



Summer/Autumn 2023

NOAH'S ARK
children's hospice

MOMENTS THAT MATTER

Edition No. 2

jaida

How Noah's Ark
have brought
magical moments
to the life of
one family



Holidays at
the Noah's Ark
Holiday Lodge

Rated
outstanding
by the CQC

Creating a
continuous bond
in grief

noahsarkhospice.org.uk

HELLO



**Welcome to the second edition of our
Noah's Ark Newsletter – Moments That Matter.**

At Noah's Ark Children's Hospice we help babies, children and young people who are seriously unwell, and their families, make the most of every day. We are not here to change a prognosis – instead, we help those we support to enjoy the time they have together. We create moments of joy by organising fun activities, providing outstanding care and helping families overcome the challenges they face.

In this edition you can read about some of the amazing moments the children and families we support have experienced. Some have been on a week's free holiday at our new, fully adapted Noah's Ark Holiday Lodge. Others have had incredible sensory experiences at The Ark. There have been baking days, visits to the farm, magical family days and so much more.

As a charity, we know how important partnering with other organisations and professionals is in delivering excellent care. We are working hard to strengthen our relationship with those who also help babies, children and young people who are seriously unwell. Together, we can ensure that those who need us most get the support they need.

We are so thrilled to share that we have been rated **OUTSTANDING** by our regulator The Care Quality Commission (CQC)! From 2006, to opening up the first children's hospice building in north London 13 years later – our community of supporters have been with us every step of the way. We couldn't have done it without you.

Thank you!



Much of our marketing activity, including this publication, is made possible thanks to the generous support of our creative and media partners, who provide their services free of charge. In particular, we would like to thank the following businesses for helping the stories of those we support travel further:



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THE 10 GROUP

“Noah’s Ark has been life changing for my family – I don’t know where we’d be without them.”

Jaida with Mum and Dad, Faye and Kam



At Noah’s Ark, it is very rare that we tell a child or family that they can’t do something – we always try and find a way. But a few weeks ago, we did have to tell one child that they couldn’t do something....

We had to tell Jaida and her Specialist Carer, Alice, that they couldn’t listen to Rihanna quite as loudly as they were listening to her in the sensory room.

Not everyone loves listening to Rihanna as much as Jaida – which is A LOT. Jaida is three and a half and has been looked after by Noah’s Ark since she was less than a

year old. As well as listening to music, her favourite things are wearing bright trainers (which have made her famous at The Ark!), being read to, and relaxing in the sensory room.

Recently, Jaida started enjoying being cuddled more – something Alice noticed and reported back to mum.

“It’s so special that Alice really takes the time to know and see Jaida, as outside of Noah’s Ark, Jaida can often go unnoticed.

“People sometimes don’t know how to act around a child who has a disability. They aren’t trying to be mean, but because of this Jaida can fade into the background.”

At Noah’s Ark, Jaida is far from fading into the background – like all the children we support, she is treated like an individual with the team taking the time and care to get to know her properly.



