



THE UNIVERSITY OF BRITISH COLUMBIA

Shared Decision Making and Advance Care Planning: Child and Caregiver's Voice at the Centre

Esther Lee, MD, FRCPC,
Pediatrician, BCCH Complex Care Program;
Canuck Place Children's Hospice (Palliative Medicine program)

Kim Bhatnagar, RN
Parent Partner, Person with Lived Experience



Canuck Place
CHILDREN'S HOSPICE

Developmental and Epileptic Encephalopathies - Parent & Caregiver Education Day
March 28, 2026



LAND ACKNOWLEDGEMENT

LAND OF THE COAST SALISH PEOPLES—
SK̓W̓X̓W̓Ú7MESH (SQUAMISH), STÓ:LŌ AND
SƏ́LÍLWƏTƏʔ/SELILWITULH (TSLEIL-WAUTUTH)
AND XʷMƏΘKʷƏÝƏM (MUSQUEAM) NATIONS
(VANCOUVER)





- **Disclosure and Bias Mitigation**
 - In the creation of these materials, we have to the best of our abilities, used inclusive language, pronouns, photos and images.
 - We also used the [Upstate Bias Checklist](#) to decrease bias
 - Despite our best efforts and intentions, if there is any concerning content, please contact the conference organizer and let us know.



Objectives

1. To recognize that healthcare decisions are best made through a collaborative partnership between patients, families, and healthcare professionals.
2. To understand that children and families experience a healthcare journey over time, during which their perspectives, priorities, and goals may evolve.
3. To learn about various resources that are available for caregivers supporting children with health complexity / serious illness

These slides will be put on Esther's lab webpage -
<https://www.bcchr.ca/EstherLeeLab>



Timeline

- 0-5 (5min) : Intro & background: children with serious illness
- 5-10 (5 min): Kim #1
- 10-15 (5 min): discussion between E and K
- 15-20 (5 min): Kim #2
- 20-30 (10 min): Discussion between E and K
- 30-35 (5 min): Resources and summary
- 35-45 (10 min): Questions

Be curious.

