Pediatric Palliative Care in the Maritimes

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NBHPCA Conference
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Objectives

- Describe the scope and key components of the IWK Pediatric Palliative Care (PPC)/Pediatric Advanced Care Team (PACT) and compare and contrast it with Adult Palliative Care
- Understand the unique challenges in PPC care delivery for children and families
- Discuss a collaborative model of PPC for interdisciplinary teams, including pediatricians, adult palliative care providers, and community health teams, to support the unique needs of pediatric patients with serious illnesses
- Discuss advanced care planning in pediatrics and recognize youth’s capacity to understand and participate in decision-making, ensuring their voices are heard and respected
- Understand basics of communication with children and explore helpful resources for health providers and families

Pediatric Palliative Care in the Maritimes

IIWK PACT: Consultative team- nursing, physician, grief social work—under the IWK Division of Pediatric Palliative Medicine

Focused on quality of living: symptom management, communication/decision making, advanced care planning, end of life care and grief support

Delivered concurrently alongside active disease directed treatments

Collaboratively work with teams within IWK and externally in Maritime communities

IWK Pediatric Advanced Care Team (PACT)

1.0 FTE Physician (24/7 call-shared)

- Role shared between Dr. Stacie Colwell and Dr. Lauren Hanes
- 0.5 FTE PACT and 0.5 FTE Complex Care Program

1.0 FTE Clinical Nurse Specialist

- Shauna Wilcox

0.8 FTE Bereavement Coordinator
- Linden Hardie

0.5 FTE Administrative Assistant
- Katie Balsor

Bereavement Follow Up Program

Offered to all persons (primary patient or parent/caregiver) who experienced a death or loss

Consent collected at time of death/loss (can also opt in or opt out later)

Supportive contacts (phone, video, mail, in-person) at/around 1 mo, 3 mos, 6 mos, & 1 year post-death/loss

Majority provided by Bereavement Coordinator & Medical Social Workers

Supportive counselling, acknowledgement, validation, reframing, psychoeducation, resourcing, etc.

Documentation & tracking for quality improvement purposes

Consent reminders, seasonal & 1 year post-death mail-outs, physical library resources, online resource lists, etc.

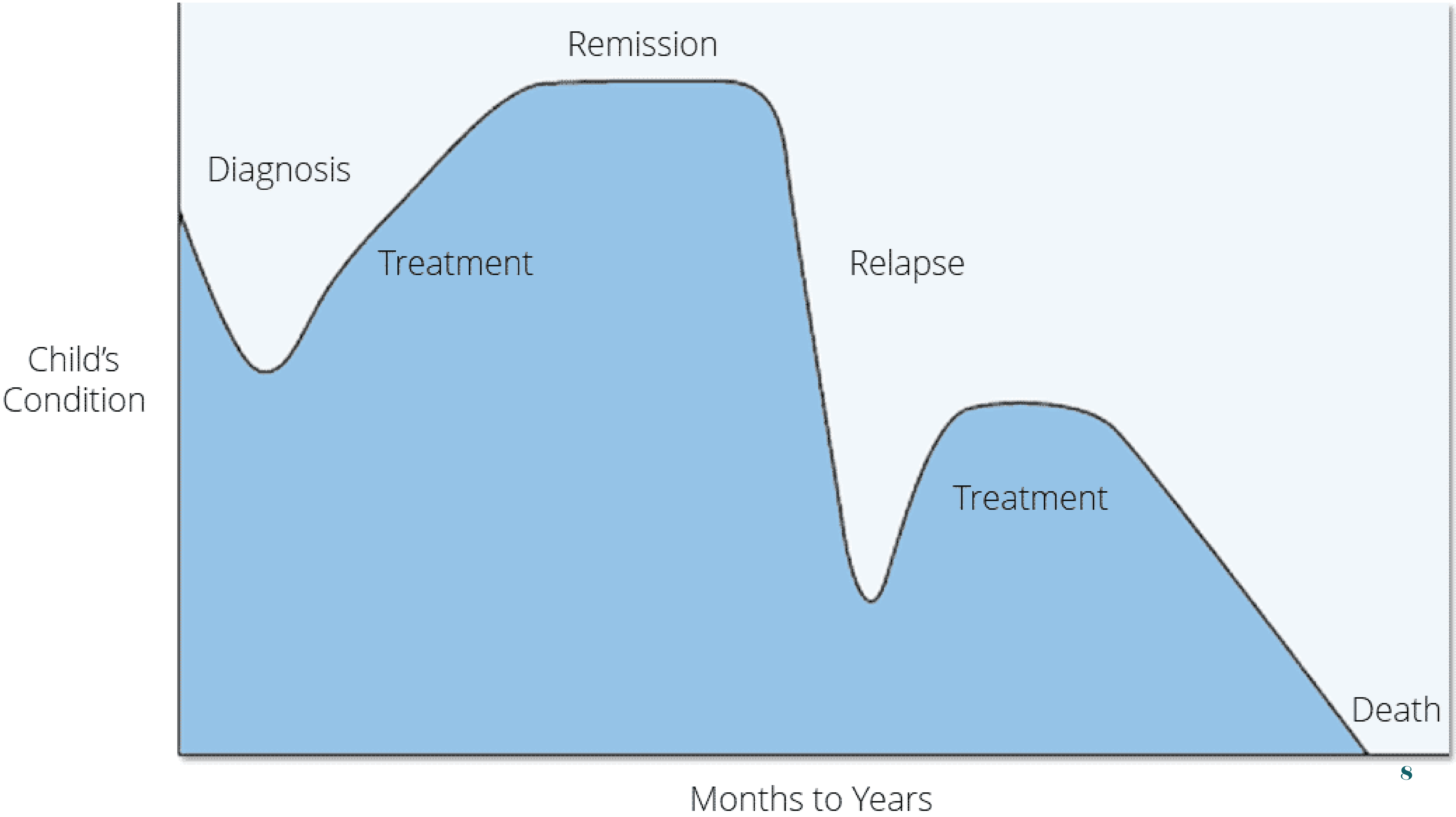
<u>Under Development:</u>

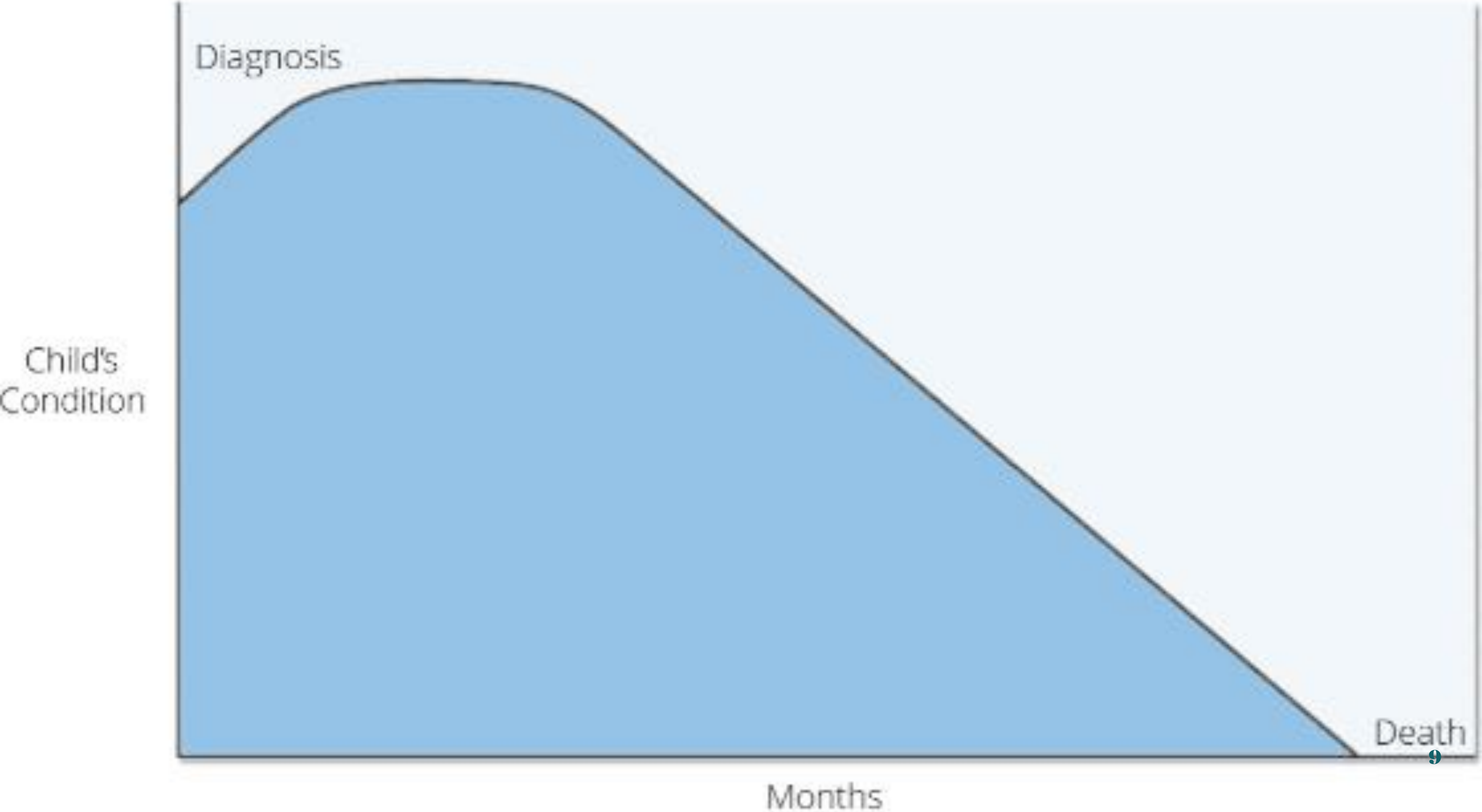
- Kids’ Virtual Grief Groups (potential Sept 2025 launch)
  - Concurrent parent/caregiver support
- Pregnancy & Infant Loss Support Group (potential partnership with PILSC for an ADT zone virtual group)
- Regular feedback opportunities for BFU recipients
- New additions to PACT library for distribution
- Public education sessions on children’s grief, child loss, and pregnancy/infant loss

