Pediatric Palliative Care: How Can You Play a Role?



Host: Holly Finn

Presenters: Kira Goodman & Dr. Dave Lysecki

Date: October 09th 2025

Territorial Honouring



The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.





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Learning Essential Approaches to Palliative Care (LEAP)



Pallium Canada's award-winning suite of LEAP courseware transforms health care practice through interprofessional and evidence-based palliative care training:

- Build the skills and confidence to deliver compassionate, patient-centred care.
- Developed and peer-reviewed by Canadian palliative care experts.
- Online, in-person or hybrid course delivery options.
- Earn annual learning credits and a nationally recognized certification.
- Backed by evidence and best practices.
- Practical, case-based learning with real-life scenarios.

Learn more at: pallium.ca/courses



Introductions

Host

Holly FinnSenior Manager, Program Delivery
Pallium Canada

Presenters

Dr. Dave Lysecki

Pediatric Palliative Medicine Specialist, Medical Director of Canada's Pediatric Palliative Care Alliance

Kira Goodman

RN, BSCN, Project Director for Canada's Pediatric Palliative Care Alliance

ECHO Support

Elias Cherfan

Program Manager, Support Desk Pallium Canada



Welcome and Reminders

- For comments and introductions, please use the chat function!
- For questions, please use the Q&A function, these questions will be addressed at the end of the session.
- This session is being recorded—this recording and slide deck will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.

Disclosure

Relationship with Financial Sponsors:

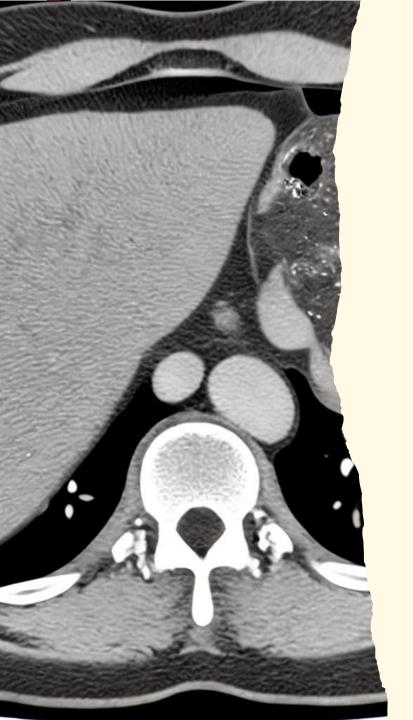
Pallium Canada

- National registered charitable organization
- Funded by Health Canada

Host/Presenter

- Holly Finn: Employed by Pallium Canada
- Dr. Dave Lysecki: Nothing to disclose
- Kira Goodman : Funded by Health Canada

Pediatric Palliative Care: How Can You Play a Role?



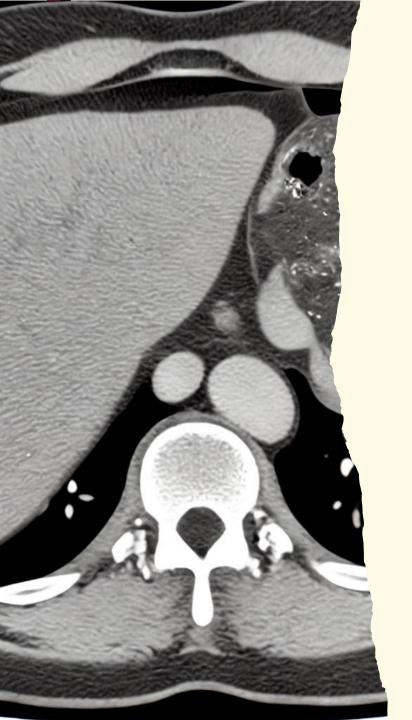
Case - Jerry

13y.o. with relapsed metastatic hepatoblastoma and Trisomy 21

Loves "fishing, fishing, and more fishing"

Friendly, but dysregulated with pain 2° to traumatic medical stress (since ICU admission post-surgery with delirium)





