Together for Short Lives

Focus

- To look at some of the issues in end of life care
- To provide some information on the role of Together for Short Lives

Together for Short Lives

Together for Short Lives is the leading UK charity that speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

Our mission is to secure the best quality of life and best end of life care for children who will have short lives.

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Children, young people and families are at the heart of our work

- 49,000 children and young people in the UK living with a life-limiting/shortening condition which means that may not reach adulthood

- That’s the equivalent of 1 in every 270 children

- 1 child in every school across the UK

- Enough to fill the Royal Albert Hall nearly 10 times


Together for Short Lives is the leading UK charity for children’s palliative care

We’re here for the

49,000

children and young people up to the age of 18 in the UK living with a life-threatening or life-limiting condition


Enough to fill the Royal Albert Hall almost 10 times over!

Together for Short Lives

Definition for Children's Palliative Care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond.

It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family.

It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Life-Limiting /Life-Shortening Conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-Threatening Conditions are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or following successful curative treatment are not included.

Definitions of life-limiting conditions

Group 1	**Curative treatment may be feasible but can fail.** Access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included. Examples: cancer, irreversible organ failures of heart, liver, kidney.
Group 2	**Where premature death is inevitable.** There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Examples: cystic fibrosis, Duchenne muscular dystrophy.
Group 3	**Progressive conditions without curative treatment options.** Where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses.
Group 4	**Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.** Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult.

Some numbers

- More than 49 000 children with palliative care needs in UK, with about 8000 accessing hospices
- Prevalence was highest in under 1’s
- More boys than girls
- Marked rise in 16 – 19 years

Key aspects of children’s palliative care

- Range of conditions (365)
- Life-limiting and life-threatening conditions
- From birth (antenatal too) to young adulthood
- Range of professionals involved in child’s life
- Role of family – parents; siblings and extended family
- Capacity and consent
- Palliative short breaks
- Long term support
- Complexity of care
- Parallel planning

A Strategic Priority

2. Quality of life, quality of death – so families receive high quality care **through** life <u>and</u> at **end of life** and supporting professionals and services to understand and meet the needs of more children and families in their diverse communities.

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What’s important to Families

- Choices in all aspects of their care
- Co-ordination of services
- Care and services appropriate to the age of the child from neonates to young adults
- Care services that are culturally sensitive
- End of life care
- Specialist support for siblings
- Bereavement support

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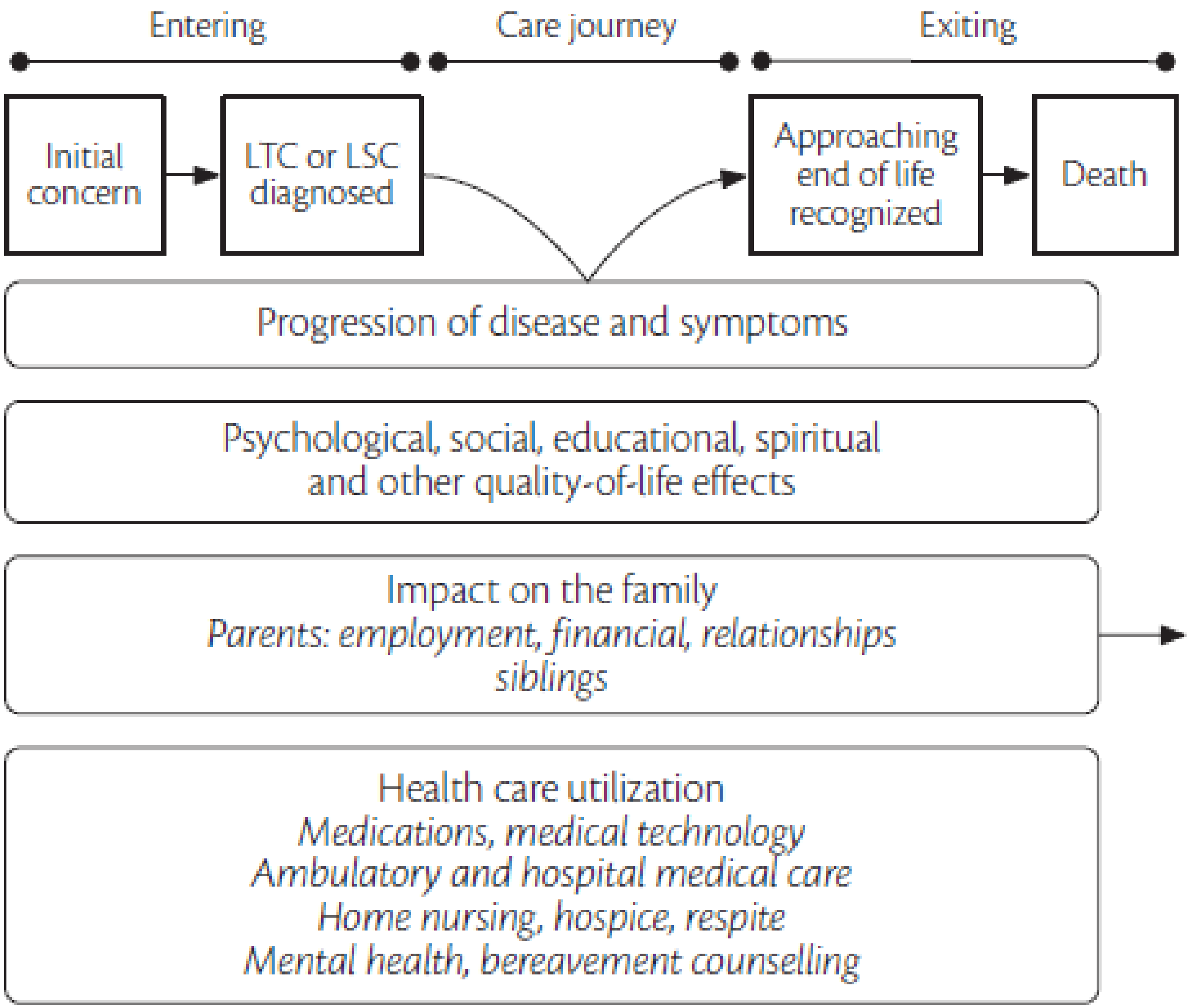
Conceptual framework of an illness journey

