

Media Fact Sheet



When a child's life is expected to be short, there's no time to waste.

Together for Short Lives is here to make sure the 49,000 seriously ill children and their families across the UK can make the most of every moment they have together, whether that's for years, months or only hours.

We stand alongside families, supporting them to make sure they get the vital care and help that they need.

Why we're here

- We support and empower families caring for seriously ill children by listening to their needs and helping them find the right care.
- We provide easily digestible information about available support so families can spend less time searching for help and have more time together. We connect families with support services and other families who understand what they are going through, so they don't feel as alone.
- We provide a dedicated Together for Families Helpline and information service so families know they have someone to turn to, available 10am - 4pm Monday to Friday.
- We support all the professionals, children's palliative care services and children's hospices that deliver lifeline care to children and families across the UK. Working with professionals and organisations we provide a strong, unified voice and help services deliver the best quality care and support for children and families.
- We lobby governments and campaign for a secure future for children and families so the services they rely on are there tomorrow and families know they will always get the support they need.
- We raise funds for children's hospice services so they can continue to deliver lifeline care to children and families.



Facts and figures

Prevalence

There are around **49,000** children (age 0-19) in the UK with a life-limiting or life-threatening condition. Many of these children have complex conditions and need specialist care 24 hours a day, seven days a week.

5,000 children die each year in England and Wales. Of these, **2,500** children and young people die each year from life-shortening or life-threatening conditions. (Sidebotham P et al (2014). Child death in high income countries 2: patterns of child death in England)

Isolation and mental health

84% of families with a child who has a life-limiting condition say they have felt isolated and alone since their child's diagnosis. (Hidden Lives: Tackling the Social Exclusion of Families Caring for a Seriously Ill Child, 2018, Together for Short Lives)

72% of families of disabled children experience mental ill health such as anxiety, depression or breakdown due to isolation (Forgotten Families: The impact of Isolation on Families with Disabled Children Across the UK, 2011, Contact a Family)

Financial hardship

Four in every ten disabled children are living in poverty. (4 in every 10, 2011, The Children's Society)

83% of families with a disabled child 'go without' due to financial pressures – 31% without food and 33% without heating. (Counting the Costs, 2014, Contact a Family)

41% of families surveyed with a disabled child needed a loan to pay for food and **36%** needed a loan to pay for heating. (Counting the Costs, 2014, Contact a Family)

Siblings

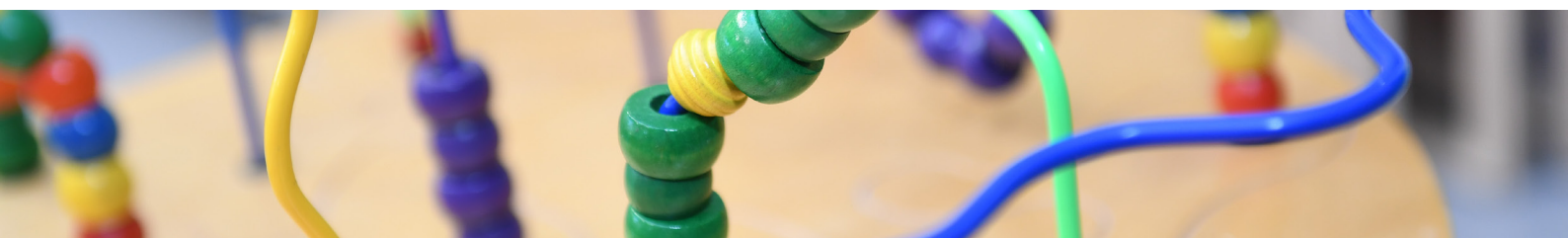
A 2017 study of 39 siblings age 3-16, showed that siblings of children with life-limiting condition presented higher levels of **emotional and behavioural difficulties, and lower quality of life** than population norms. (Fullerton J et al, Siblings of children with life-limiting conditions: psychological adjustment and sibling relationships, 2017)

Funding

The public think that children's hospices receive **38%** of their funding from statutory sources, when in reality they only receive **22%**. (2016 YouGov survey by Together for Short Lives)

81% of the public think that children's hospices receive too little funding from statutory sources (2016 YouGov survey by Together for Short Lives)

On average, the overall amount of statutory funding for charities providing children's palliative care continues on a downward trajectory, falling year on year (**22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14**) (Statutory funding for voluntary sector children's hospice and palliative care providers in 2016/17)



Key Definitions

Children's palliative care

Children's palliative care 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 or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.

