

WELCOME TO NOAH'S ARK CHILDREN'S HOSPICE



**A GUIDE FOR
FAMILIES**

making the most of every day



WELCOME!



A warm welcome to Noah's Ark

This booklet is designed to tell you all about us and the services we can offer your family.

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We look forward to welcoming you very soon

Our website is also a useful source of information – find us online at noahsarkhospice.org.uk

You can also follow us on social media and stay up to date with our latest news:



About Noah's Ark



We are Noah's Ark Children's Hospice



NOAH'S ARK
children's hospice

We help babies, children and young people with life-limiting and life-threatening conditions, and their families, make the most of every day. And for those that die young, we do all we can to bring comfort to their last moments.

We put your child and family at the heart of everything we do. We provide exceptional care, organise fun activities and help you do things you may have never thought possible.

We exist to help support your child to enjoy life as a child, rather than as a patient – and for you to enjoy life as a family, not just as carers.

We take an individual approach, adapting our care to meet the needs of your child. We offer support to your whole family, not just your child who is unwell, including dedicated sibling support if you have other children too.

Our help is available wherever it's needed:

- In the home.
- In the community (including in hospital).
- And at our hospice building, The Ark.



Our support is available:

- Up to your child's 25th birthday (we offer clinical care up to the age of 18).
- Or, if needed, for up to three years and three months after your child has died.

“ At Noah's Ark you can meet people in a similar situation and immediately have an open conversation with them because you know they get it. You don't have that anywhere else. ”

Roscoe and Gina, parents to Arthur and Ray who are supported by Noah's Ark

Our Values



KINDNESS

We show compassion and empathy in all our interactions.



EXCELLENCE

We are compassionate and exacting about our mission.



COURAGE

We are strong and ambitious in all we do.



Our Approach



FAMILY FOCUSED

We put the baby, child, young person and family at the centre of all we do.



INDIVIDUALITY

We approach each family individually and build care provision in partnership according to need.



EMPOWERMENT

We promote resilience through building on family strengths and are careful not to build over dependence upon our services.



FLEXIBILITY

We offer care both at The Ark and within the community.



HOLISTIC

We have a holistic social and clinical care model, with equal focus on both.



“ A children’s hospice is a place for children to live. It’s a place where memories are made and where you feel supported. It’s about making the most of the life you have, even if it’s not as long a life as the average person. ”

Katie, mum to Leia who is supported by Noah’s Ark

OUR JOURNEY

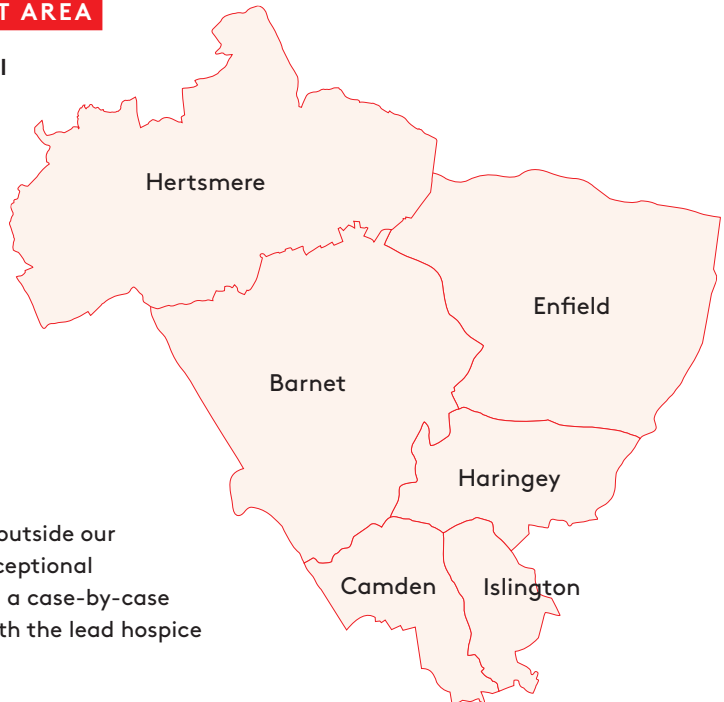
The last two decades have been quite a journey. Whilst a lot has changed, what hasn't is our unwavering dedication to being there for children and families, and putting their needs at the centre of all we do.

Our focus on the needs of children and families has fuelled the expansion of our services. We offer one of the widest ranges of services in the children's hospice sector.