Cases: Pediatric Palliative Care in Practice

Case Study: Geneva

- Geneva is a 1-month-old baby girl with large midline brain tumour
- Lives with biological mother and father, 4 yr old brother. Parents have strong family support father has struggled with substance use and mental health
- Presented to Waterville ED with high-pitched crying, difficulty feeding, vomiting, bulging fontanelle, downward gaze-
- Transferred to IWK for further investigations
- Met with Neurosurgery, Oncology for initial diagnosis
  - VP Shunt placed for hydrocephalus- improvement in comfort, able to eat, improved eye gaze
  - Treatment options discussed- surgery; chemo + surgery; supportive palliative care
  - PACT consulted for ongoing support


Remission
Diagnosis
Treatment
Relapse
Child's Condition
Treatment
Death
Months to Years


Diagnosis
Child's Condition
Death
Months

Case Study: Mateo

Background & Family Context

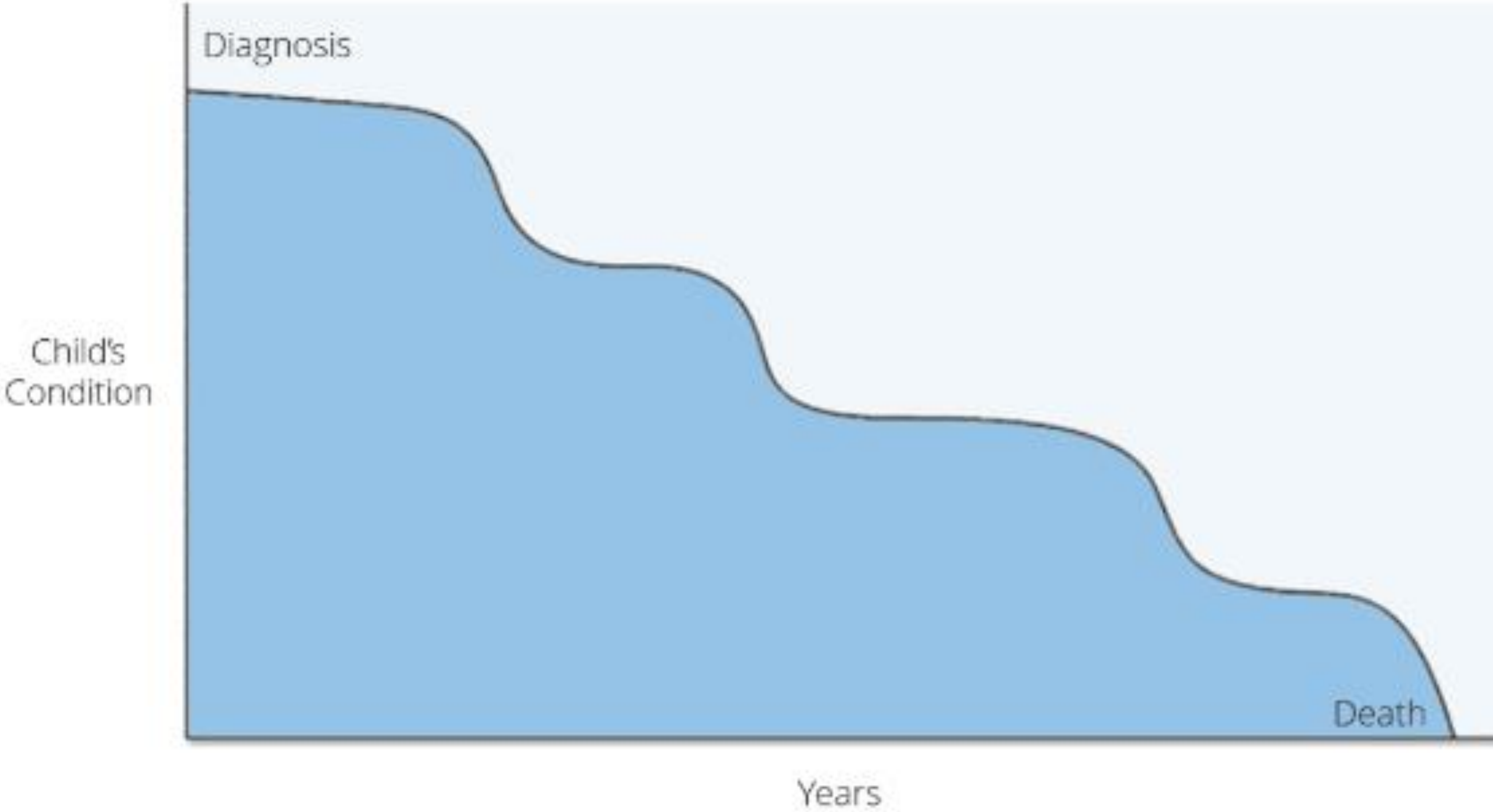
- Diagnosed at age 3 with Sanfilippo syndrome (MPS III)
- Family: Married parents (both working), 1 older brother (6 y), 1 younger sister (1 y)
- Mother became primary caregiver following diagnosis

Development & Early Concerns

- Initial milestones met: crawling, walking, speech
- Later regression: stumbling, difficulty walking, loss of speech
- Behavioral challenges: hyperactivity, compulsiveness, poor sleep
- Macrocephaly noted

