

# Toolkit for palliative care needs in children

## Domain 1: Child and family needs

This domain focuses on the immediate wellbeing and identity of the child and their closest caregivers.

**Physical & Clinical:** Management of pain, distressing symptoms, and ensuring the child and family get enough rest and sleep.

- How are the child’s physical symptoms being assessed and managed?
- Is the family getting enough rest and sleep?

Green
  Amber
  Red

**Emotional wellbeing:** Supporting the mental health and resilience of the child, parents, and siblings.

- How is the mental health and resilience of the child, parents, and siblings being supported?
- Could the family benefit from referral to local hospice or NHS palliative care psychosocial services, or is there a need to refer to child and adolescent or adult mental health services?

Green
  Amber
  Red

**Identity, Spiritual & Cultural:** Respecting the family’s values, beliefs, and cultural preferences to ensure care “fits” their unique identity.

- Are spiritual, cultural, and existential needs being met?
- Are there specific considerations regarding sexuality or gender?

Green
  Amber
  Red

**Planning:** Offering memory-making opportunities and preparing families for the death of their child with compassion.

- Is an Advance Care Plan (ACP) with/without ReSPECT in place, and are the child and family’s wishes documented?

Green
  Amber
  Red

Provide information from the Together for Short Lives Family Support Hub, and local children’s hospices for information and support.

Refer to Together for Short Lives Family Support Hub, Rainbow Trust, WellChild, or Sibs.org.uk and local children’s hospices for information and support to proactively support family.

Immediate referral to a Specialist Paediatric Palliative Care Team and local children’s hospices for information and support and refractory symptom management.

**Key**

- The family feels informed, their current needs are met, and adequate support is already in place. Aim to provide baseline information and resources to empower the family’s management.
- A need has been identified that should be planned for in the near future, or the current support is adequate for now but may soon change. Aim to proactively plan referrals and involve core services to prevent the situation from reaching a crisis point.
- Support is non-existent, insufficient, or there is an immediate crisis that threatens the family’s ability to cope. Aim to immediately refer to specialist teams or emergency practical services, as required.

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## Domain 2: Support networks

This domain looks at the wider “team around the child” and their social integration.

**Wider Family & Friends:** Assessing the needs of siblings and the support available from extended family and the local community.

- How are the family currently supported by friends or their local community?
- Are there other responsibilities, such as caring for elderly relatives?

Green
  Amber
  Red

**Faith & Community:** Connecting families with their faith groups or local community-led support initiatives

**Respite & Leisure:** Ensuring access to short breaks (respite care) and supporting the child’s right to play and social interaction.

- Are there other responsibilities, such as caring for elderly relatives?
- Does the family have access to short breaks or respite care?

Green
  Amber
  Red

**Education & Work:** Helping the child stay in childcare, school or college and supporting parents with their employment needs.

- Is the child supported in play and leisure?
- How are the child and parents supported at school or work?
- Is the child able to continue education with adaptations? What could that look like?

Green
  Amber
  Red

Share local community directories or national youth advocacy contacts through Together for Short Lives Family Support Hub and local children’s hospices for information and support. Access to multidisciplinary support, including hospital teams, hospice services and AHPs, should be considered when assessing needs.

Contact Make-A-Wish UK, Over the Wall, or refer to local Children’s Hospices to plan respite; engage SEND coordinators for school needs and local children’s hospices for information and support. Access to multidisciplinary support, including hospital teams, hospice services and AHPs, should be considered when assessing needs.

Urgent legal/safeguarding help via Cafcass, Coram Children’s Legal Centre, or Citizens Advice. Access local children’s hospices for information and support or community teams where available. Access to multidisciplinary support, including hospital teams, hospice services and AHPs, should be considered when assessing needs.

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## Domain 3: Practical needs

This domain addresses the practicalities and financial security required to maintain a safe home environment.

**Finance & Benefits:** Ensuring the family is accessing all available financial support and grants.

- Is the family's financial situation secure?
- Could they cope with a sudden change in circumstances?

Green
  Amber
  Red

**Living environment:** Checking that housing is suitable, accessible, and meeting the child's physical requirements.

- Is the living environment suitable, accessible, and safe for the child and family's needs?

Green
  Amber
  Red

**Equipment & Transport:** Coordinating the medical technology, home adaptations, and transport needed for safe care.

- Are there unmet needs for medical equipment, adaptations, or transport?

Green
  Amber
  Red

**Food & Nutrition:** Ensuring the family can access appropriate nutrition to meet the child's specific medical needs

- Does the family have access to appropriate food and nutrition?

Green
  Amber
  Red

Information on benefits and grants via Together for Short Lives Family Support Hub and local children's hospices for information and support. Support may be provided across hospital teams, hospices, and community services, including access to allied health professionals (AHPs) for equipment, adaptations and transport planning.

Signpost to Citizens Advice for planned financial or family support and local children's hospices for information and support. Support may be provided across hospital teams, hospices, and community services, including access to allied health professionals (AHPs) for equipment, adaptations and transport planning.

Immediate contact with the Trussell Trust for food, the Family Fund for emergency aid, or Law Works for housing crises. Referrals can be made through Together for Short Lives Family Support Hub. Contact local children's hospices for information and support or community teams where available.