

Enhancing Care Delivery: Principles and Practice of Perinatal Palliative Care



Host: Holly Finn

Presenters: Lesley Sabourin and Shauna Wilcox

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Territorial Honouring



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Introductions

Host

Holly Finn, PMP

Senior Manager, Program Delivery

Pallium Canada

Presenters

Shauna Wilcox, BScN RN MN CHPCN(C)

Clinical Nurse Specialist, IWK Pediatric Advanced Care Team

Lesley Sabourin RN, CHPCN(C)

Perinatal Palliative Care Coordinator

CHEO Palliative Care Team & Roger Neilson Children's Hospice

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.

Disclosures

Relationship with Financial Sponsors:

Pallium Canada

- National registered charitable organization
- Funded by Health Canada

Host/Presenter

- Lesley Sabourin : Nothing to disclose
- Shauna Wilcox : Nothing to disclose

Objectives

By the end of this presentation, participants will be able to:

- Describe the core components of perinatal palliative care.
- Identify the practices applied in supporting families before, during, and after birth.
- Explain key elements of effective communication, shared decision-making and care planning with families facing life-limiting diagnoses.
- Recognize opportunities for anticipatory guidance, memory-making, and holistic support throughout the care continuum.
- Apply basic principles of comfort care and symptom management relevant to the perinatal population and identify where and how to access additional resources for support.

Perinatal Palliative Care

Palliative Care for a fetus, neonate, or infant with a life-limiting condition is

“an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, at the time of death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of QoL for the infant and support for the family. It includes the management of distressing symptoms, provision of respite, and care through death and bereavement.”

Together for Short Lives, a children’s palliative care group in the UK



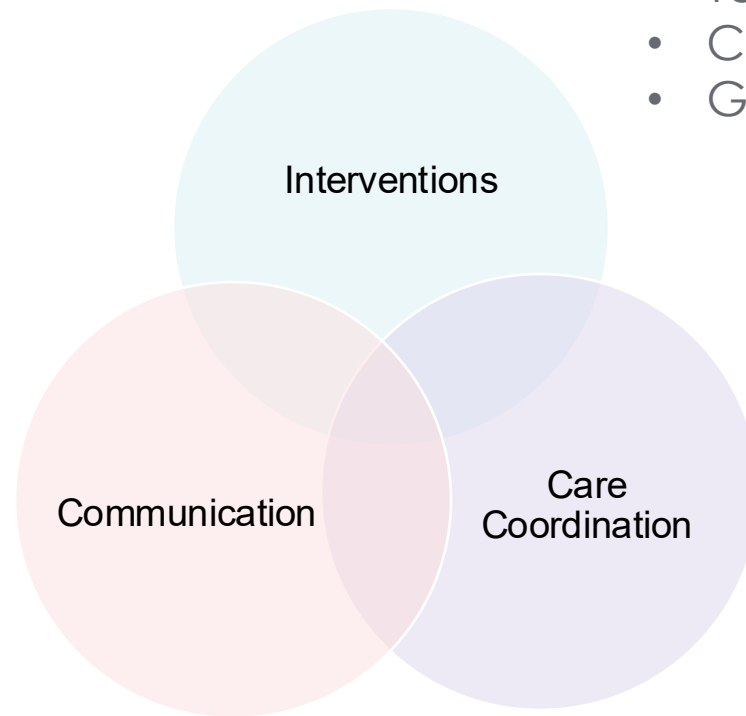
Referral Criteria

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail</p> <p>Provision of palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: extreme prematurity, severe necrotising enterocolitis, congenital heart disease.</i></p>
Category 2	<p>Conditions where premature death is inevitable</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Example: chromosomal abnormality, severe spina bifida, bilateral multi-cystic dysplastic kidneys, bilateral renal agenesis.</i></p>
Category 3	<p>Progressive conditions without curative treatment options</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Example: anencephaly, skeletal dysplasia, severe neuromuscular disorders.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death</p> <p><i>Example: severe hypoxic ischaemic encephalopathy.</i></p>

Together for Short Lives. A Perinatal Pathway for Babies with Palliative Care Needs. 2nd Ed. 2017.

