Categories of children's palliative care

These categories are designed to help professionals recognise babies, children and young people who may benefit from a palliative care approach.

The categories are not based on precise prognostic timelines and should not be used to predict life expectancy. Instead, they reflect patterns of vulnerability, complexity, and need that often indicate when palliative care involvement can help.

Within the descriptions of the categories, the term 'children' covers those in utero, babies, children and young people. Advances in treatment and changes in clinical practice may alter how children move between categories over time. Regular review is essential to ensure categorisation reflects current clinical context and treatment options.

Developed with the support of the Association for Paediatric Palliative Medicine (APPM) and made possible thanks to funding from the True Colours Trust.

Category A: Life-threatening conditions

Clinical definition

Conditions for which disease-modifying or life-prolonging treatment may be available but may fail, or where intensive therapies and interventions are required to sustain or prolong life. These conditions carry a significant risk of premature death even if treatment is pursued.

Clinical characteristics

This can include situations where:

- Curative treatment exists but has a high chance of failure or non-response.
- Child requires intensive or high-risk interventions to maintain organ function or survival.
- Treatment decisions involve weighing the anticipated or likely burdens and benefits due to uncertain outcomes.
- There is significant risk of sudden, unpredictable deterioration.
- Situations where survival following birth or a specific intervention is uncertain

Clinical examples

- Childhood cancers with uncertain response to treatment, such as relapsed neuroblastoma.
- Complex congenital cardiac conditions requiring ongoing intervention.
- Congenital conditions where outcomes may be uncertain.
- Severe immunodeficiency requiring high-risk therapy.
- Congenital anomalies where interventions may help but may also fail (e.g., certain cardiac or metabolic conditions).
- Neonatal and antenatal situations where survival or viability of the baby is uncertain before or after birth.
- Children undergoing or eligible for organ transplant where treatment may succeed but carries significant risk of failure or complications.

Long-term remission or sustained recovery may remove the need for ongoing palliative involvement. Review should occur at defined treatment milestones.

Category B: Life-shortening conditions

Clinical definition

Conditions where death in childhood or early adulthood is likely due to the progressive nature of the condition or the absence of effective disease-modifying or curative treatment.

Clinical characteristics

This can include situations where:

- The condition is expected to shorten life.
- The child experiences progressive decline over time.
- The focus increasingly includes quality of life and symptom management.

Clinical examples

- Neurodegenerative conditions, such as spinal muscular atrophy type 1.
- Progressive genetic or metabolic conditions, such as Batten disease or Sanfilippo syndrome.
- Severe congenital anomalies with limited life expectancy, such as Trisomy 18 (Edwards Syndrome) or Trisomy 13 (Patau's Syndrome) with significant multisystem involvement and uncertain trajectory.
- End-stage organ failure where transplant is not a viable option or where prognosis is limited.

It is acknowledged that trajectories within this category can be highly variable, particularly in perinatal palliative care, where uncertainty is common and early supportive involvement may be appropriate.

Category C: Severe medical complexity

Clinical definition

Children with severe medical complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

Clinical characteristics

This can include situations where:

- A child relies on medical technologies for vital functions (e.g., ventilation, feeding, oxygen, shunts).
- There is high risk of sudden deterioration
- There is an increased susceptibility to life-threatening events, even when the underlying condition is static.
- The child has significant functional impairment and care needs
- There is clinical frailty, particularly in adolescents transitioning to adult services.

Clinical examples

- A child with cerebral palsy with significant medical fragility and technology dependence.
- A child with hypoxic-ischaemic encephalopathy (HIE) with profound care needs.
- Multi-system conditions causing significant impairment.
- Severe neurological disability with marked functional limitation.

Some children with severe medical complexity will benefit from a palliative care approach, while others may be best supported through alternative specialist pathways. This distinction should be explored sensitively with families.

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