

together for families

Issue 21
Summer 2017



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In this issue:

Frank's story

Parents speak at our conference

Launch of the 'Secret Life of Us' campaign



Together for
Families helpline

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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 families@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.

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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).

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together
for short
lives



Welcome to the summer issue of *Together for Families*.

The last few months have been really busy here at Together for Short Lives, with our 'Defining Moments' conference, launch of the *Perinatal Pathway* resource, Children's Hospice Week and the Midsummer Ball, not to mention the snap General Election!

Our conference this year on 10-11 May was themed around 'Defining moments in children's palliative care: Transforming the family experience' and was all about untangling some of the knottiest challenges children, young people and families face. Our conference was opened by Julie Kembrey and Josie Pavey, two bereaved parents who spoke movingly of their defining moments from a parent's perspective. We also launched a vital resource for babies expected to have very short lives - *The Perinatal Pathway for Babies with Palliative Care Needs*. This new care pathway is designed to support professionals working with affected families to enable them to spend precious time with their baby, in a more home-like environment where possible, and with as little technology dependent care as possible.

We went straight from a successful conference to the launch of Children's Hospice Week, which took place between the 22-28 May. This year we turned up the volume on children's palliative care to raise awareness about the number and needs of children with life-limiting conditions and to celebrate all the lifeline services that children and families rely on.

The needs of such families were highlighted on 7th June by mum Rachel Thompson, who gave a powerful speech at the Midsummer Ball hosted by our Patron, Simon Cowell, to support our work helping seriously ill children and their families. Rachel shares her own experiences of caring for her son Frank with us on page 6.

Do remember that if you'd like to receive more regular news from us then you can sign up to our e-bulletin, or if you would like to connect with other parents, please join our private Facebook group. Head to our website to find out more: www.togetherforshortlives.org.uk/families/familys_journey.

Julia and Cat

The Duchess of Cambridge launches Children's Hospice Week

Her Royal Highness, The Duchess of Cambridge recorded a personal video message to celebrate and mark the beginning of this year's Children's Hospice Week, which ran from the 22-28 May.

The Duchess, as Royal Patron of East Anglia's Children's Hospices (EACH), has seen first-hand the remarkable work that children's hospice services like EACH provide for children and families – helping families make the most of every precious moment.

You can watch the video message on our website here: www.togetherforshortlives.org.uk/childrenshospiceweek/royal_message_of_support.



Turning up the volume

This year's Children's Hospice Week was all about turning up the volume on children's palliative care to raise awareness and to celebrate all the lifeline services that children and families rely on.

We wanted to amplify families' voices and change people's perceptions about some of the myths surrounding children's palliative care.

Lots of stars joined the campaign to turn up the volume, including Together for Short Lives Patron Holly Willoughby, who said: "I'm turning up the volume this Children's Hospice Week to celebrate all the amazing services supporting families across the UK. As Patron of Together for Short Lives I know the difference these lifeline children's hospice services make to families facing the unimaginable. They are such positive, happy places helping families make the most of their lives together."

As part of Children's Hospice Week we shared Isabella's story. Six-year-old Isabella lives with her mum Michala, dad Roger and sisters Aimie, Daisy, and Molly. Isabella has a number of neurological conditions including complex refractory epilepsy and global developmental delay, as well as developing psychological and behavioural issues. She has been receiving care at EACH for the last four years. You can read Isabella's story on our website: www.togetherforshortlives.org.uk/childrenshospiceweek/isabellasstory.

Perceptions of children's palliative care

A new survey, commissioned for Children's Hospice Week, gives fresh insight into people's perceptions, feelings and experiences of children's palliative care.

It shows a worrying lack of public understanding about what children's hospices and palliative care means (over a quarter (26%) said they don't know what it is). It also shows people are uncomfortable talking about serious illness and death in children.

Over one in three people (38%) would not feel comfortable talking to a friend whose child had been diagnosed with a life-limiting or life-threatening condition. Our survey reveals almost 35% have had, or know someone who has had, some experience of serious childhood illness or a child dying young.

We know that families caring for seriously ill children often say they feel lost and alone when coming to terms with the news that their child may not reach adulthood. The taboos around serious childhood illness and death in childhood can leave families feeling isolated, abandoned and vulnerable without support. Mum, Vicky Whyte said: "When someone didn't find a way to show us that they cared, we assumed that they didn't..."

