

## *Step 1: Assess for presence of a Serious Illness*

Within the context of Pediatric Palliative Care, a child with a Serious Illness includes all children with a life-threatening/life-limiting condition that carries a high likelihood of death before full adulthood AND negatively impacts a child's daily function OR quality of life OR excessively stresses their caregivers.

- This may include other factors such as uncertainty around prognosis, a prolonged/multiple hospitalizations/ICU stays and/or where there is complex care coordination, fragility, instability, and medical technology dependence.

Within the specialty of pediatric palliative care, the term child refers to any age. A child could be a fetus diagnosed in utero with a life-threatening condition or an adult diagnosed with a pediatric condition and/or followed by pediatric specialists.

## *Step 2: Consider child's possible care quadrant*

### **Category 1: Life-threatening, curative treatment available but may be unsuccessful**

A curative treatment option, but there is a high risk that this may fail. The most common are cancer and complex or severe congenital or acquired heart disease. If long-term remission can be reached or following successful curative treatment like surgery there is no longer a need for palliative care services (can be discharged from CPCH program).

### **Category 2: Long period of treatment which aims to prolong life but premature death is anticipated**

Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.

### **Category 3: Progressive conditions where treatment is palliative from diagnosis (no cure but symptoms can be managed)**

Children where the conditions are progressive from the time of diagnosis and there is no treatment which can extend the child's life. This includes Trisomy 13 and 18 as well as many different rare genetic and metabolic conditions, such as mucopolysaccharidosis, Rett Syndrome, and Adrenoleukodystrophy. Typically the conditions in this category are very rare.

## Step 2 continued: Consider child's possible care quadrant

### Category 4: Severe disability that leads to extreme vulnerability to complications and premature death is expected

Condition includes a severe disability which leads child to be vulnerable to complications/ premature death. Conditions include many severe brain injuries of disabilities such as severe cerebral palsy, severe brain injuries from trauma/ infections, and severe brain malformations (disorders where the brain does not form/develop properly). Wide range of conditions in this category, but the end result is similar for most children - they have very impaired neurodevelopment which causes a range of issues including difficulties with feeding, secretions and airway clearance. This is the category of children who are often not consider for PPC services as they do not have a progressive process, however, their disability puts them at risk for symptoms (seizures, recurrent infections, feeding difficulties, spasticity) and risk of death and therefore the potential of a prolonged period of suffering. This is the group of children that we can help and improve quality of life for child and family over a long period of time.

## Step 3: Consider the fragility and instability of the child's health condition

(CPCH Zones of Health Framework)

**Health zones:** a health zone is the intersection of the fragility and instability of a child's serious illness.

- Serves as a common language or communication tool between practitioners.
- Help determine what CPCH program services might be a good fit as well as role of CPCH for advance care planning, symptom management, and care coordination. A child's health zone is one factor to consider when understanding, supporting, and providing care to a child/family.

**Fragility:** the child's risk of deterioration, exacerbation, or progression of their health condition/disease.

- This increases when multiple systems are involved or the pathologies/conditions are known to change rapidly.
- It is impacted by the rate, severity (real or potential) of change and the reserve of a child.

**Instability:** the rate of change in a child's well-being (symptoms, function, and development) and care needs.



## Assessment guide for determining health zone

To determine a child's fragility, assess the **risk** of significant deterioration or progression of health condition or disease related to:

- Central Nervous system (e.g. seizures, increased intracranial pressure, hemorrhage)
- Cardiovascular (e.g. arrhythmia, blood pressure instability)
- Respiratory (e.g. apnea, aspiration, infection)
- Gastrointestinal (e.g. weight loss, obstruction)
- Immune system (e.g. dysfunction, recurrent sepsis)

To determine a child's **instability**, assess the rate of change (hour to hour, day to day, and week to week) in a child's well-being as evidenced by:

- Symptoms (e.g. pain, N/V, dyspnea, feeding intolerance)
- Care needs (e.g. medications, technology, treatments)
- Function (e.g. eating, ambulation, interaction)
- Development (e.g. loss of milestones)

## Step 4: Consider the 'surprise questions'

- Would you be surprised if this child or young adult were to **die** in the next 12 months?

OR

- Would you be surprised if this child or young adult were **alive** in the next 12 months?

## Step 5: Evaluate whether the child/AYA you are caring for meets ANY of the above criteria

Contact Canuck Place to discuss a possible referral or consultation at (604) 742-3476 or toll-free in B.C. at 1-877-882-2288 ext. 3476