Helen & Douglas House

your local children's hospice

Quality Account

2025-26



Our vision

Every life a full life, every death a dignified death

Contents

Vision, mission and values	**3**
Part One: Statement of assurance from the Chief Executive on behalf of the board	**5**
Part Two: What we have achieved	**7**
Patient safety and outcomes	
Clinical effectiveness and accessibility	
Patient experience	**8**
Part Three: Priorities for improvement 2026/27	**10**
Patient safety and outcomes	
Clinical effectiveness and accessibility	
Patient experience	**11**
Part Four: Overview of services	**12**
Financial considerations	
Funding sources	
Information governance	
Clinical coding error rate	
Participation in national clinical audit	
Local clinical audits	**13**
Infection, prevention and control	
MHRA and patient safety alerts	
Research	**14**
Publications	**15**
Education	**16**
Part Five: Review of quality performance	**17**
Incident reporting	
Type of incident	**18**
Safeguarding	**21**
Equality, diversity and inclusion strategy	**22**
Duty of candour	
Freedom to speak up	
Patient experience	
Patient feedback	**25**
Activity report	**28**
Service capacity	**29**
Breakdown of bed nights	**30**
Supporting deaths	**31**
Community and family support services	**32**
Therapies	**33**
Part six: What others say about us	**34**
Care and Quality Commission	
Commissioner Quality Assurance visits	
Complaints/compliments	**35**
Part seven: Service improvements	**37**
Part eight: Responses to the Quality Accounts	**42**

Vision, Mission and Values

Vision
Every life a full life, every death a dignified death

Mission
Helen & Douglas House is the world's first children's hospice, supporting children with life-shortening and life-threatening conditions and their families across Oxfordshire and surrounding counties. We help children live their lives to the full, even when those lives are short. We help families create lasting memories and ensure every child and family can access exceptional hospice care when and where they need it.

Values
- We are creative and resourceful
- We are open and honest
- We are caring
- We lead by example
- We are committed to partnership

Who we are and who we serve
Helen & Douglas House is a registered charity providing palliative care for children and young people until their 19th birthday. Our services cover the Thames Valley area and surrounding areas, which include Oxfordshire and the surrounding counties (*please see map below*):



Helen House is a hospice building surrounded by a lovely garden, in the centre of the diverse city of Oxford. We are committed to caring for and supporting children and young people throughout their shortened lives by offering the following services:

- Supportive stays
- Outreach
- Symptom management
- Community and family support services
- Youth and transition into adult services
- End-of-life care
- Cold suite/Little Room and post-death care

We also extend our support to families and carers through death and bereavement. Family support is provided at the hospice, in the family home and community settings.

Children, young people and their families have access to a wide range of opportunities at Helen & Douglas House. We provide a breadth of professional health and social care support; delivering specialist palliative care, through a wide skill mix of doctors, registered nurses (including children's nurses, learning disabilities nurses) a midwife, and skilled care support workers, social workers, physiotherapists, sibling support and bereavement support workers. Alongside medical and nursing care, there is plenty of fun and play guided by our specialist play team. All school-age children have access to schooling on two days per week when staying at Helen House. Our teacher, from the Oxfordshire Hospital Schools, works closely with the child or young person's school to access their Education, Health, and Care Plan (EHCP) to work with the same curriculum and goals.



Our clinical team provide one-to-one support

Paediatric Palliative care outreach (medical and nursing) is provided within Oxfordshire and surrounding counties, working in partnership with Secondary care, community services and other local hospice services. We are proud to have strong partnerships with professionals, both regionally and nationally, to ensure that we provide the highest-quality, safe care.

We remain a central voice in regional and national forums relevant to palliative and supportive care; actively seeking opportunities to deliver education, improve practice, work collaboratively, and advocate for the sustainable funding of services for our population.

Part One: Statement of Assurance from the Chief Executive on behalf of the Board

A sincere welcome to this year's Quality Accounts. Since August 2025, I have had the privilege of leading Helen & Douglas House as Chief Executive Officer. This report demonstrates another full year of dedication, resilience and commitment from our staff and volunteers. It is my pleasure to share this overview of quality, safety and patient experience delivered over the last 12 months. Throughout this report, we aim to provide clear information about the quality of our services so children and their families may feel reassured, safe and well cared-for.

We have much to celebrate this year, some highlights include Helen & Douglas House being rated **'Outstanding'** by the Care Quality Commission (CQC), retaining the regulator's highest rating following an inspection in November 2025.

Inspectors visited the hospice on Tuesday 11 November 2025, and the report of their inspection confirmed the 'Outstanding' overall rating. The charity achieved 'outstanding' in four out of five categories – a further improvement on its previous inspection, reaffirming its commitment to delivering exceptional care and support to terminally ill children and their families. We have also received the **' Winner of the Best Not-for-Profit / Charity Internal Wellbeing Programme'** at the 'This Can Happen Global Awards'. Celebrating the diversity of our staff, volunteers and the children, young people, and families that use our services is at the heart of all that we do, and we are honoured to have maintained our Investors in Diversity 'Silver' accreditation awarded by the National Centre for Diversity accreditation.

Helen & Douglas House has remained a substantial contributor in Paediatric Palliative Care education, research and publications locally, regionally, nationally and internationally. We have also remained dedicated in supporting medical and nursing placements from Oxford University, Oxford Brookes University and this year from the University of Southampton.

We are proud to continue to meet our strategic aim of reaching more children, with 239 children/ young people on our caseload at the close of the year, 14% more than last year. This engagement with new families is further demonstrated by a 75% increase in the number of first stays we have delivered, attributed to increased awareness of our services and significant collaboration with other stake holders to refer families earlier.

We have provided a specialist service that was responsive to the continuously increasing complexity of needs presented by children, whilst also providing routine support and increasing opportunities for fun, play and memory making. Accomplishments I would personally like to share are a 4% increase in accepted referrals from the previous year, maintaining an average bed occupancy of 93.5% throughout the year and a 21% increase in the number of individual children that used our in-patient facility.

Our community and family support team delivered an incredible 8489 hours of support, care and treatment, an increase of 23% from the previous year. Increasing

Continued.
sibling support and activity days meant more families were able to spend quality time with their child with a life-limiting or life-shortening illness, while the siblings were able to enjoy time with other children/young people who understood their situation. Increasing youth and transition support has enabled more children aged 13 years and older to be supported to prepare them for adulthood and adult services after their 18th birthday.

Care for children and young people after their death has also increased. 39% of families whose child died chose to use our Little Room (cold-suite), and we provided 7.8% more Little Room nights of care. In close collaboration with other healthcare providers, we supported 70% of the total deaths within our footprint, to die in their preferred place of death.

This year, we have completed a refurbishment of Helen House, which is now a much brighter, child-friendly and welcoming space for children co-designed by them and their families. The refurbishment included colourful flooring, a fresh new dining area and beautiful relaxing family accommodation. This is exciting as we look forward to welcoming more children and their families to benefit from our care, support and facilities in the year ahead.

Feedback from families and stakeholders continues to be overwhelmingly positive. It is a true reflection and appreciation of our competent, skilled and caring staff and volunteers. We are extremely proud of the feedback from families; 88% of respondents rated their overall experience of our service as 'very good', the highest rating.

We are entering the second year of our five-year strategy, where we continue to; aspire to deliver world-class palliative care, develop our clinical service to meet the needs of every eligible child and family, and focus on enhancing care quality through learning, education and research, in collaboration with external stakeholders.

We commend the account to you and extend thanks to our colleagues, supporters, commissioners, volunteers and many others who have supported us this year. We are proud of all we have achieved and pleased to have been of service to people who have sought our help in this time.

To the best of my knowledge, this Quality Account is an accurate and fair representation of the quality of services provided by Helen & Douglas House for children, young people and their families. We hope you find this Quality Account both informative and useful, and please do not hesitate to contact us with any questions or comments that you may have.



David Whittingham - CEO

David Whittingham
Chief Executive Officer
Date: June 2026

Part two: What we have achieved

At the beginning of 2025 - 2026, we set three main clinical priorities to deliver during the year. Below are the priorities and an update on how we successfully achieved them.

Patient safety and outcomes

Support and Develop Our Workforce to Deliver High Quality, Compassionate Care

We will concentrate on the development of nurse-led perinatal care with the aim to provide compassionate, family-centred support from the point of diagnosis through birth, and into the postnatal period, however long that may be. This approach ensures continuity, emotional safety, and clinically excellent care for families facing complex or life-limiting diagnoses during pregnancy. Our specialist nurse will work in close partnership with our medical team, regional foetal medicine units, maternity services, neonatal teams, and community services to coordinate care that is responsive to each family's unique needs. The purpose of this model is to enhance quality of life, promote informed choice, and provide expert support at every step of the journey, enabling families to make the most of the time they have with their baby.

The introduction of a clinical volunteer co-ordinator role will allow us to increase the number of volunteers offering support in Helen House, in the local community and within family homes.

Update

Our Advanced Care Practitioner (ACP) is a registered nurse and midwife. They have fully embedded the perinatal pathway at Helen & Douglas House. This role has been instrumental in enabling expectant mothers and families to access hospice support at the earliest possible stage, providing continuity of care and emotional safety for mothers/unborn babies/newborn babies and their partners/families. The ACP has established strong collaborative relationships with partners in maternity, neonatal, and specialist services, ensuring families are at the centre of making decisions around what, how and where they wish to receive care and support. This role has significantly increased the number of families accessing hospice services prior to the birth of their baby. Earlier referral and intervention have enabled families to benefit from timely specialist advice, care, and emotional support, helping them to navigate uncertainty, understand complex information, and process challenging decisions during an exceptionally difficult time.

Clinical effectiveness and accessibility

Strengthen the Use of Evidence to Improve Care

In the coming year, we will be offering an exciting opportunity in a pioneering new role that will place research at the heart of high-quality, compassionate care. The appointment of our first dedicated Clinical Research Practitioner (CRP) will help shape the future of paediatric palliative care by embedding research within our Nursing, Midwifery, and Allied Health Professional (NMAHP) workforce alongside

Continued.
our medical colleagues. This will allow us to support research that enhances clinical practice, contributes to national knowledge, and ultimately improves the lives of the children and families we serve. We will be working on developing an education framework to embed a robust programme of training and professional development. This includes a review of current and potential educational resources to identify gaps and opportunities, alongside the increased use of simulation training to enhance practical and situational response skills. These initiatives will provide staff with the tools and confidence to identify early signs of clinical deterioration and respond appropriately.