Children's Hospice Week sought to challenge those preconceptions, giving people the confidence to talk to and support families in their community when they need it most. We will continue to raise awareness to increase understanding – so families don't feel so isolated.

Family Support Volunteering

For many years we have talked to families about the pressure they are under juggling looking after their sick child, caring for siblings and trying to keep up with housework and other chores.

Over the past 12 months, Together for Short Lives has been running a Family Support Volunteering pilot project in 3 locations (Bristol, London and Warwickshire) to explore how volunteers can support these families. In each of the sites volunteers were recruited to provide support to families in their homes, undertaking everyday tasks, such as cleaning, ironing, dog walking or helping siblings with their homework. The project aimed to test the extent to which this would help take some of the pressure off and was generously supported by The True Colours Trust and The Royal Foundation of The Duke and Duchess of Cambridge and Prince Harry.

During the pilot we developed a set of training materials for volunteers and piloted these and a range of materials that we hope can now be used in other sites across the UK to promote this approach to Family Support Volunteering. We have carried out a full evaluation of the pilot, exploring the experience of families, volunteers and the organisations that have been involved.

Families told us that they had very much valued the support provided:

Having an extra pair of hands – having the ironing done – it's my worst job, it's great to have a week's worth of clothes ready in piles to put away.

It's been really good for the siblings to have someone coming just for them and for them to feel special too. It has also been really positive for the family having a male presence in the home and this has been positively received

from the children. Both the children have a really great relationship with the volunteer.

It has made a huge difference to me and P as well. I was finding it frustrating that there were things I wanted to do but didn't have the time to do. I feel less stressed.

We are currently exploring how we can best embed the learning from the pilot across other organisations.



Something I've realised since I started volunteering is that these families aren't really any different from my own: they're just as hectic, loving and full of laughter.



The Secret Life of Us (DCP)

In England today there is an unacceptable contrast between the quality of life and opportunities available to disabled children, when compared to those without disabilities.

Did you know, 69% of families with disabled children receive no support in caring for their child? Or that 43% of the general public don't even know anyone who is disabled? And that 97% of parents with disabled children say that people do not understand the challenges they face, every day?

That's why Together for Short Lives is really excited to be a part of the Disabled Children's Partnership, a growing coalition of more than 35 organisations that have joined forces to fight for better health and social care for disabled children, young people and their families in England.



To make this change, on 28th June we launched the **Secret Life of Us** campaign. It will bring to life the realities of the challenges disabled children, young people and their family's face in living a life many of us take for granted.

We want to open the eyes of the public and improve understanding of the issues faced by families on a day-to-day basis. We want to remove the barriers to people being able to relate to the lives of disabled children, creating greater understanding, affinity and empathy for them and their families.

If we do this we will have the support to make the changes that will make a real difference to disabled children, young people and their families across England.

We will do this by revealing the part of their lives that the public do not see. Revealing the **Secret Life of Us**.

You can read more about the campaign on the DCP website: www.edcm.org.uk or engage with the **#SecretLifeofUS** campaign on Facebook and Twitter **@DCPcampaign**.

Center Parcs prize draw

Having donated short breaks to our families for a number of years, April 2016 saw the start of a two-year charity partnership with Center Parcs. Year one went so well they decided to extend our partnership for an additional year, taking us to June 2019! During this time they will fundraise to support the vital work of children's hospice services and help spread awareness about the sector to staff and guests. During the first year of the partnership, they raised an incredible £193,551!

As part of their ongoing support for our work, they have kindly donated 15 short breaks to members of our family community. As in previous years, the breaks can be taken at any of the five UK Center Parcs village locations: Whinfell Forest in Cumbria, Sherwood Forest in Nottinghamshire, Elveden Forest in Suffolk, Woburn Forest in Bedfordshire and Longleat Forest in Wiltshire. Accommodation will be in a three-bedroom Woodland Lodge. The breaks can be taken for a long weekend (Friday-Monday) or midweek (Monday-Friday) but excludes school and public holiday periods. We are inviting members of Together for Short Lives' family community to enter into a draw to win one of these breaks.

We need you!



Learning from families is key to the work of Together for Short Lives. Your personal experience is the most powerful tool to raise awareness and understanding among the general public, services, policy and decision makers.

