

# ADVANCING HIGH QUALITY, HIGH VALUE PALLIATIVE CARE IN ONTARIO

A Declaration  
of Partnership  
and Commitment  
to Action

December 2011

## Preface

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In Canada, most people die as the result of an advanced chronic disease. These illnesses include heart disease, stroke, chronic obstructive pulmonary disease, kidney failure and Alzheimer's disease.

These diseases may run their course over many years – requiring extended care and support from family members and health care professionals. Yet despite this need, it has been estimated that only 16-30 per cent of Canadians have access to formal palliative care and support appropriate to their needs. Of these, most are cancer patients. This leaves a tremendous gap to fill in providing appropriate services and support for people who need care for advanced chronic illness.<sup>1</sup>

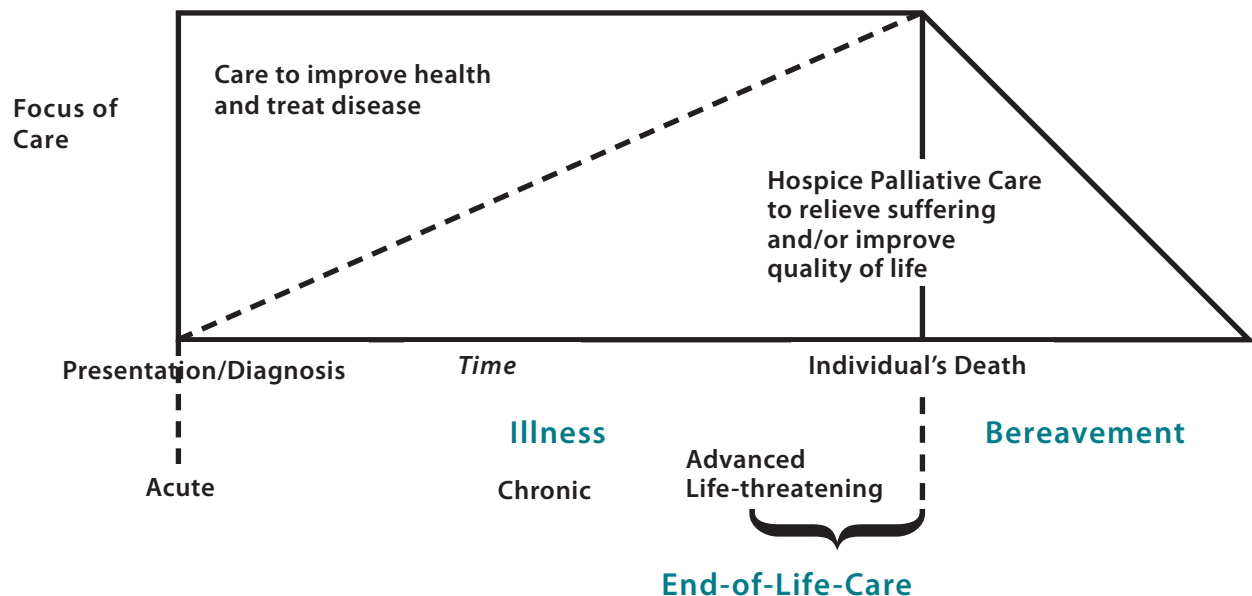
It is in this context that the partners of this Declaration have come together to set forth a new vision and a new plan for palliative care in Ontario. Through this plan, we can provide better care for Ontarians at end of life while we better manage our health care resources over time.

<sup>1</sup> Carstairs, 2010

## What is hospice palliative care?

Hospice palliative care – also simply called “palliative care” – is a philosophy of care. The term “residential hospice care” refers to the care setting.

Our definition and understanding of hospice palliative care is adapted from the Canadian Hospice Palliative Care Association (CHPCA) Model to Guide Hospice Palliative Care (2002):



**Hospice palliative care aims to relieve suffering and improve the quality of living and dying. It strives to help individuals and families to:**

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage end-of-life choices and the dying process
- cope with loss and grief
- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, and personal and spiritual growth.

## Hospice palliative care:

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- Is appropriate for any individual and/or family living with, or at risk of developing a life-threatening illness, at any time they are prepared to accept this type of care and support
- May enhance other types of care – including restorative or rehabilitative care – or may become the total focus of care
- Is most effectively delivered by an inter-professional team of health care providers skilled in all aspects of palliative care – including volunteer staff
- Is most effective when the care is integrated at the clinical, organizational and overall system level
- Is person and family-centred, respecting people's social, spiritual and cultural practices
- Includes end-of-life care, but is not limited to the time immediately preceding death.

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## About this Declaration

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This *Declaration of Partnership and Commitment to Action* is the result of a collaborative effort from more than 80 stakeholders from across Ontario. Each person involved brought a special set of insights and expertise to the table. Together, we have achieved a common consensus on a vision for palliative care in Ontario.

This work outlines the steps we need to take together to make that vision a reality. There is no single author – we are all contributors and accountable to advancing this common vision through our individual and collective actions.

Each participant will use this tool to help inform change within his or her realm of influence and control. Similarly, the Local Health Integration Networks (LHINs) may choose to use this document to help inform their regional planning. The Ministry of Health and Long-Term Care can also choose to use this Declaration as a tool to help inform policy decisions and system-wide planning.

Finally, we can all use this document as a framework to engage more broadly with our colleagues and stakeholders. Yet we should not lose focus of the ultimate goal: greater system integration that puts the person and their family at the core of every decision we make.

# CHARTER FOR ADVANCING HIGH QUALITY AND HIGH VALUE HOSPICE PALLIATIVE CARE IN ONTARIO

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## An agreement to work together to improve the quality and value of health care and palliative care delivery for Ontarians

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We are a partnership of individual, family, professional, volunteer, policy, planning and research representatives of Ontario’s health care and hospice palliative care community (the “partners”). We are committed to working together to advance high quality and high value health care and palliative care delivery for Ontario residents and their families.

As partners, we share a common purpose: to better support adults and children with life-limiting illness to improve their comfort, dignity and quality of life preceding death. This support extends to families and caregivers following a loved one’s death. Achieving these goals requires collaboration and commitment. It requires shared ownership of solutions and actions between all partners and across all care settings.

How we treat those who are living with or dying from life-limiting illnesses in our community reflects who we are as a society. All Ontarians have the right to quality palliative care. This includes the right to enjoy the highest quality of life possible . . . to have access to physical, psychological, social, bereavement and spiritual care . . . to be treated with respect . . . and to die with dignity.

We aim for the delivery of quality care that is needs-based, proactive, holistic, timely, on-going, consistent, connected and respectful. We work to improve the individual’s and family’s experience of care, while working to improve our health care system and the health of everyone in Ontario. We support an integrated continuum of care. We recognize the important role that all care settings, services and providers play in providing care to those with progressive life-limiting illness.

**This Declaration of Partnership** sets out our individual and collective commitments, common priorities and appropriate actions to optimize palliative care in Ontario. Our goal is to improve the experience of the individual and caregiver, and the quality of care and the value the system delivers. The Declaration identifies the next steps to provide equitable access to safe, comprehensive and high quality palliative care and support for individuals and their families across the province. We are committed to implementing the recommended actions – both short and long-term.

**We are approaching our palliative care partnership as a foundation for broader health care transformation and not just as a unique project for a specialized population.**

## **Our vision**

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Adults and children with progressive life-limiting illness, their families and their caregivers will receive the holistic, proactive, timely and continuous care and support they need, through the entire spectrum of care both preceding and following death, to:

- help them live as they choose, and
- optimize their quality of life, comfort, dignity and security.

## **Our top three goals**

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To focus its efforts to improve health care in Ontario, the Declaration addresses three core system goals.<sup>2</sup>

### **Quality:**

To improve client/family, caregiver and provider experience by delivering high quality, seamless care and support

### **Population Health:**

To improve, maintain and support the quality of life and health of people with progressive life-limiting illnesses

### **Sustainability:**

To improve system performance by delivering better care more cost-effectively and creating a continuously self-improving system

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<sup>2</sup>The Declaration's core system goals are based on the Institute for Healthcare Improvement's "Triple Aim"™ Framework.



## Our core values and assumptions

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The following values and assumptions have guided the development of our vision and action plan:

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- 1. All Ontarians should have equitable access to high quality care and support to optimize their ability to live well with a progressive life-limiting illness wherever they reside or receive care.**
  - All people of all ages (children and adults) living with progressive life-limiting illness or coping with complex grief fall within the scope of this vision and Declaration.
  - Palliative care is not just for individuals in the final months of life and is not limited to cancer diagnoses.
  - Quality palliative care should be integrated with quality chronic disease management for those living with progressive life-limiting illness. There is a need for better coordinated care planning throughout the entire chronic disease and aging process. This includes early and on-going advanced care planning.
  - Those served include urban, rural, remote and First Nations communities, as well as culturally and linguistically diverse and vulnerable populations.
  - Care can be provided wherever Ontarians reside or die – including at home and in all home settings (such as retirement homes and group homes, etc.), in hospitals, long-term care homes, free-standing hospices and so on.
  - When death is inevitable, every effort is made to have a person die with dignity and in peace and comfort, based on individual and family choice and preferences.
  - Services include bereavement support.
  
- 2. The individual with a progressive life-limiting illness and their family are at the centre of care.**
  - Care is client-directed. Decisions are made by the individual themselves or their substitute decision-makers (based on an advanced care plan and prior known wishes).
  - Care is client-centred. Care providers work together to smoothly provide comprehensive care.
  - Care is also family-centred. Family members will receive care and support, both before and after a loved one's death. Family includes all relationships that are important to the individual – including relative, partner or friend.
  
- 3. Family members, friends and community groups provide most of the care needed.**
  - The most appropriate and sustainable system includes support for informal caregivers and volunteers. This support is vital to help them succeed in this role.

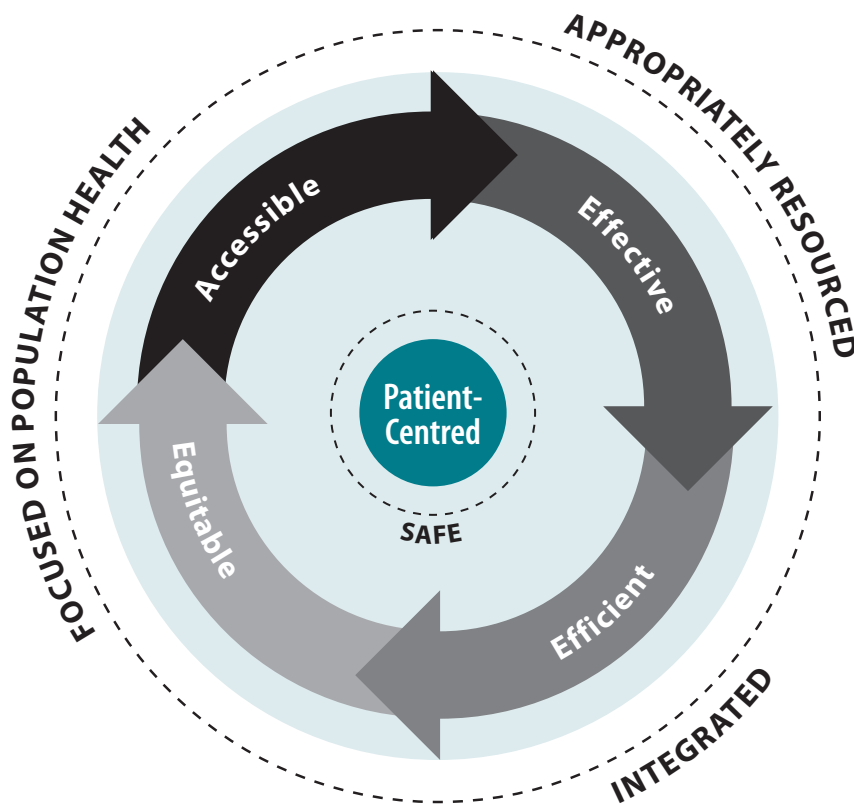
#### 4. Quality is a key driver to achieve system goals.

In the context of this Declaration, quality means that every Ontarian with a life-limiting illness and their family/informal caregivers will be able to access care and support that is:

- centred on the person and their caregivers
- safe, equitable, appropriate, effective and efficient
- properly resourced
- fully integrated
- available wherever the patient is living and dying
- population-focused.

**Figure 1: Provider roles in hospice palliative care**

Nine Attributes of a High-Performing Health System



Ontario Hospital Association and  
Ontario Health Quality Council, 2009

## 5. Increasing sustainability and value is a central focus of improvement.

- Sustainability is enhanced by delivering better value for Ontarians and for our health care system. Better value will be measured in terms of improved population outcomes and system performance relative to the cost.
- Value will be most improved to the extent we can:
  - optimize existing available resources at the primary level to provide proactive, holistic care, and
  - reserve the use of specialists for the small number of patients with highly complex needs.
- Any reforms should lead to better value for money through improved efficiencies, productivity and quality. In particular, unnecessary new administrative structures will not be added to the system.
- The value of any new investment should be measured and reported in terms of how it contributes to improving patient care outcomes relative to cost. Sustainability will be a primary lens applied to all proposed action items within the **Commitment to Action**. It is a primary component of evaluation as the health system evolves.

## A NEW MODEL FOR PALLIATIVE CARE

**“The true test of a health care system is how well it serves the people who need it most. We must move beyond a system organized around acute illness and reactive management of disease to one that deals effectively and proactively with chronic illness and the needs of an aging population.”<sup>3</sup>**

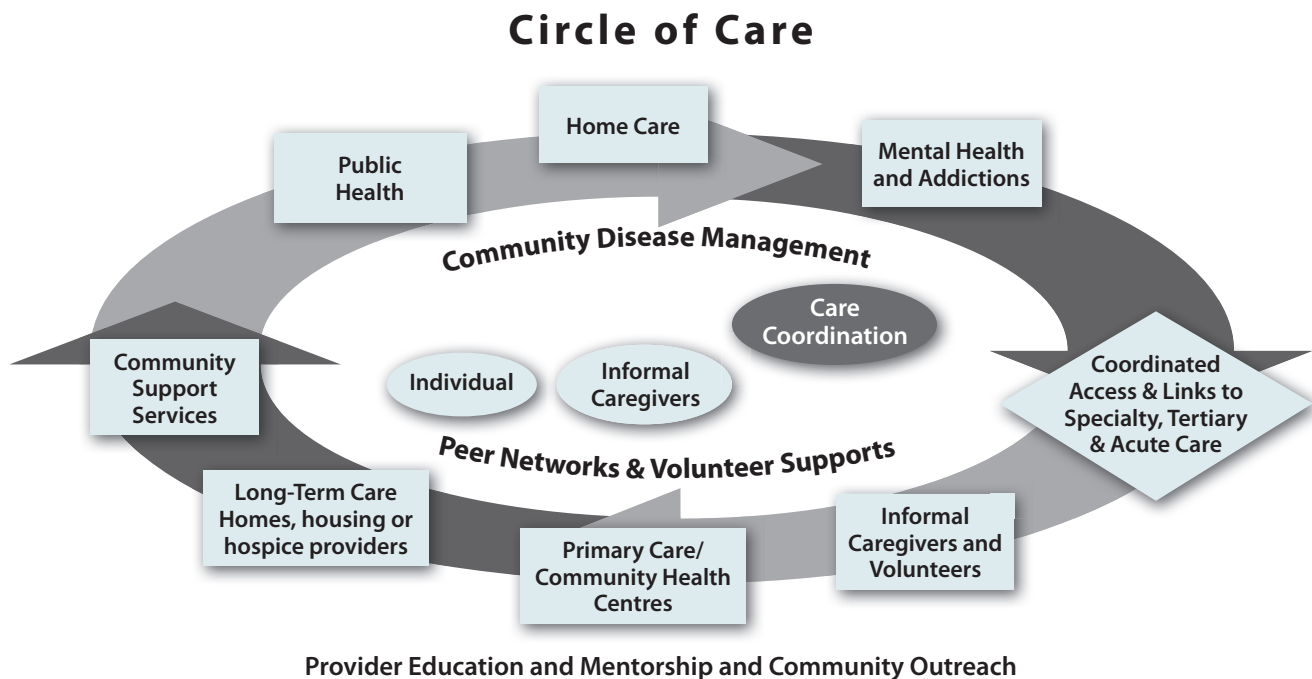
The evidence is overwhelming that excellent palliative care has the same elements as excellent management of chronic disease. Ontario’s health care system needs to shift to a single, cohesive delivery model that integrates care and support for adults and children with chronic disease at every stage – from diagnosis until death and through bereavement.

### Our current model

Today, those with advanced chronic disease(s) or complex care needs receive care that is reactive, targeted and disease-focused. Care is delivered by multiple, siloed individual providers in response to distinct acute episodes.

Our goal is to transform health care in Ontario by developing a comprehensive, integrated circle of care and support. Adults and children with advanced or end-of-life chronic disease(s) and their informal support network will receive care that is proactive, holistic, person and family-focused. We will focus on improving a person’s quality of life and managing symptoms – not just extending life.

**Figure 2: Circle of Care: A new model for health care delivery in Ontario**



<sup>3</sup>Donald M. Berwick, MD, President and CEO, Institute for Healthcare Improvement

## Proposed new model: Virtual extended inter-professional teams

We envision a system that wraps delivery around the adult or child and their family and informal caregivers and responds in a coordinated way to their goals, needs and personal situation. Care will be delivered by a virtually integrated inter-professional team. Each patient will have a coordinated and continually updated care plan. This plan will encompass all settings in which the patient receives care.

