of-Life/Hospice Palliative Care Network
  - b) Quality Hospice Palliative Care Coalition of Ontario

### **Technological Strategic Investments:**

- A. Evaluate current efforts, such as eShift (South West CCAC), to introduce technology to support the implementation of best practices in the community and make clinical information readily available to health care providers in real-time.
- B. Pilot and implement a Shared Electronic Health Record within the HPC system with full interdisciplinary team record access to maximize the effective coordination of patient shared care plans.

### **Health Human Resource Strategic Investments:**

- A. Develop, adopt and implement a human resource and capacity-building strategy for hospice palliative care. Base health human resource needs in hospice palliative care on the system design framework and the concept of three levels of expertise (primary, secondary, and tertiary).
- B. Establish core competencies in various settings and levels of expertise in conjunction with experts within each profession.
- C. Build capacity by developing a recruitment and retention strategy for all disciplines (regulated and un-regulated) involved in HPC. Include spiritual care specialists and volunteers in the plan.

### **Educational Strategic Investments:**

- A. Endorse a provincial hospice palliative care education strategy that is evidence-based and draws on already developed curricula being used in the field. Consult with the Quality Hospice Palliative Care Coalition of Ontario to identify these best practices.
- B. Expand fellowships, the creation of subspecialties and other educational opportunities for the development of additional Expert Palliative Care Physicians and Community Hospice Palliative Care Resource Physicians and other disciplines.
- C. Heighten public awareness of HPC by providing special grants to the HPC Provincial Association, for example the funding of a provincial Advance Care Planning Campaign collaborating with potential federal initiatives; defining public HPC information needs, and identifying and promoting existing effective information resources.

### **Research Strategic Investments:**

- A. Although significant progress has been made in palliative care research since 2005, much more is still required in every aspect of the hospice palliative care field. The

*Raising the Bar* report identifies several key elements that would greatly enhanced through further research evidence. Invest in research to advance knowledge in:

- i. the socio-economic benefits of palliative care;
  - ii. quality indicators;
  - iii. common data collection methods;
  - iv. how to best meet the needs of caregivers;
  - v. use of technology in providing care;
  - vi. inter-professional educational curricula; and
  - vii. differing health service configurations and models such as shared care and more comprehensive integrated care delivery models early in the disease trajectory;
- B. Invest in research to evaluate the ability and effectiveness of Hospice Palliative Care Networks as a community capacity builder to increase hospice palliative care integration and systemic improvement.
- C. Ensure knowledge translation is an integral part of all research studies to successfully integrate research into practice. Find effective ways to communicate and provide education, such as mentoring and academic detailing, across the continuum of care to improve best practice hospice palliative care and create sustainable systemic changes and cultural shifts.

#### **Enablers for the implementation of Recommendation #4:**

- a) Utilize the plan for action strategies to develop a provincial implementation plan that:
  - i. Quickly advances recommendations that do not require additional resource requirements.
  - ii. Assess recommendations that require minimum resource requirements to determine what can be achieved in the short term.
  - iii. Rank recommendations that require significant additional resource requirements into those that will have the greatest system impact and develop a short, mid and long range plan to achieve these system changes.
  - iv. Work with the Quality Hospice Palliative Care Coalition to provide advice and expertise on developing the highest performance, outcomes and cost effective implementation plan.
- b) Work towards provincial HPC service and resource equity using a population based approach.
- c) Use the Australian (2008) and Fraser Health (2006) population-based models to begin to identify and develop appropriate bed ratios and HPC services for Ontario. Where models do not yet exist, work with the Provincial End-Of-Life Care Network towards the development of such common provincial planning tools.

- d) While supporting a shift to more care being provided at home, recognize the continued need for hospice palliative care to be provided in all settings where patients die, including hospitals.

#### **Leadership for implementation of Recommendation #4:**

Responsibility for communicating the above recommendation:

- Ministry of Health and Long-Term Care

Implementation of this recommendation will be the responsibility of:

- Ministry of Health and Long Term Care through the provincial Hospice Palliative Care Lead
- LHINS
- HPC Networks
- OACCAC – Integrated Client Care Project

Assistance with implementation will be offered by:

- The Quality Hospice Palliative Care Coalition of Ontario

#### **Evidence and Discussion related to Recommendation #4:**

A population based service planning approach seeks to understand and plan for the health needs of the target population as a whole, and to implement and evaluate interventions to improve the health or well-being of that population. When planning care for a population, as distinct from caring for an individual member of that population, health services are accountable for measuring outcomes for all members of the targeted population, including those who may not, for a variety of reasons, access services.

Population based approaches have been used to plan and deliver services for people with a wide range of health conditions and diseases, including tobacco dependence, breast cancer, diabetes, asthma and chronic heart failure. By thinking in terms of whole populations at the planning stage, services have collaborated to provide the means and resources to implement systems and processes of care that have led to improved outcomes for whole populations of patients, as well as for individual members of those populations. The approach requires collaboration within all service providers and partnerships that build community capacity in individual, community and organizations.

To help advance the provincial discussion regarding the placement of strategic investments within the HPC system components of programs, infrastructure, technology, human resources, education and research across care settings and services the following section provides background and evidence for a population based planning approach for hospice palliative care.

## **Population Based Planning (PBP) for Hospice Palliative Care**

### ***Acute Care Inpatient Beds***

It is generally agreed that the numbers of patients requiring hospice palliative care are significantly higher than what is generally captured by hospitals in the Z51.5 code (See Appendix F for details on the Z51.5 code).

An indication of this under coding became evident during the process of implementing the hospital standardized mortality ratio (HSMR). The hospital standardized mortality ratio is an important measure to support efforts to improve patient safety and quality of care in Canadian hospitals. The HSMR compares the actual number of deaths in a hospital with the average Canadian experience, after adjusting for several factors that may affect in-hospital mortality rates, such as the age, sex, diagnosis and admission status of patients. The ratio provides a starting point to assess mortality rates and identify areas for improvement to help reduce hospital deaths.

During the validation process of the HSMR review, several hospitals across Canada identified challenges with palliative care coding. “Based on this feedback, CIHI issued an interim guideline for the coding of palliative care services in June 2006” (CIHI, 2007a). In response to concerns of ambiguity in relationship to chart documentation of “terminal illness”, CIHI issued a further clarification in October 2007, to be used for fiscal year 2007-2008 (CIHI, 2007b). A footnote in the HSMR report states “A national coding standard will be implemented in 2008” (CIHI, 2007c).

This national coding standard was implemented, but coding inconsistencies appear to be continuing. Coding of hospice palliative care in acute care hospitals, for the past several years, may not be consistent and as indicated in the HSMR report there is likely an underestimate of palliative care. Hence caution must be used when using the Z51.5 code as an indicator of palliative care utilization in acute care

The typical models of acute care inpatient palliative care are:

1. Dedicated units / designated beds where specialized staff care only for Hospice Palliative Care patients (CIHI, 2007).
2. Integrated units where “a palliative care unit can occupy a portion of a larger unit, dually trained staff can cross-cover and beds can swing from palliative care to other uses as needed” (Meier & Beresford, 2006).
3. Consultation teams or consulting experts– with or without a dedicated unit or dedicated beds (Essex Kent Lambton District Health Council, 2005; Meier & Beresford, 2006)

No predictive methodologies have been proposed for Acute Care Palliative Bed Equivalents in Ontario (The Health Service Restructuring Commission proposed numbers for Complex Continuing Care beds). The HSMR illustrates that Palliative Care is coded in every acute care facility in Ontario and under coding is cited, however no “right size” indicators are readily available for Ontario.

Projections below are based on the experience of two regions that have well developed Palliative Care programs both in the community and in hospitals:

- Fraser Health in British Columbia, Canada – projections are drawn from the *Fraser Health Acute Care Capacity Initiative – Plan for Acute Care Palliative Care*. These extrapolations work out to a requirement for 7.73 acute care beds / 100,000 population (combining acute and tertiary unit numbers) as well as 7 hospice beds / 100,000 population.
- Palliative care Australia – published projections are from – *Palliative Care Service Provision in Australia; a Planning Guide (Palliative Care Australia, 2005)*. This publication recommends a minimum of 6.7 designated palliative care beds / 100,000 population. Palliative Care Australia cites these as minimum levels and states that these numbers will need to be supplemented with additional resources in rural areas etc.

The Australia work indicates that “these recommendations are for specialist palliative care inpatient beds and assume that as patients are stabilized they will return to more appropriate levels of care – discharge to home...aged care facility or other sub-acute clinical environments” (Palliative Care Australia, 2005). This of course assumes that there is palliative care service developed in other environments.

### ***Tertiary Care Units/Beds***

Fraser Health describes the role of a tertiary care unit as follows:

“A Tertiary HPC (Hospice Palliative Care) unit (THPCU) provides specialized, skilled assessment and intervention in a supportive acute care environment in order to stabilize patients so they may return home or go to a hospice or residential care setting...” (Fraser Health, 2006).

In regions with defined tertiary level palliative care in acute care hospitals, this care typically is provided on a dedicated unit with:

- at least 10 beds clustered
- access to a broad range of acute care services including:
  - critical care
  - operating rooms
  - radiology and laboratories
  - oncology
  - anesthesia (Fraser Health, 2006).

Fraser Health in British Columbia, Canada – projections are drawn from the *Fraser Health Acute Care Capacity Initiative – Plan for Acute Care Palliative Care*. These extrapolations work out to a requirement for 7.73 acute care beds / 100,000 population, (combining acute and tertiary unit numbers)

### ***Emergency Rooms***

Currently the Emergency Department is the most common hospital entry point for patients who require acute care palliative care. It is universally agreed that the Emergency Department is not the optimal hospital entry point for patients requiring palliative care. Yet few alternatives exist for patients who require acute care intervention. Processes should be developed to bypass the

Emergency Department and expedite care and discharge. Examples of best practices in terms of direct admissions that bypass the ER include: Peterborough Regional Health Centre and Bluewater Health in Sarnia.

### ***Complex Continuing Care (CCC) Beds***

CCC patients are coded separately from acute care patients. Models of palliative care in CCC vary across the province, from a dedicated unit to no defined model of care. A significant percent of Ontario's population die in Complex Continuing Care beds. While an extensive data set is available relating to CCC patients in Ontario (Hospital Report Research Collaborative, 2007) there are few available published studies or reports that specifically describe and/or compare palliative care service delivery in CCC facilities across Ontario.

Currently there is no Ontario formula to determine recommended numbers of CCC beds, however for the purpose of this report, we recommend that the number of deaths in CCC could be used to give insight into the need for end-of-life care in CCC populations. However, it is expected that a formalized program of palliative care be available for these patients and families in each CCC facility (Refer to expectations articulated in the System Design Framework – realm two – PEOLCN 2010). Additionally, further opportunities may exist in many LHIN areas to explore direct admissions to CCC beds from the community, (although high occupancy levels often make this difficult).

