Helen & Douglas House

your local children's hospice

Quality Account

2024-25

Our vision

Every life a full life, every death a dignified death

Contents

Vision, Mission and Values

Vision

Every life a full life, every death a dignified death

Mission

- To enable young people (0-18 years) with life-shortening conditions, to live as well and as fully as possible to the end of their lives, and to support their needs and wishes at the time of their death.
- To provide palliative care at a specialist level for young people through medical and nursing expertise, emotional and practical support.
- To support the families and carers of young people through their shortened life, through their death, and into bereavement.
- To be a regional centre of excellence in palliative care, based in Oxford, working closely with professionals in hospitals and in the community, to plan and provide local support tailored to individual needs.

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, which includes Oxfordshire and the surrounding counties.

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 through their shortened life, 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
- End of Life Suite

We also extend our support to families and carers throughout the child's life, 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 including specialist palliative care, a wide skill mix of doctors, nurses (including children's nurses, learning disabilities nurses and 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.

Paediatric Palliative care outreach (medical and nursing) is provided within Oxfordshire and surrounding counties, working in partnership with other community services and other local hospice services. We are proud to have strong partnerships with professionals regionally, and nationally to ensure that we provide the best quality, and 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, collaborative working, and funding of services to this population.

Felix and Elliot enjoying the Helen House garden

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

A sincere welcome to this year's Quality Accounts. Since January of this year I have had the privilege of leading Helen & Douglas House as Interim Chief Executive Officer. This year has been full of dedication, resilience and commitment from our staff and volunteers. It is my pleasure to share this overview of the quality, safety and patient experience we have delivered over the last 12 months. Through 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, through every aspect of our service delivery. We are proud of meeting our aim of reaching more children, and this year we have continually held over 200 children/ young people on our caseload which is more than we have ever had at any one time. We continue to contribute to education, research and publications nationally and internationally. We have supported many visitors from international Children's hospices, including a nurse from Ghana who observed practice for a week. Our Medical Director also spent time in Ghana teaching and training consultants in paediatric palliative care. We continue to support medical and nursing student placements from Oxford University and Oxford Brookes University.

Helen & Douglas House has an Investors in Diversity 'Silver' accreditation awarded by the National Centre for Diversity accreditation. 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 been recognised as an inclusive organisation.

The number of families referred to Helen & Douglas House services has remained constant for the last two years, and we accepted 76% of these referrals. We have worked exceptionally hard to expand various aspects of the service including youth and transition to adulthood and sibling support. Increasing sibling support has allowed more families to have the ability to spend quality time with their child with a life limiting or life shortening illness whilst 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 from age 13 years to be better prepared for adulthood and understand the services that are available to them after their 18th birthday.

Anthony in a baking session

We ensured we provided a service that was responsive to the continuously increasing complexity of needs presented by children, whilst also providing routine support and opportunities for fun and play. Accomplishments I would personally like to share are an increase in accepted referrals from the previous year, the community and family support team delivered a 32% increase in support hours, we reached an 89% average occupancy in our inpatient facility throughout the year, a 16% increase in the use of our Little Room (care after death) and supported 75% of patients to die in their preferred place of death.

Feedback from families continues to be overwhelmingly positive; from families whose child is currently using our service and from families who were supported by us for their child's end-of-life and bereavement care. It is a true reflection and appreciation of our competent, skilled and sincere staff and volunteers. We are extremely proud of the feedback from families; every respondent rated their overall experience of our service as either 'very good' or 'good'.

We are very excited for the year ahead as we enter a new five-year strategy. We aspire to deliver world class palliative care, to extend and develop our clinical services to meet the needs of every eligible child and family from point of diagnosis through to bereavement care and support.The recent closure of a local specialist paediatric hospice service will bring some challenge, but also great opportunity for the expansion of our service delivery. We look forward to strengthening our strategic focus on enhancing care quality, expanding our learning, research and education, and collaboration with external stakeholders.

We commend this account to you and extend a heartfelt thank you to our colleagues, supporters, commissioners, volunteers and many others who have supported us this year. We are proud of all we have achieved as a CQC 'outstanding' rated organisation and are pleased to have been of service to people who have sought our help in this time.

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 both informative and useful and please do not hesitate to contact us with any questions or comments that you may have.

Mark Stowe
Interim Chief Executive Officer
Date: June 2025

Mark with Dr Emily, meeting MP Annelise Dodds

Part two: What we have achieved

Patient safety and outcomes

Prioritising the clinical competency and psychological safety of our clinical staff to deliver safe patient care with improved outcomes.

Through the Patient Safety Incident Framework (PSIRF) we will be developing and maintaining effective systems and processes for responding to patient safety incidents for the purpose of learning and improving patient safety.

In the coming year we will be extending our offer of physiotherapy to reach more children. We will start to expand the physiotherapy team to support more children in reducing common symptoms such as pain, fatigue and dyspnoea, and improving functional capacity to retain independence and dignity.

Update

This year we focussed on increasing staff competencies relating to all areas of their clinical practice. Regular training days have been delivered which address both ‘role-specific’ training and individual topic training. Staff have also been supported to attend additional training in areas of particular interest that will improve the quality of care we provide. This includes training in compassionate leadership, Makaton, Resilience-Based Clinical Supervision, Enhancing sleep for children, and nurse verification of death.

We developed a Patient Safety Incident Framework (PSIRF) policy and plan.

We also introduced a Shared Decision-Making Council for staff to meet and explore ways they can enact change within Helen & Douglas House.

Clinical effectiveness and accessibility

Ensuring we maximise the potential for children and families to access our services.

This coming year we are ensuring there is suitable accommodation for family members who have impaired mobility. This gives more families to access stays, as accommodation will no longer be restricted to upstairs bedrooms for family members. This will be an adaptable space which can also be used as a further end of life suite to increase capacity to care for three children/ young peopleafter their death should that be required.

We are also reviewing the capacity we have to provide more support in the community. Families’ needs and preferences are evolving and they need more support in the comfort of their homes. We are looking to enhance the experience families receive in their homes, with the play team supporting outreach nursing visits.

We are also reviewing our referrals pathway to enable the process to become more effective, ensure referrals are appropriate and enable eligible children/ families to access our services sooner.

Update

The accessible family space has been completed and utilised by many families. This space is fully accessible and allows parents to sleep in a bedroom next to their child's. It is fitted with a fully accessible bathroom and kitchenette to allow families privacy. We have also refurbished our little room designed to provide privacy, dignity and comfort for the deceased child and their family. We have diversified our body cooling systems to provide better choice for families with the after-death care for their child - this includes specially designed cold mats which can be taken out into the community to a family's home.

Significant work has been completed around streamlining our referrals process to make the point of entry to our services very simple. This new process is designed to be more efficient for families, professionals referring into us and for us as a service accepting/declining referrals. The change in process is likely to have the most positive impact on the time a family has to wait to receive a decision regarding acceptance into our services.

We have significantly increased our service offer to provide more support to children transitioning from child to adult services and to siblings of all the children and young people we care for. Both of these areas of service delivery were previously limited. Our siblings team organised more activities in the community for siblings, including our first off-site siblings residential camp. Young people have received more support to navigate various aspects of their transition from childhood to adulthood and have had more access to networking events.

Iris in an arts & crafts session with Chloe from the play team

Patient experience

To engage with more families to ensure they are key partners in their child's care and co-designers of our services.

Engaging families and connecting with them allows us to truly understand the needs of the children, young people and families using our service. Our priority for this coming year is to build the foundations for enriching the patient experience.