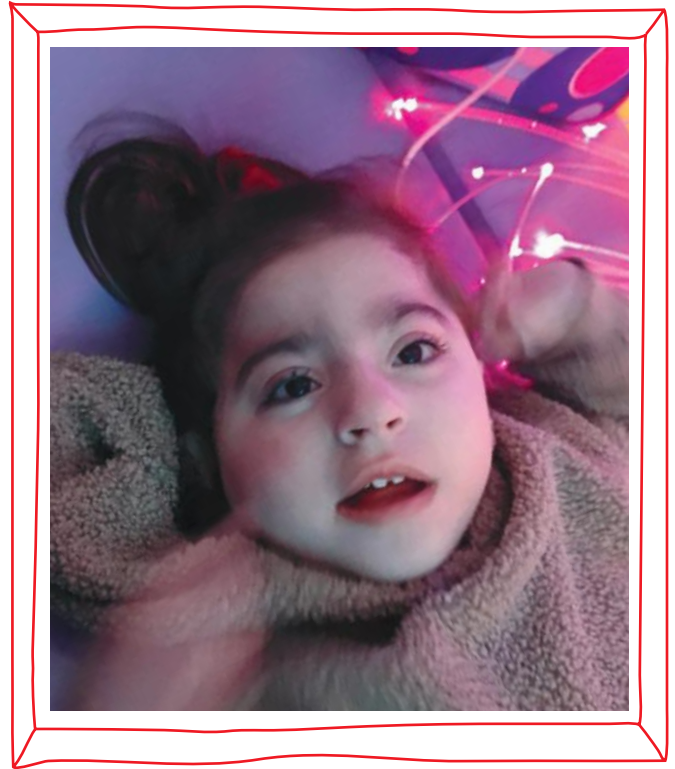
As soon as we enter The Ark Jaida is treated like the most important person. When she stays overnight they decorate her room exactly as she likes it. Everyone does all they can to make her feel special, which as a mum is so lovely to see.



The team do all they can to ensure that the entire family, not just Jaida, get the star treatment.

Faye’s partner Kam and his daughter have been gifted tickets to Tottenham Hotspurs, and both Grandmothers have attended pamper days at The Ark with Faye.

Although they know that Jaida has a rare genetic condition, she does not have



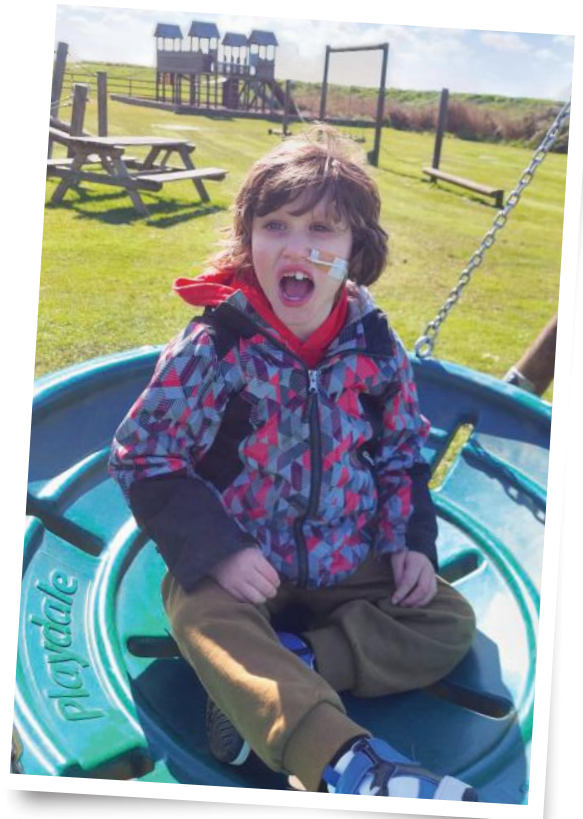
an official diagnosis. Earlier in their journey, Faye and Kam used to pursue a diagnosis, but now they have decided to pour all their energy into something else...

“Everything we do now is about enriching Jaida’s life, bringing as much happiness as possible. Without Noah’s Ark, this would be so much harder and there would be far fewer magical moments. I feel so lucky to have them in our lives.”





Noah's Ark goes on holiday!

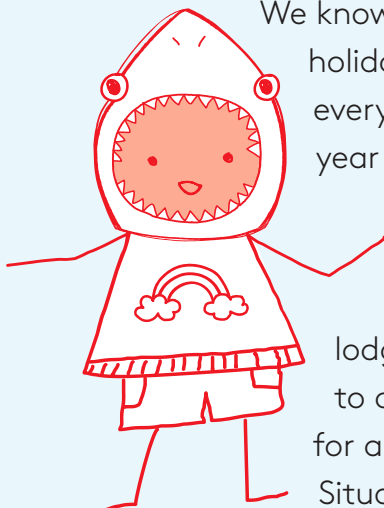


Family holidays allow time for creating happy memories that will last a lifetime.