### Moving to this new model requires that:

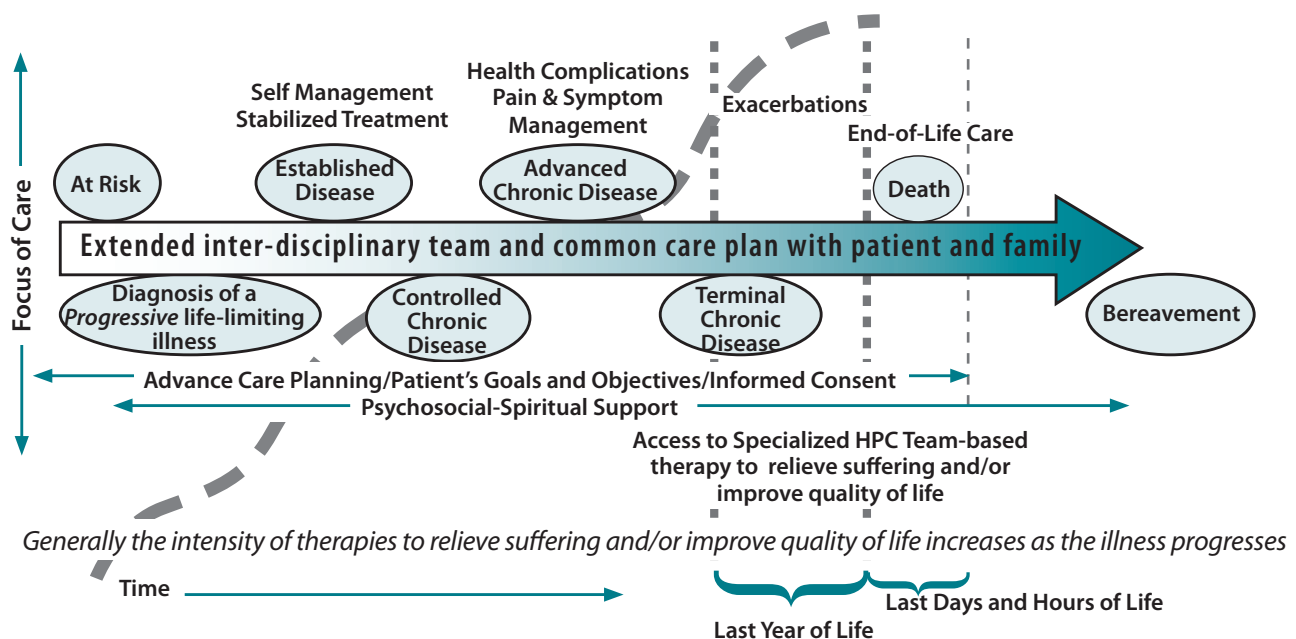
1. A full continuum of care settings and services is in place.
2. In each care setting where individuals die, there is a clearly defined care program that is founded on a palliative care philosophy and approach.
3. Sectors and services are linked by common practices, processes, structures and understanding of the palliative care philosophy.
4. Enough trained professionals and trained volunteers are available.
5. Accountability is clearly defined and communicated.
6. Funding models, guidelines and policy directions support an integrated system.

## Linking chronic disease and palliative care

This new model includes a meshing of the chronic disease management models of care with palliative care models. Figure 3 below depicts this connection.

**Figure 3: Child & Adult Hospice Palliative Care – Chronic Disease Continuum Model**

*Generally the intensity of therapies to modify disease diminishes as the illness progresses*



Modified (2011, 2013) from the Canadian Hospice Palliative Care Association, *A Model to Guide Hospice Palliative Care*, 2002  
By the Care Pathing Across the Continuum of CDM Working Group, MOHLTC, Ontario

## Creating a new kind of care team

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**The team approach outlined in this document extends team-based delivery that might already be available in primary care, home care or palliative care sectors by:**

- integrating existing teams or resources with each other where appropriate, and
- connecting health care delivery with broader social supports, such as those within the community, social services and municipal sectors.

**It includes designated resources to work with clients and caregivers (to the extent they are willing) on the development of an overarching care plan. This plan will:**

- outline the roles and expected contributions of all care and support providers
- assign clear responsibility for effective coordination, management and communication among extended team members
- identify measures to track performance and outcomes.

We note that it will be easiest to build an extended inter-professional team for clients where dedicated, formal inter-professional primary chronic disease management teams and specialized palliative care consultation teams are already available within that community or care setting. Where teams exist, many of the connected providers will already have established team protocols, clear roles and trusting relationships with each other.

The best value for clients and the system is achieved when regionally organized specialists support primary delivery.

Specialized palliative and advanced chronic disease resources need to be coordinated at a regional level through an organized program or network.

## WHAT SUCCESS WILL LOOK LIKE

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**The model set out in this paper is generic. It can be adapted to health care delivery for all Ontarians with chronic disease. Over the next 10 years, Ontarians should expect to see:**

**1. A health care system that:**

- is patient-centred
- achieves better outcomes, and
- is more cost effective.

**2. Adults and children with chronic disease and their informal caregivers will have access to:**

- comprehensive, integrated, personalized health care, and
- community and social services that respond to their needs, goals and personal circumstances.

**3. The right supports to:**

- remain in their communities
- have their chronic disease managed optimally, and
- relieve the burden on informal caregivers.

This will reduce pressures on hospitals and long-term care homes, ensuring that the health care system will be there for future generations.

Ontario will achieve this vision by shifting from fractured, sector-based delivery to a redesigned, “person-centric” system focused on chronic disease and health promotion/prevention based on three fundamental principles:

**1. We will enable and support individuals and caregivers to navigate and direct their own care.**

- At the delivery level, adults and children and their informal caregivers will receive care and supports that are proactive, holistic and person and family-focused.
- Families, informal caregivers and the individual’s paid or volunteer networks provide a critical and necessary foundation of support. They will be acknowledged as key delivery partners on the team.
- They are entitled to and should expect to receive education, information, mentorship and support from their publicly funded delivery partners to:
  - equip and enable them to optimize their role on the team, and
  - minimize the burden and stress that often goes with their caregiving role.

**2. All providers across all care settings and across time will work together as members of an integrated team to achieve common goals.**

- Care will be provided by a virtual, extended inter-professional team. Providers from multiple organizations, sectors and systems will be expected to coordinate their care and support to focus on continuity<sup>4</sup> and the achievement of common goals.
- Primary providers in all care settings will have access where appropriate to dedicated palliative consultation teams and other specialized palliative programs and resources. These include information, education and mentorship support (secondary level palliative expertise).
- Tertiary level specialized resources and interventions will be available to support individuals with highly complex care needs.
- The team will be constructed around the individual/family needs, rather than requiring the individual to fit into existing programs.
- Team members may transition in and out of the team as they are needed around the individual.

**3. Each team member will be supported to use best practices to achieve quality outcomes.**

- All primary providers in all care settings will have capacity, education and support to deliver excellent palliative care to all clients with progressive life-limiting illness. In each setting where individuals die, a defined program exists for those with advanced/end-of-life chronic disease.
  - At the regional level, primary providers will have access to specialized resources and supports that are organized through a formal program or network structure to build capacity and support high quality delivery.
  - Results will be evaluated against measurable criteria – including improved outcomes and cost effectiveness.

<sup>4</sup>“Continuity” is the degree to which a person experiences a series of discrete health care services, supports or interventions as coherent, connected and consistent with their medical, clinical and psycho-social spiritual needs and personal context. Continuity of care is achieved by bridging discrete elements in one’s care pathway – whether different episodes, interventions by different providers, or changes in health status – as well as by supporting aspects that endure intrinsically over time, such as the person’s values and sustained relationships.



**Regional programs also provide planning and funding advice to LHINs to improve access to and the effectiveness and consistency of care and supports available across the region. Examples of regional programs might include:**

- Regional Integrated Hospice Palliative Program
- Regional Geriatric Program
- Behavioural Support Ontario
- Cancer Care Ontario.

**Two key enablers to transform palliative care:**

1. Strong community capacity (non-medical determinants of health).
2. Dedicated and responsive formal program and team resources in the community.

These can be used to build the virtual extended team, processes for standardized delivery, health human resource capacity, technology support and strong governance and accountability mechanisms.

**In addition, the partners to this Declaration advocate and encourage a dialogue and supports to enhance the availability of other key supports for informal caregivers at national, provincial and business leader tables. These additional supports might include:**

- expanded cash-for-care or direct payment funding schemes, and
- more flexible job benefits or protections for compassionate care leaves.

## What difference will it make for Ontarians?

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The end result for Ontarians will be a health care system that is:

- **High Quality:** Every Ontarian will receive care that is based on the best science and is focused on the best outcomes
- **Sustainable:** We will protect public health care for future generations by measuring and continuously improving outcomes and value
- **Accessible:** Every Ontarian will have access to a health care provider in a timely fashion. This applies equally to the rich and the poor; to those who live in large cities and those in remote regions; and to those mostly in good health and those very ill or at the end of life.
- **Continuous:** Care received at one point in time from one provider is coordinated with the care received at other times – including care from other providers.
- **Person-directed:** Individuals and families are involved in developing their care plans. These plans take into account their quality of life goals and their personal and cultural preferences.

## Seven key benefits for individuals and families

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1. **The person's needs are identified early.** Individuals and families are able to connect with the supports they require simply and with minimal wait times through designated care coordinators (a “one-stop shopping” approach).
2. **The individual and/or family members are engaged** as partners in all care planning and delivery decisions, as well as in the monitoring of outcomes.
3. **Individuals receive seamless care** from one inter-professional team, which can respond quickly, around the clock. The team fits around the person/family needs, rather than fitting the individual into existing programs. The individual or substitute decision-maker gives permission for caregivers to join the team as well as to access and share information.
4. **Home- and community-based palliative care supports those who desire to remain in their communities** until the end of their lives. It is part of primary care and chronic disease management. Whenever the person is admitted to hospital, hospital staff enter the person's circle of care and collaborate with the community team to ensure the person returns to the community as quickly as possible with appropriate transitional supports.
5. **Individuals and their caregivers are fully informed** about what medications to take, what signs to watch for, and when to seek additional care. Families/caregivers know whom to contact to deal with issues that arise after normal business hours.
6. **Flexible respite care is available when needed** – whether in home, residential hospice or hospital. Towards the end of life, the location of care will be optimized to achieve an appropriate balance between acuity, preference, convenience and costs.
7. **The individual and family experiences care delivery as seamless, connected and continuous.** Where possible, the same staff and volunteers visit the individual. The team shares a single client record, including medication information, to increase safety and to avoid having individuals and families repeat their information unnecessarily.

## MOVING FORWARD

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**As we move forward, we will need to address the gap between the current state and the new model in six key areas:**

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### **1. Inadequate and inequitable access to integrated, comprehensive, high quality care**

- Key care settings and services are lacking in many catchment areas. This is especially true in rural, remote and First Nations communities (both reserve and urban). Caregivers are often not prepared to respond adequately to these communities and to culturally/linguistically diverse populations.
- Some groups are under-represented and lack access to appropriate support and resources.
- Individuals and caregivers have challenges navigating the system and finding access support.
- Palliative care is poorly understood by individuals and caregivers, as well as by many service providers. This results in referrals being made too late in the disease trajectory or referrals not being made.

### **2. Inadequate caregiver support**

- Key supports for families and caregivers are lacking or inconsistently available. This includes bereavement programs and related support.

### **3. Limited and inequitable service capacity across all care settings**

- Significant disparity exists amongst Local Health Integration Networks (LHINs) in terms of providing complex care, advanced chronic disease management, palliative care and end-of-life care. This creates a provincial landscape where care and support is piecemeal.
- Key program elements that are most often missing include:
  - Access to 24/7 palliative care expertise
  - Access to inter-professional expertise
  - Identified palliative care lead/champion/contact within every care setting
  - Clearly defined model of care delivery and formalized palliative care program.
- There is a shortage of health care professionals and volunteers with training in palliative care, grief and bereavement support. This includes a lack of expertise and specialized resources for long-term care homes and primary care settings.
- There is a lack of consistent and standardized education and training.
- There is a need to fully engage residential hospices, long-term care homes and hospitals as partners and work to better understand the role each plays in delivering palliative care.

#### **4. Lack of system integration**

- Chronic disease management and palliative care are required and provided in multiple care settings. However, programs and services are often based on stand-alone models. They are not necessarily integrated enough to provide complete care from diagnosis to end of life to bereavement.
- Certain essentials for integration are lacking or inadequate in each region. These include:
  - common clinical practices, tools and processes across sectors
  - shared functional and clinical infrastructures
  - common education.

#### **5. Lack of clear accountability**

- Health and social care in Ontario is delivered by independent sectors and by independent service providers. Each has its own Board of Directors, mandate, operational imperatives and strategic direction. Within this complex context, overall shared accountability is unclear – both for the care of the client and family and for the achievement of the health system's goals.
- There is no endorsed/funded provincial level mechanism for standardization of clinical processes or system-design best practices.
- System-level accountability, evaluation, monitoring and reporting is inadequate.
- There are no provincial performance standards in place. Development would need to allow for local flexibility in how they are achieved.
- Funding does not follow the client through the care system.
- Family and caregiver voices are not currently reflected in local and system level planning and governance.
- There is a lack of accountability based on outcomes at all levels.
- There is a lack of tracking and reporting on outcomes to drive change at all levels.
- Jurisdictional issues are a barrier to funding and providing services in First Nations communities.

**6. Lack of clear public communication/messaging (including information on the core components of hospice palliative care including Health Care Consent and determining capacity)**

- Clients and families do not know how to access the services available to them.
- Referrals are made very late in the disease trajectory – in some cases, a few weeks or days before death.
- Referrals are not consistently made for those with chronic diseases other than cancer.
- Individuals and families carry a greater burden for care and support.
- Individuals do not always die in the place of their choice.
- Lack of information and understanding can lead to increased costs in the health care system. For example, due to:
  - prolongation of costly treatments which may neither extend nor improve life
  - unnecessary use of emergency departments and inpatient hospital care.

**Addressing these key issues will support efforts to improve a number of existing structures and processes, including:**

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- caregiver supports
- system capacity
- system integration
- governance to improve person-centred, quality-related outcomes.

**We will measure progress in terms of:**

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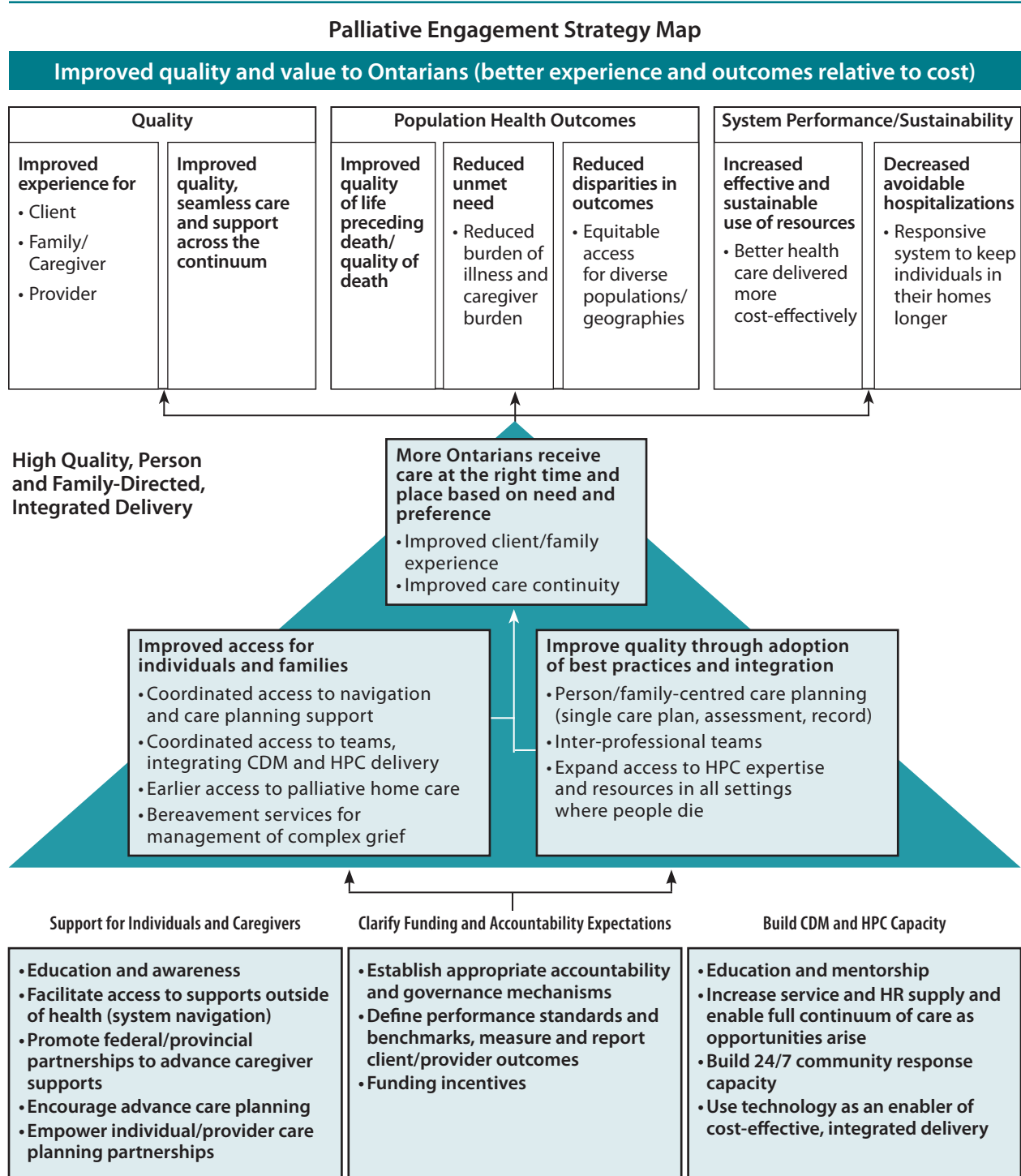
- faster, easier access to palliative care
- improved client and family experience, and
- better clinical outcomes, such as improved pain and symptom management.

By focusing on these areas initially, key population and system performance outcomes should also improve.

Further delivery considerations are discussed in Appendix C on page 69.

# An incremental change strategy

The *strategy map* below documents the strategic drivers for renewing palliative care in Ontario. These drivers establish the necessary structures and processes required to achieve TripleAim™ goals of improved quality, population health and sustainability. Achieving these objectives will contribute to the larger goal of creating value for Ontarians.



## A roadmap for change

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### To improve access, we will:

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- Use simple information to build awareness.
- Establish a care coordinator in each community or care setting.
- Create an overall care plan that establishes team members and their roles/responsibilities. Informed consent is an essential component of care plan development and should be revisited each time the care plan is updated.
- Require communities and care settings to establish coordinated and defined points of access and a standardized process for screening that includes a comprehensive holistic assessment.

### To promote integrated delivery, using extended inter-professional teams, we will:

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- Treat the episode of care as starting from the point of entry to the system through death and post-death bereavement. A team will remain with the client throughout the episode of care, ensuring continuity.
- Use a collaborative, evidence-based, preventative, proactive care plan that is continuously updated and supported by excellent communication practices.
- Use a single health record that is shared by everyone on the extended team.
- Bring specialists or other providers in and out of the team to achieve specific goals. Information and results achieved by any provider in any care setting are retained by the team as part of the client record.

### To strengthen accountability at the clinical/service, organizational and regional levels, we will:

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- Develop clear performance expectations, measure contributions of team members, and ensure transparency.
- Use networks/partnerships to mobilize and coordinate a response at the local and regional level and meet minimum standards.
- Undertake system and regional level policy and planning specific to advanced chronic disease and palliative care.