We recognise medical advancements have resulted in children with more complex care needs and who are surviving longer. These children often require care from multiple health and social care teams and other agencies, all holding individual information to enable care delivery. This puts enormous pressure on parents. We are also going to pilot a parent/carer owned personalised care pathway monitoring platform for children and young people with complex care needs. This digital application empowers parents/carers to easily capture and manage child's health and care information: symptoms, care plans, multidisciplinary team (MDT) involvement enabling personalised optimum symptom management at home and shared decision-making in the child's best interest. Through this, we aim to improve quality-of-life outcomes and improved care experiences for children and carers. This year we are going to establish a patient engagement group, where we will work collaboratively with parents to respond to their changing needs from the service. We will proactively seek feedback on projects and give families a voice, that is heard.

Update

This year we established Patient Engagement Events. Parents are invited to provide their valuable feedback on our services. These events are open to parents whose child is using the service and bereaved parents. 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. Participants in this group will also be invited to engage with our recruitment, training resources, co-production, co-design, service development and documentation review.

We have also reviewed how concerns can be dealt with in a more timely way to avoid unnecessary distress to families. Concerns when raised are dealt with as soon as possible by a senior member of staff to ensure an early and satisfactory resolution for the family and to ensure they continue to feel safe and supported in using our services.

Regrettably the pilot project for a digital shared care platform did not materialise due to technical difficulties. However, significant work has been done in creating a managed clinical network which allows better integration between services supporting professionals to provide better person-centred care whilst considering patients' increasing complexity of needs. These children often require care from multiple health and social care teams and other agencies, all holding individual information to enable care delivery.

Part Three: Priorities for improvement 2025/26

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.

Luke enjoying some dress up play time with Sian

Patient safety and outcomes

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

At Helen & Douglas House, this year we will concentrate on the development of nurse-led perinatal care aims 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 our number of volunteers offering support in Helen House and in the local community/family homes.

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. As our first dedicated Clinical Research Practitioner, this will help shape the future of paediatric palliative care by embedding research within our Nursing, Midwifery, and Allied Health Professional (NMAHP) workforce alongside 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.

Part four: Overview of services

Financial considerations

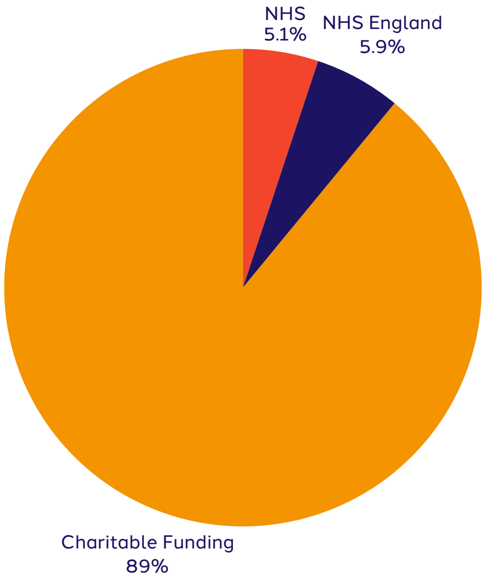
Helen & Douglas House does not charge any child, young person or family for the provision of any care or support service.

Our services are funded through a combination of fundraised income, voluntary donation, retail, lottery, and negotiated contributions from public sector/ statutory bodies. For the year 2024 - 25, public sector contributions to care represented less than 11% of the hospice's total expenditure on care services (patient care, family and bereavement support).

Funding sources for hospice care 2024-25

Exact %'s

- NHS 5.10%
- NHS England 5.86%
- Charitable Funding 89.04%



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 measure our performance against the National Data Guardian's 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 acting as a contact point for data subjects and the Information Commissioner's Office (ICO). The DPO completed a baseline audit of all aspects of data governance across the organisation to ensure compliance. We have worked through the action plan over the last twelve months.

Clinical coding error rate

Helen & Douglas House was not subject to the Audit Commission Payment by Results clinical coding audit during 2024/25.

Participation in national clinical audit

In 2024-25 there were no audits or enquiries relating specifically to children's palliative care.

Local clinical audits

This year, we concentrated on giving depth to our programme of internal clinical audits to measure, monitor and improve our quality and performance. In addition to scheduled audits, 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 action plan, and ensure improved compliance, ensuring the clinical teams' engagement in quality improvement. A prime focus this year has been to ensure high-quality electronic records were in place for all the children, young people, and families who access our services. Various responsive audits were completed to highlight areas of education to be covered on clinical training days.

Infection, Prevention and Control

Infection prevention and control (IPC) has remained a high priority and been fundamental to safe service provision throughout 2024/25. This year we implemented the use of the English Manual of IPC. We have a designated IPC Lead Nurse who is responsible for the continual auditing, review, and updating of the infection prevention and control policies and procedures, and for alerting the Senior Leadership Team of any areas requiring specific attention. A complete baseline audit was completed in November 2024 against the English Manual of IPC. Personal Protective Equipment (PPE), cleaning of near patient equipment and hand hygiene audits were completed regularly throughout the year. Training compliance for IPC was maintained above 80% throughout the year.

Pippa with the care team

MHRA and patient safety alerts

All alerts are reviewed by our medical team and senior nurses to ascertain the relevance for our service and shared accordingly.

Research

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

- Supporting the BEACON study, which interviews staff, patients, and their families about breakthrough pain, with a view to creating a tool to improve reporting and treating of pain.
- Our Medical Director presented on a webinar supporting the introduction of the Children's Palliative Outcomes Score, in collaboration with the Cicely Saunders Institute.
- Our Medical Director chaired a meeting of the APPM / Together for Short Lives joint research group, with presentations from the National Child Mortality Database, and Hospice UK – addressing palliative care in remote communities.
- One of our consultants who supports young people in transitioning to adult services presented a poster to the Adult Palliative Care Congress in Belfast, on shared transition work underway locally.
- The 2024 Association of Paediatric Palliative Medicine (APPM) research conference was convened by our Medical Director, with contributions from two other consultants, one of our medical students, and a bereaved parent.
- Our family support and bereavement team took part in a Grief Map research pilot. The findings have been analysed, identifying a range of vulnerabilities It is now being used as a tool to triage clients in bereavement.

·We invited families to take part in the Spark Study (on the impact of spirituality in paediatric palliative care) and the ENHANCE Study (NIHR funded), examining the experiences of families whose children died after care on NICU or PICU.

Publications

Our staff contributed to the following publications:

- **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. doi: 10.3310/VRFT5679. Online ahead of print. Harding R, Ziegler L, Hewitt C, Wong I, Elverson J, Harris N, Fraser LK.
- **Facilitating home birth in perinatal palliative care: a case report** Bertaud S, Kirven R, Kirven T, Harrop E, Crudgington A, and Wilkinson D. Palliative Med 2024 (online ahead of print)

- **Handbook of Palliative Care, 4th Edition (review).** Richard Kitchen (Editor), Christina Faull (Editor), Sarah Russell (Editor), Jo Wilson (Editor).

- One of our doctors and a bereaved parent contributed to an article on hospice care in the UK for the European Association for Palliative Care (EAPC).

- Our Family and Bereavement Support Lead had an article published in the Nursing Times on ‘Care at and after death’. Although this is adult, so much is reflective of the same importance of good practice in care and support after a child’s death.

Posters presented at conferences/events

- Opioid education through blended learning: A new approach to symptom management education. Dr Charlotte Holland; Dr Laura Nohavicka (APPM conference, November 2024).

- Use of buccal levomepromazine for symptom management within specialist paediatric palliative care. Dr Hannah Dobson, Dr Caroline Sprinz, Dr Naomi Taylor, Dr Laura Nohavicka (in collaboration with Martins House Children’s Hospice).

- The use of continuous subcutaneous infusions of clonidine for the management of dystonia at the end of life. L Nohavicka, C Holland, L Middleton, C Sprinz, H Parks, B Koodiyedath, E Harrop.

