

Hello and welcome to the latest family newsletter!

Updates from our Care Teams

A reminder that you can still request day and overnight respite through our website havenshospices.org.uk/little-havens-respite/. If you are experiencing any issues filling out this form, please call Little Havens on 01702 552 200.

Care in the home continues through our Children and Young People's Hospice at Home Team (including The J's) and is booked in the usual way.

All families are able to access lateral flow testing and in order to help keep everyone safe, we would be most grateful if members of your household took a lateral flow before a home visit. Information about lateral flow test kits can be found on line at <https://www.gov.uk/order-coronavirus-rapid-lateral-flow-tests>

You can talk to a member of the Care Team if you have any concerns or just want to ask a question by calling 01702 552 200 or visiting www.havenshospices.org.uk/feedback

Electronic forms

We are in the process of moving a lot of our forms and paperwork onto the [Family Area](#) of our website. We hope that this will speed up the process of admission when you come to stay with us. This includes forms such as our drug record sheet and consent for publicity

The forms can either be filled in online or printed off. We can also provide large print, audio or translation if required.

Government advice regarding COVID vaccination for clinically vulnerable children

Children under 16 years of age, even if they are clinically extremely vulnerable, are at low risk of serious illness and death from COVID-19 and are not currently recommended for vaccination. However, vaccination may be appropriate for those 12-15 years of age with severe neuro-disabilities who tend to get recurrent respiratory tract infections. This would particularly apply to those who spend time in specialised residential care settings for children with complex needs.

This option should be discussed between parents/guardians and the child's clinician or GP. For other children aged 15 and under, whilst further research is being completed, vaccination is not yet recommended.

Using the garden and bath at Little Havens

We'd like to remind you our gardens are open for families to come and enjoy. You can book visits to the garden through the 'Family Area' on our website, or families are welcome to call us on 01702 552 200 anytime to request a visit to our gardens, even on the same day. A member of the Care Team will check availability and advise accordingly. Children and young people are also welcome to use the bath at Little Havens. If you'd like to use the bath please call the Care Team to check availability.

Update on the hydrotherapy pool

Unfortunately, the pool is closed until further notice, vital replacement parts are on order but we do not yet have any dates for re-opening.

Reminders when staying for respite

- Only one parent or carer can be resident with their child or young person during a respite stay
- All adults and children over the age of 12 will require a Covid lateral flow test, which can take place at Little Havens when you arrive. Alternatively, you may complete this test at home if you have home test kits, you can then show the result to the Care Team upon arrival.

All staff, patients and visitors will be expected to continue to follow social distancing rules as well as using face masks whilst at Little Havens.

New nurses join the Little Havens Team

In July we welcomed two new nurses, Ed and Stacey, to the Little Havens' Care Team. We are really looking forward to working with Ed and Stacey, and they are both very excited to meet all our children, young people and families.

Updates on the Family Forum

Family Forum

The Little Havens Family Forum has been running for many years, but really came into its own during the last 24 months whilst the charity was undergoing a huge amount of change.

Our aim was always to be transparent, to encourage co-production and to amplify the voices of parents and carers.

Because of the contributions made at the Family Forum, driven by three Mums in particular, we've been able to make huge improvements in our care services:

- Improved communications to families including the family newsletter
- Introduced Halloween celebrations, and multi-faith festivals like Diwali into our activities
- Tested our online booking system for activities (and eventually short breaks)

- Campaigned for pool opening by demonstrating how important this aspect of care is to families
- Helped share activities such as garden visits, Saturday Socials, Cosy Sundays, cinema nights and baby massage
- Pushed for pre-admission assessments via phone or teams to maximise the time spent in the hospice
- Supported the integration of the team formally known as EPIC to provide home respite and end of life care
- Understanding the importance of extending care at Little Havens to 25 years
- And coming soon, your employed carers bringing your children to the hospice

Despite these successes, attendance to the Family Forum wasn't always representative of the number of families we are caring for. We did try different ways to increase attendance, such as offering to change the day/time, live blogging on the Little Havens Family Facebook page and arranging the forum in conjunction with lunch and social activities. We appreciate that caring for a child with a complex condition, alongside other responsibilities such as your family and work, means that it's not always convenient to attend another meeting, either in person or over Zoom.

