

# Palliative and End-Of-Life Care Provincial Roundtable Report

A Report from Parliamentary Assistant John Fraser to the Minister of  
Health and Long-Term Care

March 2016

## A Message from the Parliamentary Assistant John Fraser

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*“Life and death are one thread, the same line viewed from different sides.”*

— Lao Tzu

In November 2014, I was tasked by the Honourable Eric Hoskins, as his Parliamentary Assistant, to support the development of a comprehensive strategy for palliative and end-of-life care in Ontario. It is a mandate I asked for and one I am grateful to have. I have long been guided by the firm belief that how we care for each other at the end-of-life is as important as at the beginning of our lives.

My assignment is both challenging and rewarding: challenging because it dealt with a subject that is emotionally fraught and rewarding because I believe we are helping move Ontario closer to being a province that offers its population the very best possible palliative and end-of-life care.

Much work has already been done to identify the needs and challenges around providing quality palliative and end-of-life care in our province, including the 2011 *Declaration of Partnership and Commitment to Action*, an extraordinary piece of collaborative community advocacy by more than 80 partners to identify the key components of quality palliative and end-of-life care.

As part of the government’s effort to respond to the Declaration, I hosted 16 roundtables with dozens of individuals, organizations and hospices in Ontario over the past six months. I also began a dialogue about palliative care with Indigenous partners and I look forward to engaging with Inuit partners. This report captures what my team and I heard through these consultations, and includes some observations about the key elements of successful palliative care models from across Ontario.

I am highly impressed by the compassionate and talented people involved in palliative care across the province. Ontario has a strong group of dedicated individuals — practitioners, volunteers, administrators and community leaders — who deliver the palliative and end-of-life care that patients and their families need. They have built on the capacities in their communities, often tailoring their approaches to achieve similar outcomes. Their passion and focus provides a solid foundation for the work still to be done.

Despite the outstanding work being done by those in the palliative care sector, the simple fact is that not enough patients and families receive the palliative care, support and services they need as early as they need them, and in the most appropriate setting.

We must do better. We will do better.

This report lays out the first important steps for how we can support our communities and achieve our goal of full access to quality palliative and end-of-life care for all Ontarians who need it.

To all the people who participated in our roundtables, meetings and visits — thank you for your valuable time. Thank you for sharing your experiences and stories. Thank you for your thoughts and opinions. They helped shape mine. Above all, thank you for your commitment to improving palliative care. This report is as much yours as it is mine.



Original signed by

John Fraser, MPP (Ottawa South)  
Parliamentary Assistant to the  
Minister of Health and Long-Term Care

# INTRODUCTION

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*“Palliative care is a special kind of health care for individuals and families who are living with a life-limiting illness that is usually at an advanced stage. The goal of palliative care is to provide comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family. A “family” is whoever the person says his or her family is. It may include relatives, partners and friends.”*

— Canadian Hospice Palliative Care Association

Dying is part of living. All of us will either require palliative care ourselves or have friends or family who do. Care at the end-of-life is not an easy matter to consider, but it is critical. How can we ensure that Ontarians who need it receive the best possible palliative and end-of-life care?

## ABOUT THE ENGAGEMENT PROCESS

From July 2015 to January 2016, together with a dedicated team from the Ministry of Health and Long-Term Care, I hosted 16 roundtables with more than 325 stakeholders across the province. We met with patients and families, doctors, nurses and health system leaders.

We talked about our aging population and the inevitable increase in demand for end-of-life care that we, as a province and as a society, will be facing. We discussed the urgent need to do a better job of connecting people with end-of-life care by making sure patients and their families are aware of available options and the best ways to access them. And we talked about the vital importance of a more personalized approach to delivering end-of-life care: tailoring the services to the specific needs of individual patients and their families.

We discussed ways in which the system needs to change and how we can make those changes happen. The roundtables gave me the opportunity to hear and understand the unique perspectives of patients, caregivers and providers, and benefit from the expertise of health system leaders and experts in the field.

As part of this engagement process, I appreciated the opportunity to begin a dialogue with First Nations, Métis and urban Aboriginal peoples, and look forward to continuing those conversations as we move forward together. I also look forward to engaging with Inuit partners.

## HOW THE PROCESS WAS ORGANIZED

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We held 16 roundtables across the province:

- seven with Local Health Integration Networks
- seven with specific groups, including patients, volunteers, caregivers, health care providers, clinical leaders, and communities with diverse backgrounds such as Francophones

We began a dialogue with First Nations, Métis and urban Aboriginal partners.

Before each roundtable, we shared a presentation with participants that explained the purpose, reviewed a history of the work to date and posed a set of questions organized by five themes:

- equitable access and integration
- service capacity
- caregiver supports
- public education and awareness
- oversight and accountability

## ABOUT THE REPORT

This report is my best attempt to distil the valuable advice we heard. It does not reflect everything shared at the roundtables, but it highlights common themes, unique perspectives and the kind of innovative thinking we need to design a strategy to give Ontarians high-quality palliative and end-of-life care services.

We've organized our report by the roundtable themes:

1. Expanding Equitable Access and Integration
2. Strengthening Service Capacity
3. Improving Caregiver Supports
4. Enhancing Public Education and Awareness
5. Establishing Oversight and Accountability

I would like to note here that some participants spoke about the importance of raising public awareness about palliative and end-of-life care in light of last year's Supreme Court of Canada decision to legalize physician-assisted dying. There is a clear need for a palliative care system that is there for patients and their families. This report focuses on creating that system.

## HOW THE PROCESS WAS ORGANIZED *(cont'd)*

More than 325 participants represented a variety of sectors, including health, community and social services, academia, cultural, religious and spiritual groups, vulnerable populations and hospices.

See Appendix A for a list of stakeholders who participated in the roundtables.

See Appendix B for a list of stakeholder submissions.

# CONTEXT FOR ACTION

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*“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.”*  
— *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action*

In the coming year, approximately one per cent of Ontarians will enter the final stages of a disease or other life-limiting condition. As they near end-of-life, they and their families will need the help and support of their communities and the health care system. While people of all ages may need palliative services, most people who use them will be elderly. By 2034, the number of seniors in Ontario is expected to double, which means that — in the years to come — the need for palliative and end-of-life care in Ontario may grow dramatically.

