

# together for families

Issue 30  
Summer 2020



Our free Helpline 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.

Together for  
Families Helpline

**0808 8088 100**

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



You can also access our free legal advice service by calling the helpline.

If you would like to receive our newsletter by post or email, please contact [info@togetherforshortlives.org.uk](mailto: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 Summer newsletter

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## Keep in touch

Call the Helpline  
0808 8088 100

Email us  
[info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk)

Visit us  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

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# Applying lessons learnt from lockdown

During the COVID-19 pandemic Together for Short Lives has continued to work with families, member services and policy makers. We have learnt how important timely and consistent advice is when making decisions about the best care for the whole family.

And we've seen how well services can adapt to meet the needs of families, often working virtually to bring support and even therapies into family homes. We are working to capture this innovation and will encourage providers to continue to offer creative solutions to supporting families into the future.

Listening to families, we know that one of the most important ways of ensuring they feel heard is by keeping

in contact with others. In this edition of Together for Families, we share how our Family Support Hub links families with information, services and each other. We also share how families have supported our campaigns to raise public awareness of children's palliative care.

If you are reading this for the first time and want to get involved in our work, do email us at [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk).

## Forgotten families

We've called on government to continue to provide support to isolated families of seriously ill children who are understandably anxious about ending shielding.

Early findings from an ongoing piece of research, called the SHARE study, have shown parents caring for seriously ill and vulnerable children feel more isolated than ever under lockdown – with 95% fearful that their child will catch the virus from their parent; 93% fearing their child's treatment will be cancelled or delayed and 57% saying isolation has brought up negative memories.

Read more about the study and what we're doing to help here.



## This is not just any charity partnership

We're really pleased to announce a new partnership with M&S Food is set to make a lasting difference by raising money for the 54 children's hospices across the UK.

Together for Short Lives is now one of the 35 charities to benefit from M&S's Sparks reward scheme too. If you already have, or want to sign up for, a Sparks card **you can nominate Together for Short Lives as your chosen charity**. Every time you shop, M&S will donate 1p to UK children's hospices.



# Families count

Here for you



Together for Short Lives is here to support all family members caring for a child with a life-limiting or life-threatening condition. Here are a few key ways that we can help:

1. Free **helpline** on 0808 8088 100. This is a safe place to talk about whatever is on your mind. We have accurate information, can signpost to specific support and we provide listening support from the point of diagnosis onwards.
2. Online **support group**. A friendly and private space on Facebook to speak to other parents. There is always a chat going on – whether it be the best place to get swim nappies for older children or just a place to celebrate a good day. We also have a separate area for bereaved parents who want an additional space to talk about their child.
3. Virtual cuppa. A time in the evening to chat to other parents over a cup of tea. Keep an eye on our social pages to find out dates and times.
4. A **legal advice and support service**. Free legal advice and support for families who live in England and Wales, there to help with non-medical issues like housing and care packages.
5. Information and digital tools. There to help with all aspects of your child's life including **My Care Transfer** (a resource to make going into hospital easier).

## Ways to get involved:

1. Use your experience to shape the world of palliative care by becoming a **Family Expert**. A completely flexible volunteering opportunity to take part in research and consultations.
2. **Share your story on our website**. From time to time we also have opportunities for speakers at events, TV and radio.
3. Become a peer support volunteer and host a virtual cuppa. You'll listen to other parents and help them to feel less alone. Full support and training provided.
4. Attend a session on how to be a palliative care change maker. We'll support you to understand how you can make a difference even with limited time. Email [info@togetherforshortlives.org.uk](mailto:info@togetherforshortlives.org.uk) to register your interest for our 'How to change the world in 15 minutes session'.

For more information on any of these, do give us a ring on 0808 8088 100.



## The number of seriously ill children is growing

A new research study released in the midst of the Coronavirus pandemic shows that the number of children in England with life-limiting or life-threatening conditions has continued to rise over the last 17 years.

The Make Every Child Count study, conducted by the University of York, has revealed that the number of children in England with life-limiting or life-threatening conditions increased to 86,625 in 2017/2018 compared to 32,975 in 2001/2002.

The new research also reveals that prevalence of life-limiting conditions is by far the greatest in babies under the age of one, and that more young people with life-limiting conditions are living to the age of 19.

We're working hard to ensure that this important new research helps government, the NHS and children's palliative care providers to plan, fund and deliver children's palliative care effectively, for families who need it.

## Help us to show the stories behind the statistics

We want to change numbers for faces and make sure we are representing as many of you as possible by sharing your stories and your photos to raise awareness and help other families feel less alone. **Contact us** if you'd like to get involved.



# THIS is... CHILDREN'S HOSPICE WEEK 2020



**This summer we celebrated the 54 children's hospice services up and down the country that support thousands of children living with a life-limiting or life-threatening condition, with a special awareness-raising week.**

It was a Children's Hospice Week like no other, with so many of us facing the toughest time of our lives as Coronavirus took hold, some families caring for a seriously ill child were left feeling more alone than ever. Children's hospices were and still are there as an absolute lifeline. We wanted to show the amazing new ways they'd found to connect with families and how they even helped take the pressure off the NHS.

