

Essential Skills for Palliative Care Series

Communication: Engaging Children and Families in Serious Illness Conversations

Presenters:

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Rachel Neufeld MN, Nurse Practitioner, Canuck Place Children's Hospice

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Host and Moderator: Jennifer Campagnolo, CHCA

Date: June 14, 2023



Canadian
Home Care
Association

Land Acknowledgement



We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK

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A curriculum guide for educators and reference manual for disciplines providing palliative care.

CANADIAN PARTNERSHIP AGAINST CANCER
PARTENARIAT CANADIEN CONTRE LE CANCER

Health Canada Santé Canada

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK

A curriculum guide for educators and reference manual for disciplines providing palliative care.

What this framework seeks to achieve, and how to use it

This framework establishes a minimum national standard for palliative care in Canada.

It is written with several readers in mind:

- Individuals, managers and human resources personnel** will use it to fill skills gaps and guide hiring practices.
- Educators** will use it to identify minimum standards for palliative care competencies, weave the development of essential skills into existing curricula, or build new curricula to teach the competencies.
- National accreditation and regulatory agencies** will use it as a guide for establishing minimum national standards in palliative care.

Specifically, the disciplines with competencies in the framework:

- Nurses
- General Physicians
- Social Workers
- Personal Support Workers
- Volunteers

The framework includes:

a. Twelve domains of competency:

- Principles of a palliative approach to care
- Cultural safety and humility
- Communication
- Optimizing comfort and quality of life
- Care planning and collaborative practice
- Last days and hours
- Loss, grief, and bereavement
- Self-care
- Professional and ethical practice
- Education, evaluation, quality improvement, research
- Advocacy
- Virtual care

b. Discipline-specific skills self-assessments:

- provide the health care practitioner with a snapshot of their own competencies;
- provide managers with tools to gauge the levels of palliative care competencies within a team;
- can guide professionals and managers as they customize continuing education plans.

c. Education resources

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Transforming Home-Based Palliative Care: The SPRINT-Implementation Collaborative

Project Overview:

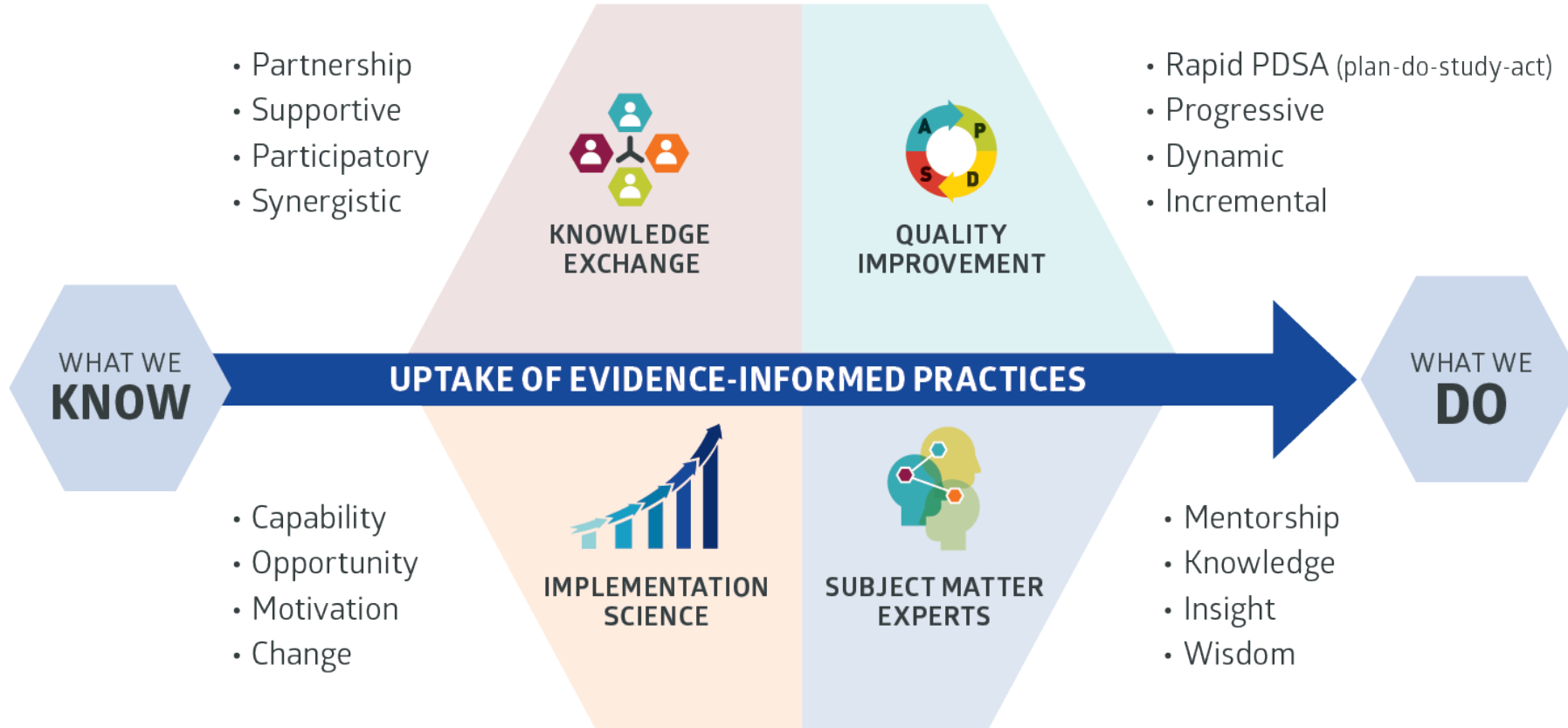
- SPRINT Implementation Collaborative launched May 23 (Call for Interest closed June 30)
- 12 teams across the country to participate beginning in September 2023

