

Our vision for children's hospice care

A pioneering strategy




Helen & Douglas House
your local children's hospice

More children than ever need our support

It is with great pride and optimism that I share our Helen & Douglas House vision for the years ahead. There has never been a more vital moment to champion the ground-breaking work that Helen & Douglas House makes possible.


In the pages that follow we share the future we aspire to create – one where every child and family we support experiences the very best care, compassion, and hope. Our commitment is to remain bold in our thinking, deeply rooted in our values and always driven by the needs of the families in our care.

The challenges to the sector are significant, but so too are the demands and opportunities to provide our services to more children and their families. This vision reflects our collective ambition: to respond to evolving needs, to work in closer partnership with our communities and to steward our resources wisely and transparently.

We are so grateful to all the people who have supported us over the past four decades, enabling us to get this far. Thank you for taking an interest in our vision and our work. With your help, we will continue to pioneer the very best children's hospice care in the UK.

A handwritten signature in black ink that reads "Jennie V Younger". The signature is written in a cursive, flowing style.

Chair of Trustees



**Elliot loves coming in
to the hospice for
sensory experiences**



86,000

children in the
UK will die
prematurely

The challenge is huge

Every child should be able to live their life to the full, even when that life is short. Today more than 86,000 children in the UK are living with a life-limiting illness meaning they will die prematurely. Their lives are often filled with hospital stays, endless medication, 24-hour care and sleepless nights. The emotional, physical and financial toll for children and families is huge.

More children than ever before need our support. Evidence shows that the number of children with palliative care needs in the UK could increase by up to 30% by 2030*.

Children's needs are changing. Advances in medicine and treatment mean that children with terminal illnesses are living longer from infancy into childhood and beyond with complex conditions that require specialised care. This makes it less easy to predict how their symptoms and pain will develop.

Families' needs are changing. More and more families tell us they want their child to be cared for at home, without the need for costly and stressful journeys. We can't reach every family in our region who needs our care.

Funding for children's palliative care is challenging. Statutory funding covers just 10–14% of what children and families need. We must reshape children's palliative care in the UK.

*Make Every Child Count, Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom. Study conducted by Professor Lorna Fraser at the Martin House Research Centre, University of York, published February 2020.

Number of children
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**30% by
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Our strategic aims

Vision

Every life is a full life; every death is a dignified death.

Mission

To pioneer, deliver and champion exceptional palliative care services that adapt to the ever-evolving needs of children and their families.

1

Care

Ensure that children and their families receive seamless, integrated palliative care services in their preferred settings.

2

Learn

Establish a leading role in advancing impactful research and education, to drive consistent improvement in care locally and nationally.

3

Collaborate

Work with partners to transform the landscape of paediatric palliative care, setting new standards that meet the unique needs of children and families.



Daniel and his siblings



“Daniel used to put on a brave face with me about how he was feeling, his symptoms and how much pain he was in. But with support from the outreach nurses, he could be open about things he didn’t want to burden me with.

They knew how to help him manage his symptoms and make him feel better when everything felt so hopeless. They had the specialist knowledge I lacked.

When you feel like you’re dying inside yourself, you need someone you can depend on. I can’t tell you what a difference Sian (our Outreach Nurse) made. I used to get worried because he was on so much medication and I was managing the dosages. I used to wonder if I was doing the right thing but someone from Helen & Douglas House was always there. All I had to do was pick up the phone and a specialist would reassure me or provide advice.”

Julie, Daniel’s Mum

Pioneering the very best children's hospice care in the UK

For over 40 years, we have pioneered the very best children's hospice care in the UK. Today, we must do more to give every child and family who needs us the highest quality care and wraparound support. This means focusing on where we provide care, how we provide it, and what we provide, at every stage listening closely to what families tell us they need.

These priorities are aimed at making our services, already rated outstanding, into something nationally leading.

Where: We will reach more families in more places in our region, by introducing **local hubs** in areas where the need for our help is greatest. This will include providing services based on what families in those communities need, such as bereavement support, group therapy, benefits advice, sessions for older siblings, complementary therapy, play specialists and a chance to meet with other families.

How: We will create a culture of **learning and innovation** to respond to the changing needs of children and families.

We will train our nurses to **lead on care** during supportive stays, as they are often those who are closest to an individual family's needs.

We will also support nurses to expand and deepen their expertise in areas such as **complementary therapies and perinatal support**. This work will mean we are better positioned to admit families swiftly, respond to changing needs, reduce stress and increase clinical capacity where it is needed most.

Local hubs



Advance research & education



We will also encourage nurses and clinical staff to advance **research** and **education** that will influence and transform the palliative landscape, both nationally and internationally. This includes research into areas such as symptom management, so our families receive the very best care reflecting the latest thinking.

What: We will continue to develop and deliver outstanding care for children and families in our area. We will **ask them** about the facilities, spaces and services that will make the most difference to them, so that they are comfortable and able to live their lives to the full.

This work will include investment in a new, larger **hydrotherapy pool** to help children increase their muscle strength and joint flexibility, alleviate and manage their pain and improve their wellbeing through relaxation and play.