Our health care system has been working for some time to improve the palliative and end-of-life care services offered in Ontario.

## **FROM VISION...**

In December 2011, the Ministry of Health and Long-Term Care endorsed the *Declaration of Partnership and Commitment to Action*, a collaborative, stakeholder-driven, multi-year framework for improving palliative care in Ontario. The Declaration envisions a system that wraps delivery of care around patients, their family members and informal caregivers, and responds in a coordinated way to their personal goals and needs. It was a call for greater integration of care between providers and across the system.

## **...TO GOALS AND PRIORITIES...**

That commitment to integration is reflected in the provincial government's *Patients First: Action Plan for Health Care*, as well as *Patients First: A Roadmap to Strengthen Home and Community Care*. That document, released in May 2015, established goals and set out the following priorities for palliative and end-of-life care:

- expand access and equity in the palliative system
- establish clear oversight and accountability
- introduce new supports for caregivers
- support enhanced public education
- implement a comprehensive approach to palliative and end-of-life care at home and in the community

## **...TO ACTIONS**

This report explores the important steps to achieve those goals. The discussions at our roundtables will inform the development of a comprehensive strategy for palliative care in Ontario.

# WHAT WE HEARD

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## 1. EXPANDING EQUITABLE ACCESS AND INTEGRATION

If we were to take only one idea away from our province-wide consultations about palliative care, it would be that not all Ontarians have the same access. The barriers are many and diverse. They range from system fragmentation to geography to challenges providing culturally sensitive care. Many participants told us that the palliative care system is fragmented, difficult for patients and families to access and navigate, and particularly stressful when patients have to move from one care setting to another. In almost all cases, however, participants agreed that access problems are best solved through integration: because the more integrated a health care program is with its community partners, the more successful it will be.

### **It is important to receive palliative care as early as possible**

Palliative care is not only intended to help people die in comfort. Its goal is to help people facing a life-limiting illness live as long and as comfortably as possible, and enhance their quality of living and dying. For that reason, the earlier we can begin delivering palliative services to patients who have been diagnosed with a life-limiting illness, the better for their health. One barrier to people receiving early palliative care is the stigma associated with the term “palliative,” which may frighten patients and their families and prevent them from accessing services. Another is the strict requirement in some programs that people be within a certain time from death — which is very hard to predict with many chronic illnesses — before they can access palliative care services.

### **Families and caregivers find the health care system difficult to navigate**

The burden on the family members and caregivers of palliative patients is extraordinary. At a time when they are coping with impending loss and grief, the last thing they need is to encounter difficulties getting information on death and dying and on the services available for them and their loved ones. Far too often in our roundtables, we heard that family members and caregivers have a hard time navigating the palliative care system. Sometimes, the problem is that information exists in some organizations or online, but is hard to find or difficult to understand; other times we heard that information about existing services and facilities simply isn't there. There is a widespread feeling that a system designed to make the final stages of life as easy as possible is often difficult to find and frustrating to navigate.

## **The system struggles to ensure continuity of care, particularly when patients move from one care setting to another**

Another recurring theme was the apparent lack of coordination among different care providers, making it difficult to ensure a consistent level of care. Palliative care is delivered by many different providers and in various settings, including hospices, hospitals, long-term care homes and patients' homes. According to participants, transitions between settings are often poorly communicated to patients and their caregivers, which can cause confusion and stress.

When a patient has to move between settings, communication is key. Everyone in his or her circle of care needs to know what is going on. For example, when someone living in a long-term care home is transferred to hospital, the care providers at the hospital need to know about that person's medical history, medications and care plan. Similarly, when that patient is discharged from the hospital back to the long-term care home, all relevant information should be shared with the long-term care providers and the patient's family physician to ensure the patient receives appropriate follow-up and continuity of care. While the need for this two-way sharing of information and coordination of care may seem obvious, it doesn't happen often enough. As a result, patients and families — who are already under stress — may have to endure unnecessary duplication of tests and assessments, and longer wait times.

During the roundtables, we were impressed to hear how communities and practitioners are working creatively together to improve access and transitions. In one Local Health Integration Network (LHIN) community, patients could not be assessed and admitted to a residential hospice over the weekend because of the Community Care Access Centre (CCAC)'s operating hours. Community organizations worked together to establish a protocol that allowed patients to be admitted to available beds when needed, with the CCAC assessment taking place after the admission. According to participants, tools and resources such as common clinical practices, referral protocols and electronic medical records are essential to support and increase service integration and continuity of care.

## **Rural and northern communities face unique barriers accessing palliative care**

Ontario is a vast province. It is challenging to deliver palliative care in rural and Northern communities, where there are great distances between communities and between patients and providers. We heard that rural and Northern communities face unique challenges allocating resources equitably.

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There are no processes to manage the continuity of care for patients as they travel in and out of different care settings.

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Patients, Volunteers and Caregivers  
Engagement Session

While we know the geographical challenges of providing access to palliative care, we were heartened to hear about creative solutions that rural communities are exploring. For example:

- the rural health hub, which is located in an existing care facility, coordinates services across the continuum of care, tailors them to meet patient needs, makes effective use of existing community resources, and ensures they are accessible. This model may allow health care providers to coordinate and leverage their services and resources through a fully integrated health care delivery system
- use of Ontario’s Telemedicine Network (OTN) with a “guest link” facilitates appointments for patients with travel, mobility and/or energy issues. This model takes OTN one step further because it allows patients to book appointments at home using their computers

Telemedicine technologies have the potential to dramatically improve service access and capacity, particularly in rural and remote areas. We heard about innovative models of care where personal support workers provide palliative care under the remote supervision of nurses. Patients receiving care under this model are able to get assessments earlier, experience less anxiety about their care and may even visit emergency departments less frequently.

I believe we must find ways to encourage and support rural and Northern communities in finding more innovative solutions like these.

### **We must provide culturally sensitive services that meet the diverse needs of all Ontarians**

Ontario is home to a great many highly diverse communities. Participants told us, time and again, about the importance of ensuring that all patients have access to culturally appropriate and safe palliative and end-of-life care, including those from urban, rural and remote communities, and including various cultural, faith and linguistic groups, vulnerable populations (e.g., people who are homeless, have mental health or addiction issues) people with disabilities and Indigenous communities.