However, if you have a child who is seriously unwell, finding a space that is safe and accessible for your family can be difficult.

We know that for many of the families we support a week's holiday feels simply unattainable, meaning they miss out on the invaluable family experience.

We want the families we support to experience amazing moments together.



We know how important holidays away are to every family – so this year we launched 'Noah's Ark on Holiday' with the Noah's Ark holiday lodge which is offered to over 30 families for a FREE week's stay. Situated in the beautiful

Essex countryside, our holiday home is the perfect place to relax and spend quality time together as a family.

With three bedrooms, so plenty of room for everyone, and a beach nearby, the lodge is also fully accessible – adapted to the needs of those we support.

Thanks to the generosity of Variety Golf and The Winter Ball Committee we have been able to drive families to the lodge in our very own fully accessible minibus!

We are so excited to continue welcoming families to our holiday lodge this year and beyond.

Thank you so much to **The Edward Gostling Foundation**, whose generous support enabled us to make this project a reality.

“Magnus enjoyed himself immensely

and came forward in his development while there, doing some things that he hadn't done before. As we don't have holidays other than Ark respite overnights, this was a great chance to be away from home. It was very nice to... relax, cook in a nice new, clean kitchen and have some stress free family time. It felt safe and the people were very friendly there, residents and employees. The park seemed friendly and understanding for disabilities.”



“We have had an awesome time at Mersea Island over the Easter break

It was a time to relax, enjoy family time and explore. We felt at home from day one and feel so overwhelmed to have been given the opportunity to experience such a lovely place.”



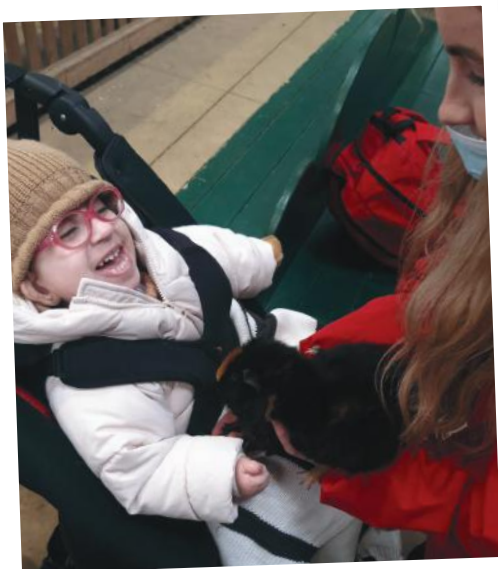
Fun Days Out



A Spurs surprise on football day out!

As the official charity partner of Tottenham Hotspur, we were thrilled to take a trip to visit their multi-award-winning stadium! As well as having a tour around the world

famous grounds, we also got treated to a surprise visit from football legend, Michael Dawson! His company delighted both our young people... and the Care Team!



Jaida at the farm

There were smiles all-round for Jaida and Specialist Carer Alice! The two had a fun-filled day out at Willows Activity Farm, where they made some new furry friends.

At Noah's Ark we offer a wide range of fun, free activities and days out, like our farmyard visit, all year round! In the safe hands of our trained and qualified team, those we support are able to have new and exciting experiences, all whilst making precious memories.

Wanted: Nurses who are experts at playing hide and seek!

In February 2022 we were so proud to launch our largest-ever nurse recruitment campaign. Through this campaign we wanted to show that at Noah's Ark our nurses have the time to get to know the children and families they care for, helping them make the most of every day.

Our Noah's Ark characters looking for nurses who can 'pull funny faces' and 'play hide



and seek' could be seen all across London and online. The campaign allowed us to DOUBLE the size of our nursing team. Luckily enough for us, Natalie was one of those incredible nurses who saw it and made the move to join us all the way from Ireland!