McNamara-Goodger and Feudtner 2012



Progression of disease and symptoms

Psychological, social, educational, spiritual and other quality-of-life effects

Impact on the family
Parents: employment, financial, relationships siblings

Health care utilization
Medications, medical technology
Ambulatory and hospital medical care
Home nursing, hospice, respite
Mental health, bereavement counselling

What is the Palliative Care Journey?

From Diagnosis through

Living with the Condition to

End of Life Care, Death and into bereavement

Each care journey is unique – as each life is unique.

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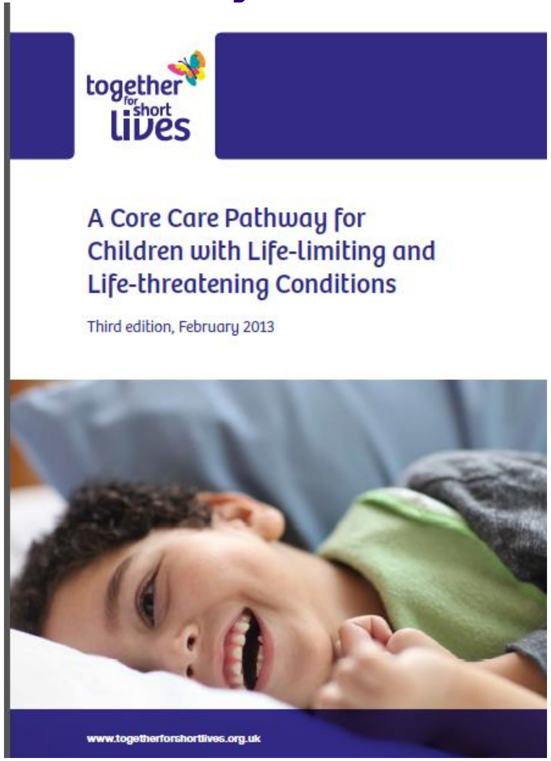
The Core Care Pathway

- The pathway is guided by key standards, based where possible, on evidence.

- The focus is on the child/family rather than the system

- The Pathway has 3 phases:
    - Diagnosis/recognition,
    - Ongoing care and
    - End of Life care



A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

Third edition, February 2013

www.togetherforshortlives.org.uk

Overarching principles

Best interests Communication Spiritual support Uncertainty and losses Multiple admissions Psychological support Coordinated care 24hr support Ability to respond quickly and flexibly Diversity and cultural issues Parallel planning Care for the team around the child Advance care plan Consent and Confidentiality A unique journey for every child and family

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Standard 1

Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

Information should be provided for the child and the family in a form that they can understand.

Standard 2

Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

Standard 3

Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.

Standard 4

Every child and family should have a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multiagency team should be identified in agreement with the family and use key working principles.

Wherever possible this should involve all agencies involved in supporting the child and family, including the child’s community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.

Standard 5

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.

What does end of life mean?

Together for Short Lives defines the end of life phase as beginning when it is recognised that death is imminent.

This may be recognised by a health or social care professional, but it is often the child or family who first recognises its beginning.

In some cases end of life will follow very shortly after diagnosis, and decisions on care need to be taken instantly. In some cases this
could be very shortly after birth.

Standard 6

Bereavement support should be provided along the care pathway and continue throughout the child’s death and beyond.

After death

The family should be allowed time and privacy with their child.

Parents should feel in control of events after death and should be able to make their own choices.

Practical advice and written information should be given about removal and care of the body, official procedures and entitlements.

