Toolkit for palliative care needs in children: Assess and plan

A child's condition rarely follows a straight line, so care must be as dynamic as the illness itself.

Coordinating care well means responding to a child's changing health as it happens. The four phases of care set out here help teams plan and adjust support as a child's condition changes. These pages also introduce key tools for managing clinical uncertainty, including Parallel Planning – planning for life and quality of life while preparing for the possibility of decline – and the formal recording of Advance Care Plans (ACP) to ensure the family's wishes are respected across all care settings.

The four phases of care needs

The phases of care describe a child's current care requirements rather than their long-term prognosis. A child can be in any phase regardless of their diagnostic category and may move between phases of care needs in a non-linear way.

Stable phase: The child's condition is stable and predictable.

- Symptoms are reasonably well managed
- Care plans are in place and working
- There are no new or escalating concerns
- The family feels supported and informed

Palliative care involvement during this phase may focus on:

- Anticipatory planning
- Relationship building
- Education and support
- Reviewing goals of care
- Ensuring services are coordinated
- Supporting the emotional/psychological wellbeing of the child, parents/carers and siblings
- Accessing therapies and interventions to maximise quality of life

Unstable phase: The child's condition is unpredictable, requiring closer review and adaptation of care.

- Symptoms are harder to control
- There may be sudden changes or new problems
- Unplanned admissions or urgent reviews may occur
- Care plans may need frequent adjustment

Palliative care involvement during this phase may focus on:

- Reassessing needs
- Adjusting care plans
- Supporting families through uncertainty
- Strengthening communication between professionals

Children may move back into a stable phase after an unstable period.

Deteriorating phase: The child's condition shows progressive decline, with increasing vulnerability and reduced response to interventions.

- Episodes of illness are becoming more frequent
- Recovery is slower or incomplete
- Baseline function is declining over time
- Conversations increasingly focus on comfort, quality of life and advanced planning

Palliative care involvement during this phase may focus on:

- Reviewing goals of care
- Strengthening advance care planning
- Supporting emotional and psychological needs
- Preparing for potential further decline

Dying phase: The child is approaching the end of life, death is likely in the coming days or weeks.

- There is a clear shift towards comfort-focused care
- The family is supported in discussing wishes and preferences
- Care is coordinated to prioritise comfort, dignity and family choice

Palliative care involvement during this phase may focus on:

- Specialist palliative and end of life care
- Emotional and psychological support
- Memory-making opportunities
- Support with preferred place of care and death
- Supporting families to understand what happens when a child dies, including practical guidance and what to expect

Notes for clinical use

- Phases describe care needs, not prognosis
- Children may move between phases over time
- A child can be in any phase regardless of category
- Phases are intended to support planning, not act as thresholds
- Use of phases should always involve clinical judgement and family discussion

Core planning tools

Effective planning helps families feel in control and ensures that a palliative approach is never a “last resort”.

Parallel planning

This is the process of planning for life – supporting the family’s hopes and quality of life – while simultaneously preparing for the possibility of a child’s deterioration or death. It is a vital tool for managing clinical uncertainty, especially in neonatal or high-acuity cases.

Advance care planning (ACP)

An ACP is a formal, reviewable document that records the child’s and family’s wishes, goals, and preferences. It should include a summary of the child’s condition, who has responsibility for decision-making and consent, and instructions for symptom management.

Core planning tools cont.

ReSPECT

ReSPECT (Recommended summary plan for emergency care and treatment) documentation provides clear, scenario-based triggers – such as what to do during a prolonged seizure or breathing crisis – to ensure healthcare professionals act in the child's best interests.

The interface of services: Universal, core and specialist

Resource allocation is structured into three tiers of delivery:

- **Universal services:** healthcare provided to all children. Delivered by primary care teams, health visitors, school nurses, social care, and education.
- **Core services:** targeted, skilled support in various settings. Delivered by community children's nursing teams, acute hospital staff, children's hospices and including community child development services (community paediatrics, occupational therapy, speech and language therapy, physiotherapy, dietetics, wheelchair services, etc.).
- **Specialist services:** consultant-led teams. These may include spin or grid-trained paediatricians, advanced nurse practitioners, specialist medical and nursing teams and multidisciplinary specialists managing complex symptoms and ethical decision-making, and including paediatric psychological medicine and community mental health services where appropriate.

When to seek specialist advice

While many needs are met by universal and core teams, a specialist paediatric palliative care referral should be triggered when clinical or ethical complexity increases. Key triggers can include:

- refractory symptoms that are difficult to manage with standard medications.
- complex ethical disputes regarding the withholding or withdrawal of life-sustaining treatment.
- end-of-life care at home, where 24/7 specialist advice and nursing support are required to maintain comfort.

Notes for clinical use

It is important to recognise that the interface between universal, core and specialist services is not uniform across the UK. Specialist support may be provided by a range of professionals, including consultant-led paediatric palliative care teams, general paediatricians with a special interest (SPIN), community children's nursing teams, hospices, and other specialist teams.

Provision exists along a spectrum, with variation in expertise, capacity and access across regions. While many hospices are charitable organisations with differing eligibility criteria, specialist palliative care input may also be delivered within NHS services. Close collaboration across services, including primary care teams as GPs and wider multidisciplinary teams, is essential.

Some hospices have highly specialised medical teams capable of supporting technology-dependent children (like those on ventilation), while others focus primarily on psychosocial and social care. Because many hospices are charities, their eligibility criteria and capacity vary. In areas where specialist care teams are not available locally, the CCN team, a general paediatrician or General Practitioner may take on a more prominent role, often supported by regional specialist advice.

Scan the QR code for more helpful tools: