Palliative Care Health Services Delivery Framework

Recommendations for a Model of Care to Improve Palliative Care in Ontario

FOCUS AREA 3: CHILDREN RECEIVING CARE ACROSS SETTINGS

Ontario Palliative Care Network | October 2025

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Executive Summary

In 2019, the Ontario Palliative Care Network (OPCN), in partnership with Ontario Health (OH), introduced the first of three models within the Palliative Care Health Services Delivery Framework (Delivery Framework). This initial model focused on palliative care for adults in community settings (Adult Community Model of Care). The Delivery Framework has two additional models: one dedicated to adults in hospital settings (Adult Hospital Model of Care) and another designed for children across all care settings (Pediatric Model of Care).

This document outlines recommendations for the Pediatric Model of Care. System planning for children's palliative care services requires a sustainable model that enables access to high-quality care across Ontario's vast geography. The Pediatric Palliative Model of Care was developed through expert consultation, engagements with diverse demographic groups, jurisdictional scans, consultations with Health System Partners, literature review and the development of case studies. The objective was to ensure that all children and their families receive comprehensive pediatric palliative care, as outlined in the Ontario Provincial Framework for Palliative Care. According to the government's strategic priorities for palliative care, this care should be provided at the right time, regardless of developmental stage[1] or location of care, and should be provided by prepared healthcare professionals.

The Pediatric Model of Care aims to organize and coordinate palliative care services based on the needs of the child and family, provide role clarity for the Interprofessional Pediatric Palliative Care Team, create and strengthen supports for healthcare providers in community settings, and describe necessary resources for tertiary centres to support regional networks.

The summarized recommendations are:

1. The child and family have access to high quality palliative care in their preferred location, as close to home as possible, enabled through a Hub-and-Spoke design[2].
2. Children with palliative care needs are identified early in their illness.
3. The child and family receive care from an Interprofessional Pediatric Palliative Care Team.
4. The needs of the child and family are regularly examined through a comprehensive and holistic assessment, including consideration for the unique needs of siblings.

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[1] This document uses the following developmental stages: perinatal 20 weeks gestation – 4 weeks post birth, newborn up to 28 days, infant 1 month to 1 year, child 1 to 12 years, adolescent 13 to 18 years and young adult 19 to 24 years. Throughout this document, the term 'child' is used to designate all of these developmental stages.

[2] The Pediatric Model of Care recognizes that providing palliative care in a child's and family's preferred location may not always be practicable, feasible, and/or possible. This applies to all references of "preferred location" throughout the Pediatric Model of Care.

5. The child and family are regularly engaged in discussions about their goals of care, to inform the co-development of a care plan.

6. The child and family experience coordinated, family/child-centered care.

7. Children and their families who have been discharged from palliative care services can readily access palliative care should new needs arise.

8. Young adults and their families are proactively supported with transitions to the adult care system.

9. The child and family are engaged in planning for end-of-life care and are supported to make informed decisions. This includes receiving care in their preferred location, whenever practicable, encompassing home, hospice or hospital.

10. The family has access to bereavement support, including developmentally appropriate support for siblings.

Implementation considerations are also outlined. At the provincial level, considerations include developing a capacity planning approach, a data collection strategy, and seeking funding support for health human resources. At the regional level, considerations include working with Health System Partners to adapt and adopt the Pediatric Model of Care, using data for improvement strategies, ensuring children's services are considered in systems planning, and aligning pediatric palliative care with other specialized children's services.

The document concludes with system-level considerations to facilitate the implementation of the Pediatric Model of Care.

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Overview

The Compassionate Care Act (2020) and the resulting Provincial Framework for Palliative Care (2021) set out Ontario's vision for access to high quality palliative care for all who would benefit from it irrespective of age or illness.

Serving as the principal advisor to the Ministry of Health and the Ministry of Long-Term Care, the Ontario Palliative Care Network (OPCN) operates as a provincial partnership focused on implementing the vision for person-centered, high quality palliative care for all individuals in Ontario. The OPCN is supported by the Ontario Health (OH) Provincial Palliative Care Program (Provincial Program), which oversees provincial planning, develops clinical guidance/standards, and provides regional leadership for implementation and performance management across six OH Regions. At the core of the collaborative efforts between the OPCN and OH lies the development of the Palliative Care Health Services Delivery Framework (Delivery Framework), which provides operational guidance for the vision articulated in Provincial Framework for Palliative Care and consists of three Models:

1) Focus Area 1: Adults Receiving Care in Community Settings including primary care, home and community care, and long-term care ("Adult Community Model of Care"),
2) Focus Area 2: Adults Receiving Care in Hospital Settings ("Adult Hospital Model of Care"), and
3) Focus Area 3: Children Receiving Care Across all Settings ("Pediatric Model of Care").

To address the specific needs of seriously ill children and their families, a Provincial Pediatric Palliative Care Steering Committee (PPPC SC) was established in 2013. For more information on the PPPC SC, please refer to Appendix A. The OPCN and Provincial Program work with the PPPC SC to improve access to pediatric palliative care, including leveraging their leadership and subject matter expertise in developing this Pediatric Model of Care.

Background

Pediatric palliative care in Ontario is a comprehensive approach designed to enhance the quality of life of children with serious illnesses, from birth to young adulthood, and their families. It also encompasses perinatal palliative care, which includes support from the moment a serious condition is diagnosed antenatally, continuing with holistic care for the newborn and their family post-delivery. Pediatric palliative care is a child- and family-centred practice that champions an inclusive support system encompassing and extending beyond physical care, to include emotional, social, and spiritual elements. It is designed to be a flexible form of care that adapts according to the unique needs and challenges of each child and family at any stage of the child's illness, aligning with the child and family's goals of care.

The underlying philosophy of pediatric palliative care is identical to adult palliative care; that is, to identify patients with serious illnesses and support them and their families with holistic person-centred care aimed at maximizing quality of life. However, the two can be quite different in practice due to the etiology, management, and natural history of pediatric illnesses.

On a patient level, children with a serious illness have palliative care needs that require specialized pediatric knowledge and resources. The illness trajectories for children are often uncertain, with many children *living* with a serious illness for an extended period of time, requiring longitudinal care. Furthermore, their clinical presentations are more diverse, and the ethical considerations in decision-making are unique.

On a system level, the number of children with serious illnesses are relatively low (compared to adults) and as a result, they typically receive specialist care at one of Ontario's regional pediatric tertiary care centres. At the time of the release of this report, this includes: (1) The Children's Hospital at London Health Sciences Centre, (2) McMaster Children's Hospital at Hamilton Health Sciences, (3) The Hospital for Sick Children & Emily's House Children's Hospice, (4) Children's Hospital of Eastern Ontario & Roger Neilson Children's Hospice, and (5) Kingston Health Sciences Centre (Appendix B). It should also be acknowledged that HSC Winnipeg Children's Hospital has, for many years, provided care for patients from neighboring provinces, including Northwestern Ontario.

A provincial Pediatric Model of Care must take into account the relationships and high degree of trust families have in these centres, while also creating opportunities for families to receive quality palliative and end-of-life care in their local communities.

Objectives

The Pediatric Model of Care:

- Identifies how palliative care services and healthcare professionals can be organized and coordinated based on the palliative care needs of the child and their family.
- Describes necessary resources and considerations for regional pediatric tertiary care centres to support regional networks.
- Provides role clarity for members of the Interprofessional Pediatric Palliative Care Team.
- Identifies opportunities to create and/or strengthen supports for healthcare providers in community settings to enable high quality, child- and family-centred pediatric palliative care.

Guiding Principles

Aligned with the Quintuple Aim[3], the Pediatric Model of Care:

- Centres care around the needs and values of each child, family, and community, considering diverse backgrounds and communication preferences.
- Enables access to equitable, high-quality, coordinated care (including end-of-life care) as close to home as possible.
- Ensures that interprofessional team members have continuous access to expert support and advice.
- Facilitates capacity building, measurement, and evaluation planning to create an effective and sustainable care system.
- Supports the mental, emotional, and physical well-being of healthcare providers so they can deliver compassionate and effective care.

Scope

The Pediatric Model of Care applies to all healthcare settings (e.g. community hospitals, specialized pediatric care facilities, children's treatment and rehabilitation centres, and independent hospices) and to usual places of residence. The recommendations apply to all healthcare providers caring for seriously ill children and their families.

Additionally, the Pediatric Model of Care also integrates recommendations aimed at supporting equity-deserving groups including Black or racialized individuals, Francophones, non-English speakers,

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[3] The Quintuple Aim is a framework for healthcare improvement that focuses on increasing population health, improving patient experience, reducing care costs, enhancing care team well-being, and establishing health equity.

members of the 2SLGBTQIA+ community, newcomers to Ontario, individuals with low income, the underhoused, residents of rural and remote areas, and persons with disabilities.

Out of Scope

First Nations, Inuit, Métis, and urban Indigenous (FNIMUI) communities have emphasized the need for culturally safe and appropriate palliative care. Engagement with FNIMUI partners is required to develop Indigenous-specific Model of Care recommendations for pediatric palliative care that reflect the self-determined priorities of FNIMUI peoples. OH is committed to an Indigenous-led process and acknowledges that meaningful engagement will require time and flexibility.

Approach

Jurisdictional Scan in Canada and Abroad

In 2022, in collaboration with clinical expert advisors and Ontario Health's Evidence Search and Review Services, a detailed review of guiding documents from 2013 to 2019 was undertaken to understand existing service delivery models. Twenty-six documents were identified including national guidelines, research studies, and a statement from the Provincial Pediatric Palliative Care Steering Committee (see Appendix A). The scan was updated during the drafting of the Pediatric Model of Care, to capture emergent literature. A current state survey was conducted in Q1 2022, to better understand service delivery and areas for improvement in Ontario.

Working Group Recommendations Development

In 2022, Ontario Health established the Pediatric Palliative Models of Care Working Group (the Working Group), chaired by a Clinical Lead, with representation from various disciplines and Family Advisors (see Appendix C). Recommendations were generated using a case study methodology (See Table 1). Four hypothetical patient scenarios were developed, each spotlighting challenges and care settings in pediatric palliative care. The cases were also designed to focus the Working Group's attention on unique and important topics (e.g. perinatal palliative care, respite, and transition to adult care) to ensure they were adequately addressed by the Pediatric Model of Care. These case studies served as testing grounds for refining early recommendations and concepts. Details for each of the case studies, including Background, Current Contextual Challenges and Optimal Care can be found in Appendix D.

Table 1: Case studies used by the Working Group

Case	#1: Baby Mei	#2: Farah	#3: Jeanette	#4: Elijah
Overview	• A 6-week-old baby in NICU • Prenatally diagnosed with lissencephaly and brainstem hypoplasia • Requires NG feeds and CPAP support (challenging to wean due to intermittent apneas) • Long-term prognosis unclear	• 5-year-old diagnosed with acute lymphocytic leukemia; curative chemo unsuccessful • Parents want home-based palliative care • Local community hospital struggles with symptom management and supporting family • Team concerned with ability to deliver EOL care at home	• 8-year-old with severe cerebral palsy, gastrostomy tube, seizure disorder, global developmental disability; overall good quality of life • Frequent admissions with respiratory deterioration • Disruptive for family, but not ready for different approach due to successful outcomes from ICU admissions	• 17-year-old with Duchenne Muscular Dystrophy (diagnosed at age 4) • Care overseen in a tertiary pediatric setting, including palliative care team • His single mother is his primary care provider • Concerns/challenges with transitioning to adult healthcare system
Focus topics	Perinatal palliative care	Home-based palliative care in a rural setting	Providing supportive community care; Respite	Transition to adult care; Involving patient in decision-making

Consultation

To inform the developing recommendations, feedback was obtained through consultation with clinician leaders (including physicians (MDs), nurse practitioners (NPs), registered nurses (RN), social workers (SWs), etc.), patient and family advisors, and regional/provincial partners. Consultations included general engagement sessions (various participants, n=72), a dedicated session for families (n=6), audience engagement during a presentation of the Pediatric Model of Care at the Canadian Hospice Palliative Care Association's Pediatric Palliative Care Symposium, and a didactic presentation through Paediatric Project Echo (participant n=79). Through these consultations, advice was sought on recommendation feasibility, potential gaps, and opportunities or parallel initiatives. Feedback came from diverse perspectives including rural and urban, as well as different health service and care disciplines and settings.

Utilizing the consultation question guide, external reviewers were invited to provide written feedback on the Pediatric Model of Care. Written feedback came from health service providers and related disciplines (Children's Hospitals, developmental health service providers, pediatric respite service provers, etc.) (n=47) and from a pediatric family advisory committee comprised of family members with lived and living experience. These perspectives were integrated into the Pediatric Model of Care.

Engagements with Equity-Deserving Groups

Using outreach by Ontario Health Regions and other partners, such as the Provincial Pediatric Palliative Care Steering Committee, four family participants from equity-deserving groups, with lived and living experience, participated in a focus group to provide input on the Pediatric Model of Care.

Key Definitions

For the purposes of the Pediatric Model of Care, the Working Group adopted the following definitions for several key terms. Additional terms are defined in a glossary in Appendix E, and a list of acronyms is available in Appendix F. Throughout this document, every effort was made to use the most current terms and definitions, however it should be noted that language is continually evolving.

Serious Illness: A health condition associated with a high mortality risk that either adversely affects a child's daily functioning or quality of life or places a significant burden on the family.

Family: Those closest to the child in terms of knowledge, care, and affection, and may include biological family (e.g. parents, grandparents, and siblings), guardians, family of choice, friends and/or organizations responsible for a child’s medical decisions (e.g. Children’s Aid Society).

Palliative Care: Focuses on providing comfort and improving the quality of life of a person with a serious illness. It may be offered at any point after diagnosis to help the patient and support the family. It can be integrated with the standard care used to treat illness. Sometimes, palliative care may be the sole focus of care.

According to the World Health Organization, palliative care for children includes, “care of the child’s body, mind and spirit,” and includes support for their family members (1). Palliative care addresses:

- A child’s physical symptoms like pain, nausea, dizziness, loss of appetite, confusion.
- A child and family members’ worries and questions.
- A child and family members’ feelings including grief and anxiety.
- A child and family members’ spiritual and cultural needs and wishes (2).

Interprofessional Pediatric Palliative Care Team: An interprofessional team of providers who work together to deliver pediatric palliative care to a child and their family. This team will be composed of the child’s current care providers, and other providers (as needed), supported by a Specialist Pediatric Palliative Care Team. The team will always include a Most Responsible Medical Provider (MRMP) for pediatric palliative care, and a provider with responsibility for care coordination (known as the “Palliative Care Key Worker”). (See Interprofessional Team-Based Pediatric Palliative Care for more details).

Most Responsible Medical Provider (MRMP): A physician or nurse practitioner responsible for managing the pediatric palliative care needs of the child and their family, including ordering tests, making diagnoses, ordering treatments, and prescribing medications to address identified palliative care needs. (See Interprofessional Team-Based Pediatric Palliative Care for more details).

Palliative Care Key Worker (PCKW): A role assigned to one member of the Interprofessional Pediatric Palliative Care Team who holds responsibility for coordinating pediatric palliative care service delivery. The PCKW serves as a single point-of-entry into the healthcare system to address the pediatric palliative care needs of the child and family. (See Interprofessional Team-Based Pediatric Palliative Care for more details).

Specialist Pediatric Palliative Care (SPPC) Team: Consists of providers with secondary-level (specialist-level) competencies in pediatric palliative care. The SPPC Team is always connected with a regional pediatric tertiary centre, and in some regions, may include staff from an affiliated children's hospice. (See Interprofessional Team-Based Pediatric Palliative Care for more details).

Region: The geographical area serviced by a pediatric tertiary centre. (See Appendix B for a map that shows the service delivery boundaries).