- **1999** – Michael McInerney establishes Noah's Ark following the death of a child in his family.
- **2006** – Noah's Ark becomes the first ever children's hospice to provide a Home Support Volunteer Service.
- **2015** – The £10m 'Building The Ark' appeal is launched.
- **2019** – The grand opening of The Ark, our purpose-built state-of-the-art children's hospice in Barnet.
- **2020** – We continue to support children during the COVID-19 pandemic, allowing families with a child at the end of their life to stay together.
- **2023** – Noah's Ark receives its first 'outstanding' rating from the Care Quality Commission.

OUR CATCHMENT AREA

The core geographical areas we cover:



We consider referrals outside our catchment area in exceptional circumstances and on a case-by-case basis, in discussion with the lead hospice for the area.

Being Referred to Noah's Ark Children's Hospice



REFERRAL CRITERIA

Children and young people can be referred to Noah's Ark if they meet these criteria:

- The baby, child or young person lives within the catchment area of Barnet, Camden, Enfield, Islington, Haringey or Hertsmere (Hertfordshire).

- The baby, child or young person is aged under 18 at the time of referral (0-17 years).

- The baby, child or young person has a life-limiting or life-threatening condition, according to these four 'Together for Short Lives' definitions:
 - 1 Life-threatening conditions for which curative treatment may fail, eg cancer, irreversible organ failure.

 - 2 Conditions where premature death is anticipated but intensive treatment may prolong life, eg complicated cystic fibrosis, HIV.

 - 3 Progressive conditions without curative treatment options where treatment is exclusively palliative eg Batters disease, mucopolysaccharidoses.

 - 4 Conditions causing severe neurological disability leading to susceptibility to health complications and the likelihood of premature death, eg severe cerebral palsy, multiple disabilities following brain or spinal cord injury. Children in this group may need further assessment if eligibility is not clear using these criteria.

BEREAVEMENT SUPPORT

We consider bereavement referrals for families of any child who has died, whether they were known to Noah's Ark or not and whatever the cause of death, providing the following conditions are met:

- Your child was under the age of 18 at the time of their death.

- Their death was within the last year.

- Your family lives within our catchment area.

“ Noah's Ark widens Sophie's world. They allow children to be more than just their diagnosis, they allow them to be children first. There's nowhere else that Sophie can play... Noah's Ark is a handhold in the darkest of times and they're the fun providers in the best of times. ”

Rose, Grandmother and sole guardian of Ben (who died in 2014) and Sophie who currently benefits from our care

REFERRALS

Anyone can refer a baby, child, or young person to Noah's Ark. This includes:

- Health Care Professionals
- Education Professionals
- Social Work Professionals
- The parent, carer, family member, friend or guardian (where evidence from a professional is supplied)
- Any young person who believes they meet our criteria.

Parents/carers/guardians/children and young people aged 16+ able to give consent must be asked if they agree to the referral being made. We give all referrals careful consideration, evaluating a child's diagnosis against our criteria.

REFERRALS

We consider all other referrals at multi-disciplinary panel meetings, which take place **every two weeks**.

If we have all the information we need for the referral to be accepted, we will allocate you a Family Link Worker who will contact you to arrange a visit to your home where we will work to best understand how Noah's Ark can support you and your family.

Sometimes, we may need to obtain further information from medical professionals involved in your child's care (such as Hospital Consultants or your GP). In this case, it may take us longer to make a decision.

Sadly, we cannot offer support to every baby, child or young person who is referred to us. Our primary focus is on those babies, children or young people who meet our criteria.

If your child is not accepted, we may be able to suggest other services you can consider contacting. We also have a referral decision appeals process.



MAKING A REFERRAL

You can make a referral on our website at:

noahsarkhospice.org.uk/referrals

Please email your completed referral form to our Care Team at:

noahs.referrals@nhs.net



Making An Urgent Referral

If your referral is for:

- Urgent Care
- End-of-Life Care, or
- Care After Death

You can also make an urgent referral by calling our Nurse On Call number. One of our registered nurses is available 24 hours a day, seven days a week. Please call the **Nurse On Call** on **020 3994 4134**.



FAMILY LINK – YOUR FIRST CONTACT

Once your referral has been accepted our Family Link Team are your first point of contact.

The Family Link Team will be a constant, reassuring presence throughout your time with us, offering guidance, advocacy, moral support and someone to whom you can talk.

Your Link Worker will carry out an initial assessment visit to help you identify the support that would be the most beneficial to you. We carry out reviews at least annually so we can adjust our services to meet your current needs.