Case - Jerry

Port-a-Cath and a G-tube with nutritional supplementation
Methadone for bony pain, mirtazapine for anxiety, oral palliative chemotherapy, and infection prophylaxis (Septra, fluconazole)





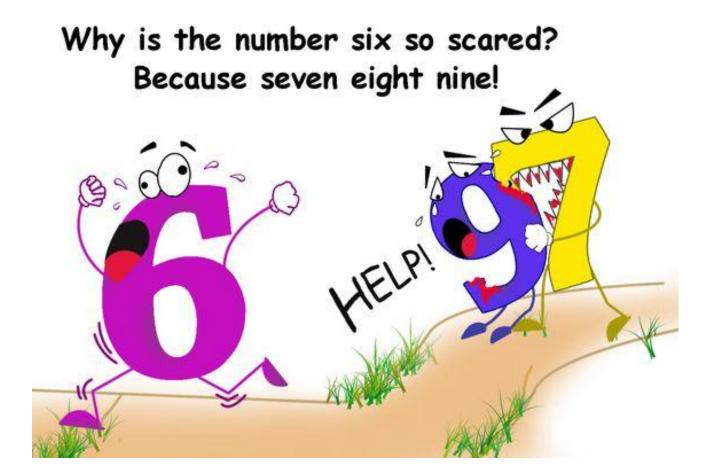
Case - Jerry

Jerry is from rural Ontario and has spent most of his last 2 years in Toronto.

Jerry and family would like to spend as much of his remaining days as possible at home by the lake