Medical Journey in the Beginning

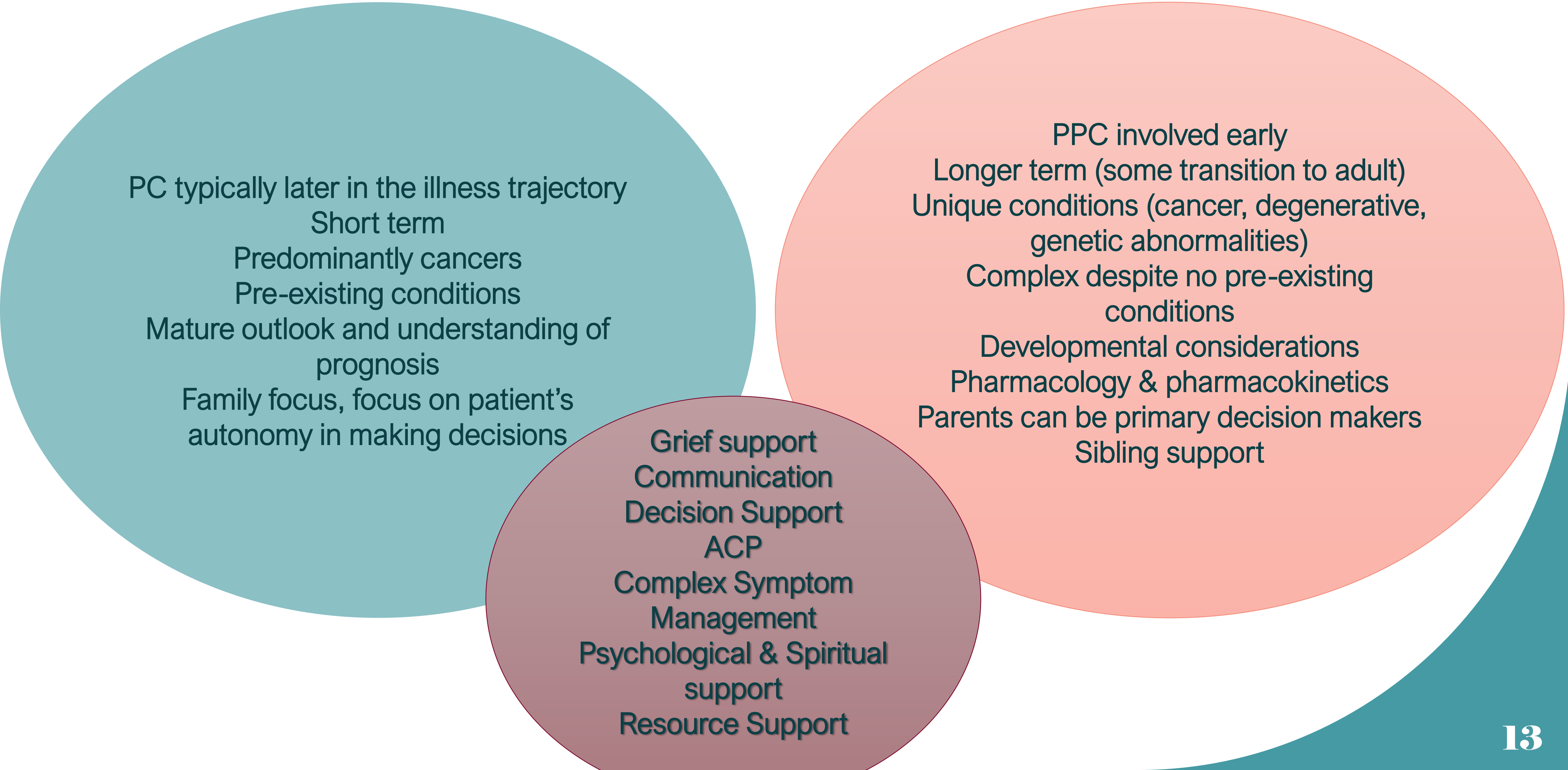
- Followed by community pediatrician for developmental concerns
- Referred to Maritime Genetics at IWK → diagnosis made
- Follow-up with Neurology post-diagnosis
- PACT involved within a year for support amid ongoing skill loss


Diagnosis
Child's Condition
Death
Years

PPC same approach as APC

IDENTIFY	Identify patients who can benefit from palliative care.
ASSESS	Assess their understanding of the illness, information needs, symptoms, psychological and spiritual needs, values, wishes, and preferences.
PLAN	Plan their care. This includes conducting Advanced Care Planning; establishing goals of care, care plans and treatment plans; linking to resources and other care providers; and preparing for emergencies.
MANAGE	Assess and support the management of physical, psychological, social, and spiritual concerns. This may require additional assistance depending on the severity of these symptoms.

Adult PC and Pediatric PC



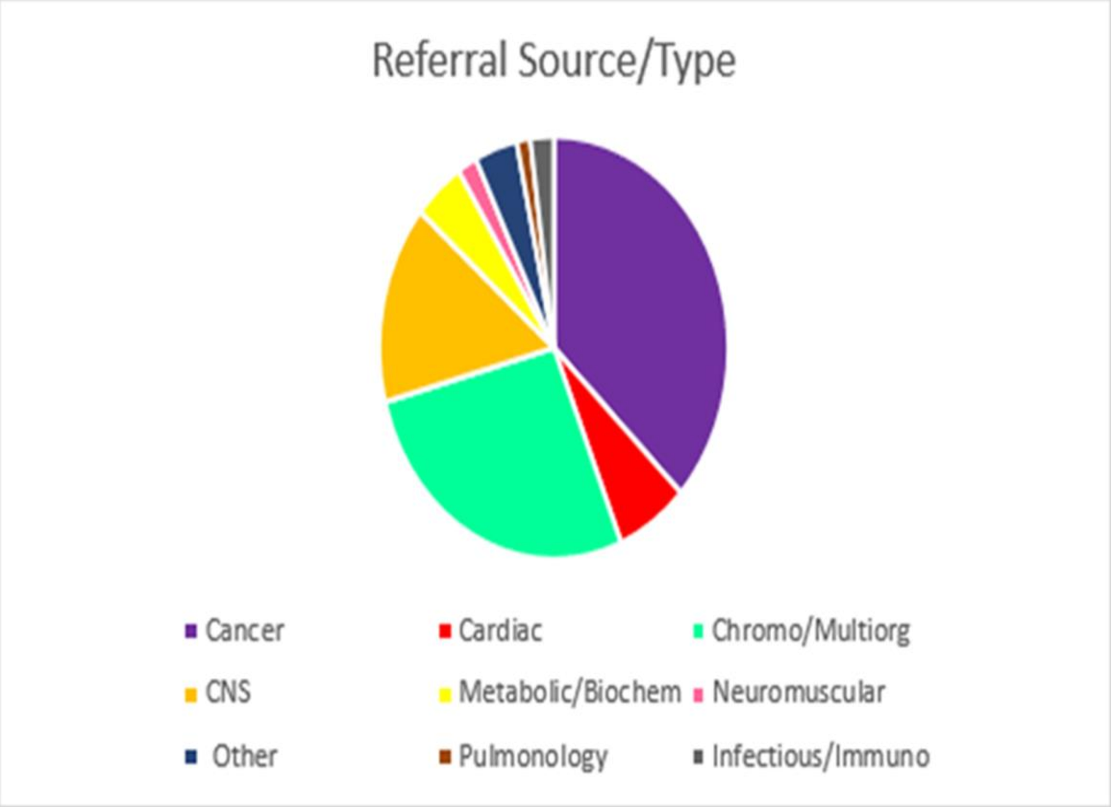
PC typically later in the illness trajectory
Short term
Predominantly cancers
Pre-existing conditions
Mature outlook and understanding of prognosis
Family focus, focus on patient’s autonomy in making decisions

PPC involved early
Longer term (some transition to adult)
Unique conditions (cancer, degenerative, genetic abnormalities)
Complex despite no pre-existing conditions
Developmental considerations
Pharmacology & pharmacokinetics
Parents can be primary decision makers
Sibling support

Grief support
Communication
Decision Support
ACP
Complex Symptom Management
Psychological & Spiritual support
Resource Support

Referral Trends- IWK PACT

- In 2023 review of our data showed we cared for 564 patients in 8-year span
- Average of 60 new referrals per year
- Fall of 2024, we were on trend for 3x the annual referrals we did back in 2015
- FTE of our team has decreased since 2014
- Large increase in education PPC education for IWK care teams, community teams, regional centers
- Children with neurological impairment and genetic conditions continue to make up the overwhelming majority of our patients- more children living longer with medical complexities



Challenges in the Maritimes in PPC

- LARGE GEOGRAPHICAL REGION- MANY RURAL AREAS; 3 PROVINCES (NS, NB, PE)
- UPWARD TRENDS IN # OF REFERRALS PER YEAR WITH NO CHANGE TO HUMAN RESOURCES
- MORE CHILDREN LIVING WITH COMPLEX MEDICAL CONDITIONS THAT BENEFIT FROM PPC
- RURAL AREAS, VARYING RESOURCES TO SUPPORT FAMILIES
- INFLUX OF REFERRALS FROM NB DUE TO LOSS OF PEDIATRICIANS WITH PPC TRAINING

From Rarity to Inequity: Need for National Coordination

Pediatric palliative care is “rare”…

- <1% of palliative care patients
- Low visibility in policy and planning
- Often not prioritized or resourced

Which leads to under-resourced systems:

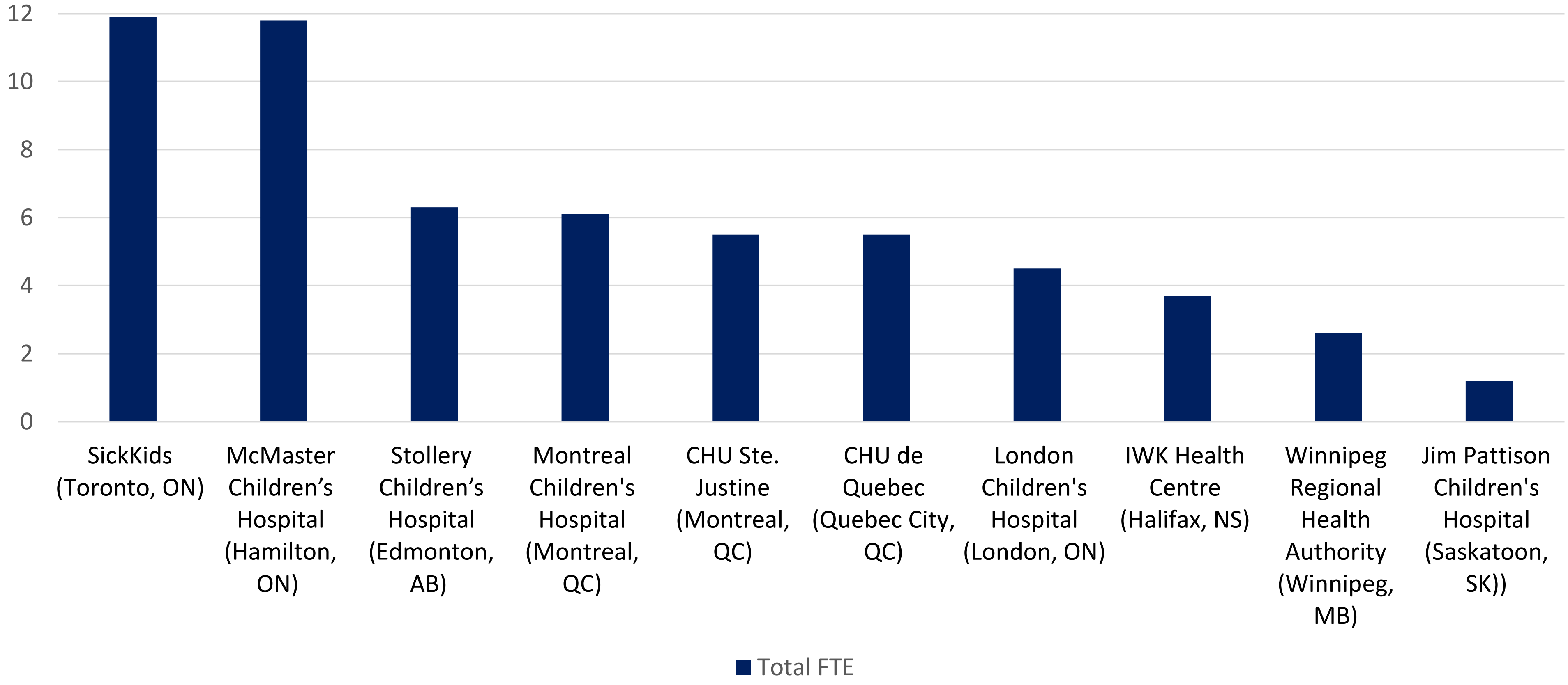
- No updated national standards
- Limited training and unclear roles
- Teams building tools in isolation

Resulting in fragmentation & inequity:

- Unequal access by geography and provider
- Greater barriers for equity-deserving families
- Families left to coordinate care alone

The average provider will only care for fewer than 5 children with palliative needs over their entire career

Findings from a Cursory Scan of Hospital Based PPC Teams (current as of Oct 31, 2024)



Bailey, L., Wright, M., & Goodman, K. (2025). *Mending the Gaps: A Systems Focused Rapid Review of Paediatric Palliative Care for Health Leaders*. *Healthcare Management Forum, 0*(0), 1–7. DOI: 10.1177/08404704251322481

Mending the Gaps: What the Evidence Tells Us

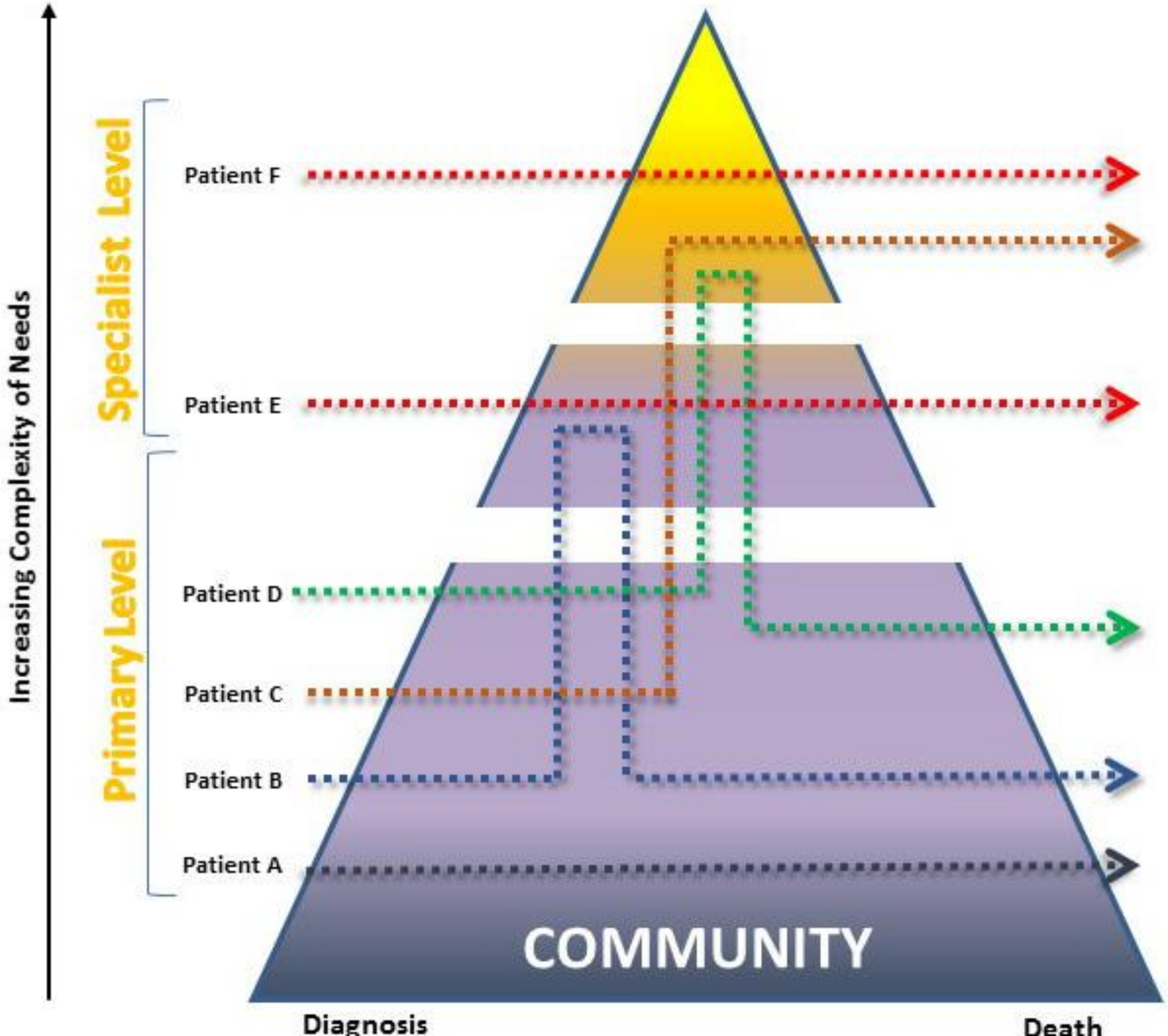
Challenges across the literature:

- Unclear roles and responsibilities between providers
- Shortage of specialized and generalist PPC expertise
- Fragmented systems and poor care coordination

Recommendations to strengthen PPC:

- Consistent education + national practice standards
- Better access: 24/7 supports, regional networks, care coordinators
- Increased awareness to shift PPC from "end-of-life only" to quality-of-life-focused care