New Resources for Implementation:

1. Canadian Interdisciplinary Palliative Care Competency Framework
2. Leading-edge training courses in Emotional Intelligence
3. Dynamic communication guides and tools to empower caregivers and patients

Organizational Impact:

- Improved nurse and personal support worker recruitment process for palliative care
- Creation of innovative continuous training programs and development of staff's emotional intelligence skills
- Streamlined performance management approaches enhancing patient care outcomes



This expression of interest is a formal application to participate in the Canadian Home Care Association's SPRINT Collaborative.

The deadline for submission is June 30, 2023, at 5:00 pm EST

Notification of results will be communicated to applicants by August 4, 2023.

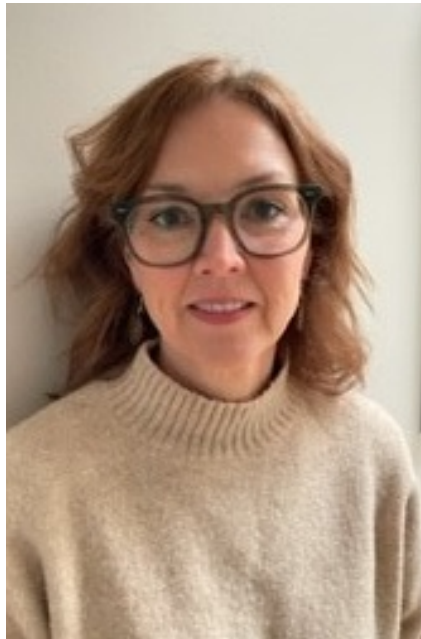
For more information on the SPRINT™ Implementation Collaborative,
visit our website:

<https://cdnhomecare.ca/sprint-collaborative/>

Contact information: Elizabeth Angelevski, eiCOMPASS Project Lead

eangelevski@cdnhomecare.ca

Introductions



Camara van Breemen MN,
Nurse Practitioner
Canuck Place Children's Hospice



Rachel Neufeld MN,
Nurse Practitioner
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Rachael Black RN, BSN,
Palliative Care Nurse Clinician
Maple Ridge Palliative Care Consult Team
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Communication

Engaging Children and Families in Serious Illness Conversations



Objectives

- Introduce a process to promote effective communication
- Discuss ways to support parents adaptation to their child's serious illness
- Describe strategies that are helpful in engaging with children
- Provide a case to illuminate serious illness conversations

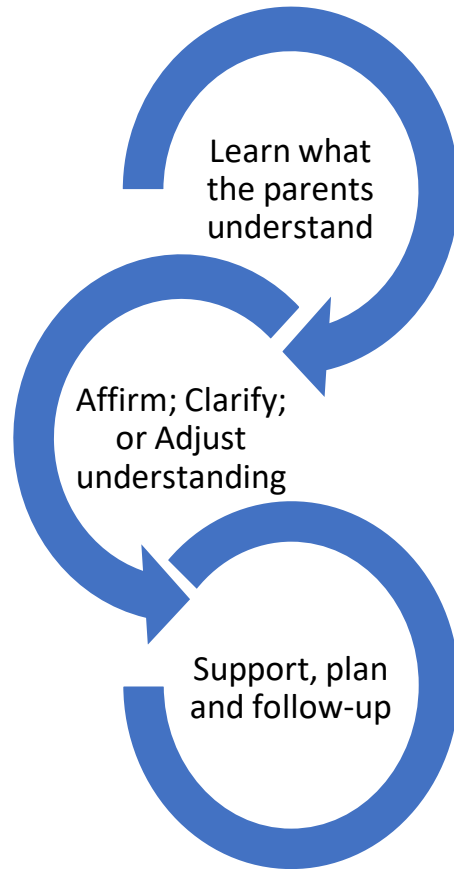


Communication with Parents Along the Trajectory – A palliative care Skill

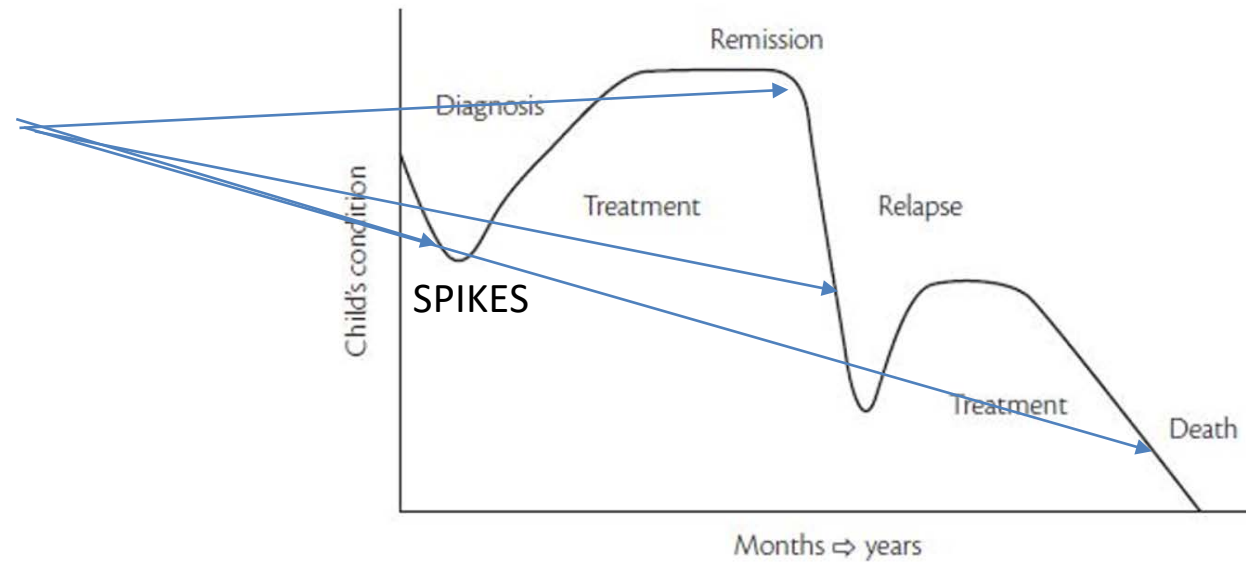
- Parents adaptation to their child's illness and dying and their ability to make loving decisions is **reliant on good communication from clinicians**
- Communication is a **two-way complex process** that requires the clinician to understand what the parents are thinking and to compassionately and **SKILLFULLY** provide information about what is happening and what is going to happen.



Not one conversation... but many



Illness Trajectory: Potentially Curable Pediatric Cancer



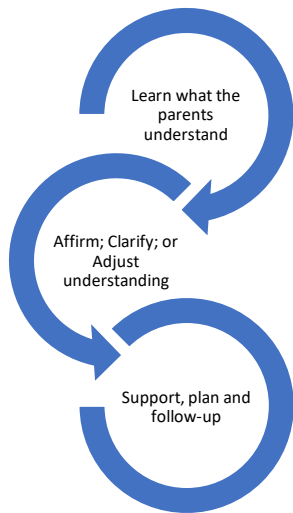
Oxford Textbook of Palliative Care for Children



