

Acorns Children's Hospice

Information for professionals

acorns

Your local children's hospice




Bluebell enjoying the hospice garden

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

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“ 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

About Acorns Children’s Hospice

Who we are and what we do

Our vision is that every life limited or life threatened baby, child and young person in our region will have access to our specialist palliative 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 funds 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. We are very proud of the collaborative partnerships we have developed with the NHS and Social Care across the West Midlands. We aim to offer families an environment for palliative and end of life care that meets all their needs.

Sophia and her mum having fun at our Worcester hospice

A woman with short brown hair, wearing a red polo shirt and a light blue surgical mask, stands in a swimming pool. She is holding the hand of a young child with brown hair who is wearing a red and yellow lifebuoy. The child is smiling and looking towards the camera. The pool has a metal handrail on the left. In the background, there is a colorful mural on the wall featuring various shapes and patterns. The overall atmosphere is calm and supportive.

I don't know what I would do without Acorns. It gives us time to recharge and I know Ezra is safe and having the best time and it's meant such a great deal to us.

- Emily, Ezra's mum

Ezra receiving hydrotherapy in the hospice pool

About our services

Providing specialist palliative care


At Acorns, we provide specialist palliative care that is tailored to the specific needs of children and their family members. We provide families with access to a range of support across disciplines including medicine, nursing, social work and allied healthcare. We also work with health and social care professionals and supporting agencies with advice, guidance and education. We support the whole family as and when they need it throughout their journey, beginning at referral and continuing through bereavement.

This support can be provided in one of our hospices, in the family home or, where appropriate, in a hospital setting. Children referred to our service can include babies not even born yet, through to childhood and adolescence. Our children's hospices accommodate children and their families for end of life care and short breaks. We are also able to offer a level of day time clinical care to children in their homes through our Outreach Service.

With advances in medical knowledge and therapies, outcomes have improved for many conditions but have also meant the children we care for have become increasingly complex. Our teams have the skills to manage children with extremely complex cares, including many forms of medical technology and equipment needs, liaising with parents and treating hospital teams to ensure optimal management is provided. There may be cases where the technological needs exceed those manageable in the community, but we will continue to support you as you consider decisions in location of care.

As well as offering the family support in one of our hospices, we'll help them to stay connected within the local community and with other professional services. We have jointly funded a paediatric nurse and a paediatric palliative medicine consultant based within Birmingham Women's and Children's Hospital Trust alongside the palliative care team providing a seamless transition to our facilities when needed. If whilst in our care a child requires medical input, we have experienced GPs at each of our hospices who can be called to provide support and advice 24/7. If a child's symptoms worsen and are not manageable with these supports, we have the necessary procedures in place to transfer the child with a member of our staff to hospital if appropriate.

In addition, we have access to a Paediatric Palliative Medicine Consultant on call where high level palliative specialist input is required, for example for expert symptom management at end of life to avoid unwanted hospital transfer.



“Acorns gives us experiences and time together. Time to just be with each other where I don't have to worry about his condition and he's just my son for the day.”
- Iram, Yusuf's mum

Care for children

Providing a tailored package of support

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

Palliative care

We specialise in this area of healthcare which focuses on relieving and preventing symptoms 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, medicine, pre and post bereavement support, physiotherapy and befriending.

Complex medical care

Our medical and nursing teams at Acorns are highly skilled in caring for children who require a high degree of often complex medical interventions. Our Care Education team can work with you to upskill Acorns staff to meet more specialised clinical needs.

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 help children, their parents or carers and siblings to live life to the full, creating treasured memories and shared experiences. We work with families to develop plans that will capture the whole family's wishes, hopes and dreams at an early stage and provide emotional and practical support according to identified needs.

Yusuf and mum Iram sharing a precious moment

Continued...

Acorns hospices

Our hospices are warm, friendly and happy environments. They have a homely environment 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 three 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 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.

Working with Health and Social Care Professionals

We collaborate with, and work alongside, professionals in the family's community, recognising that we are part of a bigger network of care services for children across the West Midlands and Gloucestershire. We support the best possible communication pathway between a child, their family and the professionals caring for them. By providing care that is evidence-based, while keeping the best interests of the child at the centre of the care they receive, we are able to share expertise with the teams caring for a child.