Source: Bailey et al., 2025 – A Canadian systems-focused rapid review



- **A small number of patients with complex needs require transfer of care to specialist palliative care services**
- **Some patients may occasionally require assistance of a specialist palliative team (a consultation or shared care support)**
- **Most patients require only primary-level Palliative Care (Palliative Care Approach)**
  - Family medicine clinic
  - Oncology team
  - Internal med clinics
  - Cardiology clinics
  - COPD clinics

Challenges with PPC at Primary and Secondary Level

Family Medicine Clinicians-insufficient to gain or maintain expertise for safe patient care

Pediatrician Clinicians- infrequent PPC exposure to maintain comfort and expertise for PPC & EOL care

Palliative Care Clinicians (Adult)- competence in PC does not fully translate to PPC. Many regions PC teams not available in home; lack of hospice for children

Specialist Pediatric Clinicians- interdisciplinary PC, inpatient only

Collaborative Model of Care in Canada

National Collaborative Pediatric Palliative Care Model for equity and accessibility

Adaptable networks, collaborative communication enhances providers role in supporting child & family

Specialist PPC programs can support care delivery both directly and indirectly

Canada's Pediatric Palliative Care Alliance

Back to our Cases….Collaborative Ongoing Care

Geneva

IWK PACT:

- Met with parents early; acknowledged grief and family impact
- Provided sibling support and resources
- Used Serious Illness Conversation Guide (SICG) for values-based decision-making
- Supported parents with their decision to pursue a palliative approach and to identify their goals for Geneva
- Facilitated the family goals e.g. minimizing hospital time and returning home to Woodstock with their strong local support network
- Coordinated with NB providers (pediatrician, clinic RN, EMP, palliative care) for a smooth transition home with appropriate supports in place

Mateo (over the years)

- **Specialty care at IWK** 2–3 times/year; **acute admissions** in PICU or Moncton for seizures/respiratory issues
- **Seizures began at 5–6 yrs**; started on medication by neurology
- **G-tube** placed due to swallowing difficulties
- Regular **PACT follow-up at IWK** visits; goals of care revisited over time
- Focused on **selective interventions**: balance between treating reversible issues and maintaining quality of life
- **Moncton pediatrician** led community care; school, SCRC, and respite were key supports
- **School was central** to Mateo's joy and routine- supportive learning centre staff and school admin
- **Mother** expressed high stress managing travel, care, and family balance
- **Care team meetings** held between IWK and NB during critical events; shared care plan maintained

Collaborative Planning for Progressing disease/EOL

Geneva

- **Care plan developed** before leaving IWK: focus on home or DECH hospital-based care; no return to IWK
- **Symptom management plan** reviewed with goals of comfort and time with family (led by PACT)
- **Virtual case conference**: IWK (PACT, Oncology, Neurosurgery) & NB team (pediatricians, DECH peds, EMP, social worker, dietitian, Adult PC)
- **Home visit** by EMP nursing arranged after return; peds clinic visit that week
- **IWK PACT remained available** via phone/email; support continued during EMP visits
- **Admitted to DECH** for symptom support; Adult PC recommended **morphine titration** for comfort
- Geneva **died peacefully at home** within a month of diagnosis, with buccal meds for discomfort
- Strong **collaboration across teams**: home (EMP), DECH hospital, IWK PACT

Mateo

- **Advanced Sanfilippo syndrome** at age 15; sleeping most of the day
- Increased **central apneas**; on BiPAP ~16 hrs/day
- **Reduced G-tube feeds**; less tolerance for nutrition
- **Frequent hospitalizations** for respiratory illness; not regaining baseline
- **Goals revisited**: focus on comfort, no further escalation or transfers to IWK
- Family's wish: **celebrate one last Christmas** together
- **EMP services increased**, more respite; Moncton Hospice & Peds unit explored
- Final weeks at **home**: BiPAP and feeds gradually withdrawn
- **Excellent symptom control** through home visits (EMP, Moncton Peds, PC and phone calls to PACT)
- **Strong collaboration**: Moncton Peds, Moncton Hospital PC, EMP, IWK PACT (remote support)

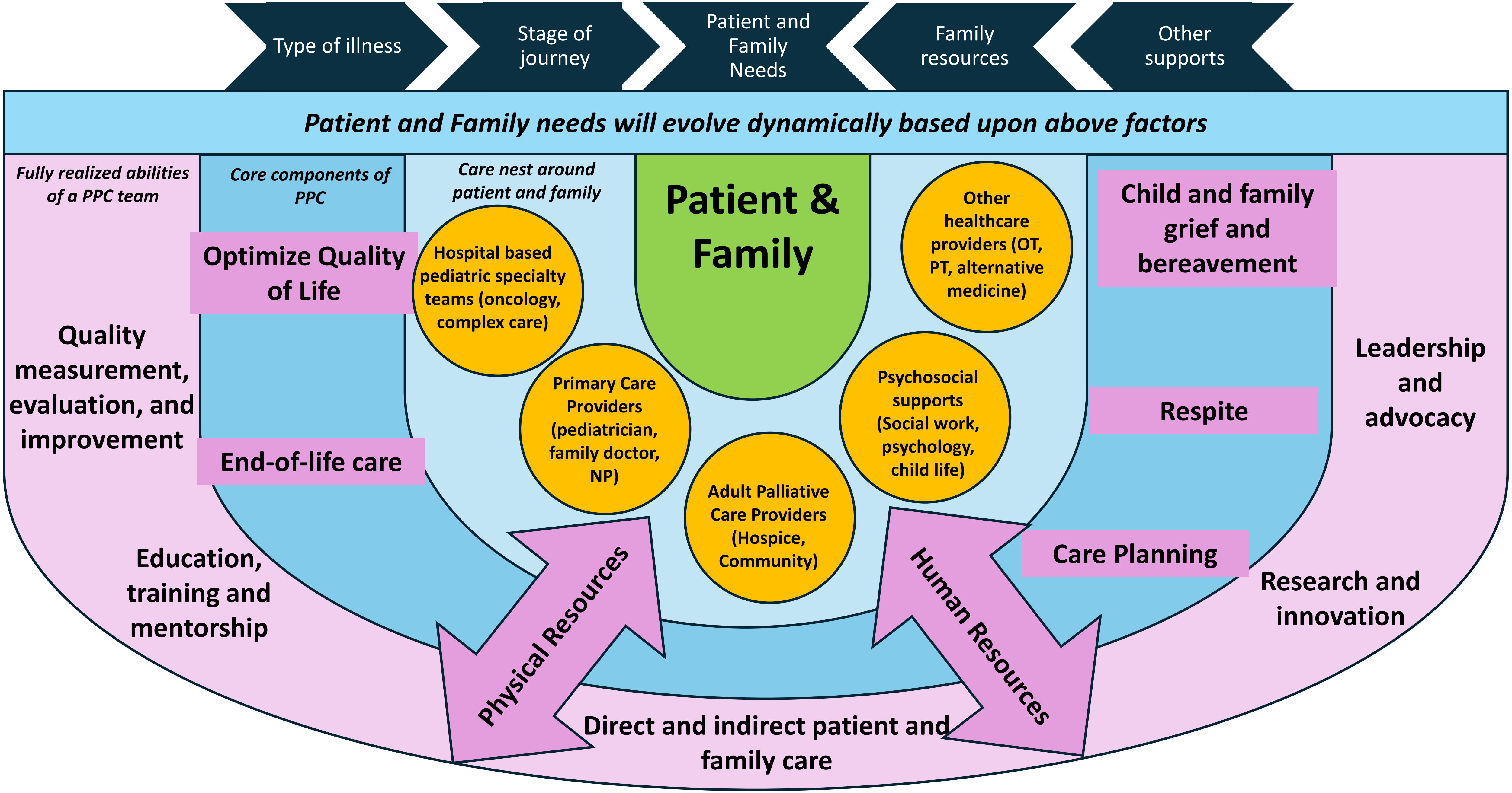
Resources & Locations of Care for Families

- Needs to be *flexible and fluid over time*- care needs depend on child's condition, illness trajectory, treatment and goals/availability of resources
- Often Involves *care coordination* across multiple locations as families travel between community providers, regional hospitals and pediatric tertiary care centers (IWK)
- Often covers *large and rural geographical regions* (NB, PEI and NS)
- Typically requires *longitudinal service integration*—community medical care, specialist care, and community life, with local therapists, school teams, home respite, etc. FOR YEARS!
- Facilitates *access and adaptation* to the variable availability of resources in Maritime communities- both in home (respite, nursing/allied health support) and community/hospital resources'
- Necessitates *collaboration* for PPC delivery that is adapted to patient/family needs and goals