Core Components of Perinatal Palliative Care

- Identifying problems & challenges
- Understanding illness
- Exploring hopes & goals
- Reframing hopes
- Advanced care planning
- Making decisions
- Acknowledgment of grief



- Symptom management
- Family Support
- Team Support
- Community Support
- Grief support

- Collaborating with other providers
- Facilitating logistics of medical and social needs
- Identify spiritual needs
- Identifying community resources
- Locations of care planning

Benefits of Perinatal Palliative Care

- Continual support in the setting of prognostic uncertainty
- Stronger family connections
- Recognizes baby as a person
- Fosters hope and acknowledges worries
- Reduces regret and increased meaning making
- Affirmation of parental roles and support for siblings
- More supportive mental health outcomes
- Sense of closure and healing
- Healthier grieving process



Communication & Decision Making

- Adequate information and time
- Balancing hopes and fears
- Best interest of the baby
- Understanding outcomes
- Clarifying goals of care
- Comfort care as active treatment
- Supporting families with grief and distress
- Acknowledging grief and hope



Hope

Hope shapes well-being & quality of life and can greatly influence decision-making

Positive benefits of hope:

- Reduces fear & anxiety
- Improves coping
- Enhances quality of life
- Promotes resilience

Care Planning

Key Elements:

Support in
decision making

Pregnancy and
delivery planning

Anticipatory
neonatal care
planning

Memory making
and family time

Symptom
management and
developmental
care

Ongoing decision-
making

End of life
planning

Transition
planning

Bereavement and
family support

Parents benefit by:

- Decreased anxiety
- Increased satisfaction with care
- Increased supportive grief
- Increased sense of control
- Support for parenting their baby



Supporting Parents – Exploring Goals in Care Planning

What have you been told about your baby up to this point?

How much information do you want about your baby ?

What are your most important hopes/goals if your baby's health were to worsen?

What are your biggest fears and worries about your baby's health?

What gives you strength during this time?

What experiences do you feel are essential to your baby's life in order for them to live as well as they can ?

If your baby becomes sicker, how much medical intervention are you willing to go through for the possibility of more time?

Goals of Care

1

Live as Long as possible

- intensive treatments & interventions
- sustain life
- requiring NICU

2

Live as long and as well as possible

- comfort and life-sustaining therapies
- may still be intensive interventions but targeted to certain treatments or symptoms

3

Live as well as possible

- maximize symptom relief
- focus on quality of life
- treatments focused on symptom control

Anticipatory Guidance: Changes at EOL

What you might see

- Breathing pattern changes / respiratory distress
- Secretions
- Agitation, irritability, seizures
- Increasing somnolence / ↓ responsiveness
- ↓ urine output
- Feeding intolerance
- Edema
- Color changes (cool, mottled skin)

Clinical Interpretation

- Reflects physiologic slowing, not suffering
- Timing and sequence are unpredictable
- Comfort assessment is ongoing
- Facial expression is a key indicator
 - Relaxed = comfortable
 - Grimace/furrow = discomfort → intervene

Clinical Action & Messaging

- Treat symptoms promptly; comfort is the priority
- Medications are used to relieve distress, not to hasten death
- Care continues even if technology is withdrawn
- Explain changes in real time using clear, calm language
- Reassure families they are not causing harm
- Normalize emotions; presence matters

Non-Pharmacological Symptom Management

- Comfort through human connection – parental presence
- Positioning for comfort
- Environmental modulation
- Oral and mucosal comfort
- Feeding and sucking for comfort
- Thermal comfort
- Pain and distress reduction techniques
- Sensory soothing
- Respecting baby's cues and provide anticipatory guidance

Medical Management of Symptoms

Pain

- Sucrose (PO & BUC)
- Morphine (PO, BUC, SC)
- Fentanyl (SC & IN)

Dyspnea

- Morphine (PO & SC)
- Fentanyl (PO & SC)
- Midazolam (PO, SL, SC & IN)

Seizures

- Midazolam (PO, SL, SC & IN)

Secretions

- Atropine eye drops (PO)
- Scopolamine (SC)

Desired Location of Care

HOSPITAL



HOME



HOSPICE



What families want at EOL

- Providing honest and complete information
- Ease of access to staff
- Good communication and care coordination
- Professional health providers who offer emotional support
- Recognition of the importance of the parent-child relationship, with effort to preserve its integrity
- Allowance for their specific cultural or spiritual practices
- Support for siblings
- Information about after death care: Funeral planning, postmortem testing (autopsy, tissue donation); grief support



Benefits of supporting memory-making for families:

- Acknowledges the loss
- Allows for healing
- Personal connection
- Legacy building
- Supports grieving
 - Coping with anniversaries
 - Navigating the grief process
- Continuing bonds



Cultural and Spiritual Support

Respect for Traditions:
Allow and support cultural traditions and rituals that are important to the family.