Update

We successfully appointed a Clinical Research Practitioner (CRP) in September 2025. The CRP has significantly strengthened the culture, capacity and capability of research within the organisation. This development directly supports our strategic objective of becoming a research-ready organisation, ensuring that the care and support we provide continues to be informed by the strongest available evidence and emerging best practice. The CRP has established tighter research governance structures, expanded collaboration with regional and national research networks and forums, established a dedicated research repository and developed a research programme for the coming year.

Together, these developments are creating exciting opportunities for staff engagement, partnership working and the generation of new knowledge that will ultimately improve outcomes and experiences for the children, young people, and families we support.

Patient experience

Expand Access to Care

Our community hub-based care model aims to extend the reach and accessibility of specialist palliative care by bringing our support closer to families' homes. By delivering care through a flexible, locality-based approach, we provide holistic, nurse-led services in familiar settings, whether in community centres or local healthcare environments. This model will enable timely, personalised support and emotional wellbeing. The purpose of community hub-based care is to reduce the burden of travel for families, strengthen relationships with local providers, and ensure continuity of care across settings. It reflects our commitment to delivering responsive, equitable care that empowers families and meets their needs where they are. The introduction of a Senior Complementary Therapist role will reflect our commitment to delivering high-quality, holistic care for babies, children, and young people with life-limiting conditions. This role strengthens our person-centred approach and ensures therapies are evidence-informed, safe, and tailored to individual needs.

Update

In October 2025, Helen & Douglas House successfully hosted its first Community Hub in Buckinghamshire, bringing together expertise from our outreach nursing, family and bereavement, social work, youth and transition, and siblings teams. The event was warmly received by the families who attended, and it provided them with valuable access to specialist advice, support, and guidance closer to home within their own locality.

Importantly, the Community Hub also created opportunities for families to connect with others who share the experience of caring for a child with a life-limiting or life-threatening condition, helping to reduce isolation and foster peer support networks. Notably, two of the families who attended had not previously accessed hospice services, demonstrating the hub's potential to extend our reach and engage families who may otherwise remain unsupported.

Feedback gathered from families and staff following the event has been overwhelmingly positive and informed the planning and development of the next Community Hub. Future events will continue to be co-produced and reflect the needs and priorities of the families we support.

We successfully appointed a Senior Complementary Therapist, who is also a registered children's nurse, in August 2025. The service offer involves aromatherapy, massage, yoga and Reiki for children/young people, parents and immediate family members.

The therapist has played a key role in strengthening the safe and effective delivery of holistic therapies across Helen & Douglas House. They are doing this through the development of a comprehensive framework, alongside robust risk assessments, policies, and clinical guidance to support best practice.

Further work has included developing of training packages to equip care staff with the skills and confidence to deliver selected complementary therapy interventions safely and effectively. Work has also been undertaken to explore current and future demand for holistic therapy services across the wider organisation, including the outreach and perinatal caseload.



Aiden at our first Community Hub

Part Three: Priorities for improvement 2026/27

Patient safety and outcomes

Advancing Specialist, Nurse-Led Models of Care Across Hospital and Community Settings

Building on the successful development of our nurse-led perinatal model, we will now focus on scaling and embedding this approach across the wider system, ensuring consistent and equitable access for families.

Our perinatal pathway will continue to provide compassionate, family-centred support from diagnosis through pregnancy, birth, and the postnatal period. In this next phase, we will strengthen integration with regional partners, including foetal medicine units, maternity services, neonatal teams, and community providers, to deliver seamless and coordinated care.

Alongside this, we will support the growth and development of our specialist nursing workforce, enabling increased capacity to deliver complex, responsive care across both hospice and community settings. This expansion will enhance continuity, responsiveness, and safety for children and families with increasingly complex needs.

The introduction of a Nurse Consultant role will provide senior clinical leadership across the organisation, strengthening:

- Advanced clinical decision-making
- Professional leadership and workforce development
- System-wide influence and partnership working

This role will be pivotal in driving quality, innovation, and evidence-based practice, particularly within community models of care.

We will also continue to expand the contribution of our clinical volunteer workforce, supported by a Clinical Volunteer Co-ordinator, to safely enhance the support available to families both within the hospice and in their own homes.

Clinical effectiveness and accessibility

Embedding Research, Workforce Capability, and Community-Focused Practice

In this next phase, we will build on the foundations of research and education to embed a culture of continuous learning and evidence-based practice, with a strong emphasis on delivering high-quality care in community settings.

The introduction of our Clinical Research Practitioner will enable us to integrate research into routine practice, supporting innovation and contributing to the wider evidence base in paediatric palliative care. Our focus will be on translating research into tangible improvements in outcomes and experience for children and families.

We will further develop and implement a comprehensive education and workforce development framework, aligned to the needs of an expanding community model.

This will include:

- Advanced skills development to support autonomous, nurse-led care in the home
- Simulation-based training to enhance clinical judgement and response to deterioration
- Strengthening capability across multidisciplinary teams to deliver safe, effective care outside traditional inpatient settings

Through the continued growth of our specialist nurse teams, we will improve accessibility to expert care, enabling earlier intervention, proactive management, and reduced reliance on hospital-based services.



Patient experience

Expanding Community and Home-Based Care to Improve Access, Equity, and Family Experience

Building on the introduction of our community hub model, we will now expand our community and home-based care offer, ensuring that more children and families can receive specialist palliative care in the place that best meets their needs.

Our evolving model will deliver flexible, nurse-led care across a range of community settings, with a particular focus on care in the family home. In this next phase, we will:

- Increase the availability and responsiveness of home-based support
- Strengthen locality-based delivery through community hubs and an expanded outreach team
- Improve continuity of care across hospice, hospital, and community services

This approach will reduce the burden of travel, enable care to be delivered in familiar environments, and support families to spend more meaningful time together.

The expansion of our specialist nursing teams will be central to this model, ensuring that children with complex and life-limiting conditions can access timely, expert care wherever they are.

In addition, the introduction of a Senior Complementary Therapist will further enhance our holistic approach, extending therapeutic support into all care settings and improving emotional wellbeing and quality of life for children, young people, and their families.

Part four: Overview of services

Financial considerations

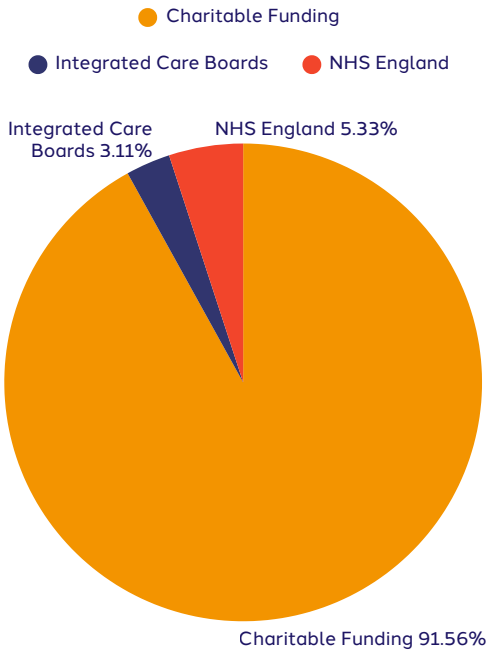
Helen & Douglas House does not charge any child, young person or family for the provision of any care or support service.

Our services are funded through a combination of fundraised income, voluntary donation, shop, and lottery, and negotiated contributions from public sector/ statutory bodies. For the year 2025 -26, public sector contributions represented less than 8.5% of the hospices total income used to provide care and treatment to children and families.

Funding sources for hospice care 2025-26

Exact %'s

- NHS England 5.33%
- Integrated Care Boards 3.11%
- Charitable Funding (Hospice UK Grant, Retail, Fundraising, Other) 91.56%



Information Governance

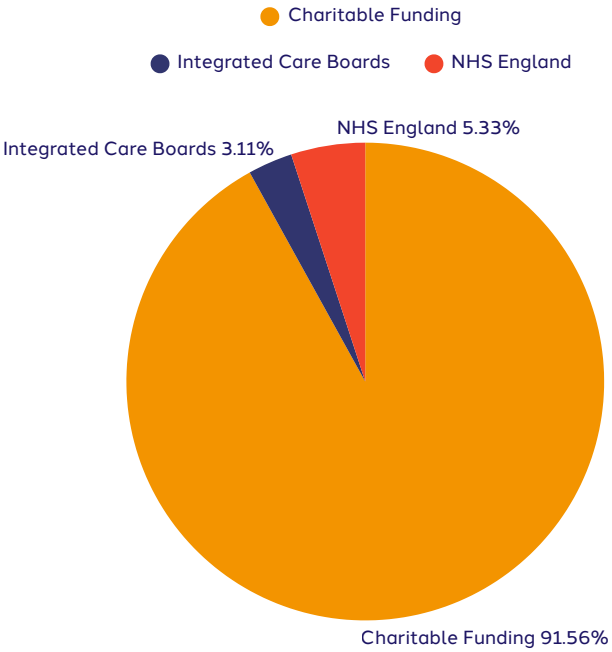
Helen & Douglas House has maintained Information Governance policies and procedures in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018. We also continue to complete the NHS Data Security and Protection Toolkit, which allows us to benchmark our performance against the National Data Guardians data security standards. Helen & Douglas House has an external Data Protection Officer (DPO) to assist with auditing and monitoring internal compliance, informing and advising on data protection obligations, providing advice regarding Data Protection Impact Assessments and act as a contact point for data subjects and the Information Commissioner's Office (ICO). The DPO has completed an audit and worked with us to action plan improvement aspects of data governance across the organisation to ensure compliance.

Clinical coding error rate

Helen & Douglas House was not subject to the Payment by Results clinical coding audit during 2025/26 by the Audit Commission.

Participation in national clinical audit

In 2025-26, we participated in the National Child Mortality Database thematic review on the deaths of children with life-limiting illnesses.


Charitable Funding
Integrated Care Boards
NHS England
NHS England 5.33%
Integrated Care Boards 3.11%
Charitable Funding 91.56%

Local clinical audits

This year we concentrated on giving depth to our programme of internal clinical audits to measure, monitor and improve our quality, performance and governance. In addition to scheduled audits, we ensured we conducted responsive audits where there was an identified opportunity for quality improvement. Results, learning, and areas for improvement are presented to the clinical governance committee and sent to staff through internal communication channels. Audit results are analysed, and senior leaders work closely with clinical leads to improve compliance, ensuring the clinical team remains engaged in quality improvement. A prime focus this year has been to migrate audits onto Microsoft Forms to provide ease and efficiency for staff using mobile devices, and also for better data collection and analysis to inform quality improvement projects. These audits are stored in a central system, which allows better governance and oversight. Various responsive audits were completed to highlight areas for improvement that were covered in a training week for all clinical staff in October 2025.

