

# together for families

Issue 23  
Spring 2018



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## In this issue:

Our work in Westminster

Support for families in bereavement

Our Lifeline Appeal



Together for  
Families Helpline

**0808 8088 100**

[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

The Together for Families Helpline provides information for families, carers and professionals; and for those calling on behalf of a friend or relative. The free helpline is for parents and carers who look after or know a child or young person who is expected to have a short life.

The helpline is open Monday to Friday between 10am and 4pm. Outside of these hours, you can leave a message and we will get back to you as soon as possible.

Email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk) to subscribe to *Together for Families*, or if you would like to contribute to a future edition – we'd love to hear from you.

Follow us and join the conversation!

 @Tog4ShortLives

 [togetherforshortlives](https://www.facebook.com/togetherforshortlives)

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Together for Short Lives is a UK wide charity that, together with our members, 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.

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is incorporated as a company limited by guarantee (7783702).

together  
for short  
lives 

## Welcome to the Spring issue of *Together for Families*.

At the time of writing this, the team at Together for Short Lives is busy collating stories that showcase achievements of the past year to form the basis of our 2017/2018 Impact Report. We have also launched our new strategy this month. Thank you to all of you who took the time to inform the strategy consultation exercise last year and we look forward to sharing headlines from the strategy with you in our Summer edition.

This issue has a particular focus on the policy and services that are in place to support families in bereavement. We are particularly grateful for the contributions on page 3 from Alison Penny, coordinator at the Childhood Bereavement Network. If you need any type of bereavement support, do contact Annie, our new Family Support and Engagement Officer, who is introduced to readers on page 4.

We're excited to be launching an updated [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) website this Spring. We know that most families who access information on our site use their mobile phones to do so, and so the new site has been designed and built to be fully responsive on mobile phones and tablets. We're currently working hard to move all our content across to the new site, and we will be launching as soon as testing is complete – so watch this space!

Finally, we were thrilled to be chosen as the charity beneficiary of **BBC2's Lifeline Appeal** in February. We are grateful to Josie and Chelsea who kindly agreed to be filmed for the appeal. Their stories helped raise both awareness and crucial funds to support our work.

**Julia and Clare**

# Taking the case for children's palliative care choices to Westminster

An update from James Cooper, Policy and Public Affairs Manager of Together for Short Lives



## 'Our Commitment to You for End of Life Care'

In July 2015, the government published 'Our Commitment to You for End of Life Care'. This sets out what ministers expect commissioners to achieve for babies, children and young people with life-limiting and life-threatening conditions, including:

- respite care, delivered in a children's hospice setting, by community palliative care services, or 'hospice at home' services
- good collaboration between different clinical and non-clinical services across a variety of different settings
- support around bereavement, both before and after a child dies
- prioritisation of children's palliative care in commissioners' strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon.

## All Party Parliamentary Group

Meanwhile, we have been supporting a group of MPs and peers to examine the extent to which the end of life care choice commitment is being met for babies, children and young people in England. As secretariat to the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, we have collected written evidence from families, children's palliative care services and professionals and organisations which plan and fund NHS care. We have also been holding a series of oral evidence sessions at Westminster, which has enabled representatives of these groups to tell parliamentarians what choices children and families can and should be able to make about how and where they receive palliative care. We are grateful to members of our family groups for their powerful contributions to these sessions.

As part of the inquiry, witnesses have been telling parliamentarians:

1. What choices children and young people in England with life-limiting and life-threatening conditions – and their families – can reasonably expect to make about the care and support they receive.
2. Whether children and young people in England with life-limiting and life-threatening conditions make these choices.

3. What the barriers are preventing children and young people from making these choices.

The APPG will publish a report of its findings and recommendations to government in the autumn, alongside all the written evidence it has received and transcripts of the oral evidence. Look out for more news in forthcoming *Together for Families*.

