Helen & Douglas House

your local children's hospice

Quality Accounts

2023-24

Jasper in the garden, playing with the bubble machine

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 purpose-built 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
- Cold room

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, physiotherapist, teacher, 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 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.

Edith enjoying playing with bubbles in the garden with Chloe from the play team

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

Leon on the roundabout

A sincere welcome to this year's Quality Accounts. Since joining Helen & Douglas House as Chief Executive Officer in October 2023, I have had the utmost privilege and honour of leading the world's first children's hospice. This year has been full of dedication, success and celebration, consolidated with the achievement of an 'Outstanding' rating from the Care Quality Commission. It is my pleasure to share this overview of 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.

Helen & Douglas House has been officially accredited by the National Centre for Diversity as achieving the prestigious Investors in Diversity Silver accreditation. Celebrating the diversity of the children, young people, and families that use the palliative care services that we deliver 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 into Helen & Douglas House has remained constant for the last two years, and we accepted 84% of these referrals. We have worked exceptionally hard to expand various aspects of the service including safely increasing our bed capacity from 4 to 5 beds, provided 6 nights per week, with provision for the 7th night if needed. This meant more children were able to access care, and more families benefited from our services. We continue to ensure we provide a service that is responsive to the 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 providing 39% more bed nights of care, 120 more admissions, having an average of 100% occupancy and supporting 33% more children/ young people to die in their place of choice, compared to the previous year.

Momentous moments this year include successfully enabling a young person to interactively access education via a robot, hosting a more inclusive and diverse remembrance event and being nominated as a food vouchers agent for bereaved families experiencing hardship.

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 care and bereavement. It is a true reflection and appreciation of our competent, skilled and sincere staff and volunteers.

Receiving voluntary commendations from professional bodies provides us with assurance that our services and support are highly valued across the region. We were honoured that the Child Death Panel recommended our medical director and care team for a Commendation Letter for supporting the first baby in the UK to have a planned homebirth with an antenatal palliative care plan. Our support was also recognised by Oxford Brookes University, as they ranked first in the 2024 Guardian university league tables for Children's Nursing programmes in the UK. 50% of the students' learning and time on the programme is in practice, and we were recognised by the university for providing 'extremely supportive placements'. We share the university's view that being rated as the best place to study Children's Nursing in the country is representative of their partnership working between university and practice.

We are very excited for the year ahead as we enter the final year of our current three-year strategy. We aspire to deliver world class palliative care, extend and develop our clinical service to meet needs of every eligible child and family from point of diagnosis through to bereavement care and support. We also look forward to giving greater depth in meaningful play, being able to provide accessible accommodation for families, and working with families to better the experience of our bereavement suite area.

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

Jane Long
Chief Executive Officer
Date: June 2024

Rayyan with Jane

Part two: What we have achieved

Patient safety and outcomes

We will prioritise the collection, analysis and reviewing of quality and outcome information to inform improvements across the service. This involves participation in local and regional audits, and/or national benchmarking programmes.

We will continue to strengthen our approach to monitoring, auditing and benchmarking the quality of the services and the outcomes for children and young people. We will ensure that we are improving outcomes for people who use our services by engaging with them in different ways to better understand their desired outcomes. To achieve this we will be participating in the pilot for Children's Palliative Care Outcome Scale (C-POS) to develop and validate a person-centred outcome measure for children, young people and their families affected by life-limiting and life-threatening conditions. Improving outcomes for us this year also includes the implementation of the Patient Safety Incident Reporting Framework (PSIRF).

Update

As we delivered more bed nights of care this year, we increased our awareness of the potential for more patient safety incidents. Whilst reviewing any patient safety incident we included parents in learning from incidents. This has empowered family members and their contribution has been very beneficial towards delivery of safe patient care.

We annually benchmark the quality of our services with national guidelines for paediatric palliative care (NICE guidelines NG61), and currently meet 90% of the recommendations. There are plans in place to improve our performance further.

We have continued to complete detailed audits of our service and to improve quality as a result. Some examples include auditing of family and bereavement support case notes leading to a more defined recording process and a discharge summary audit leading to a more refined process in line with electronic records.

We started a project to review our entire admissions process. This project will dissect all individual tasks from the point of referral to acceptance to ensure the children and families who are eligible for our services have timely access to them. Advancement in treatment leads to increased complexity in children/young people, therefore this project will also allow us to redefine our eligibility criteria to support the families who need our service the most.

We have continued to embed the principles in PSIRF into our daily practice, and it has enabled a definitive shift in the culture of investigating patient safety incidents. Close working with Buckinghamshire, Oxforshire and Berkshire West Integrated Care Board (BOB ICB) has allowed learning opportunities across paediatric palliative care.

Clinical effectiveness and accessibility

Embedding the use of electronic patient records to maintain effective and compliant record keeping processes.

Electronic records provide better security and accessibility for staff providing care within Helen House and out in the community. Our priority this year to migrate all paper records on to an electronic patient recording system and audit the quality of care records. This includes children, young people, and any supported family member (parents, siblings etc). We will be sourcing digital devices that are compatible and allow staff to have better accessibility to care records. We will also revisit electronic prescribing to minimise prescribing, administering and omission errors. To achieve this, we will be working closely with Oxford University Hospitals (OUH) who provide the electronic patient records (EPR) system to us. All training and templates will be endorsed by OUH to ensure we maintain the same quality of competency and output.

Update

We continue to embed the use of EPR. This year we reorganised all our paper records to only store a minimum set of notes that were necessary alongside our electronic recording system. This has significantly reduced duplication and enabled a more efficient system. This year we started the migration of our community and family support services on to electronic patient recording. We have continued to audit the use and quality of EPR. As we use the same system as Oxford University Hospitals, we have far better interoperability, access to real time records and seamless transfers of care. After much consideration, we decided to postpone the implementation of electronic prescribing.

We developed more efficient internal databases for the children and families we serve. Good quality information is essential to inform our clinical care. From these new databases we are able to capture better data, allowing extraction of meaningful data to monitor the quality of our service and improve outcomes for children, young people and families. An example of this is monitoring how many children died in their preferred place of death, and being able to evidence it against national guidance (NICE guideline NG61). From this data we demonstrated a 33% increase in children/young people receiving end of life care in their preferred place of death compared to the previous financial year.

Fatima enjoying her time at the hospice

Patient experience

Maximise the impact of the support we deliver through adjusting how we operate, extending how we work with others, and investing in technology.