How to Use this Document

Models of care are not prescriptive. They conceptualize how services can be organized and delivered, including roles and responsibilities of different providers along pathways of care. They are a tool to help system planners, care teams and providers respond to local needs by adapting local assets and leveraging existing partnerships and collaborations to organize care. The Pediatric Model of Care provides a reference to evaluate current practices and incrementally build on existing programs and services to increase access to high quality palliative care.

The Pediatric Model of Care is meant to be both aspirational and realistic, describing an ideal state that is achievable across the province in the near term. The Pediatric Model of Care recommendations provide guidance on how palliative care services should be organized and delivered to help achieve high quality palliative care for children across all settings. Detailed implementation plans are beyond the scope of the Pediatric Model of Care, however, System Level Considerations that are needed to operationalize the recommendations are included at the end of the document. Examples include funding, workforce capacity, regional variability, creation of a Northern Hub, measurement and evaluation, increasing out-of-home respite care, and addressing equity.

To demonstrate how the Pediatric Model of Care can lead to improvements, a case study is provided below. The story of Jeanette and her family is presented twice. The first scenario illustrates some of the current contextual challenges. The second scenario illustrates optimal care, following implementation of the Pediatric Model of Care. Jeanette's case is just one example of how palliative care could be delivered using the Pediatric Model of Care. For additional case examples, please refer to Appendix D. Each of these cases illustrate a unique focus, including perinatal palliative care (Baby Mei), home-based palliative care in a rural setting (Farrah), and transitioning to adult care (Elijah).

Case Study: Jeanette, Severe Cerebral Palsy

Background: Jeanette, an 8-year-old child with severe cerebral palsy, is fed exclusively through a gastrostomy tube (a tube inserted through the abdomen for feeding) and has a history of seizures and global developmental disability. She has often required admission to her community hospital for respiratory illnesses. Jeanette is regularly cared for by her community pediatrician and a variety of subspecialty teams at the regional children's hospital.

Current Contextual Challenges:

Jeanette's pediatrician and the teams at the community hospital sometimes struggled to fully address the multifaceted nature of her condition. While they excelled in managing her acute medical needs, there were gaps in effectively communicating the long-term implications of her condition, which was believed to be life-limiting. Towards the end of a hospital stay in the Intensive Care Unit (ICU) at the regional children’s hospital, where she was transferred for suspected aspiration pneumonia (a lung infection caused by inhaling food or liquid), the ICU team initiated a goals of care discussion. Jeanette’s parents shared that when their daughter is well, she enjoys a good quality of life; she is generally happy and comfortable, she attends school and loves interactions with her siblings.

The ICU team recommended that Jeanette’s care be focused on maximizing her comfort, that ICU admissions no longer be considered, and that the palliative care team should become involved. Jeanette’s parents were shocked and angered by this suggestion. They expressed their strong wish to continue focusing on optimizing Jeanette’s health and treating acute illnesses aggressively, finding reassurance in her consistent recovery after each hospital admission.

Unfortunately, Jeanette required readmission to her community hospital just 3 months later. The community pediatricians informed her parents that she may need to be transferred to the pediatric ICU again. The family expressed deep concern about returning to the ICU in light of the difficult conversations during the last admission, but they ultimately had no choice when Jeanette required urgent intubation (a tube inserted into her airway) to support her breathing. After a few days in the ICU without significant improvement, the ICU team recommended that Jeanette be removed from the ventilator that was breathing for her. This time, Jeanette’s parents did not voice their strong disagreement, and she died comfortably in the ICU a few hours later.

Optimal Care:

Jeanette’s care team, consisting of her community hospital affiliated pediatrician and various multidisciplinary subspecialty teams at the regional children’s hospital, conducted a thorough assessment of her palliative care needs regularly. In addition to optimal medical management, attention was directed at maximizing Jeanette’s comfort and quality of life and ensuring the family felt well supported at home. As Jeanette started requiring increased hospital admissions, the pediatrician could see the toll it was taking on her and the strain it was putting on her family. The pediatrician suggested engaging the regional Specialist Pediatric Palliative Care (SPPC) Team to provide an additional layer of support and to help introduce goals of care discussions, since she was not comfortable initiating these.

During their initial meeting, the SPPC Team learned all about Jeanette and her family. It was clear that Jeanette enjoyed a good quality of life when she was at her baseline, and she was deeply loved by her parents and siblings. The SPPC Team suggested multiple ways to further improve the situation: they recommended a new medication to manage Jeanette’s excess oral secretions, which were likely contributing to her frequent respiratory problems; they connected the family with a pediatric hospice, who sent a music therapist into the home and provided respite admissions; and they introduced the concept of a ‘Wish’ for Jeanette, and together with the parents they pictured the smiles on the kids’ faces when meeting their favourite Disney characters.

Over the next couple of years, the current care team (her pediatrician and subspecialty teams) continued to be the main point of contact, leading Jeanette’s care. The SPPC Team periodically offered expertise in managing complex symptoms and employed a 'Dial Approach' to adjust their level of involvement according to the family's needs and preferences. During acute care admissions at the children’s hospital, the SPPC Team provided psychosocial support to parents, and knowing how much Jeanette loved music, they arranged for the hospital music therapist to visit. With each admission, the

SPPC Team reviewed the goals of care with the family. Although these discussions were always emotional, Jeanette's parents appreciated the opportunity to think about what mattered most and to consider how everyone's quality of life was being impacted by the increasing hospital admissions, especially Jeanette. It was becoming evident to the family that Jeanette was having less 'good time,' but her parents continued to hope that she would stabilize and bounce back.

When Jeanette was readmitted to the pediatric ICU just a few months after discharge, intubated and ventilated, the SPPC Team visited the bedside. Jeanette's parents shared that they had been thinking more about their daughter's suffering over the past year. The ICU team convened a family meeting with members of Jeanette's current care team (including her community pediatrician who joined virtually) and the SPPC Team to review the lack of clinical improvement. Considering Jeanette's reduced happiness and quality of life, a recommendation was made to remove the ventilator and focus care on keeping Jeanette comfortable, which her parents reluctantly agreed to. Jeanette's siblings were brought in and gently informed about the situation by the SPPC Team. Their questions were answered and the whole family was given a chance to spend time with Jeanette, creating memories and legacies like hand molds to take home with them if Jeanette did not survive.

Sadly, Jeanette died a few hours after removal of the breathing tube with her family surrounding her. The SPPC Team assisted parents with funeral planning, including accessing financial support. The family received grief support from their community hospice, with whom they were previously connected, and they took part in the annual memorials offered by the SPPC Team.

Recommendations

The recommendations are divided into two parts. The first part focuses on the organization and delivery of care, describing the "Hub-and-Spoke design" for how team members should be organized regionally and locally, and how they should work together. The second part focuses on care processes and includes the Patient Pathway and the composition of the team. Each recommendation includes a set of implementation considerations. These considerations are intended to call out areas where efforts are required to enable the implementation of the Pediatric Model of Care.

Organizing & Delivering Care: The Hub-and-Spoke Design

Communities all over Ontario have access to palliative and end-of-life care through local/regional organizations and providers. Yet, these resources are often limited to adults primarily due to a lack of training and comfort in pediatrics. Conversely, pediatric community providers may be very comfortable caring for children but often lack expertise and comfort to provide palliative and end-of-life care. These limitations may be further exacerbated by constraints on funding, health human resources, and community infrastructure (e.g. internet), particularly for rural and remote communities. The result is that most children can only access palliative care through their regional pediatric tertiary centre, which may be hours away from home.

A Hub-and-Spoke design can extend the reach and promote the effective use of sub-specialist services (e.g. the "Hubs") for populations spread over large geographies, and where small patient volumes make it challenging for community providers to develop capacity and comfort (Figure 1).

To be effective, the Hub-and-Spoke design requires strong, collaborative connections grounded in the dynamic and timely flow of information needed for coordinated care. This integration allows children and families to consistently access specialist expertise and support - overcoming geographical barriers. Establishing a well-functioning Hub-and-Spoke model can provide children and families with the opportunity to develop trusting relationships with providers in various care settings, along with the specialist pediatric palliative care providers. Should a child's illness progress, these relationships provide a foundation for the child and their family to confidently receive care from a team they trust, in their preferred location, as close to home as possible.

1. The child and family will have access to high quality palliative care in their preferred location, as close to home as possible, enabled through a Hub-and-Spoke design.

Figure 1. Ontario's Hub-and-Spoke Model for Pediatric Palliative Care

The diagram depicts the Hub-and-Spoke design of regionally delivered pediatric palliative care. The central structure, symbolizing the Pediatric Palliative Care Hub, consists of the Specialist Pediatric Palliative Care Team affiliated with a regional pediatric tertiary centre and, in some cases, a pediatric hospice. Multiple Spokes, representing community hospices, local hospitals, community pediatricians, primary care clinicians, adult palliative care providers, and others, are connected to the Hub. The roads reflect the seamless collaboration and flow of support and information between the specialized services at the Hubs and the widespread care provided by the Spokes. The model underscores the commitment to a cohesive system, ensuring that every child and family has access to expert palliative care regardless of their location in Ontario.

Hubs

Current and future regional pediatric tertiary centres, and the pediatric hospices they partner with, represent the Hubs of the model design, providing essential pediatric palliative care expertise for care provided in hospitals, outpatient clinics, hospices, and homes. The Pediatric Model of Care recommends that each region should be connected to a dedicated Hub.

To ensure high quality care, Hubs should include:

- **Specialist Pediatric Palliative Care Services:** Each Hub should have a dedicated interprofessional Specialist Pediatric Palliative Care (SPPC) Team. The SPPC Team is connected with a regional pediatric tertiary centre, and in some regions, may include staff from an affiliated children's hospice. At minimum, the SPPC Team must include at least one MRMP for palliative care (MD or NP) as well as a provider responsible for coordinating pediatric palliative care delivery, a Palliative Care Key Worker (PCKW) (for more on the MRMP and PCKW roles, please see Interprofessional Team-Based Pediatric Palliative Care). Based on specific local and regional needs, the SPPC Team will include additional providers, all of whom possess additional competencies for healthcare providers specializing in pediatric palliative care (see "Additional competencies for nurses specializing in pediatric palliative care" in The Ontario Palliative Care Competency Framework). The services offered should include facilitating difficult discussions (e.g. serious illness conversations, advance care planning, identifying goals of care), managing complex symptoms, and offering tailored grief and other psychosocial support to the child with serious illness, their siblings, and their family. The SPPC Team provides direct care to children and families, as well as consultation and/or shared-care to support the providers in the Spokes, particularly when the child or family's needs become complex or as the child is nearing end-of-life.

- **24/7 Specialist Access:** Each Hub must be adequately staffed, in terms of both breadth of skills and absolute numbers, to fulfill the needs of the region. This includes provision of round-the-clock consultation and support to care providers serving as regional Spokes while also being able to provide direct care to children and families when necessary.

- **Streamlined Navigation:** As the interface between hospital and community palliative care providers, the Hubs act as connectors, establishing communication lines to facilitate access to services and to share important information (e.g. changes in patient status or care).

- **Pediatric Hospices:** Hubs facilitate access to pediatric hospice residences and/or respite services, which may provide symptom management admissions, transitional and end-of-life care. They also offer expert grief and bereavement services and support community-based adult hospice programs to work with children and families.

- **Network Building:** Hubs proactively identify willing partners and address regional service gaps. Collaborating with community partners, they establish and fortify new Spokes, forming strong networks of care and ensuring widespread accessibility for children and families.

- **Education and Mentorship:** Hubs build palliative care capacity by providing pediatric palliative care education, training and mentorship. Collaborating with community partners, they can help to develop staff support strategies for health professionals providing pediatric palliative care, including regular debriefings, peer support networks, and training on self-care and resilience. Additionally, Hubs are leaders in knowledge transfer and exchange (KTE) initiatives, conducting research rounds and conferences, establishing regional communities of practice, and developing pediatric palliative care resources tailored to regional needs (e.g. educational materials for providers and families).

- **Evaluation, Quality Improvement, and Innovation:** Hubs participate in the implementation of evaluation and quality improvement measures regionally and provincially. Hubs work with regional leaders to communicate new developments or best practices and work collaboratively on continuous quality improvement for the region. Hubs identify gaps in pediatric palliative care and propose solutions to enhance the care of children and families.

Spokes

Local community organizations and providers, serving as Spokes, offer a practical means for delivering aspects of pediatric palliative care outside of Hubs. They also play an important role in identifying local gaps in pediatric palliative care and proposing solutions to enhance the care of children and families. It is essential that these Spokes include providers who possess primary-level (generalist-level) competencies in palliative care, aligned with the Ontario Palliative Care Competency Framework to ensure a standardized level of care across settings[4].

Spokes may include:

- **Primary Care Providers:** Primary care pediatricians, family medicine practitioners, nurse practitioners, and other primary care providers play an essential role in the care of children living with a serious illness and their families in the community. They often have long-term relationships with the child and family and can offer the full continuum of care, including palliative supports.

- **Community Pediatric Consultants:** Many children with serious illnesses receive longitudinal, consultative care from community pediatricians. They can play an important role in bringing pediatric expertise and continuity, supporting assessments and prognosis determination, and providing psychosocial support.

- **Home and Community Care:** Children with palliative care needs and their families may be eligible for home and community care offered through Ontario Health atHome including care coordination, nursing care, occupational therapy, physical therapy, and social work, among other supports and services. Some children and families may also be eligible to receive funding to purchase home care services or employ care providers (through the Family-Managed Home Care program) and/or Enhanced Respite Funding (through Home and Community Care).

- **Schools and Other Non-Healthcare Settings:** Schools, daycare centres, community organizations (including those for children, families and/or caregivers), cultural and spiritual supports make

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[4] It is important to note that the palliative care competencies outlined in the Ontario Palliative Care Competency Framework should always be considered in the context of individual competencies, legislative scope of practice, professional standards, and practice guidelines, recognizing that these are updated on a regular basis. For nurses in particular, the palliative care competencies should be considered within the context of the Regulated Health Professions Act, 1991, the Nursing Act, 1991, and the regulatory framework as outlined by the College of Nurses of Ontario.

substantial contributions to a child's and family's overall well-being. While personal health information must not be shared with individuals in these settings without the expressed permission of the child and/or family, families will often choose to share important health information because of the support individuals in these settings provide. Healthcare providers are encouraged to collaborate with these allies when appropriate to provide optimal support.

- **Community Hospitals, Children's Treatment Centres, Rehabilitation Facilities, and Coordinated Service Planning Agencies:** These sites should leverage their long-term relationships with families to collaborate with Hubs. They can play an important role in identifying and addressing unmet palliative care needs and facilitating seamless care transitions. Including these care sites in Spoke design fosters a comprehensive, multidisciplinary approach to care, enriching the support system available to both individuals and their families.

- **Children and Youth Licensed Residential Services:** Some children and youth live in supportive residential group settings that work to meet their unique medical, physical, emotional, and social needs. These settings provide a wide range of services including care for children and youth with disabilities, complex medical needs, and/or children and youth in need of protection. Some residential group settings may also provide respite care.

- **Pediatric Respite Services:** Children with palliative care needs may require around-the-clock supervision and care by individuals familiar and comfortable with technology and medical complexity. Respite services provide temporary relief to caregivers and enhance the overall well-being of both the child and their family. Services may encompass tailored activities for the children, counseling support for families, and resources to navigate the complexities of pediatric palliative care. Respite services may be provided within the child's home (often for hours) or at dedicated respite facilities for blocks of time (often for days to weeks).

- **Community Palliative Care Providers:** These healthcare providers (e.g. physicians, NPs, nurses, psychospiritual counsellors, palliative pain, and symptom management consultants) offer services in a variety of settings, such as homes and hospice residences. Their integration should occur as early as possible to allow for a trusting relationship to develop with the patient and family. As they most often care for adults, they may require support from Hub experts on pediatric clinical issues.