“ The Ark has been a lifeline and a second home for us. Magnus has had some tremendous experiences here and some amazing memories have been made. It really is a gold star operation, with the highest standard of care that we’ve seen on our journey with Magnus. ”

Richard, father of Magnus who is supported by Noah’s Ark



FAMILY LINK SUPPORT

Navigating the complex world of health and social care can be challenging, our Family Link Team can help by offering you:

Practical support

We can help you with benefit applications, housing issues, taxi cards and blue badges.

Signposting

So you can access appropriate resources from other local organisations and charitable grants.

Moral support and advocacy

We offer support writing letters or attending meetings and appointments with education, healthcare and social care services.

Emotional support

We understand it can be hard coping with a diagnosis or prognosis. Sometimes a cup of tea and a listening ear can help. We cannot change or treat the diagnosis, but we will stand side by side with you on every step of your journey.

Our team will always do everything they can so your family can make the most of your time together. We can give individual emotional support and offer access to our other services:

- Parent groups
- Sibling groups
- Family events



- Creative Therapies
- Specialist Play
- Home Support Volunteers
- Counselling and bereavement support.

Our Facilities and Services



Bedroom on Woodlands



Accessible playground



Sensory play room



Soft play room



Hydrotherapy pool

AT THE ARK

Our award-winning hospice building, The Ark, has a wide range of facilities, and we offer both day visits and overnight stays. At The Ark we provide expert clinical care and organise fun and stimulating activities for the entire family.

FACILITIES AT THE ARK

- Soft Play Room
- Sensory Play Room
- Music Room
- Creative Room
- Playroom
- Hydrotherapy Pool
- Multi-Faith Room
- Sensory Garden
- Accessible Outdoor Playground
- The Den – fully adaptable into a gaming and cinema room

Staying at The Ark

CHILDREN'S BEDROOMS

The Ark's **Woodland Wing** has six fully equipped children's bedrooms with adjoining bathrooms, including sensory baths with lights, sounds and bubbles. We adapt the bedroom to your child's needs and interests.

Children come to Woodlands for respite short breaks, step-down-care (when children are well enough to leave hospital but not yet well enough to go home), urgent care and end-of-life care.

FAMILY SUITES

The Ark's **Meadows Wing** has three comfortable family suites, if you choose to stay whilst your child is being cared for.

Each suite has a double en-suite room, with an adjacent twin room to enable the

whole family to stay whilst their child is being cared for in Woodlands. There is also a well-equipped family kitchen where you can prepare your own food, if you choose.

A HOME FROM HOME

The Ark is designed to be a home-from-home. Our award-winning housekeeping team go the 'extra mile' to make you feel at home. From their exacting hygiene standards, a selection of non-clinical smelling products, choices of patterned bedding – they team do all they can to make your stay as comfortable as possible.

The team were recently recognised as providing a 'Centre of Excellence' for cleanliness by North Tees and Hartlepool NHS Foundation Trust.



OUTDOOR SPACES

Nature is never far from The Ark. Set in a beautiful 7.5-acre nature reserve, our grounds offer wheelchair accessible outdoor experiences.

In addition to our fully accessible playground and sensory garden, we have a 1.2 km sensory walkway around the nature reserve. The path passes around our Butterfly Meadow, Wildlife Ponds and Bluebell Wood, and includes various places to sit dotted around the trail.



CATERING AT THE RAINBOW

At our café, The Rainbow, our in-house team prepares wholesome, home-cooked food, with a menu that changes daily.

Visitors to The Ark can purchase food and drinks for a small cost, whilst food is available free-of-charge for families staying at The Ark. We can cater for various dietary requirements. Please note that food must be ordered in advance, before 10:30am.

If you are planning on visiting for lunch, please call The Ark to order your meal.

SPIRITUAL CARE AT THE ARK

Whatever your faith, religion or other system of belief, our aim is to support you, accommodating your family's needs and respecting the way in which you care for your child. Our Multi-Faith Room



at The Ark offers a private space for contemplation and prayer. There is also a quiet garden space directly outside.



OUR SERVICES

We offer support based on the individual needs of your family. Here are the ways that we can help:

CLINICAL CARE

Our Specialist Carers (Healthcare Assistants) and Nurses are able to meet children's complex care needs whilst creating memories and allow those they support to enjoy life as children – rather than as patients.