Canuck Place
CHILDREN'S HOSPICE

Not one conversation... but many

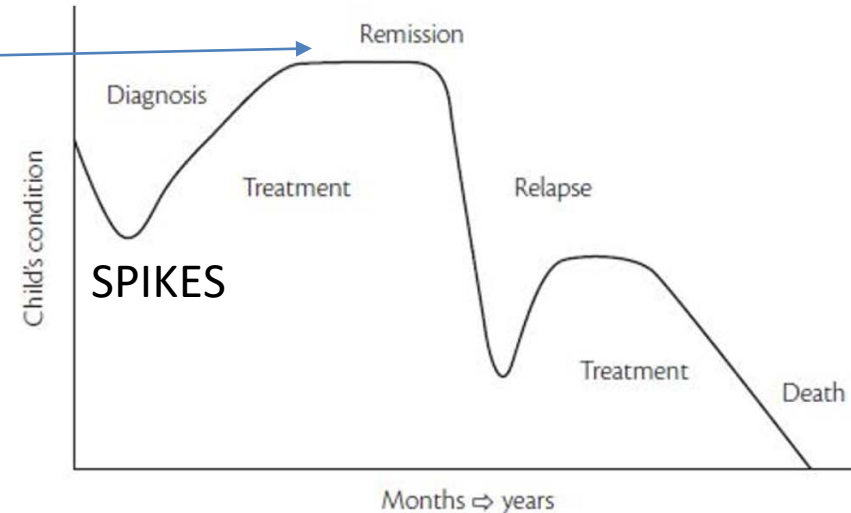
Illness Trajectory: Potentially Curable Pediatric Cancer



Our daughter is doing so well with the chemotherapy. The pain is gone and her energy is back

Yes, that is good news. Your oncology team also shared with us how well she is doing.

We will check in with you at her next oncology appointment but do call us if she has pain or other symptoms