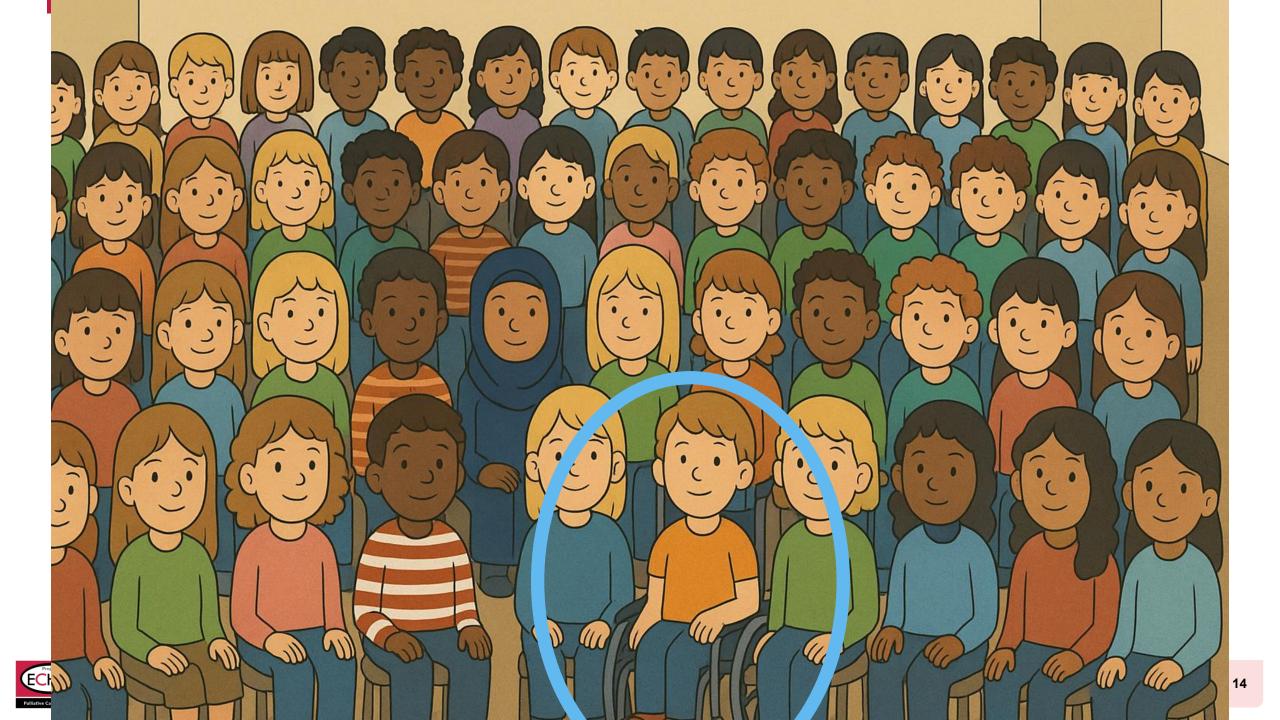


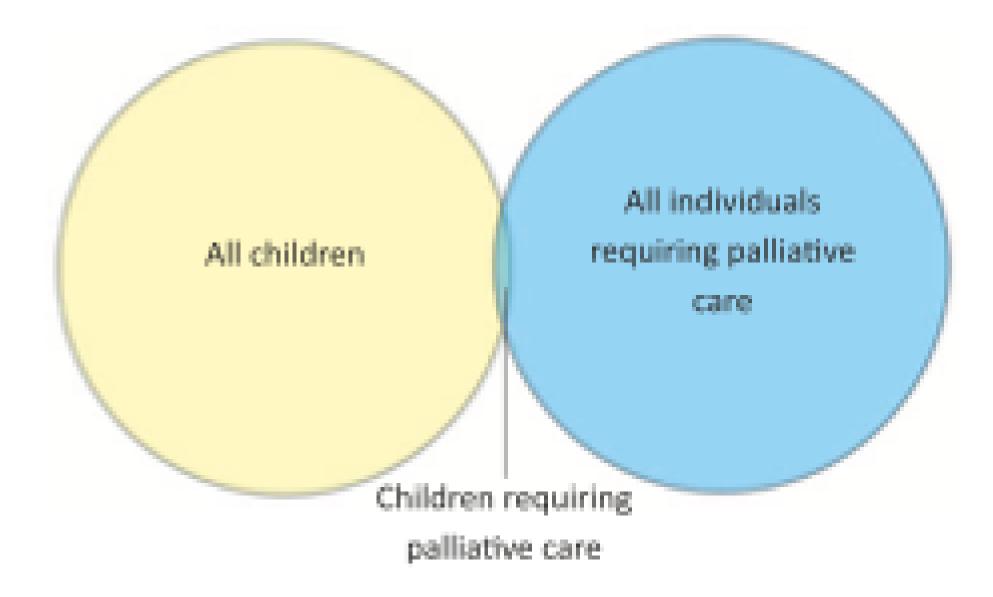
Houston, we have a *number* problem





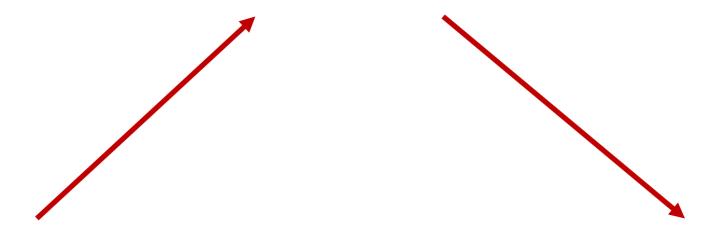








Family Health Teams



Palliative Care

Pediatrics

Palliative Care = (pro)Active care

- Health maintenance nutrition, antibiotic prophylaxis, constipation
- Chemo CBCs, Fever mgmt. plan
- Central line access, flushes
- Mental Health support: Counselling, anxiety, PTSD, mirtazapine
- Pain management methadone, escalation?
- In-home care nursing, physician visits, OT/PT
- 24/7 on call support
- Care coordination
- Death planning pronouncement, funeral planning, organ donation
- Sibling support
- Parent support social, financial, grief
- Staff Support