Play and activity is an essential element of supporting and enhancing any child's experience of receiving services and can have an active part in optimising treatments. In accordance with NICE guidelines, we will ensure we enhance our offer to ensure children and young people with palliative care needs have more access to play, art and music activities, as well as digital media. Our priority this year is to ensure that we are offering more fun to more families, including out in the community. We also aim to increase the diversity of music within the service by visiting musicians and the establishment of regular music therapy. We will engage with schools and other settings where the child or young person receives care and support. To deliver this we will need to increase the resource and expertise within the play specialist team and develop volunteering roles and opportunities. We will also increase our complementary therapy offer using volunteer support.

Update

Stay and play days have been embedded as a monthly, regular offer for families to attend. These have been particularly well attended and provide most benefit for families that need a safe space for an outing for their whole family. We also facilitated external day trips for families throughout the year to farm parks,

Music sessions are run at least once a week, and specific music therapy sessions are on offer once a month. We have expanded our family and bereavement support team to further develop our service and adapt to the ever-changing needs of families. We also supported 10 families to work with The Keepsake Circle, to memorialise their child in song and the opportunity to attend a concert where all the songs will be played.

The play team provided specialist play support for children and their siblings 6-7 days per week, giving opportunity to every child who stays with us to benefit. The play team individually assess a child/ young person's play goals and support them to achieve these through 1:1 and group support to maximise the outcome. During the coming year we will begin to scope the need for play intervention in the community.

We invested in newer technology to ensure we continue to serve the children and young people in entertainment and gaming. This included the purchase of Yoto players – portable audio devices for the children to listen to stories, podcasts, music or even white noise and iPads to deliver tactile communication sessions, allowing children to feel vibrations whilst using applications and to listen to audio/music in the bath. Ipads are also used during music therapy sessions to allow children to make music with minimal movement.

We also invited more external people who use technology to enhance the children's experience, such as Embracing Arts who delivered a musical-themed sensory show. Our social work team worked hard with a child's family to enable the childs education to continue with the use of a robot provided by the child's school and statutory services. The provision of the robot allowed the child to interactively access education remotely, promoting the right of the child to access education.

This year Helen & Douglas House employed a new executive member to lead on Data, Digital and Technology. This has had a considerable impact on how we have transformed communication with families. This includes digital webforms for invitations to events, QR codes for feedback and re-designing the website to ensure its content met family's needs.

Part Three: Priorities for improvement 2024/25

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.

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 cold-room to open up capacity to care for a third child after their death.

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.

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 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.

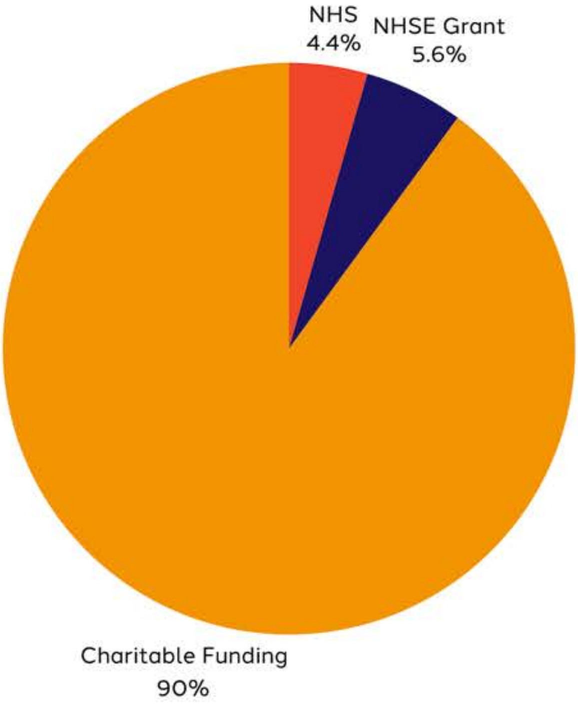
Part four: Overview of services

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 2023- 24, public sector contributions to care only represented 10% of the hospice's total expenditure on care services (patient care, family and bereavement support).

Funding sources for hospice care 2023-24



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 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). In 2023 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 Payment by Results clinical coding audit during 2023/24 by the Audit Commission.

Participation in national clinical audit

In 2023-24 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. Our quality and compliance lead maintains oversight of the programme. Results, learning, and areas for improvement are presented to the clinical governance committee and sent to staff through internal communication channels. Our quality and compliance lead analyses audit results and works closely with clinical leads to improve compliance, ensuring the clinical team remain engaged in quality improvement. A prime focus this year has been to ensure policies and procedures are easily accessible, clear and enable staff to deliver the highest quality of care.

Infection, Prevention and Control

Infection prevention and control (IPC) has remained a high priority and been fundamental to safe service provision throughout 2023/24. This year we implemented the use of the English Manual of IPC and identified a care team member and outreach staff member to support the nurse who leads on IPC. The IPC Lead Nurse 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 attention. This year our IPC lead nurse worked on additional responsive audits where a particular issue had been highlighted. Targeted education and visual prompts were used, and compliance increased as a result.

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. This year a bed safety rails alert and guidance was issued, which we responded to immediately with reviewing our current equipment, purchasing of some new compliant equipment and training for all clinical staff.

Research

One of our Associate Specialist Doctors won the Royal Society of Medicine (RSM) Impact and Evidence in Palliative Care research prize, on the completion of her MSc project on the wellbeing of children's hospice staff. Her work will be considered for repeating the methodology in adult palliative care, further celebrating an all-ages, inclusive approach to palliative and end-of-life care.

We met our recruitment target for the national C-POS study (NIHR funded), which seeks to validate outcome measures in paediatric palliative care.

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 who children died after care on NICU or PICU.

Publications:

Our staff contributed to the following publications:

- As low as reasonably practicable (ALARP): a moral model for clinical risk management in the setting of technology dependence. Journal of Medical Ethics 2023
- Coproduced resources to support parents caring for children with gastrostomies. Frontline Gastroenterol. 2022 Aug 25;14(2):144-148. doi: 10.1136/flgastro-2022-102181. eCollection 2023
- A rapid systematic review of breakthrough pain definitions and descriptions. British Journal of Pain 2023
- Several members of the team contributed to the 5th edition of the children & young person's advance care planning document, which was released in July 23
- The 2023 edition of the APPM Formulary has contributions from several of the medical team
- Contribution to the published Nuffield Council on Bioethics report on managing disagreements in the care of critically ill children

Education

Contributing towards education both within Helen & Douglas and externally, remains a high priority. Below are examples of these contributions:

Involvement in the process of defining the ethical review needed prior to children being established on long term ventilation in the Thames Valley & Wessex Operational Delivery Network.

Our consultant team delivered Paediatric Palliative Care education on the undergraduate curriculum for the University of Oxford.

Helen & Douglas House medical team supported one doctor, who chose to work with us to complete their consultant training, to complete their SPIN training (specialist interest in paediatric palliative care). Another doctor was supported to complete their post CCT SPIN training.