- **Community Hospice Services:** Hospice residences and visiting hospice services are recognized for offering a broad range of services tailored to meet the unique needs of individuals and families facing serious illnesses. Community hospice services, which predominantly cater to adults, can also serve as components and partners of Spokes to support children and families within their communities, particularly near the end of life. Hospice volunteers can play a significant part in providing much-needed practical support to families in their communities.

- **Community Grief & Bereavement Supports:** These services offer essential emotional and psychological support to families coping with the loss of a child. They provide counseling, support groups, and other resources to help families navigate their grief.

- **Funeral Homes:** They play an important role in providing support and services to families during their time of loss. They assist with the logistical and ceremonial aspects of after-death care, ensuring that families receive compassionate and professional support during this difficult time.

Implementation Considerations

PROVINCIAL LEVEL

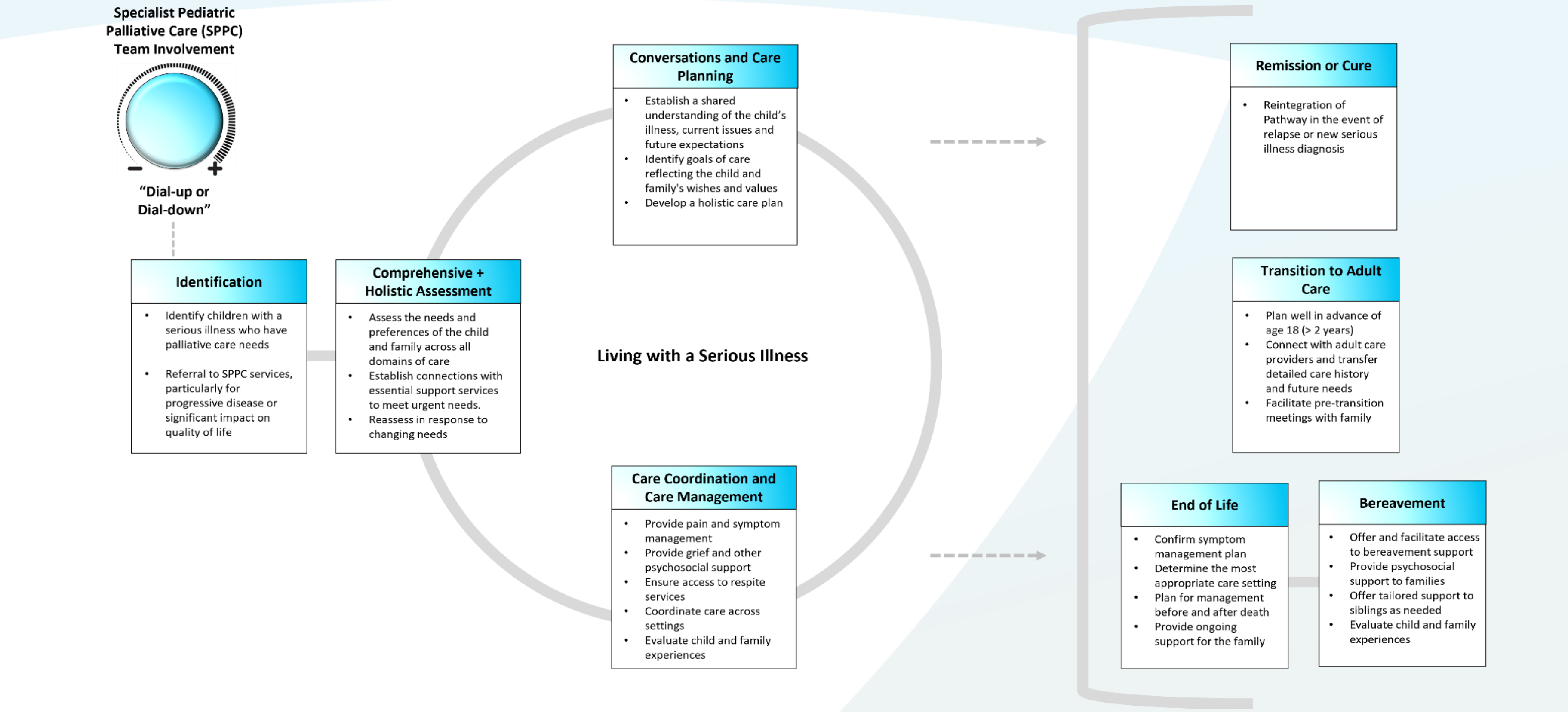
- Develop a data strategy to better understand volumes, demographics, location of care, and preferred place of death to identify resource needs and service disparities.
- Work with the Ontario Health Regions and the regional pediatric tertiary centres to identify additional resource needs for Hubs. This may include additional roles to strengthen Hubs to meet their clinical responsibilities; to support ongoing capacity building within their region; to provide 24/7 specialist access to patients, families and Spokes; and to facilitate system navigation.
- Work with the Ontario Health Regions to identify additional resource needs to support and enhance Spokes for improved access to pediatric palliative care across the province. This will be especially important in rural and remote areas, to help address resource and access disparities.
- Collaborate across OH transformation initiatives such as OHT development and home care modernization to ensure pediatric palliative care needs are included in regional model development.
- Work with Hubs to identify pediatric palliative care education and/or training opportunities for volunteers to support spread and scale provincially.

REGIONAL LEVEL

- Regional SPPC Teams are strongly encouraged to assign a dedicated team member to act as a liaison between the Hub and community providers (the Spokes) to help build capacity and comfort, and to facilitate communication between settings.
- Develop a list of organizations and providers serving as Spokes to help regional SPPC Teams identify local partners for both clinical and education efforts, and to help highlight gaps that need to be addressed.
- Work with partners across the care continuum to identify local and regional barriers to access (e.g. transportation) and collaborate to adapt and adopt the Pediatric Model of Care. Tailor implementation at the local level to address the needs of populations experiencing barriers/inequitable access.
- Work with Hubs to identify opportunities for volunteer training, which may include local pediatric hospices providing support and training to volunteers at local adult hospices, to strengthen capacity for pediatric palliative care.
- Use data to inform regional model improvement strategies. SPPC Team can leverage the Magnify Tool to explore and use their service data and information to maximize their impact. This customizable tool can be used to create action plans to address gaps in care for children and families with palliative care needs.
- Ensure children's services are adequately represented and addressed in Regional Palliative Care Network table discussions.
- Where possible align pediatric palliative care with other models for specialized children's services.

Care Processes: Pediatric Model of Care Patient Pathway

The key processes in palliative care planning and delivery for children with serious illnesses are summarized in the Pediatric Model of Care Patient Pathway, along with key recommendations for each (Figure 2 below). The full details of the recommendations are elaborated in the subsequent sections of the document.



Specialist Pediatric Palliative Care (SPPC) Team Involvement

"Dial-up or Dial-down"

Identification

- Identify children with a serious illness who have palliative care needs
- Referral to SPPC services, particularly for progressive disease or significant impact on quality of life

Comprehensive + Holistic Assessment

- Assess the needs and preferences of the child and family across all domains of care
- Establish connections with essential support services to meet urgent needs.
- Reassess in response to changing needs

Conversations and Care Planning

- Establish a shared understanding of the child's illness, current issues and future expectations
- Identify goals of care reflecting the child and family's wishes and values
- Develop a holistic care plan

Living with a Serious Illness

Care Coordination and Care Management

- Provide pain and symptom management
- Provide grief and other psychosocial support
- Ensure access to respite services
- Coordinate care across settings
- Evaluate child and family experiences

Remission or Cure

- Reintegration of Pathway in the event of relapse or new serious illness diagnosis

Transition to Adult Care

- Plan well in advance of age 18 (> 2 years)
- Connect with adult care providers and transfer detailed care history and future needs
- Facilitate pre-transition meetings with family

End of Life

- Confirm symptom management plan
- Determine the most appropriate care setting
- Plan for management before and after death
- Provide ongoing support for the family

Bereavement

- Offer and facilitate access to bereavement support
- Provide psychosocial support to families
- Offer tailored support to siblings as needed
- Evaluate child and family experiences

Figure 2: Pediatric Model of Care Patient Pathway

This pathway is a high-level summary of the key pediatric palliative care processes for children with serious illnesses and their families. It begins with identification, followed by comprehensive and holistic assessments, conversations and care planning, care coordination and care management, and routine reassessments, and is supported throughout by an Interprofessional Pediatric Palliative Care Team. The involvement of the Specialist Pediatric Palliative Care Team is depicted as a dial, to show that their support to the team can increase or decrease, depending on team members' capabilities, and the needs and goals of care of the child and family. Living with a serious illness often involves long-term engagement in the care cycle, during which care needs may fluctuate. Ultimately, children in this pathway will conclude in one of three outcomes: (1) Remission or Cure; (2) Transition to Adult Care; or (3) End of Life.

Identification

Early integration of palliative care for children and families improves quality of life, enhances communication, reduces stress and improves care coordination, and support for the entire family (1). SPPC Teams prefer to be involved early and follow the child/family longitudinally to help build a trusting relationship. Challenges to early identification include unclear referral criteria, misconceptions, and a reluctance to recognize palliative care as important from the time of diagnosis.

2. Children with palliative care needs are identified early in their illness

2.1 A current care provider (e.g. primary care, oncology, complex care) will identify children with serious illnesses who would benefit from a referral to palliative care.

  2.1.1 Referral to SPPC Teams should be considered shortly after identification, particularly in cases of progressive disease or with an illness with a significant impact on quality of life.

2.2 Upon identification, urgent needs will be assessed to determine if interventions are immediately required (e.g. uncontrolled physical symptoms, personal care services, or social work services). A provider on the current care team will either manage the urgent issue(s) or connect the child and their family with the appropriate provider to address it (e.g. SPPC Team, social worker, psychologist).

2.3 A member of the current care team will provide the family with information regarding the advantages of integrating pediatric palliative care alongside standard treatment.

  2.3.1 A current care provider will support the family to understand the potential benefits of pediatric palliative care, including symptom management, enhanced quality of life, and support for the entire family.

  2.3.2 Information will be in plain language, inclusive, and provided in the child and family's preferred language to facilitate informed decision-making and active engagement in care.

Implementation Considerations

PROVINCIAL LEVEL

- Develop and implement education strategies to promote the importance of earlier integration of pediatric palliative care, and to build primary level pediatric palliative care capacity among healthcare professionals across all care settings.
- Support research to develop standardized tools for the earlier identification of children with palliative care needs. Create a dissemination and education strategy to support provincial implementation of these tools. Tools should help identify conditions and circumstances that would benefit from the integration of specialized palliative care. These include:
    - Progressive, life-limiting congenital or genetic conditions.
    - Neurodegenerative conditions and other central nervous system disorders leading to functional impairments.
    - Cancer diagnoses with poor prognostic indicators.
    - Severe chronic respiratory or cardiac conditions.
    - Prolonged or recurrent intensive care admissions.

    - Complex chronic conditions with multisystem involvement leading and technology dependence and medical fragility.
    - Fetal anomalies or disorders with a high risk of mortality or prolonged intensive care following birth.
- Encourage the availability of a broadly accessible provincial electronic platform for providers to enable secure "real-time" exchange of patient information within and across settings and sectors. The platform would ideally enable providers to access assessment results and allow children and families to identify their own unmet palliative care needs.

REGIONAL LEVEL

- Support providers/organizations to raise awareness of the benefits of early integration of palliative care in the disease trajectory. Encourage the use of resources like CaringTogether.life and Courageous Parents Network to educate, support, and empower families of seriously ill children.
- Prioritize the adoption of early identification tools and referral processes to ensure early access to specialized palliative care.
- Create streamlined referral processes and clear communication pathways to make it easy and efficient for primary care providers to connect children and families with SPPC Teams.
- Develop tools, pathways, and mechanisms to support primary care providers to integrate perinatal palliative care when a decision is made to continue caring for families locally after detection of a serious fetal anomaly in pregnancy.

Interprofessional Team-Based Pediatric Palliative Care

All children with identified palliative care needs will receive care from an Interprofessional Pediatric Palliative Care (IPPC) Team (see Figure 3 below). The IPPC Team is responsible for ensuring the consistent delivery of pediatric palliative care throughout the child's journey.

The IPPC Team will be composed of the child and their family, the child's current care providers, Extended Services (as needed), and support from a SPPC Team from a regional Hub. The IPPC Team will always include two distinct roles: a Most Responsible Medical Provider (MRMP) for pediatric palliative care, and a provider with responsibility for palliative care coordination (known as the "Palliative Care Key Worker").

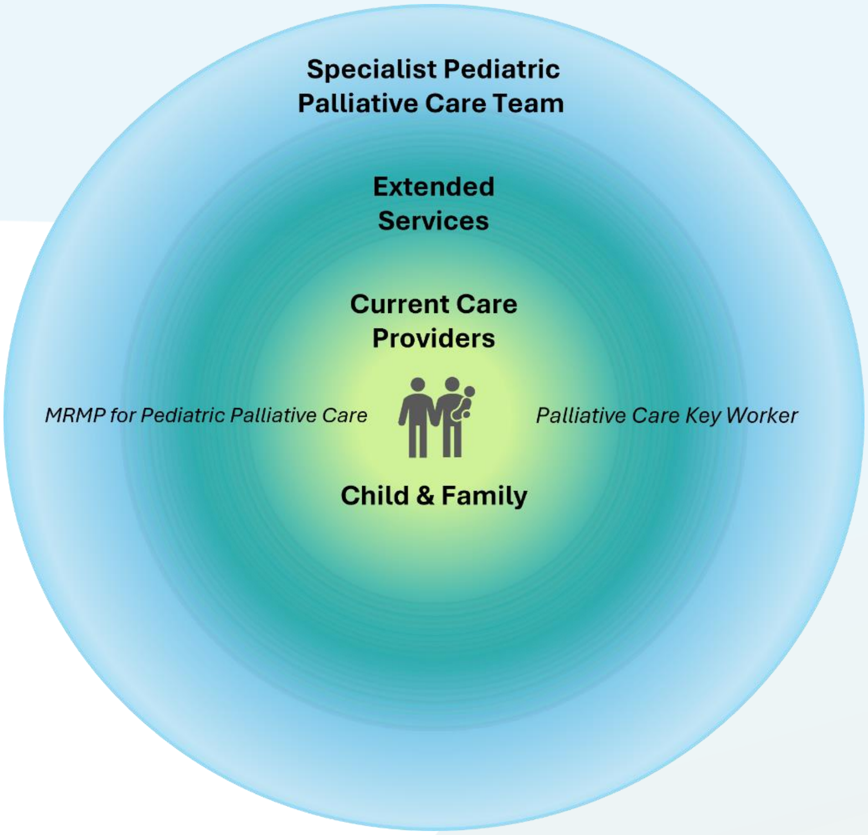


Figure 3. The Interprofessional Pediatric Palliative Care Team
This figure contains a child and family icon surrounded by three circular layers, composing the Interprofessional Pediatric Palliative Care (IPPC) Team. The child and family are at the centre, demonstrating their active role on the team. Surrounding them are the child's current care providers, who are responsible for the day-to-day care of the child with a serious illness. The next layer is Extended Services that may include home care providers, community clinicians (e.g. palliative care MDs and NPs), respite and hospice staff. Extended Services may provide consultation, or direct care as needed. The Specialist Pediatric Palliative Care (SPPC) Team serves as the insulating outer layer, providing specialized support that includes direct care to the child and family as needed, as well as mentorship and guidance to other members of the IPPC Team. The child and family will always have a Most Responsible Medical Provider (MRMP) for pediatric palliative care, and a Palliative Care Key Worker (PCKW), who is responsible for coordinating their pediatric palliative care delivery. The diagram illustrates the fluidity in team composition, allowing for changes based on the needs and goals of care of the child, and their family, as well as the location of care.

Membership of the team may vary over time and will be determined by the needs of the child and their family, the child's goals of care, their prognosis, and the main location of care (see case studies in Appendix D for examples of IPCC Team member composition). All team members should have at least primary-level palliative care competencies, such as identifying palliative care needs early in the disease course, addressing common sources of suffering (e.g. physical and psychosocial), and connecting patients and families with additional providers and services as needed.