### ***Long Term Care***

Increasingly Long Term Care Homes (LTCH) are the location of care and death for older individuals with chronic illness (Brazil, Krueger, Bedard, Kelley, McAiney, Justice, & Taniguchi, 2006). In Canada it is reported that 39% of deaths occur in LTCH, which represents over 20,000 people in Ontario alone in 2008 (Fisher, Ross, & MacLean, 2000). It is reported that most residents of a LTCH die in that home. Most residents in LTCH are over the age of 65 with the average age at admission typically being greater than 80 years of age (Kirkpatrick, 2007).

Models of hospice palliative care service delivery in LTCH vary considerably across Ontario. Although a significant percent of Ontario's population die in LTCH there appear to be few specific reported measures related to hospice palliative care service delivery in these beds. LTCH will continue to play a vital role in the care of the dying. It is currently unclear what percentage of LTCH patients move out of that setting to receive terminal care in hospital or to receive care in the emergency department. With augmented services and education, LTCH may be able to increase the number of patients who remain in that setting throughout their journey.

### ***Residential Hospice Beds***

Currently there is no Ontario formula to determine recommended numbers of hospice beds per population. While all LHINs have designated residential hospice bed funding two LHIN areas (Central East & North East) currently have no residential hospice beds or beds under construction.

Fraser Health projects the need for 7 hospice beds per 100,000 in addition to acute care beds (Bodel & Taylor, 2007).

- Currently existing hospice beds in Ontario (funded by MOHLTC) - 156
- Beds in construction or planning (with approved MOHLTC funding) - 127
- Total – 283 beds
- Required – 867 beds (based on Fraser Health ratios)

It is important to note that in Ontario, operating funding for Ontario's freestanding hospices was intended to cover direct service costs of the clinical staff. However experience thus far has indicated that funding does not completely cover for direct care provision with a shortfall of approximately \$37,000 per Hospice bed per year. All costs for administrative and other support staff are offset by fundraising and other local activities.

- Annual cost of a 10-bed residential hospice: \$1,600,000
- Current MOHLTC funding level of 10-bed residential hospice: \$580,000
- Required MOHLTC funding level for a 10-bed residential hospice: \$1,280,000

### ***Regional Cancer Centres***

Since 2005 CCO's provincial cancer control strategy has emphasized the need to improve the coordination and delivery of palliative care across the province and the need to improve the patient experience across the cancer journey. Regional Cancer programs play a significant role in the delivery of palliative care services to patients with cancer. A report released by CCO (2009) provides recommendations for regional models of care for palliative cancer patients and recommendations for the organization and delivery of palliative cancer care in Ontario. Since 2007, CCO has worked with the Regional Cancer Programs and community partners to implement common screening tools, algorithms and symptom guides to practice to improve the care of the palliative patient and decrease the number of people requiring care in emergency departments and admission to hospitals.

### ***Community Care Access Centre (CCAC) and Community Service Provider Agencies (CSPA) – Care in the Home***

There is a significant body of evidence indicating the importance of hospice palliative care in the home. Results from a recent Ontario specific study, (which used administrative data of provincial service use for adult CCAC end-of-life care clients admitted from April 1, 2005 to December 31, 2006 who died before March 31, 2007) show specific positive outcomes. Impacts of CCAC services on outcomes include the following:

- CCAC end-of-life care clients who received greater than 3 hours / week of nursing were less likely to be hospitalized or visit the ER in the last 2 weeks of life
- Hospitalizations and ER visits were halved for clients receiving more than 7 hours / week of nursing; their likelihood of dying in hospital was also halved
- Only those end-of-life care clients with greater than 7 PSW hours / week showed a significant reduction in hospitalization (40%) and ER visits (25%) in the last 2 weeks, and avoided death in hospital (50%)

- Clients referred more than a month before their death showed reduced odds of bad outcomes for any of the three outcomes; reductions were bigger the earlier referrals were made.

In summary, to avoid hospitalizations and ER visits in the last 2 weeks of life and to avoid dying in a hospital, the number of hours of home care service used makes a difference as does early referral (Seow, 2008).

The volume code used in this report to assess hospice palliative care provision in the home is MIS code 95 - End of Life. For patients coded MIS 95, the goal is to alleviate symptoms, reduce pain and provide support for client's in the last stages of their illness with high need for medical support. These are individuals whose health condition is not responsive to curative treatment and who are dying. Care is time limited, usually less than 6 months.

MIS code 95 is one of the CCAC client classifications. Two other classifications are: Maintenance and Long Term Supportive. Clients in these last two categories are often living with chronic diseases and frequently it is difficult to determine when a client actually has become End of Life vs. Maintenance or Long Term Supportive. This is especially so for clients living with diagnosis related to cardiac, respiratory and diabetic entities. These clients experience exacerbations of their disease resulting in acute interventions / changes in medical regimes which provide them with more time living with the disease. This exacerbation/remission course of the disease process makes estimation of length of life difficult to determine. Therefore by using only the MIS 95 data we may be missing a number of palliative care clients.

### ***Outpatient Palliative Care Clinics***

Clinics are a typical service offered in integrated hospice palliative programs and are seen as an efficient means of providing consultation and follow-up care for community patients who are mobile and well enough to travel. Typically these clinics are staffed by a physician and nurse team, with access to a wider interdisciplinary team. Clinics may be consultation only or consultation and follow-up or consultation and ongoing care (Most Responsible Physician - MRP). Clinic sites vary. Often these clinics are located at a Cancer Centre (refer to discussion above) or hospital facility with diagnostic testing and other services on site (Capital Health Community Care Services, 2006). Clinics may also be offered in community based settings. Support and funding for these clinics is variable. Currently, no provincial volume benchmarking is available.

### ***Interdisciplinary Consultation Outreach Teams***

CHPCA states "...interdisciplinary teams of secondary hospice palliative care experts must be readily accessible in every setting where patient and families receive care" (2002). Key features of a team often include a systematic and timely identification of end-of-life patients, needs assessments, symptom and psychosocial support interventions, regular communication between team members, and coordinated care guided by outcome-based assessment in the home. In addition, educational initiatives were provided to enhance family physicians' knowledge and skills (Marshall, Howell, Brazil, Howard, & Taniguchi, 2008).

Research demonstrates that family physicians can and will provide ongoing care to their palliative care patients and families if supported through an integrated and collaborative model of shared, inter-professional, specialist palliative care consultation (Marshall, Howell, Brazil, Howard, & Taniguchi, 2008). Where teams exist participants reported improved communication, effective inter-professional collaboration, and the capacity to deliver palliative home care, 24 hours a day, 7 days a week, to end-of-life patients in the community.

The model has great relevance to the primary health care transformation agenda, as it focuses on building and enhancing the capacity of family physicians to deliver effective primary palliative care and supports integrated inter-professional teams. That backlog of people, who could die at home but can't because there's nobody to care for them there, is also contributing to a shortage of hospital beds. That, in turn, causes cancelled surgeries and long waits in emergency rooms (Pereira & Cantin, 2010)

High-quality EOL care in Canada is achievable with this community based inter-professional team approach to provide palliative care, however sustainability of such models hinges on changes in policy and funding that will allow for partnerships customized at the community level (see Appendix F).

Currently there is no Ontario formula to determine recommended numbers of interdisciplinary teams per population. Hamilton Niagara Haldimand Brant Hospice Palliative Care Network projects the need for interdisciplinary teams using a population-based approach based on:

- Current Population/Population Projection;
- Population aged 50+;
- Total need for palliative/end of life care (i.e., total projected cancer deaths + 20% for other);(Romanow, 2002)
- Estimated 67% utilization rate for services; (Romanow, 2002)
- Estimated Average Case Load of 60 patients with an ALOS 60 Days
- Approximately 365 patients per year for 1 team

***“If we know how to provide integrated hospice palliative care and we know it increases patient quality of life and satisfaction, and reduces costs, why are the practices not more widespread?” (CHPCA 2010)***

*(Note: Much of the discussion under this section titled ‘Population Based Planning (PBP) for Hospice Palliative Care’ is adapted from work done by the Erie St. Clair End of Life Care Network (ESC EOLCN 2008).*

## **Summary of Primary Recommendations**

An abundance of work is needed in hospice palliative care in the province of Ontario to simply catch up with other provinces in Canada that are now exceeding Ontario in this regard, noteworthy examples are British Columbia, Alberta and Manitoba. Like other provinces and countries, we too need to ensure that we are prepared for the upcoming health care tsunami that will occur with our growing aging population. This report, which is a culmination of work over the last year to align provincial partnerships in a consensus approach, represents a strong move forward for hospice palliative care. There is a tremendous interest, willingness and new found optimism among many stakeholders to continue this momentum of growing collaboration towards a more integrated HPC system. The following four primary recommendations are extremely broad in nature and must be considered in part with the detail action steps that the Coalition has come in unity to describe in depth.

### **Recommendation #1**

Develop a provincial vision and principles for hospice palliative care to enable Local Health Integration Networks, Service Providers and community groups a basis for planning exemplary hospice palliative care services throughout Ontario.

### **Recommendation #2**

Develop and implement an integrated hospice palliative care system-wide policy for the province of Ontario that supports the vision and principles.

### **Recommendation #3**

Adopt and implement a fully Integrated Hospice Palliative Care Service Delivery System for Ontario based on the provincial vision, policy and Hospice Palliative Care System Design Framework.

### **Recommendation #4**

Provide strategic investments to enhance, build and sustain an integrated system of quality, safe, coordinated and comprehensive hospice palliative care services.

## Conclusion

People in Ontario expect to receive quality care as they face a life-limiting illness. The availability and accessibility of high quality hospice palliative care at the end of one's life must be as essential and natural as obstetric care is at the beginning of one's life. The new legislation entitled the *Excellent Care for All Act* (2010) puts all patients first by improving the quality and value of the patient experience through the application of evidence-based health care. Hospice palliative care provides that evidence-based care, ensuring quality, patient/client/caregiver satisfaction, and the efficient and effective use of resources within a holistic interdisciplinary approach.

A well-developed program of Hospice Palliative Care is required in all care settings where patients die (CHPCA 2002, PEOLCN 2010) (*See Appendix J*). These care settings include acute care, complex continuing care, long term care, residential hospices as well as care in the patients' home. With exemplary HPC programs across the continuum, expensive acute care utilization can be reduced. When generalist practitioners in the community are adequately supported by coordinated systems of care, access to expert advice in palliative care, and mentorship opportunities the outcome is better care coordination across care settings, and the alleviation of crisis interventions thus reducing emergency department visits and hospital admissions. In addition, volunteers may be able to provide many services at little or no cost, such as friendly visits, meal preparation and running errands.

The current health care system costs are not sustainable. A transformation of how we provide care must urgently take place to ensure that we are meeting the needs of an ever expanding aging population. The cost of doing nothing in hospice palliative care is not an option. An integrated hospice palliative care system is not only a moral imperative it is an unavoidable obligation that must be provided because it is the right and decent thing to do as a civil society.