Our Level 4 consultant and consultant paediatrician led on an APPM module on the 'Safe Use of Opioids in Children'. This was a national project funded by NHS England.

Our physiotherapist has delivered several respiratory teaching sessions to the clinical team to improve competence and skills to deliver higher-quality respiratory care.

Our clinical professional development team are members of the South East Paediatric Palliative Care Education network. Each member of our team is participating within a different workstream (education for schools, syringe drivers, ACPs, digital and nurse verification).

Our education lead for the medical team also leads the regional educational platform for the South of England, allowing flexible training for staff from a range of disciplines.

One of the consultants hosted a well-received series of evening educational events on topics relating to medical ethics in paediatric palliative care.

One of our consultants has been working with the National Child Mortality Database to improve the harvest of data on palliative care service delivery, as a member of their professional advisory group.

There are growing links with local places of education. The Head of Professional Development and an outreach nurse attended a school's careers days, where they offered presentations on the range of careers available in paediatric palliative care to multiple groups of students.

The Director of Clinical Services delivers countywide training on Safeguarding Disabled Children on behalf of the local Children's Safeguarding Board

Part five: Review of quality performance

Incident reporting

This section gives an overview of the incidents reported in Helen & Douglas House in 2023/24.

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, and lessons learnt are disseminated to staff. Patients/parents were 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 implemented small changes. These had a significant positive effect on the number and nature of reported medication incidents throughout the year.

Type of incident

Incident data shows a healthy reporting culture at Helen & Douglas House. We have separated drug related errors from clinical incidents as they are our highest reported sub-category. This year 70 clinical incidents were reported and 65 drug-related errors 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 we learn and disseminate learning from episodes of excellence, both within the service and in the wider paediatric palliative care community.

Chart showing the number of clinical incidents per quarter

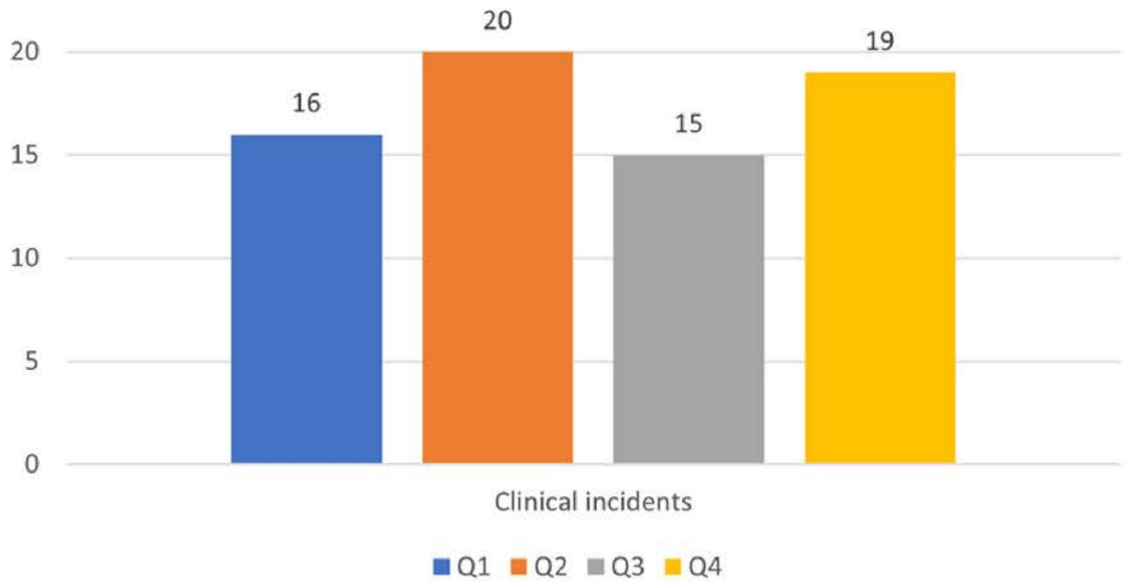
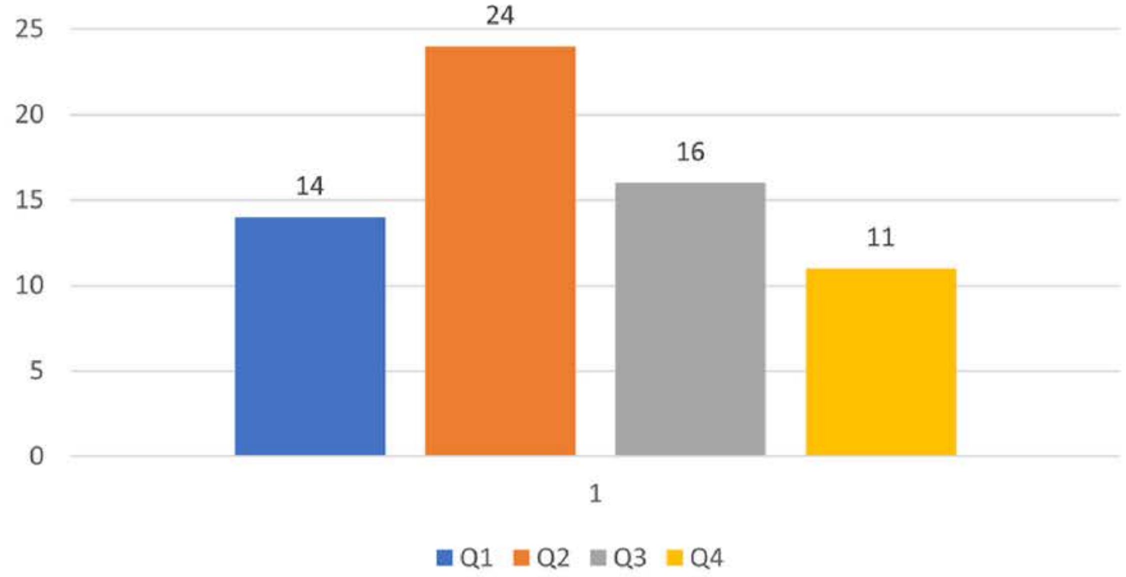
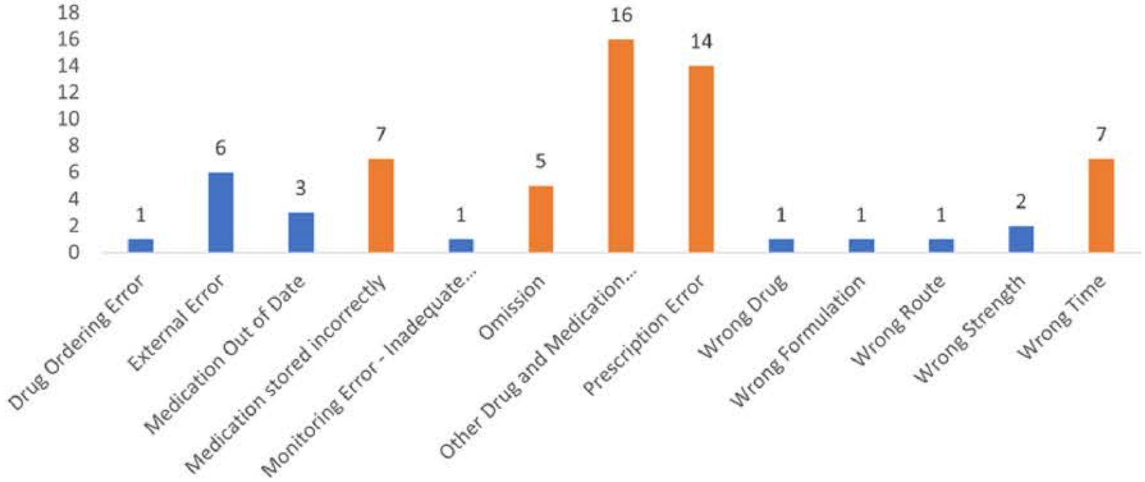


Chart showing the number of drug-related incidents per quarter



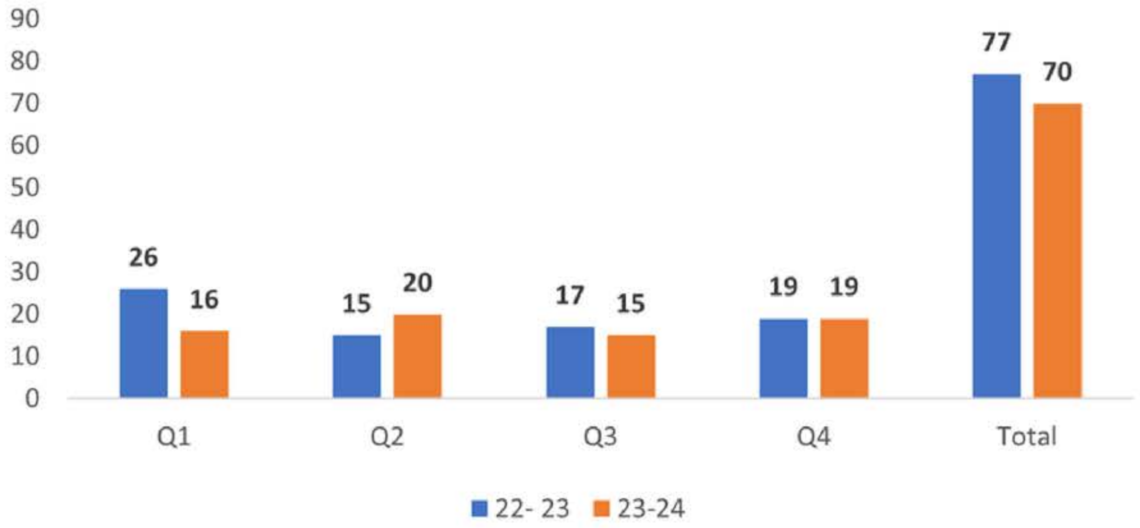
The chart below shows the number of drug-related incidents reported by sub-category



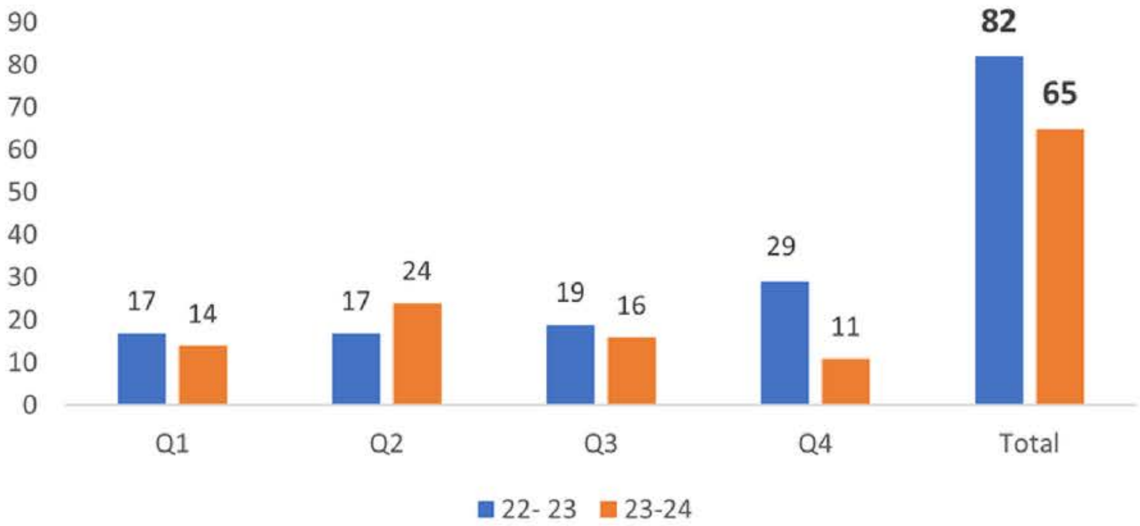
The table below shows the number of incidents in the top five reported sub-categories:

Incident category 2023- 24	Number
Other Drug and Medication Incident	16
Prescription error	14
Wrong time	7
Medication stored incorrectly	7
External error	6

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



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



After an unusually higher number of medication incidents than usual in Q4 of 22-23 we implemented several additional safety measures including double checking of medication, wearing of red aprons when drawing up medication, extra member of staff on admission days to relieve the timing pressures. These measures have proven to significantly reduce the number and the severity of drug-related incidents reported this year.

Helen & Douglas House has continued to embed its learning from incidents process to engage teams in developing 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 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 85% or above throughout the year. Patient-facing staff also complete a safeguarding passport to document any further in-depth, or topic specific learning.

Helen & Douglas House is a trusted partner within Oxfordshire's Safeguarding Children's Board sub-groups; disabled children, health advisory, training, and child death overview panel. This year we appointed a safeguarding link nurse, who is a champion within the clinical staff group. We have introduced patient specific safeguarding supervision for clinical staff to improve awareness and confidence in dealing with potential safeguarding concerns.