## Follow The Child

We have been busy making the case for better palliative care choices for children and their families at Westminster. On 31 January, Together for Short Lives teamed up with five other charities to support bereaved parent Sacha-Langton Gilks at a parliamentary reception. Together, we urged parliamentarians to 'Follow The Child' and press the government to make sure that the choices seriously ill children and families can make about their palliative and end of life care are based on their needs, wishes and best interests. We believe that choices should not be restricted by the postcode in which children and families live.

The charity coalition consists of Together for Short Lives, The Brain Tumour Charity, CLIC Sargent, Teenage Cancer Trust, Marie Curie and The National Gold Standards Framework Centre in End of Life Care. We are calling on the government to help families facing the unimaginable by meeting its end of life choice commitment for babies, children and young people – and by implementing the NICE (National Institute for Health and Care Excellence) guideline on providing children's palliative care.

Please get involved in our campaign by contacting your local MP to ask them to write to ministers and your local NHS organisations about the palliative care choices they are providing. We have created briefings for MPs in all four countries **here**. You can also see which MPs and peers attended our reception on this page.



# Bereavement

Being well supported in bereavement is so important, yet we hear too often from families that they weren't able to access the right care and support for themselves or for their family at this time. In this issue of *Together for Families* we are highlighting some resources and policy developments that will hopefully address some of the shortfalls that currently exist.

## What bereavement support should be available in each area?

The National Bereavement Alliance has published *A guide to commissioning bereavement services in England*. It sets out what support should be available in each area. It builds on guidance from the National Institute for Clinical and Health Excellence (NICE), setting out three important components.

Component one, for everyone, is information about grief and about sources of support, so that communities can support one another. Component two, for people who want more support or who might be at risk of difficulties in bereavement, is social support from self-help groups, faith groups, befriending and community groups, and trained bereavement support workers. Component three, for people with complex needs or prolonged or complicated grief, includes specialist support from bereavement counsellors and practitioners, and specialist mental health support for those with mental health problems that pre-date or are triggered by their bereavement.

All three components need to be in place for bereaved people to get the right support at the right time. The *Guide* is intended to help commissioners understand the importance of grief support in every community.

[Click here to read the report.](#)

## Campaign for Children's Funerals

**Carolyn Harris MP is leading a campaign for parents not to be charged for children's funerals. Most undertakers waive fees for children's funerals, but burial or cremation charges are still made in many local authority areas. Carolyn has succeeded in persuading the Welsh Government and some individual local authorities in England to cover these costs. She is now pressing the government to scrap fees across England.**

Before becoming an MP, Carolyn's 8-year-old son, Martin, was tragically hit by a car outside the family home. At the time Carolyn was working as a dinner lady and barmaid and her grief and despair were compounded with the worry of how she would pay for her son's funeral. Fortunately, thanks to the support of the community in Swansea, Carolyn was able to cover the cost of her son's funeral. However, not all bereaved parents can rely on the support of friends and families.

Over 165 MPs have signed a letter to the Prime Minister, showing their support for proposals to establish a £10 million Child Funeral Fund.

[Click here to find out more.](#)

## Right to paid bereavement leave discussed in Parliament

**Kevin Hollinrake MP has introduced a bill to Parliament which, if it becomes law, will give parents bereaved of a child a new right to two weeks' paid leave.**

At the bill's second reading in the House of Commons, many MPs spoke movingly of their own bereavements and their reasons for supporting the bill. A committee of MPs has now met to consider improvements to the bill, suggested by Together for Short Lives, the National Bereavement Alliance and other charities. These suggestions would make the leave more flexible for parents and extend the same leave and pay to self-employed people.

In May 2018, the Government will be consulting on the time period over which parents can take the leave. Do look out for opportunities for you to have your say.

[Click here to find out more.](#)



## The value of on-going support

In December 2008 the Yearsley family's world was rocked by the discovery that their 8-year old, Isaac, had an inoperable brain tumour and at the very best prognosis only had 9 months left to live. His mother Catherine shares how they were supported before and after Isaac's death by their local hospice.