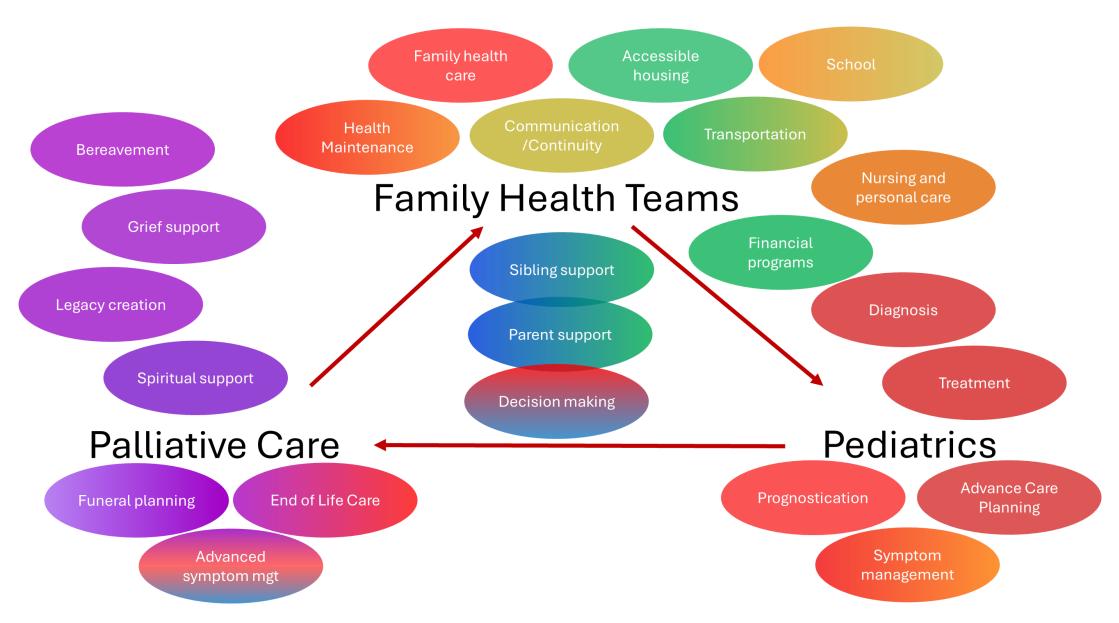






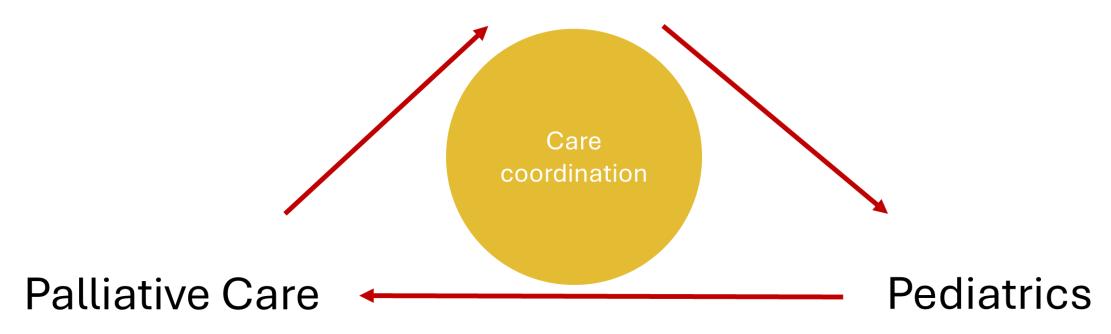




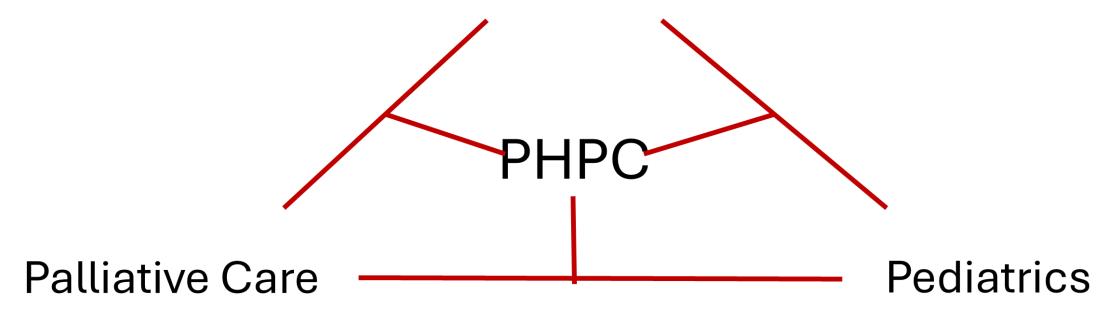


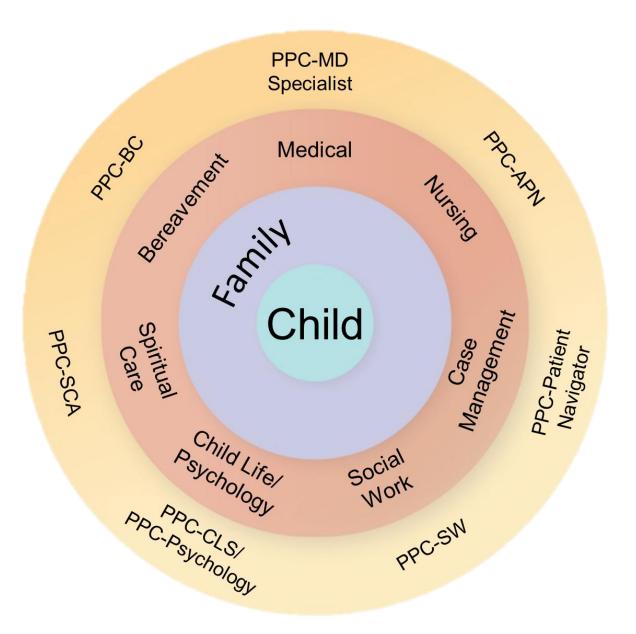


Family Health Teams



Family Health Teams







Palliative Care = (pro)Active care

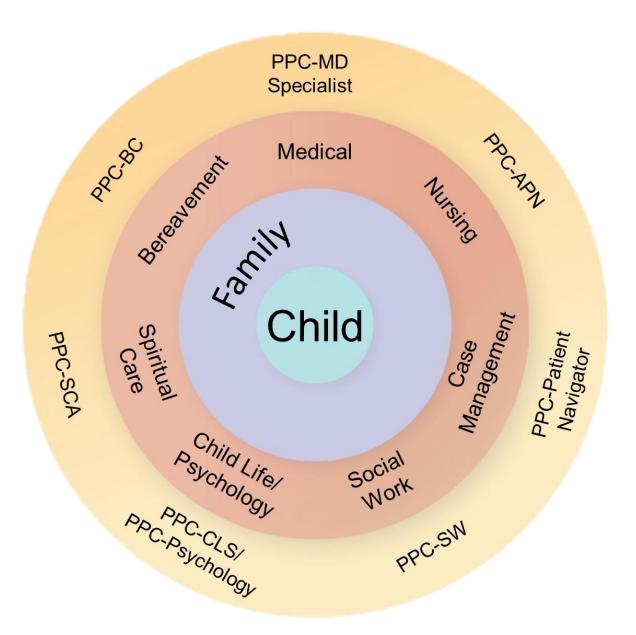
- Home care nursing regular visits, pain assessment, daily care support
- Family Health Team / Primary Care Parent/Sibling support, home visits, 24/7 support, pronouncement, funeral planning
- Pediatrics Nutrition, Constipation, CBCs, fever management, Porta-cath care
- Palliative Care Methadone
- PPC (Virtual) Counselling, Mirtazapine, 24/7 backup, staff support
- Pediatric Onc (Virtual) Chemotherapy