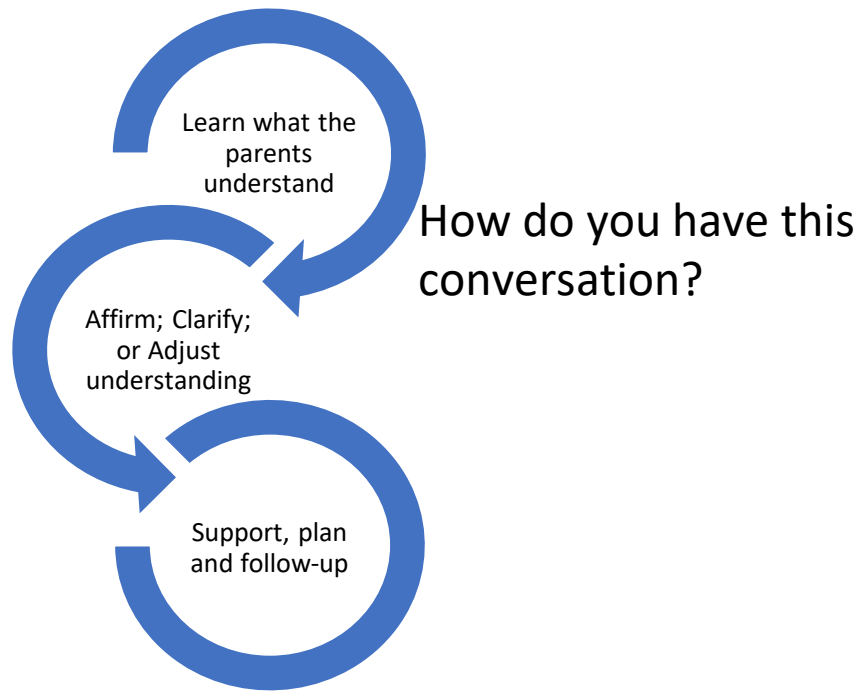


Oxford Textbook of Palliative Care for Children

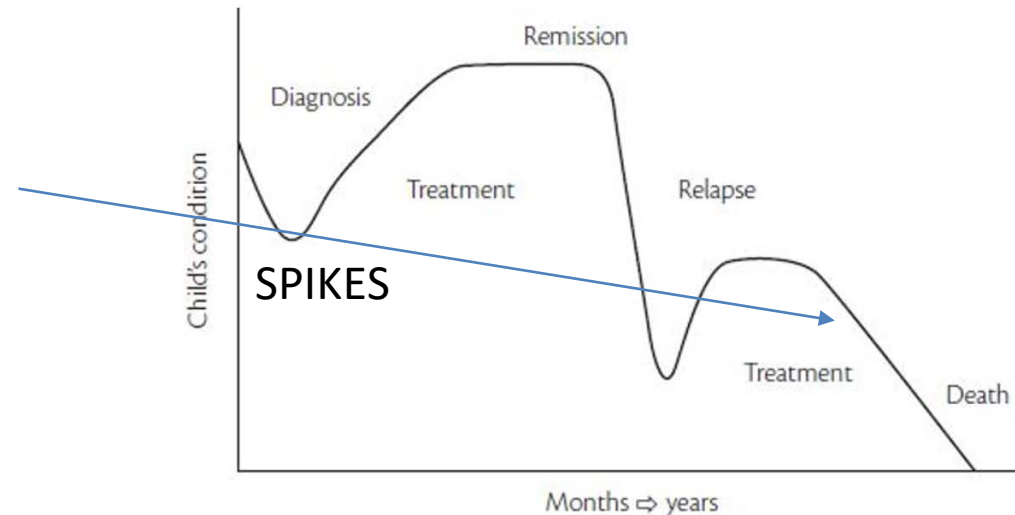


Canuck Place
CHILDREN'S HOSPICE

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Illness Trajectory: Potentially Curable Pediatric Cancer

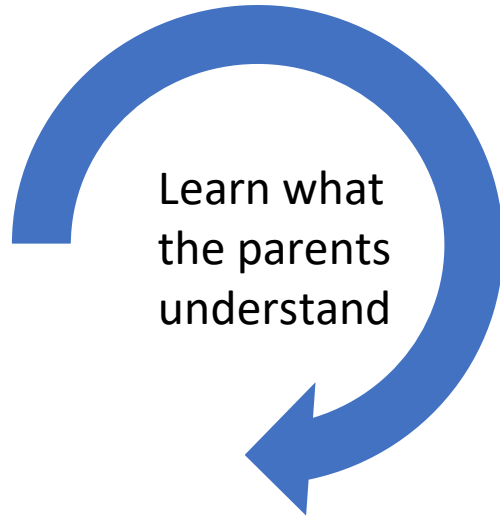


Oxford Textbook of Palliative Care for Children



Canuck Place
CHILDREN'S HOSPICE

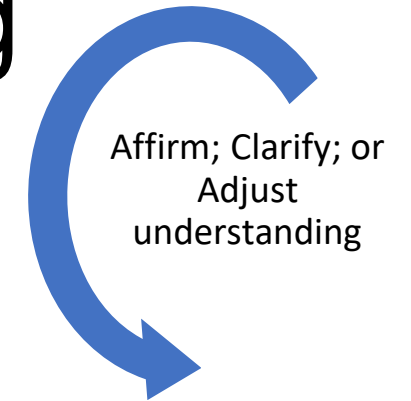
Listen before you Respond



- Tell me why you think she is having the pain, shortness or breath, not wanting to eat?
- Can you share with me what you think is happening with the cancer or with her condition?
- What have you understood from your specialist? What have they told you about what might be ahead?



Respond to the parents Understanding



Assess the parents understanding

- The parents have a good understanding
- If the parents have an emerging understanding
- If parents are over or underestimating the clinical picture

Clinician's response

- **Affirm** the parents understanding
- **Clarify - Acknowledge** what the parents know and **add** more details to support what is happening
- **Adjust** - Sensitively and skillfully provide **different** information

Wish Worry Wonder Will framework

- **“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 seek permission to share more or make a recommendation .
- **“I will”** ... is a direct way of expressing your commitment to ongoing support and care





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
 - 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**



Differences in the Pediatric Guide

- Questions aimed at the parents
- Rare and diverse conditions with more uncertainty in prognosis
- Can happen very early in the trajectory and even prenatally.
- Provides prompts for clinicians in seeking parents understanding of their child's knowledge of what is happening



Common Myths

- Young children do not need to know
- Children can adjust quickly
- Children are lucky as they are too young to understand
- Adults should avoid topics that cause a child to cry
- An active playing child does not have worries
- Children do not worry as much as adults
- Children are better off not knowing



Principles in Communicating with Children and Families

- **Understand** developmental concepts of death and dying (kidsgrief.ca), illness context, family structure, culture/background
- **Be curious:** Tell me what you know and understand? Tell me how you like to spend time?
- **Be courageous:** If you stay with children in their pain and sadness, they will trust you.
- **Support parents** – assist them to grow in their understanding of what dying children child may need
- **Self-reflection** - what are my own triggers, biases, and ability to play



Explore with children...