- The complexity of Neve’s experience of pain. Signs, symptoms and solutions. Bereaved parent.

- Facilitating regional education in Paediatric Palliative Care: a digital success. Dr Charlotte Holland, Ms Alison Pearce, Ms Sue Lakie.

- Managing extraordinary risk when there is no ‘good’ option – ALARP. Dr Emily Harrop and Dr Helen Turnham (Oxford University Hospitals).

- Professional Consensus Grids – ‘Getting the first opinion right’. Dr Laura Nohavicka, Dr Charlotte Holland and Dr Emily Harrop. In collaboration with Oxford University Hospitals.

- Navigating palliative care research during a pandemic: a practitioner enquiry approach. Dr Charlotte Holland.
- How to help young people transition from paediatric to adult palliative care services in Oxfordshire: Our experiences and lessons learned. Jac Jones, Matthew Carey, Laura Nohavicka and Victoria Bradley.

Education

Contributing towards education both within Helen & Douglas and externally remains a high priority and an aspect of our service we are immensely proud of. Below are examples of these contributions:

We have supported two doctors in the completion of their sub-specialist training, one of whom remains a Senior Associate Specialist in our team.

One of our consultants has been elected to the European Association of Palliative Care (EAPC) children and young people's task force and has produced an article about UK hospice care.

One of our doctors has joined a BOB ICB medicines optimisation group supporting access to palliative medicines in the community, as this has been identified as an area of concern locally and nationally.

One of our doctors and a bereaved parent supported The National Child Mortality Database in conducting a thematic review on the quality of the deaths of children with life-limiting illness.

Our Sibling Team Leader and a current sibling have taken part in filming for schools and education for the Paediatric Palliative Care South East education group around the impact of having a terminally ill sibling on their education and how best education professionals can support them.

An outreach nurse was invited to be a member of the faculty to provide training for the Multi-disciplinary Approach to Paediatric End of Life Education (MAPLE).
One of the consultants ran a teaching series on different aspects of paediatric palliative care, including pertinent topics such as 'ethics of addressing spirituality in paediatric palliative care'. This was followed by a 'Spotlight Series' focusing on the interface between paediatric palliative care and other specialities. These sessions were attended by many professionals across the South of England.

Two staff members were invited to present at the National Perinatal Palliative Care Conference in London.

Our consultants and Head of Professional Development continue to teach undergraduate medical students at Oxford University and invite nursing students from Oxford Brookes University to join the sessions.

Two staff members delivered a session on staff wellbeing in palliative care via the International Children's Palliative Care Network (ICPCN) to a group of learners from Ghana.

One of our consultants travelled to Ghana to deliver a one-week training programme face to face, and another consultant has been a remote mentor to a group of Ghanaian clinicians. This trip was funded by Improving Palliative Care for the World's children (ICPCN) who received an overseas aid grant from the British Government for the whole Ghana project.

We have welcomed clinical observers from Ghana, Romania, and Japan.
Two consultants have been working closely on a project with the University of York to develop educational resources for hospice staff focused on spirituality in paediatric palliative care.

Our consultants worked with the Sobell Education Centre to create a series of educational podcasts for South Central Ambulance Service, supporting them in responding to patients with palliative care needs who may need support at home. One of our consultants has launched an education platform #PPCEducate, which serves the whole South of England.

Our Professional Development Team collaborated with Oxford Brookes University to run new end-of-life simulation training to undergraduate children's nursing students.

We ran several professional open mornings for healthcare professionals to attend the hospice and raise awareness of the services we provide. This also enables attendees to share information with other healthcare professionals and children/ families who use their service.

We have supported an outreach nurse to complete the Advanced History Taking course and another nurse to complete the 'Enhancing Practice in Palliative Care for children, young people and families' post-qualifying course. One nurse is currently undergoing training for non-medical prescribing and two staff are studying to complete a Postgraduate Certificate in Practice Education.

Part five: Review of quality performance

Incident reporting

This section gives an overview of the incidents reported in Helen & Douglas House in 2024/25.

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 system and an alert is immediately sent through to clinical leads and the senior clinical team. The most appropriate person investigates the incident, and it is discussed by the senior clinical team for review at a weekly patient safety huddle, and lessons learnt are disseminated to staff. Families and children involved are given the opportunity 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 full thematic review and, in line with the Patient Safety Incidents Framework (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 data shows a healthy reporting culture at Helen & Douglas House. We have separated medication related errors from clinical incidents as they are our highest reported sub-category. This year, 77 clinical incidents were reported, and 44 medication related errors were reported. None of these relates to a serious incident. 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 levels of skill and competence of clinical staff. The next steps in our 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