Infection, Prevention and Control

Infection prevention and control (IPC) has remained a high priority and been fundamental to safe service provision throughout 2025/26. This year, we implemented the use of the Hospice UK Audit Tool to gain a baseline and completed a detailed action plan to address any areas for improvement. Two designated IPC Lead Nurses completed a two-day IPC course, are responsible for the continual auditing, review and updating of IPC policies and procedures, and for alerting the Senior Leadership Team of any areas requiring specific attention. An IPC collaborative has also been set up to maintain focus and regular review, providing reporting and assurance to the clinical governance committee.

IPC audit and training days led to several quality improvements such as implementing an IPC framework, reviewing and aligning the hospice environment with a functional risk rating, monthly IPC newsletters with audit results, and risk assessments for communicable disease and management. Ongoing work includes dermatitis surveillance, shared area IPC controls and identifying gaps and increasing compliance within our outreach staff.

Personal Protective Equipment (PPE), cleaning of near-patient equipment and hand hygiene audits were completed regularly throughout the year. IPC training frequency was changed in summer 2025 in line with NHS guidance, and organisational compliance has been maintained above 90% since.

MHRA and patient safety alerts

All alerts are reviewed by our medical team and senior nurses to assess relevance for our service. Relevant alerts are actioned immediately. Our physiotherapy team have completed a full review of procedures around breathing circuits following a national alert advising of the risk of harm from incorrectly assembled breathing circuits lacking a proper exhalation route for patients receiving invasive or non-invasive ventilatory support.



Iris during a play session

Research

This year, as a service, we have contributed significantly to research in paediatric palliative care. Some examples of this include:

- A research symposium entitled Research from Bedside to Breakthrough was hosted by Helen House in September 2025 for our network of healthcare professionals.
- We contributed to ten studies over the course of the year, including:
- The BEACON study: considering how best to assess breakthrough pain.
- The CHESS study, which encompasses various aspects of healthcare, including the development of self-care support for children with neurodisability and the prediction of mortality among persons with neurological conditions.
- The Grief Map research and data.



Publications

Our staff contributed to the following publications:

The midazolam platform trial, supported by the Collaborative Paediatric Palliative Care Network (CoPPAR) network, supported by our consultant was published in May 2025:
Paediatric palliative care prescribing: midazolam multicentre pilot study. Fraser L, Anderson AK, Wong ICK, Peat G, Harrop E. BMJ Support Palliative Care. 2025 May 25:spcare-2024-005343. doi: 10.1136/spcare-2024-005343.

Helen & Douglas House participated as the only hospice-based research site in a study of clonidine patches for dystonia:
Transdermal clonidine patch use in the management of childhood hypertonia: a cross-sectional UK-wide service evaluation. Lumsden DE, Spaull R, Abernethy S, El Gamal M, Forrest K, Lemaire LA, Lin JP, Marques S, Orr V, Carr L, De Alwis Y, Devlin A, Harrop E, Kurian M, Lundy CT, Mordekar S, Pysden K, Smallbone T, Lodh R. Arch Dis Child. 2026 Feb 19;111(3):253-259.

The final report from the Collaborative Paediatric Palliative Care Network (CoPPAR) network, supported by Helen & Douglas House published:
Learnings from the establishment and delivery of the UK Collaborative Paediatric Palliative Care Research Network. Peat G, Harrop E, Anderson AK, Box D, Murtagh F, Harding R, Ziegler L, Hewitt C, Wong I, Elverson J, Harris N, Fraser LK. Health Technol Assess. 2025 Feb 26:1-9.

A bereaved parent and a consultant contributed to an article on hospice care in the UK, for the European Association for Palliative Care (EAPC),
Learnings from the establishment and delivery of the UK Collaborative Paediatric Palliative Care Research Network. Peat G, Harrop E, Anderson AK, Box D, Murtagh F, Health Technol Assess. 2025 Feb 26:1-9.

A bereaved parent and a consultant contributed to an article on hospice care in the UK, for the European Association for Palliative Care (EAPC),
https://kinderpalliatief.nl/nieuws/details/integrating-childrens-hospices-into-a-networked-approach-to-paediatric-palliative-care-in-the-uk.

Posters presented at conferences/events

One of our consultants and a colleague from a local adults' hospice presented a Transition-themed research poster at the Palliative Care Congress in Ireland.

The clinical teams worked collaboratively to submit four research abstracts to the Hospice UK conference in autumn 2025, on topics including sibling support, patient safety, physio interventions and staff appreciation.

One of our consultants presented two posters (risk management and consensus building) at the European Association for Palliative Care (EAPC) congress in Helsinki, May 2025. She also presented at a workshop on perinatal palliative care with colleagues from the Czech Republic and Spain.

The NCMD (National Child Mortality Database) produced a thematic report on deaths of children with palliative care needs, supported by our consultant and a bereaved parent. They held a national launch event in July 2025.

A member of the sibling team attended the Hospice UK conference and presented a poster.

The Head of Professional Development presented a Quality Improvement Poster at the National Professional Nurse Advocate conference June 2025.

Education

Contributing to education and learning, both within Helen & Douglas House and across external healthcare and professional networks, continues to be a key priority and is an area of the service in which we take great pride. Below are examples of these contributions:

Two members of the Continuing Professional Development (CPD) team were supported to complete their Post Graduate Certificate in Education.

A Preceptorship programme was launched in Autumn 2025. This encompassed preceptorship aspects, clinical and non-clinical skills training, aligning with the preceptorship standards and the new Royal College of Nursing (RCN) competencies for Paediatric Palliative Care (PPC). Some of this was delivered in partnership with another local Children's Hospice.

Our medical team supported seven medical students to complete elective placements. All the students fed back that the placement had met their learning objectives, and increased confidence/knowledge in symptom management, advanced care planning and how to care for children who are dying.

The PPC educate 'Spotlight on' evening webinar series has delivered eight sessions. This is a strong paediatric palliative care education platform in collaboration with parents and local teams across multiple disciplines to produce varied content. Sessions this year have included foetal medicine, paediatric intensive care, oncology, respiratory and safeguarding. Over 600 people have signed up to the contact list: over a third in nursing roles, just under a third doctors, and the remainder include leadership, education and allied healthcare roles, with a small PPI (Patient Participation Initiative) cohort. These sessions are open to and attended by people in the Thames Valley Region, Gloucestershire, Devon, Cornwall, Dorset, Wiltshire, Hampshire/Isle of Wight, Kent and Medway, Sussex and Surrey.

One care team member and one external student have been supported to train as Registered Nursing Associates.

Our CPD team have contributed to an end-of-life study day for paediatric healthcare staff at Oxford University Hospital and supported the end-of-life simulation study days for Children's Nursing students at Oxford Brookes University.

Our Consultants, Clinical Research Practitioner, Family and Bereavement support team lead and Head of Professional Development have supported the development of new workstreams for the Paediatric Palliative Care (PPC) Educate platform, supporting collaborative education in Paediatric Palliative Care across the South of England commenced, including bereavement, Royal College Nursing (RCN) competencies and interactive worksheets.

The Head of Professional Development has collaborated with Oxford Brookes University as a practice partner, contributing to a Nursing Midwifery Council (NMC) review of their standard Nursing course, and NMC validation of their new Children's Nursing Apprenticeship.

Helen & Douglas House hosted an oncology education event for healthcare professionals across the Thames Valley

The consultant team has delivered teaching days for various stakeholders, including the ambulance service, neonatal registrars, medical undergraduates, a local Children's Hospice, and the International Children's Palliative Care Network for colleagues in West Africa.

One of our consultants has delivered a Transition monthly Teaching Programme across the South East, linking with colleagues from two other children's hospices. Staff at Helen & Douglas House have begun a Collaborative Cancer Quality Improvement project with NHS England (NHSE) aimed at earlier engagement with cancer patients.

Part five: Review of quality performance

Incident reporting

This section gives an overview of the incidents reported in Helen & Douglas House in 2025/ 2026.

At Helen & Douglas House, we ensure that we place quality and safety of care at the centre of all we do. Every incident is reported through an electronic reporting system, and an alert is immediately sent through to clinical leads and the senior clinical team, including organisational executive oversight. The most appropriate person investigates the incident, and it is discussed by the senior clinical team for review at a weekly patient safety huddle. Lessons learnt are discussed and disseminated to staff and the wider system where appropriate. Patients/parents involvement is obtained to contribute to the learning as appropriate.

Medication incidents remain our highest category within clinical incidents. Therefore, we report on them separately to allow meaningful analysis and opportunities for learning. This year, we conducted a review of our Patient Safety Incidents Framework (PSIRF) plan, which comprised of a full thematic review and in line with PSIRF, we have ensured incidents in our top three categories are monitored closely, and quality improvement projects are in place. These projects are regularly reviewed for effectiveness by the senior clinical team.

Type of incident

Incident reporting data demonstrates the continued development of a strong and positive safety culture within Helen & Douglas House. In line with the principles of the Patient Safety Incident Response Framework (PSIRF), significant work has been undertaken to encourage open and transparent reporting across the organisation, including the reporting of low-harm incidents and near misses at every level.

Helen & Douglas House has continued to embed the Patient Safety Incident Response Framework (PSIRF) policy and plan to ensure we respond to patient safety incidents, focus on learning, systems improvement, and compassionate engagement rather than blame. PSIRF is central to our commitment to improving patient safety outcomes, and we have used its principles to create an action plan addressing our highest areas of reporting to understand where systems are lending to incidents and using this process to engage teams in developing improvements in paediatric palliative care. This has minimised the risk of reoccurrence of adverse events, encouraged a healthier reporting culture and continuous improvement. This framework shifts our approach from reactive, investigation-led models to proactive, system-based learning.

To provide greater oversight and learning opportunities, drug-related errors have been separated from wider clinical incidents within our reporting processes, reflecting that these remain the largest reported sub-category. The increase in reporting seen this year is viewed positively and reflects growing staff confidence in reporting, learning, and contributing to continuous improvement rather than an increase in harm.

During the reporting period, 217 clinical incidents were reported, representing a 181% increase compared with the previous year. In addition, 93 drug-related errors were reported, an increase of 111% from last year. This upward trend demonstrates an increasingly proactive and mature reporting culture, with staff actively engaging in identifying risks, sharing learning, and supporting safer care for children, young people, and families.

None of the reported incidents fit the criteria to be deemed a serious incident; however, importantly, they have highlighted the near misses. All drug-related errors are discussed at our Medicines Management Committee and reviewed by our Clinical Governance Committee. All data has been analysed for trends and themes with a resulting action plan to inform better systems and increase the levels of skill and competence of clinical staff. The next steps in our safety journey for this coming year will be to demonstrate how effectively our PSIRF policy and plan have been implemented, how this has enabled better learning and informed quality improvement.