Some topics may be hard to hear.... You may need time to reflect after

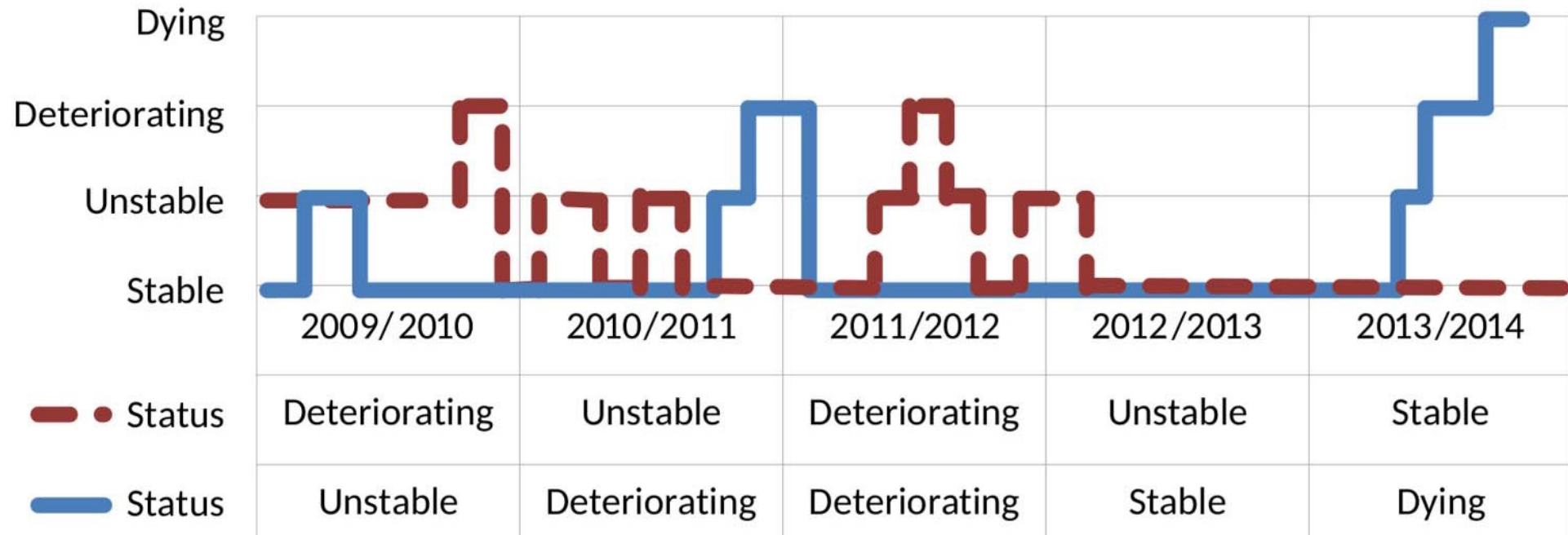


Journey for children with serious illness





Trajectory



Jarvis, *Arch Dis Child*, 2017.



NeuroJourney by Courageous Parent Network

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English ✓

 العربية

 Français

 Português

 Español

Accompanying you on your Journey

This tool will help orient and support you as you navigate the ever-evolving needs of your child and the complex decisions that lie ahead. Here you will find both practical and medical information, and insights from parents and clinicians about the social and emotional experiences common to having a child with Severe Neurological Impairment (SNI).

Arc of a Life

NeuroJourney uses four phases of a full life to help you understand the challenges you might face, anticipate the conversations you may have, and prepare for the decisions you may need to make as you determine goals of care for your child.

Follow along as you learn to adapt to a diagnosis, begin to build core skills and establish a baseline, adjust to the illness progression, and navigate the medical and emotional considerations as your child's condition declines.

During your child's life, you may find yourself moving back and forth between phases, straddling two, or even skipping a phase. Ultimately, regardless of its length, your child's life will have a full arc enabled by much care and abiding love.



Seizures

Listen To This Section

A seizure occurs when a sudden electrical signal interferes with normal signals between nerve cells in the brain. Many, but not all, children with SNI will experience seizures. Common behaviors indicating a seizure include rhythmic jerking movements of the arms and legs, stiffening of the body, not responding for short periods of time to things that would normally get a response, staring, rapid eye-blinking and/or eye-rolling. Seizure activity may worsen or change in its presentation as your child ages and/or if impairment of the brain worsens. In some cases, medication can control seizures, but for many children with SNI seizure activity will continue even with medication.



Previous Topic

Next Topic

< Muscle Tone: Spasticity and Hypotonia Dysautonomia and Hypothermia >

Your Team:

Complex Care Clinician ▾

Epileptologist ▾

Neurologist ▾

Primary Physician ▾

Listen To This Section

Your child's **primary physician** or **complex care clinician** can assess for problems or conditions that worsen seizures. A **neurologist** and **epileptologist** can recommend medications and interventions to improve problems that can look similar to seizures.

What Your Child May Experience

Listen To This Section

Seizure Behaviors

Seizures present in many different ways, which can make it hard for caregivers to understand what to watch for. In general, seizures are events that are not interruptible by touching, moving or distracting the child, and happen the same way each time they occur. Common seizure behaviors include sudden stiffening or jerking of the limbs, the head bending forward