“ The ad popped up from Noah's Ark looking for nurses who could 'play hide and seek' it almost seemed like a sign! It showed me that the role was child-focused, and with a passion for palliative care, I took the opportunity and applied... the rest is history! **”**

noahsarkhospice.org.uk/nurses'."/>

At Noah's Ark we need paediatric nurses to help children who are seriously unwell make the most of every day. Our stunning new building is set in a nature reserve just a mile from here - a place of laughter, play and real connection. If this could be you, or someone you know, visit noahsarkhospice.org.uk/nurses

NOAH'S ARK
children's hospice

We still urgently need more nurses to join our team in order to provide specialist care to more babies, children and young people who are seriously unwell. If this could be you or someone you know, please visit noahsark.org.uk/nurses

Before the death of their little boy, George, Elmira and Rupert had never heard of a bereavement suite. When George died in 2021, he was brought to The Ark to stay in our butterfly room, where Rupert and Elmira were able to say goodbye in calm and peaceful surroundings.



“ you don't want someone to solve your problem, because it's unsolvable, but you want someone to be there. ”

“We knew that we needed help. We didn't know what it would look like, or what it would feel like, but we just knew that we needed someone's help. Being left alone was scary.”

Family Link Team Manager, Alex, has been supporting Rupert and Elmira on their journey ever since.



Rupert describes Alex as a voice in the fog at that time. “The fog of palliative care, child loss and the trauma of everything means that you're unable to see clearly or be present. Alex was able to guide us on everything, from emotional to practical things.”

Elmira recalls a poignant moment with Alex when she said to her: “I've got to plan my child's funeral when I've never even been to one.”

As well as supporting and advising on more practical matters like making funeral arrangements, Alex also views her role as a nurturing one: “I'm trying to do the thinking so they can do the feeling. It was really important to check in on them both – I'm here, I'm present, I'm thinking of you.”

Often, others' discomfort around death and loss leads

Elmira and Rupert
with baby George
and sister Sasha



to feelings of isolation for many grieving families. Noah's Ark allowed space to remember George and make new memories, even after he had died.

"There's this problem that your friends and family think you want to be left alone, and you might even think you want to be left alone, but actually you're so lonely at that moment."

One of the ways Rupert and Elmira choose to remember George is by visiting his butterfly memorial tribute, placed in our Butterfly Woodland Walk. "It was very important to have George's butterfly. It's like mapping him. It's yet another place that has his presence, and there's so few places that

he had a presence." George now also has a little sister, Sasha. Rupert and Elmira like to visit his butterfly with her, as they promise to keep building those memories for her too, as a family.

"Now Sasha has touched that butterfly and we have photos of that butterfly through the seasons, it creates that narrative and that connection."

Grief never ends, but changes and evolves overtime. It is our privilege to be there for families like Rupert and Elmira's, creating a space for them to continue their relationship with their child who died, whilst supporting them as they continue to make new memories together.



Fun at The Ark!

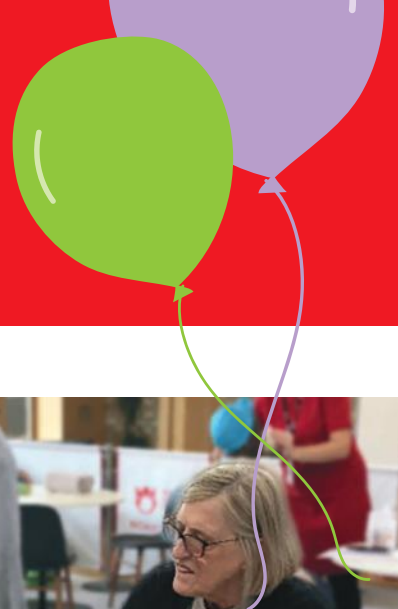
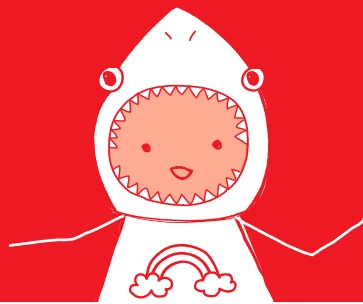
The Ark is a place of laughter and light for the babies, children, young people and families we support.