Apart from the moral imperative of relieving suffering and improving the quality of living and dying for those with progressive, life-threatening conditions, there are solid pragmatic reasons for the Ontario government to strengthen hospice palliative care. The prevailing practice of providing aggressive medical treatment in acute care settings until one's death not only results in poor quality of life for patients, it significantly increases the likelihood of major depression, poor health and even premature death for caregivers.

Emerging literature has shown that effective hospice palliative care saves money. It provides highly-skilled, compassionate service at a fraction of the cost, while allowing more individuals to receive care in the setting of their choice. The costs for enhancements to hospice palliative care are modest compared to the costs of inappropriate care and fragmented service systems.

The need to move swiftly to implement quality hospice palliative care strategies, systems and services is essential, given the aging population in Ontario, and the immediate and imminent demands on the health care system from those suffering from progressive life-limiting conditions like cancer, heart failure and dementia. The present system is ill-prepared to deal with what is to come.

This report provides recommendations for action to create an integrated hospice palliative care system in Ontario. The Ministry of Health and Long-Term Care has a historic opportunity to work collaboratively with the Local Health Integration Networks, the End-of-Life/Hospice Palliative Care Networks and the Quality Hospice Palliative Care Coalition of Ontario to ensure that all Ontarians have the right to die with dignity, to have access to services they need, and to be granted the respect consistent with other natural phases of life.

We will all die one day – this is inevitable. We need to create the required changes now that will ensure that HPC will be there for all who need it.

## Plan for Action Strategies

This Plan for Action Strategy offers a transitioning plan to the integrated hospice palliative care service delivery model. It rates the recommendations and action steps by the greatest impact with regard to patient and system outcomes; practical and achievable timelines; and those that will not cost the system any additional resources versus those that would require additional investment. It is interesting to note that of the 49 recommended actions, 26 or 53% can be achieved with no new investments required, which have been highlighted in green. The majority of these recommendations also have high outcome impact and can be achieved in the short term. Attention to these particular recommendations is not intended to negate the importance of the other recommendations, but purely to point out some straightforward launching points with which to start.

### **Legend:**

**Outcome Impact:** Patient care and system performance

**Timelines:**       Short Range – Within One year  
                      Mid-Range – Two to Three years  
                      Long Range – Four to Five years

**Strategic Investment:** None –       No new investments required  
  Realignment – Shifting of existing resources  
  Minimum – New investment less than \$1 million  
  Considerable - New investment greater than \$1 million

**Initial Leverage Opportunities:**   CCO – Cancer Care Ontario  
  CHPCA - Canadian Hospice Palliative Care Association  
  CIHR – Canadian Institute for Health Research  
  HAO/OPCA - Hospice Association of Ontario/Ontario Palliative Care Association  
  HPC Networks – Hospice Palliative Care Networks  
  ICCP-HPC – Integrated Client Care Project – Hospice Palliative Care  
  LHINS – Local Health Integration Networks  
  OACCAC – Ontario Association of Community Care Access Centres  
  OCFP – Ontario College of Family Physicians  
  OHA - Ontario Hospice Association  
  OHCA – Ontario Home Care Association  
  OHQC – Ontario Health Quality Council  
  OHPCL – Ontario Hospice Palliative Care Lead (\*New Appointment)  
  OLTCA – Ontario Long Term Care Association  
  OMOHLTC – Ontario Ministry of Health and Long-Term Care  
  PEOLCN – Provincial End-of-Life Care Network  
  QEOLCCC – Quality End of Life Care Coalition of Canada  
  QHPCCO – Quality Hospice Palliative Care Coalition of Ontario  
  SHRTN – Seniors Health Research Transfer Network  
  OMA – Ontario Medical Association  
  OCFPS – Ontario College of Family Physicians and Surgeons

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
<b>#1. Develop a provincial vision and principles for hospice palliative care to enable Local Health Integration Networks, Service Providers and community groups a basis for planning exemplary hospice palliative care services throughout Ontario.</b>				
A. Articulate the future desire for equitable access to a choice of safe, comprehensive and quality hospice palliative care services for individuals and families across Ontario who can benefit from them.	High	Short	None	QHPCCO
B. Model the National vision that all Canadians have access to quality end-of-life care	High	Short	None	CHPCA
C. Model the Charter for End-of-Life Care in Ontario that was created collaboratively during a 2004 province-wide consultation to develop a provincial strategy for end-of-life care.	High	Short	None	HAO/OPCA
<b>#2. Develop and implement an integrated hospice palliative care system-wide policy for the province of Ontario that supports the vision and principles.</b>				
A. Articulate the urgency and necessity to develop and maintain equitable access to a choice of safe, comprehensive and quality hospice palliative care services for individuals and families across Ontario who can benefit from them.	High	Short	None	QHPCCO
B. The policy endorses the implementation of the provincial Hospice Palliative Care System Design Framework, which	High	Short	None	QHPCCO

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
outline an integrated systems approach at the provincial level that will respond to rapidly changing future demand for services and unmet need.				
C. Designate within the Ministry of Health and Long-Term Care a Hospice Palliative Care Lead, with accompanying resources, responsible for supporting and monitoring the implementation of the provincial hospice palliative care policy. This centralized planning of services will ensure seamless and border-free access to quality HPC across Ontario.	High	Short	Minimum	OHPCL*
D. Provide immediate direction on the regional prioritization of HPC at the LHIN level.	High	Short	None	LHINS HPC Networks
E. Formulate central provincial program and service volumes to meet current and future demand in the next 25 years in all hospice palliative care settings (including acute care, complex continuing care, long-term care homes, in-home services through CCAC, and hospice programs).	High	Short	None	QHPCCO
F. Establish clear accountability at the provincial level, which includes a mechanism for monitoring LHIN wide progress towards these policy goals.	High	Short	None	OHPCL*
<b>#3. Adopt and implement a fully Integrated Hospice Palliative Care Service Delivery System for Ontario based on the provincial vision, policy and Hospice Palliative Care System Design Framework.</b>				
A. The system urgently incorporates the elements as described	High	Short –	Considerable	QHPCCO

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
in the Hospice Palliative Care System Design Framework.		Long		ICCP-HPC CCO
B. The Ministry designates the Quality Hospice Palliative Care Coalition of Ontario as the provincial expert in HPC responsible for working in conjunction with the Hospice Palliative Care Lead to identify and obtain the required expertise to finalize the integrated HPC service delivery model.	High	Short	Minimum	QHPCCO OHPCL*
C. All LHINs have a local hospice palliative care plan that works towards the provincial Hospice Palliative Care Service Delivery System Design. Accountability is defined on a system basis rather than a sector basis in each LHIN area. Set province-wide requirements that all LHINs must meet in their plans. Based on local readiness and capacity, the provincial Hospice Palliative Care Lead works with each LHIN to negotiate minimum deliverables and timelines that each must meet in their plans. The LHINs are a necessary and required partner in the local HPC Network.	High	Short	None	LHINS HPC Networks ICCP-HPC
D. The Ministry recognizes the HPC Networks as the local HPC experts with representation from across the continuum of care and designates them as the official advisory body informing and guiding the LHINs on a wide range of projects, programs and services related to HPC. The Networks are deemed as a regional resource to the Hospice Palliative Care Lead and the Coalition. As a collaborative governance structure, they take	High	Short	None	HPC Networks LHINS OHPCL*

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
the lead on developing the local HPC plans with the LHINs, as well as facilitating and monitoring their implementation.				
E. Based on expert advice in hospice palliative care and performance measurement (from the Quality Hospice Palliative Care Coalition of Ontario and the Ontario Health Quality Council), provide provincial direction for consistent collection of data, system level outcomes and performance indicators that can be uniformly tracked (consistent with the Ontario Health Reporting Standards), and analysis of information about services, which will support rigorous system-level reporting on the provision of hospice palliative care in Ontario	High	Short-Mid	None	QHPCCO OHQC
F. Organizations and clinical service leadership teams in all settings report to their LHINs on the hospice palliative services provided to their patients / clients / residents according to the standard provincial key indicators. Review accountability agreements at each LHIN to ensure a consistent and optimum approach to system relationships regarding effective service provision.	High	Mid	None	LHINS
G. HPC Networks in each LHIN area is charged with the lead role in analyzing and monitoring local data and submitting monthly statistics to Hospice Palliative Care Lead, the LHIN and others where appropriate. Facilitate Network's access to existing provincial databases.	High	Mid	None	HPC Networks OHPCL*

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
<p>H. The Ministry of Health and Long-Term Care Hospice Palliative Care Lead is responsible for:</p> <ul style="list-style-type: none"> <li>vii. Finalizing the integrated service delivery model</li> <li>viii. Supporting the LHINs and the Networks in overseeing the development and implementation of their local hospice palliative care plans</li> <li>ix. Supporting and monitoring the implementation of the provincial hospice palliative care service delivery system.</li> <li>x. Reviewing hospice palliative care plans and statistics from each LHIN area, and periodically monitoring their progress towards the provincial system design, and ensuring that quality, integrated services are more evenly and equitably available across the province.</li> <li>xi. Bringing together the different parts of government working on related issues to ensure their coordination and consistency throughout the province.</li> <li>xii. Facilitating the resolution of common provincial issues to maximize continuity and avoid duplication</li> </ul>	High	Short-Mid	None	OHPCL*
<p>I. The Quality Hospice Palliative Care Coalition of Ontario is responsible for informing and advising the Hospice Palliative Care Lead and the Networks on a wide range of province-wide projects and initiatives regarding HPC, such as the Integrated Client Care Project.</p> <ul style="list-style-type: none"> <li>i. Commission the Quality Hospice Palliative Care</li> </ul>	High	Short-Mid	Minimum	QHPCCO OHPCL*

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
<p>Coalition of Ontario to produce a public report on hospice palliative care resources using a population-based approach on a LHIN-by-LHIN basis.</p> <p>ii. Charge the Coalition with updating the provincial system design as new and innovative evidence based practices are developed.</p> <p>iii. Fund a Coalition Coordinator to manage the work of the Coalition</p>				
<p>J. Consistent provincial implementation of best practice hospice palliative care standards are used for hospitals, long-term care facilities, home care programs, shared care teams, specialist palliative care consultation services, residential hospices, and community volunteer programs based on the work of Accreditation Canada, the Hospice Association of Ontario's accreditation for community volunteer programs and community residential hospices, the Pan-Canadian Standard for Palliative Home Care (Canadian Healthcare Association, 2006), the New Directions for Facility-Based Long-Term-Care (Canadian Healthcare Association, 2009), Canadian Hospice Palliative Care Association Norms of Practice (CHPCA, 2002), and the Canadian Hospice Palliative Care Association's Paediatric Standards (CHPCA, 2006) to ensure consistent, safe, and appropriate care at all times.</p>	High	Short-Mid	None	OHPCL* LHINS HPC Networks
<p>K. Services are not just for individuals in the final months of life. Emphasize the need for better, coordinated care planning</p>	High	Short-Mid	Realignment	LHINS HPC Networks