Membership of the IPPC Team will include:

The Child and Family, are located at the centre, ensuring that their needs and preferences always drive the care that is planned and delivered. They are actively supported to be involved in all aspects of care.

Current Care Providers, typically encompass a diverse array of healthcare providers, from a variety of professions and specialties, and provide daily care and support to a child with a serious illness. The child's current care providers are encouraged and will be supported to play active roles as part of the IPPC Team.

Extended Services are other providers and services that may become part of the team to address specific pediatric palliative care needs of the child and family as they emerge. These providers may offer direct care and support to the child and family, or they may provide consultative support on issues related to pediatric palliative care. Extended Services may include, but are not limited to, home care providers (e.g. nursing, personal support workers), pharmacists and allied health professionals (e.g. occupational therapists, paramedics), hospice staff, and respite care providers. They may also include adult palliative care clinicians who often play an important role in the community setting, particularly when goals of care are increasingly focused on comfort or when a child is nearing the end of life.

A Specialist Pediatric Palliative Care (SPPC) Team is from the Regional Hub that supports all members of the IPPC Team. The SPPC Team is comprised of providers with expertise in pediatric palliative care (e.g. clinicians with secondary-level competencies in pediatric palliative care) along with professionals trained in providing complex psychosocial care to children and their families, including grief and bereavement support (e.g. pediatric hospice staff, social workers, psychologists, child life specialists). Palliative care for children is relatively uncommon resulting in few practitioners developing sufficient expertise or comfort. SPPC Teams can serve as an insulating layer to all members of the IPPC Team filling unmet needs, especially those that go beyond the ability or capacity of other members of the team.

SPPC Teams should be consulted routinely and early in the disease course, as this allows them to form a trusting relationship with the child and family over time. Once engaged, the level of SPPC Team involvement will depend on each unique situation and will likely evolve over time, considering the goals of care and the prognosis. The SPPC Team can be integrated in a consultative or shared-care model where their support and involvement can be "dialed up," or "dialed down," designed to enhance, not replace, the capabilities of the other members of the team. Their role may increase when the needs of the child or family become more complex, and they may assume more of a principal role during end-of-life care, depending on where the child and family are receiving the majority of their care.

The IPPC Team will always include two distinct roles: a **Most Responsible Medical Professional (MRMP) for pediatric palliative care**, and a provider who is designated with responsibility for coordinating pediatric palliative care delivery, known as the **Palliative Care Key Worker (PCKW)**.

MRMP refers to an MD or NP responsible for managing the medical needs of the child and their family. Typically, the MD or NP most closely connected to the child and/or who provides most of the child's current care would be considered their MRMP. However, children with palliative care needs are often medically complex and they will have multiple care teams with different subspecialists acting as MRMPs for different aspects of care. For example, a child with medical complexities might have a pediatrician as MRMP for most issues, a respirologist as MRMP for issues with their BiPap, while a neurologist might be MRMP for addressing seizures.

The **MRMP for pediatric palliative care** may be a current care provider, or it may be a different care provider or team (i.e. SPPC Team member, or community based palliative care provider). Assignment of this role will depend on provider competencies and the complexity of the palliative care needs, as well as the goals and location of care. The MRMP for pediatric palliative care helps to ensure continuity of care and comprehensive support for the child and family, however it is recognized that the provider in this role may change to accommodate a child's changing circumstances (e.g. location, need for end-of-life care) (please refer to Care Coordination and Care Management for more details on this role).

The **Palliative Care Key Worker (PCKW)** is the provider on the team who is responsible for coordinating the child's pediatric palliative care within the healthcare system and across systems (e.g. education, social services, recreation, etc.). This role will be assigned to one member of the IPPC Team who will act as a single point-of-entry into the healthcare system to address the pediatric palliative care needs of the child and family. Rather than having each family attempt to create and navigate a complex network of providers and institutions, the family can reach out to the PCKW who can listen, support, triage, and connect with appropriate resources as necessary. The provider in this role will often be a nurse or a social worker. Sometimes, this role may be filled by the same individual acting as the MRMP for palliative care. The PCKW may be a current care provider, or it may be different care provider (i.e. a member of the SPPC Team, or a member of the community-based palliative care team). Individuals who frequently act as PCKWs, such as members on SPPC Teams, can develop connections and expertise, becoming highly efficient and effective at providing palliative care navigation for families across the region. Similar to the MRMP, children with palliative care needs may have more than one provider responsible for care coordination. For example, a child with medical complexity who is receiving palliative care but is still pursuing life-prolonging medical therapies might also have a Complex Care coordinator. The provider in this role may also change based on the main location of care (please refer to Care Coordination and Care Management for more details on this role).

3. The child and family receive care from an Interprofessional Pediatric Palliative Care Team

3.1 The child and their family are considered active, collaborating members of the IPPC Team.
3.2 All members of the team will possess at least primary-level palliative care competencies.
3.3 The IPPC Team will always include a Most Responsible Medical Provider (MRMP), an NP or an MD, responsible for managing the pediatric palliative care needs of the child and family.
    3.3.1 The MRMP will be determined based on the goals of care, and the main location of care. (Refer to Care Coordination and Care Management for additional details).
    3.3.2 The MRMP will be clearly identifiable to the other members of the IPPC Team, as well as the child and their family.
    3.3.3 The MRMP will receive support from and, in turn, will provide support to the other members of the IPPC Team.
3.4 The IPPC Team will always include a Palliative Care Key Worker (PCKW), often a nurse or social worker, responsible for coordinating pediatric palliative care delivery, and serving as the central point of contact for palliative care services.
    3.4.1 The provider in this role may shift depending on the main location of care. (Refer to Care Coordination and Care Management for additional details).

3.5 Extended Service providers will be engaged to help address the palliative care needs of the child and their family as they change over time. They may support members of the team to address the evolving needs of the child and family through consultation (a shared-care model), or at times they may be required to lead care, particularly near the end of life.

3.6 The SPPC Team will be consulted early in the disease course, and their level of involvement will vary depending on the capability of the other members of the IPPC Team, and resources of the SPPC Team.

    3.6.1 The SPPC Team will integrate in a consultative capacity. At a minimum, they should be engaged whenever secondary-level (specialist-level) competencies are required, or existing team members palliative care capabilities are exceeded. They may also become involved at the request of a family for a second opinion.

    3.6.2 Once involved, the SPPC Team should remain available as part of a shared-care model: they will continue to follow the child and be available to members of the team and the family, as needed.

    3.6.3 The SPPC Team will be available for 24/7 support and consultation via telephone or other technologies (e.g. telemedicine, virtual care, secure electronic communication).

    3.6.4 In some instances, the SPPC Team may “dial up” to lead care. This is most likely to be the case when a child is nearing the end of life and/or in specific locations (e.g. in a pediatric hospice).

Implementation Considerations:

PROVINCIAL LEVEL

- Review and potentially revise the palliative care funding mechanisms required to support an interprofessional team-based approach to palliative care. Efficient allocation of provincial resources is essential to support the roles and responsibilities of the IPPC Team. This includes comprehensive health human resources capacity planning and integrated funding models tailored to address child and family needs across all domains and demand for services. An Alternate Funding Plan (AFP) for pediatric palliative care specialists is crucial to ensure physicians are fairly compensated for direct care and for contributing to education, mentorship, and ongoing shared-care required for team-based care.
- Work with the Ontario Health Regions to identify additional resource needs for the Hubs to support care coordination and system navigation. Regional SPPC Teams are strongly encouraged to assign a dedicated NP to act as a liaison between the Hub and the Spokes, mentoring and coaching local physicians, NPs, and other community providers to build capacity and comfort, and to facilitate communication between settings.
- Work with the Ontario Health Regions to identify additional resource needs to support the Spokes with care coordination, system navigation, and connections with the Regional Hubs.
- Devise education strategies to build primary-level competencies for healthcare providers working with seriously ill children, as outlined in the Ontario Palliative Care Competency Framework. This should include facilitating ongoing education opportunities and providing resources for providers to enhance their skills and stay updated on best practices and evidence-informed approaches in pediatric palliative care.

- Develop a broadly accessible electronic platform to support communication amongst interprofessional team members and to provide a mechanism for exchanging real-time patient information within and across settings and sectors.

REGIONAL LEVEL

- Provide additional education to support healthcare providers who work with seriously ill children with the use of technology and virtual care delivery processes.
- Provide ongoing education and skills training on stress management, opportunities, and resources for debriefing, and ensure adequate staffing levels to mitigate the risk of burnout and compassion fatigue among healthcare providers.

Comprehensive and Holistic Assessment

Comprehensive, holistic assessment is required to address the multifaceted needs of children. Assessment across all domains of care (e.g. illness/disease management, physical, psychosocial, social, spiritual, developmental care, practical considerations, end-of-life issues, and support through loss, grief, and bereavement) supports individualized and responsive care plans, aligning with the child/family's needs and wishes, thus enhancing the overall care experience (2). Members of the child’s current care team may not have the skills or expertise to conduct a fulsome assessment, requiring the support of other providers (e.g. a Regional SPPC Team). Furthermore, the evolving nature of a child's illness may require frequent reassessment, which can be overlooked due to clinical demands or system limitations. Regular reassessments are critical in adapting the plan of care to the child's changing needs and have been associated with improved outcomes, including family satisfaction and symptom control (3).

4. The needs of the child and family are regularly assessed through a comprehensive and holistic assessment, including consideration for the unique needs of siblings.

4.1 The MRMP will initiate a comprehensive and holistic palliative care assessment of the child and family across all domains of care.

  4.1.1 The assessment will be iterative and involve collaboration with other providers (as per the needs of each child). The assessing providers become part of the ongoing IPPC Team.

4.2 The MRMP will determine the optimal providers (e.g. the SPPC Team) and timing for the assessment, with input from the child and family. Translation services should be utilized as necessary.

  4.2.1 Integration of SPPC Teams is encouraged at the time of palliative care assessment. Their expertise may contribute to a more holistic assessment.

4.3 The assessment of palliative care needs may be conducted in-person or virtually. The assessment must include:

  4.3.1 Assessing the child’s knowledge and understanding of their illness, and their actual and desired level of involvement in their care and decision-making.

  4.3.2 Defining the immediate family, guardianship, and substitute decision-makers.

  4.3.3 Assessing the communication preferences of both the child and the family, recognizing its significance in establishing rapport and facilitating comprehensive care planning and delivery.

4.3.4 Reviewing medical information shared with family to date, as reported by the family, including active issues, expectations, and prognosis. Any discrepancies between a family's report and the understanding of the medical team will be explored.
4.3.5 Assessing any active uncontrolled symptoms, including physical examination.
  4.3.5.1. A complete physical examination may be deferred, at the discretion of the assessor, if the assessment is conducted virtually. However, a complete physical examination is recommended at the earliest opportunity.
4.3.6 Assessing the child's ability to perform age-appropriate activities of daily living (ADL) and instrumental activities of daily living (IADL).
4.3.7 Assessing the child's recreational needs and interests, recognizing their importance in the child's quality of life and well-being.
4.3.8 Reviewing the care network including home, school, community, and hospital providers/teams.
4.3.9 Reviewing care measures including medications, procedures, technology, accessibility tools, and human resources (e.g. home care nursing hours).
4.3.10 Reviewing the child and family's experiences within the healthcare system, specifically experiences of trauma or discrimination and inequity.
4.3.11 Assessing the child's and family members' experiences, coping abilities and required supports, particularly focusing on parents, siblings and other close family members.
4.3.12 Assessing the child's personal, cultural, and spiritual values, beliefs, and practices, as well as those of their family members.
4.3.13 Assessing all medical supplies and equipment the child may need. This can include, but is not limited to, mobility aids, respiratory devices, feeding tubes, and other assistive technologies. This assessment should consider systemic barriers (e.g. finances, wait times) that may impact timely access to necessary equipment.
4.3.14 Reviewing socio-financial needs, including access to necessary finances, secure housing, schooling, transportation supports, physical and psychological safety, respite opportunities, and available governmental and philanthropic supports (e.g. Assistance for Children with Severe Disabilities, Disability Tax Credit, March of Dimes, Make-a-Wish, Northern Travel Grant, Enhanced Respite Funding).

4.4 Families will be encouraged and supported to actively participate in the assessment process, empowering them to effectively communicate their needs and preferences.

4.5 The MRMP (or a delegate) will conduct a reassessment of palliative care needs and goals of care in response to clinical, functional, social, or locational changes and at least once every 12 months.

Implementation Considerations

PROVINCIAL LEVEL

- Develop a pediatric palliative care focused assessment toolkit to standardize approaches across the province. The toolkit should include a focus on enabling children and families to identify and express their palliative care needs and assessing the effectiveness of their current care in meeting those needs. The toolkit should address the various social determinants of health and include a list of resources and guides for families to support their socio-financial needs.
- Trauma-informed approaches are essential for providing child- and family-centred care. Ensure healthcare providers have access to education that integrates the social determinants of health

and includes harm reduction and anti-oppressive practices (e.g. gender affirming language, cultural safety, etc.). This education should be interactive, incorporating real-life case studies to enhance learning and application.

- A broadly accessible electronic platform should be made available to enable providers to access previous assessments and to build on these across time and location of care.

REGIONAL LEVEL

- Develop and implement a standard workflow to plan, conduct, and document a comprehensive palliative care assessment within existing health record infrastructures.
- Ensure service providers can access training programs on effective assessment techniques with a special focus on empathy and cultural safety by engaging in regional education planning.
- Establish clear procedures for ensuring reassessments occur regularly, particularly in response to changes in the child's clinical status, ensuring continuity and responsiveness in care delivery.

Conversations and Care Planning

Engaging children and their families in discussions about serious illness is vital and challenging. Regular dialogue ensures a shared understanding of the condition and prepares everyone for future decision-making by exploring preferences, needs, values, and expectations. This includes identifying realistic goals of care and developing a care plan aligned with family values. Aligning care and treatment with identified goals leads to greater patient and family satisfaction and more consistent care, potentially reducing non-beneficial interventions (4). Regular review of goals accommodates the evolving needs of the child and family, adjusting the roles of care teams to ensure clear communication and defined responsibilities.

5. The child and family are regularly engaged in discussions about their goals of care to inform the co-development of a plan of care.

5.1 The MRMP (or delegate) will engage translation and accessibility services to support all discussions with the child and family as needed.

5.2 The MRMP (or delegate) will engage children, and their families in an exchange of health knowledge and experiences to achieve a shared understanding of the medical condition, current issues, and expectations for the future. Extended Services and SPPC Teams should be involved in these discussions, as required.

5.3 The MRMP (or delegate) will explore the values the child and family use to guide decision-making, including personal, familial, cultural, and spiritual values. A member of the team will share processes for healthcare decision-making, including therapeutic, professional, or legal limitations.

5.4 The MRMP (or delegate) will have discussions with the child and family to identify their goals of care. These goals will be reflective of the child and family's wishes and values, while being grounded in the context of the child's prognosis and the limitations of medical treatment.

  5.4.1 The SPPC Team will be engaged as necessary to support and, in some cases, lead these discussions.

  5.4.2 Discussions will be revisited periodically as goals of care are subject to change, especially when the child's health or prognosis changes.

5.5 The IPPC Team will develop a holistic plan of care with the child and family, addressing their current and anticipated palliative care needs and aligning them with identified goals of care.

5.5.1 The plan should identify the various teams and organizations involved in addressing palliative care needs (e.g. the IPPC Team) and outline their roles and contact information.
5.5.2 The child and/or family will receive a copy of the plan and will review and approve it prior to distribution.
5.5.3 The plan will be shared with all providers and organizations involved.

