

Impact Report

2022/23



Helen & Douglas House

your local children's hospice

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▲ Jasper enjoying water play with Chloe and mum Christina

With all interaction the staff were very caring and couldn't do enough. All our son's symptoms were addressed and managed and we couldn't be more grateful that he was kept comfortable and for the compassion shown.

Improving lives of terminally ill children and their families



A warm welcome to our Impact Report for 2022/23 which shows the impact you have made to improve the lives of local families with terminally ill and life-limited children in Oxfordshire, the Thames Valley and beyond. This report contains many successes and celebrations during what was our 40th year which I am delighted to share with you.

Feedback from our families has been overwhelmingly positive, from families using our services during their child's life through to families supported by us at the end of their child's life and in bereavement.

We aspire to deliver world-class palliative care, and extend and develop our service to meet the needs of every eligible child and family from the point of diagnosis through to bereavement and provide care wherever they need that support. I am very happy with our progress against this goal.

We are proud of what we have achieved in 2022/23 and over the last 40 years. I would like to thank our wonderful supporters, our amazing specialist staff, and our passionate volunteers. Without you none of this would have been possible.

Clare Periton
Chief Executive Officer

▼ Clare and Jasper playing pool at the hospice



66

Nowhere else can parents find people who can care for their child like you do.

99

Parent of a child using our service 3



About US

Our reputation as an organisation at the forefront of research into children's palliative care, has seen many of our staff invited to speak at conferences, both in the UK and internationally. As the world's first children's hospice, inspiring a further 54 in the UK and across the world, Helen & Douglas House's clinical team continue to share knowledge and learnings with other health care professionals.



Helen & Douglas House improves the lives of local terminally ill children and their families in Oxfordshire and the surrounding counties. We help children live life to the full, even when that life is short.



▲ HRH The Duchess of Kent and Catherine Worswick Helen's sister at the opening of Helen House in 1982



You have helped 430 children and their families

It cost £4.7m last year to provide our specialist care and support to 430 children and families. Without you, this would not be possible. Thank you.

90% of our funding this year came from donations, legacies and our shops – so thank you to everyone who has fundraised, donated or shopped with us.



Our Vision

Every life a full life, every
death a dignified death

Our Values



We are
creative and
resourceful



We are
honest and
open



We are
caring



We lead by
example



We are committed
to partnership

Meet Rayyan

▼ Nadia with her children Alisha, Rayyan and Zaky at the hospice summer party



Nadia first came to Helen & Douglas House in 2014 with her son Zayn who died in 2017. Now, her son Rayyan comes for supportive stays and her other children are supported at our siblings club.

"Never in a million years did we expect to be a family that needed to use a children's hospice. No family imagines it will be them. But it was us, twice over. For me it is a home-from-home, somewhere I can relax knowing Rayyan is in the best of hands. I trust them to do a wonderful job and can never thank them enough."

Nadia, Zayn and Rayyan's mum

Meet Tillie

Mum Jodie, Dad Darrell and older sister Annie all come to stay in our family flats so they can enjoy time together.

"It's the little special things they do, like put Tillie's name on the bed when she comes for a supportive stay. Without Helen & Douglas House we wouldn't have felt as strong and as confident to care for a sick child like Tillie."

Jodie, Tillie's mum



▲ Tillie at one of her supportive stays at the hospice

We wouldn't be where we are today without it.
We are one of the lucky families that have
the support of Helen & Douglas House.

What you have helped us achieve in 2022/23



87

New referrals – 38% up on last year



430

Children and families supported*



889

Bed nights of care – 54% increase



63

Families staying for end-of-life care – 103% increase



541

Supportive stays at the hospice – 58% increase



207

Children staying for symptom management – 56% increase



Helen & Douglas House allows parents to be just parents, not just carers. It is extremely exhausting as families trying to do both. At the same time allowing your child to die with love and support desperately needed.

*Source Quality Report 2022/23 – A total of children, families and siblings who were supported across our service

These percentage increases are compared to 2021/22 figures

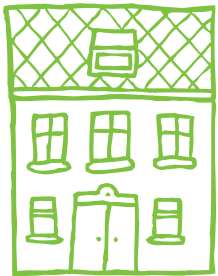
Thanks to you we are now offering more care to more families and have extended the services we provide



Supportive stays at the hospice – As well as reviewing the children's medical and nursing needs, giving parents a much-needed break from the 24/7 care, to help improve their well-being and mental health.



Symptom control & pain management stays – Helping relieve children's symptoms and pain, often preventing a hospital stay.



Specialist support at home – Providing families with specialist paediatric palliative support in their own homes, with 24/7 access to help and advice, 365 days a year.



End-of-life care – Supporting the whole family through incredibly sad and difficult times at the end of their child's life and helping them make precious memories.



Siblings support – Providing support to siblings to help them discuss their fears and emotions via one-to-one sessions and group activities.



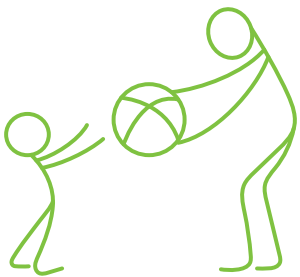
Social worker support – Offering emotional, social and practical support and advocacy to families to help them navigate their child's care.



Bereavement support – Supporting the whole family after the loss of a child, through one-to-one and group support.



Transition to adult care – Preparing 13-18 year olds and their parents for leaving children's services to start adult care.



Stay and play days – Providing a chance for families to enjoy whole day play sessions with other families facing similar challenges.