We offer care that is safe, effective, promotes wellbeing and is underpinned by the principles of the United Nations Convention on the Rights of the Child (UNCRC).



Harry and George having fun in the sensory room

Making a referral

Our referral criteria and process

We welcome referrals to Acorns Children's Hospice from across the West Midlands.

Referrals are accepted from a paediatrician, nurse or midwife. To meet our criteria babies, children and young people need to be diagnosed with a life limiting or life threatening condition and have not yet reached their 18th birthday. Applications for a referral to Acorns can be made via our website at acorns.org.uk/referral

It's important that referrals are discussed with the family before submission. We recognise it can be hard to know the right time to refer so we welcome an informal discussion enabling you to consider whether our services can support the family you are working with. Families often feed back that they wish they had been referred earlier in their child's journey.

Acorns criteria for services

Acorns is a palliative care service for babies, children and young people with life limiting and life threatening conditions. In line with other contemporary palliative care services, we have reviewed our referral criterion which now reflects the medical advances that have been made for children and young people with many now surviving into adulthood. **Acorns will accept children where the referrer would 'NOT be surprised if the child will die before their 25th birthday.'** We continue to be a flexible and responsive service however and are always happy to support discussions about potential referrals.

Acorns hospice acceptance criteria

- > **Category One:** Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for a palliative care services.
- > **Category Two:** Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health.
- > **Category Three:** Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.
- > **Category Four:** Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health conditions and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care.

Making an emergency referral

Usually, referrals are planned and carefully considered, but sometimes you may need to make an emergency referral for a child who is at end of life. In this situation, it is best to phone the appropriate hospice ahead of submitting a referral so that it can be picked up and responded to as quickly as possible. We will always consider emergency referrals outside of our normal acceptance process and make a decision as soon as possible. We will liaise with the referrer and other professionals involved in the child's care and agree on a support pathway. If possible and if time allows, we will always aim to visit the family at home or in hospital prior to them being admitted to Acorns for end of life care.

When a 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

It is important that the family are aware of and agree to the referral and that as much information is provided as possible to enable us to make a decision without too much delay. It is recommended, in order to streamline the referral review process, that a recent clinical review letter is included with the referral, as with complex conditions we are likely to request this.

Assessing the situation

When a referral is received it's assessed by our multidisciplinary panel who consider the child's diagnosis. We may need to speak to professionals involved in caring for the child, or contact you for additional information before we can decide whether the child meets our criteria. We will always write to you as the referrer to let you know our decision.

Getting our timing right

Sometimes when we are approached about a child being referred, after we've assessed the situation, we may decide that it's not the right time for the child to be accepted. Obviously, this can be distressing, but a decision to decline is never taken lightly and is usually made because at that point in the child's disease trajectory there's no clear evidence of palliative care need. Whenever we decline a referral we always explain our reasons fully and discuss them in detail with the original referrer.



Always here to help

The range of services that Acorns offers families

Every family is different and we work hard to ensure the right level of care and support is offered. Over the years our services have expanded to include specialist nursing, medical, pre and post bereavement support, physiotherapy, hydrotherapy, sensory experiences, play and a range of support groups.

Short planned breaks in our hospices

This is perhaps the service that we're best known for. Families can stay together in one of our hospices or the child can stay on their own. During stays at Acorns, children can take part in a range of activities from crafts and

Ethan enjoying a sensory story with his mum Sarah

music, to enjoying time in the wonderful gardens. Young people love the opportunity to have sleepovers together, watching films and playing video games.

Families can enjoy time with friends and family and have the freedom to go out for a meal or see a film, safe in the knowledge that their 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 and where they can simply find space to be quiet and contemplative.

Services designed to help families

- Emergency admission if the child experiences a sudden deterioration in their condition
- End of life care and after death care
- Symptom management admissions
- 24-hour advice and support
- Step-down care which involves us stepping in for a planned period when the child has been in hospital for treatment or due to a change in condition
- Planned overnight and/or day care short breaks in one of our hospices
- A team who will work with the child and their siblings to give them opportunities for fun and access to the special experiences that all children should enjoy
- Emotional support for the child and family to help them to process what is happening and be as resilient as they can under incredibly difficult circumstances
- A comprehensive family service which includes pre and post bereavement support, sibling support and a range of therapeutic based groups
- Therapeutic based support for siblings of all ages, including opportunities to attend groups and access one to one support and complementary therapies

Spiritual care is available to everyone, whatever their faith, religion or other system of belief. Our aim is to reach out and support everyone, accommodating the family's needs and respecting the way in which they care for their child and approach the end of their child's life. All our hospices have rooms that can be used for contemplation or prayer.