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**We need supports in our communities. We went through death with our grandmother. No training was received. Community care came twice a week and it helped. However, we didn’t know how to care for her.**

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**Chiefs of Ontario Leaders in the Legislature Session**

We also heard that the approach to palliative care should be tailored to each unique community. For example, care providers should be flexible when delivering care to:

- patients who are homeless and who may lack proper identification, health cards or places for providers to visit
- patients from the Lesbian, Gay, Bisexual, Transgender and Queer LGBTQ community who may have different circles of care, requiring care providers to collaborate with a wider range of people

The system's response to any barriers related to diversity must be to overcome them. We heard about some innovative efforts to reach out to vulnerable people and provide them with culturally sensitive care. For example, one LHIN is planning to integrate palliative and end-of-life care into the existing specialized services for marginalized populations. People accessing services for mental health, addiction, HIV and housing have existing relationships with service providers so they will be more likely to access palliative and end-of-life care services sooner if they are part of the services they already receive.

For all communities, we heard the importance and value of fostering relationships that are built on knowledge, respect and trust.

### **First Nations, Métis and urban Aboriginal perspectives are not captured or reflected in palliative and end-of-life services**

We share the common goal of improving health outcomes for Indigenous people in Ontario. First Nations leaders told us that their seniors are not receiving the support they need, and often must leave their communities — where they feel culturally safe and respected — to receive palliative care far from family based supports.

We heard that Indigenous people need more access to long-term care supports from trained culturally competent staff. Indigenous partners spoke about the challenges that families experience when few health care providers offer culturally appropriate palliative care and few organizations accommodate traditional practices. When providing end-of-life care to Indigenous people, appropriate space is required for traditional practices such as smudging, cedar baths or other ceremonies.

Indigenous partners also talked about having few resources to build palliative care capacity for caregivers as well as frontline workers. Given that many First Nations communities are not close to urban centres, their leaders told us that,

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The physical space needs to be made for traditional practice. Small things make a difference.

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Urban Aboriginal Health Table Session

when patients need more intensive care and have to go to larger centres, their families may not have the resources to cover the high cost of bringing their loved ones back home. They felt that the option of flying people home should be available.

### **Despite the large Francophone population in the province, patients are not always able to get services in their language of choice**

We know Ontario faces issues delivering French-language health care services, and that the lack of services in French sometimes causes patients to hesitate or delay when accessing services. Our roundtable discussions confirmed that this is the case when it comes to palliative care services. Participants suggested that health care providers who speak French should actively offer their services in French, either through self-identification and/or by posting signs indicating that they provide services in French. They also suggested the system ensure that organizations designated under the *French Language Services Act* are actively offering their services in French.

### **Delivering palliative care to children is more complex and requires specific expertise**

However hard it is to prepare for an adult's death, it is harder and more complex to prepare for a child's death. Children rely more on family caregivers, and parents experiencing the early death of a child may simply be unable to cope. Some health care providers may also have a difficult time coping with a child's death and providing end-of-life care for a child. A relatively small number of providers have experience and expertise in paediatric palliative care.

To ensure that all families have access to that expertise, the paediatric palliative care sector recommended adopting a regional approach. For example, paediatric hospitals (e.g., Hospital for Sick Children, Children's Hospital of Eastern Ontario) could serve as centres of excellence to help providers in communities across the province serve children.

We also heard about innovative examples of care for children faced with life-limiting illnesses, including

- a model in which experienced palliative oncology nurses across the province work to link home, hospital and community resources. They meet patients and families at the time of diagnosis and work with them to ensure they are linked with appropriate resources. If the child's health starts to decline, the nurse will connect the family with tertiary care providers

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**Patients may be scared to request services in French for fear they might go to the end of the waiting list.**

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**French Language Health Services  
Advisory Council Session**

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**Age should not be a determinant of who can access palliative care. Children should not be turned away because health care providers are not comfortable with treating children.**

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**Paediatric Care  
Focus Group Session**

- a model in which nurse practitioner services are shared between hospital and hospice. The NPs support patients who have to move between these care settings, make direct referrals to the hospice, divert ER visits and make home visits.

Family members also told us about how important it is for support for family caregivers to continue after a child dies, because bereavement support is key to helping families heal.

## 2. STRENGTHENING SERVICE CAPACITY

Faced with an aging population, Ontario expects a significant increase in need for palliative and end-of-life care over the next decade. The growth in demand will require more capacity. We need to look for opportunities to leverage existing funding, competencies and expertise across the entire continuum of care in order to maximize the value of every tax dollar invested. According to participants, the system should focus on enhancing the knowledge and skills of existing providers, and providing policies and tools that will help them work more efficiently and effectively.

### **More health care providers should be knowledgeable about palliative care**

Participants told us that Ontario does not have enough health care providers who are knowledgeable about palliative care.

They recommended educational supports such as mentorship programs, courses, communities of practice or new training standards to improve the capacity of physicians, nurses, personal support workers, pain and symptom management consultants, and others to provide palliative care. One example we heard of was an effective training resource called LEAP — Learning Essential Approaches to Palliative and End-of-Life Care — which provides active learning opportunities focused on best practices in caring for patients with life-threatening and life-limiting illnesses.

### **We need to engage primary care providers in delivering palliative care**

Because primary care providers have regular contact with patients who have chronic and life-limiting health conditions, they are in a unique position to help meet their palliative needs. Participants encouraged the ministry to support physicians, nurses and other primary care providers — especially those working in family health teams and community health centres — to become more involved in delivering palliative care.

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All health care providers, no matter what specialty, should have a basic level of delivering palliative care.

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Clinical Advisors Session

## Nursing expertise could be maximized to deliver palliative care

In Ontario, nurse practitioners do not currently have the authority to prescribe controlled substances for pain management (e.g., opioids) and registered nurses are not allowed to complete medical certificates of death. Participants advocated for regulatory and policy changes to expand the scope of practice for nurses, which would facilitate more timely access and supports for patients nearing end-of-life.

