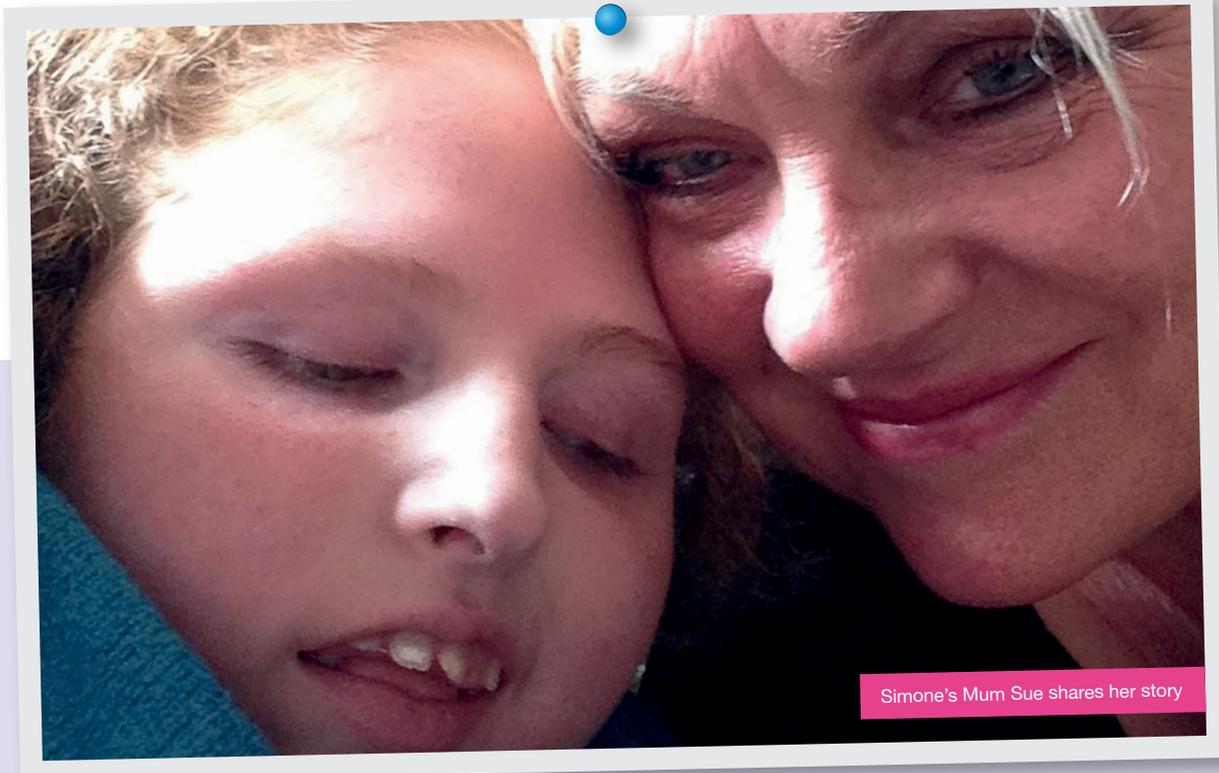


together for families

Issue 32
Spring 2021



Simone's Mum Sue shares her story

Our free Helpline and Live Chat is for any parent, carer or professional who looks after or knows a child or young person who is expected to have a short life.

Open Monday – Friday, 10am-4pm

Outside of these hours, please leave a message and we will respond as soon as we can. You can also access our free legal advice service by calling the helpline.

Together for
Families Helpline
and Live Chat

0808 8088 100

www.togetherforshortlives.org.uk
info@togetherforshortlives.org.uk



Join our Family Facebook group: www.togetherforshortlives.org.uk/get-support/supporting-you/family-group/

If you would like to receive our newsletter by post or email, please contact info@togetherforshortlives.org.uk

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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 99,000 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.

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 our Spring newsletter Inside this issue...

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We bring you some special Mother's Day blogs from Mums grieving the loss of their child

3 Get involved and get support

We are excited to launch a new family support film from Mum Carly who cared for her daughter Effie, who was diagnosed when she was a toddler

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Introducing a new footballing Patron, and we thank two of our amazing partners for their support of families during the pandemic

5 Need to know

Important policy updates that matter to you and your family right now

6 Family story

Simone's Mum Sue looks back over her life and the support she received throughout their journey from Together for Short Lives

Keep in touch

Call the Helpline
0808 8088 100

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www.togetherforshortlives.org.uk

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Mother's Day after loss

On Mother's Day we published three blogs from bereaved Mums **Hayley, Lorna** and **Jane**.