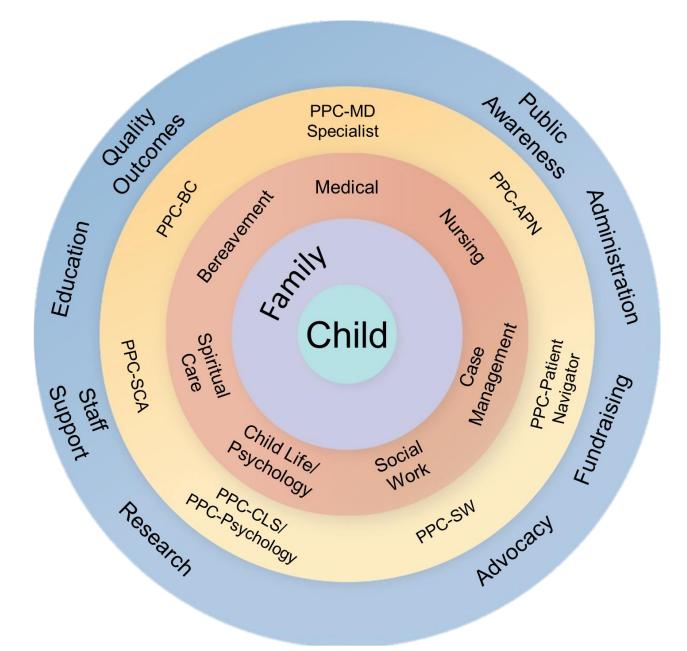
Palliative Care = (pro)Active care

- 17y.o. with cerebral palsy, severe scoliosis, recurrent aspiration pneumonia
- 12y.o. with Duchenne's muscular dystrophy and ASD
- 4y.o. with new diagnosis of Batten syndrome
- 1 week old, 24wk GA infant, with intraventricular hemorrhage
- 6mo old with infantile spasms
- 21-week fetus with Trisomy 18













The Grant:

Health Canada funded Roger Neilson Children's Hospice with \$1.2 million over 27 months.

Our Core Deliverables

- 1) A bilingual resource hub
- 2) Building a network for practitioners
- 3) A shared vision of high quality pediatric palliative care

The Overarching Vision:

A future where every Canadian child with a serious illness has access to high-quality pediatric palliative care, regardless of location, background, or circumstance.

Key Players:

- Health Canada: Funder.
- Roger Neilson Children's Hospice: Project Lead and supporter.
- Project team: Day-to-day operations.
- Other Key Collaborators: Healthcare Professionals, Families and Organizations across Canada



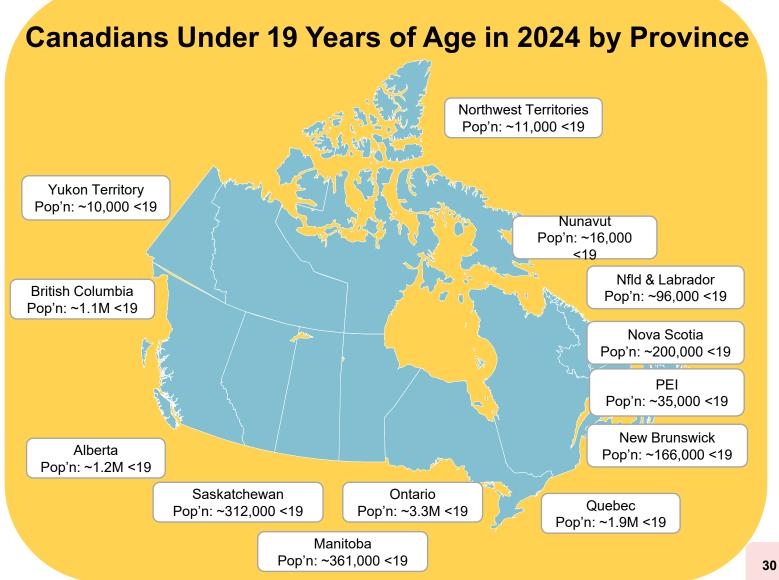
Population Distribution in Canada

Total Number of Canadians (all ages)

41.3M

Total Number of Canadians Under 19

8.6M





Distribution of Children's Hospices in Canada

Total Number of Hospices in Canada

8

There are 4 additional hospices in their advocacy stages:

Ontario – 2

Nova Scotia – 1

Quebec - 1

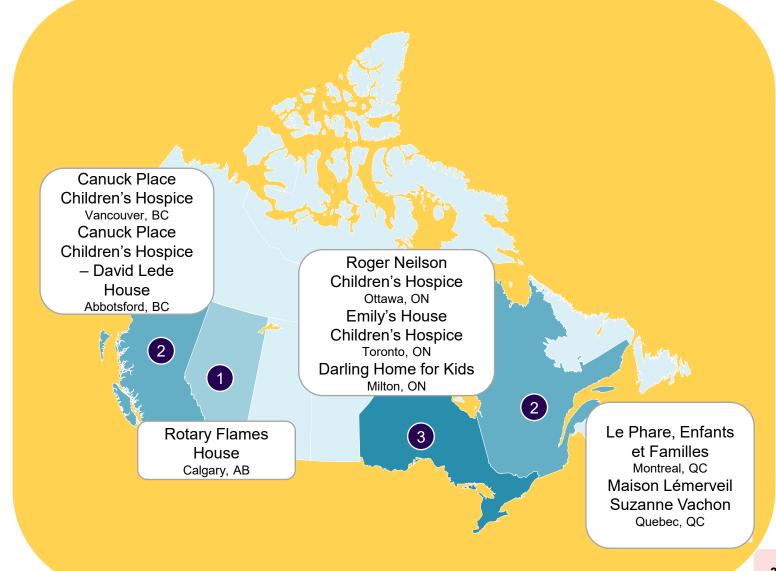
With 8.6M people <19 in Canada we have

7 Hospices

Compared with

15.7M people <19 in the UK there are

50+ Hospices







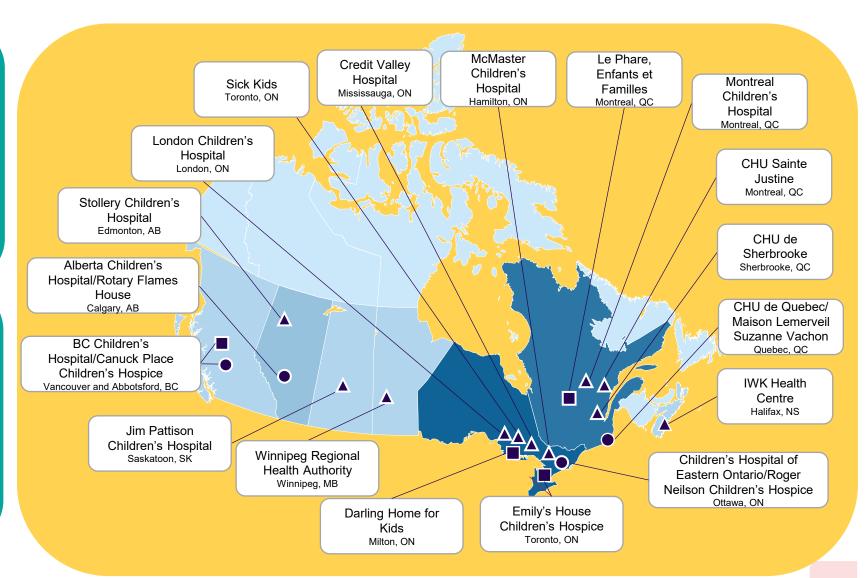
Distribution of Children's Hospices and Pediatric Palliative Care Teams in Canada

Legend

- Hospital or Community-Based Team
- Children's Hospice
- Combined Hospice and Hospital-Based Program

Total Number of Hospices and Teams in Canada

18







From Rarity to Inequity: Why PPC Needs National Coordination

Pediatric Palliative Care is "rare"

- <1% of palliative care patients
- Low visibility in policy and planning
- Often not prioritized or resourced



Which leads to underresourced systems

- No updated national standards
- Limited training and unclear roles
- Teams building tools in isolation



Resulting in fragmentation and inequity

- Unequal access by geography and provider
- Greater barriers for equitydeserving communities
- Families left to coordinate care alone

Mending the Gaps: What the Evidence Tells Us

Challenges across the literature:

- Unclear roles and responsibilities between providers
- Shortage of specialized and generalist PPC expertise
- Fragmented systems and poor care coordination

Recommendations to strengthen PPC:

- Consistent education + national practice standards
- Better access: 24/7 supports, regional networks, care coordinators
- Increased awareness to shift PPC from "end-of-life only" to quality-of-life-focused care



