



**Alexander
Devine**
Children's Hospice
Service

**MAKING A
DEVINE
DIFFERENCE**

April 2023 to March 2024

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Alexander Devine Children's Hospice Service is a charity that provides specialist palliative care and vital support to children with life-limiting and life-threatening conditions, and their families, across Berkshire and into surrounding counties.

The charity was founded in 2007 by John and Fiona Devine in memory of their son, Alexander, who sadly passed away from a rare brain tumour in 2006. Their personal experience led them to realise there was a desperate need for a local children's hospice service with a hospice facility within Berkshire.

Our mission

Reaching out to every child and family who needs us.

Our vision

Providing a children's hospice service within Berkshire and into surrounding counties that will give children and families a choice of care and support from a skilled and dedicated team.

“To be told that your child has an incurable disease is the most devastating news any parent can receive. I just can't thank Alexander Devine for everything they are doing for us.

Its hospice provides an enriched environment for our daughter as well as her siblings. We are extremely lucky to have an amazing network of support through Alexander Devine as no family should have to suffer alone.”

Imran, Habibah's Father

“My visits to the hospice are always magical and filled with so much fun. Spending time in Alexander Devine's pool helps me with my muscular pain, contractures, and mobility, which is not possible out of the water. It's the only time I can float freely on my back and move my legs myself.”

Habibah



Our service

Alexander Devine Children's Hospice Service provides palliative and end of life care to babies, children and young people with a life-limiting or life-threatening condition aged 0 – 19.

We currently support over 200 children and their families, but we are committed to growing our service and reaching out to every child and their family that needs us.

Our approach is child and family-centred in order to provide the best possible care and support they need, as well as helping them create memories, for however long they have together.

For the children and families we support, we provide:

**Community respite care**

**End of life care**

**Day care and Overnight respite**

**Hydrotherapy and Physiotherapy**

**Symptom management and Paediatric Consultant Support**

**Support for all family members before and after bereavement**

**Specialist play**

**Sibling support**

**Music therapy**

**Counselling**



200+ children and families currently supported by Alexander Devine

Our Inspiration

It all began with a very special boy – Alexander

Alexander was just four when he was diagnosed with a rare brain tumour. Without a children's hospice in Berkshire, he and his family would have to travel for hours in the car to access the specialist care he needed. These journeys were difficult and often dangerous due to his medical condition.

Alexander endured four and a half years of operations, treatments and therapy, but sadly died at the age of eight.

In 2007, Fiona and John established Alexander Devine Children's Hospice Service and so began their journey to make sure that children, like their son Alexander, and families like theirs, would be able to access the support they needed closer to home.



Alexander

What makes us Devine

Our core values set out what we stand for and what we believe in. Commitment to these values, across all our staff in every team, reinforces our ability to deliver the best possible service for the children and families that depend on us.



Determined

And resolute in our service to all those that need us



Empowering

To enable whoever comes into contact with us, the power and courage to make decisions, ask questions or simply to be



Valuing Others

We value you and each other, because we are all unique and special in our own way



Integrity

To be consistent in our ethos and values, principles and actions. To always behave and hold the integrity of our charity as core



Nurture

To provide an environment of protection, support, growth and encouragement



Empathy

To know that we will provide a place of safety for everyone to express their feelings, thoughts and emotions, without judgment



2023-24 has been an incredible year for our children's hospice service

On behalf of the Trustees, Senior Management Team and the wider team of Alexander Devine, I am pleased to share our impact report for 2023/2024.

For the Third Sector as a whole, it has proven to be another challenging year. With hard work, determination, commitment, and a philosophy that reflects our values and culture, yet again the team at Alexander Devine has risen to every challenge and obstacle placed in front of them and I am extremely proud of all that has been achieved by our staff team, volunteers, supporters, and donors. This has enabled us to support a growing number of babies, children, young people and their families.

Over the year there has been a 30% increase in referrals to our service, with over a third of new referrals receiving end-of-life care. In the last year alone there has been a total increase to 60% in the children we have supported at end-of-life.

The need for our service has never been greater.

Whilst recruitment remains challenging, we have extended our service provision in delivering more inpatient day care, play therapy, family support and overnight respite as well as introducing hydrotherapy and physiotherapy sessions. The appointment of Dr Ella Ambrose, Paediatric Consultant to our team certainly marks another milestone for Alexander Devine.

We remain ambitious in continuing to increase our capacity, to reach out to more children and families that need us.

Over the next year our attention continues to focus on financial sustainability. One way of achieving this, is in the development of our fundraising team, the other vital arm of our service. The appointment of a new Director of Fundraising, the expansion of existing income generation streams and investment in new ones will help us to accomplish this.

More than ever the generous support, commitment and kindness of our community is the foundation on which we will continue to grow. It would not be possible to provide the specialist care that we do, without the incredible support of people like you. I could not be more grateful for your continued help.

Fiona Devine

Fiona Devine MBE
Chief Executive and Founder



“Every staff member in Alexander Devine that we have met so far is amazing. Smiles always, very welcoming, not just there for our daughter but for the whole family. And it means a lot for us as we are going through tough times. Thank you to each one of you.”

Alexander Devine Supported Parent

Franké

When Franké was just four weeks old, he stopped breathing. This frightening episode led doctors to discover that Franké has a genetic condition and a number of complex health conditions including severe heart abnormalities. By the time he was two a half years old, Franké had undergone nine surgeries, including several open heart surgeries.

When he was four years old, his Mum Sarah was told that sadly there was nothing more the medical teams could do for him and he was given a terminal diagnosis. Franké and Sarah were referred to their local children's hospice service, Alexander Devine.

Initially, Alexander's Nurses and Carers visited them at home to provide specialist care and play, along with counselling sessions for Sarah with our Family Support Worker. Gradually Franké came in for Day care and overnight stays to give Sarah much-needed respite.

Our Clinical Nurse Specialists have provided symptom management for Franké to enable him to remain out of hospital as much as possible. They have also helped Sarah in thinking about what her wishes for Franké might be when his condition deteriorates and there is a need for end of life care.

“A couple of years ago the thought of leaving him with anyone else was just horrendous. However, Alexander Devine has opened up both of our worlds. I know that I can leave Franké with them and have peace of mind and utter trust that the wonderful and amazing team will love and look after my boy.”

Sarah, Franké's Mum

“I don't think the team at Alexander Devine will ever know the extent to which they make my life so much easier. They are all truly amazing and I don't know what I would do without them.”

Sarah, Franké's Mum





What **YOU** have helped us do



18,758
hours of care
delivered



200+
children and
families supported



13
children given
end of life care in
the hospice and in
the community



We are so lucky to have such an amazing service for our family. I can truly say I would not have been able to cope as well, if I did not have the support from the respite. The Alexander Devine team have offered us invaluable home respite and Day Care so I can meet the needs of my other child and "recharge my batteries". Thank you so much for your outstanding care and support!

Alexander Devine supported parent



48
families had
access to our
specialist care for
the first time



37
children had
overnight stays
at the hospice



37
family events
including sibling
days, family fun
days and
remembrance
events



4350+
hours of respite provided in the
community - in families' homes,
schools and hospitals



1,500+ hours play therapy sessions in our children's hospice as well as in families' homes

What we have **ACHIEVED**

Growing our service

In the last 12 months, we were able to extend the amount of care delivered to children and families at the hospice and across the community.

We are proud to have delivered:

- 182%** more overnight respite at the hospice
- 23%** more children and families supported by Alexander Devine
- 60%** more end of life care, at the hospice and in the community, and bereavement support

The appointment of a Consultant Paediatrician with a special interest in palliative care.

Introduction of physiotherapy and hydrotherapy support with the appointment of a part time physiotherapist



Alexander Devine is an amazing hospice, providing the best care possible for the children they support. The team here at Alexander Devine is so caring and compassionate. They have allowed for me to get the experience I need to further my studies, which has meant everything to me.

Georgie, student nurse at University of West London



Listening to our Families

In our 2023 Family Survey, families told us they would really value access to even more Day care, Splash sessions and Overnight respite. 22% of the families who responded also really wanted physiotherapy support.

We are therefore delighted to have appointed a part-time specialist paediatric physiotherapist, who offers land-based physiotherapy and hydrotherapy sessions in the hospice pool, individually and in groups. She also visits children at home to help with home physio plans, working closely with parents to assist them in caring for their child and ensuring they have appropriate equipment.

We also have a new music and positioning group held once a month which is run by our Alexander's Physiotherapist and our Music Therapist. During these sessions, the children are assisted into different positions whilst accompanied by a song or piece of music.