Spiritual Practices:
Provide space and support for spiritual or faith-based practices, including prayer and ceremonies.

Inclusive Environment:
Ensure that the healthcare environment is inclusive and accommodating of diverse cultural and spiritual needs.

https://hpcconnection.ca/wp-content/uploads/spiritual_assessment_tool-fica.pdf



Perinatal Loss: A unique grief experience

- Loss of both baby and a future
- Anticipatory grief
- Decision-related grief
- Grieving multiple losses
- Societal expectations
- Emotional and physical isolation
- Grief with minimal shared memories
- Timing of attachment



Canada's
**pediatric
palliative
care** alliance

Care for every short life



Resource
Hub



Network



Shared
Vision



ABOUT US

Canada's Pediatric Palliative Care Alliance is a new coming together of healthcare professionals, organizations, and families with lived experience. We are working collaboratively to create **a future where every Canadian family and every child with a life-limiting illness can access high-quality pediatric palliative care in a location of their choice.**

OUR WORK

The Alliance exists to address the gaps in how care is delivered to children living with serious illness and their families in Canada. We're working to strengthen national coordination and collaboration, support the providers of pediatric palliative care, and foster sustainable, system-level change to advance equitable access across the country.

WANT TO GET INVOLVED?



Register for our Resource hub

<https://www.pediatricpalliativecare.ca/resource-hub/>



Connect

hello@pediatricpalliativecare.ca



[linkedin.com/company/
pediatricpalliativecare.ca](https://www.linkedin.com/company/pediatricpalliativecare.ca)



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Resources:

- Canada's Pediatric Palliative Care Alliance – A resource hub for pediatric palliative care in Canada
- **IWK Bereavement Support Services** offer a variety of services in person and remotely.
<https://iwkhealth.ca/clinics-programs-services/bereavement-support-services>
- Canuck Place Children's Hospice – A pediatric palliative care hospice located in Vancouver that supports families through perinatal loss and infant loss.
- RogerNeilsonHouse.ca - A pediatric palliative care hospice located in Ottawa that supports families through perinatal and infant loss.
- Philip Aziz Centre & Emily's House | Toronto, ON – A pediatric palliative care hospice located in Vancouver that supports families through perinatal loss and infant loss.
- PailNetworkSunnybrook.ca - The Pregnancy and Infant Loss Network is an organization families turn to for support and hope in dealing with pregnancy and infant loss.
- **Canadian Virtual Hospice** @ [Canadian Virtual Hospice](http://CanadianVirtualHospice.ca)
- **My Grief.ca** – Modules 17, 18, 19 @ <https://www.mygrief.ca/>
- AskAProfessional.ca - A web-based resource where you can ask a professional about terminal illness, end-of-life care, loss and bereavement.

- KidsGrief.ca - A free online resource that helps parents support their children when someone in their life is dying or has died. It equips parents with the words and confidence needed to help children grieve life's losses in healthy ways.
- Home | Bereaved Families of Ontario Bereaved Families on Ontario (BFO) -
- **Public Health Canada** - <https://www.canada.ca/en/public-health/services/publications/healthy-living/maternity-newborn-care-guidelines-chapter-7.html>
- Sands | Saving babies' lives. Supporting bereaved families. – Sands is an on-line resource for families who have experienced perinatal loss
- Baby loss information and support | Tommy's . Tommy's is an on-line support for families who have experienced perinatal loss.
- Pregnancy and infant loss – AboutKidsHealth Sickkids supporting families coping with pregnancy and infant loss including perinatal palliative care.
- Resources – CHPCA – Canadian Hospice Palliative Care association provides a repository of resources for pediatric palliative care.
- Perinatal Hospice and Palliative Care: Continuing Your Pregnancy – provides recourses for families who receive a fetal diagnosis of a life-limiting condition.
- Together for Short Lives. (2017). *Perinatal pathway for babies with palliative care needs* (2nd ed.) Together for Short Lives. <https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/> Toget

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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