= Accessible and equitable access to PPC for all children and families living with serious illness

- Home
- Hospital (local or tertiary)
- Adult Hospice (in select cases if appropriate and possible)

A Collaborative Model of Pediatric Palliative Care



Type of illness

Stage of journey

Patient and Family Needs

Family resources

Other supports

Patient and Family needs will evolve dynamically based upon above factors

Fully realized abilities of a PPC team

Core components of PPC

Care nest around patient and family

Patient & Family

Hospital based pediatric specialty teams (oncology, complex care)

Primary Care Providers (pediatrician, family doctor, NP)

Adult Palliative Care Providers (Hospice, Community)

Psychosocial supports (Social work, psychology, child life)

Other healthcare providers (OT, PT, alternative medicine)

Optimize Quality of Life

End-of-life care

Child and family grief and bereavement

Respite

Care Planning

Physical Resources

Human Resources

Quality measurement, evaluation, and improvement

Education, training and mentorship

Direct and indirect patient and family care

Research and innovation

Leadership and advocacy

Advanced Care Planning in Pediatrics

Advanced Care Planning in PPC

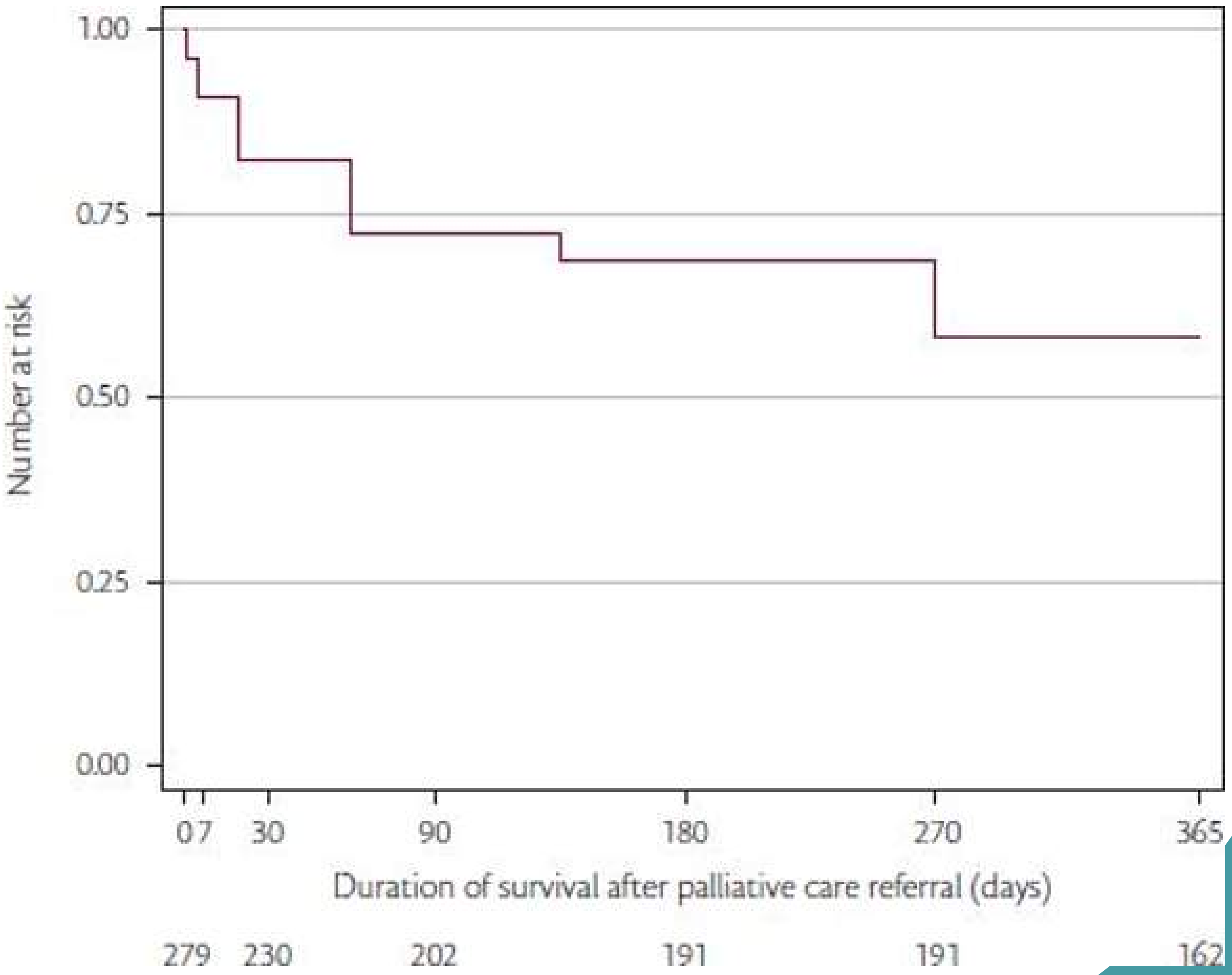
- Improved quality of life and symptom management
- Less time in hospital; more goal-concordant care
- Fewer emergency department visits
- Less intensive treatment at end of life
- Higher likelihood of child dying at home (if desired)
- Earlier and iterative conversations (think palliative approach!)
- Greater child participation, granting a greater sense of control
- Reduced caregiver stress and burden- true for providers too!

Mortality of children referred for Palliative Care

- One year after referral 40% of children referred to PPC have died

→Hence, the urgency of having serious illness conversations early with referred families

- *(Pallium, LEAP Pediatrics)*



Which children need ACP discussions?

- Life-limiting or life-threatening conditions
- Prolonged hospitalizations
- Complex care needs
- Medical fragility
- Dependency on medical technology

Canuck Place
CHILDREN'S HOSPICE

Serious Illness Conversation Guide—Pediatrics©

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?"

*Denotes an infant, child, teen

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?"

**The clinician may use illness, condition, or diagnosis to better align with the child's circumstance

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)

***For many parents the word 'experiences' may better illicit parents hopes and goals for their child (rather than what the child can do – what the child can enjoy and experience)

Thinking about the future is important, even if you don’t have all the answers. This information may help you get started.

Your care should be based on your values, beliefs, needs, hopes and goals for the future. What is important differs for each child and family.

Start early, ask questions and learn about your options. Individuals and families tell us that this has helped prepare them to make challenging decisions.

Talk to your healthcare provider to learn more.

Some important conversation topics for families and children with medical or developmental conditions to consider when thinking and planning for the future*?

Function

- Education and developmental needs
- Future functional skills and independence

Family

- Long-term caregiver education and support
- Financial planning and housing

Fitness

- Exercise, recreation and wellness activities

Friends & Fun

- Opportunities for participation and inclusion

Future health

Advance care planning conversations:

- Possible future health and medical needs
- Preparation in case of severe or life threatening illness or condition

Consider what else is important.