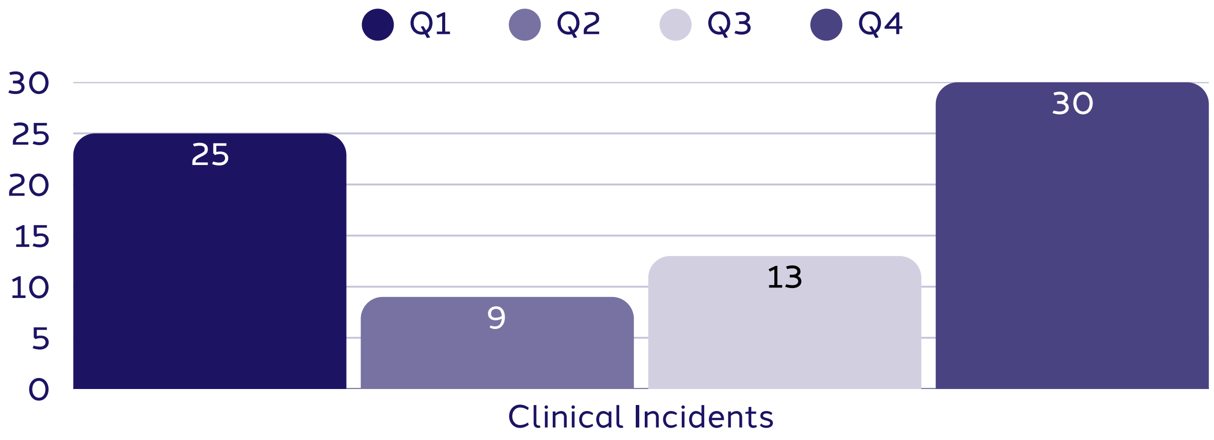


Chart showing the number of drug-related incidents per quarter

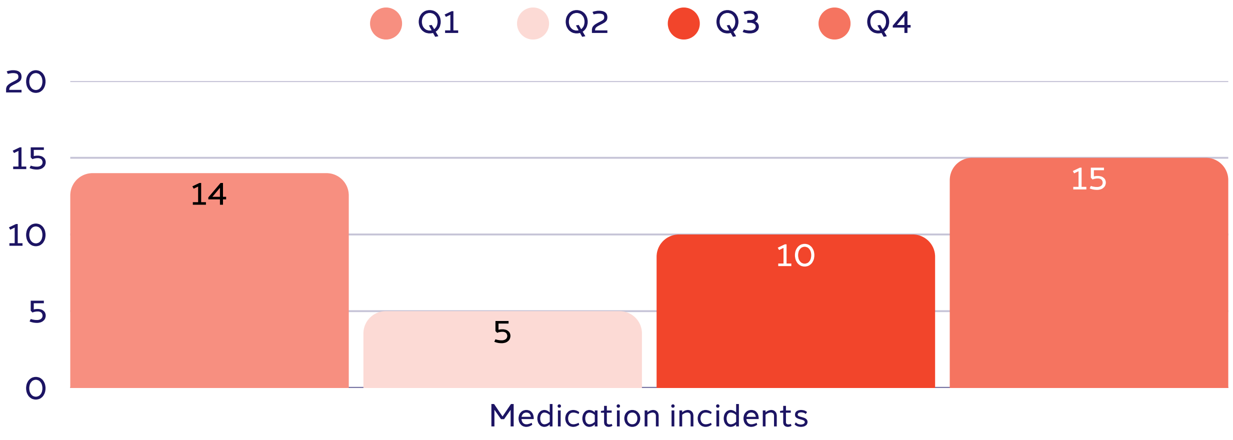
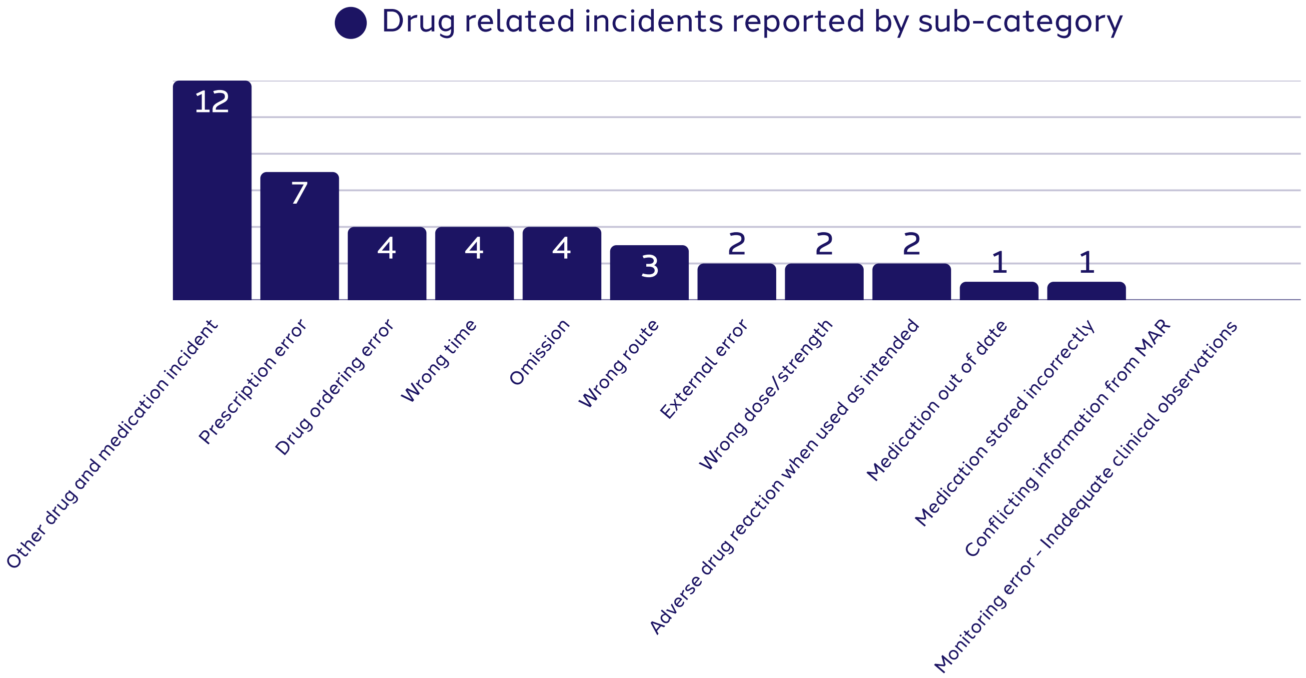


Chart showing the number of drug-related incidents reported by sub-category

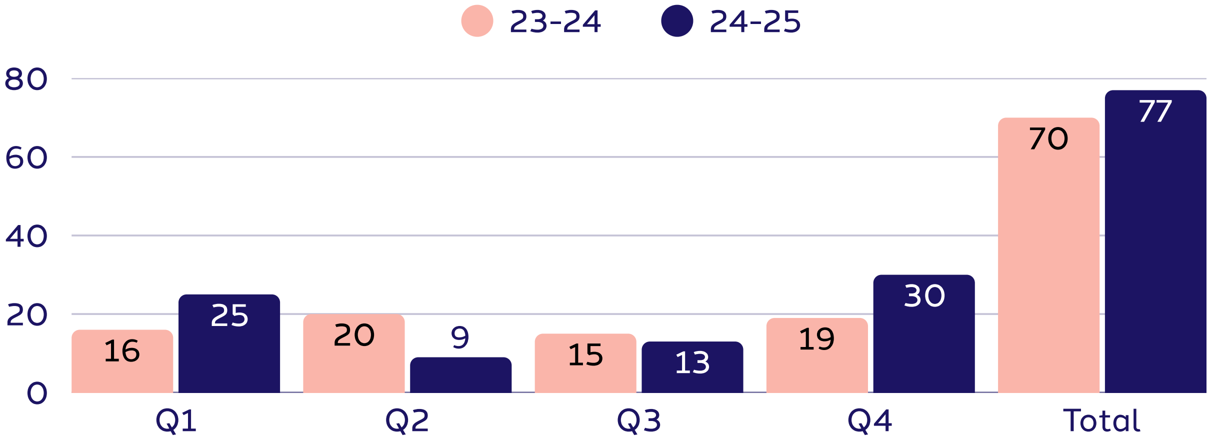


The table below shows the number of incidents in the top five reported sub-categories:

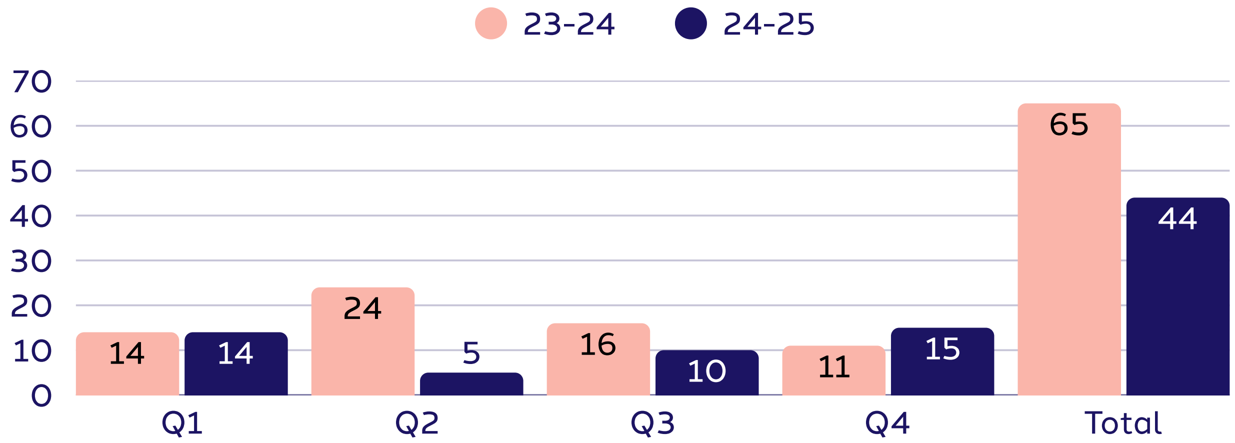
Incident category 2024-25	Number
Other Drug and Medication Incident	12
Prescription error	7
Wrong time	4
Medication stored incorrectly	4
External error	4

Other medication incidents, prescription errors, and wrong time administration have been in the top five subcategories consecutively for the last two years. This is an area of focus for the coming year and has an action plan.

Comparison of number of reported clinical incidents over the last 24 months



Comparison of number of drug-related incidents over the last 24 months



This year, we saw a 32% decrease in the number of reported medication incidents, with particularly lower-than-usual incidents in Q2. We did targeted teaching during Q3 around a healthy reporting culture, including reporting of near-misses and reminding of the importance of learning from incidents, preventing reoccurrence. We continue to have several additional safety measures in place, including double checking of medication, wearing of red aprons when drawing up medication, an extra member of staff on admission days to relieve the timing pressures.

