

Quality Account

2022-23



Iris with the PAT dog - animals bring
therapeutic benefits and wellbeing


Helen & Douglas House
your local children's hospice

Our Vision

Every life a full life,
every death a
dignified death

Contents - Helen & Douglas House

Quality Account 2022-23

Our vision, mission and values	
Who we are and who we serve	4
Part One - Statement of Assurance from the Chief Executive on behalf of the Board	
Part Two - Celebrating 40 years of paediatric palliative care	8
Part Three - What we achieved in 2022/23	9
Patient safety	
Clinical effectiveness	10
Patient experience	
Family story - Meet Tillie	12
Part Four - Priorities for improvement 2023/24	13
Patient safety	
Clinical effectiveness	
Patient experience	
Siblings' story - How we support siblings	14
Part Five - Overview of services	15
Financial considerations	
Information Governance	16
Clinical coding error rate	
Participation in National Clinical Audit	
Local clinical audits	
Infection, Prevention and Control	
MHRA and Patient Safety Alerts	17
Research	
Education	18
Part Six - Review of quality performance	19
Incident/excellence reporting	
Safeguarding	20
Equality, Diversity and Inclusion Strategy	21
Duty of candour	
Freedom to speak up	
Patient experience	20
Activity report	25
Part Seven - What others say about us	29
CQC	
Commissioners	
Stakeholders	
Part Eight - Service improvements	31
Part Nine - Responses to Quality Account	35

Our 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, and 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
- Transition
- End-of-life care
- Cold bedroom for children to be placed when they have died



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 in community settings.

Our Vision, Mission and Values

Who we are and who we serve continued.

Children and young people 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 consultant-led palliative care, a wide skill mix of 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 nursing and medical 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. The teaching assistant 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 in hospitals and community settings to ensure that care is seamless and coordinated.

We remain a central voice in national forums relevant to palliative and supportive care, actively seeking opportunities to improve practice, structural delivery, and funding of services to this population.



Edith with Chloe from the Play Team

Part 1 - Statement of Assurance from the Chief Executive on behalf of the Board



A warm welcome to this year's Quality Accounts. This year has been particularly special with the celebration of 40 years of the opening of Helen House and children's hospice care. I take great pleasure in sharing the successes we have achieved over the last 12 months.

As Chief Executive Officer of Helen & Douglas House, I feel privileged to share the Quality Accounts as a key part of our public accountability as a care provider. I welcome the sharing of this overview of the formal and informal aspects of quality, safety and patient experience. This report aims to provide clear information about the quality of our services, so children and their families may feel reassured, safe and well cared for.

This year we saw a 38% increase in referrals to our service, so meeting this demand has been a rewarding challenge for us. We have worked exceptionally hard to expand various aspects of the service including our medical provision, nursing staff, play team, sibling support and social work support. The care team have been immensely dedicated and supportive to induct over 15 new members of staff whilst working tirelessly, but enthusiastically to support children and families. Our community and family support workers have kept in regular and close contact with the parents of the children we support. One of the biggest accomplishments I would like to personally share is safely increasing our bed occupancy by 60% and being able to achieve 91% occupancy over the last 12 months. This meant we could be more responsive to families needs, such as increasing our end-of-life support by 103% compared to the previous year.

Staff across the clinical team from consultants to nurses, have been involved in a variety of research projects and articles that have appeared in peer-reviewed journals. Our Medical Team have made an important contribution to local and regional teaching and training sessions. Collectively these resources have provided opportunities for better joined-up working, increased regional competence in the delivery of palliative care and increased the prominence of Helen & Douglas House.

Staff across the care team have enjoyed providing plenty of opportunities for fun and play for children and their siblings. These wondrous occasions included farm parties, stay-and-play days, music sessions, animal visits, concerts, trips off-site and Disney-themed parties. Our sensory room was refurbished this year to provide a bigger, better, and more sensational experience for children and families.

Feedback from families has been overwhelmingly positive; from families whose child is currently using the service and from families who were supported by us for their child's end-of-life and bereavement. It is a true reflection and appreciation of our competent, skilled and sincere staff and volunteers.