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
<p>along the entire disease trajectory. Integrate hospice palliative care strategies with chronic disease management strategies. Extend services to individuals with progressive life-threatening illnesses other than cancer for whom hospice palliative care is not easily accessible, with the understanding that doing so will contain costs and improve quality of care in the long-run.</p>				<p>OACCAC OCFP ICCP-HPC</p>
<b>#4. Provide strategic investments to enhance, build and sustain an integrated system of quality, safe, coordinated and comprehensive hospice palliative care services.</b>				
<b>Program Strategic Investments</b>				
<p>A. Fund the creation and expansion of inter-professional teams across the province as a means of building palliative care community capacity within primary care. When generalist practitioners in the community are adequately supported by coordinated systems of care, access to expert advice in palliative care, and mentorship opportunities the outcome is better care coordination across treatment settings, and the alleviation of crisis interventions thus reducing emergency department visits and hospital admissions.</p>	High	Short-Mid	Considerable	ICCP-HPC
<p>B. Expand the Alternative Payment Plan for the development of additional expert Palliative Care Physicians. Optimize their role by integrating them within inter-professional teams. This approach is also recommended by the Ontario College of Family as a means to facilitate, engage, support and expand primary care physicians' roles in HPC. Ensure provincial consistency and access to these important HPC resources.</p>	High	Short-Mid	Considerable	<p>OMOHLTC OMA OCFPS</p>

<b>Recommendations</b>	<b>Outcome Impact (high, medium, low)</b>	<b>Timeline (Short, Mid, Long Range)</b>	<b>Cost (None, Minimum, Considerable)</b>	<b>Initial Leverage Opportunities and Partnerships with MOHLTC</b>
C. Fund 80% of the operating costs of residential hospices.	High	Short	Considerable	HAO
D. Review the adequacy of funding for palliative care services in hospitals.	High	Short-Mid	None	OHA
E. Provide effective and sustained supports for informal caregivers, including more respite and bereavement services	High	Mid	Considerable	HAO
F. Expand home care nursing and home support availability over the 24 hour period, seven days a week based on client need.	High	Mid	Considerable	OACCAC
G. Embark on a sustained quality improvement program, supported by dedicated funding, to ensure that hospice palliative care services are working effectively in long-term care homes across Ontario.	High	Mid	Considerable	OHQC
H. Enable access to specialized quality hospice palliative care services and expertise from other care settings within long-term care homes, including interdisciplinary teams. This would build core competencies among long-term care home staff.	High	Short	None	OACCAC OLTCA
I. Build community capacity by protecting, designating, and equitably and adequately funding existing community-based hospice palliative care programs, such as <ul style="list-style-type: none"> <li>a. Palliative Pain &amp; Symptom Management Consultation Service</li> <li>b. Facility and Community Interdisciplinary HPC</li> </ul>	High	Mid	Minimum	OMOHLTC

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
Education Service c. Physician Education d. Hospice Volunteer Services				
J. Support work with diverse cultural and social communities to develop approaches that are responsive to their needs, particularly French Language Services and Aboriginal communities with unique and distinct traditions for end-of-life care. Ensure that local Networks include and engage these communities in the development of their local LHIN area Hospice Palliative Care plans.	High	Short	None	HPC Networks LHINS
<b>Infrastructure Strategic Investments:</b>				
A. Define clear, consistent accountability relationships between LHINs, the Ministry's designated lead and other Ministry departments with respect to the implementation of hospice palliative care policies.	High	Short	None	OMOHLTC
B. Define clear, consistent accountability relationships that support integrated systems of quality hospice palliative care services between LHINs and their respective Hospice Palliative Care Networks.	High	Short	None	OMOHLTC
C. Re-establish a funding mechanism for the Hospice Palliative Care Networks that ensures that they are sustainable and able to deliver on their mandate of helping to ensure the delivery of quality HPC across the continuum of care, in keeping with the new provincial HPC policy and system design framework.	High	Short	Minimum	OMOHLTC

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
D. Recognize the primary mandate of the Quality Hospice Palliative Care Coalition of Ontario is to act as a provincial advocate body for quality hospice palliative care for all Ontarians, working in alignment with The Canadian Hospice Palliative Care Association, the Quality End-of-Life Care Coalition of Canada, and other provincial hospice palliative care coalitions across Canada.	High	Short	None	OMOHLTC
E. As a well-connected expert provincial resource in HPC, the provincial Hospice Palliative Care Lead should continue to work with the Quality Hospice Palliative Care Coalition of Ontario to define essential hospice palliative care services based on the System Design Framework, and the work of the Canadian Hospice Palliative Care Association.	High	Short	None	OHPCL* QHPCCO
F. Recognize the Provincial End-of-Life Care Network as the interim secretariat for the Quality Hospice Palliative Care Coalition of Ontario until such time as the Hospice Association of Ontario and the Ontario Palliative Care Association take on this role as a single merged organization.	High	Short	None	PEOLCN
G. Resource the Seniors Health Research Transfer Network's hospice palliative care Community of Practice and the Community of Practice for Health Care Consent to broaden its membership and agree on provincial best practices in health care consent and advance care planning. Support projects to introduce these practices into a variety of care settings across the province.	High	Short	Minimum	SHRTN

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
H. Define the accountabilities and communication channels between the Hospice Palliative Care Lead and the: a) Provincial End-of-Life/Hospice Palliative Care Network b) Quality Hospice Palliative Care Coalition of Ontario	High	Short	None	OHPCL* PEOLCN QHPCCO
<b>Technological Strategic Investments:</b>				
A. Evaluate current efforts, such as eShift (South West CCAC), to introduce technology to support the implementation of best practices in the community and make clinical information readily available to health care providers in real-time.	High	Short	Minimum	SWCCAC
B. Pilot and implement a Shared Electronic Health Record within the HPC system with full interdisciplinary team record access to maximize the effective coordination of patient shared care plans.	High	Mid	Considerable	OMOHLTC
<b>Health Human Resource Strategic Investments:</b>				
A. Develop, adopt and implement a human resource and capacity-building strategy for hospice palliative care. Base health human resource needs in hospice palliative care on the system design framework and the concept of three levels of expertise (primary, secondary, and tertiary)	High	Mid-Long	Considerable	OMOHLTC OHPCL* QHPCCO
B. Establish core competencies in various settings and levels of expertise in conjunction with experts within each profession.	High	Mid-Long	None	Professional Regulatory Colleges
C. Build capacity by developing a recruitment and retention strategy for all disciplines (regulated and un-regulated)	High	Mid-Long	None	OMOHLTC QHPCCO

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
involved in HPC. Include spiritual care specialists and volunteers in the plan.				HPC Networks
<b>Educational Strategic Investments:</b>				
A. Endorse and implement a provincial hospice palliative care education strategy that is evidence-based and draws on already developed curricula being used in the field. Consult with the Quality Hospice Palliative Care Coalition of Ontario to identify these best practices.	High	Short-Mid	Minimum	QHPCCO
B. Expand fellowships, the creation of subspecialties and other educational opportunities for the development of additional Expert Palliative Care Physicians and Community Hospice Palliative Care Resource Physicians and other disciplines.	High	Mid-Long	Considerable	OMOHLTC Ministry of Education
C. Heighten public awareness of HPC by providing special grants to the HPC Provincial Association, for example the funding of a provincial Advance Care Planning Campaign collaborating with potential federal initiatives; defining public HPC information needs, and identifying and promoting existing effective information resources.	High	Short-Mid	Considerable	HAO/OPCA QHPCCO CHPCA QEOLCCC
<b>Research Strategic Investments:</b>				
A. Although significant progress has been made in palliative care research since 2005, much more is still required in every aspect of the hospice palliative care field. The <i>Raising the Bar</i> report identifies several key elements that would greatly enhanced through further research evidence. Invest in	High	Short-Long	Considerable	CIHR OHQC

Recommendations	Outcome Impact (high, medium, low)	Timeline (Short, Mid, Long Range)	Cost (None, Minimum, Considerable)	Initial Leverage Opportunities and Partnerships with MOHLTC
<p>research to advance knowledge in:</p> <ul style="list-style-type: none"> <li>viii. the socio-economic benefits of palliative care;</li> <li>ix. quality indicators;</li> <li>x. common data collection methods;</li> <li>xi. how to best meet the needs of caregivers;</li> <li>xii. use of technology in providing care;</li> <li>xiii. inter-professional educational curricula; and</li> <li>xiv. differing health service configurations and models such as shared care and more comprehensive integrated care delivery models early in the disease trajectory.</li> </ul>				
<p>B. Invest in research to evaluate the ability and effectiveness of Hospice Palliative Care Networks as a community capacity builder to increase hospice palliative care integration and systemic improvement.</p>	High	Short-Long	Minimum	OMOHLTC QHPCCO HPC Networks
<p>C. Ensure knowledge translation is an integral part of all research studies to successfully integrate research into practice. Find effective ways to communicate and provide education, such as mentoring and academic detailing, across the continuum of care to improve best practice hospice palliative care and create sustainable systemic changes and cultural shifts.</p>	High	Short-Long	Minimum	QHPCCO HPC Networks SHRTN

