

Your journey with Acorns Children's Hospice

A guide for families

acorns

Your local children's hospice



Kasim having fun at the hospice

Inside this booklet
you will see photos
of and hear from real
families who have
used Acorns

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“When Hugh was diagnosed, we didn’t know what his future looked like. We had so many unanswered questions. Coming to Acorns meant I could meet other parents in the same situation. They had the same kind of worries and understood what I was going through.”

- Emma, Hugh’s mum

Understanding your journey

We are here for you every step of the way

If you have been given this booklet to read, we know that you may be involved in the support and care of a child with a life limiting or life threatening condition. Or you may be waiting for the birth of a baby who you know will only survive for a short time, or be born with a life limiting or life threatening condition.

It’s a sad, stressful and often exhausting situation. That’s why we are here for you. We understand and we want to help you.

This booklet is not just for parents but for brothers and sisters, aunts and uncles, grandparents and friends to read too. It is also for teachers, group leaders and community groups – in fact, anyone who’s involved, in whatever way, in the support and care of a child with a life limiting or life threatening condition.

Even today, despite huge leaps in medical science, babies with life limiting or life threatening conditions are born into families across our region. Life limited because no amount of medicine, or love, can cure them.

Often rare, these conditions may be identified before birth but sometimes won’t emerge for days, weeks, months or even years later. While some babies will reach childhood and even become young adults, for many their lives will be short.

The aim is to give you clear and helpful information about how Acorns can become involved – providing specially tailored support and help that’s exactly right for you, your child and your family.

Hugh and mum, Emma, having fun at the hospice



It's hard being 'that' mum - the one who is always worried about their child and has to keep an eye on them. At Acorns everyone understands and will talk to you about what is going on with you. I feel like the normal mum for once when I'm here."



- Chantelle, Sophia's mum



Introducing Acorns Children's Hospice

Who we are and what we do

Caring for a child with complex medical needs can place unimaginable demands on a family, both physically and emotionally. We are here to support you on your journey, in any way we can to meet all your individual needs.

Our vision is that every life limited or life threatened baby, child and young person in our region will have access to our care when and where they need it. This sits at the heart of everything we do.

We are a charity providing care and support to families from our three hospices and within the family home and community.

We provide **CARE** from our three hospices

- > Acorns in Birmingham, based in Selly Oak, supports families from Birmingham, North Warwickshire and Coventry.
- > Acorns in the Black Country, based in Walsall, supports families from Walsall, Sandwell, Dudley, Wolverhampton, Staffordshire and Shropshire.
- > Acorns for the Three Counties, based in Worcester, supports families from Worcestershire, Herefordshire, Gloucestershire and South Warwickshire.

We generate **SUPPORT** for our work through fundraising and commissioning arrangements to secure the money needed every year to run our hospices and provide services to families.

We make **CONNECTIONS** between families, health and social care professionals and supporters and promote a joined-up service provision for those we care for.

Sophia and her grandma painting in the craft room



Setting the scene

How and where Acorns can help

At Acorns, we provide specialist care that is tailored to you and your child's specific needs. This care can be provided in the home and community or in one of our hospices.

We will work directly with you and the health and social care professionals involved in looking after your child. As well as offering you support in one of our hospices, we'll help you to stay connected within your local community and with your local services.

Palliative care

We specialise in this area of healthcare which focuses on relieving and preventing pain, and addresses the physical, emotional, spiritual and social impact of illness.

It involves a multi-disciplinary approach that means an emphasis on specialist play and fun activities as well as nursing, medical, emotional and practical support.

Complex medical care

Our professional medical and nursing teams at Acorns are skilled in looking after children who require a high degree of complex medical care. This can include ventilation, intravenous medication and feeding and peritoneal dialysis (used to remove excess fluid and toxins from the kidneys). These may or may not be terms you're familiar with, but it's reassuring to know that if your child, now or in the future, is able to cope with such treatments at home, we can look after them at Acorns too.

“Acorns have changed my state of mind. I don't know what I'd do without them, they're there for me no matter what.”

- Shabana, Haniya's mum

Haniya and mum Shabana sharing a precious moment

Continued...

Emotional and practical support

At Acorns, our approach is to put the child who needs care and support at the heart of everything we do. This means providing opportunities for lots of fun and enjoyment alongside palliative and medical care, even when we're dealing with very serious illness and end of life care. We will help your child and his or her siblings to live life to the full, creating treasured memories and shared experiences. We will work with you to develop plans that capture your whole family's wishes, hopes and dreams at an early stage and provide emotional and practical support according to your needs.

Acorns hospices

Our hospices are warm, friendly and happy environments. They have a homely atmosphere but with round the clock help and support from our caring and highly skilled professional and medical staff. Families who come to one of our hospices often refer to them as a 'safe haven' – a place where the family can enjoy a rest and a break from the challenges of day to day life. We are often told that spending time with our team and with other families gives families practical ideas and tips for dealing with some of the specific care needs of their child. This can be achieved by staying at the hospices in our family accommodation or by attending one of the many support groups we run.