## Our guiding principles

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- 1. We will improve access to care in the community.** We believe that dying people who want to end their days in their home community should have access to the care they need through primary providers. End-of-life care should also include access to specialty care where and when needed.
- 2. We will provide more support for primary providers.** We will work together to strengthen the ability of primary providers to provide high quality care by providing access to:
  - information
  - education
  - mentorship
  - regionally organized, specialized palliative care services in all regions and local communities.

We need to help primary providers across all care settings to effectively serve adults and children with a wide range of needs, diseases and conditions. Palliative care must be based on:

- a holistic view of the person at every step of the care process, and
  - a realistic understanding of their support environment.
- 3. We will improve palliative care first for those who are in their last year of life, including those with advanced chronic disease.<sup>5</sup>** Many chronic diseases are life-limiting. However, people who are likely to be entering their final year of life have the most urgent need for high quality palliative care and support. We therefore agree that adults and children with advanced chronic disease and their families should be targeted for delivery improvements first, for two main reasons:
    - they will benefit most from the actions outlined in this paper, and
    - they are currently at higher risk for poorer quality of life and poorer system outcomes.
  - 4. We will work to raise awareness of palliative care in general.** We will promote dialogue with families and caregivers, with professionals who serve individuals with chronic disease and with the public. We need to raise awareness about palliative care and advanced care planning to improve access to available supports and resources earlier in the course of a person's disease.
  - 5. We will improve quality of care by optimizing the best of what is currently available while building for the future.** We recognize that reforms must lead to better value for money. We will achieve this through improved efficiencies and greater productivity, as well as improved quality of care.

<sup>5</sup>See Appendix A for more definitions.

**To build awareness and integrate the Hospice Palliative Care philosophy into the management of individuals with chronic diseases, we will:**

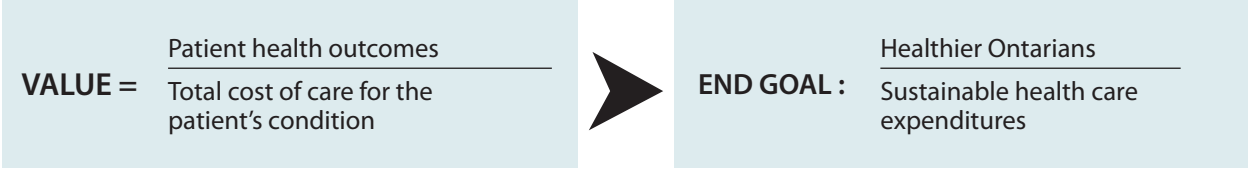
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**Adopt a model that integrates palliative care into chronic disease management from onset/diagnosis. The model:**

- Spans all phases of illness, recognizing that palliative care can be given at the same time as disease treatment, and with intensity of support increasing towards end-of-life.
- Puts the client and their family at the centre of care and includes them in the development of a collaborative care plan that supports team communication and consistency.
- Includes a designated care coordinator to follow the patient across care settings.
- Promotes access to specialized palliative care teams, particularly as the client enters the advanced and end-of-life phases of their disease.

# Key measures of success

Moving forward, we will measure better quality delivery and success in relation to improved population and system outcomes. We will start from the fundamental principle that the test of value resides in the person. Improving outcomes one patient at a time leads to better overall results.



## Any new delivery model should be designed to achieve a balanced set of outcomes:

- improved quality (individual, family and provider experience)
- improved population health (improved quality of life for Ontarians), and
- improved system performance/sustainability.

For this reason, we recommend adopting a balanced scorecard approach to measure our success. Four measures are proposed here for initial/immediate development and tracking in all care settings where data is currently available. At the same time, we will build capacity to track standardized data across all care settings:

### 1. Change (decrease) in caregiver burden

- Currently, indicators can be applied to only a few care settings, including long-term care homes (LTCHs), complex continuing care (CCC) and home care.
- In the future, we will investigate capturing data for individuals receiving services in acute settings. This includes acute care, ER and palliative patients living in the community under the care of a family doctor but without home care.

### 2. Change in location of Ontario deaths as most individuals prefer to die at home or as close to home as possible

- This measure would apply to the entire continuum of care settings.
- There is a three-year lag in reporting of deaths by the Ontario Registrar General. As such, this indicator will not be able to reflect immediate, real-time process improvement. However, it could be used as an indicator of outcomes.
- We will need to further review quality of data that may impact validity.

### **3. Change (increase) in quality of life preceding death/quality of death**

- There is no existing data source for all care settings that can directly measure quality of life for palliative patients.
- However, there are objective measures that might enable us to use functional information as proxies. The use of proxies could enable us to begin monitoring improvements in care settings that currently apply these functional assessments (e.g., LTCH, CCC, home care, etc.).
- Another option could be to conduct patient surveys using existing questionnaires, or develop new ones. Both approaches would require the creating of a new data holding system across the province, testing/validation, training, etc.

### **4. Change (reduction) in avoidable hospitalizations**

**We propose to track and assess the following two indicators:**

1. A decrease in the rate of admissions for ambulatory care sensitive conditions (ACSCs) for palliative patients.
2. A decrease in the rate of 30-day hospital readmission for palliative patients.

Over time, we anticipate that all health care providers will be measured and held accountable in terms of their ability to add value to service delivery. We are proposing a blended accountability mechanism where all publicly funded providers – primary, secondary and tertiary – would share responsibility for achieving system and population outcomes.

## Tracking broader measures of success

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The key measures identified above are just the beginning in our efforts to pursue a broader strategy for data and performance measurement. To establish a system-wide approach to monitoring and reporting will require a significant amount of analytical and infrastructure work.

Comprehensive and real-time data collection, analysis and feedback are critical to driving continuous improvement – both in direct care delivery and system design. We have identified the following additional measures to support continuous improvement:

### 1. Process-based measures of success

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**Initial measures of broader process improvements might include enhancements to the number of:**

- Integrated delivery teams
- Individuals and families who receive care and support through consultation and integrated delivery teams
- Professionals – and type of professionals – connected to the individual’s care
- Organizations collaborating on a care plan
- Individuals with advance care plans, and
- Access to – and uptake of – education initiatives.

### 2. Quality-based measures of success

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**Initial measures of quality improvements might include:**

- Decrease in caregiver burden
- Improved individual, caregiver and provider experience
- Improved pain and symptom management
- Increase in the number of persons with advanced or end-of-life chronic disease receiving team-based care
- Increase in the number of persons with advanced or end-of-life chronic disease discharged from hospital to team-based care
- Change in location of Ontario deaths.

As shown in the strategy map on page 22, improvements in these areas should in turn lead to improved population and system performance outcomes:

### 3. Measures of improved outcomes for key populations

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**Initial measurements here might include:**

- Increase in quality of life preceding death/quality of death
- Reduction in unmet needs reported (individual and family)
- Reduction in disparities in outcomes across vulnerable populations, geographies and First Nations communities.

### 4. Measures of impact on health system

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**Initial measurements here might include:**

- Lower costs per episode of care (cost/service efficiency)
- A decrease in:
  - unscheduled ER visits
  - Alternative Level of Care days (where patients remain in hospital due to a delay in finding an alternate care facility)
  - drug costs
  - 30-day and 90-day re-admissions
  - number and length of hospitalizations in the last month of life
  - deaths in hospital
- Increase in number of organizations that offer palliative care programs.

Ultimately, improvements across these measures will drive value to Ontarians. Over time, individuals and their families will see improved outcomes and experience a higher quality of care relative to cost.

## A COMMITMENT TO ACTION

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As family, professional, volunteer, policy, planning and research partners, we are committed to working together to advance high quality, high value health care and hospice palliative care delivery for Ontario residents and their families. We are committed individually and collectively to moving forward with implementation of the recommended actions – both immediately and in the longer term.

**We share the belief that the priorities and actions outlined in this document will significantly enhance the quality and value of palliative care delivery in Ontario by:**

- improving the person, caregiver and provider experience
- enhancing the quality of life prior to death
- easing bereavement after death
- reducing avoidable ER visits and hospitalizations, and
- making it possible for more people to die with dignity in their place of choice.

Where an action is within our own sphere of control, we commit to implement this action as soon as practical. We further commit to share knowledge and influence our colleagues, organizations and networks to take similar actions.

Where taking action depends on other partners or decision-makers, we commit to continuing to collaborate and engage in dialogue with those involved to advocate for change. We will also continue to build the case for change from wherever we sit in the system.

**We agree that we will work first to advance the following shared priorities:**

1. Broaden access and increase timeliness of access.
2. Strengthen caregiver supports.
3. Strengthen service capacity and human capital in all care settings.
4. Improve integration and continuity across care settings.
5. Strengthen accountability and introduce mechanisms for shared accountability.
6. Build public awareness.

## A final word

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This *Declaration of Partnership* is a “living” document. It will be maintained, reviewed and updated as new evidence and information becomes available. As such, this document is a reflection of its time. It will continue to become increasingly comprehensive as further input is received, discussed and canvassed for greatest system consensus.

The Declaration presents a vision of the future state that we aspire to create. It offers a population-based approach for Ontario’s health system, beyond the areas of advanced chronic disease and palliative care. At the same time, we acknowledge that moving to a more integrated, population-based system is a complex process. Improvements will be iterative. However, we as a partnership are committed individually and collectively to moving forward immediately.

We have set our course. We will proceed with a targeted focus that puts us on the path to achieving a more integrated health care system for all Ontarians.

The chart that follows details our shared priorities and the specific actions we will take to move forward.

**Note:** The order of the Action Commitments in the plan below does not reflect the actual sequence we will follow. Instead, we have listed the actions according to theme (“Key Issue”). Partners will need to consider the best sequence as they develop their work plans.



Shared Priorities	Specific Action Commitments
<p><b>Take action now</b></p> <ul style="list-style-type: none"> <li>• All partners agree to take action within their respective scope of influence and control to advance high quality and high value palliative care in Ontario. These actions must be consistent with the <b>Declaration of Partnership</b>.</li> <li>• All partners will share the <b>Declaration of Partnership and Commitment to Action</b> with their respective organizations, associations, etc.</li> <li>• All partners will develop work plans or processes to carry out their action commitments.</li> </ul>	<ul style="list-style-type: none"> <li>• By January 2012, the Ministry of Health and Long-Term Care (MOHLTC) will report to the Minister of Health and Long-Term Care (the “Minister”) about this process.</li> <li>• By January 2012, Local Health Integration Networks (LHINs) will present the <b>Commitment to Action</b> to all LHIN Chief Executive Officers (CEOs).</li> <li>• Through winter 2011/12, MOHLTC, LHINs, the Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) and the Ontario Association of Community Care Access Centres (OACCAC) Integrated Client Care Project will: <ul style="list-style-type: none"> <li>– develop implementation guides and public materials</li> <li>– organize next steps for broader engagement, including working with relevant associations and partners.</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• All partners agree to pursue the model of care endorsed through this Declaration as one of the foundations for broader health system transformation – and not as a one-off, specialized model unique to palliative care.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC and LHINs will consider the model of care endorsed through the Declaration in the context of a strategic dialogue on health system transformation. This includes models for shared accountability that may apply to other priority policy areas.</li> </ul>
<p><b>KEY ISSUE: BROADEN ACCESS AND INCREASE TIMELINESS OF ACCESS</b></p>	
<p><b>Ensure early identification and access to services and supports</b></p> <ul style="list-style-type: none"> <li>• Implement the proposed “Child &amp; Adult Hospice Palliative Care – Chronic Disease Continuum Model.”</li> <li>• Develop and implement additional and complementary mechanisms at the front line to help those with advanced life-limiting illness to identify symptoms that could be eased through appropriate pain and symptom management and other palliative care services – including episodic support.</li> </ul>	<ul style="list-style-type: none"> <li>• Through an agreement with the Ontario College of Family Physicians, MOHLTC is supporting the uptake of the chronic disease continuum model and the integration of palliative care with chronic disease health care. This includes: <ul style="list-style-type: none"> <li>– disseminating knowledge of best practices</li> <li>– promoting uptake, and</li> <li>– linking sectors and services through common practice, processes, structures and education.</li> </ul> </li> <li>• QHPCCO will expand its provincial representation to include chronic disease associations (i.e., Congestive Heart Failure, Chronic Obstructive Pulmonary Disease, Dementia, Diabetes, Stroke, Renal, Lung, etc).</li> </ul>

Shared Priorities	Specific Action Commitments
	<ul style="list-style-type: none"> <li>• LHINs will focus on developing regional palliative care programs and networks that are integrated with advanced chronic disease management sectors and services – including those not typically identified as palliative.</li> <li>• The Integrated Client Care Project will: <ul style="list-style-type: none"> <li>– expand the timeframe for palliative services to the last year of life</li> <li>– include people living with chronic diseases (as in the CCAC’s new population-based service models, where palliative care is a sub-population of both chronic and complex care).</li> </ul> </li> </ul>
<p><b>Enhance navigation and care coordination to improve access</b></p> <ul style="list-style-type: none"> <li>• Following diagnosis of a life-limiting illness, introduce a dedicated navigator to follow the individual throughout their disease process and ensure seamlessness across the necessary health care settings.</li> <li>• Promote awareness and support the cultural shift related to palliative care.</li> <li>• Encourage individuals diagnosed with a chronic disease to adopt a system navigator to promote knowledge and quality throughout the palliative care journey.</li> </ul>	<ul style="list-style-type: none"> <li>• Ontario Association of Community Care Access Centres (OACCAC) and Community Care Access Centres (CCACs) will build improved navigation and coordination into the ongoing implementation of their Client Care Model – initially targeting those with advanced chronic disease.</li> <li>• LHINs will engage CCACs or other Health Service Providers (HSPs) to implement enhanced navigation and coordination of care through: <ul style="list-style-type: none"> <li>– optimizing existing resources</li> <li>– building on learning from evidence-guided models as well as the Integrated Client Care Project (which includes navigation with many services outside the traditional CCAC or health care systems).</li> </ul> </li> <li>• MOHLTC will consider ways to improve coordination of care in the context of HPCO policy development.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Provide more equitable access across all population groups</b></p> <p>Improve access for:</p> <p><b>1. First Nations</b></p> <ul style="list-style-type: none"> <li>• Leverage learning and knowledge from research (e.g., “Developing End-of-Life Care in First Nations Communities,” a toolkit of evidence-informed community-based strategies to develop local palliative care programs, funded by Canadian Institutes of Health Research).</li> <li>• Ensure that people living in First Nations communities have access to culturally sensitive and appropriate palliative care services at home on reserve.</li> <li>• Ensure that Aboriginal people living in urban areas have access to culturally sensitive and appropriate palliative care services.</li> </ul> <p><b>2. Marginalized populations</b></p> <ul style="list-style-type: none"> <li>• Require correctional institutions to work with palliative experts to ensure that incarcerated individuals have access to palliative care.</li> <li>• Develop ways of identifying people in each community who could benefit from palliative services but are not currently identified as in need (e.g., those with chronic illnesses, homeless populations, residents of long-term care homes, etc).</li> <li>• Ensure resources are available to enable health care providers to provide interpreter services when needed for the individual and family – including print material, electronic or phone access.</li> <li>• Consider key findings and implications arising from research concerning the palliative care needs of people living with disabilities (e.g., VP-NET research) and develop new ways to improve access, delivery and support options to this population.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC will consider improving access to palliative care, particularly for noted population groups, in the context of ongoing policy development.</li> <li>• Researchers will make the findings of the referenced work available to MOHLTC and the Chiefs of Ontario via the Canadian Virtual Hospice website and other appropriate venues (January 2012 onwards).</li> <li>• The Health Director of Six Nations will work with the Chiefs of Ontario to advocate with MOHLTC and the federal government to address the jurisdictional issues that contribute to lack of palliative care services.</li> <li>• LHINs will ask their Aboriginal Health Leads to develop a coordinated plan to address this gap in service at the regional level.</li> <li>• MOHLTC will seek opportunities to raise awareness of the issue with federal and provincial ministries responsible for correctional services.</li> <li>• Through their Regional Networks/Programs, LHINs will develop a plan to identify people who are chronically ill or otherwise marginalized and would benefit from palliative care services, but are currently not receiving access. As part of this plan, LHINs will engage the appropriate stakeholders. These could include the Quality End of Life Care Coalition of Canada, VP-NET researchers and various associations.</li> <li>• As part of this process, LHINs will consider population needs, as well as rural and urban characteristics, and initiate planning discussions with HSPs in all care settings.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Provide more equitable access across geographies</b></p> <p>Develop and implement a provincial model of rural palliative care based on best practices specific to the realities of rural and remote areas.</p> <p>The goal is to ensure that people living in rural and remote communities have access to appropriate care services that enable them to remain in their communities and in their own homes as long as possible.</p>	<ul style="list-style-type: none"> <li>• MOHLTC will consider improving access to palliative care to rural and remote communities in the context of ongoing policy development.</li> <li>• Hospice Palliative Care Ontario (HPCO) will initiate a dialogue with hospices on expanding the volunteer’s scope of practice in response to increasing pressure from rural communities for volunteers to do more. At the April 2012 provincial conference, HPCO will host an open space event for visiting hospice services to examine scope of practice for volunteers and determine how the scope may be widened.</li> <li>• Through their Regional Networks/Programs, and working collaboratively with HSPs and other local health and social service providers, LHINs will develop an integrated regional plan and model to deliver community rural palliative care, building upon local resources.</li> <li>• Rural palliative care researchers will synthesize best practices from their work and the literature to inform LHIN planning – including a review of “Timely access and seamless transitions in rural palliative/end of life care” and Niagara-West “Shared Care” teams.</li> <li>• Through their Regional Networks/Programs, LHINs will: <ul style="list-style-type: none"> <li>– engage the Ontario Telemedicine Network about opportunities to leverage its technology to improve access to Telehomecare, remote consultation and other strategies</li> <li>– leverage learnings through the Integrated Client Care Project.</li> </ul> </li> <li>• HPCO will work with MOHLTC, Ontario College of Nurses, Registered Nurses Association of Ontario and the Registrar General’s office to implement the Expected Death in the Home protocol. This will allow a nurse to certify death and arrange removal of the body from the home.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Create effective planning and measurement tools to ensure resources are used optimally, based on needs</b></p> <ul style="list-style-type: none"> <li>• Develop benchmarks for population-based capacity and resource utilization, and ensure resources are distributed equitably.</li> <li>• Measure use of services to ensure that most people receive ongoing care and support through primary or blended primary/secondary teams. The goal is to reserve direct services from specialists for the small percentage of individuals with highly complex needs – except for paediatrics, where specialists may act in a primary role.</li> <li>• Further explore and clarify the expectations of different care settings as part of an integrated continuum of care. Examples include Complex Continuing Care, Long-Term Care Homes, hospitals (acute, rehab and tertiary), Residential Hospices and any other setting where individuals live and die – such as an individual’s home, retirement home, group homes, or shelters.</li> </ul>	<ul style="list-style-type: none"> <li>• In the context of an overarching data strategy for palliative care, MOHLTC and LHINs, working with Health Quality Ontario (HQP) and other experts, will assess palliative population-based and resource utilization benchmarks. These will include: <ul style="list-style-type: none"> <li>– exploring jurisdictional, regional and organizational comparisons</li> <li>– leveraging work completed as part of the Integrated Client Care Project.</li> </ul> </li> <li>• Through their Regional Networks/Programs, LHINs will seek opportunities to implement agreed upon benchmarks through their normal planning processes.</li> </ul>