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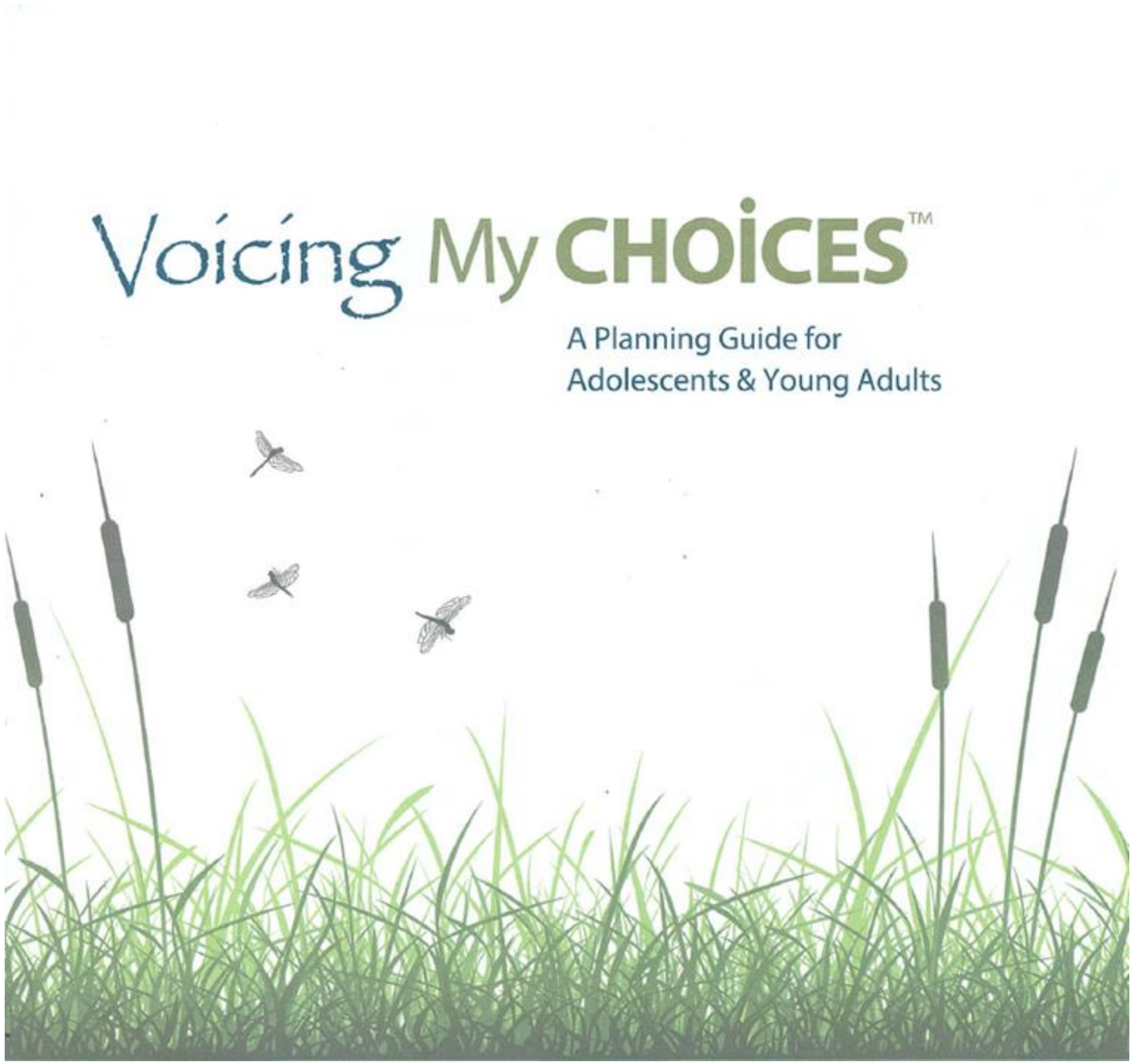
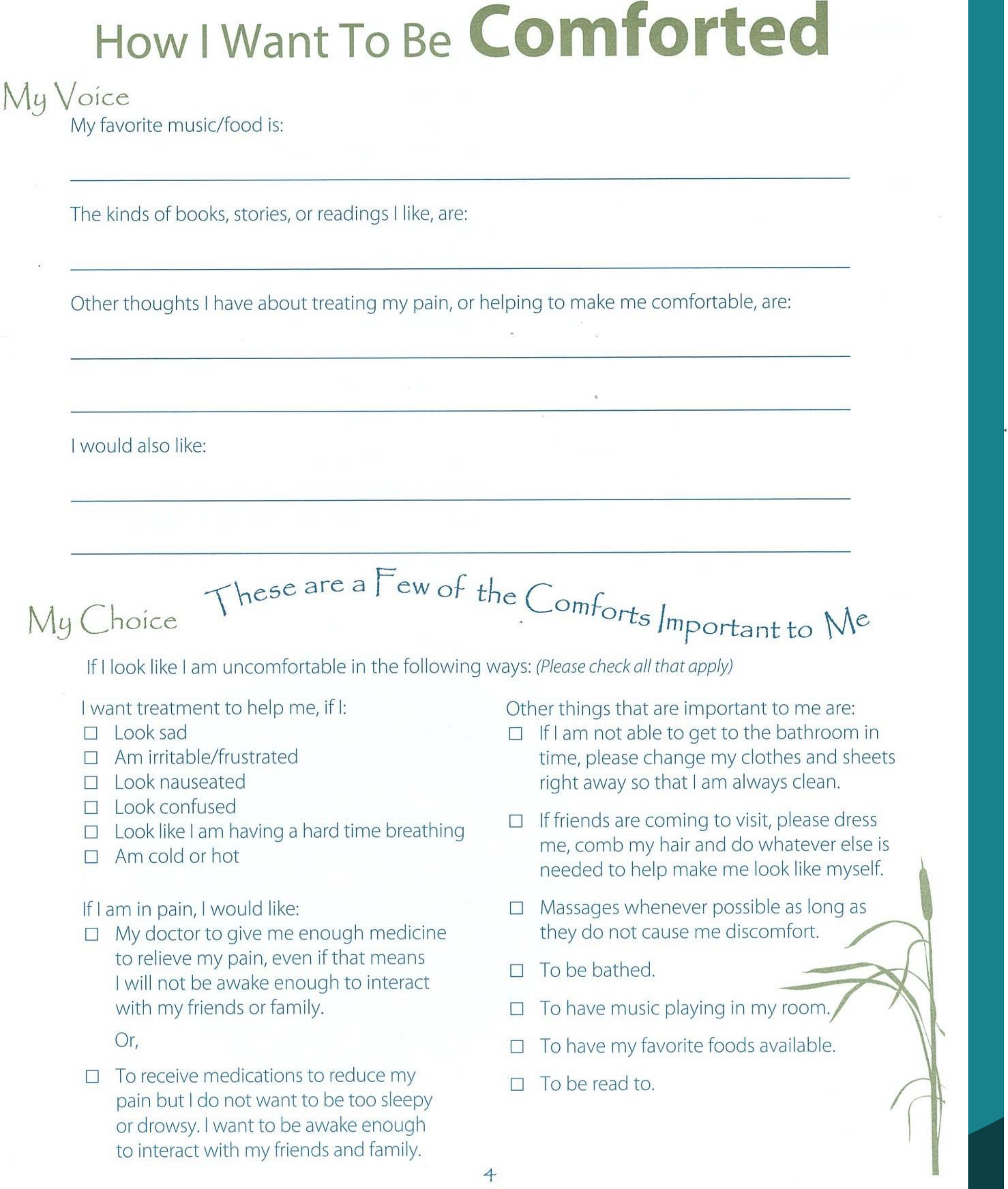
*Rosenbaum, P., & Gorter, J. W. (2012). The ‘F-words’ in childhood disability: I swear this is how we should think! Child: care, health and development, 38(4), 457-463. www.canchild.ca/f-words

ACP tools for teens



Voicing My CHOICES™

A Planning Guide for
Adolescents & Young Adults



How I Want To Be **Comforted**

My Voice

My favorite music/food is:

____

The kinds of books, stories, or readings I like, are:

____

Other thoughts I have about treating my pain, or helping to make me comfortable, are:

____

____

I would also like:

____

____

My Choice

These are a Few of the Comforts Important to Me

If I look like I am uncomfortable in the following ways: *(Please check all that apply)*

I want treatment to help me, if I:

- ☐ Look sad
- ☐ Am irritable/frustrated
- ☐ Look nauseated
- ☐ Look confused
- ☐ Look like I am having a hard time breathing
- ☐ Am cold or hot

If I am in pain, I would like:

- ☐ My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family.

  Or,

- ☐ To receive medications to reduce my pain but I do not want to be too sleepy or drowsy. I want to be awake enough to interact with my friends and family.

Other things that are important to me are:

- ☐ If I am not able to get to the bathroom in time, please change my clothes and sheets right away so that I am always clean.
- ☐ If friends are coming to visit, please dress me, comb my hair and do whatever else is needed to help make me look like myself.
- ☐ Massages whenever possible as long as they do not cause me discomfort.
- ☐ To be bathed.
- ☐ To have music playing in my room.
- ☐ To have my favorite foods available.
- ☐ To be read to.

People in your life will always love you and think about you. There may be special ways that you want to distribute your belongings and be remembered, especially on certain days such as your birthday, holidays or any other day that is important to you. This is a page to detail any wishes that you have for how you would like to be remembered for the years after you are gone.

As with the other pages, take your time filling this out. Your family and friends will appreciate knowing what you desire and how you would like to be remembered so that they can fulfill your wishes and know that by doing so, they have your special approval.

