



**MAKING A  
DEVINE  
DIFFERENCE**  
**2020- 2021**



**Alexander  
Devine**  
Children's Hospice  
Service

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

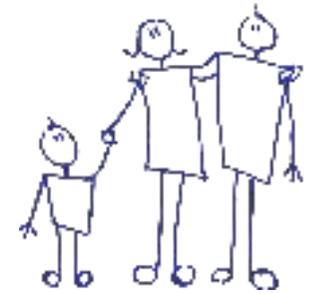
The charity was founded by John and Fiona Devine in memory of their son Alexander who sadly passed away from a rare brain tumour in 2006. Their personal experience led them to realise there was a vital need for a local children's hospice service with a hospice facility in Berkshire.



Our hospice is in Maidenhead, which complements our community service

## OUR MISSION

# Reaching out to every child and family that needs us



# 135+

children and families currently supported by Alexander Devine

## WHAT WE DO

We deliver palliative care to children and families through a holistic approach that supports the individual needs of each child and their family.



*Your team are all amazing and she loves you all so much. It gives us so much peace knowing she is happy and safe in your care. Everyone goes above and beyond*

AN ALEXANDER DEVINE PARENT

## MAKING EVERY DAY MATTER

When a child's life is limited it's important to make the most of every day, and our aim is to help children and families to live life to the full. We offer a range of care services and support, including respite care, specialist play, symptom management and family support. We are also here to provide support at end of life and bereavement support.

Our Alexander's Care Team consists of qualified nurses, clinical nurse specialists, carers, play specialists, music therapists, counsellors and doctors. The team is skilled in looking after children with complex healthcare needs and provide care in the community, in families' homes, in hospital, in schools and at our children's hospice in Maidenhead.



Community respite care



Family support for all family members before and into bereavement



End of life care



Specialist play



Day care and overnight respite



Sibling support



Hydrotherapy



Music therapy



Symptom management



Counselling

## THE DEVINE DIFFERENCE

We make a real difference to people's lives, but in the past year what does that really mean?



### FOR 27 FAMILIES

It meant they had access to our specialist care for the first time



We delivered more hours of care in the last year than ever before

### MORE CARE FOR MORE FAMILIES



### MAKING MEMORIES

We gave families opportunities to make precious memories together, including time in our hydrotherapy pool

**59 SIBLINGS**  
supported with specialist play sessions, both individual and as part of groups



Providing a real choice of care for families with respite at our hospice, as well as delivering care across our community in family's homes, schools and hospitals



**FOR 10 FAMILIES**  
it meant having our specialist support during their child's end of life care



### OPENING UP OPPORTUNITIES FOR MORE CHILDREN

including music therapy and specialist play - virtually, at the hospice and out in the community



Working closely with our faith communities to strengthen relationships with the diverse populations across Berkshire

### WORKING WITH OUR FAITH COMMUNITIES



### SERVICE DEVELOPMENT

We introduced overnight respite at the hospice, giving families more much-needed rest and time for themselves

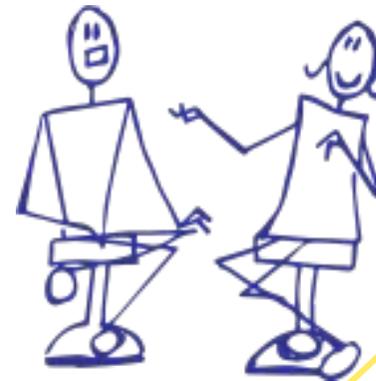
## WHAT OUR SERVICE MEANS TO FAMILIES



"Alexander Devine provides **excellent support**. The nurses are **exceptional**, work to a very high standard"

"I honestly don't know what we would do without you"

"The hospice always makes us happy!"



"The support from Alexander Devine has been **exceptionally helpful this year** especially the specialist nursing practitioners. Thank you!"

"Can't fault your services, **absolutely priceless to us.**"

"Your team are all **amazing** and T loves you all so much. It **gives us so much peace** knowing she is happy and safe in your care. Everyone goes above and beyond."

We love your thoughtful and resourceful approach for home and hospice Day care, **putting the emphasis on creative, fun and exciting activities** rather than 'care' which is excellently delivered in the **background!**"

"Alexander Devine provides a wonderful environment in which, not only our daughter, but **the whole family can relax and enjoy spending time together**, doing fantastic activities arranged by the team."

**97%**

of our families rated their overall experience of our service as excellent or very good

## CONTINUING CARE THROUGH THE PANDEMIC

Shielding and isolating for much of the last year has been exhausting and lonely for families.

But one less thing families have had to worry about during the pandemic is our continued support. We were responsive and adapted the way we work in order to make sure families were able to continue accessing the specialist care and vital support that they needed in a way that suits them.

Indeed over the last 18 months we have extended our support, offering even more care to make sure they did not face the pandemic alone.

**100%** of families told us that of the adapted care provision they experienced it was either very helpful or helpful to them. [Page 4](#)



Day  
Care



Splash  
sessions



Food  
parcels



Activity  
packs



Community  
Respite



Virtual  
Contact



music  
therapy



Doorstep  
visits



“

*Whilst the added worry and stress that pandemic causes us is still there, we are so grateful to be able to have Alexander Devine help us cope.*

AN ALEXANDER DEVINE PARENT



## The challenges of caring for a child with complex healthcare needs during the pandemic

Five year old Aidan was born with a rare condition called cystic hygroma. It is an abnormal growth that severely affects his windpipe, which has resulted in a tracheostomy. His condition requires daily medical management and affects his breathing, eating and speech.



Aidan's mother Carly, talks about the challenges of caring for Aidan and the additional struggles brought on by the pandemic:

*The last year has been like a pressure cooker for our family. We have had to make hard decisions in order to protect Aidan and keep the risks down within our home. All the things that brought so much joy to Aidan and the respite care we needed and depended on had to stop in order to shield him and our family. We have had to rely so much on family and friends for help with basic things like shopping. Life was challenging enough before the pandemic, but now there is so much more worry and stress to deal with.*

*Aidan loves his visits to the hospice and all the adventures and fun he gets up to. So not having that for several months last year was so hard on him and the rest of us too. The respite the hospice gives us is much-needed and it was exhausting without that support. Whilst we were able to stay connected with the Alexander Devine Care team and have support through phone calls and doorstep drops with activity bags for Aidan and his siblings, as a family we have never felt so isolated.*

*We know how hard the team at Alexander Devine have worked to put precautions in place that have now allowed us to reintroduce Aidan for day care again. It is such a relief for us and it means the world to Aidan. He is such a super happy, dinosaur-loving boy and loves using his imagination to play. Visits to Alexander Devine give him the stimulation and opportunities he needs. Be it dipping his feet in the hydro pool, baking or painting, he always has the most amazing time and comes home smiling and signing all that he has done that day.*

*I can't tell you how much our family values this time, the hospice is simply amazing and we hope as a family we never have to be without them again and the support they give us."*

“The impact of having a child with complex medical needs is something you are never prepared for, but with help from places like Alexander Devine they give families like ours that tiny bit of normality back.

Aidan's mum, Carly



## THE GIFT OF VOLUNTEERING IS INVALUABLE TO OUR CHARITY

The contribution of our volunteers is hugely valuable to our charity. With a diverse range of skills, interests and hobbies, each and every day our wonderful force of volunteers help to make a huge difference to local children and their families with the gift of their time.

We have volunteers supporting our care team, tending to our hospice grounds and also providing office administration. Throughout Berkshire and the surrounding counties, we also have volunteers fundraising for us and organising events.