Hayley is Mum to Holly who died shortly before Mother's Day 2020. Hayley writes about Mother's Day taking on a brand-new meaning when you "join a club for bereaved Mums that I never signed up for." Jane is Mum to Laura and Lynn who died within two years of each other 21 and 19 years ago. Jane blogs about the sadness in knowing nobody will ever call her "Mum" again, and Lorna is Mum to triplet daughter Essie who died in August 2017 at 18 months old. Lorna writes about 'preparing' for Mother's Day as she knows it is one of the hardest days of the year.



Rising numbers

New research published recently shows that the number of young adults with life-limiting conditions has risen significantly over the last eight years.

The study, conducted by the University of York and University of Leeds, reveals that the total number of young adults (aged 14-25 years) with life-limiting conditions in England has increased by 40% between 2009/10 to 2017/18. Looking just at the number of young people with a life-limiting condition who were diagnosed in childhood, the increase is higher at 53%. More young adults living longer is something to be celebrated, and it is vital that adequate services are put in place to ensure that these young adults and their families can live life to the full.

The research confirms the growing need to provide more support for young adults with very complex needs and we are pressing on NHS organisations, local councils and voluntary sector palliative care providers to deliver this.

If your child is approaching transition or if you are a young adult transitioning to adult care our **transition webpages** are a useful resource aimed at improving the experiences of young people moving from familiar children's services into adult services.



Get involved and get support

We need you!

Become a family expert and help to shape our work, projects and research. There's no minimum time requirement or obligation, just get involved in the projects that feel appropriate for you. Sometimes it's answering a simple questionnaire or providing feedback on a new publication.

It's this simple:



Go to www.togetherforshortlives.org.uk/get-support/your-voice/family-community/



Sign up to become a Family Expert



Wait to receive our emails and get involved!

Camp in the clouds

Camp in the clouds is an engaging virtual programme, where campers and families can experience the magic of an Over The Wall camp from the comfort of their home.

Campers are given exclusive access to the bespoke platform, where you can engage with a mixture of online and real-life activities. Campers are sent an activity pack in the post, containing every single resource you need to participate. Find out **more**.



Effie's Mum Carly and Dad Paul tell Effie's story in our new charity short film. Click the image to watch.

Launch of new film

Carly, a bereaved Mum, has shared her devastating story of the loss of her daughter Effie in a new short film released in March.

It's hoped the film will help us to reach out to the growing number of families caring for a seriously ill child, so they can get the help they need and won't feel so isolated and alone. The family contacted Together for Short Lives, for advice, support and someone to talk to following Effie's shocking diagnosis when she was three and a half years old.

"We thought we were on our own, but that's when Together for Short Lives said: You are not alone."

Watch the film, and find out about the range of support we offer to families and carers **here**.



Children's Hospice Week – coming up!

Save the date: 21-27 June 2021

Children's Hospice Week is the only week in the year dedicated to raising awareness and funds for children's hospice and palliative care services across the UK, and the seriously ill children and young people they support.

If you would like to share a story of how your hospice has supported you and your family through the pandemic and lockdown we would love to hear from you. Reach out to us: **marcella.pinto@togetherforshortlives.org.uk**

Raising awareness



Small acts. BIG difference

In December Centre Parcs offered ten amazing Winter Wonderland day-trips to families from Jigsaw Hospice in Cumbria. Visits included a trip to Santa's woodland workshop, access to all the decorations, an enchanted light trail and entrance to shops, restaurants and the Leisure Bowl.

Sarah, Mum to Cameron said: "We had an amazing time at Center Parcs. It was a much needed break and our first trip out for the year. It meant the world to us that we were able to enjoy ourselves and get into the Christmas spirit."

Despite a challenging year, Center Parcs have continued to support our work and in the summer of 2020 guests were asked to donate 10p to Together for Short Lives when booking their slots to go swimming. Since June those donations have raised an incredible £105k. That's 4,000 hours of lifeline children's hospice care that's been funded.

Amazon: Delivering a smile

More than 200 wellbeing hampers were donated by Amazon which were distributed to families across Bristol, supported by Jessie May Children's Hospice at Home.

The hampers were picked, packed and delivered by the team in Bristol and included family board games, biscuits, flavoured tea and bath bombs. The donation was made as part of the "Amazon in the Community" programme, whereby the company supports the communities around its operating locations across the UK.



Welcome Mason!

Chelsea and England midfielder Mason was announced as our new charity Patron in January on his 22nd birthday.

Welcoming the news he said: "I'm so proud of the work Together for Short Lives do to support children with life-limiting conditions and their families. Together for Short Lives is a lifeline to them and I have seen first-hand the truly amazing work they do."

To celebrate the announcement he auctioned off two Chelsea home-game tickets and raised over £12k. Our Chief Exec Andy said: "Mason's support and generosity will make a huge difference, and we are so honoured to have him on our team! Thank you, Mason, and welcome to the Together for Short Lives family."