Implementation Considerations

PROVINCIAL LEVEL

- Implement education strategies focused on communication skills training that emphasize active listening and exploring the child and family's values and wishes. Examples include the Serious Illness Conversation Guide - Pediatrics Training and VitalTalk.
- A broadly accessible electronic platform should be made available for documenting and managing plans of care as well as enabling real-time patient information exchange within and across settings and sectors. This should focus on seamless integration with existing systems and accessibility for all members of the IPPC Team, including first responders and emergency health services (who may play a role as an Extended Service).
- Establish and maintain a centralized repository of standard visual aids, decision trees, and other interactive tools to facilitate discussions about illness understanding and decision-making. These resources should use plain language, ideally in multiple languages, and be easily accessible and relevant to different disease contexts.
- Develop a template to support standardized documentation of a plan of care for pediatric palliative care.

REGIONAL LEVEL

- Engage health service providers in system design planning to support seamless exchange of patient information.
- Ensure service providers can access communication training programs by engaging in regional education planning.

Care Coordination and Care Management

The provision of comprehensive pediatric palliative care is essential for achieving optimal outcomes (5; 6). This proactive, family-centered approach not only enhances the child's quality of life but also reduces the burden on the family by ensuring seamless access to a diverse range of support services (7; 8). Children receiving pediatric palliative care are typically involved with several different organizations, agencies, and staff across various settings. Supports and services may include pain and symptom management, psychosocial support, respite, and spiritual care tailored to the family's beliefs.

Seamless transitions throughout the child's care requires integration and coordination between and across providers and settings, from the time a child's palliative care needs are identified, during their illness, and through bereavement.

To ensure the palliative care needs of the child and family are comprehensively met, an MRMP for pediatric palliative care (MD or NP) will be responsible for managing the child and family's pediatric palliative care throughout the illness. To ensure smooth care transitions and that all providers are working together, a PCKW (typically a nurse or social worker) will be responsible for coordinating pediatric palliative care delivery. This provider will also be the single point of contact for the family for the child's palliative care needs.

The providers in these roles will likely change over the course of the child's illness, shifting based on the needs and goals of care of the child and family, and/or based on the main location of care to ensure a patient- and family-centred approach. Recognizing this, it is essential that the child and family, and all members of the IPPC Team, are always made aware of the individuals acting as MRMP for palliative care and PCKW, their responsibilities in these roles, as well as how and when to contact them.

Ongoing assessments, and regular meetings between the various providers involved in caring for the child and family play an important role in adapting care strategies to reflect the child's evolving condition and incorporate the family's preferences. By fostering consistent and coordinated care across various settings such as hospitals, homes, and schools, effective care management and coordination contribute to better treatment outcomes and overall well-being for the child and their family (7; 9)**.**

6. The child and family experience coordinated, family/child-centered care.

6.1 Following the development of the plan of care, the child and family will be assigned a PCKW. The PCKW will be the key point of contact for the child and family's pediatric palliative care needs and will be responsible for coordinating supports and services, liaising with other healthcare providers, and managing care transitions.

- 6.1.1 The PCKW will be determined based on the needs of the child and family, and the main location of care.
- 6.1.2 The PCKW will be the primary contact for the child and family's palliative care needs, ensuring ongoing communication and collaboration, connecting them to supports and services across settings, as required, and acting as their advocate when needed.
- 6.1.3 The PCKW will facilitate seamless communication between the various providers on the IPPC Team to address identified needs, as required. This will include scheduling regular collaborative meetings.
- 6.1.4 The PCKW will connect with the other members of the IPPC Team on a regular basis to exchange relevant information and ensure that all team members are up to date on the health status of the child and their family, the current services they are receiving, and any new service requests or change in care plan.
- 6.1.5 The patient and their family, as well as all members of the IPPC Team, should always be aware of who the PCKW is, especially when a shift occurs.
- 6.1.6 A member of the SPPC Team can be engaged to act as the PCKW, to support care coordination, particularly for children with complex needs, who may require care across multiple providers and care settings.

6.2 The responsibilities of the PCKW will evolve based on the location of care, but their focus is always on maintaining continuity of the palliative care plan and communicating changes in the plan with other members of the IPPC Team as needed.

- 6.2.1 In hospital settings, responsibilities of the PCKW will include discharge planning, and ensuring continuity of and follow through with care, including sharing the discharge summary and clinic notes with community providers. Hospital care coordinators should be involved well before discharge to provide ample time to understand the family's needs, familiarize the family with the care process, and prepare the community for their discharge.
- 6.2.2 In community settings, responsibilities of the PCKW will include facilitating smooth transitions between settings and community service providers and collaboration amongst community providers; informing IPPC Team members in hospital settings about relevant changes in the child/family's status; and ensuring all palliative care needs (e.g. medical, psychosocial, practical) are adequately met. When multiple community providers are involved, role clarification is essential to prevent service duplication.
- 6.2.3 Regardless of the location of care, or for a child that is moving frequently between different settings, the SPPC Team should be involved to support more complex system navigation (including integration of school settings).

6.3 The MRMP will be the provider (MD or NP) responsible for managing the pediatric palliative care needs of the child and family, and will often be determined by the goals of care and/or the main location of care:

- 6.3.1 **Focus on prolonging life**: a member of the child's current care team (e.g. primary care, oncology, complex care) will be encouraged and supported to act as MRMP for pediatric palliative care when care is received at home, or in hospital settings. A member of the SPPC Team may be MRMP if care is received in a pediatric hospice.
  - 6.3.1.1. In cases with a guarded prognosis or high symptom burden, specialist palliative care (i.e. those with secondary-level expertise) should be involved. If community palliative care providers are engaged, the SPPC Team should also be involved to ensure they have access to continuous support [5].
- 6.3.2 **Focus on achieving as much good time as possible** (i.e. a blend of quantity and quality): a member of the child's current care team will be encouraged and supported to act as MRMP for pediatric palliative care when care is being received at home or in hospital settings. A member of the SPPC Team may be MRMP if care is received in a pediatric hospice.
- 6.3.3 **Focus on comfort and end-of-life care**: the regional SPPC Team should be involved, with community palliative providers integrated as needed (i.e. for care in the community setting). Community palliative care providers or the SPPC Team will assume a greater role, sometimes providing shared-care, and other times becoming the MRMP to provide direct care as needed. (Please refer to End-of-Life Care for more details).

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[5] The child and family may occasionally be resistant to community palliative care provider engagement. This can be for a variety of reasons, including misconceptions about their role and how they work with the larger Interprofessional Palliative Care Team. The SPPC Team can help support the early integration of community palliative care providers, allowing time for relationships to build.

6.3.4 Regardless of the focus, SPPC Team will remain accessible to provide consultation and guidance to the MRMP. While actively involved, they will continue to monitor the situation and be available to all members of the team, and the child and family, as needed.

6.4 When the responsibilities for pediatric palliative care coordination and care management change, it must be clearly communicated across the IPPC Team, including with the child and family. This includes clarifying who the family should contact to address aspects of care that may fall outside of the IPPC Team's responsibilities.

6.5 The MRMP, in collaboration with other members of the IPPC Team, will ensure the child and family receive comprehensive support and services tailored to meet their unique and changing needs. Extended Services will be engaged as needed, and providers determined based on care location and available resources:

6.5.1 Pain and symptom management will be accessible 24/7, ideally in the family's preferred setting. When these needs go beyond the capabilities of other IPPC Team members, the SPPC Team will provide this support. Processes for contacting the SPPC Team will be clearly communicated.

6.5.2 Spiritual and cultural care needs will be addressed by providers aligned with the family's beliefs whenever possible. If preferred providers are unavailable, families will be offered non-denominational support or encouraged to seek their own external spiritual care support.

6.5.3 Children's and families' psychosocial care needs will be addressed by appropriate Extended Services (e.g. social workers, mental health professionals, play-based therapists, Indigenous providers) that are developmentally, spiritually, linguistically, culturally, and age-appropriate.

6.5.4 Respite care and funding will be pursued for children with medical complexity who are technology dependent (please refer to Services Delivered: Enhanced Respite for Medically Fragile and/or Technology Dependent Children and Youth). Members of the IPPC Team will encourage families of children who qualify for enhanced respite funding to proactively engage these services, and help them to do so, in order to expand their support and reduce caregiver fatigue.

6.5.5 Practical needs (including consideration for age-appropriate activities of daily living (ADL) and instrumental activities for daily living (IADL) will be addressed by appropriate Extended Service providers such as personal support workers, physiotherapists, occupational therapists, social workers, or others. These services will engage and educate caregivers in the delivery of these services.

6.5.6 Caregiver's knowledge and comfort in providing care for their child at home will be discussed in a collaborative, empathetic manner. Appropriate resources and supports will be secured as needed by the family.

6.5.7 School support systems will be proactively engaged to ensure appropriate care for the child while attending classes, including advocating for additional services from the school board as needed and providing resources for teachers and classmates.

Implementation Considerations

PROVINCIAL LEVEL

- Identify and implement key components to include in forms for children being referred to community providers, hospices, and hospitals for pediatric palliative care supports and services, aimed at standardizing and streamlining communication and linkage with care coordinators.
- Develop a checklist that can be used by care coordinators in any setting to support comprehensive care planning and coordination.
- Conduct a province-wide scan of respite and psychosocial care services available, assessing both current and anticipated future needs, and develop recommendations to address unmet needs and equity. Use the results of the scan to create a directory or list of services that can be shared with families to help them with accessing local resources.
- Establish standardized discharge planning protocols for children receiving palliative care, ensuring that all necessary arrangements and supports are in place prior to discharge. This may include identification of the child's MRMP for palliative care and PCKW, oversight of prescribed medication, equipment provision, home care services, and follow-up appointments.

REGIONAL LEVEL

- Regional SPPC Teams are strongly encouraged to assign a dedicated team member to act as a liaison between the Hub and community providers (the Spokes) to help build capacity and comfort, and to facilitate communication between settings.
- Develop comprehensive lists of available community resources (including information about Regional SPPC Teams, hospices that offer pediatric palliative care support, and mental health professionals) to share with community providers, and with children and families, to help ensure access to appropriate supportive services and to identify gaps.
- Leverage existing educational materials and resources (e.g. Registered Nurses' Association of Ontario's Transitions in Care and Services Best Practice Guideline) to support the development of policies, procedures, protocols and educational programs to support service delivery (10).
- Leverage and implement existing educational materials and resources to inform children and their families about the discharge process, available support services, caregiver education resources, and self-management strategies. Providing clear and accessible information can empower patients and families to actively participate in their care transitions. Provide education to healthcare providers to enhance their understanding of care coordination principles, communication strategies, and the importance of collaborative teamwork. Focusing on topics such as effective communication, conflict resolution, and interprofessional collaboration.
- Explore the use of technology-enabled solutions, such as telehealth platforms, mobile applications, and remote monitoring devices, to support ongoing bi-directional communication and coordination between healthcare providers, and families during care transitions.

Remission or Cure

Children who achieve remission or are cured of a serious illness continue to face the risk of relapse or new, serious health conditions, sometimes secondary to their previous treatment. Streamlining their reintegration into the palliative care pathway ensures they receive optimal care quickly and efficiently should the need arise (11).

7. Children and their families who have been discharged from palliative care services can readily access palliative care should new needs arise.

7.1 The MRMP, and other members of the IPPC Team will establish a streamlined process for reintegrating children into the palliative care pathway in the event of a relapse or new serious illness.

Implementation Considerations

PROVINCIAL LEVEL

- Consider reassessment and reintegration requirements in capacity planning for pediatric palliative care.

Transition to Adult Care

Young adults with a serious illness that started during childhood typically have a complex care network unique to their needs. Some components of this care network, however, cannot follow the youth into their adulthood and need to be transitioned to providers, teams, and institutions specializing in adult services. Challenges often arise during this transition from pediatric to adult care, commonly attributed to differing care models and a lack of coordination (12). Understanding and implementing best practices for this transition, as outlined by the Provincial Council for Maternal and Child Health, is essential to ensure that these young adults receive continuous and effective care without disruption (13).

8. Young adults and their families are proactively supported with transitions to the adult care system.

8.1 The MRMP for pediatric palliative care will collaborate with the young person and their family as early as possible to plan for the transition to adult healthcare services. Planning will include:

  8.1.1 Initiating specific discussions about the transition process well in advance (e.g. > two years) of the child turning eighteen.

  8.1.2 Conducting regular collaborative reviews of transition readiness to support the ongoing preparation needs of the young person and their family. This includes discussing changes to services, resources, and financial planning.

  8.1.3 Creating an individualized transition plan based on prognosis and goals of care, documenting and sharing it with all involved providers and organizations to ensure they are aligned and fully informed about the young person's care.

8.2 The SPPC Team will be responsible for creating a specific transition plan related to palliative care, and for helping to identify an appropriate MRMP to manage any ongoing palliative care needs. The MRMP will be determined based on the young adult's and family's goals of care.

  8.2.1 **Focused on prolonging life:** An MD or NP from a primary care team (e.g. Family Health Teams, Community Health Centres, Nurse Practitioner-Led Clinics, solo or group practices of general practitioners) will likely become MRMP for the young adult's palliative care upon transition. Community palliative care clinicians may or may not become involved at this stage depending on local resources and patient specifics.

8.2.2 **Focused primarily on comfort and/or end of life care**: the SPPC Team will discuss with the adult primary care provider to determine their standard practice for provision of palliative care, and the availability of local community palliative care clinicians and/or resources to help determine an appropriate MRMP. Where there is no identified adult primary care provider, and goals of care for the young adult are primarily focused on comfort, the SPPC Team will refer to a community palliative care clinician (i.e. MD or NP), if not already involved, to oversee care post transition.

8.2.3 Once the new MRMP for palliative care is identified, the SPPC Team will provide a detailed handover regarding palliative care involvement with the young adult to date and offer guidance regarding anticipated palliative care needs now and in the future.

8.3 The SPPC Team will remain available to provide consultative support to the adult MRMP, as needed, after transition has occurred. The unique expertise and knowledge of SPPC Teams, especially in rare pediatric illnesses (e.g. genetic conditions), will continue to be leveraged to provide guidance when necessary.

8.4 The SPPC Team will facilitate transfers to community healthcare providers, hospices, hospitals, and other necessary supports and services specific to the delivery of ongoing palliative care. This involves ensuring that all involved parties are informed and fulfill their designated roles effectively.

8.5 As part of the handover, adult care providers will be informed about the communication and decision-making preferences of the young adult with palliative care needs, as well as the involvement of their family.

8.6 Post-transition, the young adult will be encouraged to continue participating in their care, with regular assessments of their decision-making capacity. Their preferences and wishes, when known, will always be factored into goals of care and care decisions.

Implementation Considerations

PROVINCIAL LEVEL

- Increase awareness, education, and preparedness of providers, teams, and institutions providing adult care regarding the growing number of pediatric patients with serious illness living into adulthood, with special attention to management of a young adult with rare conditions and/or complex needs (e.g. appropriate equipment size).
- Develop and implement provincial criteria for the equitable and appropriate extension of pediatric services in certain cases (e.g. when a child’s cognitive or functional status requires constant supervision by their family, when death is expected to be near, and transitions may be challenging).

REGIONAL LEVEL

- Facilitate the accessibility of the SPPC Team for consultations with adult care providers both during and after the transition period and include this in resource planning.
- Encourage pediatric hospice services to consider providing care for individuals up to age 24, based on service capacity, established patient relationships, family preferences, and the patient's developmental stage.

End-of-Life Care

End-of-life care for children requires nuanced planning that accommodates the child and family's preferences. Personalized end-of-life plans have been shown to improve the quality of end-of-life care and family bereavement outcomes (14). Providers who are less familiar and comfortable with end-of-life care for children are encouraged to work in collaboration with SPPC Teams.

9. The child and family are engaged in planning for end-of-life care and are supported to make informed decisions. This includes receiving care in their preferred location, whenever practicable, including home, hospice or hospital.