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

We have remained committed to developing the competence and level of skills of our staff. This includes supporting two nursery nurses through the Nursing Associate registration, one Nurse to complete Level 7 Advanced History Taking and Assessment, and one nurse to complete Prescribing for Clinical Practice.

We have been working together with statutory partners and commissioners as active members of the Managed Clinical Network for Children and Young People's Palliative Care for the Berkshire, Oxfordshire and Buckinghamshire (BOB), Integrated Care System. This aims to provide better choice, better access to palliative care and seamless transfers of care.

We are very excited for the year ahead as we continue to meet the aims of our three-year strategy. We aspire to deliver world-class palliative care, and extend and develop our clinical service to meet the needs of every eligible child and family from the 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 this year. We are proud of all we have achieved and pleased to have been of service to people who have sought our help during this time.



Clare R Periton
Chief Executive Officer
Date: June 2023



Nathan releasing the butterflies



Local company Dentons on their fundraising day

Part Two - Celebrating 40 years of paediatric palliative care

November 2022 was our 40th birthday and the 40th anniversary of children's hospice care worldwide. Helen House was the first place in the world where someone took a stance and declared that children had an equal right to a dignified death. The United Nations has accepted Specialist Palliative Care as a Human Right for Children: **that journey started with us.**

Helen House opened its doors in 1982, starting as a home-from-home experience to support families of a child/children with a life-limiting condition.

During the first 20 years, Helen House increased its service offer to include bereavement support and sibling support, and supported the opening of other UK children's hospices and one abroad.

Helen House spent the next 20 years working on enhancement of quality of life, and support for the family; including the management of distressing symptoms, provision of support stays and care through death and bereavement.

Helen & Douglas is now a place where specialist paediatric palliative care is delivered, where we have an active and total approach to care, embracing physical, emotional and social elements, for children and young people with life-limiting or life-threatening conditions. Helen House has gone on to inspire 54 children's hospices across the UK and around the world.



When Helen & Douglas House was opened 40 years ago

Part Three - What we have achieved

Patient safety and outcomes

Strengthen our approach to monitoring, auditing and benchmarking the quality of the services and the outcomes for children and young people.

We will prioritise the collection, analysis and review of quality and outcome information to inform improvements across the service. This involves participation in local and regional audits, and/or national benchmarking programmes. There is no nationally agreed outcomes framework for hospice care, therefore strong relationship building with similar services will be required to achieve this.

To 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.

Update

We are confident that we have a high reporting culture across the organisation. This year we ensured that action plans from audits were regularly reviewed and individuals managed identified tasks to increase compliance.

We worked collaboratively with other children's hospices to ensure that we covered a wide range of audits. This year we included responsive audits to broaden the breadth of our quality and compliance. Some examples of this are auditing the use of electronic patient records and repeating a hand hygiene audit after a quality improvement initiative.

Learning and areas of improvement were disseminated face-to-face during regular training days for Clinical Teams. Themes and trends from audits and incident analysis were discussed with the Learning and Development Team to influence the content of the training sessions and further education requirements.

We completed six monthly trend analysis for medication errors, as they are the most reported clinical incident category. We found the increase was proportionate to the increase in bed nights of care we have delivered.



We helped Riley celebrate his 10th birthday in our garden

Part Three - What we have achieved

Clinical Effectiveness and accessibility

Ensure our service offer is accessible to all families who are eligible.

Becoming more proactive in identifying and understanding the needs of children and young people from the whole community, reflecting diversity at an individual level. Particular emphasis to be given to under-represented communities, people who have a protected equality characteristic and people whose circumstances may make them vulnerable. Ensuring that our teams have the resources, competencies and skills to meet the needs of the diverse people who use our services and deliver high-quality, person-centred and safe care.



Habibou enjoys a music session

Update

We expanded the clinical team this year to meet the increasing needs of children and families, and to meet the demands on the service. In line with our strategy, we identified the need and recruited the following positions: an additional Level 4 consultant, nine registered nurses (RN), two play team members, one social worker, a head of professional development, and a physiotherapist. To safely do this, we staggered the employment of new recruits to ensure that we were able to support high-quality care to children whilst providing a comprehensive induction to new members of staff. We have also increased the skill mix in the team with the addition of a registered midwife.

We had active participation in the development of a Managed Clinical Network for Children and Young People's Palliative Care for the Berkshire, Oxfordshire and Buckinghamshire (BOB) Integrated Care System (ICS), working together with statutory partners and commissioners. This enabled us to continue to understand the changing needs of children and young people across the demographic and locality.

We were fortunate to be part of a small group of children's hospices to take part in a project-led by Disney and Together For Short Lives, 'Unlocking the door to Children's Hospices'. This focused on understanding the reasons why families find it difficult to take up the offer of hospice care.

Patient Experience

To extend our bereavement support to families to more family members and to families that have not previously had contact with our service.

Supporting families and connecting with them at the time of a child's death, allows us to offer that family a unique experience in the days and weeks following the death. Our priority for this coming year is to extend our service to more families and all family members, including siblings and grandparents. Long-term outcomes for these families will be better than families who do not receive acute bereavement support. To deliver this we will need to increase the resource within the family support teams and develop volunteering roles and opportunities.

Part Three - What we have achieved

We will engage with other service providers (such as local NHS services) to promote and optimise the use of our Little Room (cold bedroom). We will also engage with local emergency services (police, fire and rescue) to optimise the use of our Little Room in the event of unexpected death so that families that have never used our service can benefit from the immediate support and care that we can offer.

We will work within our planned volunteering strategy to extend the reach of our bereavement services to our existing clients and to facilitate referrals from external agencies, partners and self-referrals.

Update

The family and bereavement support team has done a considerable amount of work on increasing awareness of the services we deliver. This includes work on building stronger working relationships with professionals in the local NHS trusts; acute hospitals and community nursing teams. Literature in the form of learning and teaching sessions, leaflets and attending ward rounds has contributed to a better understanding of our services and an increase in referrals.

This year we recruited a Family and Bereavement Support Team Lead to fully explore the gaps within this part of our service and lead this team in meeting unmet needs. We began to develop a staff understanding of how we can support families who experience the sudden death of their child, as we now offer our services to any family affected by this.

We have started to develop a model of bereavement support that can be delivered by trained volunteers. Our bereavement team are working in close collaboration with our volunteering service to ensure that we have the governance, training and supervision structures in place to deliver this. We are grateful to the many hospices that have shared their experiences.



Meet Tillie

Tillie, from Oxfordshire, was born in January 2021 during lockdown. She was her mother's fourth child and had a healthy birth. But, a day later they noticed Tillie had breathing difficulties. She was rushed to hospital in Banbury, later ending up at the John Radcliffe on life support. Then, just six days into little Tillie's life, a decision was made to turn off her life support. This is when she came to Helen & Douglas House for end-of-life care.

Over two years later, Tillie has defied all odds and is now a regular visitor to the hospice for supportive stays. At one day old she was diagnosed with a rare condition which meant that her right lung didn't develop. This then caused other complications for her heart and surrounding organs. After the decision was made to turn off her life-support machine, they didn't think she would even survive the journey to the hospice.



Once Tillie and her family arrived at Helen & Douglas House, they were finally able to spend time together. Her three older siblings, Millie, Mason and Annie, could meet her for the first time, and get to say their goodbyes in a comfortable safe space. After being separated due to lockdown, they could be together for those final days. Her parents could also spend the nights with Tillie. When they thought she was dying, it meant they could be together.

The family spent 15 nights at Helen & Douglas House after Tillie came off life support until the family made the plan to go home together. The care team trained them on everything and anything they needed to do to keep Tillie healthy and feel confident to care for her on their own at home.

'Without Helen & Douglas House we wouldn't be as confident caring for Tillie and her conditions'. Jodie, Tillie's mum.