Chart showing the number of clinical incidents per quarter

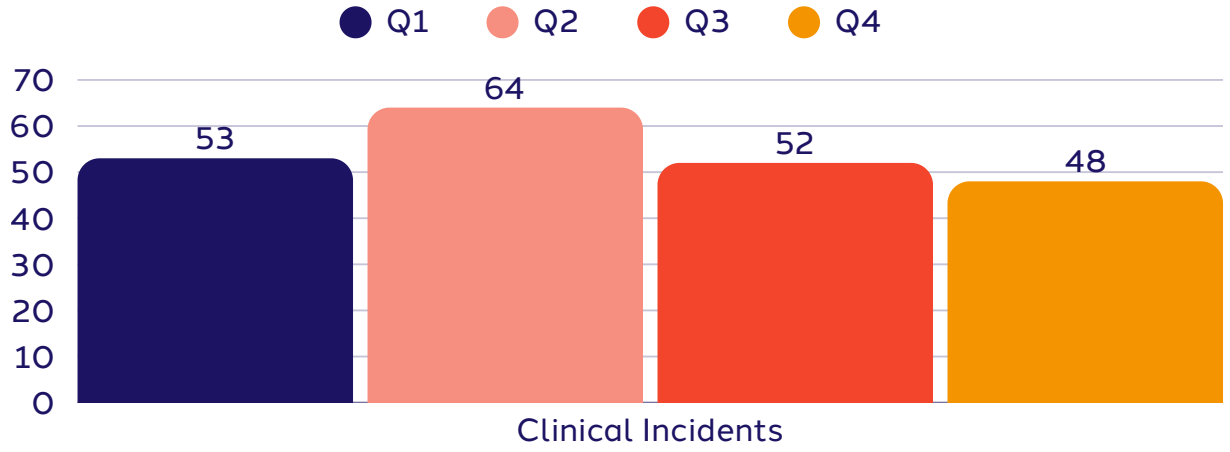


Chart showing the number of drug-related incidents per quarter

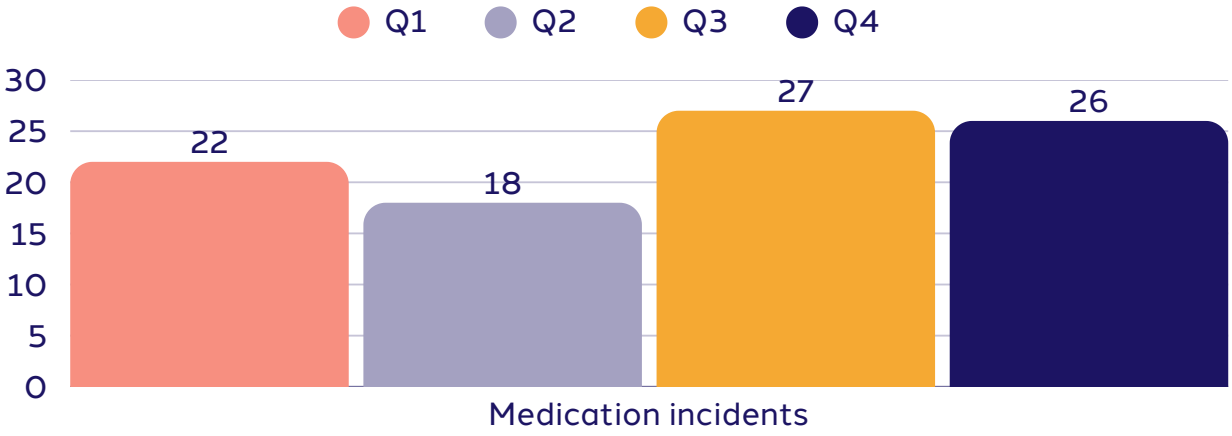
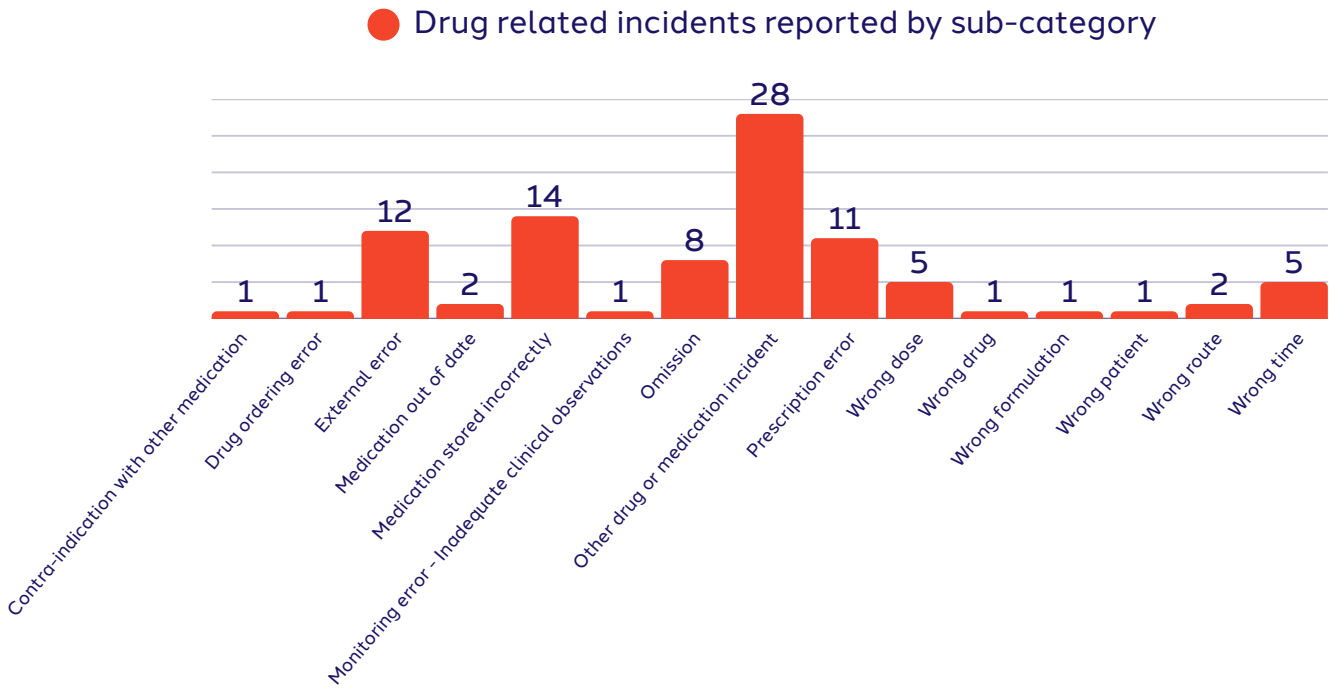


Chart showing the number of drug-related incidents reported by sub-category

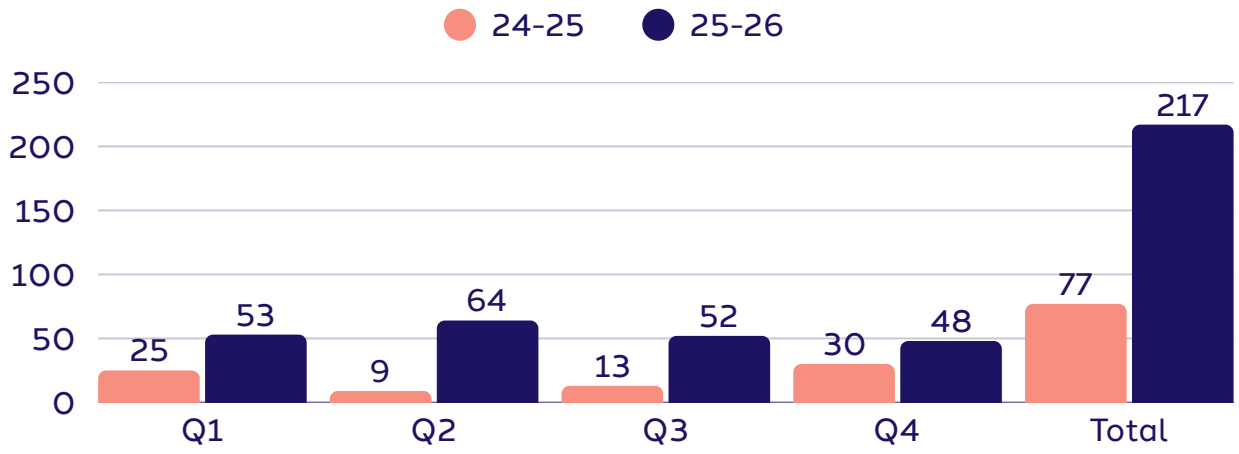


The table below shows the number of incidents in the top five reported sub-categories:

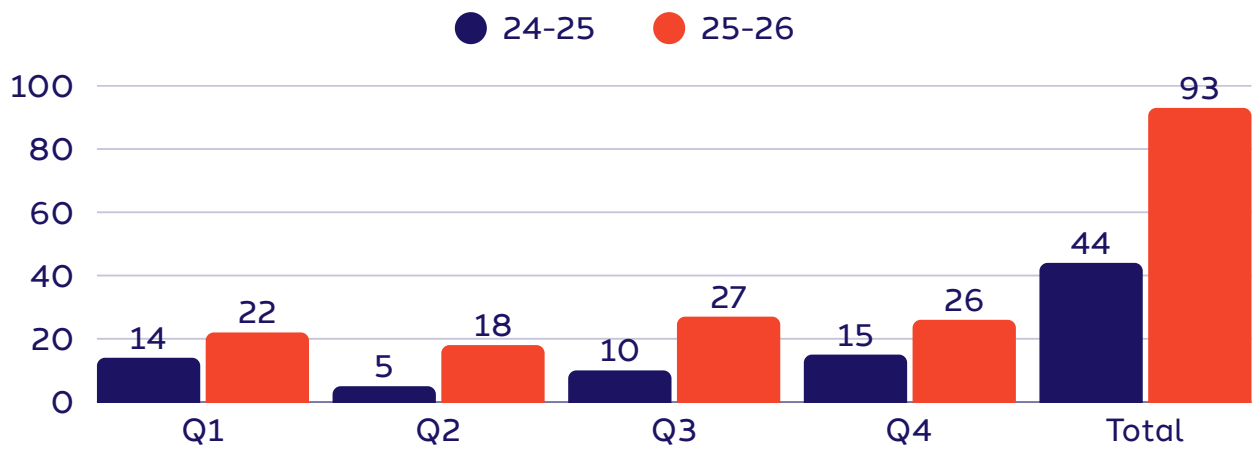
Incident category 2025-26	Number
Other Drug and Medication Incident	28
Medication stored incorrectly	14
External error	12
Prescription error	11
Omission	8

As shown above, other medication incidents, medication stored incorrectly, external errors, prescription errors and omissions have been in the top five subcategories consecutively for the last two years. We have worked on minimising the risk of potential errors and harm in these areas, including a review of processes, increased auditing, sharing lessons learnt in fortnightly briefing slides, and proactively anticipating areas of risk and responding with increased staffing for more complex admissions. In the coming year, we will be working closely with our local acute hospital to explore electronic prescribing, as this addresses a significant number of prescribing errors.