Shared Priorities	Specific Action Commitments
<b>KEY ISSUE: STRENGTHEN CAREGIVER SUPPORTS</b>	
<p><b>Empower clients and caregivers</b></p> <ul style="list-style-type: none"> <li>• Develop a “caregiver declaration of rights” and embed it in HSP service plans to clarify expectations and accountability for all partners to support informal caregiving.</li> <li>• Develop a “client declaration of rights” to embed in HSP service plans and build on existing legislative rights.</li> <li>• Include the individual and their family and designates in developing the goals of care and an overall care plan, as well as organizing the team to the extent the person wishes.</li> <li>• Encourage the use of client and family care conferences with the inter-professional care team to discuss or update goals of care, disease prognosis and advance care planning, as well as provide overall information and support.</li> <li>• Adopt self-management as a core philosophy where appropriate, respecting individual choices and independence.</li> <li>• Build definition of palliative care into existing caregiver education programs, university and college programs, and patient and family education materials. The goal is to improve understanding of individuals, families, care providers and society that palliative care is not only for end of life. This will lead to earlier willingness for people to be identified as benefiting from palliative supports.</li> </ul>	<ul style="list-style-type: none"> <li>• Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) will develop a “caregiver declaration of rights.” Work will include a review of existing “care” or “caregiver” bills (legislation) or declarations (policy) of rights within Ontario as well as nationally and across other jurisdictions.</li> <li>• QHPCCO will develop a “client declaration of rights” that builds on existing legislative rights. Work will include a review of the Canadian Hospice Palliative Care Association (CHPCA) Patient/Client Bill of Rights and feedback from LHINs through their Regional Networks/ Programs.</li> <li>• Following completion, QHPCCO will work with its members and LHINs will work with their HSPs to embed the declaration of rights into their service plans. Sectors/HSPs will include the individual and their family and designates in developing the goals of care and overall care plan and organizing the team to the extent the person wishes.</li> <li>• MOHLTC and LHINs will seek direction to publicly engage individuals and caregivers more broadly to further inform policy directions and actions.</li> <li>• The Integrated Client Care Project is using experienced-based design to ensure that services for any one client/patient and family/ caregivers are built upon individual needs and preferences.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Develop more flexible benefits</b></p> <ul style="list-style-type: none"> <li>• Educate individuals and families about the Compassionate Care Benefit when appropriate at end of life.</li> <li>• Leverage and strengthen policy related to all unpaid support systems, based on current evidence and knowledge about caregiver support requirements. For example, advocate for the extension of the Compassionate Care Benefits from 6 weeks to the CHPCA model, where opportunities arise – including the Health Accord with respect to existing provincial and federal caregiver benefits.</li> <li>• Liaise with corporate and business sectors to promote the value in ensuring employees have access to appropriate caregiver support benefits.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC will seek opportunities to raise issues with other provinces/territories and with the federal government related to federal programs and funding to support caregivers.</li> <li>• QHPCCO and MOHLTC will examine the recommendations of the federal parliamentary committee on palliative and compassionate care to improve caregiver benefits.</li> <li>• QHPCCO will liaise with CHPCA and private and public business leaders to promote corporate awareness. This work can involve Ontario Chambers of Commerce and other business-led initiatives.</li> <li>• QHPCCO will gather examples of workplace policies from across Ontario in all sectors that support employees to take compassionate leave. They will then identify and publicly acknowledge best and leading practices.</li> </ul>
<p><b>Improve access to services and support</b></p> <p><b>Bereavement</b></p> <p>Access to grief and bereavement support is core to palliative care delivery. LHINs and HSPs should ensure that appropriate bereavement support is available, based on need, before and after the death of a loved one.</p> <p><b>After Hours Support</b></p> <p>Care teams need to provide individuals and their family members with clear information and a designated point of contact to use when questions or issues arise after normal business hours. This will ensure that the hospital ER is not the default. The point of contact could vary according to the individual’s needs and their care setting. The contact might also change over time.</p>	<ul style="list-style-type: none"> <li>• LHINs and HSPs will review program mandates and seek opportunities to expand the availability of bereavement services. LHINs will clarify the expectation that HSPs should proactively follow up with family members after a client’s death to identify whether they need bereavement support.</li> <li>• The Integrated Client Care Project has defined bereavement services as an integral part of palliative care.</li> <li>• LHINs will clarify the expectation for 24/7 support in accountability agreements with all HSPs.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Improve information provided to caregivers</b></p> <p>All partners will work together to:</p> <ul style="list-style-type: none"> <li>• Identify caregiver needs in different contexts (community, long-term care, rural, dementia care, etc.) and develop a simple pamphlet and supporting toolkit for caregivers that raise awareness and provide guidance.</li> <li>• Strengthen and leverage existing on-the-ground supports for informal caregivers. These include financial, skill building, social networking, mentorship, and web-based supports.</li> </ul>	<ul style="list-style-type: none"> <li>• QHPCCO will centrally coordinate common information guides and develop a common toolkit. This toolkit would be available provincially and adopted by all regions and available to all sectors. It will include supports resulting from this work as part of the “Central Hub.” (See public awareness actions below.)</li> <li>• Through their Regional Networks/Programs, LHINs will build on the common toolkit by supplementing and maintaining information that is specific to their region – including information on available programs.</li> <li>• Through their Regional Networks/Programs, LHINs will examine ways to strengthen and leverage existing on-the-ground supports for informal caregivers.</li> </ul>
<p><b>Measure the experience of individuals and caregivers and engage them in system planning and evaluation to continually improve experience</b></p> <ul style="list-style-type: none"> <li>• Explore the use of a standardized tool or objective proxies to measure individual and caregiver experience based on the entire episode of care – including their experience of continuity and service quality across different care settings. Explore how the system can report regularly on individual and caregiver experience as part of the proposed balanced scorecard approach.</li> </ul>	<ul style="list-style-type: none"> <li>• The MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will work to develop a process to collect data on patient experience in the context of an overall palliative care data strategy. This will include leveraging work completed as part of the Integrated Client Care Project.</li> </ul>



Shared Priorities	Specific Action Commitments
<b>KEY ISSUE: STRENGTHEN SERVICE CAPACITY AND HUMAN CAPITAL IN ALL CARE SETTINGS</b>	
<p><b>Strengthen primary delivery through access to secondary and tertiary level expertise</b></p> <ul style="list-style-type: none"> <li>• Ensure primary and secondary care providers in each community have timely and appropriate access to specialized palliative expertise. This may involve making inter-professional palliative consult teams available to all care settings and creating shared processes for education, mentorship and specialized consultation.</li> <li>• Provide expert palliative care (when it is needed) through an inter-professional team approach that includes skilled palliative care service providers becoming a part of the core team of primary providers.</li> <li>• Determine what resources are needed within each community to ensure access to palliative consult team(s).</li> <li>• Avoid duplication of consultation level services in any one region.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC will consider ways to strengthen primary delivery in the context of ongoing policy development.</li> <li>• Through their Regional Networks/Programs, LHINs will examine ways to strengthen and leverage access to palliative care expertise at all levels (primary, secondary, tertiary).</li> <li>• Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) will synthesize available literature and evidence-based consultation team models, any identified population guidelines, funding formulas, etc. They will provide this information to LHINs through their Regional Networks/Programs to support planning.</li> <li>• Through their Regional Networks/Programs, LHINs will complete a gap analysis of what currently exists within each LHIN area to determine what resources can be leveraged or what new resources may be required.</li> </ul>
<p><b>Establish consistent and standardized<sup>6</sup> education and competency requirements for all levels of care provision across care settings</b></p> <ul style="list-style-type: none"> <li>• Adopt the Canadian Hospice Palliative Care Association (CHPCA) model of “Provider Roles in Hospice Palliative Care” (e.g., <b>primary, secondary, and tertiary</b>).</li> <li>• Involve professional colleges in the development of palliative care education at all levels. Implement palliative care core competencies as part of the basic training curriculum for health professionals – including regulated and non-regulated professionals working in palliative care.</li> <li>• Base educational training for all palliative care providers on the “Domains of Issues Associated with Illness and Bereavement” (CHPCA, 2002).</li> </ul>	<ul style="list-style-type: none"> <li>• Quality Hospice Palliative Care Coalition of Ontario (QHPCCO), working together with the Palliative Care Consultants Network and the relevant associations, will gather competency documents related to palliative care for all professional disciplines. This initiative will: <ul style="list-style-type: none"> <li>– Identify palliative care competencies for each discipline (regulated and non-regulated) at each level (primary, secondary, tertiary).</li> <li>– Provide a snapshot survey of current competencies of palliative care providers in all care settings. This will be used to determine a baseline.</li> <li>– Include a scan of competencies being developed through research (e.g., Lakehead University work on palliative care competencies for Personal Support Workers in long-term care homes).</li> <li>– Identify gaps.</li> </ul> </li> </ul>

<sup>6</sup> For the purposes of this document, standardized delivery, education or tools means that common core elements will be consistently available provincially, while respecting and promoting the need for local flexibility and adaptation through implementation.

Shared Priorities	Specific Action Commitments
<ul style="list-style-type: none"> <li>• Deliver clear communication targeted at new and existing health care professionals and HSPs to ensure these palliative care competencies are met.</li> <li>• Ensure education targets those who will be in a position to put the skills into practice, building champions.</li> <li>• Consider making research and knowledge translation a standard for Inter-professional Practice.</li> </ul> <p><b>For Primary Care Providers:</b> Incorporate palliative care into core services across the primary health care system. This includes Family Health Teams (FHTs), Community Health Centres (CHCs), etc. Education and chronic disease programs will integrate palliative care early in the illness trajectory.</p> <p><b>For Nurse Practitioners (NPs):</b> Consider innovative ways to optimize the role of Nurse Practitioners (NPs) in the system – in particular, to leverage the new palliative care NP investments from MOHLTC to accelerate system change. This will include finding ways to train NPs in palliative care competencies through coaching and mentoring models that leverage the skill and expertise of Palliative Pain and Symptom Management Consultants.</p> <p><b>For Personal Support Workers (PSWs):</b> Identify core competencies that align with other inter-professional team members to strengthen the role and recognition of PSWs as a critical team member. HSP training activities should highlight the role of PSWs and the value they bring to the client experience – rather than just the tasks they perform in care delivery.</p> <p><b>For Volunteers:</b> Ensure that all palliative care volunteers (including non-hospice volunteers) have appropriate and specific palliative training. Identify gaps where training may not exist and commission the development of the related curricula.</p>	<ul style="list-style-type: none"> <li>• Based on the above, MOHLTC, LHINs, and QHPCCO will seek opportunities to raise awareness of issues and gaps with the Ministry of Training, Colleges and Universities and professional colleges. The goal is to strengthen palliative care core competencies as part of the training curriculum for health care workers.</li> <li>• The QHPCCO and the Palliative Care Consultants Network will: <ul style="list-style-type: none"> <li>– Provide education aimed at the three streams (primary, secondary and tertiary) to support continuing education needs and teach the identified competencies.</li> <li>– Ensure their representative sitting on the Canadian Nurses Association (CNA), College of Nurses of Ontario (CNO) and Registered Nurses’ Association of Ontario (RNAO) advisory committees are aware of the issues related to education and practice requirements at each tier.</li> </ul> </li> <li>• LHINs will clarify expectations that HSPs ensure their staff and volunteers receive appropriate ongoing education and skill training.</li> <li>• Ontario College of Family Physicians (OCFP) will engage the Ontario Medical Association (OMA) and regional medical societies to provide education on new OCFP-endorsed standards of practice.</li> <li>• QHPCCO will work with Hospice Palliative Care Ontario (HPCO) to identify gaps where training may not exist and also leverage existing volunteer competencies and education programs (e.g., training or certification programs).</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Develop a comprehensive curriculum for health care service providers at all levels</b></p> <p>Ensure that curriculum for care providers includes:</p> <ul style="list-style-type: none"> <li>• A social science based practice</li> <li>• Knowledge exchange on cultural norms</li> <li>• A relational-based, diversity approach</li> <li>• A focus on grief and bereavement care at all levels, but emphasized at the primary level as fundamental to care pre- and post-death</li> <li>• A health and wellness model for families and care teams. This model may include mindfulness meditation for non-pharmacy pain management, stress reduction, managing depression/anxiety/ self-regulation and enhancing resiliency (as in the work of Dr. Richard Davidson, Dr. Dan Segel)</li> <li>• The integration of Chronic Disease Management into each level of palliative care (primary, secondary, tertiary) and vice versa</li> <li>• Education supports for students in each of the three levels of care</li> <li>• Opportunities for ongoing interdisciplinary education for existing palliative care providers</li> <li>• Self-management strategies – including caregiver and client education in symptom management and advanced care planning</li> <li>• New or adapted education models based on cultural needs, taking into account intergenerational considerations.</li> <li>• The law regarding Health Care Consent and Substitute Decisions Act</li> </ul> <p>Our goal is to support an evolving and evidence-based curriculum that is informed by research and knowledge translation from education institutions and the evaluation of practice – including social science-based practices.</p>	<p>See above: MOHLTC, LHINs and QHPCCO will seek opportunities to raise awareness of issues and gaps with the Ministry of Training, Colleges and Universities and professional colleges. Together, they will work to strengthen palliative care core competencies as part of training curriculum.</p>

Shared Priorities	Specific Action Commitments
<p><b>Enhance skill and expertise available in coaching, mentoring and other specialized support</b></p> <ul style="list-style-type: none"> <li>• Identify coaching and mentoring roles required at each level of care (primary, secondary, and tertiary).</li> <li>• Develop competencies for coaching and mentoring.</li> <li>• Include coaching and mentoring skills as part of the competencies at each level of education/training and care.</li> <li>• Establish an expectation that providers need to access coaches and mentors.</li> <li>• Establish a coaching/mentoring program in each inter-professional team in the community.</li> <li>• Provide education on coaching strategies, such as “knowledge to action,” especially to secondary and tertiary experts.</li> <li>• Introduce funding to incent individuals to provide coaching and mentoring.</li> </ul>	<ul style="list-style-type: none"> <li>• Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) will develop a work plan to survey existing information on coaching and mentoring strategies.</li> <li>• Through their Regional Networks/Programs, LHINs will complete a gap analysis of what currently exists within each LHIN area to determine: <ul style="list-style-type: none"> <li>– what resources can be leveraged</li> <li>– recommendations for capacity building and improvements.</li> </ul> </li> </ul>
<p><b>Create a central hub for care providers that coordinates hands-on coaching, mentoring and other specialized support</b></p> <p>Create a Central Hub to support care delivery across the three levels of care. The Hub will:</p> <ul style="list-style-type: none"> <li>• Provide a single source of expert advice and information that is accessible in multiple ways – including internet, social networking, email, telecommunications, outreach, etc.</li> <li>• Include a central registry of palliative care mentors for all levels of care providers (primary, secondary and tertiary).</li> <li>• Introduce regular sessions and small group solution-based learning, as well as other multi modal approaches – including telecommunications and social media. The goal is to enhance knowledge transfer/knowledge exchange/knowledge to action across care providers.</li> <li>• Ensure it is a safe place for sharing and for enquiries.</li> </ul>	<p>MOHLTC, LHINs and QHPCCO, working collaboratively, will consider options and seek opportunities to develop a “central information hub,” including consideration of what existing resources can be leveraged.</p>

