Paramedic Community of Practice – Series 2

Serious Illness Conversations

Facilitator: Diana Vincze, Pallium Canada
Presenter: Karen O’Brien and Dr. Jitin Sondhi
Date: January 16th, 2024

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.

LEAP Paramedic

Learn the essentials for providing a palliative care approach

- Ideal for Paramedics and Emergency Medical Service professionals

- **Key features:**
  - Created and reviewed by Canada's leading palliative care experts
  - Taught by local paramedic experts and experienced palliative care practitioners
  - Nationally recognized certificate
  - Evidence-based and case-based

Learn more about the course and topics covered by visiting

https://www.pallium.ca/course/leap-paramedic/

Introductions

Facilitator:

Diana Vincze
Palliative Care ECHO Project Manager

Presenters:

Karen O'Brien
Frontline Paramedic since 1999, with a side of community paramedicine.
SWORBHP Associate Instructor
Pallium Facilitator

Dr. Jitin Sondhi, MD, CCFP (PC), FCFP
Regional Clinical Co-Lead, Palliative Care, OH West
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Panelists:

Lisa Weatherbee
BN RN CHPCN©
Provincial Palliative Care Practice Leader, NS
Pallium Master Facilitator/Coach

Kristina Anton, ACP
Paramedic Specialist, BC Emergency Health Services

Stuart Woolley
Paramedic since 2003 in UK & Canada, current Paramedic Practice Leader in BCEHS leading Palliative Care, Low Acuity Patient management & Paramedic Specialist support.

ECHO Support:

Aliya Mamdeen
Program Delivery Officer

Welcome and Reminders

- Please introduce yourself in the chat!
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function at any time to ask questions and add comments.
- Remember not to disclose any Personal Health Information (PHI) during the session.
- This session is being recorded and will be emailed to registrants within the next week.

Overview of Topics

Session #	Session title	Date/ Time
Session 1	Self-Care	November 14, 2023 from 12–1:00 p.m. ET
Session 2	Serious illness conversations	January 16, 2024 from 12–1:00 p.m. ET
Session 3	Alternate destination in paramedicine; redirection to institutions other than a hospital	March 12, 2024 from 12–1:00 p.m. ET
Session 4	Addressing management of neurodiverse populations receiving a palliative approach to care	May 14, 2024 from 12–1:00 p.m. ET
Session 5	Pain and Symptom Management	July 29, 2024 from 12–1 p.m. ET

Session Learning Objectives

- To reflect on current practice of serious illness conversation.
- Building on the Wish, Worry, Wonder (from LEAP Paramedic Course).
- To become familiar with the serious illness conversation framework.
- Pediatric serious illness conversation case study.

Conversation Starters in Palliative Approach to Care

For health-care providers

Before having a serious illness conversation educate yourself on the patient's illness, possible trajectory, and likely prognosis.

Learn to manage emotions with empathy

Expect conversations to be emotional. Avoid pushing medical facts or information on emotions or resistance, and meet emotions by articulating empathy.

3 Ws (I wish– I worry–I wonder):

I wish *that this was not the case.* ***I worry*** *your health is going to change quickly and* ***wonder*** *about preparing for that possibility.*

I wish *that treatment worked. Or* ***I wish*** *you were not in this situation.*

I worry *that this may be as strong as you will feel, and things might get worse, and that time may be as short as __ (weeks/days).*

I wonder *if we can discuss how best we can meet your needs now.*

NURSE:

Naming emotion: *It sounds like you are ___.*

Understanding: *Thanks for sharing. It helps me understand what you are thinking/feeling more.*

Respecting: *I can see you are following our recommendations.*

Support: *I will do everything I can to ensure you get what you need.*

Exploring: *Could you tell me more about what you mean when you said ____.*

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Initiate dialogue

Ask for the patient's permission, identify who else they would like to include, and when and where would make them most comfortable.

In my experience, most patients want me to discuss what might happen in the future with their illness. Others are not interested. Would this be a good time to discuss your illness? (When would be a good time to discuss your illness?)