Number of reported clinical incidents over the last 24 months



Number of medication incidents reported over the last 24 months



Clinical training days had bespoke agendas based on the training needs of the staff, including addressing themes that arose from incidents.

Safeguarding

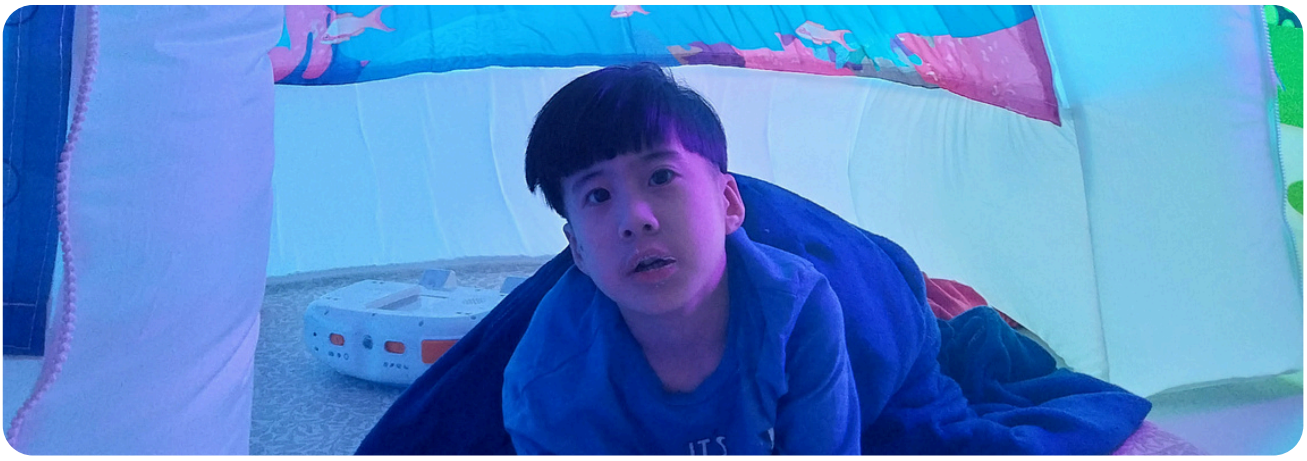
Helen & Douglas House maintains safeguarding policies which are in line with current legislation and adhere to the Intercollegiate Documents for children and adults. Mandatory training compliance is closely monitored at monthly intervals, and completion of safeguarding training is always given high priority. Training compliance across the organisation has been maintained at 91% or above for clinical staff throughout the year. We have two senior staff members trained in Level 4 Safeguarding Children to ensure that there is always a member of staff available with this specialist knowledge.

Helen & Douglas House is a trusted partner within Oxfordshire's Safeguarding Children's Board child death overview panel. We have embedded our use of safeguarding huddles, which are held in response to any safeguarding concern, attended by as many of the safeguarding team as available. These are also attended by our social workers to ensure the relevant external stakeholders are involved/ notified (statutory social workers, Multi-Agency Safeguarding Hubs, police, etc.).

We continue to offer patient-specific safeguarding supervision for clinical staff to improve awareness and confidence in dealing with potential safeguarding concerns. Our social work team maintain strong working relationships with the local safeguarding team, and work closely with a child/family's statutory social worker. We maintain strong collaborative working with the Head of Safeguarding and Designated Nurse for Children across Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) and maintain 100% compliance with the safeguarding self-assessment tool.

Helen & Douglas House Designated Safeguarding Officer (DSO) chairs a Safeguarding Steering group with representation from across the organisation and allocated Trustees. This group meets every six weeks to share learning, review safeguarding incidents and subsequent learning/ actions/ implementations and a

Continued.
safe space to discuss any low-level concerns. Following agreement by this committee we reviewed our safeguarding training for all clinical and home volunteers to receive Safeguarding Adults Level 2 training, instead of Level 1.



Marlon in our sensory room

Our DSO completed a DSO assurance audit to identify and address any gaps within the organisation. Some improvements included updating the Safer Recruitment Policy and associated training, updating the Whistleblowing policy, Chaperone policy and associated training, behaviour code of conduct for staff and volunteers, domestic abuse policy and reviewing gaps in safeguarding volunteers. All staff are now required to complete Preventing Radicalisation training once every three years.

Helen & Douglas House approached NHSE to be one of three hospices to pilot the use of the Child Protection Information Sharing System (CP-IS) in Hospice care. This is a secure NHS service in England, allowing health and social care workers to share information to protect vulnerable children. This system will be implemented fully in 2026.

Following the Fuller Inquiry, Helen & Douglas House has reviewed all policies, processes and guidance care for a child after death. This included changes to clearly auditable, authorised limited swipe access to the cold-suite (Little Room), swipe access to other bedrooms, close monitoring of any visitor passes allocated to family members and a detailed funeral director handover form.

Equality, Diversity and Inclusion Strategy

Over the past 12 months, we have continued to embed equality, diversity, inclusion and wellbeing at the heart of our organisational culture, ensuring colleagues feel valued, supported and able to thrive. Building on staff feedback, organisational insight and external best practice, we have strengthened inclusive approaches across recruitment, leadership, engagement and wellbeing.

We are proud to maintain our accreditation with the National Centre for Diversity and our Investors in Diversity, Silver status, reflecting our sustained commitment to continuous improvement. Engagement activity throughout the year included expert-led sessions and awareness events on menopause, fertility and baby loss, neurodiversity, mental health and suicide prevention, delivered in partnership with trusted external organisations and shaped directly by employee feedback.

A major highlight was national recognition of this work. In November 2025, Helen & Douglas House was named **Winner of the Best Not-for-Profit / Charity Internal Wellbeing Programme** at the This Can Happen Global Awards, acknowledging our organisation-wide approach and demonstrable impact.

Staff feedback over the year has remained strongly positive, with growing psychological safety, high levels of perceived fairness and increased confidence that equality, inclusion and wellbeing are lived values across the organisation

Duty of Candour

Helen & Douglas House continues to encourage a culture of actively reporting both actual and potential incidents, and policies and systems are in place to support this. Helen & Douglas House follows the Duty of Candour process to meet statutory requirements to be open and transparent with children and families if mistakes occur when providing care and treatment resulting in moderate or serious harm. This year, we voluntarily invoked the duty of candour for some incidents which did not result in this level of harm, but we felt an official apology and further investigation would benefit the learning. We actively engaged the family in learning from a particular incident.

Freedom to speak up

Within the organisation, we have two Freedom to Speak Up (FTSU) Guardians. Both members of staff were appointed through an anonymous application process. We endeavour to become an organisation where there is a strong speaking-up culture, where employees and volunteers are listened to, and lessons are learnt, so our services can improve. The role of the FTSU Guardians' aims to ensure that staff and volunteers, regardless of seniority, feel supported and confident to raise concerns about patient care or workplace safety. We have a designated lead on the trustee board for Freedom to Speak Up who maintains oversight of the concerns raised.

Our Freedom to speak up Guardians have completed training specific to this role, which is stipulated and delivered by the National Guardians Office. They also attend regular South East Guardians' networking meetings and separate hospice sector meetings.

Our Freedom to Speak up Guardians have spent time embedding their role throughout the organisation, including shop visits, attendance at all staff meetings and displaying posters. They meet quarterly with the Chief Executive Officer to report themes, and these are then reported to our trustees. All cases are also reported anonymously to the National Guardians Office every quarter.

At Helen & Douglas House, we also acknowledge that some staff prefer to remain completely anonymous, so we introduced a 'Whistleblowing' platform where concerns can be raised anonymously through an electronic submission.

Patient experience

At Helen & Douglas House, our vision remains firmly centred on delivering exceptional standards of care and enhancing the quality of life for the children, young people, and families we support. Over the last 12 months, we continued to focus on inequities in access to services, particularly focussing on extending our

Continued.
reach and ensuring as many children/young people as possible are on our caseload and able to access Hospice support. We have seen a growing number of families choosing to care for their child at home, reflecting both changing preferences and evolving care needs. In response, we remain committed to providing flexible, family-centred support that is responsive to individual needs, delivered at the time and in the setting that families choose.

To ensure we continue to meet these changing demands, we have begun expanding our Outreach team, strengthening our ability to deliver high-quality specialist care and support within the community and enabling more children and families to access personalised care closer to home.

This year, we embedded our Family Engagement Group. This group of parents meet once every three months, either virtually or in person, to gain feedback on various aspects of our service. The goal of this patient participation is to hear the voice of families to increase the quality and safety of care by creating a partnership between patients, family members and Helen & Douglas House. We have engaged families in co-design of care plan documentations, information leaflets, films and environment refurbishments. We remain committed to expanding family engagement into supporting with recruitment, training resources, co-production and co-design. We have representation from parents whose children are currently using our service and some bereaved parents. In the coming year, we aspire to welcome young people who are using our services to also participate.

We held a focus group for our young people and their families, looking at the support they anticipated requiring when transitioning into adult services. This was completed in collaboration with our clinical colleagues in adult hospice care.


Families at our summer party

In May 2026, we wrote to all current families inviting them to complete our annual feedback survey. We requested feedback on all aspects of the services and support we provide, including in-house care, outreach services, family support, and our facilities, as well as the impact our services have on families We wrote separately to families whose child had died in the last two years, ensuring relevant questions. The bereavement families questionnaire requested feedback regarding their experience of the delivery of end-of-life care, how well our facilities met their needs, and the impact of our services and teams support had on them as a family after their child's death.

Please see below for a summary of response rates and families' overall experience of our service. This year, nearly all of the families who replied to the annual survey rated Helen & Douglas House either 'very good' or 'good'.

- **Current families: Survey sent to 224 families and had a 20% response rate.** Overall experience of our service; 88% of those who responded rated our service as very good - highest rating (37 respondents), 10 % good (4 respondents), 2% poor (1 respondent).

- **Bereaved families: Survey sent to 63 families and had a 21% response rate.** Overall experience of our service: 75% of those who responded rated our service as very good - highest rating (9 respondents), 25% good (3 respondents).