Need to know

Latest COVID guidance for families of clinically vulnerable children in England

On 22 February, the government published its **roadmap out of the current lockdown in England**. This included news that children and young people who had not already been asked to shield by their GP or health professional would be returning to school from 8 March.

Following this, the **Children's Minister Vicky Ford again wrote to parents of children with special educational needs and disabilities (SEND) with advice and guidance**. In the letter, the minister states that schools and colleges are required to provide remote education for clinically extremely vulnerable children. The minister also said that current advice on shielding would be reviewed shortly and would continue to apply in England until at least 31 March.

The pace of lockdown easing and return to education for children varies across the UK's nations and regions. Information is available on the **Northern Ireland Executive, Scottish Government and Welsh Government** websites.

Calls for COVID recovery plan as disabled children struggle to access vital services

In February, the **Disabled Children's Partnership (DCP) published results from its survey on families' experiences of the third lockdown**. In the results, among other things, parents reported that disabled children had not been receiving support for their disability or medical condition via health services or their school placement.

Since publishing these results, DCP has called for an ambitious and funded COVID recovery and catch-up plan for disabled children. This would cover not just education, but also health and wellbeing; and for swifter access to COVID vaccines for them, their parent

carers and siblings. **Together for Short Lives joins DCP in this call** – please write to your MP and ask them to call on the government to fund and implement this essential recovery plan.

Budget 2021 fails to address needs of seriously ill children and families

We were disappointed that Chancellor of the Exchequer Rishi Sunak **failed to use Budget 2021 to announce a funded plan to help seriously ill children and their families recover from the devastating impact of the COVID pandemic**. As we set out in our asks earlier in the year, Budget 2021 was a chance for ministers to level the system up for seriously ill children and their families. While this is disappointing, we will continue to press the government to allocate funding for a COVID recovery plan, sustainable short breaks and 24/7 access to children's palliative care.

Proposals to reform the NHS in England

The government has published proposals to reform the way in which the NHS in England is organised. These would see new 'integrated care systems' (ICSs) becoming responsible for planning, funding and organising NHS care. ICSs would bring together the NHS, local government and the voluntary sector in an attempt to better integrate health and social care. **Together for Short Lives prepared a briefing on these reforms and what they could mean for children who need palliative care and their families.**

CHAS launches manifesto in Scotland

Ahead of the Scottish Parliament elections in May, **Children's Hospices Across Scotland (CHAS) has launched its manifesto**. The manifesto looks for action to deliver sustainable funding, more specialist workforce training, and better support for children living into adulthood.

We join CHAS in calling on all candidates to make sure seriously ill children and families in Scotland have timely access to high quality palliative care, where and when they need it.

We press Welsh Government to address community nursing gap

In March **Welsh Minister for Health Vaughan Gething issued an update** on palliative care and hospices in Wales. The minister said that the government is conducting a stocktake of the capacity of children's palliative care services, which would result in proposals for how they should develop further.

The statement follows a debate in the Senedd on palliative care in Wales in which **Rhun ap Iorwerth MS highlighted the 240 children's community nurses** that are currently needed in Wales. Together for Short Lives has called on the Welsh Government to take action to address this gap and to also commit to sustainable state funding for children's hospices in Wales.

New framework aims to improve care for people with rare conditions

The new **UK Rare Disease Framework** was published in January by the Department for Health and Social Care. The Framework identifies four key priorities for the next five years:

- help patients get a final diagnosis faster
- increase awareness of rare diseases among healthcare professionals
- better coordination of care
- improving access to specialist care, treatments and drugs

Following this publication, the four UK governments will each develop action plans which will set out how the priorities identified in the framework will be addressed. Each plan is expected to be published in 2021.



From Simone's Mum Sue...

When I look back on Simone's uncomplicated birth in 1998, I remember my only concern was how tiny she was, how very tiny and perfect. Her brothers had been big babies, so she seemed more vulnerable, more delicate, how wrong could I have been?

Four weeks after her birth, events took place that shook our lives with such force, that life, as it was, was gone forever. She was rushed to hospital with suspected streptococcal septicaemia. On arrival we were told she may not make the next 24 hours, but she survived, and what she survived can only be imagined. She was incredibly sick. The streptococcal septicaemia developed into meningococcal of the brain and the trauma left her with secondary degree brain damage.

After her initial discharge and several harrowing weeks looking after her at home, she developed swelling of the brain and was rushed to hospital, where she underwent surgery to have a shunt fitted.

"I remember a big white bandage wrapped around her small head, it was Boxing day 1998."

After surgery for the shunt, she lived for nine months on the paediatric ward in Devon.