Acorns outreach service


For some families, coming to one of our hospices is just what they need, but others prefer us to go to them and provide medical support in the family home. Acorns outreach service doesn't replace your local services. In fact, we can help you to get all the support you need within your local community. If there's a gap in care, or you need some extra help because of a change in your child's condition or family circumstances, then that's where we can step in.

“ Whatever dark days are coming and whatever the future holds, Acorns are going to be there to support me and my whole family. Until then, they help us enjoy every moment of the time we have with Esme. ”

- Jenna, Esme's mum



Esme with mum Jenna and Head Nurse Lindsey



Yusuf loves it at Acorns and seeing him smile and do things he couldn't at home just makes me so happy. It may sound small but doing things together and filling his day with fun means the world to me.

- Iram, Yusuf's mum

First steps

What happens when you make a referral to Acorns?

Applications for a referral to Acorns, with your consent, can be made by your child's paediatrician, a hospital consultant, or a nurse or midwife who knows your child well. It's important that you discuss the referral together so that the correct decision is made for you and your child.

Making an emergency referral

Usually referrals are planned, but sometimes we need to respond to an emergency at very short notice. This can be because your child has suddenly become very ill or is approaching the end of their life. In this situation we'll aim to visit your child at home or in hospital and arrange to admit them to one of our hospices as soon as possible.

When your referral is planned and non-urgent

A planned referral is made using the Acorns referral form which is available on our website at acorns.org.uk/referral

Assessing your situation

When a referral is received it's assessed by our multidisciplinary panel who consider your child's diagnosis. We may need to speak to the people already involved in caring for your child, such as their consultant, before we can decide about whether your child meets our criteria. This process, in a non-urgent situation, can sometimes be quite quick or sometimes take a while – we ask you to bear with us while we gather all the information we need. We will always write to you as well as the referrer to let you know our decision.

Getting our timing right

Sometimes we are approached about a child being referred and, after we've assessed the situation, we may find that it's not the right time for the child to be accepted. This can be distressing, however, it doesn't mean that the door is closed to you and that Acorns will never be involved, simply that at that point in time your child doesn't meet our referral criteria. If this is the case we'll always explain our reasons and help you to understand why it might be better to apply at a later date.



Ongoing support

*Your relationship with Acorns,
now and in the future*

We're here to help every family who is accepted for Acorns services. For care in one of our hospices or in your own home, whatever your circumstances or background. Although we cannot be there for you in person 24 hours a day, we are available to offer telephone support and advice.

At first, you might feel uncertain about what Acorns can offer or what level of support you may need. After acceptance at our panel, you will be allocated a Family Team Worker who will visit you at home, and work with you to assess your child and family's needs. This is called a Holistic Needs Assessment. It may take a while for us to gather all the information and we may need to speak to some of the other professionals involved in your child's care. It's important that we get a clear idea of all your family's needs so that the services we provide enable you to get the best possible experience from Acorns. Once the Holistic Needs Assessment is complete, we will agree on a plan of support.

Your family support plan is developed by you and your Family Team Worker and is individually tailored to address the needs of each and every member of your family. It helps you to consider everything from practical childcare to community support, work through any concerns and assists you in developing coping strategies. If it is decided that your child needs short breaks, either in the hospice or at home, we will write a care plan.

Your child's care plan is created following an assessment by the nursing team and lets us understand your child's care needs. The care plan captures practical and medical information and where possible, your child's hopes, wishes and desires. It is core to your relationship with us.

Your child's care plan will be reviewed with you every time your child stays at one of our hospices and your family support plan will be reviewed with you annually, or sooner if you inform us of a significant change in your circumstances which you'd like to discuss.

Bluebell having fun in the hospice gardens



Always here to help

The range of services Acorns offers

Every family is different and we always want to make sure you get the level of care and support that's right for you. For example, if you're coping well at home and your child's condition is relatively stable, we may offer you a different level of service than if the situation at home is more challenging.

Over the years we have expanded the services we offer to include nursing, psychosocial support, physiotherapy, hydrotherapy, multisensory play and a range of support groups.

Short planned breaks in our hospices

This is perhaps the service that we're best known for. If you are assessed as needing short breaks, your family can stay together in one of our hospices or your child can stay on their own. During stays at Acorns, children can take part in a range of activities from crafts and music to enjoying time in the wonderful gardens.

You can enjoy time with your friends and family and have the freedom to go out for a meal or see a film, safe in the knowledge that your child is being well looked after by us.

Although our hospices can be places where families experience sadness, they are also places of great joy, where families can rest, connect with other people in similar circumstances or simply find space to be quiet and contemplative.