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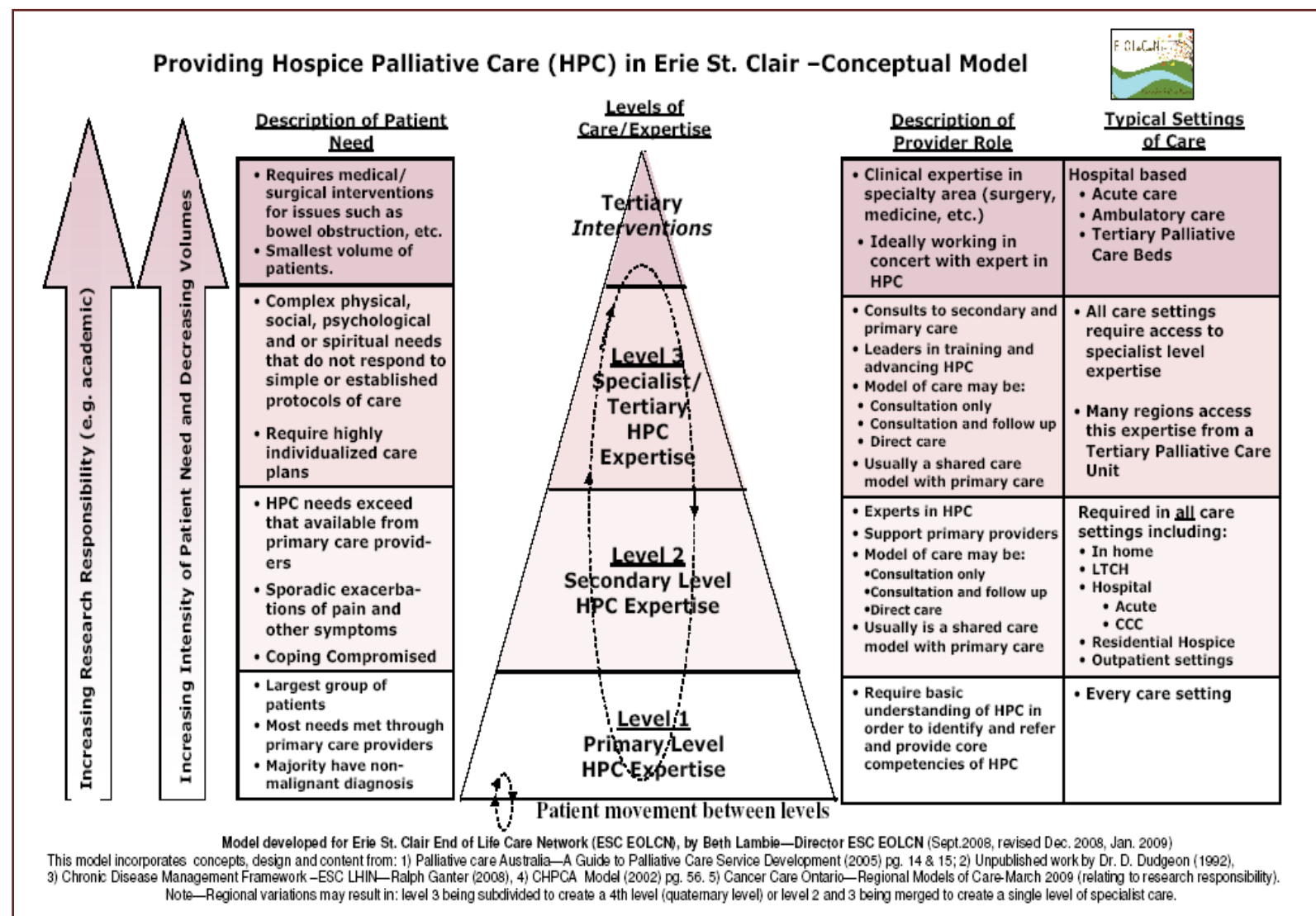
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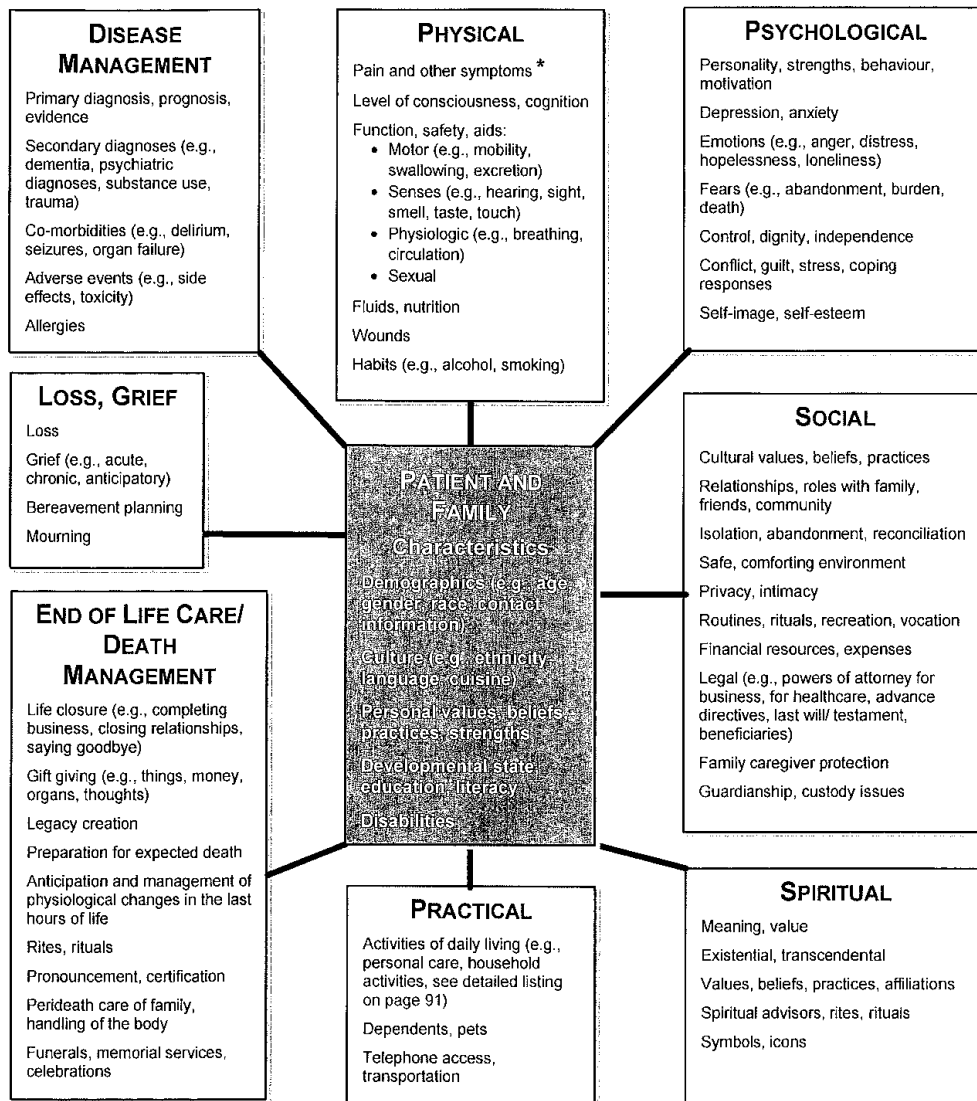
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## Appendix A: Conceptual Model





## Appendix B: Domains of Care



\* Other common symptoms include, but are not limited to:

**Cardio-respiratory:** breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

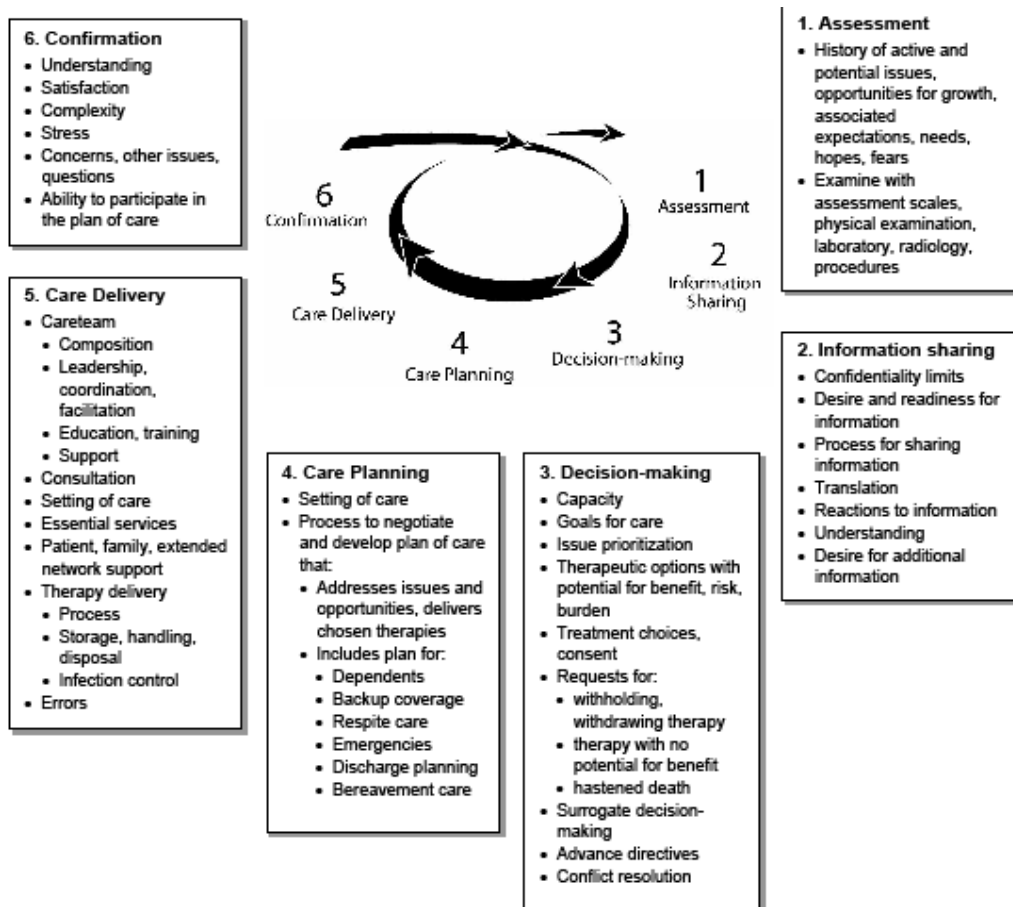
**Gastrointestinal:** nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

**Oral conditions:** dry mouth, mucositis

**Skin conditions:** dry skin, nodules, pruritus, rashes

**General:** agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

## Appendix C: Process for Providing Care



## Appendix D: End Stages of Life

### Objective Criteria to assist in identifying the end stages of life

End-Stage Pulmonary Disease	<ul style="list-style-type: none"><li>• Disabling dyspnea at rest (FEV1 &lt; 30% predicted)</li><li>• Increasing hospitalizations for COPD/infection.</li><li>• Hypoxemia (pO<sub>2</sub> &lt; 55) on room air.</li><li>• Hypercapnea (pCO<sub>2</sub> &gt;50%).</li><li>• Cor pulmonale and right heart failure secondary to pulmonary disease.</li><li>• Progressive weight loss greater than 10% total weight over last six months.</li><li>• Resting tachycardia &gt;100/mi</li></ul>
End-Stage Heart Disease	<ul style="list-style-type: none"><li>• NYHA Stage 1V: signs of CHF at rest.</li><li>• Already optimally treated with recommended cardiac medications</li><li>• Ejection fraction of 20% or less on ECHO.</li><li>• Symptomatic ventricular and supraventricular arrhythmias.</li><li>• History of cardiac arrest.</li><li>• Embolic CVA</li></ul>
End-Stage Renal Disease	<ul style="list-style-type: none"><li>• Chronic renal failure; coming off or not a candidate for dialysis</li><li>• Creatinine clearance &lt;15cc/min</li><li>• Signs and symptoms associated with renal failure;<ul style="list-style-type: none"><li>○ Uremia, oliguria, intractable hyperkalemia, intractable fluid overload</li></ul></li><li>• Mechanical ventilation, malignancy, chronic lung disease, advanced cardiac or liver disease, sepsis</li><li>• Cachexia or albumin &lt;35</li></ul>
End-Stage Liver Disease	<ul style="list-style-type: none"><li>• End stage cirrhosis; not candidate for liver transplantation</li><li>• INR &gt; 1.5 and serum albumin &lt;25</li><li>• Ascites despite treatment</li><li>• Spontaneous peritonitis</li><li>• Hepatorenal syndrome</li><li>• Hepatic encephalopathy despite tx</li><li>• Recurrent variceal bleed</li><li>• Progressive malnutrition, muscle wasting, continued alcoholism</li></ul>
End-Stage Dementia	<ul style="list-style-type: none"><li>• Unable to walk, dress, bathe without assistance</li><li>• Urinary and fecal incontinence</li><li>• Severe comorbid condition within past 6/12;<ul style="list-style-type: none"><li>○ Aspiration pneumonia, pyelonephritis, septicemia, decubitus ulcers, fever after abx</li></ul></li><li>• Unable to maintain fluid/caloric intake to sustain life</li><li>• If on feeding tube;<ul style="list-style-type: none"><li>○ Wt loss &gt;10% in 6/12</li><li>○ Serum albumin &lt;25</li></ul></li></ul>



## Appendix E: A FRAMEWORK FOR UNDERSTANDING THE CONSULTATION ROLE BY PALLIATIVE CARE SPECIALISTS (©Pereira, Cantin 2010)

The following is a framework to understand the consultation/shared care role, based on early research conducted by Pereira and Cantin.