Now, over two years later, Tillie is a happy child who brightens up the hospice with her smile on her visits. She is still very vulnerable to respiratory problems and infections and has had many different types of illness over her short life. But, as her parents say, 'she is a miracle and always pulls through. We monitor her stats at home as much as possible, but sometimes she does need a bit of extra support'.

Tillie's life expectancy is unknown, but her parents say that she will always be on palliative care. She goes for regular heart scans and visits lung specialists, but the longer she goes on, the stronger she gets in terms of adapting to her complications.

Tillie and her family come to Helen & Douglas House for both regular supportive stays and for complex symptom management. They firmly believe that they have coped better with the help of Helen & Douglas House as part of their journey in caring for Tillie.



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).

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 is to migrate all paper records on 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 access 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 EPR system to us. All training and templates will be endorsed by OUH to ensure we maintain the same quality of competency and output.



Jasper during a supportive stay

Patient experience

Maximise the impact of the support we receive 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.

How we support siblings

It is well known that we care for children living with life-shortening and terminal conditions, but we are also proud to support the brothers and sisters of the children who come to the hospice. We offer this in a variety of ways, depending on the level of support the sibling requires, their age and other factors.

When a child is diagnosed with a terminal or life-limiting illness everyone in the family is affected. The stress of frequent hospital visits, multiple treatments, and the other harsh realities of dealing with a terminal or life-limiting illness can take a major toll on family life. That inevitably includes brothers and sisters, who find it upsetting to see their sibling's health decline. It can also mean they have less time and attention from their parents as their vulnerable sibling often needs 24/7 care. This is where our support comes in.

We can offer one-to-one sessions in a place where a sibling feels most comfortable, group support and also day trips and residential camps. Our support groups are divided up into The Elephant Club - for 6-11 year old siblings, and the Siblings' Group - for those aged 12-17.



Harry and his sister visited the Blenheim Lights

We understand that younger siblings may be worried about discussing their worries and fears with their parents because they don't want to add to their concerns. This can make them feel anxious and alone. With our groups, meetings and outings, we can provide a supportive place where siblings can talk about what they're going through with people who understand. This might be with our trained counsellors, with our play specialists or even with other children going through the same thing as them.

Finn, whose brother was cared for by the hospice until his 19th Birthday (when he transitioned to adult care), has been part of the Helen & Douglas House siblings club for over 10 years. He said

'The team organised lots of fun group activities including trips, outings and, during lockdown, online quizzes. Our family have enjoyed many activities organised with the Siblings' Group.'

A few years ago Finn and his sister Niamh went to the Longridge Centre in Marlow for a two-day residential trip which included lots of activities like life-raft building and laser tag. They also took part in an Escape Room in Oxford which they said 'was amazing'. The group also provides them with the opportunity to meet and talk to other children in similar circumstances to them, to discuss how they are feeling and just have fun.