Baking with Rocco and Mickey

Mickey Mouse had his very own baking lesson from our Master Chef, Rocco! The pair baked up a storm in the family kitchen and made some scrumptious rice-crispy cakes to enjoy and share with everyone at The Ark. Yummy!

Chef Rocco with kitchen assistant Helen and willing cookery student Mickey Mouse





Pamper Day for Parents and Carers

Earlier this year, our parents and carers group were treated to a very special and much needed pamper day.

We wanted to give them all a day to remember, so all the stops were pulled out for some well-deserved relaxation time! They were treated to massages, manicures, make-up, hair, and skin care.



“Thank you so much, this day has been amazing. I’ve had acupressure and I feel so relieved from it. I felt so tense before – now I feel like a different woman! I think I needed some self-care a long time ago, with everything that is going on, this is so great that you have done this for us.”

Mother of a child supported by Noah’s Ark



Sensory Story Time with Debutots

At Noah’s Ark we LOVE bringing smiles to faces through play!

We were so pleased to welcome **Debutots** to The Ark for Sensory Story Time where stories came to life – we just loved seeing Adam’s cheeky smile! The children were treated to a fun-filled afternoon to light up all of their senses.

Easter at The Ark

**Sunny skies, smiles
and chocolate...
what more could
you want?**

The children (and adults) had fun exploring our Nature Reserve on the hunt for Easter eggs over the holidays! Our winding paths around the trail are fully wheelchair-accessible so that everyone could participate in the spring shenanigans!





Days at The Ark are always full of surprises... and this one involved some special guests.

The children got the chance to be up close and personal with lots of different animals, from fluffy rabbits to scaly snakes!

Events like this at The Ark are always filled with lots of smiles and laughter – and they are a wonderful opportunity for families to connect with people going through similar experiences.



We have been rated OUTSTANDING by the CQC!

Following an inspection in January and February 2023, Noah's Ark has been rated OUTSTANDING by the Care Quality Commission (CQC)!

When providing essential care to babies, children and young people who are seriously unwell, external validation matters. We know that the care we provide is outstanding, but it is important to



receive the external recognition from our regulator the Care Quality Commission. CQC is to us what Ofsted is to schools – they are responsible for ensuring that health and social care services are safe, effective, compassionate and of a high quality. To be recognised as outstanding is a true reflection of the incredible work that takes place at Noah's Ark every day – we couldn't be prouder.

“ When we inspected Noah's Ark – The Children's Hospice, we were extremely impressed by what staff had done to take this service from good to outstanding since we last inspected.

The service really understood what children and young people as well as their families needed, both clinically, and emotionally at a really difficult time in their lives. We are very pleased to award the service an outstanding rating and the whole team deserve to be congratulated

for all their hard work and commitment. We would urge other services to read this report and see what they can learn from this outstanding example. **”**

Jane Ray, CQC Deputy Director of Operations in London

“ When I started at Noah's Ark Children's Hospice 10 years ago as a nurse team leader, we were reaching only a fraction of the number of children and families we now care for. Whilst we

rapidly expanded our services and worked tirelessly to open our hospice building, The Ark, we never lost sight of the importance of putting children and families right at the centre of all we do. This outstanding rating is a reflection of that dedication to the children and families we care for. I am immensely proud and privileged to be a part of the Noah's Ark team. ”

Hayley Manley, Director of Care at Noah's Ark Children's Hospice



Providing outstanding care through excellent partnerships

At Noah's Ark Children's Hospice we are just one part of the ecosystem of charities, hospitals and professionals working together to help babies, children and young people make the most of every day.