Building on a number of successful recent refurbishments, we will also invest in further **modernising spaces within the hospice**, so that families have bright and welcoming spaces to enjoy precious moments together.

Modernise spaces including new hydrotherapy pool



Train nurses to lead on care



Helen & Douglas House will lead the way

We strive to make sure children and their families have the most joyous life, no matter how short it is. At any one moment, we have over 200 children and their families on our caseload, providing access to our services both in our hospice and the place of their choosing – home, schools, hospitals – across the Thames Valley region. This number continues to rise as other local services close and referral rates increase.

As the world's first children's hospice, Helen & Douglas House has gone on to inspire 54 others across the UK and around the world. We were the first to stand up and say children have a human right to a dignified, pain-free death.

Since 1982 we have developed our care to meet families' changing needs. Initially offering mostly respite care, we have adapted to provide complex medical support. We have also expanded our range of services to, for example, offer support in our community, and continue to improve our grounds and spaces. In 2023, our care was rated "outstanding" by the Care Quality Commission.



Sumayya loves every
moment at the hospice

“When Nathan fell extremely ill in September 2023 the first call I made was to Helen & Douglas House. They were there from day one. Explaining things when I couldn't understand, for a hug when we were low, for pain management after his long stay in intensive care and reassurance when we had to make hard decisions. We planned discharge to Helen & Douglas House so I could rest and get ready for the long road ahead.

From food packages to a shoulder to cry on, they were there every step of the way. I couldn't have done it without them.”

Jenny Best, Nathan's Mum.



Nathan enjoying music time at the hospice

We are 100% family and child centred

Families tell us they treasure the wraparound support for the whole family, with all services – such as clinical care, bereavement counselling, and support for siblings – under one organisation. Families tell us the hospice is a haven, a homely space and a sanctuary at the most difficult time.

We further research that shapes palliative care

We have contributed to WHO and NICE guidelines on the management of chronic pain in children and to many other international children's palliative care policies and guidelines. Examples of our recent impact include: co-creating guidelines for withdrawing life-sustaining treatment outside hospitals; collaborating on standards to support the safe care of ventilated children; exploring how to improve pain medication; and ensuring families get clear, consistent messages from clinicians.



Roman came to Helen & Douglas House at just a few weeks old

Care Quality Commission report on Helen & Douglas House, November 2023

“The service was leading the way nationally in educating third parties on the complex needs of paediatric palliative care... We saw some staff were on numerous boards that led to the implementation of guidance and legislation and were members of national committees relating to paediatric palliative care.

We saw numerous examples of staff going the extra mile, especially regarding make-a-wish requests. For example, staff arranged for llamas to be brought into the garden where a child or young person and their family were able to walk and feed them. Staff set up a fairground including rides, in the grounds.

Other service providers should look at this report to see if there’s anything they can learn about supporting people during such a difficult time in their lives.”



Our garden offers a tranquil and calming space for children like Habibou

Join us in leading the way

With your help we will reach more of the families who rely on our support, when and where they need us. We will innovate to evolve our services so we can look after children with the most complex needs and offer additional therapies to children, siblings and parents that truly improve their quality of life. And we will invest in and improve our spaces, so children and families can feel kindness, warmth and support during the toughest times.

If you would like to join us and support our vision, please contact Charlie Drummond, Head of Fundraising by emailing chdrummond@helenanddouglas.org.uk.

What our funders says about us

“The Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) is proud to support this outstanding children’s hospice and the vital work they do for children and families across our region. The Helen & Douglas House team brings exceptional expertise and compassion to paediatric palliative care, making a tangible and lasting difference to the lives of those they support. Our confidence and trust in them are borne out of a long-standing and collaborative relationship at all levels across our organisations. We value our close partnership with the charity and are pleased to share a united vision and commitment to enhancing care for children with life-limiting conditions.”

*Zo Woods, Head of Palliative and End of Life Care (PEoLC) and
Community Services, Buckinghamshire, Oxfordshire and Berkshire West
Integrated Care Board*

“We’ve proudly supported Helen & Douglas House since 1985, and over the years have come to feel part of the family. From its pioneering beginnings as the world’s first children’s hospice, we’ve admired its compassionate, innovative care.

Our contributions have always been directed toward specific projects – sensory room equipment, garden enhancements, and the music programme – allowing us to witness the real impact on children and their families.

To us, the hospice is a place where expert care transforms every moment into something meaningful. Supporting it has deepened our understanding of the challenges families face, and we’re grateful to play a small part in helping them through their journey.”

Ian and Mave Richens

“While we race across the globe, our local community is incredibly important to us, and we want to ensure that our presence positively contributes to those around us.

We are incredibly proud to support Helen & Douglas House – a charity that brings comfort, care, and joy to children with life-limiting conditions and their families.

Our charity partnerships are chosen and led by our team members, and we trust Helen & Douglas House to use our support wisely and with real impact.

Their team goes above and beyond to create moments of happiness and dignity, and we’ve seen first-hand the difference they make.”

Mercedes AMG Petronas F1



AMG
PETRONAS
FORMULA ONE TEAM



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Registered charity number 1085951