That is why we encourage families who have cared for, or are caring for a child with a life-limiting or life-threatening condition to join one of our family groups.

We are currently looking to recruit new members to our Family Reference Group (formerly referred to as our Advisory Group). The group meets by telephone four times

a year to help shape our work and reports directly to our Board of Trustees. To be representative of members of our family community, we are particularly looking to invite parents and carers with recent experience of care in Scotland, Wales or Northern Ireland, who have received support from a neonatal intensive care setting and those who foster children with life-limiting conditions.

If you are interested in applying for a position on this group, or would like to discuss further, please email julia.hodgson@togetherforshortlives.org.uk with a brief paragraph outlining what experience you could bring to the discussions.

We look forward to hearing from you.

Visit our website to join one of our family groups: www.togetherforshortlives.org.uk/families/familys_journey/get_involved_in_our_work



Evie received essential equipment from Newlife.

When you just can't wait....

Newlife the Charity for Disabled Children has recently become a member of Together for Short Lives. We invited them to inform our readers of the support they offer to our families.

The agonising wait for essential equipment that can ease pain or aid mobility, health and social outcomes is something with which many readers can identify. When your child is life-limited there is always the concern that support could come too late.

Which is why Newlife the Charity for Disabled Children offers a special service for those families providing Emergency Equipment Loans of specialist beds, wheelchairs, buggies, seating and portable hoists.

Newlife's Care Services Team is on hand to help – call **0800 902 0095** or email nurses@newlifecharity.co.uk. All applications must be supported by a relevant health professional. The charity aims to deliver equipment anywhere in the UK within 72 hours.

Our team works with the child's professional to establish eligibility and specification. While on loan the equipment is fully maintained and when no longer needed is quickly collected. It is then tested by the supplier and clinically cleaned before being made ready for reissue.

Carrick Brown, Newlife's Care Services Senior Manager, said: "We have a core suite of equipment within this service, which offers families a rapid response; this is the only national service of its kind. Newlife recognises the need for flexibility – and for that reason we can also pull on the resources of our 'Newlifeable' recycling initiative, which takes items donated by local statutory services and individuals and refurbishes them to national standards before getting them back into use anywhere in the UK, either through a Newlife Equipment Grant or by selling them at significantly reduced prices."

Newlifeable can, at any time, include items like portable hoists and bathing aids in

addition to beds and seating, wheelchairs and buggies, standing and walking frames. "We review individual need and look at temporary loans of this equipment."

Emergency Equipment Loans are made for around six months, while Newlife works with local statutory services to secure provision. If this isn't possible, the charity can look to make permanent provision through its Equipment Grants service.

Newlife's swift response meant three-year-old Evie Appleyard was able to be discharged from hospital to spend precious time at home in Stockport with her mum and dad.

Evie has a rare life-limiting undiagnosed neurometabolic condition which has resulted in developmental delay, epilepsy and a visual impairment. She has spent five months of her life in Manchester Children's Hospital.

Mum Christine said: "It would have been a lot longer if it wasn't for Newlife; the organisation has provided us with several pieces of specialist equipment vital in helping us care for Evie."

Newlife's Emergency Equipment Loans service provided a specialist Stingray buggy to get her out and about, as well as safe and comfortable P-Pod seating so she wouldn't be confined to bed at home. Christine said: "Both pieces of equipment were a massive help at the time. It was several months before wheelchair services could make provision, so we were able to get her out and about in the interim. And without the P-Pod Evie would have had to have spent most of the time at home in bed. Instead, she was able to sit, supported and comfortable, in the lounge and be part of the family."



If you have not previously received a break from us and are keen to enter the draw, please email your contact details to sarah.knight@togetherforshortlives.org.uk by 12 pm on the 1st September 2017. Please include details of your child's condition, age and access requirements. Together for Short Lives will contact the lucky families and organise the holiday for a convenient time. All holidays need to be taken by April 2018. We wish you the very best of luck!

One of the lucky winners from our 2016 Centre Parcs draw said:

"We just wanted to thank you for a wonderful holiday. Center Parcs really do cater for wheelchair users very well and the lovely train drivers always made us smile. The accommodation was beautiful and quiet. A time to think and reflect. We saw lots of wildlife. We even had a deer outside our accommodation. Thank you Center Parcs and Together for Short Lives for a holiday we desperately needed. We have made some very happy memories."