9.1 The MRMP and other members of the IPPC Team will work with the child and family to proactively develop, document and implement a comprehensive end-of-life care plan. The plan will clearly indicate who is responsible for managing the child's symptoms, and whom to contact if help is required. The plan will be revisited as the child's condition evolves. The planning process will include:

- 9.1.1 Preparing and supporting the family for changes to expect as death nears and the symptoms the child is at risk of developing. Create a symptom management plan for if/when these symptoms arise. The level of detail provided should be based on the identified preferences of the child and their family.
- 9.1.2 Discussing emergency and crisis management plans, including whom to contact, and when to use or how to avoid Emergency Medical Services.
- 9.1.3 Ordering emergency symptom relief medications to ensure these are available to manage potential end-of-life crises.
- 9.1.4 Providing education to caregivers on preventing burnout and managing symptoms of stress as they care for children at the end of life, including ensuring awareness of financial resources and respite services or alternative locations of end-of-life care where additional supports are available (e.g. hospice, hospital).

9.2 The MRMP and other members of the IPPC Team will collaborate with the child and family to identify the preferred location of care as end of life nears, ensuring appropriate planning. It is important to recognize that this preference and/or practicability of this preference may change, necessitating the creation of alternative plans.

- 9.2.1 To make an informed decision, families need to be aware of all options, including the resources and level of support available in various settings.

9.3 As a child nears end of life, the MRMP will be determined by the main location of care:

- 9.3.1 When receiving care at **home**, the MRMP will either be a primary care provider (e.g. family physician, NP, pediatrician[6]) or a community palliative care provider (i.e. MD or NP). Caring for a dying child, and their family, is always challenging. It is recommended that whenever possible, care in the home should be provided by a physician and nurse working in tandem. The SPPC Team will be available 24/7 for consultation and support, and in some cases a member may become the MRMP.

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[6] A family physician, NP or community pediatrician can be a significant source of support for children, families, and adult care providers. It is important to engage a dying child's local pediatrician to the extent they are willing and able, and to consider integrating a local pediatrician if one is not already involved.

9.3.1.1 The MRMP for the child at home will ensure that local processes and procedures for managing an expected death in the home are initiated (often referred to as an "Expected Death in the Home" (EDITH) Protocol or similar).

9.3.1.2 The family should be well-informed about who to contact for clinical concerns or when death occurs, providing them with clear instructions and support.

9.3.2 At a **pediatric hospice**, a provider from the regional SPPC Team will assume the role of MRMP.

9.3.3 In a **community (adult) hospice**, MRMP will be determined by the hospice model, which may include their primary care provider or a community palliative care provider, with 24/7 support from the regional SPPC Team.

9.3.4 At a **community hospital**, a pediatrician or primary care provider will be the MRMP with 24/7 support available from the regional SPPC Team.

9.3.5 At the Regional Pediatric Tertiary Centre, a member of the child's current care team will typically be the MRMP (i.e. the admitting physician). The Regional SPPC Team will work in close collaboration and may sometimes lead care. If there are specifically dedicated palliative care beds, a member of the SPPC Team will be MRMP.

9.4 The SPPC Team will provide assistance throughout the transition to end of life in any location, ensuring that the child and their family receive holistic support.

Implementation Considerations

PROVINCIAL LEVEL

- Implement a provincial palliative care education strategy to increase primary palliative care capacity for healthcare providers who work with seriously ill children, including primary and subspecialty pediatric healthcare professionals, to increase comfort with providing primary level palliative care, including end-of-life care.
- Engage secondary palliative care providers in the community in planning for implementation of the Pediatric Model of Care, to encourage their active participation in providing pediatric palliative care.
- Work with the OH Regions to identify the necessary resources for Hubs and Spokes to ensure children can access EOL care in their preferred location, as close to home as possible.
- Facilitate dissemination of guidance documents developed by the Provincial Pediatric Palliative Care Steering Committee for supporting children and families nearing end of life, including the formulary of commonly used medications in the care of dying children (refer to Appendix A and POGO's guide for symptom management and guide for approaching end-of-life). It is essential that these resources be distributed to community clinicians, such as pediatricians and palliative care providers, who may be less familiar with and/or less confident in providing this type of care. Ideally, a centralized online repository would be created for these guidance documents and other pediatric palliative care resources.
- Leverage existing resources (e.g. Registered Nurses' Association of Ontario's End-of-Life Care During the Last Days and Hours Best Practice Guideline) to support the development of policies, procedures, protocols, educational programs, and assessment and documentation tools (15).
- Implement the province-wide use of family-reported tools to measure the quality of end-of-life care, such as the Quality of Children's End-of-Life Care Instrument (developed in Ontario) and

Caregiver-Voices. These tools could be developed further and administered posthumously to families.

- Ensure that adult hospices accepting pediatric patients have access to quality standards to guide and increase comfort in providing care.
- Explore and assess the feasibility, including funding, and health human resource needs, of supportive group living settings to provide end-of-life care for the children and youth residing there.

REGIONAL LEVEL

- Ensure regional engagement including pediatrics, family medicine, community palliative, and local hospice resources for the planning, actioning, and evaluation of end-of-life care options for children.
- Establish a process to ensure that all families are offered comprehensive information and education about what to expect during the dying process (including caregiving activities), procedures for after death, and key points of contact.
- Promote collaboration between regional Hubs and community grief counselors or bereavement support groups, virtually and in-person, to ensure continuous and tailored support for families even after the child's death.
- Collaborate with health service providers who work with children with serious illnesses to conduct training on diverse death-related cultural, religious, and spiritual practices to ensure respectful and culturally sensitive safe care. Establish organizational practices to accommodate cultural needs and religious practices or rituals, such as providing extra time after death, facilitating smudging ceremonies, or arranging direct transport to the funeral home.
- Develop or partner with programs that offer debriefing, and bereavement supports to staff after any death.
- Community (adult) hospices are encouraged to collaborate with regional SPPC Teams to accommodate the care of children, offering flexibility with age limits and building relationships with families. The availability of 24/7 support and guidance from pediatric specialists can ensure high-quality care for children and increased comfort for health service providers.

Bereavement

Access to bereavement support services for families is essential for long-term emotional health and can help mitigate the risks of complicated grief and psychological distress [15]. Providing comprehensive bereavement support is often hindered by a lack of co-ordinated resources and recognition of the unique grief experienced by parents, siblings, families, and communities when a child dies.

10. The family has access to bereavement support, including developmentally appropriate support for siblings.

10.1 The MRMP for pediatric palliative care will ensure that the child and family are offered timely grief and bereavement support and resources.

10.1.1 Culturally safe grief support and counseling will be arranged for family, including siblings, as needed, throughout a child's illness (with consideration for anticipatory grief) and extending into bereavement.

    - 10.1.2 Supports will be person-centered, ensuring that information and care are offered early and consistently.

10.2 After the death of the child, a member of the IPPC Team will support the family to access ongoing grief and bereavement support in their community (e.g. bereavement information and education, one-on-one counseling, peer and/or group sessions, virtual supports, their primary care provider).

    - 10.2.1 The unique needs of siblings will be considered.
    - 10.2.2 The MRMP will follow up with the family to evaluate the effectiveness of services and to address any gaps in care.

10.3 A member of the IPPC Team will ensure families are informed about financial resources and assistance available for post-death care, including costs associated with burial or cremation and basic funeral services.

10.4 The regional SPPC Team will remain available to the MRMP and the family to address any gaps in bereavement care, including the provision of direct support when indicated.

Implementation Considerations

PROVINCIAL LEVEL

- Develop a provincial resource repository for primary care teams, families, and children to address grief associated with the loss of a child, including children's grief and pregnancy and infant loss (e.g. Sunnybrook Health Sciences Centre's PAIL Network). This repository should include virtual resources to increase accessibility, with special consideration for integrating resources that facilitate peer connections and shared experiences. Support should be continuously offered throughout the child's illness and extended after death, recognizing the need for long-term support, with special consideration for integrating resources that facilitate peer connections and shared experiences.
- Develop a provincial model and capacity plan for bereavement services that considers and strengthens the resources needed to support the specific and unique needs of children and their families. This should consider the needs of the child's broader community (e.g. resources for schools and peers).

REGIONAL LEVEL

- SPPC Teams are encouraged to collaborate with adult hospices or local chapters of Bereaved Families of Ontario across their region, to strengthen supports offered to families that have lost a child.
- Expand the availability of bereavement support services for siblings of the child, recognizing the deep and evolving impact of loss across their developmental stages. Acknowledge that siblings' grief is a lifelong journey influenced by their growing understanding of death and loss. Ensure a process is in place to provide long-term grief and bereavement support for years, not just months, after the loss. Incorporate age-appropriate resources and interventions to help siblings.

System-Level Considerations

In addition to the recommendations above, system-level considerations and opportunities have been identified by the Working Group to address the complex challenges within Ontario's current healthcare landscape. These considerations are intended to complement existing strategies, aiming to strengthen the overall effectiveness of pediatric palliative care supports and services.

Building a Foundation for High Quality Palliative Care: To enhance pediatric palliative care across the province, particularly in underserved communities, it is essential that the necessary capacity for community-based adult palliative care is in place first. As long as there are communities struggling to meet the palliative care needs of adults, the effective implementation of the Pediatric Model of Care in these regions will be a challenge. The ongoing implementation of the Adult Community Model of Care should remain a provincial priority to address regional disparities in palliative care access (e.g. geographic distance, health human resource constraints), and better support the Hub-and-Spoke design of the Pediatric Model of Care. To address these inequities, OH Regions should collaborate with system partners to tailor implementation to local needs, expand pediatric palliative care education for adult teams in underserved regions, and provide virtual consultation supports from tertiary centres to remote providers, ensuring more equitable access to care across all regions.

Building Workforce Capacity in Pediatric Palliative Care: The availability of skilled human resources is a key factor in the successful implementation of the model. Currently, there is a shortage of pediatric palliative care specialists (MDs, NPs) and community-based providers trained in pediatric palliative care. Building workforce capacity will be challenging with limited resources but could be enhanced by expanding pediatric palliative care training and mentorship for adult palliative care providers, establishing sustainable funding for fellowships, continuing education, and peer mentorship programs, and incentivizing providers in underserved regions to receive pediatric palliative care training.

Ensuring Appropriate Funding for Specialist Pediatric Palliative Care Teams: A sustainable funding model for SPPC Teams, needs to encompass both physicians and allied health professionals. Given the relatively low patient volumes in pediatric palliative care, an Alternate Funding Plan (AFP) for Pediatric Palliative Care Specialist physicians is an essential enabler to afford ample time to dedicate to families without the pressure to increase patient numbers for billing optimization. Moreover, it would account for the significant time spent by all members of the SPPC Team supporting others on the IPPC Team. When operating at peak efficiency, the proposed Hub-and-Spoke model would decrease the direct-patient care provided by the SPPC Team, enabling them to concentrate on capacity building within the community through 24/7 clinical guidance, support, educational initiatives, and ultimately providing access to palliative care supports to greater numbers of children and families in need. Lastly, this approach recognizes the intricate nature of pediatric palliative care, which often requires prolonged provider-patient interactions and a multidisciplinary approach—elements not easily accommodated by billing options in the Schedule of Benefits.

Adjusting Compensation Models to Support Community Providers: Community providers are integral to the provincial pediatric palliative care Hub-and-Spoke model. To encourage their participation and sustain their educational efforts, particularly their involvement in initiatives like

Project ECHO, compensation models will need to adapt accordingly. Appropriate compensation will support the critical role that community providers play in delivering pediatric palliative care in the community. The adjustment in compensation would not only recognize their efforts at continued professional development, but it will also ensure that interprofessional team development is an ongoing process, ultimately improving patient and family outcomes.

Creating a Hub in Northern Ontario:
Establishing a Northern Ontario Hub would improve access to pediatric palliative care by addressing challenges posed by the vast geographical spread and low population density of the region. A Northern Ontario Hub would ideally provide accessible and culturally sensitive pediatric palliative care services, strategically located to offer comprehensive support, training, and coordination, ensuring that children and families, particularly in First Nations communities, receive essential care closer to their homes. With 78% of the province's First Nations communities located in this region, a Northern Hub could improve equitable access and support the unique experiences of First Nation's communities. Northern Hub development should include engagement with all appropriate interest holders (e.g. First Nations communities, Francophone communities).

Enhancing Data Collection, Governance and Outcome Measurement: Provincial data collection processes are required for evaluating system performance and identifying opportunities for service enhancement. Clear quality measures and measurable goals for pediatric palliative care need to be established provincially, focusing on key metrics to identify successes and areas needing improvement. Establishing a provincial pediatric palliative care data governance strategy would enable standardized metrics. Efforts should aim to align pediatric palliative care quality with child and family needs and health system objectives and should include consideration for family-reported outcome measures to ensure patient and caregiver voices inform quality improvement.

Increasing Pediatric Out-of-Home Respite Care: Pediatric out-of-home respite plays a vital role in enhancing family wellbeing by providing high-quality, developmentally appropriate care for children with medical complexity. Currently, too few out-of-home respite facilities exist, and those that do are concentrated in urban settings. Identifying key locations to build more pediatric out-of-home respite facilities across Ontario should be prioritized to better support families across the province. Building capacity to provide end-of-life care in these sites should be pursued.

Addressing Equity: To ensure care is equitable and inclusive, improved access is required for all children and families from equity-deserving groups. Ongoing engagement of equity deserving groups, organizations, and system partners should occur throughout the implementation process to identify gaps in care delivery and develop strategies to address barriers and increase equitable care. Developing strategies within healthcare settings, such as signage and posters, tailored resources that include gender affirming language, and nametags/buttons with a provider's spoken language(s) (e.g. "Je parle français"), can increase accessibility, safety, and inclusion for children and their families.

Establishing a Dedicated Pediatric Palliative Care Leadership Table within Ontario Health: To ensure that the unique needs of children and families are fully addressed, Ontario Health will establish a dedicated pediatric palliative care table(s) to guide implementation of the Pediatric Model of Care. This specialized table(s) would also provide sustained pediatric expertise to advise on provincial planning processes and priorities for pediatric palliative care.

Next Steps

System planning for children’s palliative care services requires the development of a sustainable model that will enable access to high quality care for the relatively small numbers of seriously ill children who live across Ontario’s vast geography. Recognizing pediatric palliative care is delivered across settings and sectors, and that the planning environment is complex, various system-level partners will need to be engaged to collaboratively plan for implementation. In addition, many children will receive care at one of Ontario’s pediatric tertiary care centres for their entire lives, and as such, these centres are vital partners in implementation planning. Following implementation planning, the work will shift towards testing the Pediatric Model of Care. Collective implementation and evaluation will help to identify Health Human Resource needs, funding, and policy limitations, and will inform capacity planning efforts, as well as refinements to the Pediatric Model of Care.