By working collaboratively in partnership with others whose mission aligns with our own, we are able to have a greater impact on those we support. Here are just some of the fantastic organisations we are proud to partner with to deliver our mission:



Creating magical moments with

SPREAD A SMILE

Alongside 25 NHS hospital partners, Spread a Smile provides support to two children's hospices, one of which is Noah's Ark Children's Hospice. ✨

Spread a Smile has been supporting Noah's Ark Children's Hospice and their families since 2019, initially through weekly virtual sessions during Covid-19 and now supporting

in-person. We were lucky enough to welcome Spread a Smile's Fairy Kirsten, Mr Magic, singer Tasha and Olivia with

Therapy Dog Thomas to our Family Day, where they all gave their time to helping to entertain and spread some joy and laughter.

The impact that our partnership with Spread a Smile has on the children and families we support extends beyond Family Days.

Earlier this year we called on Spread a Smile as we were caring for a child at the end of their life. As a team, we wanted to create a moment of magic for the entire family, including the child's older sibling. Within hours the Spread a Smile fairy arrived at the doors of The Ark,



creating a wonderful moment for the siblings to experience together. ✨

Laura Walter, Director of Services for Spread a Smile said: ✨

“For families with a seriously ill child, the support of different healthcare settings alongside or beyond the hospital setting is often vital, particularly over longer periods of time. It is therefore important for Spread a Smile to be able to reach these children at every stage of their journey and we're proud to be working with Noah's Ark Children's Hospice to do just that.”

changing how
people think
and talk about
children's
palliative care

Children's palliative care is life-long, supportive care for children with life-limiting or life-threatening conditions.

It's all about helping children enjoy life as children, rather than as patients; as families, not just as carers. As medical advancements mean that children with complex needs are able to live for longer, the need for life enhancing palliative care is growing on a global level.

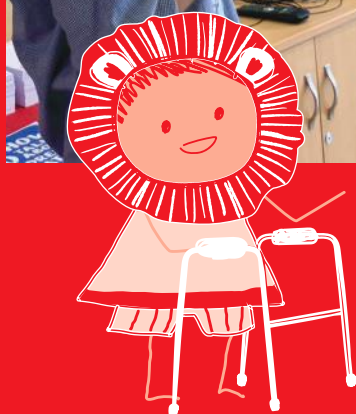
Despite being such an essential pillar to modern healthcare, palliative care is not very well understood by both the general public and healthcare professionals alike. We know that this adds to a

family's sense of isolation and prevents children and families from accessing our services.

'HEARD

Heard, a charity that works with people and the media to inspire content and communication that

changes hearts and minds, is working tirelessly to overcome these barriers in communication. Their programme on Children's Palliative Care has been invaluable as we continue to develop our communications, and we were delighted to partner with them in delivering a talk on how to talk about children's palliative care at our first ever 'Charity Partner's Brunch' in April this year.



Thank you to the entire team at *Heard* for your excellent work in this area – we know it will help more babies, children and young people across the country get access to the support they need.

Meet the Team



From our Medical Directors and Chief Executive to play specialists, nurses and volunteers, everyone at Noah's Ark is here to help the children and families we support enjoy life together, no matter the challenges they face.



Rebecca Taylor, Transition Coordinator

Rebecca Taylor, our Transition Coordinator, has always been passionate about empowering young people. Having seen how poor the transition from child to adult services can be for those with additional needs, Rebecca is dedicated to making the experience for young people at Noah's Ark as fulfilling as it can be.

Rebecca said: "It isn't like young people suddenly change overnight on their 18th birthday, but the system is almost designed like they do. Using my previous experience in hospices and hospitals, my role is designed to improve the experiences of the teenagers we support – starting from when they turn 14, right up until they transition to adult services.

A large part of this involves looking at how we can work with them to develop their life skills – skills that will enable them to have as much independence as possible. For some, this may mean learning how to book appointments themselves, for others it may be learning how to take public transport on

“ The most important source of learning ”



their own, making a cup of tea or cooking dinner.

We also need to look at the culture at Noah's Ark and see how we can better adapt our services to be inclusive for the young people we support. For example, I am working closely with the Family Activities

Allowing children to be children... also means allowing teenagers to be teenagers...