"In February 2009, Isaac and I travelled by ambulance from Bristol Children's Hospital to Little Bridge House in Fremington. It was a crisp, Spring day and I remember feeling peaceful and relieved as we pulled up outside. I felt an overwhelming sense of hope for the first time in months, not because Isaac's diagnosis had changed but because I strongly believed that here he would really enjoy his precious remaining days. Equally importantly, we could stay together as a family.

Our last visit to Little Bridge House was from 1 April to Isaac's death on Saturday 18 April. During that time, I could just be "mum" rather than carer or nurse. We were never rushed to say our goodbyes as Isaac rested peacefully in his Thomas the Tank Engine duvet in the special Starborn room.

The hospice offered bereavement support as long as we needed it and they did not abandon us after Isaac's funeral. My husband and I both joined the bereaved mums and dads support groups and over the years we have continued to visit on remembering days and fetes. Both of Isaac's younger sisters value the contact that we continue to receive from the hospice too.

The time and space offered at the hospice allows us to reflect back on memories. For the girls, it provides an ongoing link to their big brother."

# Grief can be a lonely journey when undertaken on your own

## The Jessie May Purple Group: A parent led peer support group for bereaved parents

Jessie May provides hospice at home services for children and young people with life-limiting conditions and their families. From diagnosis to bereavement support, the services provided by Jessie May nurses are based on the values of working in partnership, listening and responding to the needs of families.



Bereaved parents have shared with us how nothing can prepare them for the death of their child and described the grief that follows as isolating, chaotic and overwhelming in its intensity. Here, Julie Kembrey, a bereaved mum, describes how together they worked to develop a peer support group:

“In 2010, as a bereaved parent, I not only identified a gap in the Jessie May bereavement support offer but also proposed a way forward: the Purple Group, a peer support group for bereaved parents that I led with support from the bereavement lead at Jessie May. The group aimed to provide an opportunity to share authentic experiences.”

“From 2010-2017, 32 group meetings have taken place attended by 39 parents (27 female and 12 male). Some parents have attended a single meeting and others up to 16 times.

“The group has an established structure for the two-hour meeting. After introductions

and a reminder of the ground rules – covering confidentiality, personal wellbeing and safety – the first hour is a group support session, usually started by a reflective story shared by the parent lead.”

“After an hour, group members socialise and continue talking over food and refreshments, in 1-1s or smaller groups. The conversations tend to continue to focus on loss and bereavement. At the end of this hour, the facilitators formally close the meeting.”

Formal evaluations using questionnaires have been undertaken three times on a bi-annual basis, which indicated that those who replied had found the group helpful. Anecdotal feedback has been captured during meetings, in 1-1 bereavement support sessions and as part of the regular reflective practice sessions provided by a clinical psychologist for myself and the Jessie May bereavement lead.

“This has been used to develop strategies to enable the group to be psychologically safe

and contained whilst also providing a responsive and fluid approach so that group members can share their personal experiences.”

Feedback on this part of the meeting has included how normalising and assuring the responses of others has been and what an antidote to isolation it can provide for those seeking a safe space to talk about their child and their grief.

“Groups will not be for everyone, but for those who want to interact with others in the same situation it appears the Purple Group can reflect the beneficial elements identified by the research base in that it may offer identity, empathy, a sense of belonging, an opportunity to express feelings and learn from others in a manner which cannot be offered elsewhere.”

If you would like to know more about the group, please email [helen.williams@jessiemay.org.uk](mailto:helen.williams@jessiemay.org.uk).

## After Umbrage

**After Umbrage** is a charity established in 2013 to care for those who care. The charity offers free breaks at their cottage near Bath to carers of loved ones with life-limiting conditions and to those who have experienced bereavement in the past twelve months.

It's founder, Tara Belcher explains how the charity got its name. “When I was a child, my Mum gave me her old teddy bear. Umbrage was a bear who featured highly in my world. He was there to provide care, comfort and love when I needed it most. He's still with me in my heart and represents all the best bits my parents offered when we were growing up.”

With first hand experience caring for both her parents Tara appreciates how important it is to have some breathing space – “a slice of calm in a very turbulent time”.