An army of families, services, staff, politicians and celebrities got behind us to show what an incredible impact children's hospices can have, but that without widespread support they simply couldn't survive:

Together for Short Lives Patron, Holly Willoughby, explains why children's hospice services are such a lifeline for families caring for a seriously ill child, now more than ever. Click the image to watch.

The Duchess of Cambridge, as Patron of East Anglia's Children's Hospices, took part in a very special Zoom call with the Duchess of Cornwall, as Patron of Helen and Douglas House and Children's Hospice South West, to talk to hospice CEOs and one very special family; as well as joining families from East Anglia's Children's Hospices to plant a garden at The Nook, one of EACH's purpose-built hospices near Norwich.



"This Children's Hospice Week, I'd like to thank the amazing staff for all the work that you do in children's hospices around the UK. The care and the nurture that you provide children and families in the most unimaginable circumstances is just awe inspiring."

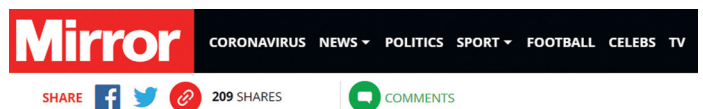
**HRH, The Duchess of Cambridge**

And we shared some moving stories, like this one from Dad, Ibrahima who admitted that trying to shield conjoined twins Marieme & Ndeye during the pandemic, on top of caring round-the-clock was just exhausting. So Ty Hafan Children's Hospice arranged for the girls to visit a few days a week. The hospice will always be their "second family"

## In the spotlight

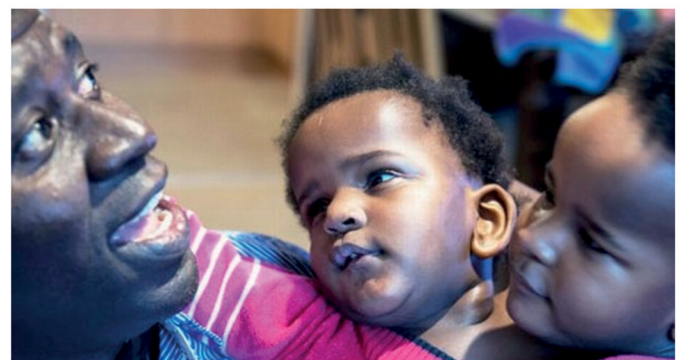
**Metabolic diseases are not something that often make it into the mainstream media, but recently Mitochondrial Disease has hit the headlines following a new Coronation Street storyline about Leanne, Steve & their son Oliver.**

The Lily Foundation, the UK's leading mitochondrial disease charity, describes the story as "a momentous step in raising awareness about mitochondrial diseases and the impact they have on families."



Children's Hospice Week starts today and celebrates the UK 54 children's hospices.

For Ibrahima, Ty Hafan Children's Hospice in Penarth, Cardiff, has been a lifesaver and an important part of his family's daily life for the past four years.



# Need to know

## Specialist vehicles for children under three

**Motability have launched a scheme to provide specialist vehicles to children across the UK under the age of three who must always be accompanied by bulky medical equipment and/or need to be near a motor vehicle in case they require treatment for their condition.**

Families can apply now through the Family Fund grant scheme [here](#).

Thank you to all families who have worked with Together for Short Lives over the past few years to push for children under the age of three to be able to access this mobility support.

## New coronavirus education guidance for autumn term

**For many of us, sending our children back to school might seem a daunting prospect and we've had lots of questions about whether there are any particular rules or considerations for families caring for a seriously ill child.**

We can tell you that the UK Department of Education (DfE) has published a range of new guidance for parents, early years providers, schools and further education settings in England ready for September 2020. In terms of children who need palliative care, the guidance for parents states:

- some pupils no longer required to shield but who generally remain under the care of a specialist health professional may need to discuss their care with their health professional before returning to school in September
- where children are not able to attend school as parents are following clinical and/or public health advice, the absence will not be penalised
- if parents have concerns about their child returning to school/college, because they consider they may have other risk factors, they should discuss with their school/college the measures they are putting in place to reduce risks.

### What about getting to school?

The Schools Minister Nick Gibb has summarised the government's guidance on transporting pupils to special schools during the pandemic [here](#).

### What about the devolved nations?

**Guidance on school reopening in Northern Ireland**

**The Scottish Government's guide**

**The Welsh Government's guide**



## Temporary SEND law changes in England continue

Guidance on the current changes to the law on the provision that has to be made for children and young people with education, health and care (EHC) plans is available at: [www.gov.uk/government/publications/changes-to-the-law-on-education-health-and-care-needs-assessments-and-plans-due-to-coronavirus](http://www.gov.uk/government/publications/changes-to-the-law-on-education-health-and-care-needs-assessments-and-plans-due-to-coronavirus)

Ministers say the review will consider how staff in schools and colleges can be equipped to respond effectively to their needs – and how the postcode lottery families often face can be ended.