“ 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

The right support at the right time

Supporting families on their journey

We're here to help every family who is accepted for Acorns services, either for care in one of our hospices or the family home, whatever their circumstances or background. Although we cannot be there in person 24 hours a day, we are available to offer telephone support and advice. We aim to offer support that reflects a child's stage in their illness trajectory.

Completing a Holistic Needs Assessment

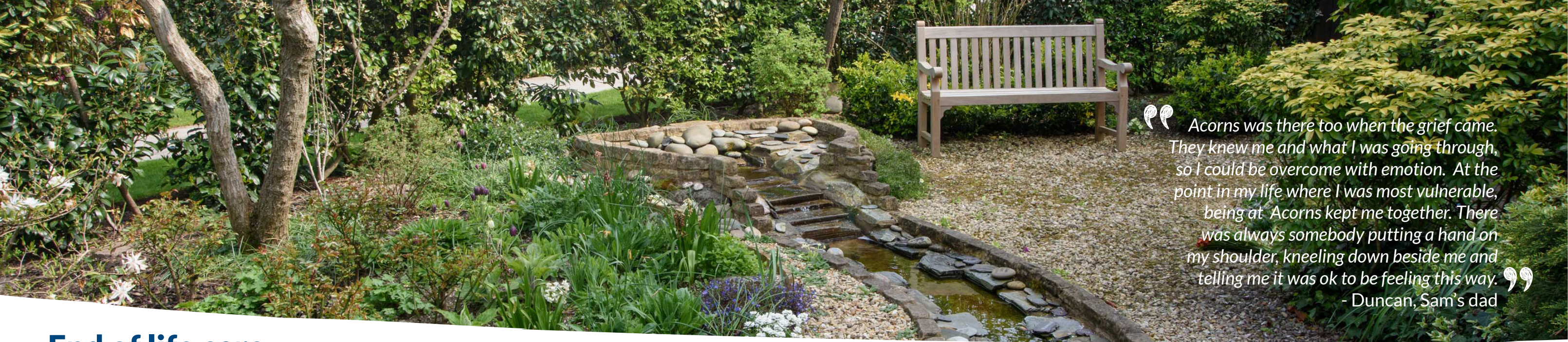
After acceptance at our panel, the family will be allocated a Family Practitioner who will visit them at home or in hospital and work with them and the professionals involved to complete a Holistic Needs Assessment, assessing their child and family's needs. This aims to establish the family's expectations of Acorns, their own goals and aspirations as a family, and any areas of their life they identify as needing support. We specifically focus on issues around loss, anticipatory grief, complex family systems and child care. Our aim is to help families stay connected to their natural and local support networks and help them to maintain and develop positive coping strategies as a family. Once the Holistic Needs Assessment is complete, a plan of support capturing how our service will support them is agreed with the family.

Developing a family support plan

A family support plan is developed by the family and Family Practitioner. It is individually tailored to address the needs of each member of the family considering everything from practical childcare and community support to psychosocial support. We offer a personalised service to ensure that each family gets the correct level of care and support at the right time. For example, a child who is clinically stable may be offered a smaller number of short planned breaks each year, and other aspects of the service as appropriate. For some other families whose child is in an unstable or deteriorating phase, we will tailor an increased level of support accordingly.

Creating a child's care plan

The child's care plan is created as a result of an assessment by the nursing team, either in the hospice or in the home. It captures practical care needs and all medical information and, when possible, the child's hopes, wishes and views. The care plan will be reviewed each time the child accesses our services and the Family Support Plan will be reviewed annually or sooner if we are made aware of a significant change in family circumstances.