Explore understanding of the illness

Use open-ended questions. There may be silence as the patient thinks, give them time and remain quiet until they respond.

How much information about your health would you like from me?
What do you think about what's happening with your health right now?

Then, reflect back on what the patient tells you to ensure you understand their perspective.

Serious Illness Conversations

Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish...worry", "hope...worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness..." *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ____ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*." OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ____. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

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Other considerations

- Document with summary SIC,
- Patients understanding (teach back technique)
- Plan- Recommendations -Write out for patient
- Encourage frequent interactions with care team
- Normalize serious conversations, have more frequently if there is a change in condition-
- Any treatment or care-Clearly understood and written
- Sit quietly, and allow time for news to sink in
- Allow time for patient to ask questions
- Be aware of tone, body language
- Give hope that there is always something that can be done–ex pain management, to social support
- Normalize and validate emotions: numb, angry, sad, frustration

Case

- You are called code 4 to residence for alerted level of consciousness
- When you arrive, you are met with family members outside, stating the patient is weak and lethargic.
- You are presented with a 54-year-old female, with brain cancer with mets to bones. She is conscious and lethargic her locx2.

- Her vitals are the following 02 sat 93%, HR 108, temperature 37.2, and BP 108/72

- Would you do anything different if this was a pediatric patient?

Case Based Discussion

Canuck Place CHILDREN'S HOSPICE | Serious Illness Conversation Guide —PEDS

1. Set up the Conversation • Introduce the idea and benefits • Prepare for future decisions • Ask permission	"With your permission I'm hoping we can talk about where things are with your child's [insert child's name] illness and where things might be going —is that ok?" OR "Talking today will help us get to know you and your child better and help us prepare and plan for the future. Is this okay?"
2. Assess Illness Understanding and Information Preferences of Parent	"What is your understanding now of where your child is at with his/her illness?" "How much information about what is likely to be ahead with your child's illness would you like from me?"
3. Share Prognosis • Frame as "I wish …worry, and/or I hope …wonder …" statement • Allow silence, explore emotion Clinicians have a responsibility to provide parents with ongoing support and guidance as symptoms of dying become present.	"My understanding of where things may be at with your child's illness is …" **Uncertainty:** "It can be difficult to predict what will happen and when. I hope he or she will continue to live well for a long time, but I worry given what we know (Insert information about illness/condition) …he or she could get sick quickly …" **Function:** "I see the following (fragility, instability, assessment of function) and I am worried that this represents …" **Time:** "It is very difficult to predict time. Like you, I also want your child to …But I am worried that time may be shorter than we hope." *If using time in prognosis, it MUST be paired with a statement of uncertainty and with function information.
4. Explore Key Topics • Goals • Fears and worries • Sources of strength Optional points to explore • Critical abilities/experiences • Trade-offs (balance of interventions) • Involvement of child and/or siblings	"What are your most important goals/hopes if your child's health worsens?" "What are your biggest fears and worries about the future with your child's health?" "What gives you strength as you think about the future with your child's illness?" "What abilities are so critical to your child's life that you can't imagine him/her living without them?" "If your child becomes sicker, how much medical intervention are you willing to go through for the possibility of gaining more time?" (see reverse) If involvement of child / sibling is appropriate / necessary, arrange for another meeting to explore (see reverse)
5. Closing the Conversation • Summarize • Make a recommendation • Check-in with parents • Plan follow-up	"I've heard you say (insert goals/hopes)…. is very important to your family and that you also worry about …" "Keeping this in mind and what we know about your child's illness, I recommend that … (e.g.; change the care plan, create ACP, watch and wait)." "How does this plan seem to you?" "We will schedule/check-in again in (time frame — days/weeks/month) to ensure ongoing support."