Children's hospices

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. They are delivered by a multidisciplinary team and in partnership with other agencies and take a holistic approach to care, aiming to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services. There are 53 children's hospice services in the UK with support available on a local level across the whole country. Find your nearest service here.

Life-shortening conditions

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

Life-threatening conditions are those for which curative treatment may be possible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings children's palliative care into the home environment. Hospice at home works in partnership with parents, families and other carers.

End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team responsible for the care of the patient, but it is often the child/young person or their family who first recognise its beginning.

End of life care

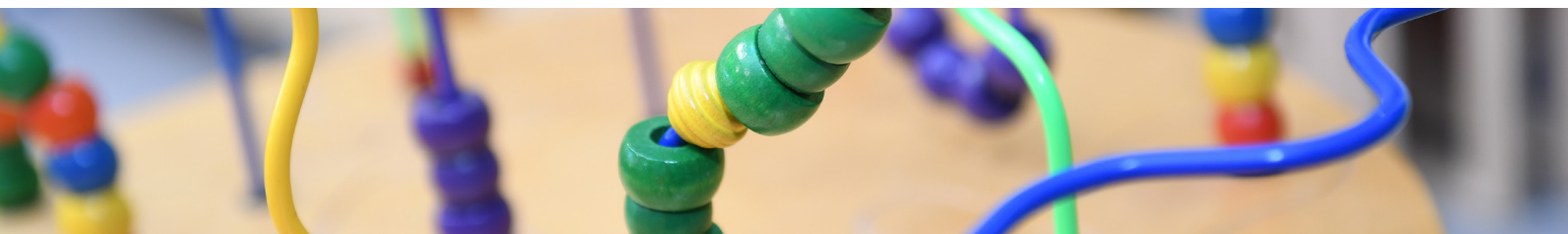
End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition – this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the child/young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.

Short breaks

Short breaks have three main functions: providing the child or young person with an opportunity to enjoy social interaction and leisure facilities; supporting the family in the care of their child by providing a break (respite) from caring and to provide opportunities for siblings to have fun and receive support in their own right. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Transition

The process that children and young people go through as they prepare for and move from children's services to adult services. Together for Short Lives has established Transition Taskforce that leads the development of providing care and support to young people with life-limiting or life-threatening conditions.



Myths

There are many myths surrounding the role of children's hospice and palliative care services including:

“Children's hospice services only offer end of life care”

Children's hospice services offer a vast range of support from the moment of diagnosis. Whilst end of life care is an important part of this service, children's hospices provide support including: short breaks; 1-1 counselling; music and play therapy; sibling support groups; craft activity sessions and In Memoriam days.

“Support from children's palliative care services does not extend to the whole family”

Children's hospices support the entire family, often over many years and at any stage of a child's illness. They offer the opportunity for healthy brothers and sisters to take part in activities including craft activity sessions and sibling support groups. A short break at a hospice gives families the opportunity to relax, play and spend time together – it also gives

“Children can only receive palliative care in a hospice of hospital”

Children's hospices support families in their local hospice buildings but most also provide support in people's homes and in their community.

“Children's hospices and palliative care services are fully funded by the government”

It costs around £3.3 million a year to run a children's hospice, but these lifeline services only receive around 22% of their funding from the government. For the other 78%, children's hospice and palliative care services rely on voluntary contributions.

“Children's hospice services are sad and depressing places to visit”

People often have a picture of children's hospices as dark and depressing places. Yet if you walked into any children's hospice you would be left in no doubt that they are bright, colourful and vibrant, focused on life – however short it may be. Children, young people and families will tell you how much they love their hospice and the staff that work there. They are a real home from home.

“Palliative care is giving up”

When treatment stops, palliative care will continue, and this should include pain and symptom management, as well as care and support for the whole family. When doctors talk about palliative care, not continuing with treatment or allowing someone to die it can sound frightening. But none of these approaches mean abandoning the child's care, pain management or comfort. Children's palliative care is never about giving up, it's about care – and helping children and families make the most of every moment.

If you have a question or would like to find out more information about Together for Short Lives, please speak to the communications team between 8.30am – 5.00pm, Monday to Friday. For out of hours enquiries, please [contact Myra Johnson](#) or call 07775 336460.