“ 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

End of life care

Supporting the family’s wishes

We will help families establish their wishes about where they would prefer to be when their child dies. This may be at home, in hospital or in one of our hospices. Our aim is that admission to a hospice for end of life care is always available. However, this is not the only option and we are committed to working with other teams and in other settings as and when required to provide best care to each child and family. For example in supported transition from intensive care units to end of life care at home or in a hospice.

End of life care in our hospice

Each of our hospices has a cool room (special bedroom) which gives families the opportunity to spend time with their child after their death. If a child dies in hospital or at home, they can be transferred to one of the special bedrooms if the family wishes, providing we have accepted a referral for the child or young person prior to their death. The use of our special bedrooms or cooling equipment offers families the chance to create an environment where they can spend some final time together as a family following the death of their child.

At this stage we will spend as much time with the family as they need, listening, talking and supporting the siblings. We can also help with planning the funeral and dealing with the many potentially overwhelming tasks which have to be undertaken following the death of a child. We will always work in partnership with other agencies and encourage the family to link into their own support network.

End of life care at home

When the family home has been chosen as the preferred place for a child to die we will work with partner agencies such as community and hospital nursing teams to help support palliative nursing and medical care in the home.

End of life care in hospital

When hospital is the preferred place or only option for a child to die due to fragility, we offer support to hospital teams by providing advice and visits from our own team. We actively encourage the hospital teams to speak to us about what support will be most helpful.

Ongoing bereavement support

Bereavement care is a vital part of our service and we will continue to offer families professional support after the death of their child, in the most appropriate way. We use recognised grief assessment tools to assist the family and to determine the most appropriate level of support for each family member.

Ongoing bereavement support may include one or more of the following options: facilitated support groups, individual support, complementary therapies, spiritual support, telephone support and memorial days.

We recognise that individuals within families may have their own unique ways of expressing grief. We assess the needs of parents and ensure they are able to support each other and their children.

Funding

How we fund our care

Fundraising

As a registered charity we rely heavily on voluntary donations from individuals and organisations across our region to fund the majority of our services.

Commissioning

We have extensive partnerships with NHS Integrated Care Boards (ICB's) and Local Authorities commissioners across our geographic region, ranging from Staffordshire in the north to Gloucestershire in the south and across the whole West Midlands region. The ICB's make a contribution to the cost of funding care for our children and their families. We work closely with all our Statutory Partners to assist them in meeting their statutory obligations and tailor our services to meet the unique requirements for our individual children. We report our activity and quality audits to each ICB on a quarterly basis.

Children and young people may need some additional support due to a medical or social situation and at such times we are able to offer additional support that is individually commissioned by the relevant commissioner. We can assist our partners in meeting the support for children ready to be discharged from hospital who require a "bridging" placement until they can be cared for back in their community. We also support children and families who need additional short breaks or an emergency placement due to a social or family crisis.

If you would like to discuss these options, please get in touch.

Step-down beds

A step-down bed may be commissioned for a child who is ready to be discharged from hospital but is unable to return home. This may be due to a lack of facilities and equipment or because a care package is yet to be arranged.

Paid-for beds

A paid-for bed is usually commissioned for children who need additional planned short breaks or need an emergency placement due to social reasons.

“ Now Acorns is Kasim's home from home, he loves it! He's so happy when he knows he's coming to Acorns and that gives me such peace of mind. ”
- Aimee, Kasim's mum



Appendices

Definitions of children’s palliative care

Together for Short Lives

Palliative care for children with life limiting and life threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

World Health Organisation (WHO)

The WHO’s definition of palliative care appropriate for children and their families is as follows: Palliative care for children is the active total care of the child’s body, mind and spirit, and involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child’s physical, psychological and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in hospitals, in community health settings and even in a child’s home.

References, key policies and documents that underpin our work

References

- Together for Short Lives, A Guide to children’s palliative care services, (2018)
- Together for Short Lives and University of Birmingham, Spectrum of Children’s Palliative Care Needs, (2012)
- World Health Organization (WHO), Integrating palliative care and symptom relief into paediatrics, A WHO guide for health care planners implementers and manager, (2018)

Key policies and documents

- UN General Assembly, United Nations Conventions on the Rights of the Child (UNCRC), (1989)



Get in touch

**To refer a child please visit
acorns.org.uk/referral**

**For an informal discussion,
or for any further information,
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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