“Amazing session, would definitely come again.

The staff were spot on; there to help when needed and praised my child for their efforts.

They loved it, as did I. ”

Feedback from a parent



Looking forward: Our priorities for the year ahead

1 - To address health inequalities to ensure families have access to the service they need

Achieved by:

- engaging with families, children and young people to better understand their perspective and needs
- developing our family support services and the family support programme to meet their perspectives and needs
- enhancing connections with our multi-faith communities to develop our understanding of the needs of families

2 - To enhance the financial stability of the charity to ensure we can continue and extend our service

Achieved by:

- The development of the fundraising team to increase our capacity and skills
- Extending our fundraising activities to encourage wider support of our organisation and our mission

Outcomes:

- **More families from underrepresented groups have access to the services they need**
- **We can extend our services in the future and continue our mission of reaching out to every child and family that needs us.**

Pippa

Pippa was born with multiple complex conditions including chronic lung disease, Down's syndrome and a severe form of epilepsy, which causes life-threatening seizures, on a daily basis. Pippa is non-verbal, has global development delay, requires feeding through a peg in her tummy and cannot support her own body weight independently. Pippa could stop breathing at any moment so can never be left on her own and she requires round the clock care.

Alexander Devine supports the family by providing respite for Pippa at home and in the hospice, as well as symptom management for Pippa's complex health needs. We also offer hydrotherapy in our pool and provide Pippa's older brother Elliot, with sibling support, spending time with other children his age in a similar family situation.

“We don't know what we would do without Alexander Devine Children's Hospice Service. The day care and respite support mean we have some time to recoup.”

There aren't many places we can go as a family that are accessible and where we feel safe. At the hospice we can just be a family and make family memories, playing, swimming, or just relaxing and having a cuddle. We don't have to wear all the other hats; nurse, carer, physio, occupational therapist. We can just be Mum, Dad and a brother.”

Danielle, Pippa's Mum



“We want to thank Alexander Devine from the bottom of our hearts for everything they have done for us and all the other families at the hospice.”

Danielle, Pippa's Mum

What families told us

The families are at the heart of everything we do, so we value their comments and feedback. Ensuring that we align with their needs and continually enhance our children's hospice service. A survey conducted in March 2024 provided valuable insights into how families perceive the specialised care and essential support we offer.

“ You provide an exceptional service,
We cannot ask for more.”

100%
rated their
experience as
**Excellent or Very
Good**

94%
of families said that
the hospice **always**
offered a **safe and
welcoming**
environment

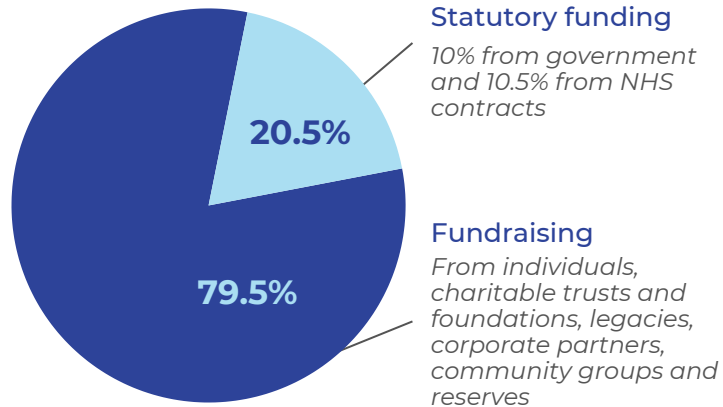
“ I feel extremely
lucky to have
access to Alexander
Devine and the
benefit it provides
my child and us as
a family.” ”

“ We are so grateful to
Alexander Devine for the
amazing support you offer
our daughter and family!
Everyone is so **welcoming**
and atmosphere so positive
and friendly.” ”

Couldn't do it without you, you
make life easier in the hard
times. You have such a **positive
impact on our lives.**



