Toolkit for palliative care needs in children: Recognise

Identifying which babies, children, and young people will benefit from a palliative care approach is the first step in ensuring they receive holistic, timely support.

Recognition is a process that moves away from rigid prognostic timelines, focusing instead on patterns of care needs and clinical uncertainty. Please note that the term 'children' covers those in utero, babies, children and young people.

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.

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.

Category B: 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.

Notes for clinical use

The categories are designed to be used alongside:

- Clinical assessment
- Professional judgement
- Family discussion
- The surprise question
- The phases of care

Children and young people may move between categories over time. Some children may benefit from a palliative care approach for a limited period, while others may require longer-term involvement.

The Surprise Question

To help identify children who may benefit from a palliative care approach, clinicians often use the "surprise question". Because clinical environments and child trajectories vary significantly, we propose a graded, spectrum-based approach. This better reflects clinical uncertainty and ensures that no child is missed across different service provisions. Ask yourself and your multidisciplinary team:

"Would you be surprised if this child were to die in the next week/month/year/or before they reach adulthood?"

Where the answer to the question is 'no' and it would not be a surprise if the child died that should prompt the team to actively consider/discuss a palliative approach to care with the child (if appropriate) and their family.

Notes for clinical use

The surprise question must be used alongside the three categories of care, not as a replacement for them. If the answer to any of these timeframes is "no" (meaning you would not be surprised), this should act as an immediate prompt to:

- actively discuss a palliative approach with the child and family.
- initiate parallel planning (planning for life alongside planning for deterioration).
- review or develop a current advance care plan (ACP).

Be mindful that adult services often use a narrower 6–12 month window. Using a graded approach helps clinicians better identify and advocate for young people as they move toward adult services.

While this question is a valuable tool for supporting clinical judgment and early recognition, further research is currently required to fully understand its validity and reliability within the specific field of children's palliative care.

Complexity and eligibility

Families may describe their child as medically complex or feel that palliative care is appropriate. This toolkit supports professionals to distinguish between the complexity of care needs and the eligibility for specialist palliative care services.

Some children with complex needs will benefit from a palliative care approach, while others may be better supported through alternative specialist pathways. These conversations should always be handled sensitively, with families' perspectives recognised and respected.

Perinatal and antenatal context

Recognition may occur during pregnancy. In cases of diagnostic uncertainty, life-limiting diagnosis or concerns regarding viability, a palliative approach should be considered alongside obstetric and neonatal management.

Uncertainty is common in perinatal pathways. Early multidisciplinary discussion is recommended. For more information about babies facing an uncertain prognosis and outcome please refer to the framework for palliative care perinatal medicine.

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