	Consultation Model		Shared Care Model			Substitution Model
Palliative Care Specialist (PCS) involvement	Limited Consultation (CL)	Broader Consultation (CB)	Shared tending to Consultation (S-C)	Shared Equal (SE)	Shared tending to Substitution (S-S)	Substitution (Sub)
Scope of intervention by PCS	Limited to one or a few problems, provides recommendations to MRP; may sometimes initiate treatment	PCS explores all the palliative needs of the patient, makes recommendations to MRP	PCS explores all the palliative needs of the patient	PCS manages all the palliative needs of the patient	PCS manages all the palliative care needs of the patient as well as some other health issues (e.g. hypertension medication)	PCS takes care of all aspects of care, not only palliative care related ones
Prescribing and orders	Seldom if at all provides repeat prescriptions or orders	Orders or prescribes treatments only until situation stable and then withdraws.	Continues to order or prescribe treatment related to palliative care needs	Continues to order or prescribe only treatments related to palliative care	Provides most of the follow-up orders and prescriptions for the patient	Provides all the follow-up orders and prescriptions for the patient
Final decision-making	Most Responsible Physician (MRP)	MRP	Shared by PCS & MRP, but largely delegated to MRP	Shared equally between MRP & PCS	Shared by PCS & MRP, but largely delegated to PCS	PCS
Extent of visits by PCS	Limited number of visits, usually only one	Continues visiting until situation stable & then withdraws	Regular ongoing visits, plus regular visits by MRP (may or may not be jointly with PCS)	Regular ongoing visits, plus regular visits by MRP (may or may not be jointly with PCS)	Regular ongoing visits. Occasional visits by MRP	Regular ongoing visits. MRP seldom if at all visits

This model proposes the following:

- The consultation role, including the “shared care role”, is not a homogenous concept. The roles are represented across the continuum, with a limited consultation at one end of the spectrum, and substitution (where the “consultant” or person providing “shared care” takes over all the care and responsibilities of the primary attending physician and in essence becomes the most responsible physician or nurse or team (MRP)
- There is a thin line between practicing in one model and practicing in the next along the spectrum. Some teams use different modes, depending on the circumstances, while others stay closer to one model.



**Appendix F: Canadian Institute for Health Information, *Coding Standards for Version 2009 ICD-10-CA and CCI, Revised September 2009* (Ottawa, Ont.: CIHI, 2009).**

Released: February 2009  
Revised: September 2009

**Acute Care Coding for Palliative Care**

The metrics used to gain insight into acute care Palliative Care (PC) volumes are based on the Z51.5 code as defined by CIHI. (See attached excerpt).

It is generally agreed that the numbers of patients requiring palliative care are significantly higher than what is generally captured by hospitals in the Z51.5 code. During the validation process of the HSMR review, several hospitals across Canada identified challenges with palliative care coding. Based on this feedback, CIHI issued an interim guideline for the coding of palliative care services in June 2006. In response to concerns of ambiguity in relationship to chart documentation of “terminal illness”, CIHI issued a further clarification in October 2007, to be used for fiscal year 2007-2008. A footnote in the HSMR report states “A national coding standard will be implemented in 2008”.

Although this national coding standard has been implemented the consistency of application of this continues to be a matter for concern.

We believe that, in Ontario, attention needs to be given to encouraging consistent application of the Z51.5 code. Without this, we have no reliable baseline from which to measure improvements in hospital utilization, or from which to make any valid assumptions or statements related to Palliative care in acute care hospitals. This “attention” need not be an expensive undertaking. For example, even a one day case based seminar emphasizing consistent Z51.5 coding, with hospital health records personnel from each hospital in Ontario), would go a long way towards insuring consistency.

■ **Excerpt from “Canadian Coding Standards” – Version 2009 – pg 308-313**

**Palliative Care**

*In effect 2008, amended 2009*

Palliative care is part of the continuum of patient care, not necessarily a formal organizational designation.

Documentation to support coding palliative care may include:

- Palliative care consultation with initiation of a palliative care treatment plan, or
- Physician documentation such as “palliative patient, palliative situation, end of life care, comfort care, supportive care, or compassionate care.”

Palliative patients typically fall into one of the following three categories:

**Known palliative patient admitted for the sole purpose of palliative care**

- No life sustaining/curative treatment for reversible or irreversible (palliative) conditions.

**Known palliative patient admitted for treatment of a reversible condition(s)**

- Life sustaining/curative treatment for reversible (e.g. pneumonia, blood clot, sepsis, electrolyte imbalance, dehydration) but not irreversible conditions.
- It is assumed that palliative care is part of the treatment plan and qualifies as a significant diagnosis type.
- These patients are often expected to go home, however, they may deteriorate and the focus of care may change to that described in the first category above.

**Note:** Assign prefix "8" (palliative care that is documented as a known component of the patient's care plan prior to admission) with Z51.5 *Palliative care*. See Group 10, Field 1 in the Discharge Abstract Database (DAD) Abstracting Manual for specific instructions for applying the prefix.

**Patient not known to be palliative on admission**

- These patients initially receive investigation and/or treatment but are subsequently changed to a palliative care plan.

- ① Assign Z51.5 *Palliative care* as a significant diagnosis type whenever there is physician documentation of palliative care.
- ① When a known palliative patient is admitted to the hospital for the sole purpose of receiving palliative care, assign Z51.5 *Palliative care* as the MRDx:
  - Assign an additional code(s), mandatory, to describe the palliative condition(s).
- ① When a known palliative care patient is admitted for treatment of reversible condition(s) assign Z51.5 as a diagnosis type (1), (W), (X), or (Y) and
  - Assign the reversible condition as the MRDx unless palliative care subsequently consumes the majority of the length of stay.
  - Assign an additional code, mandatory, to describe the palliative condition(s).
- ① When a patient who is not known to be palliative at the time of admission and subsequently changes to a palliative care plan:
  - Assign the condition that is investigated or treated as the MRDx, unless palliative care subsequently consumes the majority of the length of stay (i.e. at least 24 hours in short stay admission).

**Notes:**

- Palliative care does not have to be provided in a designated palliative care bed, palliative care unit, or managed by a palliative care team.
- DNR orders alone do not constitute palliative care; there must be documentation of palliative care. While DNR orders are part of a palliative care plan, they may also be present in non-palliative care cases.
- "Pain control" alone does not constitute palliative care. While pain control is part of a palliative care plan, it may also be provided to patients who are not receiving palliative care.
- Acute conditions (e.g. pneumonia or dehydration) may be treated as part of the palliative care treatment plan.

**Example:** A patient was admitted to hospital for end of life care because of amyotrophic lateral sclerosis. On admission an IV was started to maintain hydration. Pain control was monitored and medication adjusted as necessary. The patient died three days after admission.



Prefix	Code	DAD	Code Title
8	Z51.5	(M)	Palliative care
	G12.2	(3)	Motor neuron disease
	Z51.808	(3)	Pain management therapy (for) other and unspecified pain (optional)

**Rationale:** The documentation indicates the patient is admitted for the sole purpose of receiving palliative care. The palliative condition is mandatory to assign and in this case, G12.2 meets the definition of diagnosis type (3). Code assignment for pain control is optional as it is part of the palliative care treatment plan. Prefix "8" is assigned with Z51.5 in this case because palliative care is documented as a known component of the patient's care plan prior to admission.

**Example:** A 68-year-old patient, who is on the Palliative Care Registry due to end-stage COPD, is admitted with pneumonia. The patient is admitted to a palliative care bed and all documentation describes treatment for the pneumonia. The patient's condition improves during the admission and he is discharged home in a satisfactory condition.



Prefix	Code	DAD	Code Title
	J44.0	(M)	Chronic obstructive pulmonary disease with acute lower respiratory infection
	J18.9	(1)	Pneumonia, unspecified
8	Z51.5	(1)	Palliative care

**Rationale:** The documentation indicates the patient is admitted for treatment of pneumonia in COPD, which is classified in the usual manner. Z51.5 is assigned diagnosis type (1) because it is assumed that in the case of a known palliative care patient, palliative care is part of the treatment plan and assigned a significant diagnosis type. Prefix "8" is assigned with Z51.5 in this case because palliative care is documented as a known component of the patient's care plan prior to admission.

**Example:** A patient, who is a known palliative care patient presents for treatment of dehydration. The patient has cancer of the lung with advanced secondary malignancy of the brain. She was admitted to the medical ward to receive hydration therapy and discharged home the following day.



Prefix	Code	DAD	Code Title
	E86.0	(M)	Dehydration
8	Z51.5	(1)	Palliative care
	C34.99	(3)	Malignant neoplasm bronchus or lung, unspecified, unspecified side
	C79.3	(3)	Secondary malignant neoplasm of brain and cerebral meninges

**Rationale:** The documentation indicates this palliative care patient is admitted for the purpose of receiving treatment for dehydration. It is assumed that in the case of a known palliative care patient, palliative care is part of the treatment plan and assigned a significant diagnosis type. Prefix "8" is assigned with Z51.5 in this case because palliative care is documented as a known component of the patient's care plan prior to admission. C34.99 and C79.3 are mandatory to assign to identify the palliative condition and in this example, they meet the definition of diagnosis type (3).

**Example:** A patient with ovarian cancer was receiving palliative care through a community program. She was admitted to hospital on January 4 for IV antibiotics to treat pneumonia. She deteriorated on January 6 and the family was consulted. A decision was made for comfort measures only. She died peacefully on January 10.