Shared Priorities	Specific Action Commitments
<p><b>Broaden physician engagement</b></p> <ul style="list-style-type: none"> <li>• Ensure the right financial incentives and delivery supports are in place to broaden and optimize physician engagement in palliative care across the continuum.</li> <li>• Improve uptake of palliative care billing codes (including Alternative Payments Program (APP) funding, etc.) and applications for facilitated access.</li> <li>• Explore new billing practices for consultation and shared care support in palliative care units and other care settings.</li> </ul>	<ul style="list-style-type: none"> <li>• OCFP, together with MOHTLC and LHINs, will seek opportunities to enhance physician engagement. Examples include the Integrated Client Care Project, LHIN palliative care leads and OMA negotiations.</li> <li>• All Integrated Client Care Project palliative sites have engaged physician leaders to build/strengthen the relationships among family physicians, palliative specialists, community outreach teams, community nurses and case managers.</li> <li>• OCFP (with MOHLTC and OMA) will review palliative care billing practices (including paediatricians) for barriers and opportunities to: <ul style="list-style-type: none"> <li>– innovate</li> <li>– educate</li> <li>– optimize best use of resources.</li> </ul> </li> <li>• OCFP will ensure family physicians are aware of existing billing codes.</li> </ul>
<p><b>Optimize residential hospices to support those who cannot be cared for at home but do not require hospital care</b></p> <ul style="list-style-type: none"> <li>• Ensure Ontario residents have equitable access to residential hospices, where care in this setting is the most appropriate and cost-effective, based on individual and family preferences and level of need.</li> <li>• Establish an appropriate level of consistency across regions.</li> <li>• Review client segments (e.g., profile and needs) and care delivery models within existing free-standing residential hospices to understand any variations in delivery, cost and outcomes.</li> <li>• Explore establishing formal accountability relationships with LHINs.</li> <li>• Consider innovative approaches to reduce capital costs. Examples include using existing spaces, expanded volunteer practice, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• HPCO and Provincial End-of-Life Care Network (PEOLCN), along with MOHLTC and the LHINs, will launch a residential hospice action group. Together, they will further explore issues (including policy and delivery) and develop a business case for change.</li> <li>• HPCO has convened a rural residential hospice working group to look at alternate models of care in rural settings. The group is to report back in January 2012.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Strengthen and optimize palliative care delivery in long-term care homes (LTCHs)</b></p> <p>Focus LTCH improvement activities on enhancing the palliative care experience for residents and their families. Priorities include:</p> <ul style="list-style-type: none"> <li>• Identify current challenges and improvement activities/opportunities in LTCHs to enable effective delivery of palliative care.</li> <li>• Complete a gap analysis of the resources and supports required to deliver palliative care in LTCHs – including specialty palliative care physicians and consult teams.</li> <li>• Prioritize resources, training and mentorship to support effective pain and symptom management.</li> <li>• Review regulations and compliance in LTCH to ensure they enable a shift to the new palliative care model. This includes transitioning from using Levels of Care forms as plans of treatment to a process that complies with legislation.</li> <li>• Explore the redevelopment of Learning Essential Approaches to Palliative and End of Life Care (LEAP) for LTCH.</li> <li>• Ensure integration with other care settings in cases where LTCH residents receive care outside the facility (e.g., residential hospice, palliative care in-patient bed, etc).</li> <li>• Leverage learning and knowledge from existing research to inform clinical, operational, policy, educational &amp; community engagement interventions. Examples here include SSHRC funded research, “Quality Palliative Care in Long Term Care Alliance.”</li> <li>• Ensure “Centre of Excellence” models for LTCH will include a research, delivery and training focus on optimizing pain and symptom management and comfort measures.</li> </ul>	<ul style="list-style-type: none"> <li>• Relevant associations (OLTCA, OANHSS, Ontario Long Term Care Physicians) together with PEOLCN, MOHLTC and LHINS, will launch an action group to: <ul style="list-style-type: none"> <li>– discuss how the hospice philosophy and approach to care may be implemented in LTCHs</li> <li>– further explore issues in moving forward, including policy and delivery</li> <li>– develop a business case for change.</li> </ul> </li> <li>• Ontario Long-Term Care Association (OLTCA) and the Ontario Association of Non-Profit Homes &amp; Services for Seniors (OANHSS) will develop and deliver education based on the “Quality Palliative Care in Long Term Care Alliance.” This is a toolkit of evidence-based clinical, policy, educational and community engagement interventions.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Strengthen and optimize palliative care delivery in hospitals</b></p> <ul style="list-style-type: none"> <li>• Develop a high functioning and well-integrated palliative care strategy. This strategy will fully consider the role of all kinds of hospitals (acute, complex continuing care and others) in providing palliative care and reflect how different hospitals play different roles.</li> <li>• Enable hospitals to work collaboratively with other stakeholders in an effort to provide greater clarity as to the role of different hospitals and to help drive quality improvement.</li> <li>• Enable hospitals to share their knowledge and best practices and be a partner in advancing any system changes required to deliver palliative care.</li> <li>• Determine a baseline of existing models for palliative care delivery and the typical patient profile/needs in different hospital settings (e.g., acute, rehab, complex continuing care).</li> <li>• Establish or have access to ethics committees or ethics consultation across care settings. This is to address ethical conflicts at the end of life for children, adults and inter-professional teams.</li> </ul>	<ul style="list-style-type: none"> <li>• Ontario Hospital Association (OHA) and member hospitals, working with PEOLCN, MOHLTC and LHINs, will establish an action group to further explore issues (including policy and delivery) and develop a business case for change.</li> <li>• The Integrated Client Care Project is engaging hospitals as essential partners to collaborate on: <ul style="list-style-type: none"> <li>– making better use of specific hospital palliative resources</li> <li>– avoiding emergency room visits and unexpected hospitalizations whenever possible.</li> </ul> </li> <li>• Through their Regional Networks/Programs and HSPs, LHINs will ensure that hospitals are engaged as partners in integrated delivery processes and mechanisms.</li> </ul>

Shared Priorities	Specific Action Commitments
<b>KEY ISSUE: IMPROVE INTEGRATION AND CONTINUITY ACROSS CARE SETTINGS</b>	
<p><b>Support integrated delivery through teams</b></p> <ul style="list-style-type: none"> <li>• It is vital to provide care through an inter-professional care team approach. Teams will be fluid in their members as defined by individual/family need throughout the illness journey. They will include palliative care specialists and palliative consult teams when appropriate.</li> <li>• The person and family are at the centre of the care. An overall care plan is developed collaboratively by providers, client and family to ensure it is woven around the individual needs of the person and family.</li> <li>• Providers in each care setting are part of a “virtual team” that spans all the care settings and sectors through which the person may pass. The team ensures that psychosocial and spiritual supports are a core component of the team approach.</li> <li>• Professional members of the care team make referrals to volunteer services. They acknowledge that informal care providers and volunteers are an integral part of the team (as directed by the person and family).</li> <li>• Care in any care setting and by any set of providers is part of an overall care plan. The plan follows the person throughout their illness and is shared through all settings, seamlessly. This includes community pharmacies, home care providers, community support services, hospitals, Complex Continuing Care, LTCHs and retirement homes.</li> <li>• Care plans reflect the individual’s wishes and are updated as circumstances evolve. Plans will include common elements that should be standard for all people receiving palliative care services.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC policy statements will endorse care delivery through the use of integrated teams.</li> <li>• LHINs, QHPCCO and relevant associations will leverage learning from the Integrated Client Care Project and/or other evidence-guided models.</li> <li>• The goal is to build strong teams through functional realignment.</li> <li>• The Integrated Client Care Project is testing local integration and shared accountability. The understanding is that the “team” for any one client/patient and family/caregivers is unique and reflects the needs and preferences of the client. It will often include providers from outside the traditional Community Care Access Centres (CCACs) and health care sector.</li> <li>• MOHLTC will review existing programs that do not have LHIN-based boundaries (e.g., pain and symptom management consultants).</li> <li>• LHINs will begin to implement the vision through service planning with Regional Networks/Programs and HSPs. This will include establishing expectations for palliative care philosophies and supports to be included in integrated care and for standardized delivery across all care settings within a region/community. Expectations will be included in HSP accountability agreements. The goal is to effectively implement the integrated team-based approach.</li> </ul>



Shared Priorities	Specific Action Commitments
<p><b>Develop common, standardized processes and practices, where appropriate, across all settings</b></p> <ul style="list-style-type: none"> <li>• Identify standardized evidence-based screening tools, assessment tools and guides to practice that can be linked across all LHINs, care settings and levels of care for all life-limiting diagnoses/chronic diseases. This may involve the adaptation and adoption of current best practice tools (e.g., Palliative Performance Scale).</li> <li>• Agree on which standard elements to implement for screening, assessment and guides to practice that align with best practices and the Palliative Care – Chronic Disease Continuum model.</li> <li>• Streamline referrals to palliative care settings (e.g., residential hospices and palliative care units, etc.) across LHINs and, where possible, across the province.</li> <li>• Use evidence-guided palliative care practice standards as part of Chronic Disease management in all care settings.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC policy statements will endorse common processes and practices.</li> <li>• The Integrated Client Care Project will align with the OCFP best practice work. In the meantime the Integrated Client Care Project is using the Canadian Hospice Palliative Care Association (CHPCA) standards and is developing expectations of what must be consistent across the province.</li> <li>• Through their Regional Networks/Programs, LHINs will clarify expectations for standardized delivery across all care settings within a region/community to effectively implement the integrated team-based approach to care. This will include working with researchers and HSPs to assess what work is required and address any gaps, barriers or common issues. This will enable LHINS to implement linked screening, assessment and care-planning tools in all care settings, using shared technology as an enabler.</li> <li>• QHPCCO and relevant associations will work with members to promote the adoption of evidence-based best practices.</li> </ul>
<p><b>Use innovative technologies to enable integrated delivery</b></p> <ul style="list-style-type: none"> <li>• Leverage technology solutions that currently exist as enablers for integration and coordination.</li> <li>• Evaluate and adopt solutions with features that support client-centred care, including ease of implementation and expandability.</li> <li>• Link these solutions with eHealth strategies to develop interfaces between systems. For example, identify technology enablers to support the transmission of a client care plan across care providers.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC and LHINs will consider technologies in the context of broader e-Health strategies.</li> <li>• LHINs, QHPCCO and relevant associations will leverage learning from the Integrated Client Care Project and/or other evidence-guided models.</li> <li>• The Integrated Client Care Project will reimburse CCAC-contracted providers in a way that will stimulate experimentation with innovation, including technology.</li> </ul>

Shared Priorities	Specific Action Commitments
<b>KEY ISSUE: STRENGTHEN ACCOUNTABILITY AND INTRODUCE MECHANISMS FOR SHARED ACCOUNTABILITY</b>	
<p><b>Establish cross-sector accountability at the clinical level</b></p> <p>Implement a mechanism to ensure accountability for provider performance (related to palliative care and advanced chronic disease) in each care setting where people die. This mechanism will clearly articulate and implement the following actions:</p> <ul style="list-style-type: none"> <li>• Clarify the accountability of all HSPs to integrate their delivery and function effectively as part of an extended virtual team. The goal is to ensure that care in any care setting and by any set of providers is part of an overall care plan (see integration section above).</li> <li>• Standardize performance monitoring and outcome tracking at the client/team level through a clearly defined process.</li> <li>• Hold each member of the team directly accountable to the person receiving care.</li> <li>• Hold the team as a whole accountable for their contribution towards achieving the care plan goals.</li> <li>• Ensure that the team monitors and responds to personal and family experience data or other standardized quality indicators.</li> <li>• Require that publicly funded providers share accountability for improving population and system performance outcomes.</li> <li>• Ensure that clinical programs implement best practices that are aligned with local, regional and provincial priorities and objectives.</li> <li>• Create mechanisms for team members to be accountable to each other (for example, through shared, transparent mutual performance reporting, tiered mediation and conflict resolution).</li> </ul>	<ul style="list-style-type: none"> <li>• LHINs will establish the required mechanisms through accountability agreements with each HSP.</li> <li>• Through their Regional Network/Programs, LHINs will develop a standard template to codify the shared accountability of those working in extended inter-professional teams in relation to: <ul style="list-style-type: none"> <li>– each other</li> <li>– their contribution to common client and team goals.</li> </ul> </li> <li>• QHPCCO and relevant associations will work with members to build capacity and readiness to implement. This process will include engagement with: <ul style="list-style-type: none"> <li>– HSPs (CCAC/community service provider agencies)</li> <li>– hospices</li> <li>– hospitals (acute care, tertiary and complex continuing care)</li> <li>– LTCHs</li> <li>– Palliative consult teams</li> <li>– primary care and other providers.</li> </ul> </li> <li>• MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will consider performance indicators and data collection mechanisms in the context of an overall palliative care data strategy. This will include leveraging work completed as part of the Integrated Client Care Project.</li> <li>• The Integrated Client Care Project is testing the development of shared assessment, shared care plans and shared accountability among all of the providers for each client/patient.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Establish cross-sector accountability at the organizational level</b></p> <p>Implement a mechanism to ensure organizational accountability/governance so that:</p> <ul style="list-style-type: none"> <li>• Palliative care is provided as needed in each care setting where people die.</li> <li>• Organizational resources are able to participate collaboratively and effectively in cross sector/ cross service teams.</li> </ul> <p>Also clarify accountability of organizations to add value (i.e., track outcomes relative to cost and strengthen performance and reporting relationships):</p> <ul style="list-style-type: none"> <li>• Each organization is responsible for monitoring performance, including client and family experience, and tracking outcomes related to hospice palliative care.</li> <li>• Organizations’ performance systems will be aligned with local, regional and provincial priorities and demonstrated in accountability agreements and Health Quality Ontario reporting requirements.</li> </ul> <p>Create mechanisms for organizations to be accountable to each other:</p> <ul style="list-style-type: none"> <li>• Each organization is responsible for monitoring performance and tracking outcomes as to how that care is integrated within the overall care plan. Performance will be benchmarked and transparent.</li> <li>• Organizations are accountable for supporting their staff to function effectively as part of extended teams and to ensure teams meet performance and quality expectations to achieve the goals of care.</li> </ul>	<p>See above.</p> <p>In addition, through their Regional Network/ Programs, LHINs will develop a standard template to codify organizational accountability (cross-sector and shared).</p>
<p><b>Establish stronger governance at the regional level</b></p> <ul style="list-style-type: none"> <li>• Strengthen or develop a comprehensive integrated Hospice Palliative Program in each LHIN. This program will foster inter- and intra-agency accountability at the regional level, ensuring that agencies and programs work together. LHINs will use existing or improved network/program structures that are accountable to and funded by the LHIN and are based on the provincial policy statement.</li> </ul>	<ul style="list-style-type: none"> <li>• LHINs will enhance or establish a LHIN-Regional Network/Program task force to initiate action on the identified priorities and proposed next steps. This initiative will require a detailed work plan and projections based on the achievement of other milestones. The work plan could be based on Champlain program steps and other successful models. Once enhanced, Regional Networks/Programs will be able to lead this and many other processes.</li> <li>• LHINs are to initiate these actions immediately after engagement strategy is in place and fully implement 1–3 years after Engagement Strategy Report.</li> </ul>

Shared Priorities	Specific Action Commitments
<ul style="list-style-type: none"> <li>• Promote the key principle of equitable access and opportunity for all Ontarians by supporting a consistent approach to regional palliative care service planning.</li> <li>• Strengthen/establish structured regional networks/programs acting in a delegated and/or advisory capacity to the LHINs. Members would represent all palliative care sectors/services (funded and non-funded); sectors/services concerned with advanced chronic disease management (but not typically identified as part of the palliative care sector); and appropriate community members (representing people and families).</li> <li>• Ensure adequate, consistently funded leadership of all Regional Networks/Programs.</li> <li>• Continue to oversee and monitor the performance of the Regional Network/Program to ensure it: <ul style="list-style-type: none"> <li>– operates in an efficient, effective manner; streamlines delivery</li> <li>– adds value to the LHINs and Ontarians</li> <li>– does not create unnecessary additional administrative burdens or layers, through the application of LEAN principles and processes where appropriate.</li> </ul> </li> <li>• Establish clear, consistent and transparent accountability relationships between MOHLTC, LHIN and Regional Networks/Programs and fund holding agencies (HSPs).</li> </ul>	<ul style="list-style-type: none"> <li>• Through their Regional Networks/Programs, LHINs will: <ul style="list-style-type: none"> <li>– develop integrated regional palliative care service delivery plans and outcomes</li> <li>– identify palliative care as a regional inter- and intra-agency priority</li> <li>– mandate minimum (integrated) standards for palliative care in all settings.</li> </ul> </li> <li>• LHINs will work with Regional Networks/Programs to promote integration strategies within accountability agreements with each health service provider. The strategies should ensure that collaboration occurs at all levels of planning and service delivery. In this way, policy/advisory statements will ease integration. For example, LHINs will develop and establish palliative care policy/advisory statements which will articulate that all care settings for dying individuals will: <ul style="list-style-type: none"> <li>– offer palliative care programming</li> <li>– report on this programming.</li> </ul> </li> </ul> <p>Regional Networks/Programs will:</p> <ul style="list-style-type: none"> <li>– Establish recommendations for a regional plan aligned with the provincial strategy</li> <li>– Receive regular reports submitted to LHINs from palliative care agencies, teams and other providers as needed, to establish evidence of adequate clinical service levels and quality performance metrics</li> <li>– Identify regional service gaps and priorities</li> <li>– Identify and recommend resources needed to address priorities</li> <li>– Identify and recommend ways to improve integration, including opportunities to ensure practices to manage advanced chronic disease will effectively incorporate a palliative care approach</li> <li>– Advise LHINs on how funding should flow across the system</li> <li>– Implementing consistent mandate for Regional Networks/Programs in each LHIN to strengthen equity across LHINs</li> <li>– Advise the LHINs in developing, implementing and overseeing accountability agreements with all key sectors and organizations that deliver palliative care services to the targeted client group.</li> </ul>

Shared Priorities	Specific Action Commitments
	<p>– Provide advice and recommendations to the LHINs on new programs, initiatives and funding proposals. The goal is to ensure that these are integrated to reduce duplication and fill gaps – helping to ensure that the individual and family experience is one of seamless access to and continuity of an overall agreed plan of care.</p>
<p><b>Strengthen provincial policy guidance and direction</b></p> <p>Priorities for strengthening provincial policy and accountability include:</p> <ul style="list-style-type: none"> <li>• Establish a provincial policy statement or service plan that supports a consistent approach to regional palliative care service planning.</li> <li>• Embed effective accountability measures for LHINs in existing Ministry-LHIN Accountability Agreements (MLPAs).</li> <li>• Establish clear policy, legislative and regulatory frameworks for best practices in palliative care delivery.</li> <li>• Use funding levers to ensure equitable funding while shifting sectors towards outcome-based payment models, where practical and appropriate.</li> <li>• Review funding plans for physician services.</li> <li>• Establish a centralized process to ensure ongoing oversight of the palliative care system in Ontario. This may be a newly created role or a revision of an existing process to include broader palliative care oversight (e.g., ER Alternate Level of Care (ALC) process, LHIN Collaborative (LHINC) etc).</li> </ul>	<p>MOHLTC will consider and seek direction in relation to ongoing policy development that ensures equitable access to high quality palliative care services for the people of Ontario.</p>

Shared Priorities	Specific Action Commitments
<p><b>Strengthen accreditation and academic research</b></p> <ul style="list-style-type: none"> <li>• Promote involvement of palliative care services/programs in all voluntary standardized accreditation/evaluation processes – whether provincial, national or international.</li> <li>• Promote provincial funding opportunities for academic research specializing in palliative care.</li> </ul>	<ul style="list-style-type: none"> <li>• Quality Hospice Palliative Care Coalition of Ontario (QHPCCO – including PEOLCN and HPCO) will request an opportunity to work with Accreditation Canada, Commission on Accreditation of Rehabilitation Facilities (CARF), etc., to include palliative care standards within the standard statements of each care setting where individuals die.</li> <li>• QHPCCO (including PEOLCN and HPCO) will identify appropriate voluntary accreditation options for various settings to consider (i.e., listing accrediting programs and their target agencies).</li> <li>• MOHLTC will identify research opportunities to inform policy guidance and direction.</li> <li>• Regional Networks/Programs and HSPs will seek research funding opportunities for palliative care.</li> </ul>