## Palliative care service delivery models could be improved to generate greater value for public investments

There are a number of different models of palliative care. To achieve better outcomes within existing budgets, roundtable participants encouraged the ministry to explore innovative service delivery models and approaches, including:

*Interprofessional and Interagency Teams:* Collaborative ventures have the potential to improve patient and system-level outcomes. For example:

- a supportive housing organization described how they partnered with a hospital-based palliative care team to offer their residents the opportunity to die at home
- a nurse-led outreach model supports patients discharged from hospital to ensure smooth transitions between care settings

*Effective Use of Information-Sharing Tools:* Integrated collaborative teams need effective ways to share patient records and care information. Tools such as electronic medical records, for example, can greatly improve the quality of care by better informing health care providers. However, they may also pose privacy and confidentiality issues that must be addressed.

*More Flexible Service Models:* Hospitals, residential hospices and CCACs provide excellent palliative and end-of-life care with their existing models and processes. However, it may be possible for these organizations to provide more service and achieve even better outcomes. For example, several participants suggested that residential hospices could reach more people and ensure they receive high-quality end-of-life care by operating as centres of excellence and service hubs for their communities.

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Look at patient needs — who needs to be in acute, hospice, home...  
Need a daily huddle of all providers to try to get patients the right care.  
Maximize the right resources for the right patient.

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Ontario Hospital Association Session

*Sharing Best Practices:* While participants acknowledged the need for local flexibility, they stressed that successful models of care need to be shared so they can be adapted and replicated across the province. For example, we heard about:

- hospitals that developed hospice-friendly strategies, such as palliative suites with dedicated beds
- acute palliative teams in hospitals that worked across settings, providing specialized palliative expertise to support health care providers in the community

### **Long-term care homes should be an important part of the continuum of palliative care**

Most Ontarians with life-limiting illnesses would prefer to be cared for and to die at home rather than in a hospital. For the many residents of long-term care homes, those facilities are their homes. In a palliative care system that values caring for patients where they live, more should be done to provide access to high-quality palliative care in long-term care homes. At the current time, long-term care homes face operational and regulatory barriers that impede their ability to provide palliative care. Participants urged us to consider strategies to eliminate these barriers and make long-term care homes an important part of the continuum of palliative and end-of-life care.

### **Consideration should be given to the role of CCACs in providing palliative home care services**

CCACs coordinate professional, personal support and homemaking services for eligible patients living in their own homes. While participants acknowledged that the CCACs make valuable contributions to patient care, they were concerned about the consistency of quality and availability of palliative home care services. Different communities seem to experience different levels of palliative and end-of-life care, and these differences were often attributed to a lack of consistency in how CCACs function. One area of concern raised was that CCACs may only be available during office hours (i.e., 9 am to 5 pm). If a person with a life-limiting illness experiences an urgent issue after hours, families often have to wait until the next day when CCAC care coordinators are available.

Participants recognized that CCAC services benefit family caregivers as well as patients because supporting caregivers results in better patient care.

### 3. IMPROVING CAREGIVER SUPPORTS

Anyone who has had a friend or relative in palliative care knows the burden that families and caregivers shoulder. At every roundtable, we heard about the important and difficult role that families and caregivers play in providing palliative and end-of-life care. Many participants expressed concern about how much family caregivers endure, putting both their physical and mental health at risk, and they identified ways to improve support for caregivers.

#### Home visits from health care providers are vital supports for patients and caregivers

Participants agreed that home visits from physicians, nurses, nurse practitioners and volunteers help patients remain in their homes and with their families longer, reduce the time and energy required to travel to and from appointments, and provide peace of mind for families and caregivers. We also heard that regular contact with the patient's palliative care team at home helps family members manage expectations, anticipate future health changes and complications, understand what their loved ones are experiencing and how they can help, and avoid unnecessary visits to the hospital or emergency department.

#### More supports would help caregivers avoid burnout

Throughout the palliative care process, it is critical that caregivers have access to respite services so that they can take breaks and manage other responsibilities. During the roundtables, participants told us that they frequently had difficulties accessing adequate respite services. Finding nurses to provide palliative and end-of-life care, especially for night shifts, can be particularly challenging. Participants asked the ministry to expand caregiver supports, which would allow family members and friends to continue caring for their loved ones at home or in the community.

#### The system should consider compensating caregivers for the services they provide

Financial pressures often prevent family members from taking time off work to care for dying loved ones. Ontario's Caregiver Benefit supports people who need to be away from work temporarily to care for family members who are gravely ill and at significant risk of death. However, participants told us that this benefit is not always sufficient to cover lost wages. Because it is difficult to know patients' disease trajectory and their care needs can fluctuate, caregivers cannot predict

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We cannot assume that all patients have family. Sometimes there is no one so we need to develop a protocol for people who don't have family.

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Patients, Volunteers  
and Caregivers Session

how much time they will need off work. They frequently spend more time off the job than they are compensated for through Ontario's Caregiver Benefit, which creates financial hardship for the family.

### **Families need more access to grief and bereavement services**

The grief that accompanies losing a loved one is real, palpable and often debilitating. Participants reminded us that the patient's death is not the end of the palliative care journey for family members, who must then cope with their own grief and loss. According to participants, families would benefit from stronger supports for anticipatory grief, loss and bereavement, including information, ongoing support groups and counselling services at all stages of care. Families also asked for help to connect with emotional and spiritual supports through their communities or religious leaders.

During the roundtables, we heard about innovations that could increase access to grief and bereavement supports including

- A partnership between eight organizations identified barriers that prevent children and youth from accessing grief and bereavement services when family members are dying — including lack of available services, stigma, cost, transportation, geography, timing of death, time and energy needed for care, and access to support. To address these barriers, the partners developed a volunteer training handbook for working with youth.
- The HUUG program (Help Us Understand Grief) offers in-home visits to support children and youth who have a family member dealing with a life-limiting illness.
- Community education and wellness programs offer complementary therapy programs that help grieving families address physical, mental, emotional and spiritual wellness.

## **4. ENHANCING PUBLIC EDUCATION AND AWARENESS**

Participants told us that public understanding of palliative and end-of-life care is limited. They talked about the public's misperceptions about palliative care as a service that is given to patients when "nothing else is working." Too many people think that palliative care just helps people die comfortably, instead of helping them to live longer and better.