- Because children know when they are very sick and can sense the extraordinary stress of their parents and doctors when death is imminent, they may feel tremendous isolation if they are not given permission to talk openly about their illness and impending death.

Hilden JM et al. J Clin Onc 2000; 18(17): 3193-5



Canuck Place
CHILDREN'S HOSPICE

Assessing Child's Understanding

- What do you believe your child (or sibling) understands about what is happening to their body?
- How much information do you think your child is wanting and from whom?
- Be curious – tell me more about your worries in sharing information with your child or answering some of their questions
- Provide education / support about what benefits children
- Collaborate with child life / play therapists



Communication with Parents and Children

- CLUE

- C - Connect with the child / family
- L - Listen to what they have to say through engagement
- U - Understand together (not one-way)
- E - Explore what they need now and what they may need in future



How do you answer the question “Am I going to get better?”

- You could say:
 - Why do you ask? Tell me more.
 - That’s a big question.
 - I can tell that you have been thinking about this. What do you think is happening in your body?
 - When did you start wondering about that?
- Let child guide the conversation, so you answer their underlying question, concern, or fear.



Use Wish – Worry – Wonder framework to share your thoughts

- “I worry that your illness is very serious and even with all the medicines and all your hard work, you might get sicker”
- “I hope you feel good for a long time. I wonder what you think may happen if that isn’t the case?”
- “I wish we could get rid of this cancer and make everything in your body better. I am not sure we can so I want to make a plan with you and your parents to.....”



Summary...

- Seek to understand what the parents understand first – then respond
- See the child – consider what they are feeling, experiencing, and holding on to before asking questions
- Work with your team to establish who is the best person to share information and explore with the child what is going on in their mind
- Accept that some things just can't be 'made better' and be present
- Give family and child choices and control about how much information they want and from who



**Case study:
complex communication
For a young woman at home**



Kaylanna: April '03 – July '22

- first referred to us in March 2022, a 19 yr old young woman with metastatic cholangiocarcinoma , radiation induced secondary malignancy, involving hepatic ductal system, portal vein, SV, liver, bone, right ventricle, embryonal rhabdomyosarcoma of the common bile duct. Previous pediatric history of embryonal cell rhabdomyosarcoma (treated with radiation and chemotherapy, 2008).
- Canuck Place community care team reached out to family once she was home from hospital, to offer ongoing collaborative support with the adult oncology team for pain and symptom management. (pt and family still very focused on treatment and prolonging time)

Social history:

Kaylanna had a young baby of her own (born 2021), and was living with her mother and sister and mother's boyfriend. Her dad lived with his wife in Calgary.



Why did we get involved as pediatric palliative care team for this young lady who was already 19 yrs old?

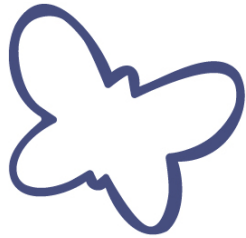
Pediatric palliative care is:

Role may be as

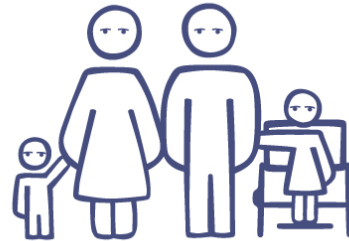
- Consultant
- Collaborative or
- Primary Provider

Location of contact may be

- In hospice
- In hospital
- In home
- Or virtual



Pain and symptom management



Family support



Care coordination



Complex communication



Management of health conditions

- **Communication**
and
- **Care coordination**



Collaboration with care team



Because Kaylanna was diagnosed at 19, her cancer care and treatment was done by the BC Cancer agency in the adult health care sector.

After we received the referral and spoke to her mom, we reached out to her medical care team at the adult cancer centre to build a collaborative working relationship.

Her team consisted of:

- Oncology team at BCCA Surrey
- Pain clinic at BCCA Surrey
- CPCH
- GP (not very involved in Kaylanna's care)

❖ The adult oncology and pain clinic were not used to collaborating with a program like our, including our community services.