Shared Priorities	Specific Action Commitments
<p><b>Measure system performance and impact from the perspective of clients and caregivers</b></p> <ul style="list-style-type: none"> <li>• Create provincial level performance measures and targets.</li> <li>• Establish a strong mandate for consumer-defined system performance using indicators that measure: <ul style="list-style-type: none"> <li>– quality of life, quality of dying/death, system responsiveness and person-centred care</li> <li>– integration from the client/family/caregiver perspective</li> <li>– outcomes, system impact, provider engagement, experience and sustainability.</li> </ul> </li> <li>• Leverage work to date on performance metrics (e.g., Integrated Client Care Project, Cancer Care Ontario).</li> <li>• Recommend evidence-based metrics that will drive ongoing improvements in integrated, team-based delivery structures and processes.</li> <li>• Develop scorecard and processes for public reporting.</li> <li>• Develop checklists for HSPs as a way to monitor process, qualitative and quantitative outcomes on an ongoing basis to inform continuous quality improvement.</li> <li>• Establish ongoing longitudinal evaluations to reflect ability to analyze and synthesize new knowledge and tools for continuous quality improvement.</li> <li>• Include a process to refresh metrics on an annual basis as evidence and knowledge evolve.</li> <li>• Ensure that all organizations providing palliative care meet the quality and reporting expectations of the Excellent Care for All Act.</li> <li>• Conduct system-level evaluation, monitoring and reporting on education improvements. Translate outcomes into comprehensive system level evaluation, monitoring and reporting.</li> <li>• Ensure findings assist LHINs and HSPs to establish expectations for performance (e.g., through clearly defined outcomes). These must be appropriate and measurable as a way to ensure organizations are delivering appropriate care and to enable providers to continuously improve.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC and LHINs, working with Health Quality Ontario (HQO) and other experts, will establish a process to develop recommendations for: <ul style="list-style-type: none"> <li>– performance indicators</li> <li>– measurement and reporting</li> <li>– performance corridors or benchmarks</li> <li>– experience data</li> </ul> <p>in the context of an overall palliative care data strategy. It will include leveraging work completed as part of the Integrated Client Care Project.</p> </li> <li>• Through their regional networks/programs, LHINs and QHPCCO will consider a process for developing supporting resources/toolkits to support continuous quality improvement.</li> <li>• LHINs and HSPs will review accountability agreements to include accountability for monitoring integration and palliative care performance.</li> <li>• MOHLTC has provided funding to the Institute for Clinical Evaluative Sciences (ICES) to commission a rigorous impact assessment as part of the Integrated Client Care Project.</li> </ul>

Shared Priorities	Specific Action Commitments
KEY ISSUE: BUILD PUBLIC AWARENESS	
<p><b>Build public awareness and engage in public dialogue</b></p> <ul style="list-style-type: none"> <li>• Develop, fund and implement a Public Awareness campaign using “Speak Up” (tailored to Ontario). The goal is to increase the general public’s understanding of palliative care and its broader role in chronic disease management. The campaign will include messages to make Ontarians aware that advanced care planning happens early on after receiving a life-limiting diagnosis.</li> <li>• Develop a consistent, transferable and seamless mechanism for all care providers to share information about advance care planning and ensure conversations continue throughout the disease journey across all care settings.</li> <li>• Initiate a campaign (linked to above) to encourage open discussions about end of life and earlier referrals to palliative care. This will include: <ul style="list-style-type: none"> <li>– Developing communication and relational strategies/tools to assist health care providers in “truth telling” to individuals and families in a way that respects their beliefs, values and culture. Examples include training on relationship-based models as well as tools to assist providers in explaining the likely course of a disease.</li> <li>– Educating individuals and their families on the models of care and community supports that are or will be available.</li> <li>– Ensuring individuals and their families know that they will have access to skilled palliative care teams, residential hospices, CCC and/or palliative care beds when /if they ever become required.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC, LHINs and Quality Hospice Palliative Care Coalition of Ontario (QHPCCO) will work together to explore options and seek opportunities for increasing the public’s understanding and awareness. Communication plans will capitalize on existing work to date.</li> <li>• OCFP clinical expert care pathing committee will work with HSPs, including providers from various chronic disease specialties, to facilitate open discussions with individuals around palliative care.</li> </ul>



Shared Priorities	Specific Action Commitments
<p><b>Improve access to information and support through a central hub</b></p> <ul style="list-style-type: none"> <li>• Create a single source of expert advice and information that is accessible in multiple ways (internet, social networking, email, telecommunications, outreach, navCare, etc).</li> <li>• Ensure it is a safe place for sharing and for enquiries.</li> <li>• Include information that is customized for different groups.</li> <li>• Develop a peer mentorship program for the public.</li> </ul>	<ul style="list-style-type: none"> <li>• MOHLTC, LHINs and QHPCCO will work together to consider options and seek opportunities to develop a “central information hub.” Where possible, existing resources will be leveraged.</li> </ul>

## Appendix A: Definitions

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### Accountability

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A relationship based on obligations to demonstrate, review and take responsibility for performance – both the results achieved, in light of agreed expectations, and the means used.<sup>7</sup>

### Advanced Chronic Disease

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**Adults or children with an active, progressive life-limiting illness in which clinicians and others would not be surprised if the person were to die within 12 months. Clinical evidence supports that the disease is advanced. There are medical conditions associated with advanced disease, severe and progressive symptoms, rapid decline or decreased function. Some examples of advanced disease include:**

- extensive metastatic disease in cancer
- refractory cardiac failure
- total dependency in neurodegenerative conditions
- multi-organ system failure (e.g., end-stage renal disease)
- advanced heart and/or lung disease (e.g., chronic obstructive pulmonary disease or chronic heart failure)
- advanced genetic, metabolic or other congenital or acquired conditions which are predicted to shorten their life (usually death is possible or probable by the mid- twenties)
- severe frailty and/or dementia, especially with first occurrence of medical complications
- older adults at risk of requiring or already in long-term care who have multiple co-morbidities and/or extensive polypharmacy – especially those who experience significant decline.

End-of-life chronic disease refers to those individuals where death is likely imminent.

It is noted that individuals with these above conditions are more likely to require multiple hospitalizations. With proper disease management and palliative care, we can prevent unnecessary acute care.

<sup>7</sup>Report of the Auditor General of Canada to the House of Commons Chapter 9 Modernizing Accountability in the Public Sector pg. 1  
Accessed at <http://www.oag-bvg.gc.ca/internet/docs/20021209ce.pdf>

## Caregivers – Formal and informal

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Formal caregivers are members of an organization. They are accountable to defined norms of conduct and practice. They may be professionals, support workers or volunteers. They are sometimes called “providers.”

Informal caregivers *“are not members of an organization. They have no formal training and are not accountable to standards of conduct or practice. They may be family members or friends or other people in the client’s/patient’s network who are partners in providing care and personal support.”*<sup>8</sup>

## Hospice palliative care<sup>9</sup>

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**Also simply called “palliative care,” is a philosophy of care that aims to relieve suffering and improve the quality of living and dying. It aims to help individuals 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 end-of-life and the dying process
- cope with loss and grief during the illness and bereavement
- treat all active issues and prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization.

Individuals with palliative care needs are those where much (but not necessarily all) of the focus of care is the relief and prevention of suffering and improving quality of life and comfort.

## HPC/End-of-life Care Networks

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Local collaboratives of HPC organizations and caregivers. They have a formal mandate to use their collective expertise to work together to promote high quality integrated HPC in their regions. The Networks are proactive, adjusting their organizations to meet local needs through new regional programs. Network leaders come together to form the Provincial EOL Care Network. Their mandate is consistent across the province. They are accountable to their corresponding LHIN.

<sup>8</sup>HPCO Residential Hospice Standard

<sup>9</sup>(CHPCA) Model to Guide Hospice Palliative Care (2002)

## Hospice volunteer

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### Individuals who:

- volunteer with a Visiting Hospice Service or Residential Hospice
- have received formal training based on the standardized curriculum of Hospice Palliative Care Ontario.

## Integration/“integrated care”<sup>10</sup>

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**Describes a dynamic set of methods and models for funding, administration, organization, service delivery and clinical treatment that aims to align, coordinate and increase collaboration within and between the cure and care sectors. It is vital for complex, multi-problem patients/clients whose needs cut across multiple services, providers and settings. Outcomes include:**

- Improved patient/client experience and satisfaction
- Enhanced quality of care, quality of life and health-related outcomes
- Greater system/service efficiency, effectiveness and value.

## Integrated Client Care Project (ICCP)

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A collaboration among LHINs, CCACs, their contracted service providers and all other palliative care providers in the local area. Executive sponsors are the MOHLTC, LHINs, Collaborative for Health Sector Strategy at the Rotman School of Business, and Ontario Association of CCACs. Areas engaged include the Southwest, Toronto Central, Waterloo Wellington, Central West and Hamilton Niagara Haldimand Brant LHIN areas.

## Inter-professional team

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The provision of comprehensive services to individuals by multiple caregivers, who work collaboratively to deliver quality care within and across settings. It is a collaborative, team-based approach to providing optimal care. See Ontario’s blueprint for interprofessional care at <http://www.healthforceontario.ca/UserFiles/file/PolicymakersResearchers/ipc-blueprint-july-2007-en.pdf>.

<sup>10</sup> Source: Kodner, 2009; Kodner & Spreeuwenberg, 2002 (ICCP definition)

## Levels of Care

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The Canadian Hospice Palliative Care Association has identified the following levels of palliative care<sup>11</sup>:

- **Primary providers:**
  - Manage disease, its manifestations and the challenges it creates
  - Identify issues
  - Provide the core competencies of palliative care
  - Have enough basic level palliative care awareness that they can identify individuals requiring palliative care and manage this care
  - Access appropriate palliative care specialists as required to effectively support the client’s needs, goals and preferences
  - Include all providers in any sector who offer first level or first response contact with individuals in relation to their health. Examples: physicians and their assistants, nurses and nurse practitioners, personal support workers and homemakers, allied health professionals, etc.
  - Identify a team lead to manage the client’s overall care plan.
  
- **Secondary Experts:**
  - Are experts in palliative care
  - Support primary providers in every setting where individuals/families receive care
  - Identify individuals requiring tertiary level palliative care and refer them appropriately.
  
- **Tertiary Experts:**
  - Consult to secondary experts and primary providers on difficult-to-manage cases
  - Educate/train secondary and tertiary experts
  - Conduct research
  - Develop advocacy strategies.

<sup>11</sup> (CHPCA) Model to Guide Hospice Palliative Care (2002)

## Progressive life-limiting illness

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A term used to describe illnesses where it is expected that death will be a direct or indirect result of the specified illness. In the context of this report, this term includes all phases of disease, from diagnosis to death.

## Residential Hospice

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A community-based inpatient facility with a primary focus of providing palliative care to those facing end-of-life. Not a hospital, long-term care home, or retirement home. Operates in compliance with HPCO Community Residential Standard.

## Shared care

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Can have different meanings, but in this document used in the broadest sense, to mean a model where care is “shared.” Care providers can include different combinations of multi-disciplinary professionals (regulated and unregulated). They may work in different capacities, in different types of teams and with different funding models, within and across care settings. The aim is to achieve care that is coordinated, proactive, holistic, person and family-focused, centering on quality of life and symptom management issues.

- Includes primary care providers. Does not replace primary care providers with specialist level providers.
- Is not limited to relationships between primary care providers and specialist level providers.
- Is not limited to care shared between providers of the same profession.

## System navigation

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### A process which involves:

- Collaboratively assessing an individual’s needs and goals for health care and support
- helping to coordinate and connect the individual to services and resources – both within and beyond the health service sector. The aim is to support efforts to achieve optimal health or functioning, independence and psychosocial wellbeing.

## Visiting Hospice Service<sup>12</sup>

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A support service that matches trained and supervised volunteers with clients who are living with a life-threatening or terminal illness and their families. The service aims to provide practical, emotional, social and spiritual support.

<sup>12</sup> Adapted from OHRS 8.0 and HPC

## Other terms you need to know

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- CCAC** **Community Care Access Centre:** Community Care Access Centres (CCACs) are non-profit community agencies with independent community boards. CCACs are funded and legislated by the Ontario Ministry of Health and Long-Term Care. There are fourteen CCACs in Ontario that: provide simplified access to home and community care; make arrangements for the provision of home care services to people in their homes, schools and communities; provide information and referral to the public on community-related services; and manage admissions to long-term care (LTC) homes and manage the placement of persons into adult day programs, supportive housing, chronic care hospitals and rehabilitation hospitals.
- CCC** **Complex Continuing Care:** A specialized program of care for medically complex patients who have long-term illnesses or disabilities typically requiring skilled, technology-based care not available at home or in long-term care homes.
- HPCO** **Hospice Palliative Care Ontario:** An organization that provides a network of expertise, information and communications to help its hospice members provide hospice support in their communities.
- LHIN** **Local Health Integration Networks:** 14 not-for-profit organizations responsible for planning, integrating and funding local health services in 14 different geographic areas of the province. LHINs are funded and legislated by the Ontario Ministry of Health and Long-Term Care.
- LTCH** **Long-Term Care Homes:** Provide nursing, personal and medical care for people who can no longer live independently. Funded and legislated by the Ministry of Health and Long-Term Care.
- OACCAC** **Ontario Association of Community Care Access Centres:** A not-for-profit corporation that represents the common interests of the CCACs.
- MOHLTC** **Ministry of Health and Long-Term Care:** The Ontario ministry whose mandate is to build a sustainable public health care system in Ontario. Goals include helping people stay healthy, delivering high quality care when and where people need it and as close to home as possible, and protecting the health system for future generations.
- QHPCCO** **Quality Hospice Palliative Care Coalition of Ontario:** A coalition comprised of provincial organizations and associations that represent organizations and individuals providing hospice palliative care; universities that conduct palliative care research; and family caregivers with an interest in hospice palliative care.

## Appendix B: Leadership Collaborative and Workgroup Participants

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### Participants of the Leadership Collaborative

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**Susan Paetkau (co-chair)**

Director, Health Policy and Care Standards Branch, Health System Strategy and Policy Division, Ministry of Health and Long-Term Care

**Gary Switzer (co-chair)**

Chief Executive Officer, Erie St. Clair Local Health Integration Network

**Jan Kasperski (co-chair)**

Chief Executive Officer, Ontario College of Family Physicians

**Hsien Seow (writer)**

Cancer Care Ontario Research Chair in Health Services Research Assistant Professor, Department of Oncology, McMaster University

**Rick Firth (moderator)**

Executive Director, Hospice Palliative Care Ontario

**Lori Adler**

Manager, Practice Standards, College of Nurses of Ontario

**Stacey Daub**

Chief Executive Officer, Toronto Central Community Care Access Centre

**Dr. John Hirdes**

Professor, School of Public Health and Health Sciences, University of Waterloo Home Care Research Chair

**Elaine Gibson**

Vice President, Complex, Specialty Aging and Rehabilitative Care, Parkwood Hospital

**Dr. Lawrence Librach**

Professor and Head, Division of Palliative Care, Department of Family & Community Medicine, University of Toronto

**Andrea Martin**

Lead, Waterloo Wellington Hospice Palliative Care Co-Chair, Quality Hospice Palliative Care Coalition of Ontario Co-Chair, Provincial End-of-Life Care Network

**Bill MacLeod**

Chief Executive Officer, Mississauga Halton Local Health Integration Network

**Melody Miles**

Chief Executive Officer, Hamilton Niagara Haldimand Brant Community Care Access Centre

**Margaret Mottershead**

Chief Executive Officer, Ontario Association of Community Care Access Centres

**Dr. Christine Newman**

Paediatric Palliative Care Physician, SickKids Hospital

**Gail Paech**

Chief Executive Officer, Ontario Long-Term Care Association

**Kathryn Pilkington**

Director of Professional Services and Health Policy, Ontario Association of Non-Profit Homes and Services for Seniors

**Sue Thorning**

Chief Executive Officer, Ontario Community Support Association



## Integration and Shared Care

---

### **Co-Chair – Julie Foley**

Lead, Integrated Client Care Project,  
Ontario Association of Community Care  
Access Centres

### **Co-Chair – Dr. Mary Lou Kelley**

Professor, School of Social Work  
& Northern Ontario School of Medicine,  
Lakehead University

### **Co-Chair – Dr. Denise Marshall**

Associate Professor, Division of Palliative  
Care, Department of Family Medicine  
Assistant Dean, Program for Faculty  
Development, Faculty of Health Sciences,  
McMaster University

### **Writer – Jocelyne Contant**

Executive Director, Champlain Hospice  
Palliative Care Program

### **Writer – Nancy Cooper**

Director of Policy & Professional  
Development, Ontario Long-Term Care  
Association

### **Editor – Susan Warner**

Project Lead, South West  
Local Health Integration Network

### **Editor – Esther Green**

Provincial Head, Nursing and Psychosocial  
Oncology, Chief Nursing Officer, Cancer Care  
Ontario

### **Barbara Busing**

Senior Director, Client Services, Hamilton  
Niagara Haldimand Brant Community Care  
Access Centre

### **Roberta Lee**

Senior Lead, Health Systems Development,  
Mississauga Halton Local Health Integration  
Network

### **Belinda Marchese**

Clinical Director, Hospice Toronto

### **Dena Maule**

Executive Director, Hospice Toronto

### **Ruby Miller**

Director of Health Services,  
Six Nations Health Services

### **Gurjit Sagha**

Clinical nurse specialist, Palliative  
and Bereavement Care Service,  
The Hospital for Sick Children

### **Lisa Sullivan**

Lead, Health Services Planning, Champlain  
Local Health Integration Network

### **Jill Tettmann**

Senior Director, Health System Performance,  
Measurement and Integration, North Simcoe  
Muskoka Local Health Integration Network

### **Nadia Thatcher**

Director of Care, Bethammi Nursing Home

### **Sonia Johnson**

Patient Care Manager, Oncology Unit  
Tower 7 and Palliative Care Unit Tower 6,  
The Scarborough Hospital General Campus

## Accountability and Governance

---

### **Co-Chair – Dr. Nancy Merrow**

Chief of Staff, Southlake Regional Health Centre  
Chair, Central Hospice Palliative Care Network

### **Co-Chair – Beth Lambie**

Director, Erie St. Clair End-of-Life Care Network,  
Co-Chair, Provincial End-of-Life Care Network

### **Writer/Editor – Georgina White**

Director, Policy and Research  
Ontario Association of Community Care Access Centres

### **Writer/Editor – Victoria van Hemert**

Senior Director, Planning, Integration, Community Engagement, Central Local Health Integration Network

### **Moderator – Penny Anguish**

Vice President, Complex Care & Physical Rehabilitation Services  
Chief Nursing Officer, St. Joseph's Care Group

### **Angela Archer**

Director of Care, Malton Village Long-Term Care Home

### **Rossllyn Bentley**

Executive Director, Hospice Wellington

### **Carol McKenna**

Clinical Manager, Palliative Care  
Chair of Hamilton Niagara Haldimand Brant Hospice Palliative Care Network  
St. Peter's Hospital Site & Adult Acute Sites,  
Hamilton Health Sciences

### **Brenda Carter**

Regional Vice President, Cancer Services  
Kingston General Hospital and South East Regional Cancer Program Chair, South East Palliative and End of Life Care Network Steering Committee