How we cover our costs

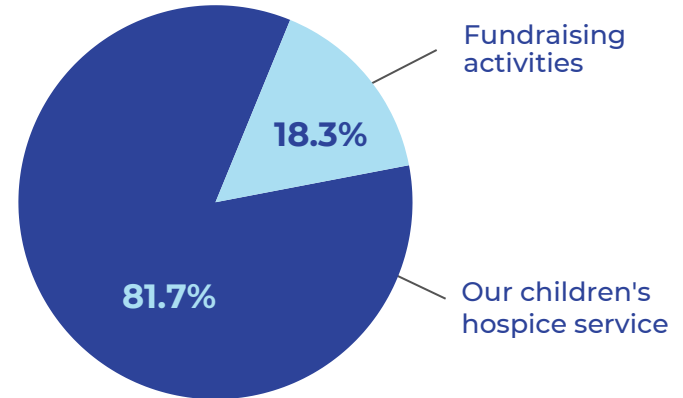


We depend significantly on the kindness and support of individuals within our community to provide specialist care and vital support to children facing life-limiting and life-threatening conditions, as well as their families, spanning Berkshire and neighbouring counties.

Our income for the year was £2.2million.*

**This excludes a one-off windfall we received during this period*

How we spend our money



For every £1 we spend **81.7p** is spent on providing specialist care and support.

In 2023-24, the annual cost of running our children's hospice service was £2.54 Million (22.7% increase from 2022/2023).

For every £1 we spent on fundraising generated a **£4.73** return.

Your £1



of every pound is spent on providing specialist care and support.



helps us raise the next pound and grow our services in the future.

We could not do it without you!

Here are some fundraising highlights from the last year.



£14,500

APRIL

Maidenhead Fundraising Group volunteers opened a pop-up toy shop in Nicholson's Centre



£52,000

MAY

Our annual Heaven Sent Ball was held at De Vere Wokefield Estate



£8,500

JUNE

We painted the town Blue together with local schools and businesses for #RockTheBlue during Children's Hospice Week



£1,951

JULY

Georgia took on an incredible challenge and climbed Kilimanjaro to raise us vital funds



£10,669

AUGUST

Each year, a group of friends come together and hold a charity football tournament in memory of their very special friend, Christopher Seymour



£23,000

SEPTEMBER

We had a TEE-rific Devine Golf Day at North Hants Golf Club



£382

OCTOBER

Westgate School in Slough held a fundraising Bake Off!



£26,000

NOVEMBER

Over 400 Santas joined us for our annual Santa Dash in Windsor

We could not do it without you!



£8,265

DECEMBER

Our Devine Light Trail was back and bigger than ever with over 30 amazing homes taking part



£8,636

JANUARY

30 heroic volunteers helped to collect and recycle over 260 Christmas Trees in Maidenhead and Marlow



£5,500

FEBRUARY

Our annual Big Curry Night was hosted at the Hospice and was a scrummy treat!



£245

MARCH

Corporate Partners Sixt volunteered to run a Toy Sale in Windsor

We would also like to thank...

- Our Patrons, Trustees, Ambassadors and Alexander's Champions.
- Families whom we support, who have shared their stories and experiences of Alexander Devine to help raise awareness and support our fundraising.
- All our Major Donors, individual and regular donors, who have helped us to raise vital funds throughout the year.
- Charitable Trusts and Foundations that have generously made grants to our charity.
- Everyone that has pledged a gift in their Will to help us plan for our future.
- All the companies that donated, fundraised, sponsored our events or volunteered their time.
- All those in our community, including fundraising volunteers, groups, golf clubs and schools that support us.

Thank you to our amazing volunteers

We are very fortunate to have many wonderful volunteers who are dedicated in their support of us. Alexander Devine's volunteers are the lifeblood of our charity. Thanks to the skills and time they donate we are able to reach more children and families.

Over the last year our volunteers gifted us over **6,355** hours, twice as many as last year. They take part in fundraising, admin, gardening, baking, support the Care team and contribute in many other ways out in the community and in the hospice.

We extend our heartfelt gratitude to each individual for their invaluable time, dedication, and unwavering commitment.



During 2023/24
our volunteers
gifted us over
6,355 hours



Volunteering
helped make a
cost saving to
our charity of
more than
£85,105



177
people generously
volunteer for our
charity at our hospice
in Maidenhead and
across our community



For every **1** team
member we have
3.5 volunteers

Thank you



To every individual, business, Trust, Foundation, school, community group and volunteer that supported us in the last year, our heartfelt thanks.

Thank you for making sure we can be there for the children and families that need us.



www.alexanderdevine.org



Registered charity number 1118947