Our Woodlands Wing (home to the children's bedrooms) is staffed by our nurse-led clinical team, who provide specialist palliative care and symptom management, as well as enabling access to our other services and emotional support.

By using sensory, interactive and other stimulating activities, our team put play and fun at the heart of everything that they do.

All our staff are highly trained to meet the ever-changing needs of your child and their medical complexities, so you can have confidence that they are in safe hands.

SPECIALIST CARE AT THE ARK OR AT HOME

Our highly skilled Paediatric Nurses and Special Carers can provide clinical, emotional, social and practical support for your child at The Ark or in your home.

Children enjoy our home visits, which also give you time for a short break or to focus on other activities. We also offer one-to-one or small group sessions at The Ark, which include creative arts, sensory play, soft play, and use of our facilities such as our accessible playground.

OVERNIGHT CARE

Overnight short breaks on Woodlands can be arranged to support your family, providing the child with a fun, stimulating environment and the opportunity to socialise and interact with other children in a safe, nurse-led environment. We can arrange short breaks for respite stays or if, for example, a family member is unwell, during home renovations or when you are expecting a baby.

All our admissions are prioritised according to need so we cannot guarantee overnight short breaks.





STEP DOWN CARE

We can also arrange step down care (supporting your child's discharge from hospital) following a prolonged hospital admission or major surgery.

You can come with your child/ren from the hospital before going home – this provides a safe place to build confidence and to determine how home-life will look before taking that final step.

SYMPTOM MANAGEMENT

Our experienced specialist nursing team can provide a 24/7 symptom management service if or when your child needs it.

Our nursing team are available for planned, ad hoc and urgent symptom assessment to manage complex and difficult symptoms ensuring your child remains comfortable.

The team work alongside the dedicated hospital, Children's Community Nurse (CCN) Teams and GP services to provide support as required.



“ When Noah's Ark came along, things changed. They have been amazing. ”

Asabea, mum to Jannick who is supported by Noah's Ark



CREATIVE THERAPIES

We offer:

- **Music Therapy**
Allowing the communication of feelings and emotions through music; everyone is given time to be seen, heard and listened to.

- **Drama and Movement Therapy**
Using a variety of verbal and nonverbal techniques such as story work, puppetry, role play and movement.

- **Art Therapy**
Understanding thoughts, emotions and behaviours by expressing feelings through art.

We also offer:

- **Hydrotherapy**
Water based therapy in our relaxing pool to aid relaxation, alleviate pain and relieve muscles.

- **Occupational Therapy**

Aims to enhance the comfort and activities of daily living for children by working with community Occupational Therapists to secure funded specialist equipment and liaising with staff and families to share specialised knowledge and practice.

Sessions are designed to support your child's development, encourage play opportunities and help your child to express themselves.

Our therapies help to address individual physical, emotional, cognitive and social needs. Our professionally registered therapists deliver sessions in The Ark, at home or at your child's school.

We also offer therapy groups and some in-reach services, such as Music Therapy in hospital, including the Neonatal Intensive Care Units at Barnet Hospital, Great Ormond Street Hospital and UCLH.

Your Family Link Worker can offer you access to our range of Therapies, based on your needs.



“ Music Therapy allowed us for the first time since my son’s very difficult start in life to experience a moment of normality as a family. ”

Mother of a child supported by Noah’s Ark

SPECIALIST PLAY

Our Play Team believe in the power of play. By focusing on what your child can do, rather than any perceived limitations, our Play Team will support your child in reaching developmental milestones, expressing themselves and exploring the world around them.

Our Play Team can provide play support for child at:

- Home
- School
- Hospital
- The Ark

We plan play sessions to meet the individual needs of your child, with specific aims and outcomes in mind. Our wide range of specialist play equipment can be used to support progress towards specific goals.

We can also use play to support your child if they have any fears or anxiety about their treatment or condition. We can use play as a distraction when your child is having an invasive treatment.

We offer play support for siblings too. A big focus of our play support is based around making memories at every stage of our care services.



Learning to Communicate with Play

Communication is a vital part of our play services. If your child needs support to communicate effectively, our specialist team can use systems to teach your child how to communicate and express themselves. Some of the systems we use include:

- **The Picture Exchange Communication System (PECS)** – enabling children to communicate without relying on speech by using cards with pictures and symbols.
- **Makaton** – a unique language programme that uses symbols, signs and speech to enable children to communicate.
- **Eye Gaze** – devices which enable children to use their eyes to communicate.