This year we strengthened our relationship with our Local Authority Designated Officer (LADO), who also delivered a bespoke training session to the safeguarding leads within our organisation. This was as a result from learning we had from an incident where LADO involvement may have been indicated, but was not necessary on this occasion. In response to this we also reviewed how our potential safeguarding incidents are reviewed. Every incident of this nature is now screened by our social workers to ensure the relevant people are involved/ notified. We have introduced same-day safeguarding huddles when any staff member has any concerns to discuss. These are attended by as many of the safeguarding team as available.

Equality, Diversity and Inclusion Strategy

Helen & Douglas House has been officially accredited by the National Centre for Diversity as achieving the prestigious Investors in Diversity, Silver accreditation. Celebrating the diversity of the children, young people, and families that use the palliative care services that we deliver is at the heart of all that we do, and we are honoured to have been recognised as an inclusive organisation. We recognise the accreditation as a milestone in our ongoing journey toward greater inclusion for all and we look forward to continuing doing all we can to drive forward impactful initiatives to reap the benefits that a diverse and inclusive culture brings.

During 2023, we worked towards furthering our progress against the National Centre for Diversity standards, steadily completing the actions which came from our Investors in Diversity first review with on-going liaison with our EDI Advisor. This past year has seen further integration of our EDI Engagement Group, who facilitate regular guest speakers, awareness days, staff stories and educational resources. The calendar of events included workshops on Neurodiversity and Black History Month, an educational session on Judaism, Stress Awareness and Burnout sessions and an informative presentation from Carer's Oxfordshire. Following the success of our Menopause Network Group, a Working Parents Network group followed allowing staff to share and support each other better than ever before.

Following our second survey results, the National Centre for Diversity report states 'There is a positive and inclusive environment where staff are encouraged to bring their best selves to work and to share their lived experiences. Staff feel colleagues and managers take Fairness, Respect, Equality, Diversity, Inclusion and Engagement more seriously now than at the beginning of this process.' 'Staff feel the organisational culture has become more inclusive since the first survey and feel more valued and respected by their managers and senior managers'.

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 evoked the duty of candour for some incidents which did not result in this level of harm, but we felt an official apology and further detail 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 of these 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 for this role, which is stipulated and delivered by the Nationals 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 increasing their awareness throughout the organisation, including shop visits, attendance at all staff meetings and display 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 Nationals Guardians Office every quarter.

Patient experience

Our vision is to remain exceptionally committed to enrich 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 every child/young person dying in their place of choice. With successful recruitment last year we were able to safely increase our bed capacity from 4 to 5 over most weekends (Friday - Sunday) after September 2023. This meant we were able to support more inpatient stays for end-of-life care and symptom control, and offer more supportive stays.

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. We have asked all these families for their participation in a patient engagement group, to shape the future of our services.

Please see below for a summary of what families told us:

- Current families: Survey sent to 179 families and had a 26% response rate
- Overall experience of our service 87% very good, 11% good, 2% neither good nor poor

- Bereaved families: Survey sent to 46 families and had a 20% response rate
- Overall experience of our service 67% very good, 22% good, 11% neither good nor poor

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, which we try to accommodate across the range of our service offer. I take great pleasure in sharing feedback from families.

Current families

- *'In Helen house I can talk to the Drs easily and pass on my concerns about my child and they look into things pretty quickly and new medication or change of medication can be sorted out while we are there. I find it so hassle free. Because sometimes calling a to b to c and still can't reach the right person to get these things done while we are at home'.*
- *'They helped to manage (child)'s symptoms so we are able to do things as a family and (child) can do things independently'.*
- *'It is hugely reassuring to know there is a team there who have the time and expertise to support us- no question is too small. Also, both in house and outreach teams are proactive in caring for (child) and sharing their observations and advise with us'.*
- *'I love Helen house stays. I think I enjoy myself more than my child. I mean he loves it there too. I get much needed rest and he get spoiled in each and every way'.*
- *'(Child) has been coming to Helen House for nearly 10 years. The support we get is a vital part of our ability to care for (child) at home and be the best parents we can be. Receiving a warm and caring welcome from people we know and meeting new members of the team helps us to feel we belong and are understood in what can be a lonely world of complex needs. Knowing (child) is cared for and happy helps us to try to relax and recharge our batteries ready to go again'.*
- *'Having supported stays for our child gives me chance to be a wife and mum to my other children and spend quality time with them'.*

Toby doing arts and crafts

Bereaved families

- *'We have attended the 2023-24 Forget Me Not group sessions and the September 2023 Remembrance and Celebration Event. We are really grateful for the support Helen & Douglas have provided to us through these groups/events, and the one-to-one family bereavement support sessions which have been a great help. We have been keen to try things that might help us get through this desperately difficult time, and these have'.*
- *'The support we have received from Helen & Douglas has been helpful in that they have provided considerable support us in talking about and trying to come to terms with our lovely daughter's death, and finding a way through into the future. I think it is unlikely we would have had the same conversations, and been aware of the possible strategies, without this support'.*
- *'While my child wanted to be at home, Helen & Douglas House offered them a safe, caring environment where we all felt reassured and respected. Having the specialist staff support us as parents was invaluable. We always felt that we were in good hands. It's difficult to put into words just how much of a difference you all made'.*
- *'The support networks have had a positive impact. It is sometimes very difficult to hear the sadness we have all been through, and will continue to go through. The understanding of those in the groups who have been through such pain is uniquely different from the support of friends and family who have not had such experiences'.*
- *'Sibling Support has been so wonderful, helping my other children (my youngest son especially) to manage following his older sibling's death'.*
- *'Helen & Douglas House was a much needed compromise for my child. He hated hospitals and we weren't prepared (time wise) to look after him at home. Having access to such wonderful staff and to such a high level of medical, emotional, and psychological care was invaluable. Being able to stay as a family in Helen House and be together in his final moments is a cherished gift'.*

Feedback throughout the year via email and thank you cards

- *'I would like to express our heartfelt gratitude to every one of you for the exceptional care you gave to our precious boy. You worked so hard to ensure he was as comfortable as he could be, you showed such kindness, thoughtfulness and understanding. You are a remarkable team, and we feel so lucky to have had you looking after (child) and us too. Your physiotherapist helped (child) to achieve the things that were important to him to be able to do himself. You were an incredible support'. (Parent)*
- *'(Child) had a period of being in and out of hospital and hospice, she was rarely home and had become distrusting of the medical world, (physiotherapist) successfully broke (child)'s mindset and she is now living a positive happy life. The service of the physiotherapist in Helen house has been perfect for the rehabilitation of both physical and mental health of (child). We are both extremely thankful for the physiotherapist'. (Parent)*
- *'Thank you to (siblings team member) for yesterday, (sibling) was in a much better place last night after your session, she sat in the living room with everyone. I think she couldn't have done that before as she was so angry'. (Parent)*
- *'I have only gratitude and appreciation for all of the bereavement group sessions and the time that the facilitators give up. I cannot explain how valuable these sessions are to families. I met friends for life and it has been a profound part in a long, painful journey'. (Parent)*
- *'(Child)'s parents would like to say thank you for all the support they, as a family, have received. They do not know where they would be now if it had not been for Helen House. (Parent) is grateful for having somewhere to go when their daughter died, and said it was like stepping in to a little oasis behind those walls, filled with love and peace. The garden at Helen House inspired (parent) to create a garden at the school where their daughter attended, and they visit regularly, and it is a great source of comfort. The one-to-one support that is still being given, and attending the Butterfly and Forget-me-not groups, has been amazing. Both parents' have made incredible friendships from these groups, they meet up regularly, support each other, and are committed to fund raising for Helen House to ensure others have the same opportunities that they have had'. (Parent)*