Prefix	Code	DAD	Code Title
8	Z51.5	(M)	Palliative care
	J18.9	(1)	Pneumonia, unspecified
	C56.9	(3)	Malignant neoplasm of ovary, not specified whether unilateral or bilateral

**Rationale:** The documentation indicates the patient is admitted for management of an acute reversible condition, however, her condition deteriorated and palliative care is responsible for the greatest length of stay. C56.9 is mandatory to assign to identify the palliative condition and in this example, it meets the definition of diagnosis type (3). Prefix "8" is assigned with Z51.5 in this case because palliative care is documented as a known component of the patient's care plan prior to admission.

**Example:** A patient is admitted for investigation of gastric symptoms. The following day, gastroscopy and biopsy revealed linitis plastica. The physician discussed the prognosis (incurable cancer) with the patient. A DNR order is written and a palliative care consultation is initiated and the treatment plan is changed to palliative care. The patient dies in hospital 20 days following orders of palliative care.



Prefix	Code	DAD	Code Title
	Z51.5	(M)	Palliative care
	C18.9	(1) or (W)	Malignant neoplasm stomach unspecified

**Rationale:** This patient is diagnosed during the admission with an irreversible condition and palliative care became the treatment plan consuming the greatest length of stay and resources. Prefix "8" is NOT assigned in this case because palliative care is not documented as a known component of the patient's care plan prior to admission.

**Example:** A patient is admitted on January 1 for treatment of congestive heart failure. The patient is given medication for the CHF. By January 8, the CHF is worsening and the physician discusses the poor prognosis with the patient and family. The patient agrees to comfort care and all aggressive treatment measures are stopped. The patient wishes to die at home and is therefore discharged home on January 10 with palliative care measures in place.



Prefix	Code	DAD	Code Title
	I50.0	(M)	Congestive heart failure
	Z51.5	(1) or (W)	Palliative care

**Rationale:** Z51.5 *Palliative care* did not meet the definition of MRDx as it did not consume the greatest length of stay and resources. Diagnosis type (1) or (W) is assigned because there was a change in the treatment plan. Prefix "8" is NOT assigned in this case because palliative care is not documented as a known component of the patient's care plan prior to admission.

**Example:** An 84-year-old gentleman was found unresponsive at home on June 8 at 1845. The ambulance was called and the patient was intubated and ventilated. Upon admission to hospital, further examination and investigation revealed the patient suffered a hemorrhagic cerebrovascular accident. The physician discussed the diagnosis and poor prognosis with the family. The physician recommended the treatment plan be changed to palliative care because nothing further could be done for the patient. The family agreed to the palliative care treatment plan. The patient was extubated at 1800 and transferred to a palliative care room where he was kept comfortable with administration of IV Morphine and Scopolamine. He died on June 9 at 0845.



Prefix	Code	DAD	Code Title
	I61.9	(M)	Intracerebral haemorrhage, unspecified
	Z51.5	(1) or (W)	Palliative care

**Rationale:** Palliative care is documented following admission and it constitutes a treatment change, therefore, qualifies as a diagnosis type (1) or (W). When palliative care is initiated after admission, it must account for the majority of the stay and for at least 24 hours to qualify as the MRDx. It would not be the MRDx in this case, because the patient was in hospital for less than 24 hours. Prefix "8" is NOT assigned in this case because palliative care is not documented as a known component of the patient's care plan prior to admission.

**Example:** A 50-year-old woman with known non-small cell cancer of the right lung was admitted on June 17 with a diagnosis of pneumonia. The physician writes that her prognosis is poor. The patient died on June 19.



Prefix	Code	DAD	Code Title
	J18.9	(M)	Pneumonia, unspecified
	C34.90	(3)	Malignant neoplasm of right bronchus or lung unspecified

**Rationale:** Palliative care cannot be assumed based on the diagnosis of cancer alone. Z51.5 is assigned only when there is documentation of palliative care.

## Appendix G: LHIN Support Unit, Inpatient Palliative Care Activity (2009)

### Estimated Comparative Costs of Providing HPC to Patients - Ontario

#### Hospital Costs for HPC (Ontario)

Total PC Hospital Separations	25,958
Total PC Inpatient Acute Cases	20,023
Total PC ALC Cases	5,935
Total PC entered via ED ~80% of total separations	20,766
 Total PC Days	 451,751
Total PC Inpatient Acute Days	356,733
Total PC ALC Days	95,018
 Total PC Inpatient ALOS (days)	 17.82
Total Average PC Inpatient Beds occupied @ .90 occupancy rate	880
Total PC ALC ALOS (days)	16.01
Total Average PC ALC Beds occupied @ .90 occupancy rate	234

#### Estimated Costs of PC Hospital Cases

Emergency Room Visit @ \$700/visit	\$14,536,480
Inpatient Acute days @ \$1,000/day	\$356,733,000
Inpatient ALC @ \$600/day	\$57,010,800
<b>Total</b>	<b>\$428,280,280</b>

#### Estimated Costs PC Per Person

Based on total PC hospital separations (per person)	\$16,499
Based on PC ALC Cases (per person)	\$9,606

#### Potential Cost Savings Using Community Based Interdisciplinary Outreach Teams

Patient Reduction of 30% PC ED visits*	6,230
<b>Cost Savings @ \$700 /visit</b>	<b>\$4,360,944</b>
 Patient Reduction of 50% PC Acute admissions***	 10,012
ALOS of PC Acute inpatient (days)	17.82
<b>Cost Savings @ \$1,000/day</b>	<b>\$178,366,500</b>
 Patient Reduction of 30-50% ALC inpatient**/**	 1,781
ALOS of PC ALC inpatient (days)	16.01
<b>Cost Savings @ \$600/day</b>	<b>\$17,103,240</b>
Potential Beds affected	117
 <b>Total Potential HPC Cost Savings</b>	 <b>\$199,830,684</b>

\* (Lawson et al, 2009, Journal of Palliative Medicine)

\*\* (Brazil et al, 2007, Journal of Palliative Care)

\*\*\* (Hsien Seow, PhD, "Use of end-of-life home care services in Ontario", 2008)

## Appendix H: Case Studies

CASE STUDY#1	
<p>Rebecca, a 3 year old female, was diagnosed with a neuroblastoma 8 months ago. She has received chemotherapy, with little improvement, and has had 2 full brain radiation treatments. She continues to suffer from grand mal seizures, and has a feeding tube. Rebecca's medical care is managed at Sick Children's Hospital (SCH), 250 km from her home. Her mother is a single parent, with 2 other children, ages 6 and 8. This family receives social assistance, and Rebecca receives CCAC services. The pediatric team at SCH has discussed with her mother that she is now actively dying. The mother is distressed because she would like to be in her own community with her other children, friends, and family.</p>	
A Hospice Palliative Care Approach	A Medical Approach
<p>The team at SCH contacts the palliative care consultation team in Rebecca's community, at the recommendation of her family physician. The consultation team confers that they care for individuals of all ages, and have a nurse practitioner with special interest and training in pediatric palliative care. They would be happy to care for Rebecca in her community, with the support of the SCH (tertiary care) palliative care team.</p> <p>Rebecca is discharged home 1 week later. SCH joins the regional palliative care team for a joint family conference to review the care plan and goals of care.</p> <p>The palliative care team along with the CCAC pediatric team services was able to support Rebecca's mother in managing her care, including her difficult management of seizures at home. Rebecca dies peacefully with her mother, siblings and close extended family present.</p> <p>Rebecca's mother was grateful for the seamless transition and continuity of the expert care Rebecca received at home.</p> <p>Assistance from the PPSMC</p>	<p>The team at SCH met with Rebecca's mother to discuss options for managing Rebecca's care. As there were no pediatric palliative care supports in Rebecca's community, the family and team saw no choice but to keep Rebecca at SCH to manage her care.</p> <p>Rebecca's mother arranges with great difficulty, care for her 2 other children with family and neighbours while she spend most of her time with Rebecca at the hospital. She tries to come home or have the children visit Rebecca once per week, however finances prohibited many of these hoped for visits. Her other children are desperately wanting to be with their mother and are having a tremendous time coping. Debt is beginning to pile as she now has to purchase her breakfast, lunch and dinner at expensive venues each day – a luxury she cannot afford. She humbly asks to borrow money from family which she has always avoided in the past.</p> <p>She tries to spend most of her time at the hospital at Rebecca's side – but the ongoing noise at the hospital makes for a very restless night's sleep. She is emotionally, physically and spiritually exhausted and becoming increasingly depressed.</p> <p>Rebecca dies in hospital 3 weeks later, with her mother present. She calls her children to let them know of the death, and returns home by bus the following day.</p>

## CASE STUDY #2

Betty is an 86 year old woman with advanced dementia who has been a resident in a long term care home for several years. Her condition is now deteriorating. Over the course of the last year she has been admitted to hospital twice for treatment of aspiration pneumonia with kidney function impairment. She also has received several treatments with antibiotics for lung infections while in the LTC Home. She is now having difficulties swallowing and is increasingly bed-bound.

### A Hospice Palliative Care Approach

Given the progression of Betty's dementia and the other complications she is experiencing, a decision is made to utilize a palliative care approach. The caregivers at the LTC Home are also concerned that she is having a lot of pain. The nurse specialist from the Palliative Pain and Symptom Management Consultation Service is called in to help the team with decisions regarding Betty's care. Together they determine that her groaning may be related to delirium rather than pain and that pain medications would not be appropriate at this time. Management of her delirium would be more appropriate.

A family conference is arranged to discuss the goals of care. Team members discuss the pros and cons of further antibiotic treatments and transfers to hospital if she develops an infection again. A decision is made to focus on comfort care rather than transferring her again to hospital for IV antibiotic treatments. Discussions are also held regarding her nutritional needs. The family is very concerned that she will starve to death if she is unable to eat on her own. The palliative care team discusses that because her overall condition is deteriorating, she will not benefit from artificial feeding, and it may indeed be more harmful. The family is not comfortable withholding nutrition as it is against their religious beliefs. With careful planning, a decision is made to trial feeding through a nasogastric tube. If Betty does not improve or tolerate the feeding, the treatment will be stopped. The family feels respected and accepts this approach.

Adapted from Champlain End-of-Life Care Network (2010) with permission. Assistance from the PPSMC

### A Medical Approach

Given the progression of Betty's dementia and the other complications she is experiencing, the caregivers at the residence are very concerned, particularly because she appears to be having a lot of pain, and they are not sure what to do to control it. After several failed attempts to manage her increasing discomfort an ambulance is called to take Betty to the emergency department.

After twenty six hours in emergency department she is eventually admitted to an acute unit, but it is not for several days before the team recognizes that Betty's symptoms are related to delirium rather than pain. An entirely different treatment is now initiated but the delirium is now advanced and will be much more difficult to get under control.

The family is also very concerned about her nutritional needs and that she will 'starve to death', since she is losing a considerable amount of weight. Due to their religious beliefs they request that the physicians put in a feeding tube. Reluctantly, the physician follows through on their request, and tube feedings are initiated.