### **Dr. Deborah Dudgeon**

W. Ford Connell Professor of Palliative Care Medicine  
Professor of Medicine and Oncology,  
Queen's University

### **Sherry Frizzell**

Consultant, Sudbury/Manitoulin,  
North East Local Health Integration Network

### **Betty Kuchta**

Chief Executive Officer, Erie St. Clair Community Care Access Centre

### **Heather Nicolson-Morrison**

Executive Director, Toronto  
Central Palliative Care Network

### **Dr. José Luis Pereira**

Full Professor and Head, Division of Palliative Care, University of Ottawa  
Medical Chief, Palliative Medicine,  
Bryère Continuing Care/The Ottawa Hospital

## Education, Mentorship and Specialized Support

---

### **Co-Chair – Cathy Joy**

Palliative Pain and Symptom Management  
Consultant, Waterloo Region

### **Co-Chair – Marg Poling**

Palliative Pain and Symptom Management  
Consultant, North West Community Care  
Access Centre

### **Writer – Anne Bell**

Director Quality and Education Services,  
Ontario Association of Community Care  
Access Centres

### **Valerie Armstrong**

Senior Manager Client Services,  
North Simcoe Muskoka Community Care  
Access Centre

### **Dr. Sandy Buchman**

Assistant Professor, Department  
of Family and Community Medicine,  
University of Toronto  
President-Elect, The College of Family  
Physicians of Canada  
Primary Care Lead, Toronto Regional Cancer  
Program, Cancer Care Ontario  
Education Lead & Family Physician  
Practising in Palliative Care, The Temmy  
Latner Centre for Palliative Care

### **Elisabeth Catalano-Bon**

Social Worker, Health Services – Region of  
Peel, Tall Pines Long-Term Care Home

### **Michele Chaban**

Director of Interprofessional Applied  
Mindfulness Meditation Program,  
University of Toronto,  
Dala Lana School of Public Health,  
Department of Family and Community  
Medicine,  
Faculty of Social Work, Centre for Bioethics  
Director of Contemplative End of Life  
Care Program, The Institute of Traditional  
Medicine Faculty liaison, McMaster Applied  
Mindfulness Meditation Certificate

### **Lynn Huizer**

Senior Manager, Health System Integration,  
North Simcoe Muskoka Local Health  
Integration Network

### **Dr. Amna Husain**

Palliative Care Physician, Temmy Latner  
Centre for Palliative Care, Mount Sinai  
Hospital

### **Donna Ladouceur**

Senior Director, Client Services, South West  
Community Care Access Centre

### **Dr. Ariella Lang**

Research Scientist, VON Canada

### **Holly Prince**

Researcher, Lakehead University

### **Dr. Adam Rapoport**

Medical Director of Palliative Care at  
The Hospital for Sick Children and Pediatric  
Consultant to the Temmy Latner Centre for  
Palliative Care

### **Kirsten Schmidt**

Network Coordinator, Central East Local  
Health Integration Network

### **Karen Weisberg**

Coordinator, Central Hospice Palliative Care  
Transition Strategy and Engagement

### **Pauline Frechette-Keating**

Manager of Continuing Care, CSR & Infection  
Control Nurse, Sensenbrenner Hospital

## Care pathing across continuum of Chronic Disease Management

---

### **Co-Chair – Julie Darnay**

Director, Hamilton Niagara Haldimand Brant  
Hospice Palliative Care Network

### **Co-Chair – Dipti Purbhoo**

Senior Director, Client Services,  
Toronto Central Community Care Access  
Centre

### **Writer/Editor – David Fry**

Director, Client Services, Ontario Association  
of Community Care Access Centres

### **Writer/Editor – Donna Laevens-Van West**

Executive Director, Central West Palliative  
Care Network

### **Maryse Bouvette**

Champlain Advanced Practice Nurse, Palliative  
Care at Bruyère Continuing Care

### **Cheryl Faber**

Senior Manager, Health System Planning and  
Development, North Simcoe Muskoka Local  
Health Integration Network

### **Catherine Goetz-Perry**

Planning and Integration Lead, South West  
Local Health Integration Network

### **Lynn Kachuik**

Palliative Care Advanced Practice Nurse,  
The Ottawa Hospital

### **Fran Lind**

Director of Care, Parkview Home  
for the Aged

### **Dr. Vincent Maida**

Palliative Care Physician,  
William Osler Health System  
Assistant Professor, University of Toronto,  
Division of Palliative Care  
Clinical Assistant Professor,  
Michael G. DeGroote School of Medicine,  
McMaster University

### **Sidney Thomson, RN**

Clinical Education Coordinator,  
Carleton Place & District Memorial Hospital

### **Dr. Andrea Moser**

Lead Physician, Geriatric Care Team,  
Algonquin Family Health Team  
Vice President, Ontario Long-Term Care  
Physicians  
Assistant Professor, Northern Ontario  
School of Medicine  
Medical Director, Muskoka Landing

### **Dr. Jeff Myers**

Head – Palliative Care Consult Team  
Odette Cancer Centre, Sunnybrook  
Health Sciences Centre  
Associate Professor and Associate Head –  
Division of Palliative Care,  
Department of Family and Community  
Medicine, University of Toronto

### **Michelle Paupé**

Senior Manager, Client Services,  
North Simcoe Muskoka Community Care  
Access Centre

### **Carol Sloan**

Manager / Palliative Care Consultant, Palliative  
Care Consultation Program

### **Dr. Patricia Strachan**

Assistant Professor, School of Nursing,  
McMaster University

### **Dr. Chris Vadeboncoeur**

Pediatric Physician, Children's Hospital  
of Eastern Ontario

## Project Management Team

---

### **Debra Bell**

Manager, Community Care  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
debra.bell@ontario.ca  
ph: 416-326-0818

### **Deborah Sattler**

Team Lead, Community Care  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
deborah.sattler@ontario.ca  
ph: 416-326-9266

### **Stephanie Lockert**

Senior Policy Advisor,  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
stephanie.lockert@ontario.ca  
ph: 416-326-6694

### **Diane Allen**

Senior Policy Advisor  
Health Policy and Care Standards Branch  
Health System Strategy and Policy Division  
Ministry of Health and Long-Term Care  
diane.allen@ontario.ca  
ph: 416-326-0721

### **Rick Firth**

Executive Director,  
Hospice Palliative Care Ontario

### **Beth Lambie**

Director, Erie St. Clair End-of-Life Care Network,  
Co-Chair, Provincial End-of-Life Care Network

### **Andrea Martin**

Lead, Waterloo Wellington  
Hospice Palliative Care  
Co-Chair, Quality Hospice Palliative  
Care Coalition of Ontario  
Co-Chair, Provincial End-of-Life Care Network

## Appendix C: Further delivery considerations

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In developing their recommendations for moving forward, the Declaration partners also considered the following core aspects of delivery:

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### Where will Hospice Palliative Care (HPC) be delivered?

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Patients requiring palliative care are found in virtually all care settings. Therefore palliative care should be provided in all care settings. Each sector requires internal expertise at both a primary and secondary level. Processes should be clearly articulated for access to specialist level (tertiary level) palliative care expertise if that expertise is not available “on site.”

#### The Canadian Hospice Palliative Care Association (CHPCA) states:

“As in any other health care situation when primary providers encounter care issues and situations beyond their level of confidence and expertise or when their practice outcomes are not consistent with accepted norms of practice...., they must be able to seek help and support from ... 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 many other specialty areas of health care, access to tertiary experts is often regarded as being possible only in a major academic or population centre. However, if patients requiring palliative care are to be maintained in their homes or in settings close to home, it is necessary for the specialist level of expertise to be available to patients in each county.

### Who will provide HPC?

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The Canadian Hospice Palliative Care Association describes roles for the following levels of care providers

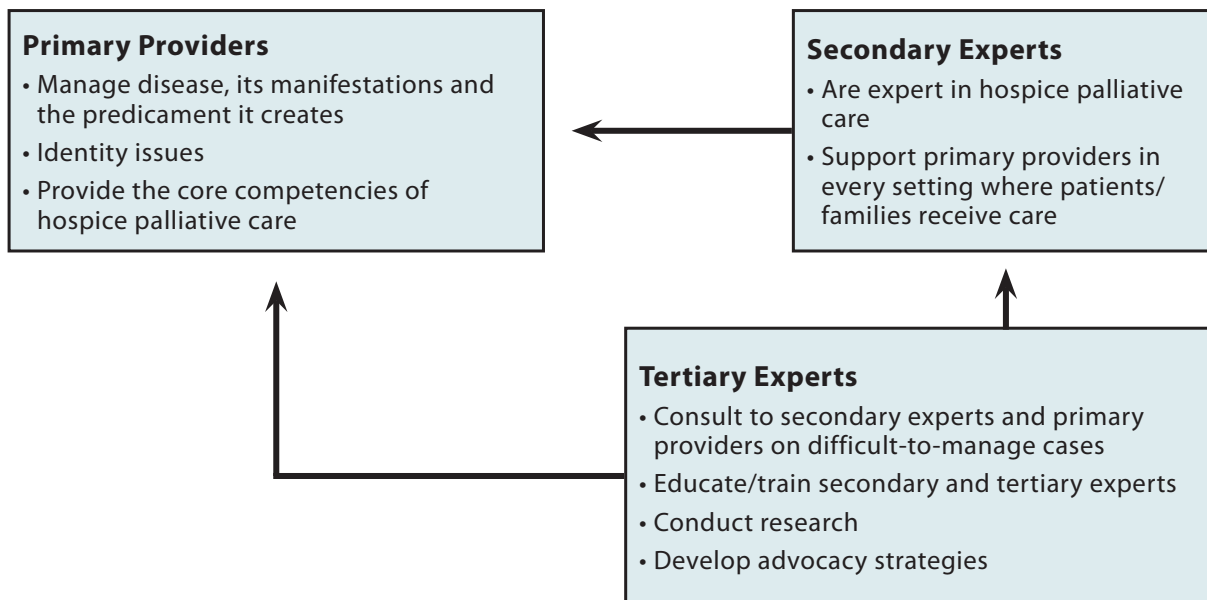
- Primary providers – available in all settings
  - Manage disease, its manifestations and the predicaments it creates
  - Identify issues
  - Provide the core competencies of hospice palliative care
  - Have enough basic level HPC awareness that they can identify patients requiring HPC and refer them appropriately

- Secondary Experts – available in all settings – preferably on site
  - Are experts in hospice palliative care
  - Support primary providers in every setting where patient/families receive care
  - Identify patients requiring specialist level HPC and refer them appropriately.
- Specialist /Tertiary Experts – available to patients in all settings (may not be on site, but must be available)
  - Consult to secondary experts and primary providers on difficult-to-manage cases
  - Educate/train secondary and tertiary experts
  - Conduct research
  - Develop advocacy strategies.

These three distinct levels may not be developed in each region and there is frequently a blurring of roles between secondary level and specialist/tertiary level expertise. In some academic settings, the opposite phenomena may occur with a subdividing of roles; a fourth level may be identified to provide consultation to secondary and tertiary levels and to lead educational/research initiatives.

Figure 4 below from the CHPCA Model of Care illustrates provider roles and interactions between/among the identified three roles.

**Figure 4. Provider roles in Hospice Palliative Care**

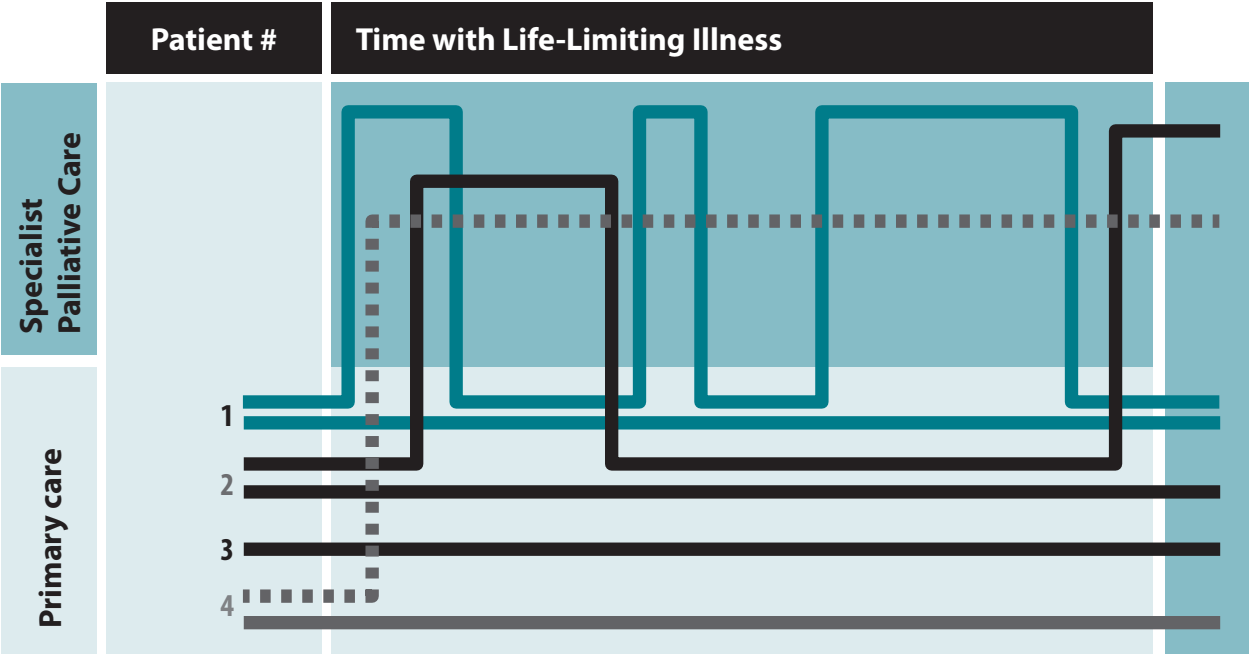


## Relationship between primary care and secondary/tertiary levels of care:

Palliative care is most frequently provided using a shared/collaborative approach to care. Figure 5 below is adapted from Palliative Care Australia and demonstrates a number of possible care scenarios for a person with a life limiting illness, based on his/her individual needs. These scenarios show the interactions between primary and specialist care providers.

- Patient #1 is cared for using a shared care/collaborative care model with Primary Care throughout and three episodes of Specialist Care. A shared care model is in place at time of death, with the patient's needs being at a Primary level.
- Patient #2 is also cared for using a shared care/collaborative care model with two episodes of Specialist Care. A shared care model is in place at time of death, with the patient's needs being at a Specialist level.
- Patient #3 requires only Primary Care.
- Patient #4 is cared for using a shared care/collaborative care model with all of the care needs requiring involvement at a Specialist Care level. At time of death, the patient's needs continued to require Specialist Level care.

Figure 5. Episode of care scenarios to meet palliative care needs

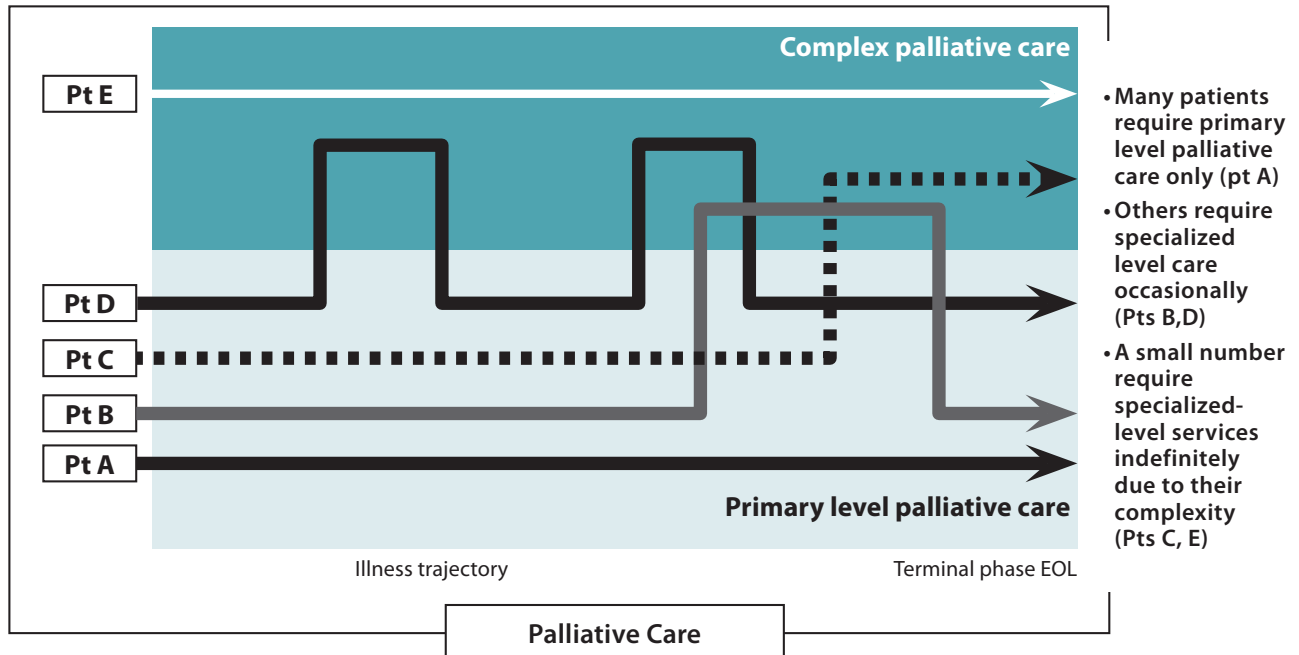




## A person's needs may shift significantly over the episode of care:

Figure 6 below (prepared by Dr. José Pereira) illustrates this point in a slightly different manner. It provides an overview of how an individual's needs might change over the course of their disease. This may not necessarily happen in a consistent or predictable way.

**Figure 6. Levels of care for palliative patients**



## Delivery must be equally fluid in response:

Hospice palliative care needs to be well integrated with primary delivery and chronic disease management. This will enable providers to respond effectively and in a timely way to the unpredictable and sometimes rapidly changing, complex needs of their patients.

## A conceptual model:

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**Figure 7 (on the following page) presents a conceptual model to assist Palliative Care development. The diagram shows patient movement between three levels of care and includes a level of *tertiary interventions*.<sup>13</sup> Figure 7 correlates the levels of care with:**

- description of patient needs at each level
- description of provider roles at each level
- typical location/setting of care for each level.

The base of the triangle in Figure 7 represents the largest volume of patient activity with the apex illustrating the smallest volume. The three levels may be combined or further subdivided depending on regional variations. For example, in some academic settings a subdividing of the third level of care may occur with a fourth (quaternary) level emerging to provide consultation to secondary and tertiary levels and to lead educational/research initiatives. The opposite may occur in other settings where a blurring/merging of roles between the secondary and tertiary levels occurs with a two-tiered model emerging (as is reflected in the Australia model). (Figure 7 does not illustrate either of these contingencies.)