Activity report
This year we have been had the honour of supporting over 580 children, parents and siblings across the range of services we offer. This is an increase of over 150 individuals from the previous year, as we continue to meet our goal of extending our reach to more families.

Referrals
In 2023 – 2024 we received 104 referrals, and 84% were accepted into the service. The majority of declined referrals were due to the child not meeting our acceptance criteria. We supported 253 individual children/young people, seven more than the previous year.

We continue to work closely with local authorities, hospitals, and other hospices to ensure families who require specialist palliative care have access to our services.

We have also been working on early intervention, particularly with oncology children, to raise awareness of support we can offer as early as appropriate in their palliative care journey.

Inpatient admissions

We had 563 patient admissions to Helen House, 25% increase from the previous year. Cancellations are only made in exceptional circumstances. The admissions break down as follows:

25 children/ young people had their first overnight stay.

128 care episodes delivered for unplanned stays in response to need: symptom management, end of life, emergency. We supported 35 individual children with symptom management and 16 children with end-of-life care and support in Helen House.

Standard bed nights available

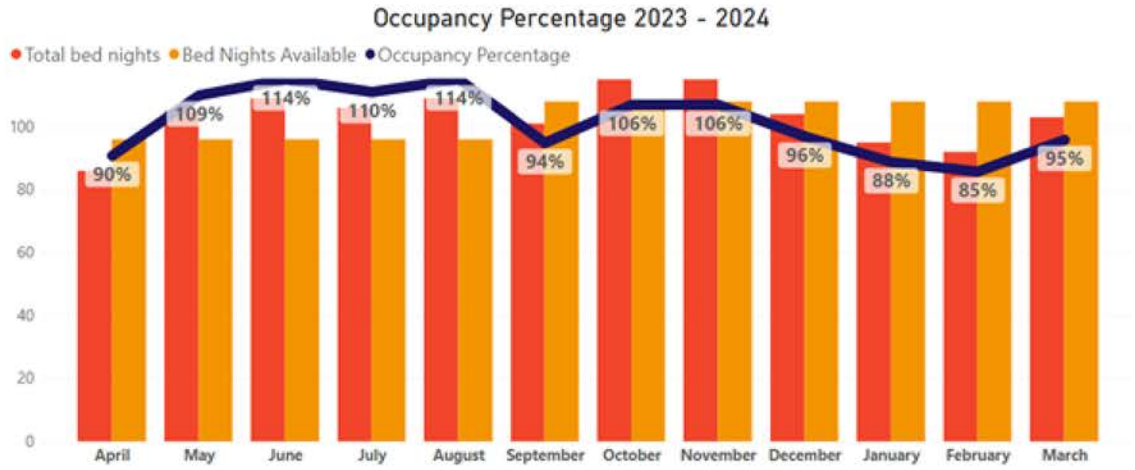
From March to August 2023, the standard bed nights available was based on a maximum of 4 children using the inpatient facility. From September we were in a position to safely provide care for up to 5 children, six nights per week. This meant we were reaching more children and meeting the needs of more children and their families. We were able to deliver more planned episodes of care, whilst remaining responsive to the changing needs of children and provide better opportunities for continuous end-of-life care. We safely enabled this to happen by gradually increasing the number of consultants, clinical leads, nurses, nursing associates and care support workers within the team.

Service capacity

This year we achieved 101% occupancy for our inpatient stays. A total of 1236 bed nights were available, and all were occupied to deliver care to children. Further additional bed nights were delivered by increasing occupancy when required to meet a child's need for continuous care (symptom management/end-of-life) and increasing staffing to maintain safety.

We provided 1240 bed nights of care, up 39% from previous year

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



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.

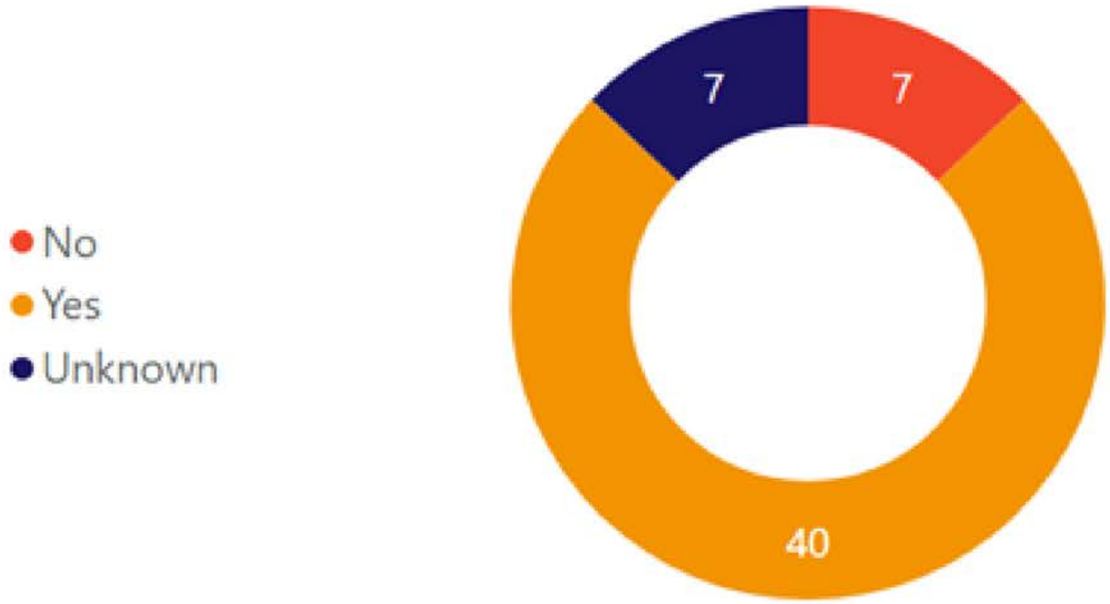
Activity	Year 22-23 (Number of bed nights provided)	Year 23-24 (Number of bed nights provided)	Comparison
End of Life	63	127	102% increase
First stay	29	58	100% increase
Supportive stay	541	825	53% increase
Little Room	49	44	10% decrease
Symptom Management	207	186	10% decrease

Supporting deaths

This year we provided care and support for 54 children/young people during their end-of-life across inpatient and outreach. This remains unchanged from the previous financial year. We continue to monitor and improve the likelihood of a patient dying in their preferred location. Patients and families are given choice in where they want to receive end-of-life care, and supported with advance care planning at an appropriate time. This year we supported 74% of these patients to die in their preferred place of death, a 33% increase from the previous financial year.