Helen & Douglas House has continued to embed its learning from the incidents reported to engage teams in developing and supporting improvements in paediatric palliative care. This has minimised the risk of reoccurrence of adverse events and encouraged a culture of continuous improvement. Clinical training days had bespoke agendas based on the identified training needs of the staff, which included 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 83% or above throughout the year. Patient-facing staff also complete a safeguarding passport to document any furthermore in-depth or topic-specific learning. We increased the number of staff trained in Level 4 Safeguarding Children from one to two, 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 introduced 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.

This year, we have strengthened our relationship with the Head of Safeguarding for children at Buckinghamshire, Oxfordshire, and Berkshire West Integrated Care Board (BOB ICB). This has been pivotal in developing our safeguarding framework and completing a self-assessment tool, with which we are now 100% compliant.

We have worked closely with our colleagues in our retail directorate to provide timely and appropriate support for any safeguarding concerns that are raised in our shops. The retail team will remain an area of focus to receive more training, so they become more confident at identifying safeguarding concerns and who to raise them with within the organisation. An organisation safeguarding flowchart has been made available to all staff across the organisation to follow if they have any concerns.


Beth in a music session

Equality, Diversity and Inclusion Strategy

Building on our commitment to fostering an inclusive culture, we have continued to champion equality, diversity, and inclusion across every aspect of our organisation. Over the past year, we have reflected on the feedback from our staff and family surveys, as well as the guidance provided by the National Centre for Diversity, using these insights to develop a new Equality, Diversity, and Inclusion (EDI) strategy. This strategy, to be launched in the new financial year, places a strong focus on inclusive recruitment, neurodiversity, wellbeing and resilience, ensuring that our workplace remains a supportive and equitable environment for all.

We take great pride in our accreditation by the National Centre for Diversity and our prestigious Investors in Diversity, Silver status, and we remain committed to upholding this achievement by fostering a culture of continuous improvement. We continue to celebrate diversity and recognise awareness days, hosting guest speakers and awareness panels in subjects such as Menopause, Fertility & Baby loss, Understanding Change, Stress Awareness, Youth Mental Health, and ADHD at work. Partnering with respected organisations such as Fertility Matters UK, Oxfordshire Mind, This Can Happen, Oxford Menopause, and Perfectly Autistic, we have responded to our employees' requests by creating sessions that address the topics most important to them.

The EDI Pulse Survey, launched in summer 2024 revealed encouraging feedback from staff:

- Staff feel valued, respected, and appreciated.
- There is a growing sense of psychological safety in raising concerns.
- Employees appreciate the continuous opportunities to engage with relevant and meaningful sessions.
- The inclusion of discussions beyond the workplace, such as parenting, menopause, and children's mental health, is highly valued.

Our recruitment films have proven to be an excellent showcase of our inclusive culture, reinforcing our commitment to diversity in hiring.

Survey results indicate significant progress, with 92% of respondents feeling accepted by colleagues and line managers, 96% reporting fair treatment at work, and 85% agreeing that career opportunities are offered equitably regardless of background, identity, or status.

As we move forward in our EDI journey, we remain committed to our goal of a truly inclusive culture—one where every individual feels valued, empowered, and celebrated.

Duty of Candour

Helen & Douglas House follows the Duty of Candour process to meet statutory requirements to be open and transparent with children and families if we make mistakes 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 details around the investigation would benefit the family, and we actively engaged the family in learning from the incident. 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.

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 is to be available for staff and volunteers to speak to, in a safe environment, about any concerns, as well as listening to those who have experiences to share, both positive and negative, where lessons can be learnt. 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 Southeast 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.

Patient experience

Our vision is to remain especially committed to providing an exceptional standard of care and enriching the lives of all we care for, children and their families. Over the last 12 months, we have been working hard to address any inequities, particularly focusing on reaching as many children/ young people on our caseload as possible. We have seen more families wanting to receive support in their own home, as inpatient stays are not always manageable. We always endeavour to be responsive to the needs of children and their families, providing support when they need it and in the place of their choice. This year, we have repurposed unused space into an accessible family bedroom, which is on the ground floor. This has allowed us to accommodate three families staying at one time and allows families to be closer to their child's bedroom overnight.

In January 2025, we held our first patient engagement event. This is a group of parents we meet once every month, either virtually or in person, to gain feedback from 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 will be engaging families with recruitment, training resources, co-production, co-design, service development, and documentation review. 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 wrote to all our current families to complete an annual feedback survey. We requested feedback on all the services and support we provide, including in-house and outreach, our facilities and how our services impact families. We separately wrote to families whose child had died in the last two years with a different questionnaire. The bereavement questionnaire asked families for feedback around our delivery of end-of-life care, how well our facilities met their needs, how well our teams supported them during and after their child's death.

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

- **Current families:** Survey sent to 193 families and had a 22% response rate
Overall experience of our service 88% very good, 12% good

- **Bereaved families:** Survey sent to 55 families and had a 15% response rate
Overall experience of our service 75% very good, 25% good

Aimee enjoying our therapeutic pool with Chloe


Adriel and family on a day out

Patient feedback

Being able to support families in a variety of different ways meant we increased our contacts with families, and this has enabled us to ensure that the families who really need our support are offered it. We recognise that families have differing needs which may change over time, and we try to accommodate those across the range of our service offer. I take great pleasure in sharing feedback from families.

Child feedback:
'I love it here! It's a 10.9 out of 10. I want to stay every two 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)

Current families:
'I am writing to express my heartfelt gratitude to you for the positive impact you have had on my daughter (child)'s life. Your presence has truly made a difference in her demeanour and behaviour. I can see a noticeable change in her attitude after spending time with you. Child has been facing numerous challenges lately, and it has started to affect her. However, today she seemed to have a more optimistic outlook, and I believe that is thanks to you. Thank you sincerely for being such a valuable member of Helen House. We are incredibly grateful to have you in our lives. Your support and care mean the world to us.' (Parent)

'(Child) had such a lovely time, he is very anxious about most tasks these days and for him to relax was such a big thing for the family also'. (Feedback from parent for Network Saturday).

'I know (child) really benefitted from her chats with you earlier this year and it has definitely helped her with strategies for dealing with anxiety and the move to secondary school.' (Parent)

'I walked in and everyone was so happy, there was a warmth and a feeling of ease, all the ladies loved (child) & cared for him amazingly, as well as being there for me too! These ladies are more than just nurses; they are incredibly special. The care (child) received at Helen House was out of this world! They truly listened to everything there is to know about (child), they spoke to him, included him, adapted to him, gave him a choice, gave him a voice, and made him feel safe and loved. I stayed with (child) at the Hospice Monday to Wednesday with my sister & we had the most beautiful time with (child). For the first time in three years, I got to be (child)'s mummy not his carer. The ladies did all (child)'s meds, feeds made up for when he needed them. I got to cuddle him and spend time with him, not clock watching for when the next meds are due!' (Parent)

'Thanks so much for the last few days. The girls (siblings) had an amazing time and came back buzzing with what a good time they had. It coincided with a tricky day for (child) on the Thursday, which was nice for the girls to avoid and for us to concentrate on (child).' (Parent)

Bereaved families:

'Helen House will forever live in our hearts; we could not have done the hardest part of ((child's) battle without the support and first-class care the team administered. The care team at Helen House were faultless, attentive, thoughtful beyond measure & most of all so loving and kind to our treasured son (child). They gave me the tools to keep my son in his beloved home for as long as I could. When we arrived for (child)'s final stay at Helen House, the care & play team had thought of everything to make his room as inviting as they could, they knew (child) loved his home & leaving his safe space was incredibly devastating for us all. With that knowledge, they created a safe space for (child, a Christmas tree, lights, beds for the girls and daddy to sleep with him and stay by his side, that was the most special camp and it would be our final camp together as our 5. Nine beautiful days to cherish and just be together. I feel so grateful we were in Helen House surrounded by phenomenal care providers, medically and holistically, the attention to detail that made all the difference & the highest level of respect to (child) in the Little room , checking on him and talking to him , that is something that I'll never forget. I cannot describe the pain of life without (child) but I can tell you forever the beautiful life we had together.' (Bereaved parent)

Leon on the Helen House roundabout

'To you all. This is a bit more of a personal thank you. Thank you for all the memories you helped create. Thank you for all the support. But most of all thank you for always looking after (child) the very best. As you are all aware I was so worried about leaving her but that soon went away when I knew that each one of you cared for ger as her own. Thank you for making her final hours and those five days special.' (Bereaved parent)

'But we did find happiness, a lot of happiness and that is largely because of the countless hours many of you invested in (child) . The love you have shown us as a family and most importantly our son, has been nothing short of fantastic. I consider everyone involved in his care over the years as a friend for life. We have so much love and respect towards you for every moment shared with (child).' (Bereaved parent)

'Thank you and the rest of the team for a lovely remembrance service. It was lovely to talk to you and some of the care team who remembered (child) & cared for him when he visited.' (Bereaved parent)

'(Partner) and I wanted to thank you and everyone involved in the Remembrance and Celebration event last Sunday. It was a very special day which meant a lot to us. It always brings back many memories of (child) and the times we spent in Oxford at Helen and Douglas House'. (Bereaved parent)

'Thank you for looking after and loving our precious nephew. We will never forget what you did for us that night, and more importantly, what you have done for (child) over the last year. The support you have given us all as a family is incredible and I know (parents) would not have got through it without you. I am sure you are told quite often how amazing you all are, but we honestly think the world of you all' (Bereaved relative).

'We just wanted to thank you from the bottom of hearts for everything you did for (child). We can't even begin to put into words what it meant for us to have you all at the end of the phone in the tough times and always there at his many symptom management stays, your support meant everything. It is a very scary and isolating journey, but we never felt alone, and that's because of you all. Every single one of you are incredible and we will forever be grateful to you all. And a very special thank you for keeping (child) as comfortable as possible the night he died. We will never forget it. It gives us such comfort that he was in his favourite place, and we both got to be with him.' (Bereaved parent)

'We wanted to take a moment to express our heartfelt gratitude for the exceptional care and compassion you provided our daughter during her recent stay at Helen House. She enjoyed all the activities and the homely environment there. 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 wellbeing. We felt fortunate to have such a supportive and caring team looking after (child) in her last few weeks of her life.' (Bereaved parent)

Feedback from bereavement group:
'We found the group helpful to be able to talk openly with other people who could understand the emotions and grief stages we were going through'. (Parent)
'I have gained a lot of positives from other parents as well as the counsellors. I would never have been able to cope with the loss of my son without you all. Thank you so much. It was lovely to meet other bereaved parents. It was a great forum to share experiences and learn coping mechanisms. It was very well facilitated by the 2 hosts.' (Parent)

'Thank you so much for putting the Forget Me Not Group together. The guidance and support of Helen & Douglas group leads, and sharing experiences, feelings, challenges, strategies, and support with the group has been a great help in moving forward through the tragedies we have all faced. (Parents)

Feedback from professionals:

'It was absolutely inspiring to meet you and your team earlier this week. Thank you for showing me around and sharing the significant complexity of your case load, which you handle with such expertise and grace. I am truly in admiration of the impact you achieve, especially with such limited resources. I know it's probably hard for you to see that, as you are in it - but it truly is the case'. (Clinical observer)

'I am writing to express my heartfelt gratitude to the entire team at Helen House Hospice for the exceptional support and guidance provided during my days of clinical observation placement. The experience I gained at Helen House Hospice has been extremely valuable to my professional growth. Your leadership and the dedication of your team offered me an opportunity to learn not only about clinical care but also about the compassionate and holistic approach that is integral to palliative care. I am particularly grateful for your warm reception, the structured orientation, and the willingness of all team members to share their expertise. Their patience, professionalism, and encouragement have left a lasting impression on me. Once again, thank you for making my time at Helen House Hospice both memorable and transformative. Please extend my appreciation to the CEO and everyone on the team for their unwavering support.' (Nurse visiting from overseas)

Activity report

This year we have had the honour of supporting 535 individual people: children, parents, and siblings across the range of services we offer. This is an 8% decrease from the previous year.

In 2045-2025 we had 280 child and young people on our caseload, of whom we actively supported 256 (91%).

Referrals

In 2024 – 2025, we received 122 referrals, and 76% (93 individuals) were accepted into the service. The majority of the declined referrals were due to the child not meeting our acceptance criteria. This equates to a 6.9% increase in the number of accepted referrals from the previous year. This increase can largely be attributed to our medical team teaching external stakeholders regarding early and appropriate referrals, introduction of an advanced care practitioner spending time with families and professionals on the local neonatal ward, and a reduction in local specialist services.

Inpatient admissions

We had 527 patient admissions to Helen House, a 6% decrease from the previous year. However, we provided 127 more outreach nursing hours which reflects families requiring more support in the community and in their own homes. Cancellations are only made in exceptional circumstances. The admissions break down as follows:

- 12 children/ young people had their first overnight stay.
- 107 care episodes delivered for unplanned stays in response to need: symptom management, end of life, emergency.
- 100 children and young people had a supportive stay.
- We supported 36 individual children with symptom management
- 12 children with end-of-life care and support in Helen House.

Standard bed nights available

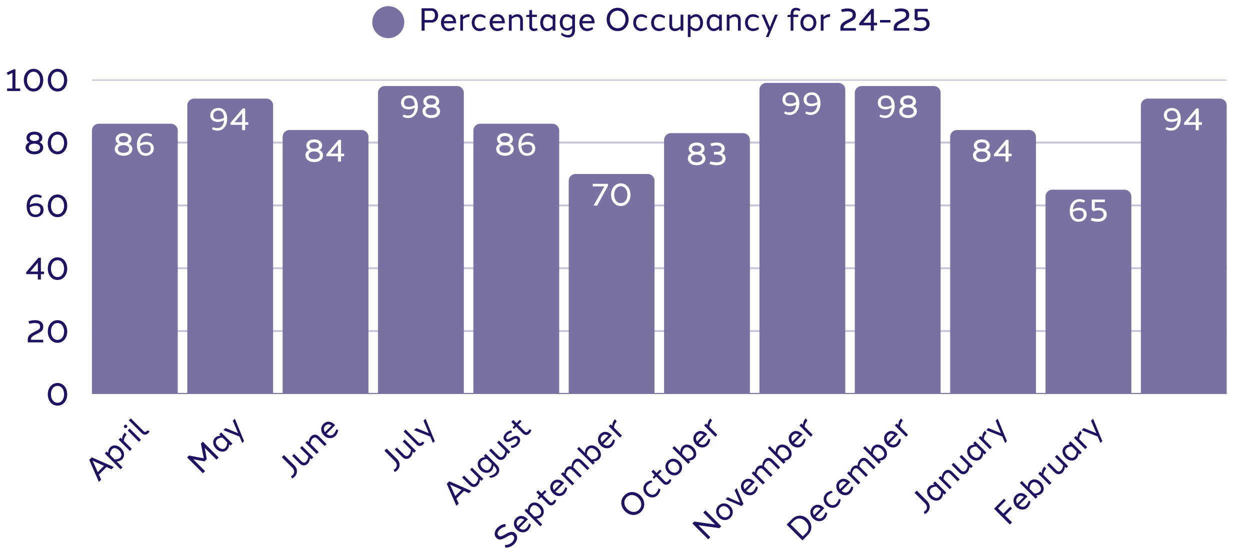
The standard bed nights available were based on a maximum of 4 children using the inpatient facility, six nights per week. We were able to deliver planned episodes of care, while remaining responsive to the changing needs of children, and providing better opportunities for continuous end-of-life care.