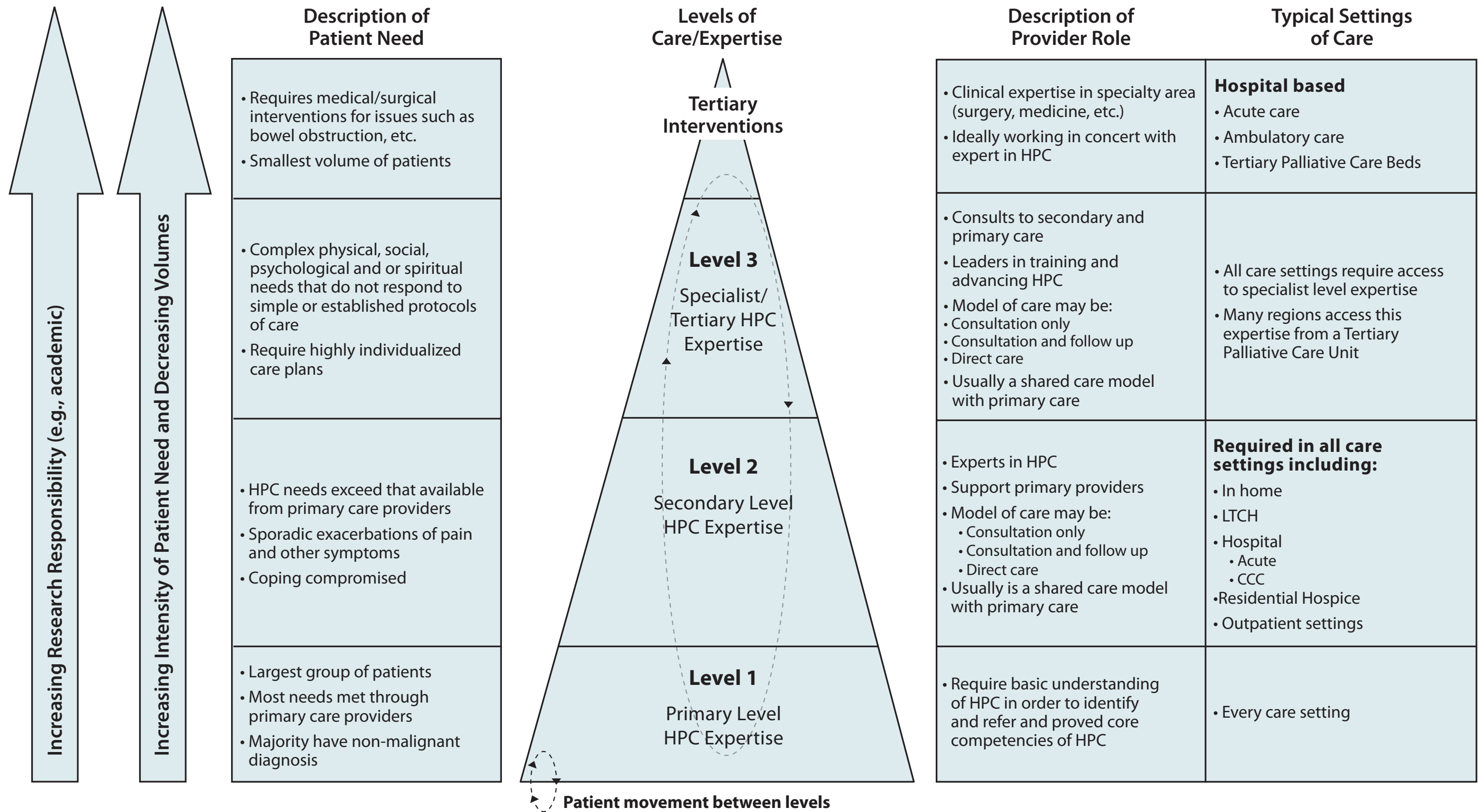
From a practical standpoint, the beginning point for implementation of a model of palliative care is to:

- acknowledge that most palliative care is, and can be, provided by primary care providers when they have adequate support
- recognize that specialty level experts must be developed to support primary care and to deal with the most complex palliative care cases
- develop a clear understanding of how primary care and specialist level care providers work together
- develop expertise in an interdisciplinary context
- build on the expertise currently available.

<sup>13</sup>The term *Tertiary* is used in three contexts:

- *Tertiary Experts* in Hospice Palliative Care – The CHPCA context cited above describes a level of expertise which should be available to patients in all care settings. (This is level 3 in the triangle of “*Levels of Care/Expertise*” depicted in figure 7 and is described by CHPCA.)
- *Tertiary Level Interventions/Procedures/Services* for patients with life limiting illnesses – Tertiary level interventions and procedures include surgery and acute medical interventions that may be necessary to manage symptoms. These procedures are conducted in a hospital inpatient or ambulatory care setting and are regarded as tertiary level interventions. (This is the apex of the triangle of “*Levels of Care/Expertise*” depicted in figure 7.)
- *Tertiary Hospice Palliative Care Unit* – “A Tertiary HPC 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...” (This is one of the “*Settings of Care*” depicted on the top far right of figure 7.)

Figure 7: Providing Hospice Palliative Care (HPC) in Erie St. Clair – Conceptual Model



Model developed for Erie-St. Clair End-of-Life Care Network (ESC EOLCN), by Beth Lambie-Director ESC EOLCN (Sept. 2008, revised Dec. 2008, Jan. 2009) This model incorporates concepts, design and content from: 1) Palliative care Australia-A Guide to Palliative Care Services Development (2005) pg. 14 & 15; 2) Unpublished work by Dr. D. Dudgeon (1992), 3) Chronic Disease Management Framework – ESC LHIN-Ralph Ganter (2008), 4) CHPCA Model (2002) pg. 56. 5) Cancer Care Ontario-Regional Models of Care-March 2009 (relating to research responsibility). Note-Regional variations may result in: level 3 being subdivided to create a 4th level (quaternary level) or level 2 and 3 being merged to create a single level of specialist care.

## Appendix D: Detailed analysis

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This Appendix provides more detailed analysis of the gaps between the current state of hospice palliative care in Ontario and the new model of delivery proposed in this Declaration.

### System Design Realm One: Care Settings and Services

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Current state	Desired state
<p>Both private and public care settings are in place, including:</p> <ul style="list-style-type: none"><li>• An individual's home (e.g., private residence, retirement home, long-term care home, group home, homeless shelter, correctional centre, etc.)</li><li>• Residential hospices</li><li>• Primary care</li><li>• Hospitals (acute, rehab and complex continuing care).</li></ul>	<p>A full continuum of care settings and services is in place, based on population and service needs.</p>

#### Issues:

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1. Currently, key care settings and services that comprise a comprehensive continuum of palliative care supports are lacking in many catchment areas. Specific gaps include:
  - Residential hospices
  - Tertiary care inpatient units/services
  - Bereavement services, for management of complex grief both before and after the death of a loved one
  - Formalized palliative care programs in long-term care homes
  - First Nations communities.
2. There is currently no clear expectation or role for each care setting in a continuum of palliative care supports. Gaps include defining the role for residential hospices, long-term care homes and First Nations communities' home and community care programs.

3. Once roles are defined and expectations are set, planners then need to have confidence in their ability to determine the appropriate balance of settings and services in each community. However, there are currently no evidence-based population guidelines that would assist in this planning and allocation of resources.
4. Where care settings and services do exist, access often remains an issue. This holds true for all levels of care, including primary, secondary and tertiary. Specific gaps include:
  - Although many programs and services are available, they vary across the province. This creates issues of inequity. For example, there is inadequate/inequitable access across the province to integrated, comprehensive, quality pain and symptom management and support.
  - Although programs and services may be available, access to them is currently determined largely by a health professional's prognosis – as opposed to being based on the needs of the individual and their family. This is of significant concern given that it is often difficult for health professionals to determine a disease prognosis and trajectory. Hence, there is uncertainty about when palliative services are appropriate. This results in:
    - a disproportionate number of referrals are made for diseases with more predictable prognoses (e.g., cancer)
    - referrals for less predictable diseases are made closer to the end-of-life or when death is imminent (e.g., a few weeks or days before death).
  - Existing programs and services often act as stand-alone models that are not necessarily integrated amongst each other to care for the complete person and their family.
5. Limited access also presents concerns over a lack of congruence between the actual locations of death for Ontarians versus their location of choice.
6. There is a need to improve public knowledge and expectations of palliative care. Palliative care is currently poorly understood by the public and by many service providers. This results in:
  - referrals being made too late in the course of a person's illness
  - referrals not being made for those with chronic disease/life limiting diagnoses.

# System Design Realm Two: Programs within Care Settings and Services

Current state	Desired state
<p>Key components of quality palliative care (including comprehensive programs and expertise) are not currently available in many care settings where individuals die. Key components and program elements that are most frequently missing include:</p> <ul style="list-style-type: none"> <li>• Adequate palliative care competencies at the front-line in all care settings.</li> <li>• Access to 24/7 palliative care expertise (for the individual with a life-limiting illness, their family, informal caregivers and front-line care providers in all care settings).</li> <li>• Access to an identified palliative care Resource/Lead/Champion/Contact within each care setting to provide education, mentorship and specialized support to primary and front-line care providers.</li> <li>• A clearly defined model of care delivery based on best practice.</li> <li>• Access to inter-professional care within and across care settings.</li> <li>• Key supports for families and caregivers (including the bereavement phase of palliative care, both before and after death).</li> <li>• First Nations communities lack basic equipment and supplies to provide palliative care at home – including hospital beds, commode chairs, incontinence products, medication and oxygen.</li> </ul>	<p>There is a clearly defined palliative care program in each care setting where individuals die.</p>

## Issues:

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1. Family members and informal caregivers often face increasing burdens during the serious illness of a loved one. Since they provide most of the care, they need more support than the system currently provides. This includes:
  - improving access to services and supports for informal caregivers – including education supports, respite, cultural navigation, system navigation and care coordination
  - providing innovative supports. For example, there are gaps in supports for single parents who are seeking treatment for an ill child, but also require child care support for their other (healthy) child(ren).
2. To be responsive to the varying needs of families and caregivers, there is a need to listen more to the voices of those living with life-limiting illnesses, their family members and their informal caregivers. Their voices need to be reflected in system, regional and local level planning and governance.
3. It is also vital to improve the identification of, and services for, family members of persons who die of sudden illness or other events. This could include bereavement services for those who experience a suicide-related loss.

## System Design Realm Three: Integration/Linkages

Current state	Desired state
<p>Specific integration essentials within each region are lacking or inadequate. As individuals move across care settings, this results in:</p> <ul style="list-style-type: none"> <li>• poor continuity of care</li> <li>• system inefficiencies</li> <li>• redundancy of processes.</li> </ul>	<p>Sectors and services are linked by common practice, processes, structures and education.</p>

### Issues:

1. Common clinical practices and processes are lacking across sectors. This includes use of common tools as well as advanced care planning.
2. Shared functional and clinical infrastructures that support cross-sector collaboration are lacking. These include:
  - venues for integrated care planning to develop common collaborative care plans
  - venues for ongoing sharing of information throughout a care plan (e.g., to communicate any changes in care goals, care outcomes, etc.)
  - venues for collaborative process development
  - shared communication and IT systems with accessible client/patient records across sectors/services
  - linked pharmacy databases to prevent medication issues that may compromise chronic disease management
  - timely, reliable program and integrated system-level data and analytic capacity to inform decision-making.
3. Common and required – not voluntary – levels of palliative care competencies/ education are missing across all sectors and organizations.
4. There is no true system navigation for individuals and their families.



5. Integration is lacking between existing chronic disease programs and palliative care supports. These programs and supports are not currently integrated into a continuum of care that spans from diagnosis of a life-limiting illness, to advanced/terminal chronic disease, to end-of-life to bereavement. Instead, individuals are not referred to palliative care supports unless they have an end of life diagnosis. For example:
  - Advanced Care Planning does not consistently occur early enough in the disease trajectory.
  - Individuals who can provide palliative care are not often a part of the care team early on and in an ongoing nature (e.g., at the point of diagnosis and throughout the disease trajectory to advanced/terminal chronic disease).
  - Lack of integration often results in prolongation of expensive and futile treatments that may neither extend nor improve life.
  - There is a current assumption that access to palliative care is “binary” (in or out) as opposed to being accessed at varying levels across a disease trajectory.
6. There is no single point of contact for all individuals/families and all care settings on a 24/7 basis.
7. The transition from paediatric to adult is fragmented. Hand-offs across care professionals and teams are inconsistent, as are service levels.
8. Pharmacy is not well integrated into all care settings and care teams.
9. Jurisdictional issues between the federal and provincial governments defining responsibility to provide care in First Nations communities creates barriers to high quality care. These barriers include a lack of funding for service provision and barriers in the transition of care from hospitals to communities.

## System Design Realm Four: Human Resources

Current state	Desired state
<p>Currently, there are no population-based:</p> <ul style="list-style-type: none"> <li>• guidelines</li> <li>• staffing levels (to help determine/quantify need)</li> <li>• palliative care Human Resource Plans for LHINs or the province.</li> </ul> <p>Given limitations within existing Human Resources, it is difficult to assess the need.</p>	<p>Enough trained professionals are available as determined by a population-based needs assessment.</p>

### Issues:

1. There is an inadequate number of health care providers with an understanding of, and/or training in palliative care. This is true at all levels of care (primary, secondary and tertiary) due to a lack of mandatory palliative care competencies for regulated and non-regulated health professionals.
2. There is inconsistent support for care providers, in terms of access to:
  - education
  - mentorship
  - 24/7 support.

It is difficult to assess the need for additional resources without first enhancing the potential of existing resources. Given recruitment challenges, there is a need to:

- improve competencies within existing resources, and
  - provide innovative technologies to ease access to secondary and tertiary level care.
3. Within existing resources, there is a lack of:
    - consistent expectations for all care professionals to engage in advanced care planning when appropriate.
    - culturally relevant palliative care education for family physicians, primary care providers and unregulated professionals.

- efficient needs assessment. For example, physicians may often act as the “gatekeeper” to palliative care through prognostication. However, a patient’s needs can be identified through the individual or family, or through needs-based assessments completed by other regulated care providers.
- retention of caregivers within the community, potentially due to variations in pay between the community and institutional sectors.

A lack of access to primary care supports with an adequate understanding of and comfort with palliative care may have a number of effects. These include:

- specialized supports are used inappropriately when primary care professionals could care for individuals.
- individuals suffering from a life-limiting illness gain access to palliative care too late in their lives. Providers often assume access to palliative care requires a definitive prognosis.

## System Design Realm Five: Accountability

Current state	Desired state
<p>Health and social care in Ontario is currently delivered by independent sectors and by independent service providers. Each has its own Board of Directors, individual mandate, operational imperatives and strategic directions. Within this multi-sector context, overall shared accountability is unclear – for the person and family and for the achievement of the health system’s top goals.</p>	<p>System level accountability is clearly defined and communicated.</p>

### Issues:

1. There is inadequate accountability, evaluation, monitoring and reporting on outcomes at all levels – provincial, regional and local. For example, there are:
  - no performance standards (all levels)
  - no accountability based on outcomes (all levels)
  - no tracking and reporting on outcomes to drive change (all levels).
2. There is no accountability for the implementation of standardized clinical or system-design best practices required for true integration of care.

3. There is no accountability for care providers to partner across care sectors and contribute to one common care plan where individuals require care from multiple care settings.
4. There is currently no provincial level or regional multi-sector performance measurement. For example, there is often independent monitoring, evaluation and reporting at a program and/or facility level. However, this has not been rolled up into a system level process or framework.

## System Design Realm Six: Policies, Guidelines and Funding

Current state	Desired state
<p>LHINs vary in the way they provide complex and/or advanced chronic disease management and palliative care. Although some local flexibility is important, the inconsistency creates a provincial landscape where care and support is piecemeal. More consistency is needed, including guidelines and funding models that would drive continuous improvements in service delivery.</p>	<p>Funding models, guidelines and policy directions support an integrated system driven by continuous improvement.</p>

### Issues

1. There is a lack of provincial performance standards for LHINs and subsequently their health service providers. For example, avoidable expenses can result from:
  - poor care transitions
  - prolongation of medically futile treatments – which may neither extend nor improve life
  - unnecessary Emergency Department visits
  - inpatient hospital utilization.

At the same time, there is a need for local flexibility in how performance targets will be achieved.

2. There is a need to develop and implement innovative funding models that incent or support integration and shared care or consultation models. Currently:
  - funding does not follow the client through the care system
  - payment mechanisms, such as those for home visits, are poorly delineated. Other areas include funding for required education and training at primary and specialist levels.

3. Every effort should be made to protect existing palliative care services and resources in all care settings. For example, we need to protect current funding for programs.
4. The system cannot be designed to provide homogenous care. Instead, care must be flexible in order to adequately and consistently respect and respond to the diversity of all Ontarians. This includes responding to:
  - culturally/linguistically diverse populations
  - urban/rural/remote populations
  - First Nations communities (both reserve and urban).

Language is not the only adaptation to consider – including the use of common terminology, interpreters, and so forth. Providers must also consider and respect the cultural values and beliefs surrounding death and dying.

5. Care must be flexible to adequately and consistently respond to the needs of rural, remote and First Nations communities. These populations struggle with access to:
  - adequate levels of palliative care services and supports
  - key care settings.

More needs to be done to reduce the expectation that individuals will travel to seek appropriate care. Travel to urban centres to receive palliative care is costly in time, energy and finances. Further, it removes people from their homes, communities and informal care supports.

First Nations people must be consulted and must guide the development of culturally appropriate palliative care programs and services for their communities. Rural, remote and First Nations communities have also identified a need to have dedicated people at the regional level who have skills in community development and can work as community catalysts. Research has demonstrated the success of this approach for developing palliative care capacity in rural and First Nations communities.

6. It is vital to better respond to other populations that are often marginalized. These include:
  - children (a unique sector requiring a specialized skill set of health care providers)
  - those living with disabilities
  - those with mental health and addictions needs
  - the homeless
  - veterans
  - prison populations.

In the case of the last two groups, roles and responsibilities must be clarified between federal and provincial governments. Specific to correctional centres, progress needs to occur to allow natural deaths as opposed to requiring cardiopulmonary resuscitation (CPR) of all inmates.

### **For those living with disabilities:**

- An unpredictable path to end-of-life can lead to barriers in accessing palliative care. The disease trajectory/decline is often not as predictable as cancer might be.
- Chronic poverty/unemployment is more common, which presents added challenges – including increased stress – in paying for extra supports when needed.
- Assumptions about living with a disability may influence decision-making at end of life. For example, doctors and nurses often assume that someone living with a disability cannot make decisions about their lives or wishes.
- People with disabilities are only seen as care recipients, and not as care providers.