A care package was negotiated with our local authority. I wanted my daughter home, but I knew that I was going to need an army of support.

I first met Moya, after she replied to my ad in a magazine for a carer to Simone.

Moya moved in with us and led the way, she showed me how to care for Simone, how to look after her holistically, how to relax and how to manage the stream of professionals that had consumed my life. We soon became the first family to be funded by the new Direct Payments scheme. This budget enabled us to expand, and we soon had our very first "Team Simone".

Making adaptations

After a succession of social workers, we were appointed Julie. This was incredibly fortunate, she was the "real deal" in social care and she knew the "ropes" inside out! It was thanks to her that we had a very well-funded care package in the home. One of Julie's brilliant achievements was the fabulous and fully adapted extension to our house.

This meant that Simone had her own beautiful, bespoke downstairs room. It also meant that we could continue to live together in our house in Brixham and avoid moving.

For over ten years Julie and I worked closely together ensuring that Simone had the very best care we could provide.

When Simone was ten years old, I very nearly lost her again, to a super bug. She got so sick that we lived for ten months in various hospitals.

"When we finally arrived home, completely exhausted and traumatised, it was Julie who suggested that we may find respite care at Children's Hospice South West, a good place to recuperate."

Finding a second home

Initially, I was not keen to go to a hospice, but I soon came to love going and realised that it was a safe haven. We all loved going there, especially Simone! It became a second home, a place to rest, recover and re-charge. Not only did they care for us all, as a family, they cared for Simone with maximum emphasis on her comfort and enjoyment. It was the best type of care she could receive, and the care team always ensured they got things right for her. It seemed to me, that Simone's wellbeing improved after a stay there, in fact, we were both ready to tackle the next hurdle, whatever that might be. We continued to visit the hospice regularly over the next twelve years.

Together for Short Lives

It was around 2007 when I first encountered Together for Short Lives. I was invited to a local meeting to discuss my experiences of navigating the services on behalf of Simone. There were many professionals at the event and a few parents.

This sealed the beginning of my long-standing relationship with the charity.

When Julie retired things started to go horribly wrong, particularly with Simone's transitioning to adult services.



Together for Short Lives sent me a copy one of their resources, and this soon empowered me to take on the system. Their free legal advice service, Voices for Families, helped me source a good lawyer and later helped advise me when the Department for Work and Pensions cut Simone's Employment and Support Allowance. It is also thanks to Together for Short Lives that I have a fantastic role working with the Care Quality Commission as an Expert by Experience.

A highlight for me, was being invited by the charity to be on an awarding panel for one of their projects. This was an amazing opportunity, not only to give a little back to the charity, but to meet the team from the Council for Disabled

Children and later become one of their core facilitators on the Expert Parent Program.

"Many years have passed since I first heard of Together for Short Lives, and their inspiring work. Just knowing they were always there, when things got tough, and they did, has been a light in a sometimes very dark tunnel."

Losing Simone

Simone passed away in January 2021.

The week leading up to her death, was the hardest week of my life. The team and I worked tirelessly to keep her comfortable, but it was simply her time, she was not sick, she was tired.

She had defied the laws of nature on so many occasions, fighting for life with her usual jaw-dropping resilience, but now it was clear that she could fight no more.

She passed away peacefully in her own surroundings, I was by her side. Her passing was felt deeply by her core team and all those who had come to know her so well. I am immensely proud of her.

A lifeline

Following her death, I turned to Together for Short Lives' helpline. I suddenly found myself financially unprepared for Simone's funeral costs. I simply did not have much money.

"The helpline team offered me a lifeline and they applied on my behalf to a response fund."

Within a few days the outstanding balance of the funeral costs had been paid in full. I felt a great weight lifted off my shoulders. We had a beautiful ceremony for her, and she rests in secluded woodland nearby.

Even though Simone has passed away I will remain in touch with Together for Short Lives and will always be most grateful for their enduring care and support.



Voices for families Expert legal advice when it matters

If you are a parent or carer of a child with a serious illness and could benefit from free expert legal advice, reach out to our helpline.

For a short time during the Covid-19 pandemic the Coronavirus Bill meant that statutory sector agencies were not required to fulfil all their legal duties. Some families really felt the impact of this as some care packages were not reviewed and levels of care were cut back. For a few, the additional anxiety coupled with greater caring responsibilities was a great pressure. While things may not be yet 'back to normal', it is important that families are receiving the care and support that they are entitled to by law.

Voices for Families can support families by matching them with a volunteer legal professional to help them to challenge decisions that may have been made and to advocate that the needs of families are met.

To find out if you would benefit from free support from a Voices for Families lawyer:

 Call us:
0808 8088 100

 Chat to us:

www.togetherforshortlives.org.uk



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