Defining Moments conference

Together for Short Lives' conference was held on the 10-11 May in Birmingham. With the theme 'Defining moments in children's palliative care: Transforming the family experience', we were delighted to invite parents Julie Kembrey and Josie Pavey to open the conference. Here they share their feedback on the event.

Thank you both so much for sharing your defining moments with everyone attending the conference. How was it for you?

Julie: Josie and I haven't been working together for very long so we couldn't believe we were given the opportunity to open the conference. Although our stories are very different, we both feel an immense love for our children and a profound sense of loss. My family were helped and supported by some amazing professionals and I will always be grateful for that, but caring for my two daughters with a rare and complex life-limiting condition was challenging and sometimes exhausting and isolating. I wanted to share my experience of diagnosis, the ultimate 'defining moment'. I still feel the impact of that moment every day. I also wanted to highlight some of the practical and logistical problems faced by children with degenerative conditions as they lose skills and require an ever-increasing array of equipment and medical input. Most of all I wanted to celebrate the joy and love of life with Francesca and Josephine and to introduce them to everyone at the conference.

Josie: It was a wonderful opportunity to open the conference, to show my 'defining moment' of the love between my daughter and myself that was only made possible by the hard work of professionals represented at the conference and to let them know how grateful I am. Also, I felt it was important to remind them how traumatic receiving the diagnosis is and how imperative it is that we are supported properly when this happens.

What was your personal highlight from the conference?

Julie: Everything about the conference was interesting and inter-connected. For me, the best aspect was to be able to meet so many hard-working professionals and parents with a desire to make a positive difference to children's palliative care services. Leah's* honesty and good sense was both moving and uplifting.

Josie: The best aspect of the conference, for me, was meeting so many dedicated people fighting our cause and working to ensure our children get the best care and treatment possible, especially in times of so much political uncertainty.

What do you feel were the key messages to the professionals attending the conference?

Julie: Communication and joint working are fundamental and I felt this was highlighted throughout. By inviting us to open the conference I feel there was a strong message that parents are a key part of multi-disciplinary working. I was very interested to hear the GP's point of view and her particular interest in children's palliative care. John Carswell's presentation about individually tailored further education (Community College Initiative Ltd in Essex) was inspirational.

Josie: I felt that the key messages were to improve communication, between professionals and to listen to the children and parents at defining points, especially regarding times like transition. I loved listening to Leah talk about how 'transition' was a meaningless concept to her, she's just growing up!

What will you personally take away from the conference?

Julie: It was important for me to hear about current thinking, practice and research. I have a huge respect for all the professionals who choose to work in children's palliative care services and I know from personal experience what a difference they can make to the child/family experience. I will continue to share my story in the hope that I can give a voice to children with life-limiting conditions and their families.

Josie: I have taken hope and a wider perspective of the complexities of the work involved in children's palliative care. I have also taken a sense of admiration for myself in being brave enough to represent the parent's perspective and our wonderful children.

Julie and Josie lead workshops for professionals "Together we Matter".

*Leah is a member of our Young Avengers group who presented during the conference.



General election result is an opportunity for a fresh approach

Following the recent general election, there have been some changes in both government and in parliament relevant to families of children with life-limiting conditions.

Stuart Andrew MP, who founded the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care in February, has sadly had to step down following his appointment as an Assistant Government Whip. Catherine McKinnell MP (Labour, Newcastle North) and Dr Caroline Johnson MP (Conservative, Sleaford and North Hykeham) are standing jointly to replace him as co-chairs and, if elected, will help give the group important cross-party credibility and leadership in the new Parliament.

At the Department of Health, Steve Brine, MP for Winchester (who has previously fundraised for Naomi House and Jack's Place), is now a minister responsible for public health. Jackie Doyle-Price, MP for Thurrock, has children's health and palliative care among her portfolio. Robert Goodwill MP is the new Minister for Children, responsible for children's social care. Penny Mordaunt MP continues her role as Minister for Disabled People, Health and Work, with responsibility for DLA and we continue to engage with her on this issue.

Together for Short Lives has written to all the new relevant ministers inviting them for early meetings to discuss how we can work together in the new parliament to improve care and support for children with life-limiting and life-threatening conditions.