Listen To This Section

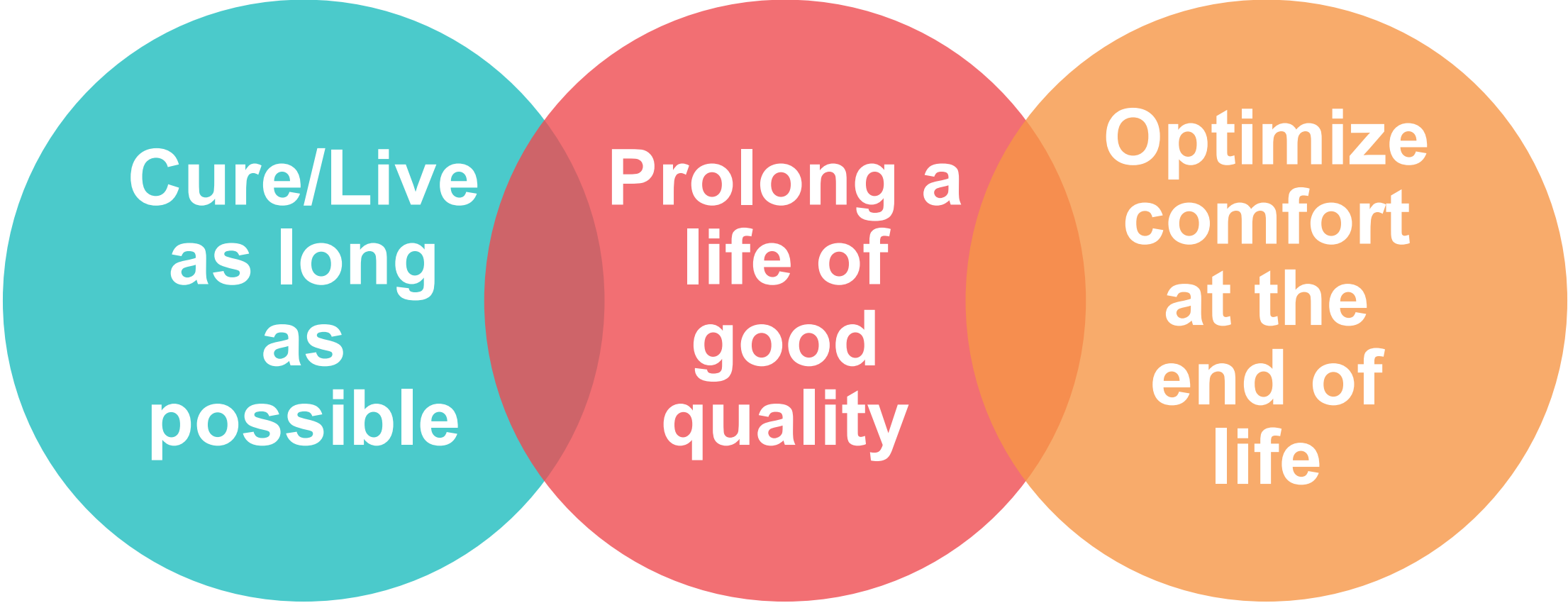
Convulsive seizures are stressful and difficult to watch, while some



Kim - Part 1



Kim - Part 2



**Cure/Live
as long
as
possible**

**Prolong a
life of
good
quality**

**Optimize
comfort
at the
end of
life**



Advance Care Planning and Goals of Care Discussion

- Advance care Planning: A **process** of reflection and communication to identify the values, wishes, and beliefs of patients' future health care plans
- Goals of Care: A plan for the future. Goals, objectives, wishes
- Advance Directive: Medical orders regarding life-saving, life-prolonging interventions. Intubation, dialysis, cardioversion, surgery, CPR
- Do Not Attempt Resuscitation: A specific order set regarding cardiopulmonary resuscitation



Serious Illness Conversation

- Focused on
 - What is the understanding of the patient/parents/caregivers
 - What are the goals/hopes, fears/worries, strengths
 - Optional:
 - What experiences give meaning to your child's life
 - Trade offs of risks vs benefit

This info helps to make decisions in the future by centering in the values of the patient/family