These advanced communications are introduced to your child through play, empowering them with choices and the ability to express their wants and feelings. We provide dedicated play spaces where your child is in complete control of what happens, something which doesn't happen often for a child with complex health conditions.

We can also help your family to learn how to play together by providing space, support and guidance to you.

“ It’s healthcare professionals like Noah’s Ark Play Team who are our real-life superheroes. The team have worked hard to ensure that play is an integral part of children’s care, particularly end-of-life care, where they enable families to create positive and long-lasting memories. The Play Team is truly inspirational. ”

Cath Gilman, Starlight Chief Executive



FAMILY ACTIVITIES

We organise a wide range of activities for all the family, throughout the year, including:

- Family days out.
- Sibling groups.
- Parent groups.
- Nurse-led groups for babies, children and young people.

These activities are a great way for your family to develop confidence, make new friends and build a community of support.

Events range from themed Family Activity Days for your whole family to special Sensory Days for the babies, children and young people that we support.



We also offer organised group activities for siblings, by different age ranges, plus regular social activities for parents.

We can also offer transport services.

We create a calendar of activities every three months, which can be sent to you following your assessment with our Family Link Team.



“ The hospice supports Arthur a lot. He used to be so shy but now he goes to all the sibling groups, which have really helped him with his confidence. Arthur has met Harry Kane, seen Spurs play and been to Chessington World of Adventures, all thanks to Noah’s Ark. ”

Gina, Mum to Ray and Arthur, who are supported by Noah’s Ark

HOME SUPPORT VOLUNTEERS

Our trained volunteers can provide support for your family at your home or within your local community. Their assistance can include:

- Playing games.
- Helping with homework.
- Carry out practical tasks such as gardening.
- An extra pair of hands helping your family enjoy time out together.
- Spending time with children whilst they are in hospital.

Our volunteer team will work closely with your family to identify what family support might be of help, or which family member may benefit from some extra support.

Our Family Link Team will help to identify your needs and help set up volunteer support in the first instance.



NOAH'S ARK ON HOLIDAY

We offer a self-catering holiday service, where you can enjoy a week's free stay at one of our two fully accessible lodges on Mersea Island in the beautiful Essex countryside.

Each fully equipped lodge sleeps seven people and is available for a self-catered break during the months of March to November. The lodges are sited on Coopers Beach Holiday Park which has

beach access, an indoor and outdoor swimming pool, bar and restaurant, and entertainment venue.

We open bookings in January.



TRANSITION TO ADULT SERVICES

We support children and young people aged from birth to 25. We know how important the transition stage from adolescence to adulthood is for your child, and you.

We only accept referrals up to the age of 18, however young people who are known to us are invited to stay with us after they turn 19 years old. Whilst we provide support for young people aged 19 and over, we do not offer clinical care.

Individual Approach

We aim to support you through the transition process by offering a plan, tailored to your unique needs.

We focus on an individual's strengths and potential rather than risks and limitations. Our aim is to empower young people to make informed decisions about their future.

Early Preparation

We begin transition planning well in advance, ideally starting at the age of 14. Early planning allows time for relationship building, assessment and goal setting so that we can facilitate a seamless transition from child to adult services and support you on this journey.

Collaborative Care

We take a holistic approach to our support and collaborate with teams across healthcare, social care, education and the voluntary sector.



Flexible and Gradual Plans

We create flexible plans that adjust on the evolving needs and preferences of young people. We aim for a gradual transition process to ensure a smooth and well managed shift from paediatric to adult-focused healthcare and support services.

Education and Advocacy

We can provide education resources and advocacy support to empower young people to understand their rights, healthcare options and available services during the transition process.

ADVANCE CARE PLANNING

We understand that navigating the healthcare system can feel daunting at times and that's where we can help.

Advance care planning focuses on giving you choices – it's about how you choose to live until you die. Part of this includes having conversations with your healthcare team to make sure that your family's wishes are followed.

This can include how and where your child wants to be cared for and what matters most to your child and your family.

And if you do have to prepare for the death of your child, we will work

with your child's team of healthcare professionals, to provide complex symptom management and holistic care.

By taking a holistic approach to this care we can support your whole family to create lasting memories to treasure, helping you to be together as a family in these final moments.

We cannot change or treat the diagnosis, but we will stand side by side with you on every step of your journey.

COPING WITH DEATH AND DYING

We understand how facing death isn't easy and we can help if and when you need support.