Frank's story

In October 2012 a Neurologist gave my husband and I the worst imaginable news. The youngest of our three children, Frank, was diagnosed with Late Infantile Batten Disease, a rare, incurable, neurodegenerative condition.

Frank had been healthy and had developed as expected until the age of three and a half. Energetic, fun and joyful he was a child who loved to run and play with his brother, sister and friends.

But things started to change – he was three and a half when the violent shaking of his first terrifying seizure woke me up. Over time Frank's seizures became more frequent and trips to A&E became common.

Getting our heads round the most heart-breaking news

It soon became clear that something was very wrong – things that had come so naturally to Frank, became more of a struggle. He was now unsteady on his feet, unable to feed himself and could no longer play with his toys. He started to regress mentally too and a succession of seizures saw Frank rushed to hospital, undergoing intensive tests.

When Frank was just four years old we had to get our heads around the most heart-breaking news. Frank would only live to be at worst six years old, and at best 12. Frank was diagnosed with Late Infantile Batten Disease, a rare, incurable, neurodegenerative condition.

Batten disease has taken his mobility, his speech, his sight, and his ability to swallow and eat safely. Today Frank, age 9, is blind, completely unable to move, fed through a tube and needs assistance with breathing. He experiences distressing seizures and suffers from dementia. He needs extensive medications and 24-hour care. The demands are unrelenting!

A bewildering array of services are involved. To support Frank we access services from almost 20 disciplines across two hospitals and in the community. To complicate things further Frank attends our closest suitable school in Westminster but has an Education budget and Keyworker in Brent.

I cannot begin to describe the complexity and stress of trying to co-ordinate the appointments, the paperwork and the preparation with all the relevant teams to care and advocate for Frank.

Why can't Education, Social Care and Health Care share electronic records so I don't have to constantly relay information between services? Why does it take two days to fill in the Disability Living Allowance application form? Why was it so hard to get a Statement of Educational Needs for a child with clearly complex needs? It is just overwhelming.

I have been close to breaking point many times and as a healthcare professional I am better placed to navigate the system than many parents. Advice, support and help from two organisations that work with Together for Short Lives may have saved my sanity.

Invaluable support

At the time of the diagnosis I was given a leaflet for the Batten Disease Family Association, who support families with Frank's condition. I was advised to contact Shooting Star House, our local Children's Hospice. My image of a hospice was of a gloomy, sombre place where adults went to die, not somewhere I would want to take my child. However, the Support Worker from the Batten Disease Family Association told me "children's hospices are not like adult hospices". Feeling encouraged I visited the hospice. My motivation? The hope that when Frank was nearing the end of his life they would have the expertise and resources to manage Frank's symptoms, ensure he was comfortable and that his death would be as peaceful as possible.

Last year, after a long admission Frank was able to leave hospital sooner because the hospice could provide 24-hour nursing care. After weeks of sleeping in hospital

beside Frank I was exhausted and grateful to have the privacy of my own room at the hospice. I was able to sleep uninterrupted, safe in the knowledge Frank was receiving the care he needed and if his condition deteriorated I could be called to his room in a moment.

It was a difficult time but it was wonderful to be together, staying as a family after weeks apart. To eat together at a table, to sit outdoors in the garden and feel confident to leave Frank's side, knowing he was safe, in a comforting and familiar place.

We stayed for almost a month while the Great Ormond Street Palliative Care team worked with the hospice to control Frank's unrelenting seizures. Support from palliative care helps our family enormously, enabling us to cope with Frank's increasingly complex needs.

It quickly became apparent that Shooting Star House offered so much more than just end of life care. The support we have received has been invaluable. At Shooting Star House we can hand over Frank's care and enjoy some precious time as Mum and Dad rather than being Frank's carers. The environment is not clinical like a hospital, but homely and welcoming with specialist equipment that benefits Frank. He enjoys the hydrotherapy pool, wheelchair swing and sensory room.

Children's palliative care services have enabled us to cope and to give Frank, his brother and his sister the best life possible. Frank's brother and sister benefit from having less stressed parents, who can better meet their needs. They have also enjoyed meeting other siblings at the hospice, children who like them have siblings with complex needs and understand the challenges they face. They have supported us from Frank's devastating diagnosis and they will continue to support us for as long as necessary.

What counts now, is making the most of every moment with Frank, doing things that he enjoys and making special memories together as a family.

Rachel Thompson, Frank's mum