Don’t forget

Ambitions for end of life care

A shared vision for better care:
2015-2020

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Six ambitions

3. All staff are prepared to care

4. Care is coordinated

2. Comfort comes first

5. Each community is prepared to help

1. Each person is seen as an individual

I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).

6. Each person gets fair access to care

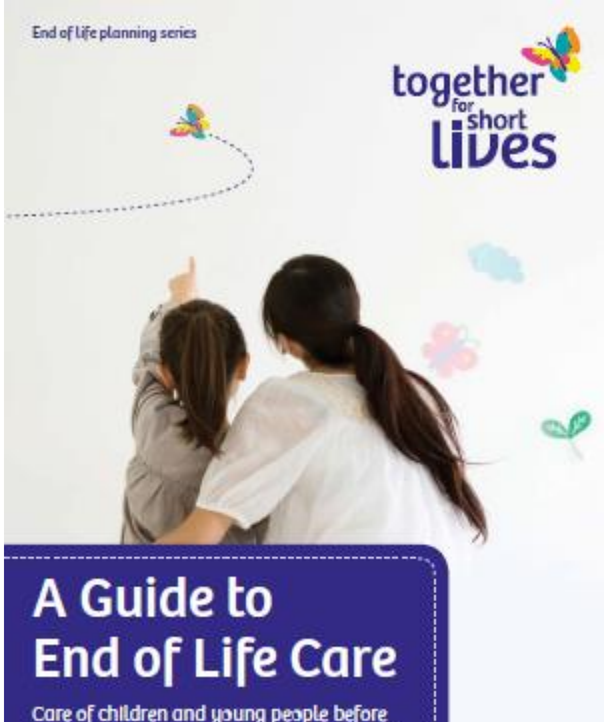
Available resources

Ninth edition, 2013

Basic Symptom Control in Paediatric Palliative Care

The Rainbows Children's Hospice Guidelines

www.togetherforshortlives.org.uk

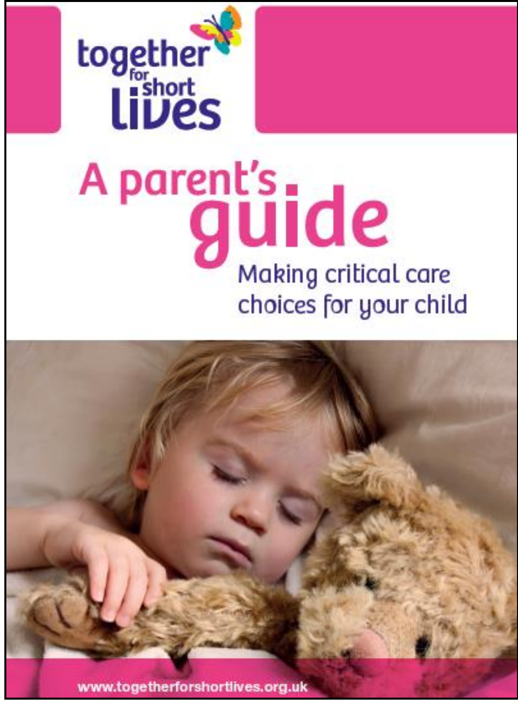


End of life planning series

A Guide to End of Life Care

Care of children and young people before death, at the time of death and after death

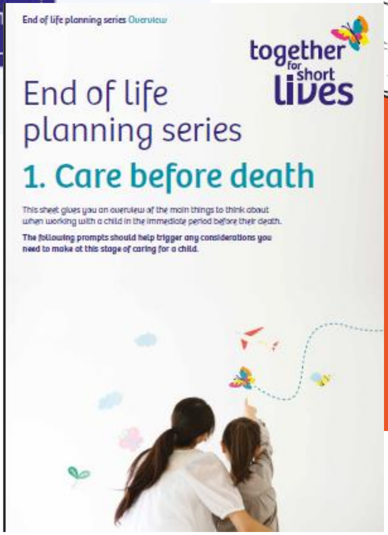
Together for Short Lives, August 2012



A parent's guide

Making critical care choices for your child

www.togetherforshortlives.org.uk



End of life planning series Overview

End of life planning series

1. Care before death

This sheet gives you an overview of the main things to think about when working with a child in the immediate period before their death.

The following prompts should help trigger any considerations you need to make at this stage of caring for a child.

Difficult Conversations

Making it easier to talk about end of life issues with young adults with life-limiting conditions.

Useful links

Together for Short Lives: http://www.togetherforshortlives.org.uk/

National Council for Palliative Care: http://www.ncpc.org.uk/

Hospice UK: http://www.hospiceuk.org/

NICE End of Life Care quality standard: https://www.nice.org.uk/guidance/qs13

NHS Choices End of Life Care guide: http://www.nhs.uk/Planners/end-of-life-care/Pages/hospice-care.aspx

Ambitions for Palliative and End of Life Care: http://endoflifecareambitions.org.uk/

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