Support at End-of-Life

Our team do everything they can to ensure the final weeks, days and hours of a child's life are as comfortable as possible.

We provide care for newborns, babies, children and young people nearing the end of their life, either at home, in hospital or at The Ark.

Together with your child's existing team of healthcare professionals, we provide complex symptom management and holistic care. We work closely with your

“ Noah's Ark is a foundation, a pillar the whole family leaned on. Without them we would have collapsed. ”

Manju, who received bereavement support after her daughter Manasa died

child, with you and other professionals to understand your child's end-of-life plans and wishes.

By taking a holistic approach to this care we can support your whole family to create lasting memories to treasure, helping you to be together as a family in these final moments.

Should you choose, we can support you to spend time with your child after they have died, in our bereavement suites or at home.

Care After Death

Our Bereavement Support Team understand what life can be like for a family after a child dies, and are here to help you through the days, weeks, months and years ahead. From help with practical issues such as funeral arrangements, emotional support or simply someone to talk to, the team are there for you every step of the way.

Bereavement Support

We offer free bereavement support to your family for three years and three months after your child has died.

We provide support whether your child died at home, in hospital, at The Ark or elsewhere.

Our support can include:

- A named bereavement support worker who will be with you throughout your journey with grief.

- Support groups for parents/carers, siblings and grandparents.

- Creation of special tributes and 'Treasures' to remember your child.

- Events where you can meet families in a similar situation.

- Counselling sessions, both one-to-one and in groups.

- Memory making activities and events such as our annual candle lighting ceremony.

- Remembrance events.



How to Contact Us

Please call our Reception and ask to speak to one of our teams.

RECEPTION OPENING/

OFFICE HOURS

Monday to Friday, 9am-5.30pm

Call: **020 8449 8877**

Call Reception to contact:

- Family Link
- Home Support Volunteering
- Family Activities
- Therapies
- Specialist Play
- Specialist Care and Nursing

OUT OF HOURS ENQUIRIES

Our Care Team is available outside opening hours for **urgent** enquiries that can't wait until our Reception re-opens.

Nurse on Call: 020 3994 4134

The number is staffed 24 hours a day, 7 days a week by a member of our nursing team. They can respond to urgent enquiries, urgent referrals and provide advice outside office working hours, including symptom management, end-of-life or care after death assistance.

The Nurse on Call is available to:

- Noah's Ark families
- Care Team staff
- Noah's Ark Volunteers
- Healthcare Professionals

USEFUL EMAIL ADDRESSES

Family Link Team: noahs.flteam@nhs.net

Care Admin Team: noahs.admin@nhs.net

Referrals: noahs.referrals@nhs.net

Specialist Care & Nursing Team: noahs.nurses@nhs.net
(This inbox is checked at weekends.)

Family Activities: familyactivitiesteam@noahsarkhospice.org.uk

Therapies: therapiesteam@noahsarkhospice.org.uk

Home Support: homesupport@noahsarkhospice.org.uk

You can also find useful information on our website at noahsarkhospice.org.uk



Supporting Noah's Ark

It takes a community to help the children and families at Noah's Ark make the most of every day. Here are some of the ways you can get involved:

BECOME A FAMILY

AMBASSADOR

By sharing your story, help us increase the understanding of Noah's Ark Children's Hospice. Experience tells us sharing stories is powerful; other families connect with your story and are encouraged to access our services or support our charity by volunteering or donating. Harnessing a sense of community will help us to build a case for long-term sustainable support for our charity.

If you would like more information, please contact:
marketing@noahsarkhospice.org.uk

HELP US RECRUIT VOLUNTEERS

Whether they're supporting children and

families at home; or helping us thrive as an organisation, our volunteers are a vital part of Noah's Ark. Do you know someone who could be our newest recruit?

Please visit: noahsarkhospice.org.uk/volunteering for more information.

SUPPORT OUR FUNDRAISING

As a charity we rely on our supporters' generosity to continue our work. You could support us through your company or community group; take part in a fundraising event; remember us in your will; or make a regular donation.

Please visit: noahsarkhospice.org.uk/support-us for more information.



NOAH'S ARK

children's hospice

KEEP IN TOUCH WITH OUR LATEST NEWS



**NOAH'S ARK
CHILDREN'S HOSPICE**

The Ark
Byng Road, Barnet, Hertfordshire EN5 4NP

020 8449 8877

info@noahsarkhospice.org.uk

Registered Charity No. 1081156

noahsarkhospice.org.uk