The team at After Umbrage understand how important it can be for carers to take even a short break, and to rediscover yourself again.

We know how difficult it may be for our readers to take a few days out of their caring responsibilities. However, if you are able to benefit from this opportunity, do visit their [website](http://www.togetherforshortlives.org.uk) and download a referral form. If you are unable to have it authorised by your GP or hospice, staff at Together for Short Lives are able to authorise applications from members of our family community. Contact [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk) for our help.

## Introducing Annie – our new Family Support and Engagement Officer



**Hi, I'm Annie. I join Together for Short Lives from a background in supporting families and young people across the charity sector and am now in post as the Family Support and Engagement Officer.**

I'm keen to hear from you how we can support you better as a charity and how you'd like to be more involved. Day to day this means you can get hold of me by calling the helpline **0808 8088 100** or by emailing me at [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).

You can call us for information, help to find local services or just for a chat about what's going on for your family today. You can also call for a referral to our advocacy service, this includes practical support to write a letter or learn more about your rights from a legally trained volunteer.

# Introducing the Comfort Capsule

**Newlife**, the Charity for Disabled Children, has been supporting children with disabilities and terminal illness for over 25 years and is the largest charitable provider of essential disability equipment in the UK.

As well as providing equipment for ongoing care, Newlife also offers support when time is short. The charity has worked closely with a team of health care professionals to create the Comfort Capsule, a suite of items carefully compiled to offer comfort and support to families when they need it most.

The capsules are loaned for free and contain items that help build memories to be treasured forever, including a voucher for a 3D hand or foot cast, a camera and a digital photo frame as well as practical items like a portable DVD player to help distract children during treatments and long hospital waits. Some items, including a blanket, teddy, memory box and talking photo album are gifted for families to keep. There is also the 'experiences envelope' that contains useful information to help families access other organisations who offer support and organise trips.

Newlife supplied a Comfort Capsule to Vicky Sansome from Nottingham, for her two-year-old son, Patrick. He has a rare brain condition called Pontine Tegmental Cap Dysplasia which has caused global development delay as well as seizures and hearing loss. Patrick also has only one kidney, which doesn't work properly and no nerves in his eyes or face.

Vicky, said: "The digital camera has been brilliant for us – we are trying to take as many pictures as possible. We also have quite a



lot of hospital stays with Patrick so the DVD player has been really helpful at distracting him when we are there. He loves the blanket and the pillow – they have gone everywhere with him since we had them."

"He also really loves the teddy bear – Patrick doesn't really like to be held but he does love contact – the weight of the bear on his tummy feels like he is being touched and helps distract him from discomfort as he is also prone to painful wind. Patrick has a twin and they were able to use the handprint maker together – we are trying to make as many memories of the two of them together as we possibly can."

Vicky, who is trying to raise more awareness of Patrick's condition also described how it can be isolating as a parent of a child with a rare illness. "There is very little research about Patrick's condition," she said. "It can be quite lonely and scary thinking that you are the only family going through it. We didn't know that anything like the Comfort Capsules existed but it is an absolutely fantastic service."

To apply for a Comfort Capsule, simply contact the Newlife Nurses on **0800 902 0095** to discuss your eligibility. For more information about Newlife, the Charity for Disabled Children, its services and to hear Patrick's story, visit the website [www.newlifecharity.co.uk](http://www.newlifecharity.co.uk).

## Ever feel motivated to take on a challenge event?

**We know how all-encompassing caring for a child with complex health needs is. That is why we are always amazed when families approach us asking how they, a relative or someone from their network of friends, can fundraise on our behalf. We have lots of different events from the London Marathon to craft-tea parties. And we have all sorts of people fundraising for us too.**

"Together for Short Lives is a great cause and I am really glad to have had the opportunity to support it. The trek was challenging but extremely enjoyable." Mridula who completed Together we Trek in 2016.

If you know someone who would like to take part in a challenge event to raise money for Together for Short Lives, visit our **website** to get some inspiration on what they might want to do. Highlights include free registration to Ride London and opportunities for the whole family to get involved in the **Superhero Series 2018**.