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**The patient is priority but mom is the real priority because without her, the patient would be dead.**

**Paediatric Focus  
Group Session**

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## Ontario should promote a cultural shift in thinking about palliative care

To help people facing a life-limiting illness access services that can drastically improve the quality of their lives, participants suggested that Ontario needed to promote a cultural shift in thinking about palliative care. To create that shift, participants said it would help if all health care providers used clear, jargon-free language when talking about death and dying so that patients, families and caregivers of all backgrounds and literacy levels can understand the services available to them. This approach is crucial to helping patients and families make informed decisions about their care.

## We need a proactive open approach to discussions about death and dying

Conversations between care providers, patients and families should include discussions about palliative care as well as Advance Care Planning. Participants emphasized the importance of normalizing these discussions, so that patients, caregivers and health care providers can plan care appropriately. To help normalize the conversation, participants suggested that the language of survivorship, which often employs expressions such as “waging a war” or “fighting a battle” must change because it can stigmatize palliative care for people who think of it as giving up.

## The public is not aware of Advance Care Planning and does not realize it is much more than just planning for death

As patients, it is our responsibility to inform the system about our needs and desires — yet many members of the public are unaware of Advance Care Planning and how it can help them get the care they want.

Advanced Care Planning is a process that encourages patients, family members and health care providers to talk about the patients’ wishes and desires, in case there comes a time when the patient may not be able to make his or her own health care decisions. It is an important ongoing conversation about end-of-life as part of life.

While Advance Care Planning conversations are often difficult and emotional, they make it much easier to provide patient-centred palliative care. Simply put, Advance Care Planning informs patients’ health care providers and lays the groundwork for patients to receive not only the services they need, but those they want.

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Encourage open and public discussion around death and dying.

Local Health Integration Network Session

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Decisions change quite often. Individuals and families should be encouraged to discuss what their decisions are again and again.

Patients, Volunteers and Caregivers Session

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As participants noted, people often plan for major life milestones but do not include death as one of them. Once patients feel comfortable talking about death and dying, they can begin to identify their values, wishes and goals for palliative and end-of-life care — which may change over time. Even if their Advance Care Plans are never used, the process can be beneficial. At the very least, Advance Care Planning engages patients and families in discussions with their health care providers, which can result in better experiences for everyone.

Participants asked the ministry to promote Advance Care Planning to increase uptake in all communities.

## 5. ESTABLISHING OVERSIGHT AND ACCOUNTABILITY

The palliative and end-of-life care services provided in Ontario should align with best practices and provincial standards. At the same time, there must be some flexibility in how services are implemented given their unique nature and different capacities in different communities. Participants suggested several strategies to improve oversight and accountability of palliative care services, while still ensuring these services can be tailored to meet individual needs.

### **A provincial partnership should be established to oversee palliative and end-of-life care**

The most common concern we heard during the roundtables was the lack of province-wide consistency in the delivery and availability of palliative and end-of-life services. The most common solution was a single provincial partnership responsible for overseeing these services.

The message was clear: if we want to ensure a provincial standard for palliative and end-of-life care, there must be one body committed to setting and enforcing that standard. According to participants, such a body would help identify and address gaps in service, drive innovation and integration, and encourage and support the sharing of best practices.

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Advance care planning isn't something that should just be left up to doctors — everyone should talk about it.

Health Care Providers  
Focus Group Session

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## **Shared accountability and performance measurement would help ensure high-quality palliative care**

According to participants, clear accountability mechanisms would help ensure Ontarians have access to consistent high-quality palliative services and provincial performance measures would help monitor progress in strengthening palliative care. When developing performance measures, participants suggested the system consider the following metrics:

- the quality of the patient’s death
- evidence that the patient received high-quality clinical care in an appropriate setting of his or her choice (e.g., at home, in the community, in other settings)
- system performance in order to optimize care across settings
- patient and caregiver experience
- transparency about the resources available, such as beds, and the targets for service volumes and referral times

## **Residential hospices should be integrated into the broader health care system**

Hospices are built and driven by the community, and have a strong community presence. To maximize the benefit of their services, participants recommended that hospices be more fully integrated within the governance and accountability structures of the broader health care system. In their view, being part of the broader system would support consistent palliative care standards, guidelines and best practices in all hospice settings.

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The work going on at the provincial level to develop standardized indicators will be helpful.

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Local Health Integration  
Network Session

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We need to build on what is working well, particularly with respect to good experiences so that we can move forward.

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Health Care Providers Session

# OBSERVATIONS AND REFLECTIONS

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Palliative and end-of-life care touches every Ontario family and every aspect of our province's health care system. Like life itself, changing how we care for each other at the end of our lives will be a journey. We must now set our direction and move forward. The engagement process we held over these last six months made two things clear to me:

- First, there is a great wealth of experience and knowledge within our communities. People and organizations are doing incredible work to help meet Ontarians' needs at the end of their lives.
- Second, there is much work still to be done to improve palliative and end-of-life care for all Ontarians.

This final section of the report contains my observations and reflections about what we heard, and outlines what I believe are our next important steps forward. I start by addressing the need for a better understanding of palliative care and the importance of Advance Care Planning, and then address the steps we can take to improve access to palliative and end-of-life care to ensure high-quality services for everyone.

## **1. Reduce the stigma associated with palliative care**

Palliative care is still not well understood in our society. To many people, it implies that the system has given up on them or their loved ones, and it is something to be avoided. We need to help people understand that palliative care is a holistic approach to addressing the needs of people with life-limiting illnesses. Helping people die comfortably is one of the goals of palliative care, and so is helping them live longer and better.

## **2. Promote Advance Care Planning**

Talking about death is difficult. Advance Care Planning helps individuals think about and communicate their values, wishes and goals of care. Making our wishes known is one of the most important things we can do for ourselves and for each other. In the event that we are not capable of making our own health care decisions, our Advance Care Plan can help providers provide the most appropriate care and prevent interventions that cause pain and suffering.

We need to be more open to discussions about death, palliative and end-of-life care, and Advance Care Planning — just as we now are with issues like mental health and organ and tissue donation. Communities and organizations need support to help start the conversations and drive the message of Advance Care Planning.

### **3. Respect patient choice**

Many Ontarians want to stay in their homes as long as possible, and that desire is often part of their Advance Care Plan. Whether patients wish to receive end-of-life care at home or in a hospice, long-term care home or a retirement residence, we need to find a way to honour their wishes.