❖ Referral to the local home care nursing team for additional home supports and navigation of the adult health care system.

Home care nursing team

- HCN & Home Health was designed to enhance, or add to Kaylanna's supports at home, in coordination with Canuck Place staff.
 - Atypical as uncommon to bridge pediatric/adult care in such a unique way
- Truly collaborative experience that was possible due to excellent communication between teams
- OT staff also offered skilled assessments and collaborated with teams to support her equipment needs funded thru Palliative Care Benefits here in BC.

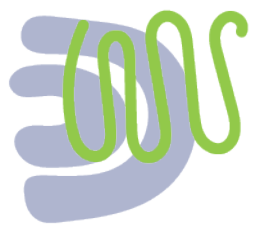
Complex Communication

- ❖ Kaylanna was 19 and in BC, considered an adult, capable of making autonomous decision about her health.

Sharing information or prognosis

Wish / Worry / Wonder / Will	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





Adult approach to SIC

Autonomous decision making



Kaylanna was admitted to a local hospital palliative unit for severe escalation of pain. During this admission, the adult palliative MDs consulted with ICU to determine they would not escalate to critical care level interventions (and thus no CPR) in light of her worsening disease.

The consultation is written as this was discussed with Kaylanna, her mother and her grandmother.



SIC: knowing who to talk to

- SIC & working with changing decision makers. Kaylanna had many roles that influenced this over time:
 - young adult competent to make her own decisions
 - young mother advocating for her own child's needs
 - at times was a scared teenager that deferred to conversations with her loved ones instead of herself as a way of coping
 - eventually a patient with end stage disease and fluctuating capacity.



Admission to hospice for PSM

When comfort could not be maintained at home

She was admitted to hospice for pain and symptom management when the pain escalated out of control at home.

This was partly due to the fact that we were needing to escalate pain management strategies that did not feel safe to do in context of both Kaylanna and her mom expressing the desire for ongoing treatments and interventions.

The other part of the decision was listening to Kaylanna: her recent blood cultures had come back positive, but she was declining admission to hospital despite worsening symptoms. She did agree to come to hospice for antibiotics and pain management.

We were even able to help her get to her graduation!





Family SIC

Balancing conversations between patient and her family



While Kaylanna was an autonomous adult, and was a mother herself, she was also cared for by her mother and other family/friends. As her condition worsened, her family/friends needed to take on more of the decision making

Kaylanna continued to present to hospital for sepsis picture, and would demand to go home quicker than medical recommendations

Documentation of SIC and FTMs



Family Team Meeting Summary

Meeting date: 09 July '22

Attendees: I (mom), Rachel (NP), Rebecca (RN)

Summary of discussion: Kaylana was admitted to Ridge Meadows Hospital again last night because of inability to find a peripheral IV again. She was given a R subclavian double lumen central line. Consult was provided in the ER by Rachel (NP), and Rebecca (RN) from CPCH. Kaylana was sleeping on the ER bed, mom sleeping in the chair at the bedside. Permission was obtained from [redacted] to have a discussion to explore her understanding and where things might be going for Kaylana. This was done outside of the room at [redacted]'s request.

Current Understanding of Illness:

[redacted] expressed understanding that Kaylana's infection was getting worse despite all the treatments. She stated that the doctor had told them Kaylana only had maybe a couple of weeks to live.

Amount of Information Desired:

[redacted] was unable to answer this question. We offered that we can stop the conversation at any point if [redacted] no longer wants to talk about it. She agreed to this.

Medical Team Understanding of Illness/Prognosis:

[redacted] gave permission for use to share some of our perspective. We expressed worries that Kaylana is showing worsening infection despite all the best efforts at treating it. We also know that in May, the imaging showed worsening cancer disease burden. We expressed worry that while it is difficult to predict, we are worried that Kaylana's time is indeed short. We talked about shifting our perspective to focus on her comfort and maybe some of the things that are most important to her and to the family now.

Exploration of Key Topics:

Goals if Health Worsens: [redacted] wasn't sure how to answer this question. We offered previous perspective that Kaylana has expressed a desire to go to the beach with [redacted]. We talked about having the CPCH team help to see if we can do that for her.

Fears and worries: [redacted] expressed the difficulty managing her care, and having lots of other people in the house, navigating it all. She did not have a particular worry that she was able to voice. However, we discussed that if Kaylana was at CPCH, our team could help with all of her care, and allow them to focus on being a family. [redacted] confirmed she was struggling with her care.