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

Preferred place of Death



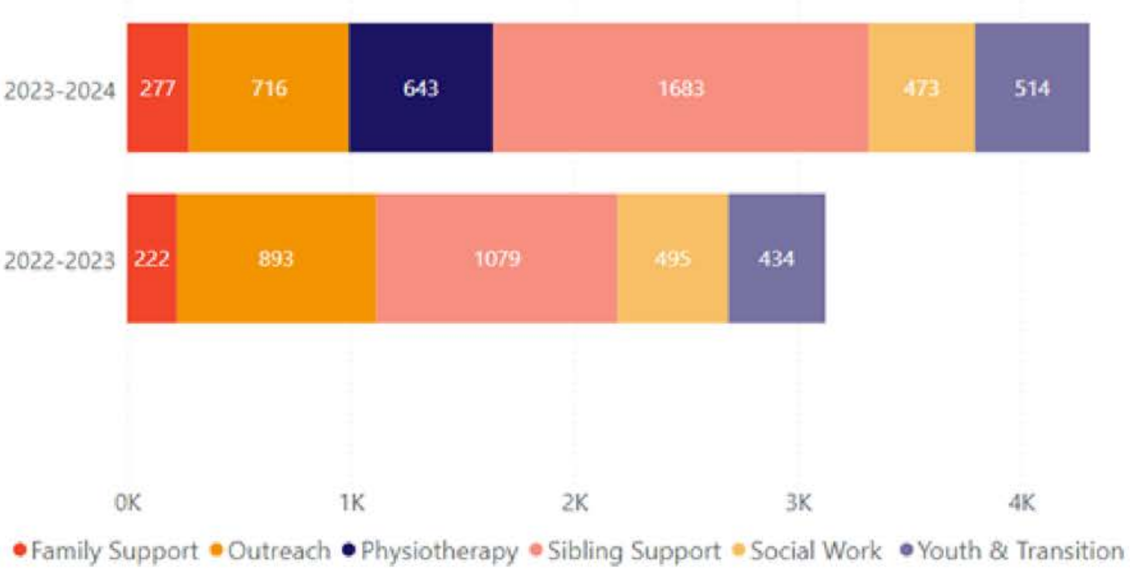
Community and family support services

More families are now choosing to receive support in their own homes. We recognised the need for more outreach nursing, and increased staffing in those service areas. The team has been joined by an additional community nurse specialist and a youth and transition worker.

The community and family support team delivered 5214 contact hours, an increase of 29% from the previous year. The increase in activity can be attributed to the introduction of a grandparents support group, The Keepsake Circle (remembering children through song) and the ability to conduct more face to face appointments with a greater pool of staff.

The graph below shows the contact hours delivered per discipline.

CAFSS contact hours



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 for 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 built much stronger and collaborative working partnerships with our main Integrated Care Board: Buckinghamshire; Oxfordshire and Berkshire West (BOB) and now welcome them on-site for quarterly visits. We have not had any requests for quality assurance visits.

Complaints/compliments

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

We have had two formal complaints this year. We always respond to feedback from service users in a timely manner. Both of these complaints were resolved satisfactorily.

We truly appreciate the value of collaborative working and this year we strived to work even more closely with the local hospital, community services and other children's hospices.

Below are some messages of appreciation from professional stakeholders:

- *'Thank you for the support that you/your team provided to our patient (child) who died at home on Saturday morning. The joint working enabled her to die at home as her parents wishes, and although there were challenges along the way as there always are, the teams worked well together. We would not be able to do this without collaborative working and your expertise.' (Paediatric Consultant, Wexham Park Hospital)*
- *'Thank you so much for your patience in waiting for (child) and her parents to be ready to come and stay. I have just caught up with Mum who said that their first stay was "phenomenal" – the staff were amazing with (child), they could 'just relax' and that Dad who had been very nervous didn't want to leave by the end of their stay. Mum couldn't sing your praises highly enough and I am so grateful to your team for ensuring that they have had a break from the stresses and strains of their hectic lives. They even 'heard and took away' when someone mentioned that if symptom control became an issue, you could potentially help.' (Children's outreach nurse, Great Western Hospital)*
- *'Sibling team member was very professional, firm and fun.' (Headteacher of school)*
- *'From the bottom of my heart, thank you for allowing me to spend my day shadowing your team today. Unsurprisingly, each and every one of you blew me away with the endless warmth, grace and care you provide.' (external professional)*
- *'Can you send this accolade on to your teams. (Child)'s parents said in this mornings meeting that Helen & Douglas House has been a huge support to them. They are so thankful. Dad, advised you have been the biggest support both on the medical and family support side which has been priceless. Dad reported (sibling) has fun going, she doesn't really understand why they go to Helen & Douglas house but loves to play there. Wonderful to hear for this family who are really struggling with so much on their plate right now.' (Community Occupational Therapist)*

- ‘I am pleased that the Child Death Panel in October recommended you (Medical Director) and the team at Helen and Douglas House for a Commendation Letter. It was shared at the meeting that (child) was the first baby in the UK to have a planned homebirth with an antenatal palliative care plan. This meant that the family and (child) were able to have her home with them for the whole of her short life. It was acknowledged that there was excellent multidisciplinary communication and team working across maternity, neonatal, and palliative care. The parents’ wishes were followed, and clear plans were created antenatally regarding birth planning and symptom management.’ (Independent Chair, Oxfordshire Safeguarding Children’s Board)
- ‘I wanted to write to you all to let you know the very exciting news that Oxford Brookes has been ranked number one in the 2024 Guardian university league tables for Children's Nursing programmes in the UK! I wanted to write to say a massive thank you and congratulations to you all as well. 50% of the students' learning and time on the programme is in practice, and we all know that you provide absolutely fantastic and extremely supportive placements. Being rated as the best place to study Children's Nursing in the country really is representative of our partnership working between university and practice.’ (Senior Lecturer in Children's Nursing, Oxford Brookes University)

Elliot meeting a chicken during our Easter family party

Part seven: Service improvements

Equality, diversity and inclusion

We are proud to say that Helen & Douglas House has been awarded a silver accreditation by the National Centre for Diversity.