Team to further adapt our activity groups for young people and working with the wider team on how we can adapt the physical space itself.

We also need to be equipped in supporting teenagers through the issues that are typical for their stage of life – including thoughts around gender and sexuality.

I am still in the early stages of my time at Noah's Ark so a lot of my time currently is spent learning – both from the team at Noah's Ark but also at other hospices. I am

working with adult providers, such as North London Hospice, to improve communication and collaboration which will improve the experience for young people as they transition to adult services.

The most important source of learning is, of course, from the young people we support themselves – they are best placed to tell us how we can best support them! Allowing children to be children, rather than patients, also means allowing teenagers to be teenagers and I'm very excited to be a part of this journey at Noah's Ark."



is from the young people themselves... ”



Meet the Team



Gill, volunteer at Noah's Ark

After taking early medical retirement Gill found herself missing working with children and young people with disabilities.

With some time to give, a Google search led her to Noah's Ark Children's Hospice. Volunteering with Noah's Ark gave her both the flexibility and life balance she desired, as well as the ability to give something back. Gill volunteers across the charity including as a vital part of the Family Link Team. In 2022 she was matched with a family who she now visits weekly to provide Home Support.

Q What's the best thing about being a Home Support volunteer?

A The feeling you get when Xander, who is supported by Noah's Ark, gives you a big belly laugh because he is so incredibly happy at a song you are singing or a toy you are playing with together – it makes your day. If we could bottle that feeling and sell it, we'd be millionaires!

Xander is also non-verbal and it takes time to learn how he communicates. When

you get it right and you're there together, sharing that moment, it is extremely special. That feeling of connection is really important.

Q What are some of the benefits of volunteering at Noah's Ark?

A It is the thing I look forward to most each week. No matter how I feel on the journey to my visit, I always feel happy on the way home. I was motivated to volunteer to help others, so I was surprised at how much I would also benefit from it – it is really good fun and so enjoyable, a real bonus.

Q What impact does volunteering have on you?

A Daily life can be stressful. Volunteering gives you the opportunity to go and do something totally different, for someone else. It gives you a chance to switch off, have a lovely time and be helpful. It is brilliant for your mental health and good for the soul.

Q What would you say to someone thinking about volunteering?

A Go for it! You will find Noah's Ark will listen carefully to what you enjoy and are good at. They then will match you carefully with a family that works for you. They won't make you feel out of your depth and have a great support system, meaning they are always there to help.

“ No matter how I feel
on the journey to my visit,
I always feel happy on the
way home. ”



Bringing Makaton to Noah's Ark

Many of the children supported by Noah's Ark are not able to communicate effectively through speech alone, leading to feelings of isolation and frustration.

In order to create an environment where all children, regardless of their condition, can thrive and connect, we need to foster other communication methods that are inclusive to those we support. All children deserve the opportunity to express their wants, needs and feelings independently – in short, all children deserve to be heard.

What is Makaton?

Makaton is the UK's leading language programme for adults and children with learning or communication difficulties. Today, more than 100,000 children and adults, including many of the children we support, use Makaton, either as their main way of communicating or alongside speech. The programme combines signs, symbols and speech to give different options for people to communicate.

How can Makaton help?

By giving them an inclusive and accessible way to express themselves, Makaton can transform the lives of people with communication difficulties. The ability of expression and to be understood is key in child empowerment and alleviating the frustration that is often felt as a consequence of not being heard. By removing this



“ It has been amazing to see the passion and drive that Noah's Ark staff have for completing training to improve their communication skills. **”**

Ellie Butcher,
Noah's Ark Play Specialist & Makaton Tutor

frustration, it opens a child up to all kinds of possibilities for children to connect with other people and the world around them. At Noah's Ark, we want to create an environment where every child feels heard – and Makaton enables us to do just that!