# Single route of SEND redress for families

**As of April 2018, all local authorities in England are expected to have transferred every child and young person with statements of special educational needs (SEN) to the new SEND system following a 'transfer review'.**

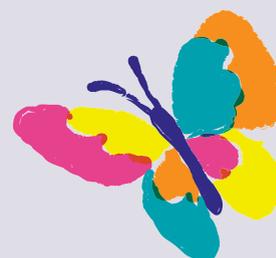
The government expects the vast majority of children with statements to have been transferred to an education, health and care (EHC) plan. To make sure that children continue to receive the support they need during the transition period, local authorities must continue to comply with the previous SEN system.

A two-year trial of a single, joined-up way of challenging decisions made by the NHS and local authorities about EHC plans began across England in March. Under the previous system, the first-tier SEND tribunal could only make judgements on the education elements of EHC plans; from March, the tribunal has been able to make non-binding recommendations on the health and social care aspects too.

The work to implement the new process – and the outcomes it achieves for families and commissioners – will be evaluated. The trial makes local authority SEND teams responsible for:

- informing parents and young people of their new rights including
- contacting the relevant health or social care lead about the issues raised and providing evidence to the tribunal on their response, bringing additional witnesses to the hearing if necessary
- once a decision has been made, sending the health or social care response to the evaluators.

A toolkit to support local areas implement the new approach is available **here**.



# Josie and Chelsea

In February of this year, Together for Short Lives were selected to be the beneficiary of BBC2's Lifeline Appeal. Two very special people shared their stories with the nation as part of the appeal.

## Josie

An antenatal scan at 34-weeks changed Josie's life forever. Josie and her partner Ben already knew that their daughter could have health challenges, but they were not anticipating the devastating news that Billy-Rose had hydranencephaly, which meant her brain was not fully formed.

At the hospital whilst waiting for their scan results, Ben, suffered a fit and hit his head. He never recovered and died a week later, seven weeks before Billy Rose was born.

Josie decided to continue with her pregnancy, but often felt as though professionals saw termination as her only option. "It was an incredibly isolating moment – I was totally lost at sea, alone in the middle of a huge field – and felt like a freak for wanting to have my baby."

Reflecting on that time, she says, "If only I'd been told about Together for Short Lives then or been given a copy of your *Perinatal Care Pathway*. Once I started to read other family stories on Together for Short Lives' website, I realised that I wasn't alone or a freak – and support was out there."

Billy-Rose's life was short: she lived for just six months, a time Josie cherishes. She remembers, "I had a wonderful opportunity to give my daughter what she needed – to see the sunshine, feel raindrops, and put her feet on the green grass."



## Chelsea

Chelsea is 24 and lives with her husband and full-time carer, Jonathan. She grew up with a range of health conditions, and often had periods of being acutely unwell, which affected her schooling and meant frequent visits to Birmingham Children's Hospital.

Shortly after she was married, Chelsea had Meningitis and started experiencing serious seizures. Following an emergency hospital admission, Chelsea was told that she had been diagnosed with Ehlers Danlos syndrome, and was now considered as being "life-threatening" and "life-limited" due to the severity of her conditions. The news was a huge shock to Chelsea, who struggled to come to terms with her new prognosis.

To complicate things further, this news came at a time shortly after Chelsea had moved from children's to adult health and social care services, a process known as transition. For Chelsea, this had been a difficult, and rather abrupt process and had left her and Jonathan struggling to get the support they needed.

After getting in touch with Together for Short Lives through Twitter and its helpline, Chelsea and Jonathan discovered they could access support from a local adult hospice, and Chelsea also joined the Young Avengers, a group established by Together for Short Lives to give young people a voice and improve young people's experiences of transition. Being part of the group has given Chelsea a voice, empowering her to improve the experience for other young people.

We couldn't do the work we do without families being willing to share their experiences. We are grateful to all the members of our family groups who add their voices to our work. If you would like to find out more about joining a family group, please email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).