Serious

<p>1. Set up the Conversation</p> <ul style="list-style-type: none"> • Introduce the idea and benefits • Prepare for future decisions • Ask permission 	Set up	<p>"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?"</p> <p>OR</p> <p>"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?"</p> <p><small>*Denotes an infant, child, or teen</small></p>
<p>2. Assess Illness Understanding Assess Information Preferences</p>	Assess	<p>"What is your current understanding of where your child is at with his/her condition, diagnosis, or symptom?"</p> <p>"How much information about what is happening or what might be ahead would you like from me?"</p>
<p>3. Share Prognosis</p> <p>Provide your understanding based on the child's function, test results, body systems</p> <p>Frame as "I wish ... worry, and/or I hope ... wonder ..." statement</p> <p>Allow silence, explore emotion</p>	Share	<p>[Use one or two of the following categories to be explicit with the family about what may be ahead.]</p> <p>Function: "I see the following (fragility, instability, assessment of function) and I am worried that this represents ..."</p> <p>Uncertainty: "It can be difficult to predict what will happen and when. I hope he /she will continue to live well for a long time, but I worry given what we know (Insert information about illness/condition) ... he/she could get sick quickly ..."</p> <p>Time: "It is very difficult to predict time. I too hope your child will improve or do well for a long time... But I am worried that time might be shorter than we hope."</p>
<p>4. Explore Key Topics</p> <ul style="list-style-type: none"> • Goals • Fears and worries • Sources of strength <p>Optional points to explore</p> <ul style="list-style-type: none"> • Experiences/activities essential to life • Trade-offs of risk vs benefits (balance of interventions) 	Explore	<p>[Given this [prognosis] it will be helpful for me to ask you some more key questions...]</p> <p>"What are your most important goals/hopes if your child was to get sicker?"</p> <p>"What are your biggest fears or worries related to your child's health?"</p> <p>"What gives you and your family strength?"</p> <p>"What activities or experiences give meaning or are essential to your child's life?"</p> <p>"If your child was to have a setback, what interventions do you think may help or be of benefit?"</p> <p>"Are there interventions or treatments that you feel may cause burden or discomfort?"</p>
<p>5. Closing the Conversation</p> <ul style="list-style-type: none"> • Summarize • Make a recommendation • Check-in with parents • Plan follow-up and close 	Close	<p>"I've heard you say (insert summary of parents words)... is very important to your family and that you also worry about ..."</p> <p>"Keeping this in mind and what we know right now, I recommend. that we...(e.g. meet again, change the care plan, document goals of care, watch and wait)."</p> <p>"How does this plan seem to you?"</p> <p>"So next steps or follow-up will include "Thank you for meeting with me today"</p>



Resources

- Navigating Medical Complexity - [MedicalComplexity.org](https://www.MedicalComplexity.org)
 - Orienting and guiding caregivers to grow in agency and confidence. American.
- NeuroJourney - [NeuroJourney.org](https://www.NeuroJourney.org)
 - Information and support for families caring for a child with severe neurological impairment, in the phases they might experience along the journey. American
- Rare Disease Foundation:
 - Offers a network for families who are dealing with rare diseases. You can find *Living Without a Diagnosis* here. The foundation wrote this road map and navigation tool for parents and caregivers of children with health and/or learning concerns and a suspected genetic health condition or syndrome, but no set diagnosis. Canadian.



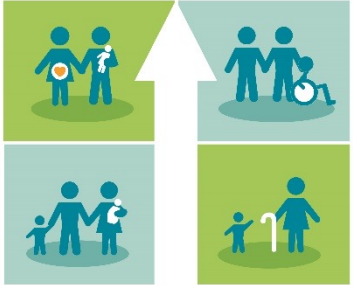
Resources

- Family Support Institute BC
 - A non-profit organization that supports families who have a family member with a disability. You can view [FSI webinars](#) developed in partnership with BC Children's Hospital
- BC Complex Kids Society
 - A non-profit organization for families and caregivers with children who are part of the At Home Program
- [Child Development & Rehabilitation InfoSource](#)
 - Development, rehabilitation and support information and resources for children and youth with neurodiversity and/or disability in British Columbia

Canuck Place



- Canuck Place Children's Hospice is BC & Yukon's pediatric palliative care provider.
- We support children and youth with **life-threatening and/or life-limiting illnesses** and their families.
- On average, a child is on the program for 7 years and their parents and siblings are in bereavement for an average of 3 years following the death of their child.



Through all stages of a child's illness: Designed to meet the needs of each family:

- Family Support & Respite Care (21 days a year)
- Pain & Symptom Management
- End-of-Life Care
- Nursing & Medical Care
- Counselling & Expressive Therapies
- Consultative Services – 24-hour/day
- Clinics (Hospital & Community)
- Community care (home visits, phone/virtual visits)
- Grief & Bereavement



Families can self-refer to our program (clinical or bereavement)

Canuck Place is:

where memories are made.

canuckplace.org



Canuck Place
CHILDREN'S HOSPICE

FEEDBACK (ANONYMOUS)

Feedback:

https://ubc.ca1.qualtrics.com/jfe/form/SV_1M2xGLk7wlRotWS



esther.lee@cw.bc.ca

Slides: <https://www.bcchr.ca/EstherLeeLab>





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