Bringing Makaton to Noah's Ark

Staff were eager to sign up to Makaton Level 1 and 2 courses when the hospice launched its training initiative. Care and also non-care staff took up the training, reflective of the shared responsibility felt by everyone at Noah's Ark to create an inclusive environment for those we support, regardless of the role we have at The Ark. By the end of the training sessions, staff had learnt over 250 signs and symbols!



London Marathon 2023? Completed it!

This year we had eight incredible runners taking on the London Marathon to raise funds for Noah's Ark! We want to say a HUGE well done to all those who took part in the race. Your strength, determination and resilience, leading up to and on the big day, have blown us all away. We want to thank everyone who kindly supported, donated and got involved – because of you, we can help more children who are seriously unwell make the most of every day.

Are you inspired by our awesome runners? If you're up for a challenge visit www.noahsarkhospice.org.uk/support-us/events for upcoming events, from marathons to 5ks. Whatever are you waiting for?



A heart that works...



“ *His music therapist, Kirsty, did the equivalent of aiming a firehose of pure joy at Henry, Leah and me. I still watch videos of them making music together on a guitar or a drum full of beans and thrill with love.*

The happiness I associate with that children’s hospice is boundless, and I will be grateful until I die and beyond. ”



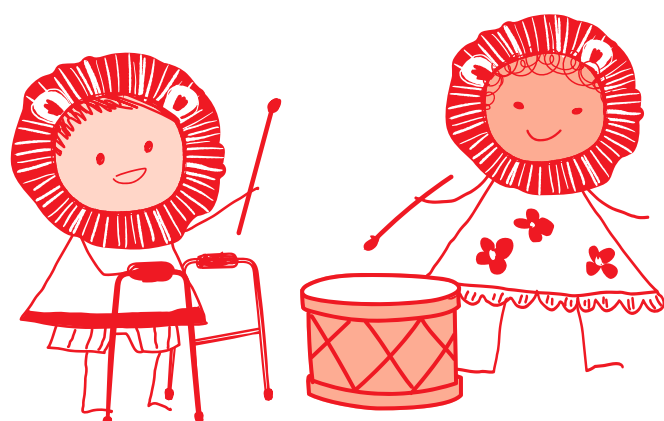
Thank you so much to writer, actor and comedian **Rob Delaney** who, in his powerful memoir *A Heart that Works*, shared these beautiful words about his experience with Noah’s Ark Children’s Hospice and the care that his son, Henry, received.

To use Rob’s words, ‘a firehose of pure joy’ is what we want to be not only for babies, children and young people who are seriously unwell, but their entire family too. It’s not our role to try and change the prognosis, but we can help create memories that families will cherish forever. We can stand by them every step of the way.

As a society we often find it difficult to think about childhood illness and death, let alone talk about it.

This often leaves bereaved families feeling isolated, unable to access the support they need. Books like Rob’s help to shed light on what many people go through, helping families feel less alone.

Thank you so much Rob for sharing your story with the world. Your book is as every bit funny as it is heartbreaking, and we are sure it will be treasured by families for years to come.



Without support from our
community we can't be
there for those who
need us the most.



It costs £4.3 million a year to provide our services. As the need for our support continues to grow, so do our costs.

Only 7% of our income comes from the government, meaning that we rely on the generosity of our community to help fund what we do.

You can make a big difference and help us to be there for more babies, children and young people with life-limiting or life-threatening conditions. Making a one-off donation, or setting up a regular gift, is an amazing way to help more children make the most of every day.



Visit www.noahsarkhospice.org.uk/donate to change lives today.





Create memories that last a lifetime, beyond your lifetime

Please consider leaving a gift in your Will to ensure that future generations of children with life-limiting or life-threatening conditions have access to expert and compassionate palliative care. Your legacy will help these children, and their families, make the most of every day.

If you would like to find out more about the impact you can make through leaving a gift to Noah's Ark in your Will, please get in touch with Rebekah Severn at RSevern@noahsarkhospice.org.uk, or by calling **020 8449 8877**.



NOAH'S ARK

children's hospice

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Registered Charity No. 1081156