Reuben and mum Jo sharing a moment at the hospice



“ Jack’s condition means I am unable to take all of my children swimming at the same time. But we can with the hydrotherapy pool and the help of staff at Acorns. This is valuable family time and a great activity which all three children love. ”
- Catherine, Jack’s mum

Services designed to help you

The range of services we can provide

- Planned day and overnight short breaks in one of our hospices
- Emergency admission if your child experiences a sudden deterioration in their condition
- Emergency or unplanned admission to one of our hospices
- Emergency or unplanned care in your home
- Care and support at the end of your child’s life
- Planned sessions of nursing care in your home to share the care and bring some of the Acorns experience to you and your child wherever you are
- Emotional support for your child and family to help you to process what is happening and be as resilient as you can under incredibly difficult circumstances
- Therapeutic based support for young people between the ages of 10 - 18, including opportunities to attend groups and access one to one support
- A comprehensive family service which includes pre and post bereavement support, sibling support, support for young people (aged 10-18) and a range of therapeutic based groups and complementary therapies
- Support to develop an advanced care plan. This is a family held document which focuses on your child and your family’s wishes during life and beyond death
- Health management support and advice for families and health and social care professionals
- 24 hour advice for families or health and social care professionals
- Step-down care - this involves us stepping in for a while when your child has been in hospital for treatment or has had a change in condition and you all need a break before going back home

Jack and his family enjoying the hydrotherapy pool



“Acorns was there too when the grief came. They knew me and what I was going through, so I could be overcome with emotion. At the point in my life where I was most vulnerable, being at Acorns kept me together. There was always somebody putting a hand on my shoulder, kneeling down beside me and telling me it was ok to be feeling this way.”
- Duncan, Sam's dad

Staying by your side

With you when you need us most

Facing the death of your child is possibly the hardest thing you will ever have to do. We promise to stay with you every step of the way giving you the help and support you need.

End of life care

As your child approaches the end of their life, we can help you to decide where you would like them to be when they die. Coming to an Acorns hospice for end of life care is always available, but it is not the only option and we will support whatever decision you make. If you choose to be at home, we will work with your community and hospital nursing teams to ensure the right level of care is provided. Or, if you decide that it is right for your child to die in hospital, we'll provide advice and visits from our staff to support the care being provided there.

Providing spiritual care

Spiritual care is available to everyone, whether or not you follow a faith or religion and whatever your system of belief. The loss of a child can raise big questions about life and death and our spiritual care advisors and staff will be able to explore these with you calmly and with empathy. Our aim is to reach out and support everyone, accommodating you and your family's needs and respecting the way you approach the end of your child's life. All of our hospices have rooms that can be used for contemplation or prayer.

Practical support for the whole family

You may wish to have the opportunity to spend time with your child after his or her death in one of our special bedrooms. These rooms provide a private, calm and restful place for you to spend time together as a family, saying your final goodbyes. If your child dies in hospital or at home they can be transferred to one of the special bedrooms if you wish.

We also have specialist equipment if you want to keep your child with you at home. In the first few days after your child's death, we will spend as much time with you and your family as you need – listening, talking and even playing with your other children. We can also help with many of the tasks which you may not feel able to face, such as assisting you to plan your child's funeral or helping you connect with your own support network.

Ongoing bereavement support

Following the death of a child, people react and grieve in different ways. We understand that you will experience many different feelings and emotions in the days, weeks, months and years that follow. A Family Team Worker will help you and your family decide what bereavement support is right for you and when. We offer one to one support, group support, telephone befriending and spiritual care. We'll also work with you to access support within your local community and, in time, you may choose to take part in one of our memorial days.

There are many ways in which we can help, but the important thing to remember is that you'll never be alone. We'll help you to find a way through your grief while you make this difficult journey.



Moving on from Acorns

Why we may need to discharge a family from Acorns services

When the time is right, we will support you to move on from Acorns.

Developments in treatment and care over the years mean that, in some cases, life expectancy is increased and your child may experience improvement or even recovery. If this happens your child may no longer meet our criteria and we may be able to discharge them from our services. We will work with you and the services in your local community to ensure that when you leave Acorns, other services are available. We will do this in a pre-planned and sensitive way and ensure that you are aware that, should the situation change for your child, they can be re-referred to Acorns at any time.

Our services care for children up to the age of 18. As your child approaches 18 we will support you to move on from Acorns. We will do this with you by liaising with the services that can support you, attending meetings with you if necessary and providing you with information to support the decisions you and your family may have to make about adult care.

Finally, if we feel that our bereavement support is no longer required and you agree with us, we may need to discharge your family from our services.

Amad taking part in music therapy

Get in touch

**If, after reading this booklet,
you would like to find out more
about Acorns services,
please get in touch.**

Acorns in Birmingham

0121 248 4850

birmingham.admin@acorns.org.uk

Acorns in the Black Country

01922 422 500

blackcountry.admin@acorns.org.uk

Acorns for the Three Counties

01905 767676

threecounties.admin@acorns.org.uk

Find out what life is like at our hospices



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