### **4. Provide equitable access to palliative care for Ontarians**

Access to palliative and end-of-life care should not depend on who you are or where you live. Any strategy for delivering palliative and end-of-life care must strive to ensure that all patients, regardless of regional, cultural, linguistic or other differences, have fair and equitable access to high-quality palliative care.

### **5. Build community connections and capacity**

Hospice palliative care is a community-based initiative supported by government. Its strength lies in community. The most successful programs in Ontario are fully integrated not only with other health care partners, but also with the broader community. These programs build on the unique capacities of each community. We must find ways to provide additional support for these programs, and reinforce the role of communities and their unique capacities.

Hospices play a key role. They provide as home-like a setting as possible, while maintaining the capacity to deliver needed medical services. As we move forward with our commitment to build 20 new hospices, it is critical that they be part of a larger integrated palliative care program in their communities as, for example, a partner or a hub.

Visiting and volunteer palliative care services can greatly improve patients' quality of life and provide much-needed relief for families. These services give patients and families a feeling of comfort and of being part of something welcoming and respectful. This is what makes community-based care an essential component of the best palliative care. It is critical that we find a way to help communities build this capacity and support existing programs.

## **6. Enhance the role of primary care**

Primary care providers are central to our *Patients First: Action Plan for Health Care*. Their participation in palliative and end-of-life services is critical. Ontario needs partnerships and strategies to build the capacity of primary care, using tools like education and peer support.

## **7. Respond to unique and diverse needs**

The strength of palliative and end-of-life care is that it recognizes and is built around the unique needs of the people it serves. It is not a one-size-fits-all approach. Many people face barriers accessing the services and supports they need at the end of their lives; others require services and supports that are vastly different than the rest of the population. An effective equitable palliative and end-of-life care strategy must acknowledge the challenge of providing care to paediatric, Indigenous, Francophone, LGBTQ, differently-abled and homeless patients, and develop unique approaches to meet their needs.

## **8. Ensure a collaborative approach to accountability**

Collaboration is the hallmark of successful palliative care programs in Ontario. The *Declaration of Partnership and Commitment to Action* demonstrated the collective desire of the palliative care sector to work together to improve palliative and end-of-life care services. I believe that the next step is to establish a formal network that will develop standards and shared accountability, as well as the performance metrics required to measure progress towards our common goals.

## **9. Encourage greater inter-ministerial collaboration**

During the roundtables, we heard much about the importance of inter-ministerial collaboration, specifically among the Ministries of Municipal Affairs and Housing, Education, Community and Social Services and Health and Long-Term Care. An effective palliative care strategy should work to align ministry policies with the needs of patients. Through effective inter-ministry collaboration, we will find ways to reduce the administrative burden for programs that deliver palliative care services to unique populations.

# THANK YOU

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In closing, I want to express my sincere gratitude to all the patients and families, volunteers, diverse communities — including Indigenous and Francophone leaders, health care providers and experts in the field of palliative care — who, over the last six months, have taken the time to share their thoughts, experiences and passion. Your contributions have been invaluable.

The consultations and this report would not have been possible without the hard work of many, including Pearl Ing and her team, Vena Persaud and Paula Ruppert, from the Ministry of Health and Long-term Care. I would like to thank everyone for their support.

# APPENDIX A:

## Palliative and End-of-Life Care Engagement Sessions: Stakeholder/Participant List

CHAMPLAIN LOCAL HEALTH INTEGRATION NETWORK SESSION		
1. Algonquins of Pikwàkanagàn First Nation	2. Bruyère Continuing Care	3. Cancer Care Ontario
4. Carefor Health & Community Services	5. Champlain Community Care Access Centre	6. Champlain Hospice Palliative Care Program
7. Champlain Local Health Integration Network	8. Champlain Regional Palliative Care Program, The Ottawa Hospital Cancer Centre	9. Hospice Care Ottawa
10. Hospice Palliative Care Ontario	11. Le Réseau des services de santé en français de l'Est de l'Ontario	12. Long-Term Care Stakeholder Liaison Committee
13. Madawaska Valley Hospice Palliative Care	14. The Ottawa Hospital	15. Ottawa Inner City Health
16. St. Francis Memorial Hospital		
NORTH EAST LOCAL HEALTH INTEGRATION NETWORK SESSION		
1. Algoma Community Residential Hospice	2. Bayshore Healthcare	3. Cancer Care Ontario
4. Cochrane Local Palliative Planning Table	5. F.J. Davey Home	6. The Friends, Parry Sound
7. Health Sciences North	8. Hospice Palliative Care Ontario	9. Hospice West Parry Sound
10. Office of the President, Huntington University	11. Maison Vale Hospice	12. Manitoulin Local Palliative Planning Table
13. Near North Palliative Care Network	14. Nipissing Local Palliative Planning Table	15. North East Community Care Access Centre
16. North East Hospice Palliative Care Steering Committee	17. North East Local Health Integration Network	18. North East Regional Cancer Program, Cancer Care Ontario
19. Réseau du mieux-être francophone du Nord de l'Ontario	20. Timiskaming Hospice Palliative Care	21. Victorian Order of Nurses
22. West Parry Sound Health Centre	23. Wikwemikong Health Centre	