Betty remains in hospital for 2 weeks until she is transferred back to the LTC Home with the feeding tube. Betty pulls out her nasogastric tube Saturday night, 3 days later. She is again sent to the ER for reinsertion of the tube. She spent the majority of that night and day on a stretcher in the ER and is returned back to the LTC Home late Sunday evening with the beginning of a sacral pressure ulcer. Her hands are covered with mittens to prevent her from pulling her tube out again. She is now totally bed bound and there is increasing evidence of her deteriorating condition despite the feeding tube. There are also obvious signs that the tube is making her very uncomfortable and agitated, however the caregivers continue to pursue the prescribed treatment plan, believing that it is in Betty's best interest. Betty's sacral ulcer has also worsened.

### CASE STUDY #3

Dave, a 56-year-old male is admitted to an acute care community hospital after presenting with a two-month history of abdominal pains, jaundice, nausea, severe weight and appetite loss. . Tests while in hospital show that he has a tumour in the pancreas which is blocking his bile duct. Scans also show that there are small tumours in the liver. This is consistent with metastatic pancreatic cancer which is confirmed through a biopsy. Dave and his family are very anxious and fearful about this diagnosis, what the next steps will be, and how and what they will share with their children and families.

#### A Hospice Palliative Care Approach

The medical floor team members that Dave is on have a care conference to discuss which interdisciplinary team members should be involved. The team identifies a lead to begin the conversations required. These include breaking the news to him and his family that his disease is progressive and that his life expectancy is in the order of several months. They then offer psychological support to help them with this bad news. They discuss with him treatment options, which includes palliation of his symptoms. They also introduce advance care directive discussions, including his wishes regarding resuscitation, should his heart and breathing suddenly stop.

Dave chooses to not have surgery or chemotherapy, but rather wishes to have treatments which help him have a good quality of life, with maximal control over his symptoms. He identifies he especially wishes his pain and nausea to be treated to allow him to return home.

The hospitalists at the hospital start him on opioids to manage his pain. They consult the palliative care consultation service (secondary expert consultants) in the hospital for advice on his nausea and managing his weight loss as well as other recommendations to improve his quality of life.

Dave is at risk for clinical depression due to a past episode requiring medication about 4 years ago. The team's social worker explores the social needs of this family and discovers that there are significant financial concerns as his wife is not working and they have a disabled son (age 17) living at home with them. The palliative consultation team determines that he does not have a clinical depression at this time, but is suffering spiritually since his diagnosis. The palliative care consultation team suggests working along-side the attending team in providing supportive counseling and care.

As part of this enhanced palliative care approach, the team also initiates discussions about who will care for him at home and explores the availability of his family physician to care for him in the community and do home visits. Dave and his family are referred to the Community Care Access Centre (CCAC) Palliative Care Case Managers. Dave, because of the assistance of the consult team and

#### A Medical Approach

The Emergency Room staff in the hospital that has admitted Dave makes referrals to the surgical team. The surgeon on reviewing the case arranges transfer to a tertiary hospital for oncological workup: surgery would be high risk in their small hospital, and the oncologist will then be able to arrange chemotherapy and possible radiation. The hospitalist in the hospital discusses the plan with the family and Dave and asks if they have any questions.

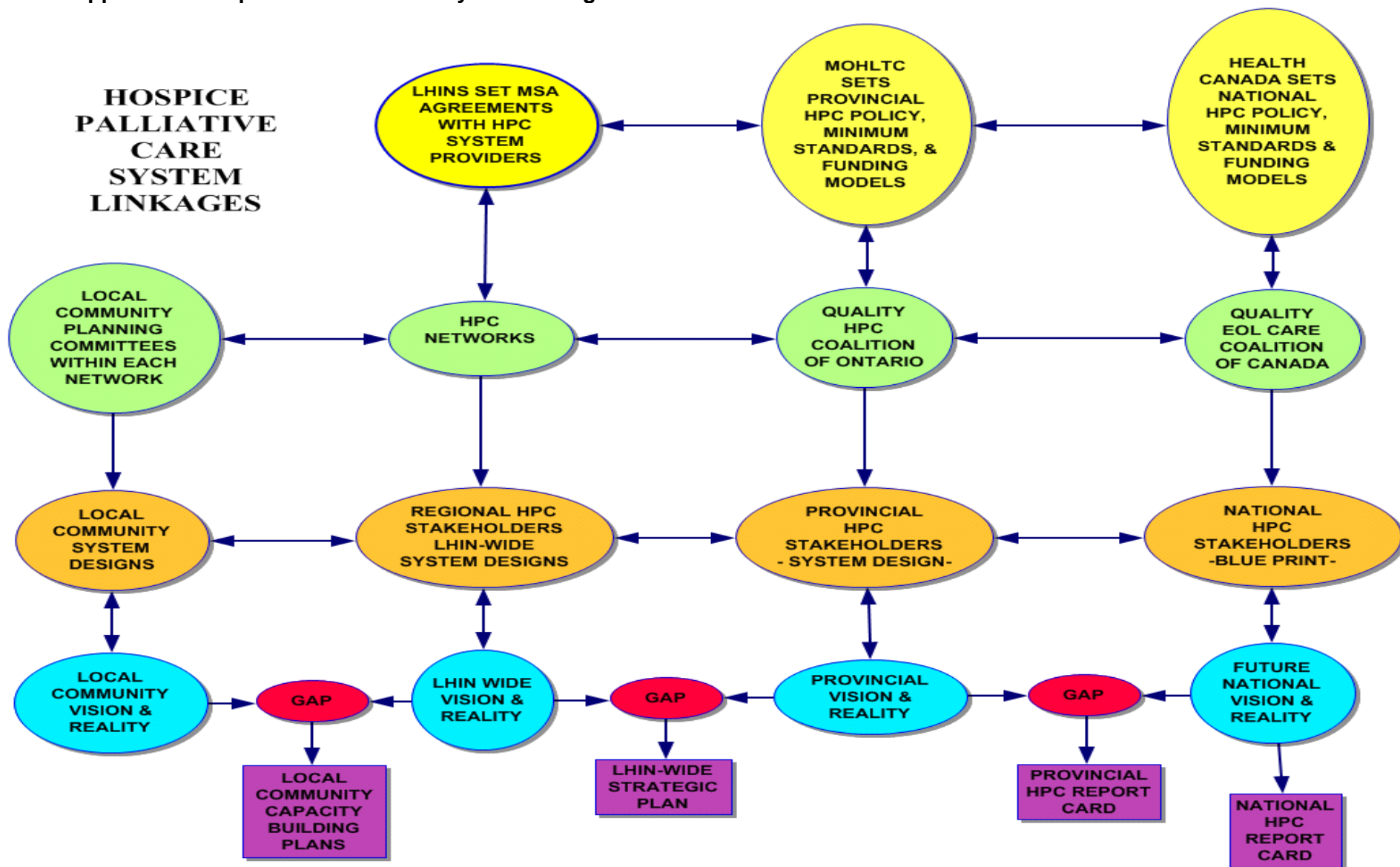
The family describes feeling fearful with all of this coming so fast, that things feel out of control. The hospitalist suggests that when they are transferred to the Cancer Centre tomorrow, that they ask for a social worker to meet with them and try to sort through things with them.

Dave is transferred the next day to the Cancer Centre, with surgery and a biopsy arranged for the following day. Dave has surgery, and receives 3 rounds of his chemotherapy as an outpatient. The chemo has no effect, and the oncologist informs him he has nothing else to offer, and discharges him from the Cancer Centre to the care of his family physician.

<p>other resources working with the attending team, is able to be discharged sooner from hospital, linked to appropriate resources in the community, including the secondary experts to manage his ongoing palliative care in the community.</p> <p>Adapted from Champlain End-of-Life Care Network (2010) with permission. Assistance from the PPSMC</p>	
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CASE STUDY #4	
Joan, a 68-year-old woman, has metastatic colon cancer. Unfortunately the cancer has spread despite surgery and several cycles of chemotherapy treatments.	
A Hospice Palliative Care Approach	A Medical Approach
<p>She has been cared for at home and has Palliative Home Care services in place and a family physician who does home visits and is following her closely. Her husband is a 76-year-old man who is frail. They have three children who live in the city and are very supportive and visit often. All three children hold their own jobs and have their own families. Joan is now very weak and mainly bed-bound. Her care needs are now such that it has become difficult for her to remain at home despite the home care services, family physician involvement and the support of a palliative care consult service. A decision is made to transfer Joan to a residential hospice.</p> <p>In the hospice, as part of a palliative care approach, her family physician, working closely with a very experienced palliative care nurse consultant, adjust her pain medications and give them via a pain pump, as she now cannot swallow. This is very helpful in making her comfortable. The hospice team also identifies that the husband is very distraught to see his wife dying and initiate bereavement care for him and the family. Three weeks later her condition begins to change and there are signs that she is in the terminal phase of her life with just days to live. The team affirms and reassures the family that providing hydration or feeding would be futile and will not contribute positively to Joan's quality of life. Joan dies comfortably several days later surrounded by the family, who feel well supported.</p> <p>Adapted from Champlain End-of-Life Care Network (2010) with permission. Assistance from the PPSMC.</p>	<p>Joan's care at home has become too burdensome and heavy for her husband to manage.</p> <p>Unfortunately they are already receiving the maximum services allowable through the CCAC. They have no private health care insurance to access. As well, there are no residential hospice beds in their region. Therefore the unfortunate decision is made for Joan to be admitted through the emergency room to the local hospital. Joan dies 4 weeks later on the acute medical floor.</p>

## Appendix I: Hospice Palliative Care System Linkages



## Appendix J: Square of Care and Organization

Square of Care and Organization		History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions				
		Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation				
		PROCESS OF PROVIDING CARE									
Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	Disease Management	COMMON ISSUES	Patient / Family							Governance & Administration	Leadership - board, management Organizational structure, accountability
Pain, other symptoms Cognition, level of consciousness Function, safety, aide Fluids, nutrition Wounds Habits - alcohol, smoking	Physical									Planning	Strategic planning Business planning Business development
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	Psychological									Operations	Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	Social									Quality Management	Performance Improvement Routine review: outcomes, resource utilization, risk management, compliance, satisfaction, needs, financial audit, accreditation, strategic & business plans standards, policies & procedures, data collection/ documentation guidelines
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual									Communications/ Marketing	Communication/marketing strategies Materials Media liaison
Activities of daily living Dependents, pets Telephone access, transportation	Practical										
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Peri-death care of family, handling of body Funerals, memorial services, celebrations	End of life/ Death Management										
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	Loss, Grief										
		RESOURCES									
		Financial Assets Liabilities	Human Formal caregivers Consultants Staff Volunteers	Informational Records - health, financial, human resource, assets Resource materials, eg. books, journals, Internet, Intranet Resource directory	Physical Environment Equipment Materials/supplies	Community Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public					

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