From Evidence to Action

WHAT THE REVIEW FOUND	HOW THE ALLIANCE IS RESPONDING
Unclear roles & care coordination	Core Care Pathway to define stages, roles & expectations
Gaps in generalist training	Resource Hub with tools for all providers, not just PPC teams
Fragmented systems	Communities of Practice + network mapping across regions
Lack of 24/7 access & rural support	Resource Hub with tools for all providers + network mapping
PPC introduced too late	Education, awareness tools
No national standards	Contributing Pediatric Voice to National Standard of Canada

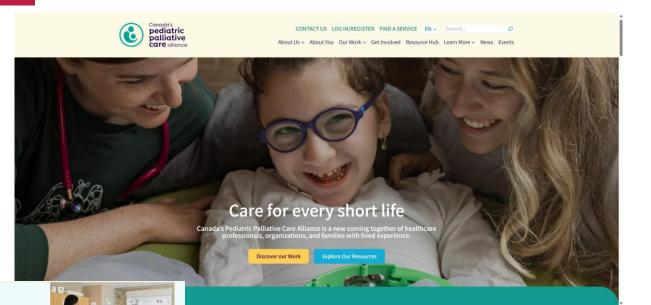




Priorities for the Year Ahead

(through March 31, 2026) – and laying groundwork beyond

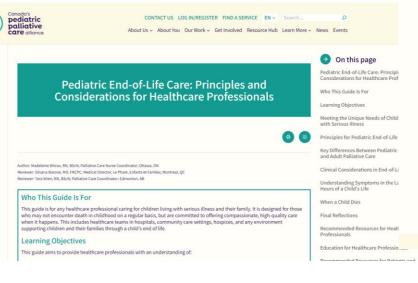
- Launch Resource Hub (TODAY!): bilingual, virtual platform with tools, resources & training
- Launch Canadian Core Care Pathway for Pediatric Palliative Care (co-developed with providers & families)
- Map & referral pathways to connect people with local services and supports
- Grow Communities of Practice & asynchronous forum for collaboration & knowledge sharing
- Stay grounded & responsive by continuing to listen to families and providers
- Expand visibility through major conferences & webinars



Specialty Teams
Click on a province to explore teams in your region.

www.pediatricpalliativecare.ca www.soinspalliaitifspediatriques.ca







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Understanding Pediatric Palliative Care

Pediatric palliative care (PPC) is considered a best practice and core component of care provided to children living with serious illness and their families. However, it is often misunderstood or introduced too late in their illness journey.



Print All Pages ③

families, healthcare professionals, and communities truly understand what predictive publisher care looks (60 to Canada, we created a series of five exected pages. What, Who, Where, When, and Why.

Each page stands on its own, but together they form a clear pathway to understanding products: pallative care in a Canadian control



What is Pediatric Palliative Care?

Pedubric patienthe core (PPC) is a historic, mierelecipinary approach to caring for infents, children and youth with annual filmes and their terrales. It aims to patientary quality of alse, release waterings and province active, total current the childr's body, mind, and quint, while offering support to the article family.



Who Provides Pediatric Palliative Care?

Pediatric pullative care can be delivered by a wide range of healthcare professionals across multiple settings including the home, hospitals, hospit and community care centres.

Character Manne



When Should Pediatric Palliative Care Be Offered?

Podutric pallative care should be introduced when a child is living with a serious library that directs their quality of the analysy power a risk of durch, it be included at any time, regardless of the programs or whether curelive insuffered risks active part of care.

mary More III



Where Can Pediatric Palliative Care Happen

Children living with service diamen, and their termines need access to packet palliative care (PPC) access a wide range of healthcare movinorments and geographers. While PPC is often associated with children's hospices led by specialized bosms, the reality of where this care occurs is far broader.

Learn More



Why is Pediatric Palliative Care Importan

Pedultric palliative care improves quality of life for children and their families, supporting them through difficult decisions and graff while helping the health system deliver care that is more coordinated, compassionate, and sustainable.

Learn More





Q & A ??

Session Wrap Up

- Thank you for joining us!
- Please fill out the feedback survey following the session—a link has been added into the chat

Thank You



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