Service capacity

This year, we achieved an average monthly occupancy rate of 87% for inpatient stays. A total of 1268 bed nights were available, and all 1268 were occupied to deliver care to children across all inpatient stay types: supportive, first stays, symptom management, end-of-life and post-death care in the little room.

We provided 1268 bed nights of care

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

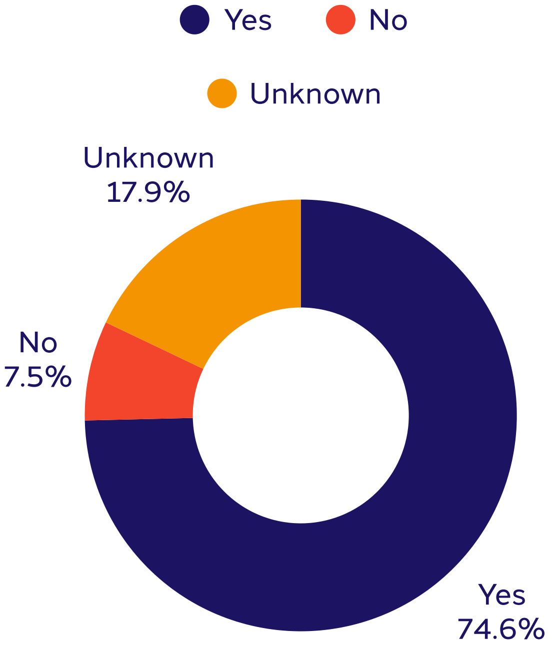


This year we altered the way we calculated occupancy therefore; it is not comparable with the previous year's figures. Previously, we included end-of-life and little room figures in our overall occupancy but realised this may not reflect the overall capacity of the hospice appropriately. Instead, we have chosen to only include planned admissions and symptom management to give a more accurate reflection of occupancy and pressures within the service. September and February had lower occupancy for planned admissions; however, during these two months we delivered more end-of-life care, which is not reflected in occupancy and regrettably we were experiencing seasonal higher staff sickness in the care team. Fewer planned stays are routinely scheduled to allow some capacity to support end-of-life patients. We have seen an increase in emergency referrals for acute symptom support and end-of-life which affects delivery of planned stays.

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 continue to meet our goals of increasing our reach and being able to offer in-patient stays for children who choose Helen House for end-of-life care.

Activity	**Year 23-24** (No. of bed nights provided)	**Year 24-25** (No. of bed nights provided)	**Comparison**
End of Life	127	92	28% decrease
First stay	58	28	52% decrease
Supportive stay	825	876	6% increase
Little Room	44	51	16% increase
Symptom Management	186	221	19% increase
	1240	1268	2% increase

Supporting deaths
Last year we provided care and support for 67 children/ young people during their end-of-life across inpatient and outreach. This is a 22% increase from the previous year. We continue to monitor and improve the likelihood of a patient dying in their preferred location. Patients and families are given a choice in where they want to receive end-of-life care and are supported with advance care planning at an appropriate time. This year we supported 75% of patients to die in their preferred place of death, having supported 10 more children/ young people to die in their place of choice this year. Our service will support families to have as much choice as possible in their preferred place of death. Please see the chart (to the right):



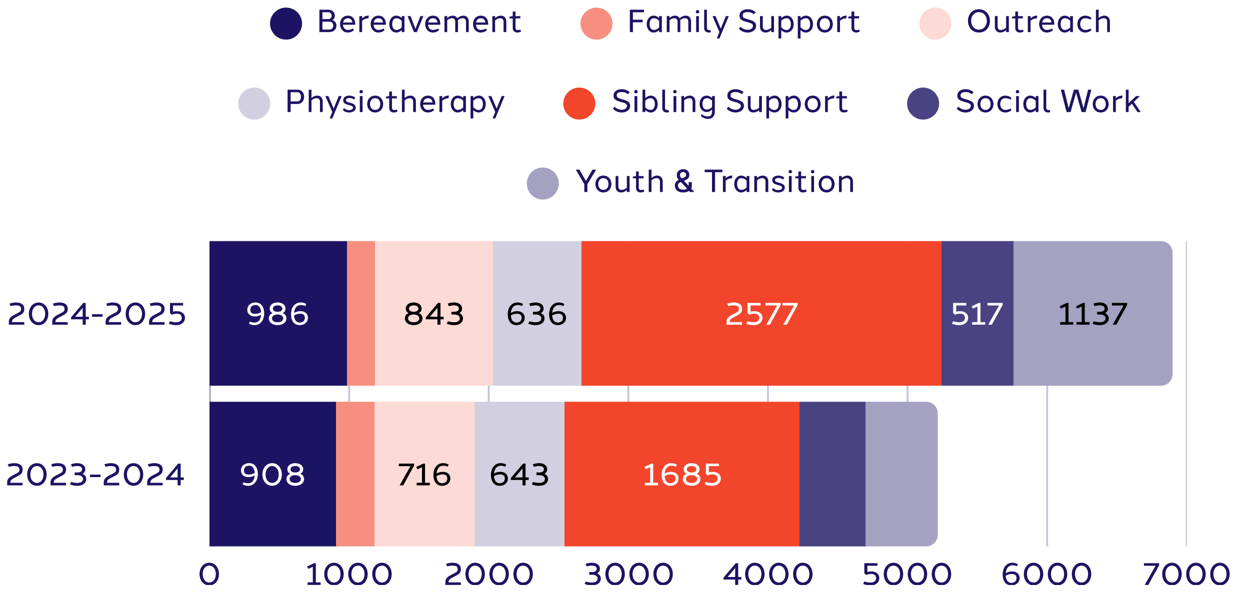
We have seen a 16% increase in the use of our Little Room (end of life suite) this year, used by 19 children/ young people in 23-24, which increased to 22 children/young people in 24-25. We have also extended our services to support families who have experienced an unexpected death of their child, such as fatal road traffic accidents.

Community and family support services

More families are now choosing to receive support in their own homes. We have increased capacity in our outreach nursing to be able to support families more in their own homes and other community settings. We have also increased capacity in the siblings team, youth and transition team, and recruited bereavement volunteers.

The community and family support team delivered 6898 contact hours, an increase of 32% from the previous year. The increase in activity can be attributed to significant increases in provision of siblings support and youth and transition care and support.

The graph below shows the contact hours delivered per discipline:



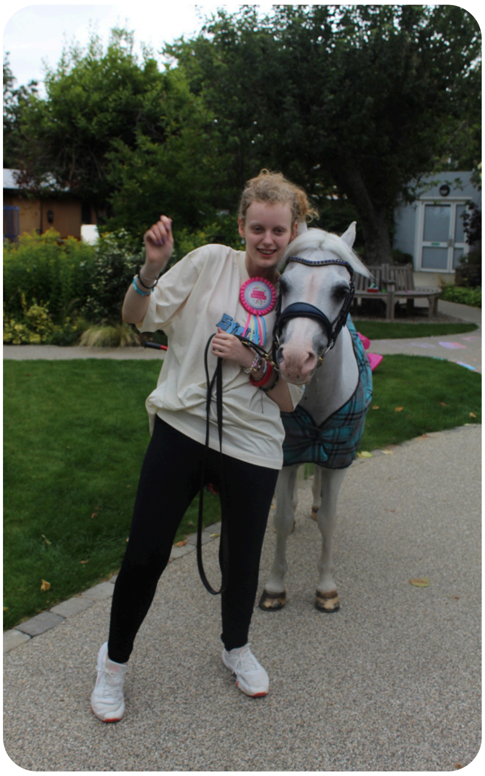
Therapies

Over 70 children/young people benefited from music therapy. A music therapist visits Helen House once a week, and the sessions are open to anyone (children and adults).

