

Children's Champions



About Us



Helen & Douglas House hospice improves the lives of local children, and their families, living with life-shortening and terminal conditions. We care for children living in Oxfordshire, and the surrounding counties and provide them with individualised respite and end-of-life care. We offer this care at our hospice in Oxford, at the child's home and in hospital, wherever the families choose.

We opened our doors in 1982 as the world's first children's hospice. Today we continue to inspire the global children's hospice movement. Each year we need to raise around \pounds 4m to fund our unique ongoing care, more than 80% of which comes from supporters like you.



The Children's Champions

This special club brings together wonderful supporters like you, who we ask to make an annual financial commitment to the work of Helen & Douglas House.

By joining the Children's Champions you'll be helping us deliver exceptional care whilst ensuring our families can create happy memories together for many years to come.

Roman's Story

Shortly after birth Roman was diagnosed with Alagilles Syndrome. This is a rare genetic condition that can cause multiple complications. For Roman it affected his heart (pulmonary atresia) which meant he had no pulmonary artery and his liver didn't function. After a few weeks in hospital for tests, they couldn't do any more for him. This was when, in March 2019, Roman and his family came to Helen & Douglas House.

"Every nurse at Helen & Douglas House is wonderful and they have done everything they can for my family". Ellie, Roman's Mum



Roman's Story continued.

"Our son was given just weeks to live. After a few exhausting weeks between various hospitals, we were referred to the hospice. The word hospice felt scary to us. But, as soon as we walked in through their doors, we felt a huge relief.

Roman got the vital lifeline of emergency care that he needed from the incredible nurses and doctors of Helen & Douglas House. And, as a family, we could start to recover and spend time with his healthy twin, Harley. Later we learnt how to care for Roman in his delicate condition until we were able to all go home together." Roman's mum, Ellie



Roman's family had never thought they would need a children's hospice. No one ever does.

When Roman went home, he continued to be supported and cared for by our incredible medical and outreach teams. As the months rolled on, we regularly visited Roman at his home and he was admitted back to us on several occasions, both for emergency and planned care. Roman went on to live for over nine months until, in January 2020, he died peacefully at home. Once again, we were there to support his whole family with bereavement care when they needed it the most.

By becoming a Children's Champion you'll be helping children and families like Roman's who live with life-limiting or terminal conditions and rely on us for regular respite care and support. You can find out more about some of the other children we care for at <u>www.helenanddouglas.org.uk/family-stories</u>.

The Shape of our Care



Helen & Douglas House is about so much more than just our beds in-house. Our incredible team of doctors, nurses and carers provide individualised care tailored to the needs of the child throughout their life, whether that life lasts for hours, days, months or years.

We also support those who transition on to adult services when they reach the age of 18.

We are there for families from their first referral, for as long as they use the hospice and, even after a life comes to an end; we are there to help them survive the loss of their child. The care we deliver includes:

- Supportive care at the hospice, or at home
- End of life care during the pandemic we supported record numbers of children to ease pressure on the NHS
- Emergency care, pain and symptom management
- Joint care planning with hospitals
- Pre and post-bereavement support for parents, siblings and extended family
- Social worker services
- Specialist play activities
- Outreach nursing in the child's home
- Educational support and guidance
- Psychiatry and psychological support

"As soon as we entered the front door the boys came first. It's an amazing place and puts the emphasis on making the most of life, for parents and the children. You make some amazing friends who understand your daily struggles. I appreciate everything they have done for my family and me."

Mike, Ben and Ollie's Dad

Clinical Research



Our clinical and medical team regularly lead on, or contribute to, important areas of national and global research, guidance and policy regarding children's palliative care. A full list of our contributions can be found on our website.