My Belongings

This is How I Would Like To Share My Belongings:

Clothes: ______	Pets: ______
Games: ______	Books: ______
Art: ______	Music: ______
Photographs: ______	Phone: ______
Computer: ______	Other electronics: ______
Furniture: ______	Money/savings: ______

Other belongings:

____

The person I would feel most comfortable going through my belongings is:

____

Special Days

How I would like to be remembered on my birthday:

____

____

How I would like to be remembered on other important days:

____

____

When people ask about me, please say the following:

____

livingoutloud.life

Young adults and teens are shattering the silence of living with advanced illness by creating a webspace of their own. Their stories are unscripted, unfiltered and unforgettable, offering help when it is needed most.

livingoutloud.life

CANADIAN
VirtualHospice

Online forums for teens

Talking with Children……

- Often a source a huge discomfort
- Preparation is Protection! Honest, age-appropriate information in small chunks
- Nonverbal, Verbal and PLAY
- Support from Child Life, PPC specialists, social workers can be very helpful
- No perfect convos! Creating safe space and honesty is key

KidsGrief.ca

The 6 C's to Explain Serious Illness to Kids

Can I CURE it?

Can I CONTROL it?

Did I CAUSE it?

Can I **CATCH** it?

Who is going to take CARE of me?

How do I stay CONNECTED to them?

https://www.sickkids.ca/siteassets/care--services/support-services/paediatric-advanced-care-team-pact/talking-to-kids-about-serious-illness.pdf

Capacity for Consent

- No universally accepted, legally defined age of consent for medical treatments in Canada
- Capacity to understand, capacity to make decisions and be actively involved
- Family centered, shared decision-making model best respects and supports emerging capacity of pediatric patients, parental roles & HCP expertise

Canadian Pediatric Society Position Statement (2018):

“The participation of children and adolescents in medical decision-making should always be sought, and their involvement should be proportionate with their capacity and circumstances. Their consent, assent or dissent must be respected whenever possible”

Canadian Paediatric Society, Bioethics Committee (Coughlin, K. W.). (2018). *Medical decision-making in paediatrics: Infancy to adolescence* (Position statement). *Paediatrics & Child Health*, *23*(2), 138–146. https://doi.org/10.1093/pch/pxx173

Resources

Educational Resources

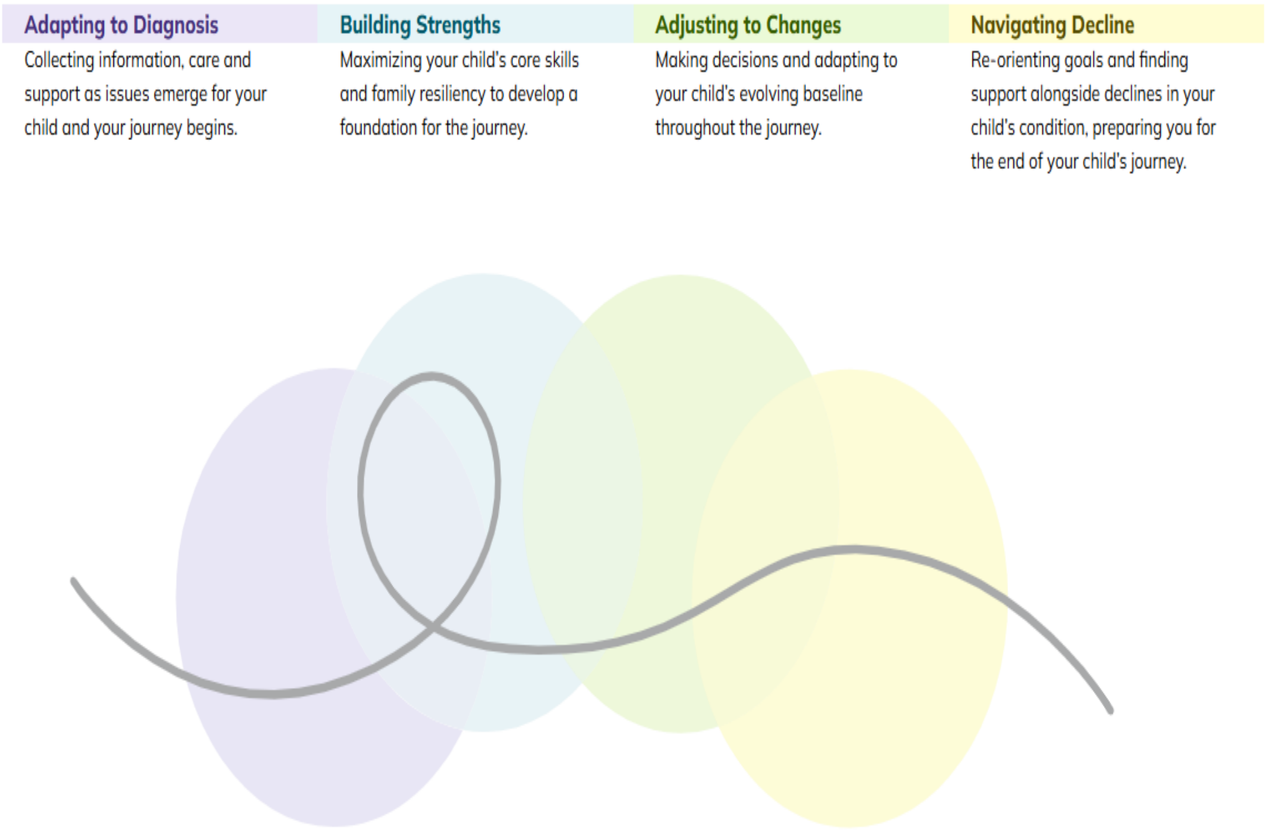
- Pediatric Project Echo (CAN)
- LEAP Pediatrics (CAN)
- EPEC- Peds (US)
- Serious Illness Conversation Guide Training- Canuck Place Children's Hospice (Free)

Canada's
**pediatric
palliative
care** alliance

Canada's Pediatric Palliative Care Alliance

Courageous Parents Network: *NeuroJourney: 4 phases of life*

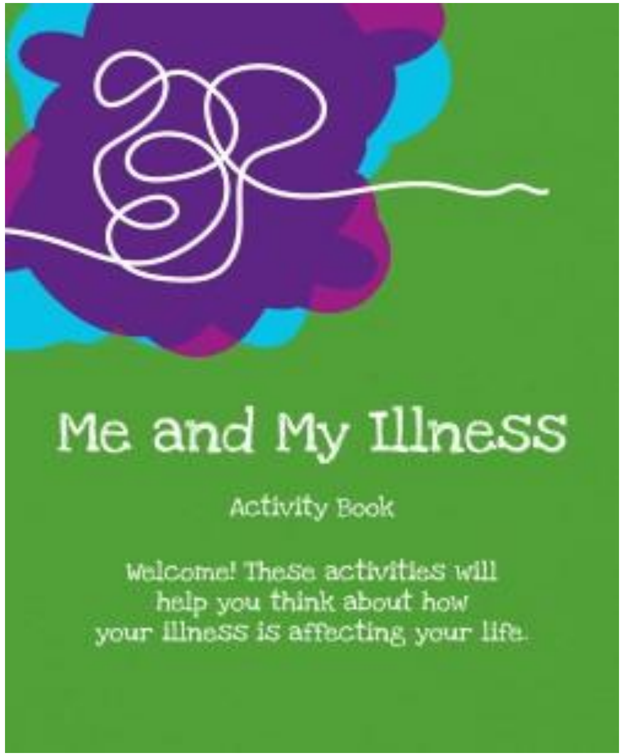
The Arc of a Life



Adapting to Diagnosis	Building Strengths	Adjusting to Changes	Navigating Decline
Collecting information, care and support as issues emerge for your child and your journey begins.	Maximizing your child's core skills and family resiliency to develop a foundation for the journey.	Making decisions and adapting to your child's evolving baseline throughout the journey.	Re-orienting goals and finding support alongside declines in your child's condition, preparing you for the end of your child's journey.

https://neurojourney.courageousparentsnetwork.org/

"CaringTogether.life is a free platform designed to educate, support, and empower parents caring for a seriously ill child and those who are experiencing pregnancy or infant loss."


Me and My Illness

Activity Book

Welcome! These activities will help you think about how your illness is affecting your life.

CaringTogether.life

Thank you!