<b>TORONTO CENTRAL LOCAL HEALTH INTEGRATION SESSION</b>		
1. Cancer Care Ontario	2. Central Toronto Community Health Centres	3. Economic Development and Employability Network of Ontario
4. Forest Hill Family Health Team	5. Hospice Palliative Care Ontario	6. Hospice Toronto
7. Hospital for Sick Children	8. Inner City Health Associates	9. Kensington Hospice
10. Mount Sinai Hospital	11. Philip Aziz Centre For Hospice Care	12. Princess Margaret Cancer Centre, University Health Network
13. Providence Healthcare	14. Reflet Salvéo	15. St. Michael's Homes
16. St. Michael's Hospital	17. Sunnybrook Health Sciences Centre	18. Toronto Central Community Care Access Centre
19. Toronto Central Local Health Integration Network	20. True Davidson Acres City of Toronto Long-Term Care Home & Services	21. Toronto General Hospital, University Health Network
22. Department of Family and Community Medicine, University of Toronto	23. William Osler Health System	
<b>CENTRAL WEST LOCAL HEALTH INTEGRATION NETWORK SESSION</b>		
1. Acclaim Health	2. Bethell Hospice	3. Cancer Care Ontario
4. Dorothy Ley Hospice	5. Central West Community Care Access Centre	6. Central West Local Health Integration Network
7. Central West Palliative Care Network	8. Centre de services de santé de Peel-Halton	9. Heart House Hospice
10. Headwaters Health Care Centre	11. Hospice Dufferin	12. Hospice Palliative Care Ontario
13. Mississauga Halton/Central West Regional Cancer Program	14. Reflet Salvéo	15. William Osler Health System
16. Wise Elephant Family Health Team		
<b>HAMILTON NIAGARA HALDIMAND BRANT LOCAL HEALTH INTEGRATION NETWORK SESSION</b>		
1. Cancer Care Ontario	2. The Good Shepherd	3. Hamilton Niagara Haldimand Brant Community Care Access Centre
4. Hamilton Niagara Haldimand Brant Hospice Palliative Care Program Council	5. Hamilton Niagara Haldimand Brant Local Health Integration Network	6. Hospice Palliative Care Ontario
7. Juravinski Cancer Centre	8. Department of Family Medicine & Department of Oncology, McMaster University	9. McNally House Hospice
10. Niagara West Palliative Care Team	11. Norfolk Hospital Nursing Home	12. Ontario Hospice Palliative Care Clinical Council
13. Shared Care Outreach Team	14. Stedman Community Hospice (Hankinson House)	

<b>WATERLOO WELLINGTON LOCAL HEALTH INTEGRATION NETWORK SESSION</b>		
1. Cancer Care Ontario	2. Hospice Palliative Care Ontario	3. Hospice of Waterloo Region
4. Innisfree House	5. Meals on Wheels	6. Village at University Gates
7. Waterloo Wellington Community Care Access Centre	8. Waterloo Wellington Integrated Hospice Palliative Care Program	9. Waterloo Wellington Local Health Integration Network
10. Office of Aboriginal Initiatives, Wilfrid Laurier University		
<b>PAEDIATRIC FOCUS GROUP SESSION</b>		
1. Canadian Association of Paediatric Health Centres	2. Cancer Care Ontario	3. The Children's Hospital of Eastern Ontario Research Institute
4. Darling Home for Kids	5. Holland Bloorview Kids Rehabilitation Hospital	6. Hospice Palliative Care Ontario
7. Hospital for Sick Children	8. Philip Aziz Centre For Hospice Care, Emily's House	9. Provincial Council for Child and Maternal Health
10. Provincial Paediatric Palliative Care Working Group	11. Roger's House, Children's Hospital of Eastern Ontario	12. Faculty of Medicine, University of Ottawa
13. Lawrence S. Bloomberg Faculty of Nursing, University of Toronto		
<b>DIVERSE FOCUS GROUP SESSION</b>		
1. Canadian Disability Alliance	2. Cancer Care Ontario	3. Community Living Dufferin
4. Community Living Haldimand	5. Norfolk Association for Community Living	6. Community Living Ontario
7. Good Neighbours' Club	8. Heart House Hospice	9. Hospice Palliative Care Ontario
10. Inner City Health Associates	11. School of Social Work & Northern Ontario School of Medicine, Lakehead University	12. Multicultural Council for Ontario Seniors
13. Northwest Community Care Access Centre	14. Centre for Education and Research on Aging & Health	15. Ontario Multi-Faith Council on Spiritual and Religious Care
16. Ontario Partnership on Aging and Developmental Disabilities	17. Rainbow Health Ontario	18. Regional Geriatric Program of Toronto
19. Yee Hong Centre — Scarborough Finch		
<b>PATIENTS, VOLUNTEER, AND CAREGIVERS FOCUS GROUP SESSION</b>		
1. Buddhist Education Network of Ontario	2. Cancer Care Ontario	3. Champlain Region, Family Council Network
4. Evergreen Hospice	5. Family Councils Ontario	6. Hospice Palliative Care Ontario
7. Kensington Hospice	8. Mount Pleasant Group of Cemeteries	9. Mt. Sinai Hospital
10. Older Women's Network	11. Ontario Association of Residents' Council	12. Ontario Coalition of Senior Citizens' Organizations

13. Ontario Retirement Communities Association	14. Patients Canada	15. Philip Aziz Centre For Hospice Care, Emily's House
16. United Senior Citizens of Ontario		
<b>CLINICAL ADVISORS FOCUS GROUP SESSION</b>		
1. Bruyère Continuing Care	2. Cancer Care Ontario	3. Central Local Health Integration Network
4. Central West Community Care Access Centre	5. Central West Palliative Care Network	6. Credit Valley Hospital
7. Hospice Palliative Care Ontario	8. Hospice Simcoe	9. Hospice Palliative Care Consultation Services Waterloo Wellington
10. Centre for Education and Research on Aging & Health, Lakehead University	11. Department of Family Medicine, McMaster University	12. Ontario College of Family Physicians
13. Ontario Medical Association	14. Ontario Palliative Care Network	15. The Hospital for Sick Children
16. Trillium Health Partners	17. Department of Medicine, University of Ottawa	18. Department of Anesthesia and Perioperative Medicine, University of Western Ontario
19. Waterloo Wellington Regional Cancer Program, Cancer Care Ontario	20. William Osler Health System	21. Windsor Regional Hospital
<b>HEALTH SERVICE PROVIDERS FOCUS GROUP SESSION</b>		
1. Association of Ontario Health Centres	2. Cancer Care Ontario	3. College of Nurses of Ontario
4. College of Physicians and Surgeons of Ontario	5. Hospice Niagara	6. Hospice Palliative Care Ontario
7. Department of Oncology, McMaster University	8. Nurse Practitioners' Association of Ontario	9. Ontario Association of Non-Profit Homes and Services for Seniors
10. Ontario Community Support Association	11. Ontario Home Care Association	12. Ontario Hospital Association
13. Ontario Long Term Care Association	14. Ontario March of Dimes	15. Ontario Medical Association
16. Ontario Public Health Association	17. Palliative Care Network for York Region	18. Palliative Pain and Symptom Management for Toronto
19. Registered Nurses' Association of Ontario	20. South East Grey Community Health Centre	21. Trillium Gift of Life Network