Our son loves coming to Helen & Douglas House, so much so that it is a task to get him to come home. My daughter also has received so much support and thrives at the sibling's activities. We are a happier family with Helen & Douglas House in our lives.

What families have told us

Every year we ask our families their views and use their feedback to improve the services we provide. Here are some of the results from our family survey conducted in February 2023.



I think the service you offer is amazing and all the staff do their very best to help families.**



88%

said we gave them the time and space to just be a parent and to make precious memories together



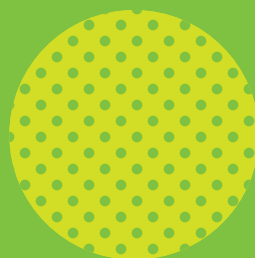
92%

said their overall experience of our service was very good (the highest rating)*



100%

said they were always treated with respect and dignity by staff*



100%

said there was always enough help available to meet their child's personal care and nursing needs*

Helen & Douglas House was a safe haven for us when our son was dying. It allowed us to be parents again and it was so good to be out of the stressful hospital environment.**



Thank you for helping provide these new services

New or extended services for local families

Impact on local families



We have recruited **9 Registered Nurses** and a second level 4 **Consultant**, increasing the number of bed nights we can offer by 54%, increasing support at home and transitioning to adult services.



Giving more families a break from 24/7 care at the hospice and helping more children with symptom and pain management in the place of their choice.



We have been joined by a new **Physiotherapist**, extending the range of care available to children in the hospice and at home.



Improved pain relief, enhanced mobility and independence as well as managing respiratory symptoms resulting in a better quality of life for children.



We have refurbished and made our **sensory room** bigger at the hospice to provide a safe and stimulating environment for children with sensory needs.



More children can improve their visual, auditory and tactile processing and motor skills including those in beds for end-of-life care because we have more space.



We have extended our **bereavement services** to wider family members and to families who have experienced the sudden death of their child.



Helping more families and family members access vital care and support after the sudden death of a child, giving them the opportunity to say goodbye in their own time.



We have expanded our **play team** with two new members, allowing us to offer play and therapeutic activities to more children.



Enabling families to access play activities seven days a week rather than five days at the hospice and at home, improving the child's well-being, allowing them to have fun and just be children.



We have recruited a new **Siblings Worker** so siblings can have access to emotional support and a peer network prior to and post bereavement.



Siblings feel less anxious and alone and helps them integrate with peers, feel less isolated and improves their well-being.



We have expanded our social work team with an additional **Social Worker**.



More families feel supported to access other services and financial benefits helping with cost of living and poverty issues, reducing the stress involved in navigating complex systems.

Thank you to everyone who fundraised, donated and shopped with us



April 2022

Oxford United bucket collection **£890**



October 2022

60 people ran the Oxford Half Marathon securing an amazing **£26,160** in sponsorship



May 2022

Butterfly Bimble Memory Walk **£12,100**



November 2022

We held our first ever Christmas concert at Christ Church Cathedral, raising **£12,372**



June 2022

The Albert Hunt Trust awarded us a grant **£20,000**



December 2022

13 schools organised their own Santa Runs raising **£13,316**



July 2022

11 year old Charlie cycled 121km in Bike Oxford **£700**



January 2023

Our Christmas Appeal raised over **£66,000** from 1,242 supporters



August 2022

The Oxford Biotech Community raised **£10,000** through a skydive



February 2023

Staff from **Taylor Wimpey** donated time and supplies to update our reception area



September 2022

£21,000 was raised by the Berkeley Homes Go-Karting Endurance event





March 2023

An early 1990s Tottenham Hotspur football shirt was sold on eBay for **£3,318**

Thank you to all our volunteers

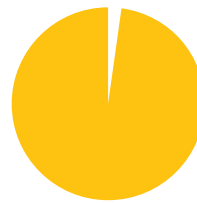
We are so grateful to all our hard working and dedicated volunteers. From trustees, gardeners and therapists to home, care team and shop volunteers – you are all amazing!

427** volunteers

| | |
|---|---|
|  |  |
| Hours | Value |
| Hospice, ecommerce and trustee volunteers | |
| 9,757 | £92,687 |
| Retail and fundraising volunteers | |
| 43,000* | £408,500* |

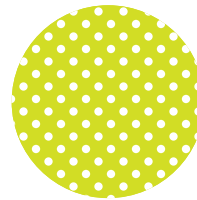
*Estimated

**Average number of volunteers



98%

of volunteers say they feel valued by their manager



100%

of volunteers said they would (90%) or might (10%) recommend volunteering with us, up from 98% last year



70%

of volunteers told us volunteering had a positive impact on their mental health

Source – 2023 volunteer survey



Volunteering at Helen & Douglas House as a medical student allows me to make a difference to a family's life without any clinical knowledge – even a simple conversation about how their day has been can go a long way to support them. I know that my time and generosity is valued by the charity, and I truly feel part of a team.



Ayeza, a care team volunteer at the hospice

Meet Fatima



▲ Fatima and Kim enjoying the xylophone in the hospice garden

Fatima is 11 years old and has been coming to Helen & Douglas House for 7 years. Her sister Sana was also cared for by the hospice before she died in 2020.

"Once when Dr Laura called me and I just said 'help' and half an hour later Fatima was booked in for a stay. If we ever have any queries, we have 24-hour access to them on the phone which is just so reassuring. They are an absolute lifeline for a family like mine. We wouldn't be here without them."

Vaida, Fatima and Sana's mum

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