After consulting with the three original members, we have decided that the Family Forum that took place on 15th April was the last one in that format.

We have made significant progress during the last year in increasing our communication channels. You no longer need to wait for a certain meeting to ask questions because we are constantly asking for, and receiving feedback. In the last year we have:

- Sent out multiple surveys to identify the needs of our families – with often good response rates
- Our staged programme of reassessments has reignited that dialogue around outcome-focussed care
- Little Havens Family Newsletter and weekly reminder communications
- Maintained 24/7 telephone access to a Little Havens nurse even when the in-patient building was closed
- Created a new feedback page on our website where people can leave feedback before, during, or after they have received a service. and [‘Bulletin Board’](#) (new)

We want to encourage this kind of regular, in the moment feedback that is accessible to all. By using these channels, your experiences, compliments and complaints can be recorded (unless you want to make it anonymous), can be fully investigated, reported to our Trustees (the governance structure that holds overall responsibility for the charity), and can provide your voice as evidence for CQC inspections.

As demand for our care gradually increases, we'll be increasing our focus on supporting and empowering our families so we are looking into regular seminars with guest speakers. This may take some time to arrange, but if you have any topics you are interested in, please let us know. We are already planning transition; power of attorney; advanced care planning; DNACPR; parallel planning for life and death.

We welcome your thoughts – as always – as we continue our journey together to improve services for children and young people.

Children's Hospice Week

Did you see our coverage for Children's Hospice Week in June? It's the only week in the year dedicated to raising money and awareness for children's hospice services like Little Havens. Together for Short Lives also shared some of our family stories too, highlighting the importance of these charities.

Two of our own families took part in some amazing fundraising during Children's Hospice Week for Little Havens. Two year old Elijah and two year old Edward, both took on their own 'Challenge 46' throughout the week to support the hospice.

Elijah and his mum Natasha took part in a range of activities throughout the week all linking to the number 46, such as 46 minutes of Zumba or 46 repetitions of physio exercises for Elijah. Mum Natasha said, "I can see how children's hospices have been pushed to their limits with fundraising, with all these different activities like the London Marathon forced to cancel. Everything at Little Havens is just tailor made for kids like Elijah – the sensory room, hoists, bath, gardens. It's nice to go somewhere where you don't have to worry about fitting in."



And Edward took on Challenge 46 by completing 46 press-ups as part of his physio exercises throughout the week. Katy, his mum, said "Edward's 'Challenge 46' is his way of saying thank you to Little Havens and helping to raise money for the hospice so they can be there for other families just like ours. We've only been going to Little Havens for a few months but I feel so overwhelmed at the help they have given to our family already. I feel I can never say thank you enough for the difference they are making in our lives."

Together Edward and Elijah have raised more than £3,350 through sponsorship from friends and family to support Little Havens.

Little Havens joined in the fun too, both in the hospice and in the community. Families staying at the hospice or receiving care in the community, along with staff and volunteers, all turned their hand to baking as part of our 'Challenge 46', 46 people baking tasty treats.



At Little Havens staff also held a bake sale during Children's Hospice Week raising over £70.

Thank you to everyone who joined in and showed their support for Little Havens during Children's Hospice Week.

Update from our Activities Team

Our Activity Team has been busy planning a programme of events and visits for you all during the summer holidays. Full details of upcoming activities can be found on the Family Area here <https://www.havenshospices.org.uk/familyarea/activities-at-little-havens/>

Activities so far include Mad Hatter's Tea Parties (to support our brilliant Hares About Town art trail in Southend), Disney/Marvel themed days, farm day at Little Havens and an accessible canal boat trip.