We worked towards attaining the National Centre for Diversity standards, steadily completing the actions which came from our Investors in Diversity first review with on-going liaison with our EDI Advisor. We embedded our EDI Engagement Group, who facilitated regular guest speakers, awareness days, staff stories and educational resources. The calendar of events included workshops on Neurodiversity and Black History Month, an educational session on Judaism, Stress Awareness and Burnout sessions and an informative presentation from Carer's Oxfordshire. Staff set up several network groups to provide valuable support to each other.

We recognise the accreditation as a milestone in our ongoing journey toward greater inclusion for all and we look forward to continuing doing all we can to drive forward impactful initiatives to reap the benefits that a diverse and inclusive culture brings.

Increased bed capacity

From September 2023 we were in a position to safely provide care for up to 5 children, 6 nights per week. The seventh night is available for children requiring symptom management and end-of -life care. This meant we were reaching more children and meeting the needs of more children and their families. We were able to deliver more planned episodes of care, whilst remaining responsive to the changing needs of children and to provide better opportunities for symptom management and continuous end-of-life care.

Play

We have extended the hours that our play team work to ensure more children and siblings have access to fun and play during their stay. The play team now offer support/activities 6-7 days per week. This dedicated team has worked incredibly hard to understand the play needs of children on our caseload and to provide meaningful, person-centred play to every child staying with us.

Digital play

This year we explored how digital technology could enhance the experience of children attending Helen House. Below are some examples of some equipment we purchased to enrich sensory interaction and communication.

- Yoto players – audio books/stories and music on a portable device for the children to listen to – removes the need for screens. Can listen to stories, podcasts, music or even white noise.
- Applications on iPads: TacPac, an application used on iPads to play music to facilitate delivery of tactile communication sessions, Spotify to listen to music in the bath whilst allowing children to feel the vibrations. Applications are also used during music therapy sessions to allow children to make music with minimal movement.

- Updated sensory wall panel which has a big mac switch on to voice record sounds, also allows recording of personalised messages for children to press and hear.
- Polaroid camera: Children can instantly see and hold their photos, and take home memories of their stay.
- Talking scales: Children can hear the weight of ingredients during baking sessions.

Siblings

Siblings over the age of 8 had a new opportunity to attend a 4-day residential camp over the summer. This created a safe space for siblings to enjoy time with other children processing similar emotions. Activities were created around giving siblings ways of expressing themselves whilst having a lot of fun. This was very popular and more residentials are planned for the coming year.

Some of the siblings doing an Easter egg hunt

Transition

One of Level 4 consultants has been awarded an extra session per week, by the BOB Integrated Care Board (ICB) to support the needs of young people with palliative care needs who are transitioning to adult care. Work has begun on piloting a Transition Tool locally to support seamless transitions for young people leaving children's services and entering into adult services. A series of transition teaching sessions for adult hospital and hospices were delivered by our consultants, outreach and youth & transition team to enhance the transition from children's to adults' services.

Digital transformation

This year was an exciting time across the organisation with a significant drive to optimise the use of technology to improve accuracy and efficiency. Some examples include a new central intranet page for all staff (The Hive), which includes pages for each directorate and generic pages for all staff. This is a central repository for clinical staff to access opportunities for training and clinical supervision, newsletters, important updates etc. Another example is the use of technology to engage families in a timely manner: web forms for feedback and invites to events.

Learning and development

Based on feedback from staff across the clinical directorate, and a scoping of the current training programme, the annual training offer for staff has been refreshed. Clinical staff can access two multiprofessional inhouse training days a year, bringing together those who work inhouse and in the community. In addition, inhouse staff access two further role specific days across the year, enabling more bespoke education for their roles and training needs. Additionally, the education offer is responsive to the needs of children and young people, and to changing guidance, so extra learning opportunities are added when required. Our inhouse offer now also encompasses Paediatric Life Support training for staff. We are further embedding conflict management training throughout the clinical directorate. The practice development nurses also provide a significant amount of one-to-one training for clinical staff, enabling the training to be tailored to an individual's unique learning needs.

Clinical supervision

We expanded the opportunities clinical staff have to access clinical supervision. There is now capacity for supervision sessions responsive to a service need, alongside pre-planned sessions. Clinical supervision facilitators continue to offer a range of models of excellent supervision. This year we also introduced restorative and resilience-based supervision held by our Professional Nurse Advocate. Restorative supervision demonstrates effectiveness in reducing burnout and stress in health professionals. We are excited that a second nurse will be undertaking the Professional Nurse Advocate masters level course later in 2024, which will enable us to offer more sessions of restorative clinical supervision. Local and national clinical supervision communities of practice provide opportunities for Helen & Douglas House to be kept up to date with wider practice, and to contribute to the discussion about delivery of clinical supervision within the unique setting of a hospice.

Increased collaboration with local universities

Members of the professional development team have worked with Oxford Brookes on the recruitment process for those wishing to study children's nursing. We hope that building these early connections with potential students will increase their awareness of PPC and may contribute to recruitment in the future. The Head of Professional Development also provided feedback on the Children's Nursing third years' service improvement projects. Several staff from the clinical directorate have taught on the subject of palliative care on the Children's Nursing undergraduate programme at Brookes. We are working to expand our offer to students to enable more students to access placements at HDH and enhance understanding of paediatric palliative care, and we have had our first student from an Open University nursing course.

Collaboration with our Tertiary Service

We now have access to a hot desk office near the Paediatric Intensive Care Unit (PICU) at the Oxford University Hospital. Our medical team worked with consultant colleagues at the hospital to understand the best models for specialist palliative care in-reach and collaborative working. This has supported early identification, which remains a key priority.

Collaboration with Integrated Care Board

One of our consultants has been appointed as a Children and Young People Clinical Lead (PEoLC) for our local integrated care board (BOB ICB). Our consultant has been working closely with the ICB's Adult Lead to collaboratively meet their objective to 'improve access and experience of palliative and end of life services to enable people of all ages to die well'. This further supports our integration into the regional system.

Expansion of family and bereavement support

We have expanded our family and bereavement support team to further develop our service and adapt to the ever-changing needs of families. This year we established a bereaved grandparents group and delivered the first workshop. We also supported 10 families to work with the Keepsake Circle, to memorialise their child in song and the opportunity to attend a concert where all the songs will be played.

Part eight: Responses to the Quality Accounts

Helen & Douglas House
your local children's hospice

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fundraising@helenanddouglas.org.uk
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Care Quality Commission Location ID: 1-1731744597

Helen & Douglas House
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Quality Account 2023-24