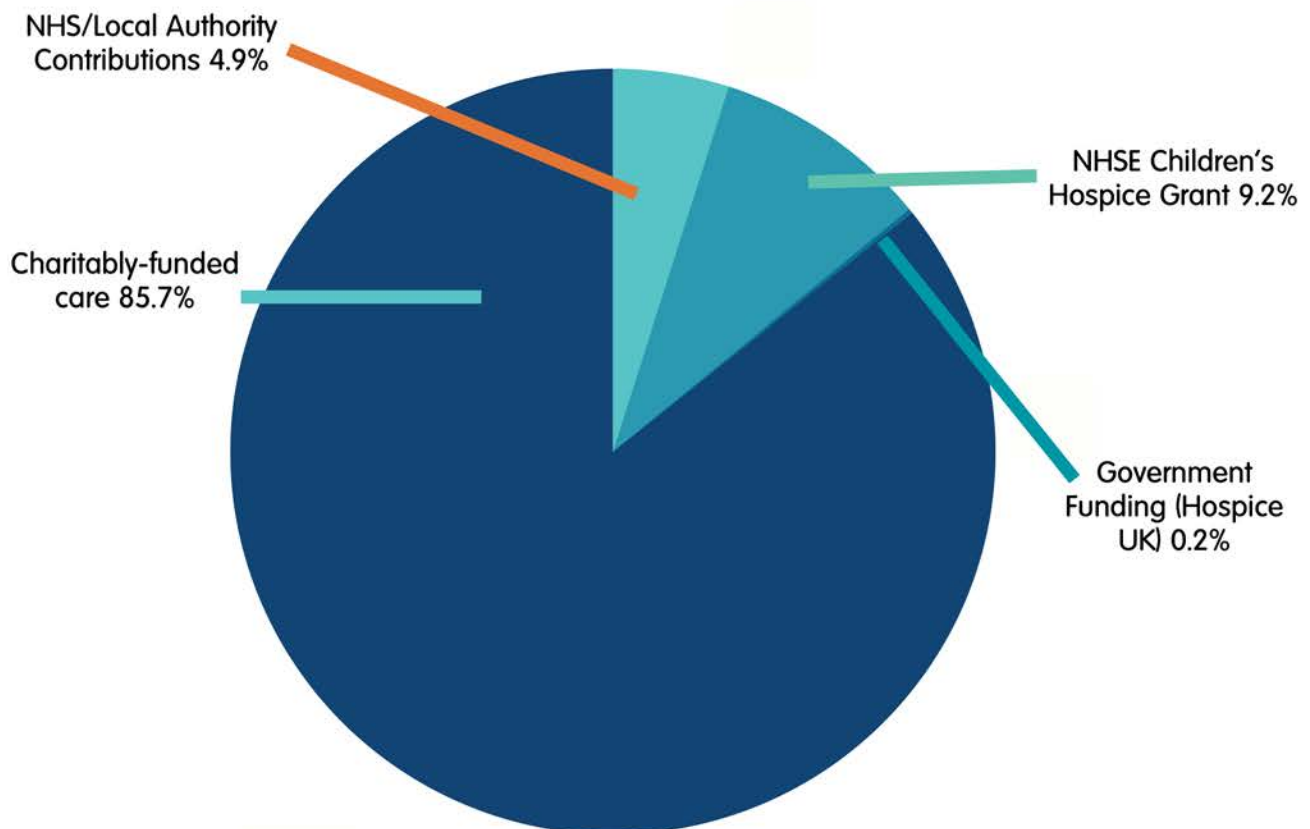
Niamh, Cian and Finn with their artwork from a sibling support session

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 donations, profit from our charity shops, and a lottery, in addition to negotiated contributions from public sector/statutory bodies. For the year 2022-23, public sector contributions to care only represented 20.5% of the hospice's total expenditure on care services (patient care, family and bereavement support).

Funding Sources for Hospice Care 2022-23



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. In June 2022, Helen & Douglas House appointed an external Data Protection Officer (DPO) to assist with monitoring internal compliance, informing and advising on data protection obligations, provide advice regarding Data Protection Impact Assessments and act as a contact point for data subjects and the Information Commissioner's Office (ICO).

Clinical coding error rate

Helen & Douglas House was not subject to the Payment by Results clinical coding audit during 2022/23 by the Audit Commission.

Participation in national clinical audit

In 2022-23 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 analyse audit results and works closely with clinical leads to improve compliance, ensuring the clinical team remains 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. In the coming year, we will be implementing some measures to ensure there are clear parameters for compliance and what actions will be taken to maintain this.

Infection, Prevention and Control

Infection Prevention and Control (IPC) has remained a high priority and has been fundamental to safe service provision throughout 2022/23. The IPC Lead Nurse is responsible for 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 with the following increased as a result. Personal Protective Equipment (PPE) and cleaning of near-patient equipment were all audited four times during the year. Hand hygiene was completed five times during this year, four times as per the schedule and an additional responsive audit to check compliance after a quality improvement project.

Services we provide

Supportive
stays



Outreach

Symptom
Control



End of life
care

Community and
family support
services



Transition

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. Any new guidelines developed in relation to the relaxation of Covid-19 protective measures/testing were implemented after a risk assessment by the Senior Nursing Team.