Patient feedback

We capture feedback from families through a range of methods; the annual family feedback survey, through our 'complaints, compliments and suggestions' leaflet, our complaints process for formal complaints and voluntary feedback (thank you cards, letters, emails). There are two versions of annual feedback survey. One is sent to families currently accessing our service to capture feedback on our provision, facilities and impact. The second version is sent to families whose child died 12-24 months ago to capture feedback on the care, treatment and support received at the end of their child's life, through death and bereavement. I take great pleasure in sharing some of this feedback with you below:

Child feedback:
'*I love it here, it's a 10.9 out of 10, I want to stay every 2 weeks, they have nice food. It's fun, they have the piano and paints. I feel safe here, and I love the adults and the company.'* (Child)

Feedback from family members:
'I like coming (to siblings' group) because it makes me feel less left out because no one else at my school has a disabled brother, so they don't understand'. (Sibling)

Current families:
'Thank you so much Youth and Transition team for all the hard work you put into organising the weekend. It was such a big undertaking, yet everything was thoughtfully planned with care and inclusivity, and ran beautifully… I know he especially loved going into town for lunch, and it was lovely to see him chatting with another boy at pick-up.' (Parent)

'We are really indebted for your kind words and effort and for assisting us during this emotional journey'. (Parent)

'Thank you for your incredible care for not just (child), not just us, but even grandparents who I wonder if at times their grief can be forgotten/overlooked. Thank you'. (Parent)

'My child had a great time last night, she was buzzing! She really liked being in a safe environment doing different activities.'

Bereaved families:
'What a lovely service and gathering (Remembrance Event) as usual. Thank you all so much for all your hard work and your impeccable care and nurturing, in this and so many other ways, over so many years. You all, and all of our children, and their families, remain forever in my prayers.' (Parent)

'The name 'hospice' conjures up sadness and loss. Yes, we experienced all of that, but we also experienced such calm, comfort and understanding. The accommodation was so personal, almost like being at home. We were able to share all those last days, hours and minutes with (child) as a very close family. How the staff manage to keep all the emotions in tack, whilst giving so much, I will never know but will be forever grateful for. You truly all have a vocation.' (Parent)

'We wanted to take a moment to express our heartfelt gratitude for the exceptional care and compassion you provided to our daughter (child) during her recent stay at the Helen House. She enjoyed all the activities and the homely environment there. Thank you for accommodating us and making us feel at home. Your kindness, dedication, and professionalism made a significant difference in her comfort. From the doctors and nurses to the support staff, everyone played a vital role in ensuring her well-being and we are grateful to each and every one of you. We felt fortunate to have such a supportive and caring team looking after (child) in her last few weeks of her life.' (Parent)



Emma had a brain tumour and came to the hospice on day visits. Since her death her family have recieved bereavement support and taken part in fundraising events in memory of their daughter

Feedback for bereavement group
Participants of the Forget-Me-Not bereavement group were invited to provide feedback after their sessions finished. A summary of the feedback mapped using the analytic codebook used to evaluate qualitative data regarding bereavement support to improve access, equity and quality in bereavement support:

100% said
- Felt less isolated or lonely/more connected to others
- Helped by the mutuality of support-giving and receiving help (support groups/online communities)
- Not enough sessions

75% said
- Valued positive relationships/rapport developed with the practitioner/other group members

50% said
- Helped by knowing that others understand, care and are there when needed
- Felt more heard/understood/accepted/seen in their grief
- The group helped by talking with others with similar experiences/shared understandings

25% said
- Felt more able to understand, accept and manage grief/feelings
- Were helped by learning about and understanding grieving process
- Helped by recognising that feelings are normal and they're not alone feeling this way
- Helped by talking about and sharing memories of their deceased child
- Felt generally better about themselves
- Helped by self-care or wellbeing activities/approaches encouraged/enabled by the support



Activity report

This year, we had the privilege of supporting 549 children, babies, young people, parents, and siblings through the wide range of clinical and supportive services we provide. While this represents an 8% reduction in the overall number supported compared with the previous year, demand for ongoing and complex support continues to grow.

By the end of 2025–26, our active caseload had increased to 239 children, babies and young people, representing a 14% rise compared with the previous year-end caseload of 209. This reflects the increasing need for sustained specialist hospice support for children and families with complex needs. We have noted a 35% increase in the number of neonatal and perinatal referrals since the arrival of the perinatal midwife role, adding a new complexity to the care provided.

During 2025–26, we actively supported 303 children and young people across our core services, including in-patient stays, outreach support, and Little Room provision, ensuring families received tailored care and support in the setting most appropriate to their needs. The fluctuation in our caseload numbers reflects children who have entered the service and left the service due to death, transitioning to adult services, moving out of the area or choosing to disengage.

Referrals

In 2025 - 2026, we received 116 referrals and 80% (93 individuals) were accepted into the service. The majority of declined referrals were due to the child not meeting our acceptance criteria. This equates to a 4% increase in accepted referrals from the previous year. This high acceptance percentage can be attributed to our medical team, outreach team and ACP Perinatal midwife engaging with external stakeholders to make earlier and more appropriate referrals. This is a continued focus for 2026/7 with the integration of location-specific specialist nursing and medical teams to allow for networking and relationship building.

Inpatient admissions

During 2025–26, we provided specialist care and treatment for 164 individual children and young people within our in-patient facility at Helen House, representing a significant 21% increase compared with the previous year (135 children and young people in 2024–25). This growth reflects both the increasing demand for our services and the trust families place in the care we provide.

Across the year, we supported 383 patient admissions to Helen House, encompassing a wide range of stays including: supportive stays, symptom management, first stays, network weekends (for our youth age group), end of life care and little room (post death care)We remain committed to ensuring families receive timely and responsive care, with cancellations occurring only in exceptional circumstances and relate to staff: patient safety ratios.

16 children/young people came for their first overnight stay, an increase of 33% from the previous year (12 children/young people).

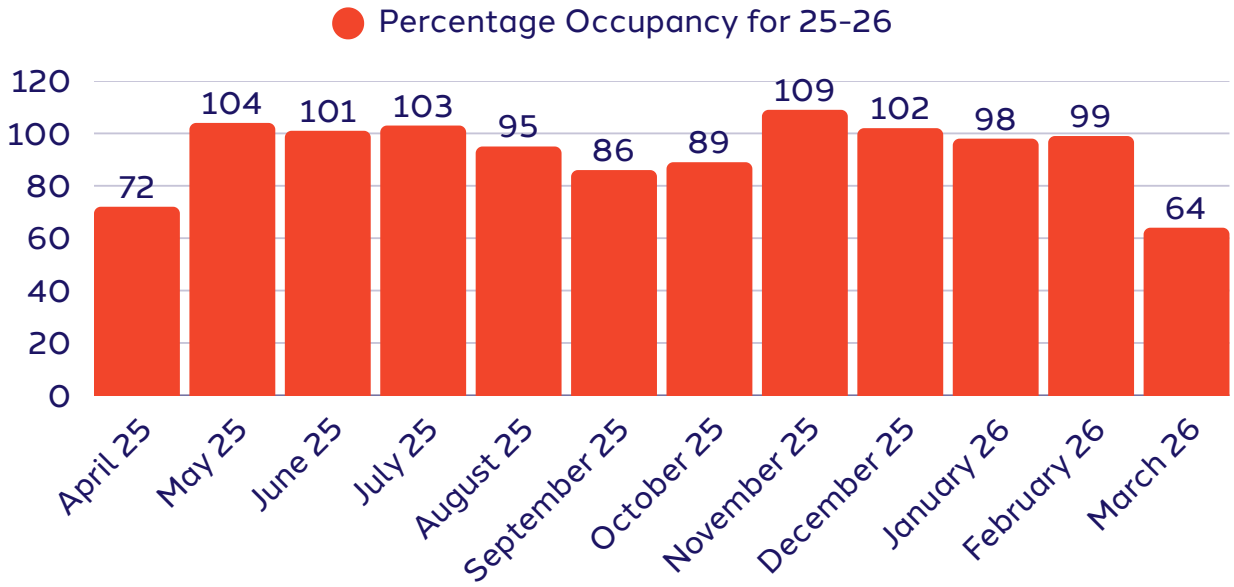
In response to urgent and changing clinical needs, we delivered 97 episodes of unplanned admissions, providing responsive care and treatment for symptom management, end-of-life care, and emergency support when families needed us most.

Service capacity

This year, we achieved an average occupancy rate of 93.5% for inpatient stays. A total of 1202 bed nights of care were delivered to provide care to children across all inpatient stay types: supportive, first stays, symptom management, end-of-life and post-death care in the cold suite (Little Room).

The occupancy rate is determined on bed nights being available for a maximum of 4 children using the inpatient facility, six nights per week. This model enabled us to deliver planned episodes of care while remaining responsive and flexible to the changing needs of children and families, including providing greater opportunities for continuous end-of-life care when required, for which we are seeing an increase in need.

The graph below shows the occupancy percentage per month over the year.



This year's average percentage occupancy has increased by 4.5% compared to last year, reflecting the growing demand for our in-patient services and our ability to maximise the use of available capacity. Our occupancy figures are calculated using planned admissions and symptom management stays only. End-of-life and Little Room figures are not included as these highly specialised and responsive services do not accurately reflect bed occupancy pressures, or the true intensity of care being delivered within the hospice. Instead, we only include planned admissions and symptom management to give a more accurate reflection of occupancy and pressures within the service.

While the graph demonstrates lower planned occupancy during April and March, this coincided with periods where the hospice provided increased levels of end-of-life care, often over significant lengths of time, alongside higher levels of staff sickness. During end-of-life care, fewer planned stays are intentionally scheduled to ensure the care team has the time and capacity to provide exceptional, compassionate, and family-centred support to the child and those closest to them. Throughout the year, we also experienced an increase in emergency referrals for acute symptom management and end-of-life care. Although this can impact the delivery of planned stays, it highlights our ability to remain responsive and flexible, ensuring children and families receive urgent specialist care when they need it most

Breakdown of bed nights:

The table below shows a comparison between the number of each bed night activity provided over the last two years. We have increased our reach and had 75% increase in first stay bed nights.