6. Document your Conversation
7. Provide Documents to Parents
8. Communicate with Key Clinicians

Canuck Place
CHILDREN'S HOSPICE

Assessing with Parents their Child(ren)'s Understanding/ Involvement

Questions to be considered if child (or sibling) is able to participate in the conversation:

- "What do you believe your child understands about his/her illness?"
- "How much information do you think your child is ready for? And from whom?"

Consider exploring the child's (and/or siblings) biggest:

HOPE "What goals or hopes do you think your child(ren) have?"

FEARS AND WORRIES "What worries or fears do(es) your child(ren) have?"

STRENGTH "What are your child(ren)'s strengths?"

CRITICAL ABILITIES/EXPERIENCES "Have you spoken with your child or other children about your priorities and wishes? Do you know what theirs are?"

If you are sharing or supporting the parents to share the prognosis with the child or siblings, consider stage of development, temperament, and available supports (e.g. parent, counsellor).

Reciprocal/Attuned Responses

NON-VERBAL

- Use of silence, pauses
- Physical space/body positioning

VERBAL

- Inquiry
- Advice (given when asked)
- Reflection (paraphrase words, meaning or circumstance)
- Responding safely to emotion
- Normalizing/acknowledging experience

Assessing Clinical Status to Help with Prognosis Wording

FRAGILITY: degree of risk of a significant deterioration

ROBUST — FRAGILE

INSTABILITY: rate of change in child's wellbeing

STABLE — UNSTABLE

CNS: seizures, increased ICP, hemorrhage

CVS: heart function, arrhythmia, hemodynamics

RESPIRATORY: central +/- pulmonary

GI: nutritional status, obstruction

IMMUNE SYSTEM: sepsis

SYMPTOM BURDEN: pain, nausea, feeding intolerance, dyspnea etc.

CARE NEED CHANGE: feeding, respiratory, transfusion support

FUNCTIONAL CHANGE: eating, ambulation, interaction/ engagement

DEVELOPMENTAL CHANGE: loss of or failing to meet milestones

Wish/Worry Framework

RATIONALE

- "I wish" allows for alignment with the parent's & child's hopes.
- "I worry" allows for being truthful while sensitive.
- "I wonder" is a subtle way to make a recommendation.
- "I will" is a direct way of expressing your commitment to ongoing support and care.

Examples:

- "I wish we could slow down or stop your child's cancer/disease and I will continue to look for options that could work for him/ her."
- "But I worry that you, your child, and your family won't be prepared if things don't go as we hope."
- "I wonder if we can discuss a plan if symptoms continue to get worse."
- "I will continue to connect with you daily so we can ensure this plan is working."

Goals of Care

SUSTAIN LIVING — SUSTAIN LIVING + COMFORT CONSIDERATIONS — COMFORT-FOCUSED

Optional Questions to Explore

CRITICAL ABILITIES/EXPERIENCES

Explore if parents have indicated that they are weighing development and abilities in treatment decisions. Listen for subtle inquiries about what is 'ok' to do or not do.

With infants or critically ill children, ask about 'future' abilities and hopes and fears related to those.

With non-verbal children with disabilities, listen for the abilities the parent's value and explore potential losses of those.

TRADE-OFFS — BALANCE OF INTERVENTIONS

Examples of trade-offs are time in hospital vs time at home, increasing respiratory support (bipap, intubation), treatment for potentially reversible causes, or care planning directed at comfort treatments. Provide recommendations about what may or may not be of benefit instead of offering a 'choice' or a menu of options.

INVOLVEMENT OF CHILD/SIBLINGS

(See Assessing with Parents their Child(ren)'s Understanding/ Involvement)

Self-Awareness – Consider your Tendency to…

- Fix, placate or falsely reassure
- Overly identify
- Feel responsible (role or relationship)
- Be triggered by strong emotion
- Avoid difficult feelings or difficult comments from parents
- Be attached to own agenda

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Session Wrap-Up

- Please fill out our feedback survey! A link has been added to the chat.
- Join us for our next session about **Alternate destination in paramedicine; redirection to institutions other than a hospital** on **March 12th, 2024 from 12-1pm ET.**

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