Separately, the government has proposed that a number of elements of the relaxation of legislation affecting children's social care should be extended to 31 March 2021. These are due to expire on 24 September and include for visits between social workers and children to take place virtually when local lockdowns or self-isolation make in-person visits impossible.

The Children's Minister has said that most other exemptions from children's social care duties introduced in response to the coronavirus pandemic are no longer required. However, the laws will remain in place until the end of September as planned and councils can still relax their duties to vulnerable children if they can justify it.

### How has COVID-19 affected young adults aged 18-40 living with a life-limiting condition?

We are supporting a study led by the Open University to better understand how the pandemic has impacted on this vulnerable group to affect change in the future. Call or email Dr Sarah Earle on 01908 654260 [sarah.earle@open.ac.uk](mailto:sarah.earle@open.ac.uk) to take part.



# Need to know

## SOP: we won, thank you!

**NHS England and NHS Improvement (NHSE&I) has finally published its standard operating procedure (SOP) for children and young people who need palliative care in hospice and community settings.**

It is an achievement to have gotten it over the line, so thank you to all those who were part of the work to draft it – and to all those who have engaged with MPs and officials to ask for their help to make sure that it was published.

**In other related news**, NHSE&I has also published **guidance** for how community health services for children and young people should prioritise their work during Coronavirus. It says that it expects local teams to work together across community children's nursing teams, special school nursing, hospital teams and children's hospices to ensure there is capacity in the community for palliative and end of life care for children and young people where needed. However, it also said that it may not be possible to provide care in a family's preferred place. We'll keep you updated on this.



## Have your say

**There are a number of opportunities for you to help shape policy in the coming weeks.**



**The Department for Education is consulting on a revised version of the School Admissions Code in England which could have an impact on vulnerable children.** The government is proposing a new deadline of 10 school days in which to make decisions on an in-year application, in addition to clearly defined timescales for each stage of the process.



**The All-Party Parliamentary Group (APPG) for Special Educational Needs and Disabilities (SEND) has opened an inquiry** on the impact of Covid-19 on children and young people in England with SEND during transition within educational establishments.



We will happily talk these opportunities through with you – what they might mean for you and your family and what you would like to change or advise, so that this can be fed in. Just contact **[james.cooper@togetherforshortlives.org.uk](mailto:james.cooper@togetherforshortlives.org.uk)** or give us a call.

# Jensen's story

Support from our local hospice,  
whatever happens

**For Nicola Norris and her husband Lee, their local children's hospice, ellenor, has been a lifeline in providing them with a whole range of services to help support and stimulate their six-year-old son, Jensen.**

In 2013, Nicola and Lee had a longed-for only child, Jensen Norris. Jensen was born with two rare conditions – Sturge-Weber and Klippel-Trenaunay syndromes, which have meant his development has been limited and he can suffer from some distressing symptoms like seizures.

The family has been supported by ellenor since Jensen was just 15 months old: "We've had real continuity of care over the years," says Nicola. "Support from staff who know us well has ensured we really understand the implications of Jensen's condition and how to respond to them. Plus, vitally. Jensen just loves Sian, his nurse – he'll always go straight to her when she's around – I don't get a look-in!"



Jensen's syndromes are rare and require highly specialist care – expertise that can be hard to identify and access.

**"That's where ellenor's problem-solving relationship with us has been so helpful," says Nicola. "Sian is always on hand to help identify Jensen's needs and to smooth our path towards meeting them – she's unstoppable!"**

Jensen usually goes to a special school, but in the current circumstances he is at home full time. This has brought additional challenges to the family, especially as Jensen has no spatial awareness, meaning social distancing is not an option. "Lee and I usually work outside the home – I'm based in the admin department at London Bridge Hospital, and initially I was worried that I might have inadvertently brought Covid-19 back from the hospital into our home," explains Nicola.

**"Again, the ellenor team were there to reassure me whenever I needed it, and to explain how we'd handle a crisis if it arose. So far, though, thankfully, we're all virus-free and are doing everything we can to stay that way."**



With Jensen away from his regular school routine and out of his comfort zone, the priority is to keep him as stimulated and engaged as possible at home. "The ellenor team have come up with plenty of ideas," says Nicola. "For instance, he received home visits from ellenor's music therapist, Petra, when he was smaller, responding well to the guitar and cymbals she brought and clearly enjoying the music they made together, so we might try more classes via video link and see how those go down with him."

Nurse Sian has also said she's going to try to find some multi-sensory lights and toys for the family's garden, so they can keep Jensen entertained and enjoy any sunshine at the same time. "It's not easy to access the right equipment at the moment – believe me, I've tried – but if anyone can track it down for us, it'll be Sian," says Nicola.

Children's hospices like ellenor have been going above and beyond to help families access the care and support they need in these unsettled times and beyond – you can find more family stories published as part of Children's Hospice Week on our website at [www.togetherforshortlives.org.uk/get-support/your-childs-care/family-stories/](http://www.togetherforshortlives.org.uk/get-support/your-childs-care/family-stories/).



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