Activity	Year 24-25 (Number of bed nights provided)	Year 25-26 (Number of bed nights provided)	Comparison	
End-of-life	92	89	3.3% decrease	In 24-25 we supported 13% of the children who died with an end-of-life stay In 25-26 we supported 26% of the children who died with an end-of-life stay
First stay	28	49	75% increase	We have met our strategic aim of significantly increasing first stays and awareness of our service offer. Substantial planning and delivery has gone into helping families cross the 'hospice' threshold.
Supportive stay	876	810	7.5% decrease	This year there has been a shift in families preferring to engage in day activities more than overnight stays. Throughout the year we monitored this shift and remained response to families' needs and increased opportunities for day visits (parties, events)
Little Room - Cold Suite	51	55	7.8% increase	We increased the provision of cold storage this year to allow more than one child to receive after-death care at Helen House at the same time.
Symptom Management	221	198	10.4% decrease	Our medical and outreach team have provided significantly more symptom management in the community where the child is residing at the time, to minimise the need for transferring a child between different settings unnecessarily.
Total	**1268**	**1202**	**5.2% decrease**	

Throughout the year, we closely monitored a slight reduction in supportive stay bed nights through ongoing engagement with families, ensuring we remained responsive and adaptable to their evolving needs. Feedback highlighted an increasing preference for more flexible, day-access opportunities at the hospice, which many families found easier to manage alongside daily life and caring responsibilities.

In response, we expanded our programme of day-based activities and events, including parties, stay-and-play sessions, and other inclusive opportunities for families to access hospice support in ways that best suited them. This responsive approach resulted in a significant 76% increase in day case activity compared with the previous year, demonstrating our ability to adapt services to better meet the needs and preferences of the children and families we support. See table below:

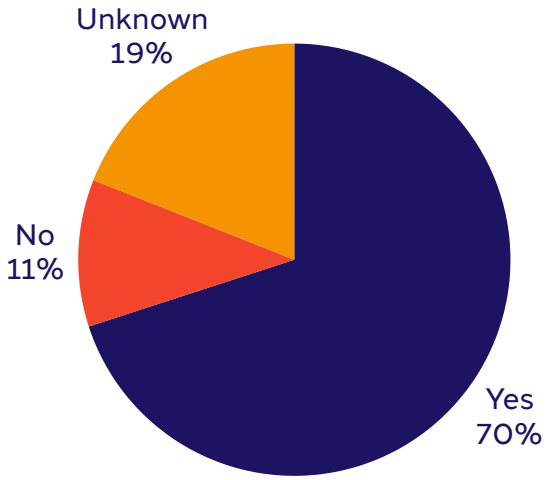
	Activity for 24 -25	Activity for 25 -26
Day cases	75	132

Supporting deaths

This year, we provided care and support for 54 children/young people during their end-of-life across our inpatient and outreach services. Last year, we supported 67 children. Advances in research, treatment options and advancements in medical technology mean that children and young people with complex conditions are now receiving more specialist care earlier and are living longer, fuller lives. This positive progress is reflected in our data, demonstrating a 19% reduction in the number of deaths since 2024-25.

We remain committed to ensuring that every young person and family is supported to make informed decisions about their care and preferred place of death. Through sensitive advance care planning and close partnership working with families and healthcare professionals, we continue to strengthen personalised end-of-life support. This year, 70% of patients were supported to die in their preferred place of care, demonstrating our ongoing focus on delivering compassionate, family-centred care that respects individual wishes and priorities. Please see the chart below:

Child died in preferred place of death



Our service always supports families to have as many choices as possible in their preferred place of death. There were 10 children/young people for whom we didn't have a documented preferred place of death for; this can be attributed to late engagement and unexpected deaths. Our commitment over the next year is to ensure we capture this for every child, where this is possible.

Over the last year, we have continued to progress our strategic aim of increasing access to our cold-suite facilities, enabling families to spend precious time with their child after death in a calm, supportive, and compassionate environment. While the overall number of deaths supported by the hospice reduced, the proportion of children using the cold-suite increased from 32% in 2024/25 to 39% in 2025/26, reflecting growing awareness and uptake of this important service. In addition, the total number of cold-suite nights of care increased by 7.8%, demonstrating the value families place on having additional time and support during the earliest stages of bereavement.

We have also broadened the scope of our bereavement support to respond to the needs of families experiencing sudden and unexpected child deaths, including those following fatal road traffic accidents. To ensure families receive the highest standard of compassionate care, we have invested in additional education and

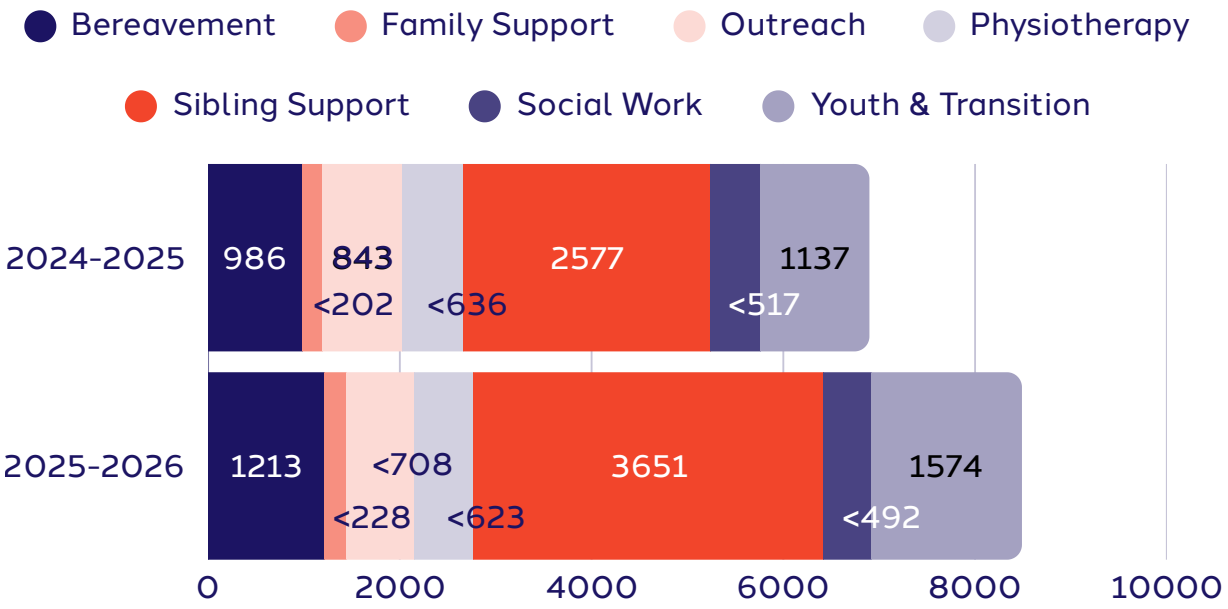
Continued.
development for our bereavement team, strengthening their skills and confidence in supporting families through traumatic and complex loss experiences.

Community and family support services

Helen & Douglas House community and support services team comprises outreach specialist nursing, social work, physiotherapy, youth and transition to adult services, siblings support family, and bereavement support. To remain responsive to the needs of children/young people and their families, we recently increased capacity in our specialist nursing outreach and support services to offer more choice in receiving care in their preferred place of choice, including their own home and other community settings. We have also increased capacity in the siblings, youth and transition team and recruited bereavement volunteers to support with the bereavement group facilitation.

The community and family support team delivered 8489 contact hours, an increase of 23% from the previous year. The increase in activity can be attributed to significant increases in the provision of siblings support, youth and transition and bereavement support. There was a slight reduction in outreach nursing hours during the year, primarily due to maternity leave within the team and challenges in recruiting fixed-term cover in a highly competitive workforce environment. Despite this, the nursing and care team, alongside the medical consultant team, remained committed to maintaining high-quality, responsive care for children and families, with services prioritised to ensure those with the greatest need continued to receive support. The period also provided an opportunity to review workforce planning and strengthen future recruitment and retention approaches to support the ongoing development and resilience of the outreach service.

The graph below shows the contact hours delivered per area of support



Therapies

A total of 1042 hours of structured physiotherapy were provided, benefiting 104 children/young people.

Complementary therapy was introduced this year. The therapist joined us part-time in October 2025 and spent two months setting up the new service; this included ensuring appropriate clinical governance processes and procedures were in place to deliver the service safely. Since December 2025, the therapist has delivered 49.5 hours of therapy (40 hours in-house, 7.5 hours to perinatal mothers (as a new and evolving part of the service delivery) and 2 hours outreach in the community). This benefited 30 children and 10 parents. Therapies offered include aromatherapy, massage, yoga and Reiki. Over the coming year, we plan to ensure one day per week is designated to outreach in the community to support parents and the specialist nursing teams to learn how to deliver safe massage techniques in the home environment.

Over 115 children/young people benefitted from music therapy. A music therapist visits Helen House once a week, and the sessions are open to inpatients (and children and families on a day case visit).



Habibou enjoying a music session

Part six: What others say about us

Care and Quality Commission

Helen & Douglas House is registered as a hospice by the Care Quality Commission (CQC) under the Health and Social Care Act (2008) to provide:

- Treatment of disease, disorder, or injury for children (0-18years). Specialisms include: diagnostic and screening procedures, learning disabilities, physical disabilities and sensory impairments.

Our current registration status is unconditional, and our current ratings from a comprehensive inspection carried out in November 2025 are:

- **Overall: OUTSTANDING**
- Safe: Outstanding
- Effective: Good
- Caring: Outstanding
- Responsive: Outstanding
- Well-led: Outstanding

Commissioner Quality Assurance visits

We have different contracts and reporting requirements with four commissioners. We provide our commissioners with quarterly quality reporting electronically and engage in regular contract review meetings. We have established strong collaborative working partnerships with our main Integrated Care Board: Buckinghamshire, Oxfordshire and Berkshire West (BOB), and now welcome them on-site for visits. We have not had any requests for quality assurance visits.



Jasper with our doctors

Complaints/compliments

Compliments:
We have received many compliments over the last year, including letters, cards and emails. Some examples are shared in the patient feedback section of this Quality Account.

Complaints:
We have changed our reporting process to also capture concerns from patients and their families. This is a more proactive approach to recording concerns, even when these do not progress through the formal complaints process. This shift allows us to capture a broader range of insights and learn more effectively from the experiences shared by families, carers, and visitors.

Five concerns were raised with us informally this year. Two expressed overall dissatisfaction with an admission, one regarding the management of diabetes care during their child's stay, one regarding the consent to use photographs on our website and one regarding the accuracy of information sent to an external professional. All of these concerns were thoroughly investigated, assurance was given to families concerned and supportive conversations were held with staff to explore the antecedents and concerns. All of these concerns were resolved satisfactorily and did not progress to formal complaints. Learning from these concerns has been used to inform learning and quality improvement of our services.

A dedicated email inbox has been set up to capture complaints/concerns and feedback to assist with oversight and reporting.