60 children/young people received hydrotherapy, within Helen House and the community.

Complementary therapy was introduced this year and was provided to 13 family members. This included yoga sessions and massage.

Part six: What others say about us



Sienna meeting a therapy pony

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- 18 years). Specialisms include: diagnostic and screening procedures, learning disabilities, physical disabilities, and sensory impairments.

Our current registration status is unconditional.

A full comprehensive inspection of Helen and Douglas House was carried out on 18 July 2023. Our service was rated 'Outstanding' overall. Caring and well-led domains were rated as 'outstanding', safe, effective and responsive were rated 'good'. We are incredibly proud of this rating and acknowledge the enduring effort from every staff member and volunteer that has contributed to make this possible.

Highlights from the report include:

- We found a service that was leading the way nationally in educating third parties on the complex needs of paediatric palliative care. Leaders encouraged innovation and participation in research. Staff working for the service produced numerous pieces of legislation and were members of national committees related to paediatric palliative care.
- There was an exceptionally strong focus on multidisciplinary working, with the service developing multidisciplinary teams whenever there was an opportunity for shared learning. Staff were committed to working collaboratively and took a clear, coordinated, and holistic approach to ensure seamless care.
- Staff repeatedly went above and beyond to find ways to make a difference to children and their families. Staff went above expectations to establish and meet children's individual needs and were passionate about the care they delivered. We found an exceptionally caring culture with whole staff buy-in to promote dignity, respect, and understanding. Staff developed positive, trusting relationships with children and their families and did everything possible to ensure that last requests could be achieved. Feedback from families was overwhelmingly positive.
- The service was well-led, and governance processes ensured the hospice ran smoothly. Leaders had the skills, knowledge, and experience to perform their roles, had a good understanding of the services they managed, and were visible in the service. Staff felt respected, supported, and valued, and knew and understood the provider's vision and values and how they were applied in the work of their team.

Commissioner Quality Assurance visits

We have different contracts and reporting requirements with five commissioners. We provide our commissioners with quarterly quality reporting through electronic means and engage in regular contract review meetings. This year, we have developed significantly stronger and more collaborative working relationships with our main Integrated Care Board: Buckinghamshire, Oxfordshire, and Berkshire West (BOB). As a result of this improved partnership, we now welcome commissioners on-site for informal quality assurance visits, enabling them to gain a deeper understanding of our care environment, staff expertise, and the complexities of children's hospice care.

These visits have fostered greater mutual trust and transparency, allowing for meaningful discussions around service development, challenges, and shared priorities. Although we have not received formal requests for quality assurance visits, the increased frequency of informal visits and direct engagement reflect the commissioners' growing confidence in our quality governance and their interest in maintaining a close, supportive relationship with our service

Complaints/compliments

We have received many compliments over the last year, including letters, cards, and emails.

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. As part of this effort, we have also reviewed and updated our Complaints, Comments, and Concerns leaflet. This refreshed version will be included in the new welcome pack for visitors, which is set to be introduced later in 2025. This update aligns with our commitment to ensuring transparency and fostering a culture of continuous improvement.

We have received four concerns informally this year. Two relating to our post bereavement care/ after care support and two concerns raised by parents during an in-patient stay. All of these concerns were thoroughly investigated, and supportive conversations were held with staff to explore the antecedents, the concern and viewpoint from the family perspective. 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 has been set up to capture complaints/ concerns and feedback to assist with oversight and reporting.

Part seven: Service improvements

Patient engagement group

This year, we established Patient Engagement Events. 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. These events are open to parents whose child is currently using the service and bereaved parents. Participants of this group will also be involved in our recruitment, training resources, co-production, co-design, service development, and documentation review.

Shared decision-making council

We introduced a shared decision-making council for all clinical staff to empower them to make meaningful change, to improve the psychological safety of our staff. The staff were keen to review the shift patterns in place to support better work-life harmony. A proposal was made and considered by the senior clinical team. The proposal was implemented and is under a trial period.

Homeward Bound hub

We have worked closely with Oxford University Hospitals to trial a new system to provide continuity of care for children being discharged home from hospital. The Homeward Bound Hub (a joint project across the ICB) uses care agency staff working within the acute hospitals to support earlier discharge of patients with medical complexity and technology dependence. The care agency staff are trained and competent in providing care for the child whilst they are still on a hospital ward, and the same carers provide care to the child in their home once they are discharged.

Climbing session at the siblings summer camp

Extending sibling support

We have significantly increased the number of support hours available to siblings. This includes parties, axe throwing, street dance sessions, pottery painting, ice cream parlour visits, and circle time for siblings to share stories with each other. Siblings also had great fun at their residential trip where friendship groups formed with the sharing of stories and photos.

Bereavement volunteers

Expanded our bereavement offer to include volunteers to support bereavement groups initially. Bereavement theories training was provided for all bereavement volunteers, and we aim to expand this offer in the coming year.

Riley and mum Shailza enjoying play in the garden

Advanced Nurse Practitioner

We introduced the Advanced Nurse Practitioner (ACP) role to lead on nurse-led services in-house and perinatal support service development. This enables our consultants to focus on supporting more specialist consultancy and care to the children/young people. Our ACP is a midwife and is beginning to provide specialist support to families from pregnancy through to 1 year of age. This includes support on a hospital ward, 1:1 sessions, and antenatal classes.

Inclusive remembrance event

This year, we ensured our annual remembrance event was delivered to represent families from all faiths and none. We endeavour to become a more inclusive service, celebrating the diversity of the many faiths, cultures, and beliefs that the children and families represent. The event was well attended and well received. In the coming year, we aim to increase capacity for attendance at this event as it has become very popular.

Complementary therapy

We recognise complementary therapies can play a valuable role in supporting individuals experiencing grief by offering additional avenues for coping and healing. This year we introduced yoga and massage for family members to help address emotional, physical and spiritual aspects of grief, helping individuals manage stress and promote relaxation.

Little room refurbishment

We have refurbished our little room, designed to provide more privacy, dignity, and comfort for the deceased child and their family. We have diversified our body cooling systems to provide a better choice for families in after-death care for their child - this includes specially designed cold mats which can be taken out into the community to a family's home.

Accessible accommodation

The accessible family space has been completed and has been used by many families. This space is on the ground floor and fully accessible to anyone with limited mobility. This room allows parents to sleep in a bedroom next to their child's, which has had a significant impact for families, particularly when they are staying at the end of their child's life. It is fitted with a fully accessible bathroom and kitchenette to allow families privacy.

Paediatric Immediate Life Support (PILS)

This year, we have enhanced our life support training to include Paediatric Immediate Life Support. This is a higher level of training than the basic life support requirement to give staff specifically tailored skills and an accredited qualification. This has been delivered by a Resuscitation Council UK-accredited trainer who delivered the sessions specifically for the hospice.

Expansion of physiotherapy support

In September, we employed a physiotherapy assistant, which enabled more families to receive physiotherapy. We are providing more physiotherapy for children and young people in Helen House and children's own homes to enhance quality of life and prevent hospitalisation. Our physiotherapist provides specialist respiratory physiotherapy in collaboration with other local services.

A trip to the Ice rink

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

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

Helen & Douglas House
14A Magdalen Road, Oxford OX4 1RW
Quality Account 2024-25