

UNIVERSITY OF
BIRMINGHAM

The Spectrum of Children's Palliative Care Needs

Introductory Leaflet



In collaboration with
**together
for
short
lives**

acorns
Care for the child,
support for the family
Registered charity no. 700859



What is the Spectrum of Children's Palliative Care Needs?

The Spectrum of Children's Palliative Care Needs is a prognostic based framework to identify children and young people who have palliative care needs. Its primary purpose is to facilitate the collection of standardised data to improve services for children and their carers. Additional copies of the Spectrum of Children's Palliative Care Needs can be found at www.togetherforshortlives.org.uk/spectrumofcpcneeds

Who should use the Spectrum of Children's Palliative Care Needs?

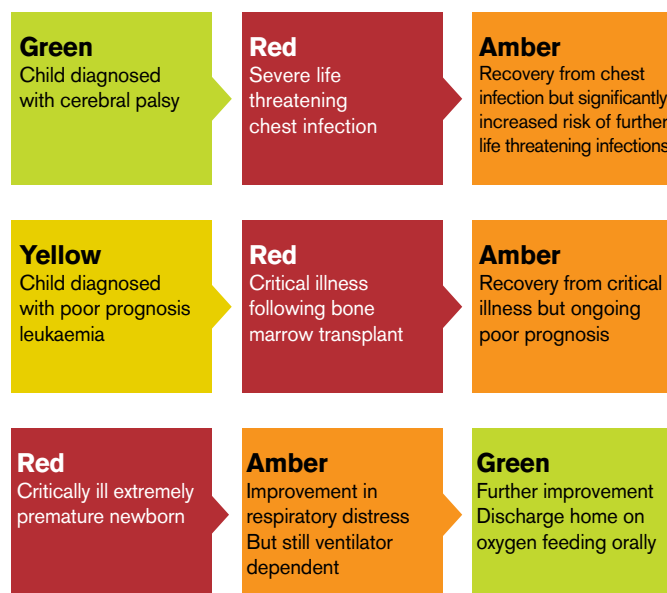
The Spectrum of Children's Palliative Care Needs should be used by those involved in the planning, delivery and evaluation of children's palliative care services. This includes clinicians, researchers and those responsible for service provision and the strategic implementation of children's palliative care policy, including commissioners. However, preliminary evaluation also suggests that it can be used by care teams to facilitate case-reviews, workload management and communication between professionals.

How was the Spectrum of Children's Palliative Care Needs developed?

Previous work undertaken by Together for Short Lives.¹ (formerly ACT and Children's Hospices UK) showed that a robust framework was needed to capture the palliative and end of life trajectories of children. Expert review led by Lancaster University resulted in the first version of the Spectrum of Children's Palliative Care Needs (originally named the Rainbow of Children's Palliative Care Needs).² The usefulness of this was explored by researchers at the University of Birmingham who worked with palliative care professionals to develop this revised version and introductory leaflet.³

How are the categories in the Spectrum of Children's Palliative Care Needs arranged?

The Spectrum of Palliative Care Needs organises children into different prognostic groups that are likely to have meaningful and distinct support needs. These are colour-coded for ease of use and include 'surprise questions' that prompt clinicians to consider the possibility that a child might die within a specified period of time. The use of 'surprise questions' has been recommended in national policies for adult end of life care and recognises that professionals are often more comfortable with the uncertainty implicit in 'not being surprised' than 'expecting' a child to die.² It is important to note that the vertical arrangement of categories is not meant to imply a linear trajectory. Children can enter the Spectrum of Children's Palliative Care Needs at any point and move between categories non-sequentially in either direction. Eg.



Good practice points for using the Spectrum of Children's Palliative Care Needs

- Where possible, use the Spectrum of Children's Palliative Care Needs in a multi-disciplinary group setting
- Make regular assessments that are based on up-to date information
- If in doubt (ie. where a child is considered borderline between two adjacent categories) place child in category that reflects worst case scenario and revise as soon as new information is available.

Why should I use the Spectrum of Children's Palliative Care Needs?

The Department of Health has stated that, 'One of the biggest challenges facing children's palliative care commissioners, providers and service users is a lack of uniform, regular and accurate information about the nature of life-limiting conditions and the services available to support them'.⁴ The Spectrum of Children's Palliative Care Needs addresses this problem by providing a standardised and meaningful approach to identify children with palliative care needs.

Importantly, the Spectrum of Children's Palliative Care Needs was developed by clinicians, for clinicians. It offers a quick and simple way to collect information and can be used by a range of professionals in a variety of clinical settings. It can be used as part of minimum datasets or service-mapping to provide a snapshot of palliative care needs at a particular point in time. However, regular use of The Spectrum of Children's Palliative Care Needs to review the same population over time, (eg. a community nursing caseload), will help chart the many different journeys experienced by children and their families. This information can be used to evaluate current services, develop a vision for the future and design a road map to make meaningful change.

What are the next steps in developing the Spectrum of Children's Palliative Care Needs?

Further work is required to find out the true care and cost implications of the colour-coded categories and to understand how the Spectrum of Children's Palliative Care Needs relates to families' perceptions of need and priorities for care. We would therefore be interested to hear from you if you are planning to use the Spectrum of Children's Palliative Care Needs.

Who can I contact to find out more about the Spectrum of Children's Palliative Care Needs?

For general enquires and information about using the Spectrum of Children's Palliative Care Needs, please contact **Lynda.Brook@alderhey.nhs.uk** (Macmillan Consultant in Paediatric Palliative Care). For information about the research and development of the Spectrum of Children's Palliative Care Needs, please contact **k.i.shaw@bham.ac.uk** (Research Psychologist).

How can I find out more about children's palliative care?

Together for Short Lives (www.togetherforshortlives.org.uk) provides a range of tools, guidance, information and publications to support children's palliative care. Many of these are free to print or download.

References:

1. Ezergallis S, Brook L. *Making Life-limited Children and Young People Count: A Framework and Guide for Local Implementation*. ACT (Association for Children's Palliative Care)/Children's Hospices UK. 2009.
2. Brook LA, Kerr C, Hawker S. *Defining children who may have palliative care needs: a Delphi consensus building study*. Arch Dis Child 2011;96:A79
3. Shaw KL. *Beyond labels. Improving care with the 'Rainbow of Children's Palliative Care Needs'*. www.30millionstars.org.uk
4. Department of Health. *Better care: Better lives*. London: The Stationary Office, 2008.