Compliments from medical students who elected to have a placement at Helen & Douglas House:
'I feel much more comfortable talking about uncertainty, rather than committing myself to one expected outcome. I've also heard and subsequently used, some beautiful questions to determine what really matters to patients and families around the time of decline and towards death.' (Medical student)

'I feel that I can offer better and more informed information to families regarding referrals to palliative care and feel more confident in making early referrals to palliative care in oncology patients.' (Medical student)

'HDH has given me an incredible opportunity to see some of the highest standards of holistic care I have ever seen as a medical student. The opportunities for supporting complex patients and their families provided at HDH are second to none, and it was incredible to see how much the broader, more holistic aspects of patient care were central to the ideology of the entire team at HDH. I will take this with me wherever I end up as a doctor in the future.' (Medical student)



Compliments from professional stakeholders:
'Helen House is an oasis of peace, and I am always keen to help families and babies transfer there from the neonatal unit for care before or after death. I know the love, nurture and care that they will receive at Helen House will be outstanding'. (Neonatologist)

'Our local team of community midwives covers the geographical area that Helen & Douglas House is in, so we have often provided postnatal care there. The perinatal palliative care offered to families and their precious babies is so important for supporting and facilitating the only time they have with their little babies. We have visited babies and their parents who have gone there for compassionate extubation, end-of-life care, or after-death care, and all have been treated with kindness and supportive care. We see families offered precious last moments in an environment that is beautiful, calm and peaceful. It facilitates a space for their relatives and friends to share loving care with the baby and allows parents to feel like parents. We are so grateful to have this incredible facility in our area and honoured to visit these families.' (Community midwife)

'I just wanted to reach out to you personally to say thank you for all the social work team have done for the children and their families. You are kind, listen, have empathy, compassion and never judge. You have always been excellent at joint working.' (CCN team)



Children's bedroom at Helen House

Part seven: Service improvements

Electronic rostering

This has been a significant area of improvement for Helen & Douglas House to enhance workforce efficiency, accuracy and fairness. It has optimised staffing levels to meet demand, reduced administrative burden and enhanced compliance with employment regulations and safety. Staff can now view their rotas 8 weeks in advance, which allows for better planning with planned stays and staffing larger in-house events.

Journal club

A monthly Journal Club was set up in January 2026 collectively by one of our medical consultants, physiotherapists and clinical research practitioner. The aim of the journal club is to broaden organisational interest in research, support evidence-based practice and translate key learning themes into quality improvement activity. The club is a welcoming space to learn, share and reflect on a presented topic aligned to research activity. The group have explored evidence on topics including challenges faced by caregivers of children with medical complexity, a multidisciplinary framework to promote a holistic approach to improving quality of life and a tool for identifying children who are more imminently at risk of dying to support timely end-of-life planning.

Community Hub

In October 2025, we successfully launched our first Community Hub in Buckinghamshire, marking an important step in expanding access to hospice support closer to where families live. The Hub brought together a wide range of multidisciplinary services, including outreach nursing, family and bereavement support, social work, youth and transition services, and the siblings team, creating a more accessible and joined-up approach for children, young people, and their families.

The Community Hub provided families with opportunities to connect with hospice professionals, access practical and emotional support, and build relationships with other families within their local community. By delivering services in a community setting, we were able to increase visibility of the support available, reduce barriers to access, and strengthen engagement with families who may find travelling to the hospice more challenging.



Hosting our first Community Hub at PACE

The positive response to the Buckinghamshire Hub has highlighted the value of integrated, community-based support and will help inform future developments in outreach and partnership working across the region.

Refurbishments

Over the past year, we have refreshed and enhanced several key spaces used by children and families, including family accommodation, dining areas, and play spaces. Improvements such as new flooring, redecoration, and essential repairs have helped create a warmer, calmer, and more welcoming environment that supports comfort, dignity, and wellbeing for the families we care for.

Alongside these enhancements, we have completed a number of important facilities improvements, including replacing taps and repairing fire doors, helping to maintain a safe, compliant, and well-maintained environment for children, families, volunteers, and staff. These ongoing investments reflect our commitment to providing high-quality surroundings that positively support the experience of everyone accessing hospice services.

Staff wellbeing room and staff room

We have repurposed unused space in Douglas House into a tranquil and comfortable space for staff to take time out for reflection, wellbeing and practising their faith/ spirituality in private. We have also repurposed office space in Helen House for a bright, inviting and well-equipped staff room. Feedback from staff below shows appreciation for this space:
'It is such a calm and positive space which really allows us to step away to recharge, and it is very clear how much thought and commitment has gone into it and in looking after us as a team, so I really wanted to express my gratitude and appreciation. This space was so needed and it's making a huge difference, so thank you again.'

Increasing opportunities for day play and off-site visits

In response to children and families' needs and requests, we have increased the opportunities for more 'stay and play days 'and increased capacity for more families to attend parties and events. This included a summer event called the 'Helenbury' festival, and Christmas and Easter parties. In addition to this, we have increased the number of outings into the community, such as a silent disco at Millets Farm amongst the dahlia fields, a trip to the local ice rink, and an amazing trip on a Jumbulance to the London Eye and London Aquarium.

One child who is non-verbal but uses Makaton to communicate, when asked if she'd had a good time, she put her thumbs up and replied with a massive beaming smile. There is another who is also non-verbal, but wears yes and no wristbands to communicate, and we held his hands to ask if he'd had fun, and he very strongly indicated yes!

'Thank you for making special moments for all the children, what a fabulous adventure'. 'This will really lift his spirits; he's been in hospital for 5 days so it will really cheer him up, thank you for asking us'. (Parent)



A trip to the London Eye was a real highlight for the children who attended

Simulation Practitioner

We introduced a secondment opportunity for a senior nurse as a Clinical simulation practitioner to enhance our learning and development offer. The role has been effective in providing a safe, controlled and realistic environment for the care team to practice high risk tasks, learning from incidents without real-life consequences and gain immediate feedback. The simulation practitioner has been designing, delivering and facilitating immersive scenario-based learning, which has been successful in building confidence, expertise and effective sign off of clinical competencies.

Enhanced Care Practitioner (ECP)

This year we introduced this role to encourage nurse-led admissions and discharges for supportive stays. This allows the medical team to spend more time clinically with children and their families for more specialist complex children's symptoms. The ECP has developed a stepped hospital discharge framework, strengthened 'deteriorating child' policies and processes, and streamlined transitions between the hospice and hospital. Having this role allows families greater flexibility with admission days and times and has contributed to smoother and earlier discharges from Hospital and supported families through changes in care, taking time to explain medication updates and provide reassurance. The ECP has also visited complex children and families in advance of their stays, supporting detailed care planning before arrival, which has greatly aided smooth transitions into the hospice.

Perinatal- Advanced Care Practitioner (ACP)

Over the past year, our Advanced Clinical Practitioner (ACP) Midwife has played a key role in developing and strengthening our perinatal and neonatal support services. She has successfully developed a dedicated framework and perinatal pathway for families referred to Helen & Douglas House, helping to ensure families receive compassionate, coordinated, and consistent support from the earliest stages of care.

Working closely with both hospital and community teams, our ACP Midwife provides seamless support to antenatal and neonatal mothers, babies, and their wider families. This includes supporting families within local Neonatal Intensive Care Units (NICU), including during sensitive and complex situations such as extubation, and facilitating transfer to Helen House for ongoing specialist palliative and end-of-life care when appropriate.

Alongside direct clinical support, our ACP Midwife has delivered education and training to hospice care staff, enhancing their confidence, skills, and competence in caring for babies and families with highly complex needs. This investment in workforce development is helping to build a sustainable and responsive service for families requiring perinatal and neonatal palliative care.

We recognise the growing need for specialist perinatal support and are committed to continuing to develop this area of our service, strengthening partnerships and ensuring families receive high-quality, family-centred care at every stage of their journey.

Holistic Therapist

Holistic therapy increases the potential for better outcomes for children and their families. We introduced this role to complement and enhance the experience of children, young adults and their families under our care. Holistic therapy can be a powerful tool when supplemented with conventional medicine to support with wellbeing and other symptom burden. Our holistic therapist has developed a framework, risk assessments, policies and guidance around the safe use of holistic therapies.

Clinical Research Practitioner

We introduced a Clinical Research Practitioner (CRP) position in September 2025 to strengthen the research culture, capacity and capability within the organisation. This supports our strategic objective to be research-ready, promoting and building on evidence-based practice. The CRP has established tighter research governance structures, increased collaboration with other research forums, established a research repository and developed a research programme for the next 12 months.

Band 6 development programme

We previously used external leadership training, which is generic across all healthcare settings. After feedback from staff, we have developed and delivered a new leadership programme in-house to deliver a programme that provides healthcare leadership skills, with the addition of specific skills for leaders in paediatric palliative care. The programme includes four parallel streams: timetabled teaching, clinical supervision, coaching and research symposium. All staff on the programme reported they had the opportunity to progress in leadership and staffing decisions. Some reported they had the opportunity to progress in IT skills, assertiveness, safeguarding, dealing with incidents and management.

Bereavement volunteers

We have expanded our volunteering team to include bereavement volunteers, whom we have provided training to enhance the family support and bereavement team. The introduction of these roles means families are able to access appropriate support, provided by staff trained to provide that level of support. This has allowed counsellors to support families requiring a higher level of more acute support.

Bereavement support to non-clinical colleagues

Our Family and Bereavement Lead identified the need for our fundraising and marketing colleagues to have bereavement support, as they often spend a lot of time with bereaved families telling their stories. In response to this, she delivered

Continued.
training around bereavement and theories of grief to these teams, who are now being supported in a structured way. We are exploring the training of and use of supervision across the organisation to offer more support to our support services teams in their involvement with families.

Support for families who experience sudden death

This year we have built strong working relationships with SUDCUK (Sudden Unexplained Death in Childhood United Kingdom), a charity providing support for families who have experienced a Sudden Unexplained Death in Childhood. Around 40 children are affected every year in the UK, comparable to 1-2 seemingly healthy children dying every fortnight, often going to sleep and never waking up. This networking has facilitated families to receive seamless, appropriate support and ultimately better wellbeing outcomes for families facing sudden death.

Family Engagement group

This year, we embedded our Family Engagement Group. This forum allows us to hear the voice of families to improve the quality and safety of care, whilst creating a partnership between patients, family members and Helen & Douglas House. Parents have been involved in the review of child young/person's care plan documentation, family information leaflets, family introductory film and providing ideas for the family accommodation renovation project.



One of the sibling enjoying creative play at our family Christmas Party

Part eight: Responses to the Quality Accounts

(from commissioners)

Helen & Douglas House
your local children's hospice

Donate - Fundraise - Volunteer - Shop

hdh.org.uk

fundraising@helenanddouglas.org.uk

01865 799150

Registered with FUNDRAISING REGULATOR

Company number 4120488
Registered charity number 1085951
Care Quality Commission Location ID: 1-1731744597

Inspected and rated Outstanding
Care Quality Commission

Helen & Douglas House
14A Magdalen Road, Oxford OX4 1RW
Quality Account 2025-26