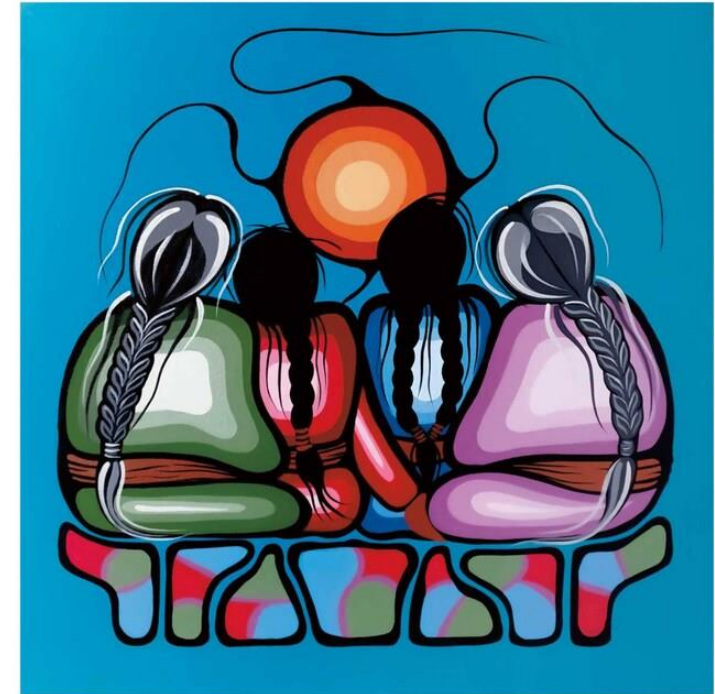


Essential Conversations: Talking to parents whose seriously ill adult child cannot 'speak' for themselves

- Camara van Breemen, MN, CHPCN
 - Nurse Practitioner (F)
- Canuck Place Children's Hospice

I acknowledge the land on which I live, work, and play is the unceded territory of the Coast Salish peoples, including the territories of the x^wməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), Stó:lō and Səlílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

- **I have no Disclosures**



Growth From Love By Simone Mcleod

Objectives

- Review the definition of serious illness and the zone of health that can guide advance care planning with seriously ill young adults
- Reflect on parental journey of caring for a child with complex needs and the transition of care into the adult service
- Discuss issues of inclusion, competency, shared-decision making
- Discuss the serious illness conversation guide – pediatrics and application of this to this population.

How Do We Define “Serious Illness”

- Carries a high risk of death over the course of a year (or within childhood – pediatric palliative care)
- Has a strong negative impact on QOL and functioning in life roles
- Is highly burdensome to a person and his/her family



Categories of Life-Threatening / Life-Limiting Illness

<https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/categories-of-life-limiting-conditions/>

1. Life-threatening conditions for which curative treatment may be feasible but can fail

Examples: Cancer - relapsed, Cardia - post “palliative” surgeries including Glenns, Fontans, and potentially transplants (prognosis - 15-20 year timeline)



2. Conditions where premature death is inevitable

Examples: cystic fibrosis, duchenne muscular dystrophy.



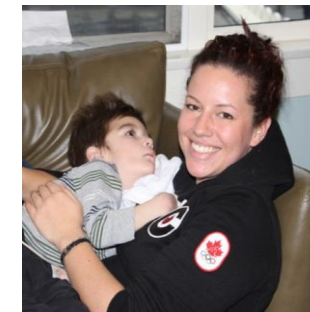
3. Progressive conditions without curative treatment options

Examples: single gene neurological and/or multi-organ conditions., e.g. SCN1A gene mutations (Dravet syndrome) will have life-long seizures.



4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and an increased likelihood of premature death.

Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.



Young Adults with medical complexity – considerations

- Parents are most often the decision-makers and may also be long-time, intensive caregivers (which has taken a toll)
- Parents describe the transition to adult care as being difficult due to a less coordinated or resourced system. “feel like we fell off the edge”
- There is minimal ability to transition from pediatric palliative care to adult palliative care because the referral criteria is much more narrow

Cliff or bridge: breaking up with the paediatric healthcare system

Jennifer Baumbusch, RN, PhD, FAAN, FCAN

Paediatrics & Child Health, 2023, XX, 1–3; <https://doi.org/10.1093/pch/pxad061>

Principles of health care decision-making in pediatrics

- ***Parents/Caregivers*** are responsible for the welfare of their children; to support and guide children, so they can understand, to their ability, and contribute to the decisions that involve their bodies, health, and care.
- ***Healthcare teams*** have the responsibility to seek the participation of children, by respecting to the extent possible, their developmental ability, and expressed preferences.
- ***Children*** have the right to be supported:
 - to understand (to the best of their ability) their condition and care
 - to know what to expect and anticipate
 - to share their preferences and participate in decisions related to their health
 - to be involved in important decisions in meaningful ways, even when they are not the primary decision-maker

Dylan - 20 year old with adrenoleukodystrophy



Important resources – Beyond this presentation

- The [Representation Agreement Fact](#) sheet breaks down capacity and decision making that can be helpful in determining what types of legal supports/agreements someone may need. It also references and links relevant legislation.
- This resource reviews Health Care Consent, including capacity:
https://www.nidus.ca/PDFs/Nidus_HealthCareConsent_YourRights-BC.pdf
- This resources reviews how health care decisions are made, including if someone is incapable:
http://www.nidus.ca/PDFs/Nidus_HowHealthDecisionsMade_ifAdultIncapable-BC.pdf

Decision-making and Capacity – a place to start

- How does your family make decisions for Dylan's health care?
- Who provides Dylan his day to day care?
- What do you feel Dylan understands about his condition?
- How does Dylan communicate with you about the things he likes or doesn't like?
- Does Dylan prefer to be involved in the meetings about his care or does that bore or distress him?

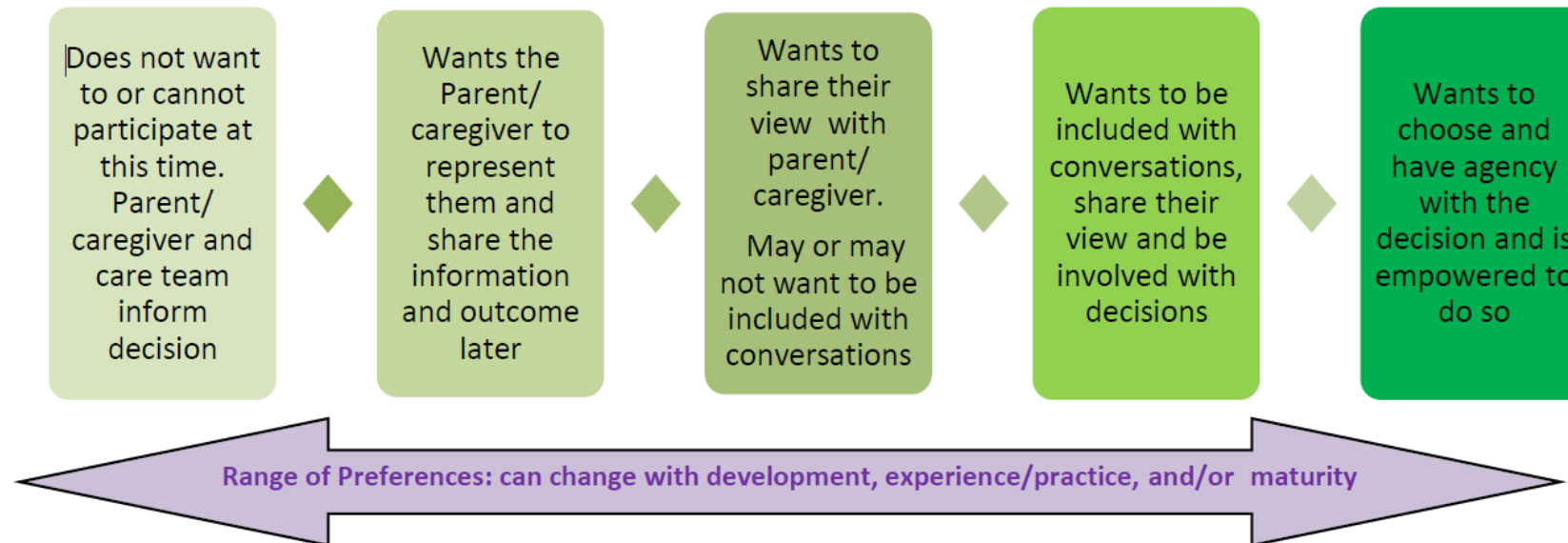
How involved can the (adult) child be?

Clarify control of preferences

Once permission has been communicated, children need control of how involved they wish to be with exploring decisions.²⁰ Be clear as to the choice of preferences children have.

Children need to know:

- the decisions they can have control over
- the decisions that will include their view as much as possible
- if there are situations that others will need to make the decisions for them²¹



Early conversations about GOC benefit patients and families

Are associated with:

- Enhanced goal-concordant care
- Time to make informed decisions & fulfill personal goals
- Improved quality of life
- Higher patient satisfaction
- Better patient and family coping
- Eased burden of decision-making for families
- More and earlier hospice care
- Fewer hospitalizations
- Improved bereavement outcomes

Aggressive care for Patients with advanced illness is often harmful...

For patients:

- Lower quality of life
- Greater physical and psychological distress

Wright, AA JAMA 2008; Mack JCO 2010

For caregivers:

- More major depression
- Lower satisfaction

Wright, AA JAMA 2008; Teno JM JAMA 2004



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



Serious Illness Conversation Guide – medically complex young adults

- Ensure the right decision-makers and the caregivers are involved. Include adult child as they wish to be included
- Book more time to review the parents understanding – allowing them to share their story of the ups and downs and the interventions thus far can be very therapeutic for the family AND help the clinician to really hone in on the approach to sharing information
- Use wish, worry, wonder AND **hoping for the best / planning for the rest** as prognostication is often even more difficult to provide given the rare conditions and the medical / technologic care inputs (eg: bipap, use of duflazicort, gene therapies)

Helpful hints...Critical Experiences

- Instead of 'critical abilities' the question should be framed as 'critical or essential experiences'
- What are some of the things (experiences) he really enjoys now that you can not imagine him living with out?
- What would be 3 wishes you have for Dylan? What do you think Dylan's are?

Helpful hints....Trade-offs

- If your child had a set back, what are some things you think may be worth trialing to see if he gets better? What are some things that you feel would not be of benefit or may do harm?
- Be prepared to face resistance about trade-off perspectives (many of the children will have had multiple ICU visits that ‘worked’)
- Consider ‘end points to medical or treatment trials’ as a way to bridge and keep connection.
- “Sounds like going back to ICU for non-invasive ventilation is the care you want. If Dylan does not show recovery after X time, it would be important for us to talk again about things you feel are benefit and things that might not be”

Breakout groups

- Have you worked with complex young adults in the past? Share some of your experiences (challenges or rewards)
- What are some things you could try and integrate into your practice if you were meeting with a family who had a young adult with medical complexity and limitations in decision-making / communication?

Questions

- <https://www.ariadnelabs.org/communication-gaps/>
- <https://bc-cpc.ca/all-resources/hcp-resources/serious-illness-conversations/>
- cvanbreemen@canuckplace.org

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.

Stay connected: www.echopalliative.com

Thank You

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada.

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