We are also continuing to run a number of virtual activities such as online music therapy and virtual concerts with Music in Hospitals and Care.

Hares About Town Farewell Event

Our spectacular art trail, Hares About Town, has launched in Southend. Running for 10 weeks, there are 30 giant hare sculptures about the town, and 53 baby hares called leverets to find. There's even an app where you can collect the hares and unlock prize draws and discount codes! Trail maps are available for a small donation of £1 each at all our charity shops, Little Havens and the 'Hare-Quarters' in the Royals Shopping Centre.

At the end of the trail we will be holding a Farewell to the Hares public event at Wellbeing Garon Park in Southend. As well as having the unique opportunity to see all 30 Hares and 53 Leverets together, there will be plenty of attractions, activities and entertainment with lots to eat and drink.

We are offering our Little Havens and The J's families free entry to this event (tickets are normally £5 per adult and £3 per child). If you would like to attend this event please visit <https://www.havenshospices.org.uk/tickets-for-little-havens-thejs-families/> where you can complete a form to be added to the guest list.

This offer is available for our families only please do not share this link with anyone else, if your friends or family would also like to attend they can purchase tickets by visiting www.havenshospices.org.uk/events

We'd love to see your 'hare selfies' if you spot any out in the wild. If you're happy to share these, just tag @HavensHospices and @HaresAboutTown on all the social channels.

Family Area on the website

There is a dedicated Family Area on the Havens Hospices website which has a wide variety of resources, videos and links. Some of our recorded films include creative therapy art, baking, music therapy and wellbeing story massages.

A new addition is our Family Noticeboard - [havenshospices.org.uk/family-noticeboard/](https://www.havenshospices.org.uk/family-noticeboard/) - where you can post links and recommendations for other families, like an accessible park you've discovered or a really interesting conference or webinar.

Infant Massage for Under Three's

We are excited to be offering our Little Havens families the opportunity to take part in an Infant Massage workshop held at Little Havens.

This course is designed for children up to the age of three years old (but not walking or crawling) and will run weekly over a course of five weeks in person at Little Havens. The sessions are 75 minutes long and will be led by Sophie - one of our Care Team nurses - who is a qualified instructor, as well as having experience working in neonatal care and within the hospice.

During the five week course you will learn a comprehensive baby massage routine that is designed to relax you and your baby in a safe peaceful environment. The routine involves both Indian and Swedish massage techniques, reflexology and yoga principles. We will also cover colic alleviation as well as settling techniques.

We understand that all children are individuals therefore we offer a holistic approach within a group setting to meet other families under the Little Havens service.

This is the perfect opportunity to spend some one to one time with your child, enhancing your bond and building your confidence with gentle settling routines.

Our next course will run every Friday for five weeks starting on September 17th at 10-11:15. If you would like to attend this course please register your interest on the Family Area of the website here www.havenshospices.org.uk/familyarea/infant-massage/

Chelmsford Racecourse Family Fun Day

On August 15th our Fundraising Team is holding a Family Fun Day at Chelmsford City Racecourse in aid of Little Havens. The day will have entertainment, fancy dress, inflatables, themed activities and street food village and of course, a great afternoon of live racing. It's free for children to attend, with adult tickets at £23. However we will have a special guest list for our Little Havens and The J's families if they would like to attend this event for free.

If you would like to attend please reply to Lucy Smith, lsmith@havenshospices.org.uk, by August 6th so we can add you to the guest list and guarantee free entry.

You can find out more information about the event [here](#)

Are you a keen runner?

We have a few charity places left for the Virtual London Marathon and the Royal Parks Half Marathon in October.

To be part of Team Havens and raise vital funds for Little Havens, we ask you to pledge to raise £250 in sponsorship which includes your entry fee.

If you are interested in taking part in either of these events please visit our [website](#).