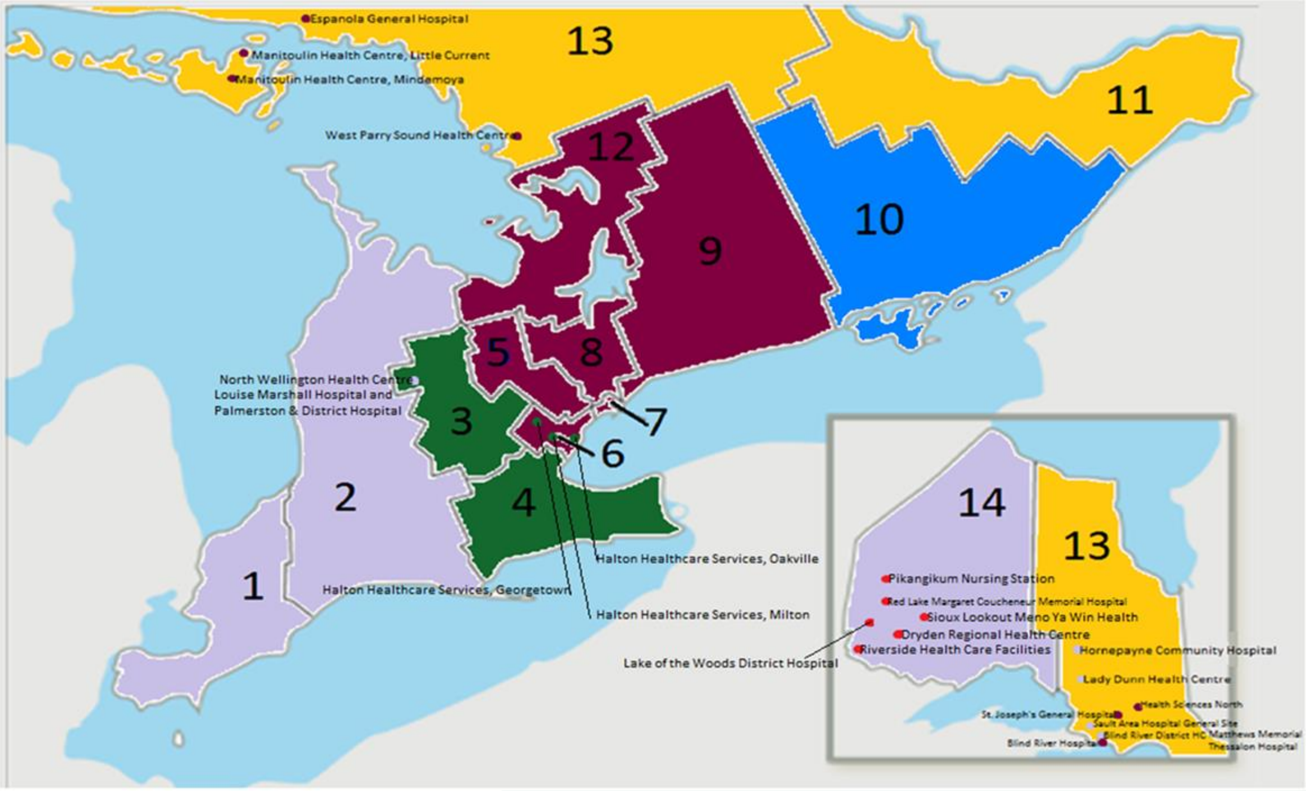
Appendix A: Provincial Pediatric Palliative Care Steering Committee

In 2010, at the behest of the Ministry of Health and Long-Term Care (now Ministry of Health), the Provincial Council for Maternal and Child Health (PCMCH) and the Pediatric Oncology Group of Ontario (POGO) formed a multidisciplinary, multisector Pediatric Palliative Care Work Group (PPC-WG) to identify priorities and recommendations for a provincial system of pediatric palliative care (PPC). The PPC-WG gathered data to establish the current state of PPC and formed several subgroups to develop recommendations to optimize care delivery. These recommendations were submitted to the Ministry of Health (Ministry) in 2011, including the need for recognition of the unique nature of PPC.

In follow-up to the recommendations, an initial Provincial Pediatric Palliative Care Steering Committee (PPPC SC) was established in 2013. Subsequently, as a result of MPP John Fraser's consultations on palliative care, a change in the composition of the PPPC SC occurred to include senior decision makers from the five pediatric tertiary centres, and representation from community organizations, POGO, PCMCH and Ontario Palliative Care Network (OPCN). The representatives of each of the five pediatric tertiary centres were asked to constitute a Regional Implementation Working Group (RIWG), comprised of key participants in PPC within each region, to guide implementation of the principles and recommendations of the PPPC SC using regionally available appropriate resources. These RIWGs included a representative from the Regional Palliative Care Network to enable integration of PPC in the broader palliative care agenda at the local level. In addition, a Family Advisory Group, drawn from the RIWGs, was established, whose chairpersons sit on the PPPC SC.

The PPPC SC recommended development of a regional Model of Care for the province of Ontario based on a Hub-and-Spoke design. The five pediatric tertiary centres serve as the Hubs, with PPC expert advisors at these locations reaching out regionally to community providers (the Spokes) to provide 24/7 support. This model has had some success in areas where Hubs have more fulsome PPC teams, such as in Toronto and Hamilton, however, insufficient resources have been a major barrier to the implementation of this Model of Care across Ontario. The Ministry launched the OPCN in March 2016, a provincial network dedicated to developing a coordinated and standardized approach for delivering palliative care services in the province regardless of age or illness. While the initial focus of the OPCN was on addressing issues pertaining to adult palliative care, the PPPC SC was recognized and acknowledged for their expertise and advice on matters pertaining to PPC. The OPCN continues to work with the PPPC SC to ensure coordination of PPC with the adult palliative care services wherever appropriate and possible.

Appendix B: Service Delivery Boundaries of the Pediatric Tertiary Centres in Ontario



Legend	
🟪	Children's Hospital at London Health Sciences Centre
🟩	McMaster Children's Hospital at Hamilton Health Sciences
🟥	Hospital for Sick Children & Emily's House Children's Hospice
🟨	Children's Hospital of Eastern Ontario & Roger Neilson Children's Hospice
🟦	Kingston Health Sciences Centre

This image shows the service delivery boundaries for each of the existing Pediatric Tertiary Centres in Ontario.

This image was developed by the Provincial Council for Maternal and Child Health. For more information, please visit www.pcmch.on.ca

Appendix C: Working Group Membership List

Member Name	Title	Organization & Location
Adam Rapoport (Chair)	Clinical Lead, Pediatric Palliative Care Health Services Delivery Framework Working Group	The Hospital for Sick Children & Emily’s House Children’s Hospice, Toronto
Kim Widger	Professor and Tier 2 Canada Research Chair	Lawrence Bloomberg Faculty of Nursing, Toronto
Jitin Sondhi	Regional Clinical Co-Lead	Ontario Health West Region Palliative Care Network, London
Mark Greenberg	Senior Clinical Lead, Strategic Initiatives	Pediatric Oncology Group of Ontario (POGO)
Stephanie Veldhuijzen van Zanten	Physician with Pediatric Palliative Care Team	CHEO, Roger Neilson Children’s Hospice, Ottawa
Gurjit Sangha	Paediatric Palliative Care Facilitator	Trillium Health Partners, GTA
Pam Newman	Consulting Pediatrician	Orillia Soldiers Memorial Hospital, Orillia
Vicky Wilton	POGO Pediatric Interlink Nurse	Health Sciences North, Sudbury
David Lysecki	Medical Director and Staff Physician, (QoLA Care)	McMaster Children's Hospital, Hamilton
Rebecca Williams	Nurse Practitioner - Pediatrics	The Hospital for Sick Children, Toronto
Ariadna Randall	Nurse Practitioner, Palliative Care	Home and Community Care, West Region
Kimberly Daffern	Manager of Clinical Programs	Emily's House Children's Hospice, Toronto
Alexandria Friesen	HUUG Children’s Grief Counsellor	Heart House Hospice, Mississauga
Craig Goldie	Program Director, Palliative Care physician and Assistant Professor	Kingston Health Sciences, Kingston
Michelle Verbeek	Children’s Care Coordinator	Home and Community Care, West Region
Marion Knutson	Patient and Family Advisor (PFA)	Central Region
Valerie McDonald	PFA, Co-chair of the Family Advisory Council of the PPPC-SC	Toronto

Ontario Health Staff Project Team Members

Member Name	Role, Program Team
Susan Blacker	Provincial Clinical Co Lead, Ontario Palliative Care Network
Darren Cargill	Provincial Clinical Co Lead, Ontario Palliative Care Network
Aliya Pardhan	Manager, Program Design and Implementation
Deanna Bryant	Manager, Provincial Palliative Care Program
Tara Walton	Manager, Provincial Palliative Care Program
Elan Graves	Senior Business Partner, Provincial Palliative Care Program
Emily Field	Lead, Provincial Palliative Care Program
Heather Vines	Senior Specialist, Provincial Palliative Care Program
Junell D’Souza	Manager, System, and Infrastructure Planning
Aileen Jia	Lead, Program Design and Implementation
Daniel Gillespie	Senior Specialist, Program Design and Implementation
Timur Gomellya	Coordinator, Provincial Palliative Care Program

Appendix D: Case Studies

CASE STUDY 1: BABY MEI - PERINATAL/NEONATAL CARE

Background: Baby Mei, a 6-week-old infant in the Neonatal Intensive Care Unit (NICU), was diagnosed before birth with serious neurologic anomalies - lissencephaly (a rare brain disorder) and brainstem hypoplasia (underdevelopment of the brainstem). Mei’s parents were offered the option to terminate the pregnancy given the poor prognosis, but Mei's parents elected to proceed and requested that all possible life-prolonging interventions be provided at the time of delivery. While they understood that Mei’s brain abnormalities were permanent and would lead to a shortened life, they hoped Mei’s neurologic impairment would be on the milder end of the spectrum. Given their clear life-prolonging goals, there was no consideration of palliative care during the pregnancy or afterwards.

Current Contextual Challenges: Mei's diagnosis and subsequent care in the NICU presented her family with a series of challenging decisions and emotional burdens. She initially required nasogastric feeding (a tube that goes through the nose into the stomach) as well as intubation and mechanical ventilation for continuous breathing support. When the NICU team suggested involving palliative care, Mei's parents refused; they were scared this meant ‘giving up’. After many weeks in hospital, Mei was eventually discharged home with a permanent g-tube for feeding and with low flow oxygen. She would be followed by a community pediatrician and referrals were made to outpatient Neurology and Respirology clinics. Parents understood that Mei was ‘fragile’, and they were instructed to come to the Emergency Department if they were ever concerned, something they had to do frequently over the next year.

Optimal Care: Recognizing the need for a holistic approach to care, the Maternal-Fetal Medicine (MFM) Team specializing in high-risk pregnancies, initiated a comprehensive treatment plan from the moment of diagnosis. They introduced the Specialist Pediatric Palliative Care (SPPC) Team early in the pregnancy, ensuring Mei's family understood that palliative care would support the family during this difficult time and was not about ‘giving up’. The SPPC Team helped Mei’s parents walk two roads during the pregnancy: (1) planning for life with their daughter who might live with permanent impairments, likely requiring medical technology; while at the same time (2) grieving the loss of the healthy child they had hoped for, knowing that if she survives the pregnancy, her life may still be short despite best efforts. The SPPC Team also helped the parents explain Mei’s situation to her older siblings, leaving room for optimism and hope while preparing them for the possibility that their baby sister might have a shortened life. The birth plan would encompass both life-extending treatments and care that would optimize her comfort by providing relief from the symptoms associated with her serious illness.

Upon Mei’s successful delivery and transfer to the NICU, the SPPC Team continued to follow. They integrated opportunities for Mei’s parents to bond with her and create memories while their daughter received intensive care. They included Mei’s siblings by encouraging them to draw pictures to decorate their sister’s room in the NICU; her siblings were excited to see all their artwork surrounding Mei’s crib when they came to visit shortly after delivery.

Eventually, Mei got a g-tube for feeding and she required oral suctioning and low-flow oxygen to assist her breathing. She developed seizures that occasionally impacted her breathing and heart rate, despite multiple anti-convulsant medications.

After months in hospital, the medical team and the family agreed that this fragile state was the best that could be achieved for Mei considering her irreversible brain abnormalities, and they planned for discharge home. Parents remained hopeful that Mei would improve, but their goals changed slightly; they became more accepting that she might have a shortened life, and they hoped for as much good time as possible. They agreed to a ‘No CPR’ (or Do-Not-Resuscitate) order and welcomed the involvement of a home palliative care NP, who followed Mei together with a community pediatrician. The community palliative care NP had 24/7 access to the SPPC Team for support; the NP’s ongoing role would be determined over time, as Mei’s clinical situation became clearer.

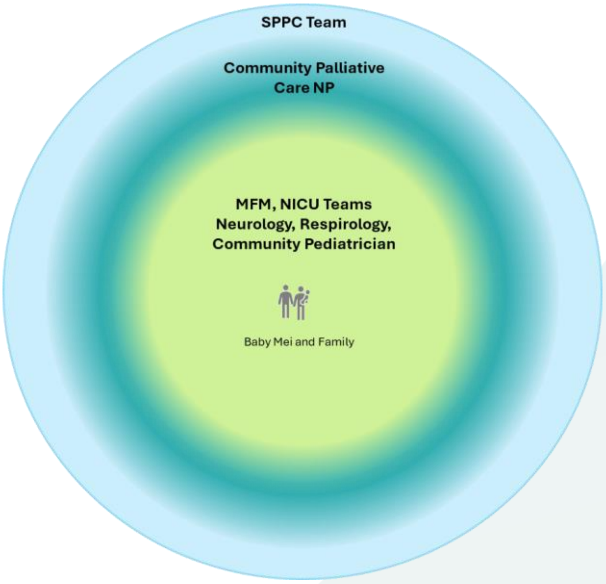


Figure 4
Baby Mei and her family are at the centre of all decisions and active participants in care. Her Interprofessional Pediatric Palliative Care Team comprises the Maternal-Fetal Medicine (MFM) Team, who are closely involved from the perinatal stage, leading the coordination of care and ensuring the family is supported and informed. The MRMP for pediatric palliative care will transition to an MD or NP on the Neonatal Intensive Care Unit (NICU) team postnatally, who will provide the intensive care required by Baby Mei. Eventually, the MRMP role will transition to a community pediatrician and outpatient subspeciality teams (e.g. Neurology, Respirology) upon discharge. The MRMP for palliative care will be an MD/NP from the current care teams because Mei’s goals of care are focused on prolonging life. The community palliative care NP will provide in-home support focusing on comfort and maximizing quality of life. The SPPC Team would be integrated early to provide supportive care intermittently, to the family, and other members of her team, including the Community Palliative Care NP, as needed.

CASE STUDY 2: FARAH - CANCER DIAGNOSIS

Background: Farah, a 5-year-old girl, was diagnosed with acute myelocytic leukemia (a type of blood cancer). She moved with her parents to be near a specialized children's hospital for intensive chemotherapy and her siblings stayed in their home community with their grandparents. Two courses of chemotherapy were given with the hope of getting Farah to a stem cell transplant, but sadly her disease never went into remission. The oncology team offered to proceed with a stem cell transplant despite the cancer’s lack of response, but the chances of cure would be very low. Farah’s parents decided to return to their rural home with their daughter, to be with friends and family, and to consider their next steps.

Current Contextual Challenges: At home, distant from the advanced care offered by their pediatric oncology team, the family confronted new challenges, like nose bleeds and abdominal pain. Farah’s family physician and oncology satellite centre (40-minute drive from home) struggled to manage her symptoms and to provide the comprehensive support needed by the family, including Farah's siblings. This situation placed an immense emotional and psychological burden on the parents. They found themselves overwhelmed by the transplant decision; Farah hated being at the children's hospital, away from family and friends, but her parents felt guilty about not trying. Even as they started thinking more about Farah's death, it felt like a return to the specialized children's hospital was inevitable given the lack of local supports where they live.

After a few days at home, Farah developed a fever and complained about severe pain throughout her body. To be safe, her parents drove her straight to the children's hospital more than two hours away. Her oncologist determined that her disease was rapidly progressing; IV medications were started to ease her pain, and the Specialist Pediatric Palliative Care (SPPC) Team was consulted. A few days later, Farah died peacefully in hospital with her parents by her side. Her siblings were brought in to say 'goodbye' after her death.

Optimal Care: From the onset of Farah's cancer diagnosis, which is known to be difficult to treat, the oncology team integrated a palliative care approach. They involved local resources, such as an Interlink nurse[7], to ensure the family was optimally supported, and they communicated regularly with Farah's primary care physician to keep her updated as things changed. Even though Farah's care mostly occurred at the regional children's hospital, her community primary care physician regularly connected with family, offering support and guidance. A few weeks into treatment, the oncology team chose to involve the SPPC Team. The SPPC Team provided an additional layer of support to Farah and her parents in hospital, focused on building relationships, improving Farah's quality of life, and helped manage any distressing symptoms. They also provided practical suggestions for including and supporting Farah's siblings who were being cared for at home by their grandparents for the past few weeks.