These area of research include:

- Working with The National Institute for Health and Care Excellence (NICE) in writing the national guidance for end-of-life care for children (2016)
- Contributing to the development of the NHS Novel coronavirus (COVID-19) standard operating procedure, for children and young people with palliative and end-of-life care needs, who are cared for in a community setting (home and hospice) during the COVID-19 pandemic (2020)
- Our Medical Director contributed to The Association of Paediatric Palliative Medicine Master Formulary (5th Edition) 2020 which represents the first significant attempt to collate all available dosing information to support prescribing in paediatric palliative care in a single volume (2020)
- Informing the research which leads the World Health Organisation (WHO) to adopt new guidelines into the diagnosis, treatment and management of chronic pain in children (2021)



"Helen & Douglas House provides Sienna with a welcoming and safe place to go. They are sensitive to the needs of our family and in that way it feels a lot like coming home; a safe haven. It makes me feel normal again and able to carry on." Kay, Sienna's mummy

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A Typical Year in Numbers

160 children cared for by the hospice



3,000 hours of support provided in the community

By becoming a Children's Champion you will be helping to provide expert care and support which is so desperately needed. You will also be making it possible for our children and families to create happy memories together. These are memories that will last forever.

Create precious moments that matter every day

Join the Children's Champions

Become a Children's Champion by making an annual financial commitment of between £500 - £5.000.

There is complete flexibility about how and when you want to donate. You may choose to donate in an annual sum, or by monthly instalments. The amount you give and timing are up to you.

Every member of the Children's Champions is making a real difference to the lives of families going through the unimaginable, and as our relationship develops, we look forward to bringing you more real-life examples of the incredible differences your support is helping to fund.

Becoming a member and making an annual commitment to Helen & Douglas House means that we can plan our services with more confidence; knowing that we have your regular support enables us to better predict income coming into the charity, and therefore allows us to accurately plan delivery and expansion of services. Together we can help to improve the lives of terminally ill children and their families.



£500 per vegr

£42 per

Could help to pay for six days of medical supplies for the children supported by the hospice.

£1,000 per year

Could help to pay for the provision of specialist end of life care for two children in their own home. including daily phone calls and regular visits.

£3,000 year

£5,000 year

£416 p

Could help to fund 12 hours of bereavement support for four families who have lost a child

Could help to fund the costs of providing a supportive stay at the hospice for up to three families - giving parents a break from carina

"Helen & Douglas House opened more than just its doors to us. They opened their hearts, and we gained another family. They help us to make fantastic memories, while giving me the chance to be a Mummy and not a nurse. They give me some much-needed comfort and also time to enable me to recharge my batteries." Libby, Alexanda's mummy

Words from our Supporters

Steve, one of our Children's Champions said:

"I've been supporting Helen & Douglas House for a few years already because my children wanted to get involved with this local charity. Making a regular gift means I know I am fulfilling my responsibility to give what I can, whilst making sure they can continue to do their amazing work."



Ellie started supporting Helen & Douglas House after we cared for her daughter Evie who died at the hospice. She started running after seeking something to focus on whilst raising vital funds.



"I'd never imagined I would ever have to go through the pain of losing a child, but I did. Helen & Douglas House provided a space for us to make magical memories, away from the hospitals, where we could be together as a family.

The days we spent at the hospice are so precious to us, even now a year on. But their care didn't stop when we all left, the hospice has supported us with specialist bereavement support since." Ellie, Evie's mummy.



Our Commitment to You

As well as making a vital difference to the many children and families for whom we care, by becoming a Children's Champion you will also enjoy a special relationship with the charity.



We will:

- Send you a special Children's Champions email three times each year, sharing stories from the families you have helped care for and other news from Helen & Douglas House
- Invite you to exclusive events where you'll hear about our ongoing and developing work with Clare Periton, our Chief Executive, and with Dr Emily Harrop, our Medical Director and Senior Consultant in Paediatric Palliative Care. There, you will also hear first-hand stories directly from our families
- Reward you with an exclusive pin badge, featuring our unique 'Children's Champions' logo for you to wear with pride and show your commitment to the charity

Become a Children's Champion

Thank you for reading more about becoming a Children's Champion of Helen & Douglas House. To join, please get in touch with Kathryn Worthington.

We look forward to welcoming you as a Children's Champion.

Kathryn Worthington - Partnerships Executive and Children's Champions Lead kworthington@helenanddouglas.org.uk / 07776 959 241 Helen & Douglas House, 14A Magdalen Road, Oxford, Oxfordshire, OX4 1RW

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your local children's hospice

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Contact us on 01865 799150 Email kworthington@helenanddouglas.org.uk Registered charity number: 1085951