### FRENCH LANGUAGE HEALTH SERVICES ADVISORY COUNCIL SESSION

1. Bendale Acres	2. Bruyère Continuing Care	3. Centre de Santé Cognitive de Glendon
4. Centre de santé communautaire Hamilton/Niagara	5. Centres d'Accueil Heritage	6. Champlain Hospice Palliative Care
7. Entité de planification pour les services de santé en français #4	8. Entité2 de planification des services de santé en français, Hamilton Niagara Haldimand Brant, Waterloo Wellington	9. Foyer Richelieu Welland
10. French Language Health Services Advisory Council	11. Hawkesbury & District General Hospital	12. Hospice Niagara
13. Hospice of Windsor and Essex County	14. Maison Vale Hospice	15. Montfort Hospital
16. Reflet Salvéo	17. South East Local Health Integrated Networks	18. Timiskaming Palliative Care Network

### SOUTH EAST LOCAL HEALTH INTEGRATION NETWORK SESSION

1. French Language Health Services Network of Eastern Ontario	2. Hospice Kingston	3. Hospice Prince Edward
4. Hospice Prince Edward Foundation	5. Lennox & Addington County General Hospital	6. Moira Place
7. Perth & Smiths Falls District Hospital	8. Providence Care	9. Palliative Care Medicine Program, Queen's University
10. Quinte Health Care	11. South East Community Care Access Centre	12. South East Local Health Integration Network
13. South East Regional Cancer Program, Cancer Care Ontario	14. South Frontenac Community Services Corporation	

### ONTARIO HOSPITAL ASSOCIATION SESSION

1. Baycrest Health Sciences	2. Bruyère Continuing Care	3. Haliburton Highlands Health Services Corporation
4. Hamilton Health Sciences Centre	5. Ontario Hospital Association	6. Southlake Regional Health Centre
7. St. Joseph's Care Group, Thunder Bay	8. St. Joseph's Healthcare, Hamilton	9. St. Joseph's Health Care, London
10. Sunnybrook Health Sciences Centre	11. The Temmy Latner Centre for Palliative Care, Sinai Health System	12. Toronto Grace Health Centre
13. Toronto Rehabilitation Institute, University Health Network		

### CHIEFS OF ONTARIO LEADERS IN THE LEGISLATURE SESSION

1. Alderville First Nation	2. Bkejwanong First Nation (Walpole Island)	3. Caldwell First Nation
4. Chiefs of Ontario	5. Curve Lake First Nation	6. Grand Council Treaty #3
7. Hiawatha First Nation	8. Independent First Nations	9. Kenora Chiefs Advisory
10. Mississaugas of the New Credit First Nation	11. Mitaanjigamiing (Stanjikoming) First Nation	12. Mohawks of the Bay of Quinte
13. Northwest Angle #33 First Nation	14. Six Nations of The Grand River	15. Union of Ontario Indians

### URBAN ABORIGINAL HEALTH TABLE SESSION

1. Métis Nation of Ontario	2. Ontario Federation of Indigenous Friendship Centres	3. Ontario Native Women's Association
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### OTHER STAKEHOLDER SESSIONS

1. Bridge Hospice	2. Bruyère Continuing Care	3. Canadian Cancer Survivors Network
4. Cancer Care Ontario	5. Carpenter Hospice	6. Catholic Health Association of Ontario
7. Dorothy Ley Hospice	8. Dying with Dignity Canada	9. Emily's House
10. Hamilton Family Health Team	11. Health Quality Ontario	12. Heart House Hospice
13. Hospice Care Ottawa	14. Hospice Palliative Care Ontario	15. The Hospice of Windsor & Essex County Inc.
16. Hotel Dieu Grace Hospice	17. Madawaska Valley Hospice Palliative Care	18. Matthews House Hospice
19. May Court Hospice	20. Milton Hospice	21. Muskoka Hospice
22. Ontario Association of Social Workers	23. Ontario Hospital Association	24. Ontario Seniors Secretariat Liaison Committee
25. Pallium Canada	26. Rural Ontario Residential Hospice Association	27. Spectrum Health Care
28. Stedman Hospice	29. Temmy Latner Centre for Palliative Care, Mount Sinai Hospital	30. Vale Hospice
31. Vaughan Hospice	32. Wendy Muckle Mission Hospice	33. Yee Hong Centre for Geriatric Care

# APPENDIX B:

## Submissions Received

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1. Buddhist Education Network of Ontario & Buddhist Education Foundation of Canada  
Patients, Volunteers and Caregivers Focus Group — Responses to roundtable questions
2. Canadian Disability Policy Alliance  
Letter on Palliative Care in Ontario and Assisted Suicide
3. Central West LHIN  
Palliative and End-of-Life Care Presentation
4. Community Living Ontario  
Diverse Focus Group Engagement Discussion Comments
5. Dr. Darren Cargill  
4-5 Point Plan for Improving Palliative Care in Ontario
6. Florence Péretié, Chair, Provincial Network of the French Language Services Coordinators of the LHINs  
Feedback/Comments from Roundtable engagement session with Francophone community
7. Jean Roy, membre du Conseil consultatif des services de santé en français  
Feedback/Comments from Roundtable engagement session with Francophone community
8. Health Care Access Research and Developmental Disabilities  
Applied Health Research Question Report: Aging profiles of adults with and without developmental disabilities in Ontario
9. Home Care Ontario  
Enabling Palliative Care at Home — June 2015
10. Ontario Association of Residents' Council  
Patients, Volunteers Caregivers Focus Group — Comments
11. Pediatric Oncology Group of Ontario & Provincial Council for Maternal and Child Health  
Report of the Paediatric Palliative Care Work Group
12. South West Community Care Access Centre & South West LHIN  
South West eShift Intervention Model
13. Toronto Central LHIN  
Palliative and End-of-Life Care Preliminary Comments
14. Quality Palliative Care in Long Term Care (QTC-LTC) Alliance  
Improving Quality of Life for People Dying in Long Term Care Homes is the Quality Palliative Care in Long Term Care (QTC-LTC) Alliance's five-year comparative case study research involving four long term care (LTC) homes in Ontario.