As Farah's care needs evolved, the SPPC Team's involvement increased. Together, the oncology team and the SPPC Team met with Farah's parents to discuss her clinical status, her worsening prognosis, and to engage in important discussions regarding goals of care. Farah's primary care physician also participated in the meeting virtually. Farah's parents remained hopeful, but they communicated that their daughter's comfort and happiness was most important. As they left hospital to take some time to consider the transplant option discussed in the meeting, the SPPC Team involved community palliative care services (i.e. a local palliative care physician and the community hospice) to support Farah and her family and to work with their trusted primary care physician. The SPPC Team maintained ongoing communication with the primary care physician and the community palliative care supports and offered round-the-clock assistance to address any concerns, including new nose bleeds and abdominal pain.

After time at home with the community palliative care supports in place, Farah's family made the difficult decision to not proceed with a stem cell transplant. Instead, they would keep her at home and make occasional visits to their regional oncology satellite centre, with the hope of having as much

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[7] Interlink nurses are oncology nurses with experience in caring for children with cancer. They are members of the child's hospital and clinic team, and work together with families to link services from the hospital to the community, home and school.

good time as possible. Throughout Farah's illness, her family was well-informed about who to contact for assistance. The SPPC Team periodically checked-in with the community clinicians and they regularly updated the oncology team at the children's hospital as Farah began to slowly deteriorate. On one occasion, a virtual meeting was set up to discuss the value of ongoing blood transfusions at the satellite centre. Key representatives from Farah's Interprofessional Palliative Care Team all took part – oncology team members from both the children's hospital and the satellite centre, the SPPC Team, the primary care physician, the community palliative care physician, and one of Farah's homecare nurses. All agreed that the transfusions were now more burdensome than helpful and so they were stopped. The SPPC Team continued to support the community clinicians, as needed, until Farah eventually died at home surrounded by her family. The social worker from the local (adult) hospice was able to build a relationship with the family before Farah's death and she felt comfortable providing ongoing support to parents and siblings in their bereavement. Nonetheless, the social worker and the family were grateful that specialized grief support would continue to be available through the SPPC Team.

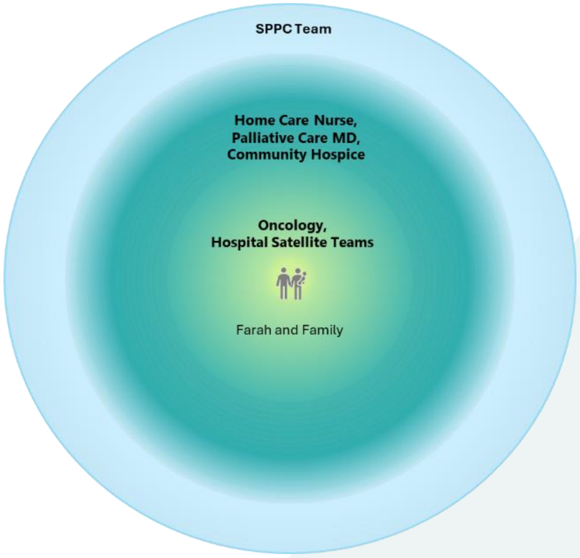

Figure 5
At the centre, Farah and her family are emphasized as active participants in care. As Farah's care shifts to a comfort focused approach at home, members of her current care team (i.e. pediatric oncology, pediatricians at the community hospital satellite centre) continue to be closely involved, even while others take the lead. Home care (through Ontario Health atHome) and community palliative care supports (i.e. physician, local hospice staff) are integrated. Their role expands as a trusting relationship develops, with the community palliative care MD eventually taking on the MRMP role when goals of care become focused on maximizing comfort at home. The role of the Specialist Pediatric Palliative Care (SPPC) Team gradually increases over time, shifting from intermittent support during active treatment to close, coordination and guidance to all layers of the Interprofessional Palliative Care Team as Farah approaches end of life.

CASE STUDY 3: ELIJAH - DUCHENNE MUSCULAR DYSTROPHY

Background: Elijah, a 17-year-old, has been living with Duchenne Muscular Dystrophy (DMD; a progressive muscle-weakening disease) since he was diagnosed at four. He has needed to be in a wheelchair full-time since age 11 and he has severe scoliosis (curvature of the spine) due to his progressive weakness. Elijah is followed at the regional children's hospital by a variety of subspecialists, including: the neuromuscular team, respiratory medicine, cardiology, orthopedics, and palliative care. His mother, a single parent, is Elijah's primary caregiver. Now, as Elijah nears adulthood, they are facing the challenge of transitioning to adult healthcare services.

Current Contextual Challenges: As Elijah and his mother approached his transition, which would need to occur by the time he turned eighteen, they felt a mix of uncertainty and fear. His mother was particularly apprehensive about navigating this new phase without the familiar support of the pediatric team. Each of Elijah's subspecialty teams would be responsible for creating a transition plan; his family doctor, who has rarely been very involved in his care, would become his primary physician responsible for overall care coordination. For their part, the Specialist Pediatric Palliative Care (SPPC) Team approached the adult palliative care team working in Elijah's community. Even though DMD is a serious illness, because Elijah's goals of care are focused on prolonging life and he likely still has years to live, the adult palliative care team would not accept him as a patient. The SPPC Team explained the situation to Elijah and his mother, who worried about losing the psychosocial support they had received from the SPPC Team, and other practical supports such as funding and respite.

Months after being discharged from the children's hospital, members of Elijah's former pediatric teams received an email from Elijah's mother sharing a frustrating and scary experience. Elijah required hospital admission for dehydration secondary to a viral infection. Although she was able to stay with her son during visiting hours, she was not permitted to stay overnight. Furthermore, Elijah informed his mother about several interactions with healthcare providers where he had to give consent to tests and treatments on his own, something he had never been in a position to do previously.

Optimal Care: Elijah's transition to adult care is a well-coordinated process that is openly discussed with Elijah and his mother as soon as he becomes a teenager. To help develop his autonomy, his multidisciplinary teams have been including Elijah in his healthcare and encouraging him to be an active participant since childhood, gradually increasing his involvement in decision-making as he matured and showed interest. The SPPC Team would routinely meet with Elijah without his mother present to explore his hopes, wishes, fears, and worries about the future. While he appreciated the privacy given to him as a young adult, Elijah admitted that when it came to the 'hard stuff' he always preferred to make decisions together with his mother.

Each of Elijah's pediatric subspecialty teams developed an adult transition plan. In the absence of an adult multidisciplinary clinic for DMD patients, Elijah's family physician would need to serve as his primary care provider who would integrate and coordinate all his new adult specialists. Because Elijah's family doctor was unfamiliar with the complexities of DMD, she would need to work closely with the various pediatric multidisciplinary teams to understand and address his needs. Ideally, this would be accomplished through a series of joint visits involving Elijah, his mother, the family physician together with representatives from Elijah's pediatric teams leading up to his transition.

The SPPC Team connected with adult palliative care physicians, a nurse practitioner, and the adult hospice serving Elijah's community to explore the possible supportive role they could play post transition. However, given Elijah's goals of care and prognosis (believed to be years), they felt under-resourced to provide assistance at this stage. The SPPC Team also contacted the family physician to provide an overview of their role in Elijah's care: conducting periodic reviews of Elijah's quality of life and his goals of care; assisting with important decisions, such as the use of technology, to prolong his life; and the assessment and management of symptoms associated with his progressive DMD. The SPPC Team and the family physician (who joined virtually) participated in combined outpatient visits leading up to Elijah's transition to further illustrate the role of palliative care in Elijah's holistic care plan. The SPPC Team continued to be available to the family physician, even after the transition to adult care, to provide guidance and support as needed. Similarly, the pediatric hospice where Elijah accessed respite supports throughout his childhood continued to offer services between the ages of 19-24, to bridge his transition to adult care.

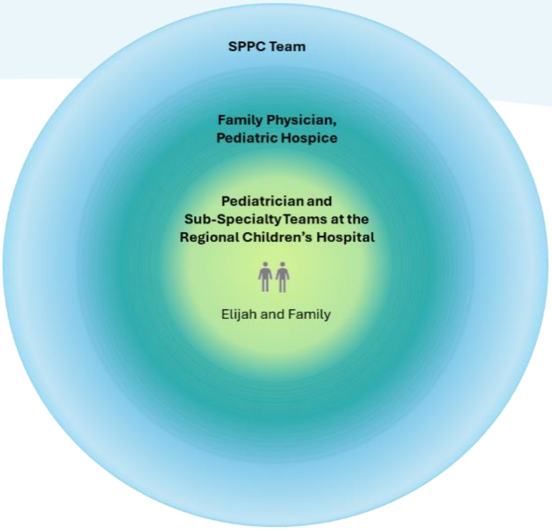

Figure 6
Elijah and his mother are central and active participants to healthcare decisions and transitioning to adult care. His Interprofessional Pediatric Palliative Care Team includes the pediatrician and sub-specialty teams at the regional children's hospital. They lead Elijah's care, managing his complex medical needs. As Elijah approaches adulthood, the role of MRMP will transition to the family physician and new adult specialists. The SPPC Team is involved intermittently from the start, assisting in goals of care discussions and decision-making around technology. As transition approaches, the SPPC Team works with Elijah's family physician to integrate palliative care. The SPPC Team and the pediatric hospice remain available, as needed, to support the family physician and Elijah respectively, even after transition to adult care.

Appendix E: Glossary

Comprehensive and Holistic Assessment: Includes a full examination of the domains of care (i.e., illness/disease management, physical, psychosocial, social, spiritual, developmental care, practical considerations, end-of-life issues, and support through loss, grief, and bereavement). Examples of validated instruments for assessment include the Edmonton Symptom Assessment System and the Palliative Performance Scale.

Culturally Safe Spaces: A culturally safe space is an environment where individuals feel respected, secure, and comfortable expressing their cultural identity. This concept emphasizes the importance of understanding, recognizing, and responding to the unique cultural needs and preferences of others. In such spaces, power imbalances and cultural biases are actively addressed to prevent discrimination and ensure equitable treatment. Culturally safe spaces enable people to feel valued and understood, fostering an atmosphere of trust and openness.

Disability: The Ontario Health definition of disability aligns with the Ontario Human Rights Code and the Ontario Disability Support Program (ODSP). Disability is broadly defined to include any degree of physical disability, infirmity, malformation, or disfigurement, as well as mental or developmental conditions that impact an individual's ability to function or participate fully in society.

Goals of Care Discussion: This involves open and honest conversations among the healthcare team, the child, and the family. These discussions will focus on the child's prognosis, the potential benefits and burdens of various treatments, and the family's values, beliefs, and desires for the child's care. The primary aims are to:

- Clarify the medical situation and possible outcomes. These are initially addressed during the disclosure interview following the initial diagnosis and are consistently reinforced by members of the Interprofessional Pediatric Palliative Care Team.
- Understand the values of the family and child, particularly what they consider to be a good quality of life.
- Align medical treatment with these values and goals.
- Make informed decisions about potential interventions, prioritizing the child's comfort and the family's wishes.
- Foster a supportive environment where families feel empowered and supported in their decision-making. This aspect is continually reviewed by the IPPC team as appropriate.

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Hospice: A community-based service that provides support to individuals living with a serious illness and their care partners, family members, and friends. This support is available in various settings, including the individual's home or a home-like setting. The primary goal is to enhance the quality of life of the individual and the well-being of anyone that is impacted by the person’s illness or death. Volunteers play a vital role in achieving this goal, making significant contributions to the care provided. The services provided by hospices encompass the aid of trained volunteers, day programs, psychosocial support, grief and bereavement counseling, spiritual care, support for families, wellness activities, complementary therapies, children's programs, collaborative care with other healthcare providers, and end-of-life care within hospice residences. These comprehensive services offer holistic care that honors the dignity of the individual and promotes the well-being of everyone involved.

Ontario Health atHome: An organization responsible assessing patient care needs and delivering in-home and community-based services to support health and well-being. They also provide access and referrals to other community services and manage Ontario’s long-term care home placement process.

Ontario Palliative Care Network (OPCN)**:** The OPCN is a partnership of health service providers, community and social support service organizations, health systems planners, as well as patient and family/care partner formed in 2016 to develop a coordinated, standardized approach for delivering palliative care services across the province. The OPCN is funded by the Ministry of Health and is accountable to Ontario Health.

Ontario Health Regions: Ontario Health has defined six regions to organize and manage healthcare services across the province. These regions are designed to help improve patient experiences, health outcomes, and overall system efficiency by working with local community and healthcare partners. The six Ontario Health regions are:

1) **North East Region:** This region serves communities from Parry Sound to Sault Ste. Marie and extends to the Hudson Bay and James Bay coasts. The region covers a significant portion of Ontario's landmass and includes large rural areas.
2) **North West Region:** This region includes communities from Thunder Bay to Kenora and up to the Hudson Bay coast. It also covers a large geographical area with many rural communities.
3) **East Region:** This region serves areas from Pickering to Deep River and Hawkesbury. It encompasses a mix of urban and rural communities.
4) **Central Region:** This region includes communities from Mississauga to Huntsville and Orangeville to Markham. It covers a diverse range of suburban and rural areas.
5) **Toronto Region:** This region serves 73 unique urban neighborhoods within Toronto, focusing on the specific healthcare needs of the city.
6) **West Region:** This region includes communities from Waterloo to Windsor and Tobermory to Niagara Falls, covering both urban centres and rural areas.

These regions work to implement health system changes, lead regional health systems, fund healthcare providers, and monitor healthcare performance to meet the diverse needs of Ontario residents.

Palliative Care Competencies: This refers to the knowledge, skills, and attitudes required by care providers to deliver high-quality palliative care. Implementing these competencies in practice will improve care for individuals with serious illnesses and foster collaboration among professionals and organizations involved in palliative care. According to the Ontario Palliative Care Competency Framework, there are two levels of palliative care competencies. Level 1 competencies, also known as primary-level competencies, encompass both shared and profession-specific competencies for all health professionals and volunteers involved in caring for people with serious illnesses and their families or care partners. This includes generalist and non-specialist palliative care providers. Level 2 competencies, or secondary-level competencies, detail the shared and profession-specific competencies for health professionals who specialize in or focus their practice on palliative care, namely Palliative Care Specialists. These competencies are applicable across all care settings, including hospitals, collaborative care clinics, ambulatory clinics, and community settings.

Provincial Pediatric Palliative Care Steering Committee (PPPC SC): The Pediatric Palliative Care Steering Committee (PPPC SC) in Ontario, established in 2010, is a partnership between the Pediatric

Oncology Group of Ontario (POGO) and the Provincial Council on Maternal and Child Health (PCMCH). This committee is dedicated to supporting the development and implementation of a unified provincial strategy for delivering pediatric palliative care. It comprises a diverse group of clinicians, administrators, family advisors, professional associations, and community organizations throughout Ontario, all collaborating to further the goals of pediatric palliative care.

Appendix F: Acronyms

ADL	Activities of Daily Living
DNR	Do Not Resuscitate
EMR	Electronic Medical Record
IADL	Instrumental Activities of Daily Living
IPPC	Interprofessional Palliative Care Team
MAID	Medical Assistance in Dying
MD	Doctor of Medicine
MRMP	Most Responsible Medical Professional
NICU	Neonatal Intensive Care Unit
NP	Nurse Practitioner
OPCN	Ontario Palliative Care Network
PCMCH	Provincial Council on Maternal and Child Health
PPC	Pediatric Palliative Care
POGO	Pediatric Oncology Group of Ontario
PPPC SC	Provincial Pediatric Palliative Care Steering Committee
RIWG	Regional Implementation Working Group
SPPC	Specialist Pediatric Palliative Care

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