Sources of Strength and critical experiences: While not discussed specifically, [redacted] shared that she has her mother, sister, friends that are helping. She is struggling with her partner [redacted] in their relationship which is adding to her stress. She also shared that

Summary of discussion:

Physical

Kaylana has been developing more episodes of increased sleepiness and fewer periods of wakefulness over the weekend. We had prior discussions with parents who were wondering if it was due to the medications versus the progression of the disease. We explained that at it was most likely due to the disease; however, for that reason, we rotated opioids from Hydromorphone infusion to Sufentanil. The aim was to have a faster relief in PRN boluses to avoid developing pain crises. In addition, the PRN dose would wear off faster, which would not cause more sleepiness. A few hours before rotating to Sufentanil, Kaylana became more alert and enjoyed a more wakeful time with her family, which further confirms that the disease's progression is the leading cause of her reduced alertness. We further discussed balancing medical management with Kaylana's needs and priorities. Family members have described that when Kaylana is asleep or unresponsive, they recognize that she can hear them and that pain could be identified from her facial grimacing and hand gestures. We concurred with these observations and encouraged them to use them when Kaylana was less responsive.

Emotional

Kaylana enjoys her wakeful time and likes to spend it with [redacted] (daughter) and her family outside her room. Much of her energy is spent going to the washroom, most of the time in Urgency. To conserve her energy for activity, we offered Kaylana the option of indwelling Foley's catheter yesterday. However, she declined and would like to use the washroom. We respected her wishes and explained that the Foley's is an option she can ask for whenever she thinks it would be appropriate.

Furthermore, [redacted] explained that to be weary, Kaylana listens when she is not alert and does not feel comfortable being close to her face. Therefore, if it needs to be, we should take her permission or warn her that we are getting close to her face to reduce discomfort.

Social

Kaylana is enjoying the many members of her loving family and friends that visit or stay at Canuck. Parents are good at organizing the crowds not to drain Kaylana's energy or overwhelm Canuck place capacity. [redacted] has assisted the family to complete the "compassionate care benefit" forms.

Trajectory:

Parents understand the poor prognosis of Kaylana's disease and that her time is short. Therefore, their priorities are for comfort care that is mainly reasonable pain control and to have a good quality of life when she is alert.

Goals

End-of-Life Care

A focus on living while dying.

Kaylanna was admitted to hospice for the last time after SIC with mom. Mom heard our worries of time being short, and chose to spend that time making memories together as a family



Thank You!
Questions?
Thoughts?



Canuck Place
CHILDREN'S HOSPICE

Questions & Discussion



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Contact information: Elizabeth Angelevski, eiCOMPASS Project Lead

eangelevski@cdnhomecare.ca

CHCA ECHO Hub

<https://cdnhomecare.ca/palliative-care-echo-hub/>

Upcoming Fall/Winter topics:

- Domain 1: Principles of a palliative approach to care
- Domain 5: Care planning and collaborative practice
- Domain 6: Last days and hours

*Thank
you!*

For taking a few moments to
complete the feedback survey

ECHO SESSIONS FOR 2023-24

Essential Skills for Palliative Care

Do you have the core competencies to provide high quality home-based palliative care?

The Canadian Interdisciplinary Palliative Care Competency Framework establishes a minimum national standard for palliative care in Canada and provides a guideline for core competencies for nurses, personal support workers, social workers, doctors, and volunteers. For home-based palliative care providers, the Canadian Interdisciplinary Palliative Care Competency Framework offers a foundation for continuous education, skill-building, and practical application.

Essential Skills is the theme for the 2023-24 Home-Based Palliative Care ECHO sessions. The learning sessions and resources will address the priority competency domains in the Framework and share knowledge, experience, and expertise in specific palliative care domains.



Cultural safety and humility

**Creating Safe Spaces for
People with Life-Limiting Illness**

April 27, 2023 | 12:00 – 1:00pm EST



+ LEARN MORE



Self-care

**Caring for Yourself when
you Care for Others**

May 10, 2023 | 12:00 – 1:00pm EST



+ LEARN MORE



Communication

**Engaging with Families in
Conversations about Serious Illness**

June 14, 2023 | 12:00 – 1:00pm EST



+ LEARN MORE