### 165 volunteers

currently supporting our charity - at the hospice and out in the community

During 2020, nearly all of our volunteering activities had to halt. Yet despite lockdown and many of our volunteers shielding, many of our amazing volunteers turned their hand to new ways of supporting us and help us navigate one of the toughest times we have ever faced.

Here is just a snapshot of what they got up to...



## A CHARITY AT THE HEART OF ITS COMMUNITY

In what has been one of the toughest years our charity has faced, the kindness shown by those across our community has been overwhelming.

Whether it was responding to our emergency appeal in March 2020, taking on a fundraising challenge, making facemasks and PPE for us, virtual quizzing with family and friends, donating items, joining us for our first ever virtual Santa Dash or simply spreading the word about our charity across our community; every bit of kindness added up to a world of difference to our charity.

Your amazing fundraising efforts throughout the pandemic helped us raise over

**£440k**



## HOW WE ARE FUNDED

The specialist care and support is free of charge for families.

We only benefit from a small amount of government funding, so we rely on donations, fundraising and gifts in Wills for the funds we need each year.

Without you, there would be no Alexander Devine for mums like Simone and her son Barnaby, 12, who was born with a severe and rare brain disorder called Lissencephaly. We give her the respite from round-the-clock caring that she needs, as well as the chance to spend quality time with her son at our hospice making precious memories.

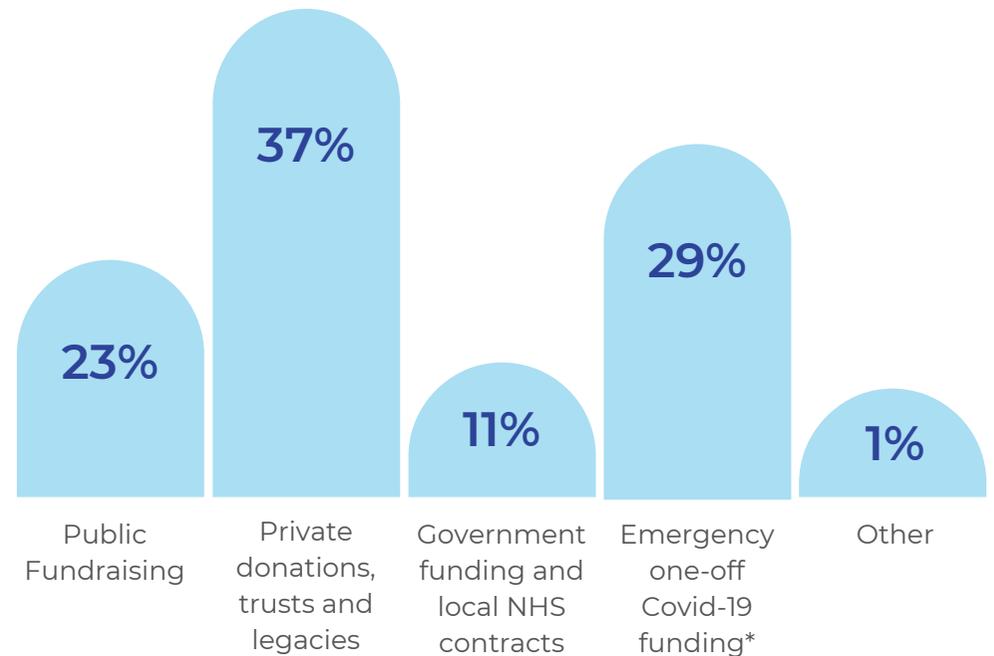


**£1.8 million**

is the cost of running our children's hospice service each year

## Our vital work is only possible because of people like you

Where our income came from in 2020/21



*\*Emergency one-off Covid-19 funding helped to cover some of the significant fundraising losses caused by the pandemic. The majority of our fundraising activity and events had to be cancelled in 2020 and also into 2021.*



[www.alexanderdevine.org](http://www.alexanderdevine.org)

Tel: 01628 822777

Email: [fundraising@alexanderdevine.org](mailto:fundraising@alexanderdevine.org)



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