Research

One of the RN's has been appointed to a half-day-a-week research nurse post funded by the CoPPAR network. This nurse has formed a community of practice with other research nurses in paediatric palliative care nationally and has begun networking with the National Institute for Health and Care (NIHR) clinical research network locally.

We were chosen to be a recruiting site for the Children's Palliative Outcome Scale (C-POS) study into palliative care outcome measures for children, hosted at the Cicely Saunders Institute in London. We successfully recruited more than 10 families to partake in this study.

Our Medical Director continued to co-Chair the Together for Short Lives/Association of Paediatric Palliative Medicine (APPM) joint research group throughout the year.

Publications this year include:

- Co-produced resources to support parents caring for children with gastrostomies. Bethan Page, Emily Harrop, Tania Beale, Katherine Boyce, Colette Smith, Siobhan Butler, Alison Sharrard, Charles Vincent, Alex CH Lee Frontline Gastroenterology Epub ahead of print: doi:10.1136/flgastro-2022-102181.
- Co-producing a library of videos to support families caring for children with gastrostomies: A mixed-methods evaluation with family carers and clinicians. Page B, Lee ACH, Harrop EJ, Beale T, Sharrard A, Yeung N, Vincent CA. Health Expect. 2022 Feb 9. doi: 10.1111/hex.13449. Online ahead of print. PMID: 35141999.
- Pain assessment tools in paediatric palliative care: A systematic review of psychometric properties and recommendations for clinical practice. Chan AY, Ge M, Harrop E, Johnson M, Oulton K, Skene SS, Wong IC, Jamieson L, Howard RF, Lioffi C. Palliat Med. 2022 Jan;36(1):30-43.
- Healthcare Professionals' Experiences of the Barriers and Facilitators to Paediatric Pain Management in the Community at End-of-Life: A Qualitative Interview Study. Greenfield DK, Carter B, Harrop DE, Jassal DS, Bayliss MJ, Renton DK, Holley DS, Howard DRF, Johnson MM, Lioffi C. J Pain Symptom Manage. 2022 Jan;63(1):98-105.

Education

Helen & Douglas House has been active within the NHS England Strategic Clinical Network for all-ages palliative and end-of-life care (PEoLC) in the south-east of England. Our Medical Director is the co-clinical lead for children and young people's PEoLC and another of our consultants is the regional lead for education in the speciality.

Two of our nurses had abstracts accepted for presentation at the Together for Short Lives Conference in September. One abstract described the introduction of Makaton to Helen & Douglas House, which has also resulted in us becoming registered formally as a bronze-level Makaton-friendly organisation. The other abstract was 'Developing a tool to support the contextualised assessment of medically complex paediatric palliative care patients across settings.' Our CEO also delivered a presentation on 'Celebrating 40 years of Helen & Douglas House' and 40 years of world-class hospice care for children.

Helen & Douglas House (care team, medical team, parents, and a trustee) have been key partners in a quality improvement project, which produced important gastrostomy videos and resources and was shortlisted for the Health Service Journal Patient Safety Awards. The two categories we were shortlisted for were: 'Service user engagement and co-production' and 'Patient safety education and training award'.



One of our outreach nurses completed the Non-Medical Prescriber course this year, with a very impressive score in her final assessment. This means she can provide support to families in the community as an autonomous professional.

We have offered placements to a total of three national GRID paediatric trainees in Community Paediatrics and Neurology, as well as training our own SPIN trainees in paediatric palliative care. The Nursing Times also shortlisted our patient safety work (above) for an award in the category of 'Patient Safety Improvement'.

Our Medical Director worked with adult palliative care consultants from across the region to support South Central Ambulance Service (SCAS), to provide care for palliative care patients at home. Education has been provided on advance care planning and the use of anticipatory medication.

Helen & Douglas House was involved in leading the guidance on 'seizures' and 'agitation' for the APPM/Cochrane evidence-based guidelines. These are now ready for stakeholders to use.

Part Six - Part Six: Review of quality performance

Incident reporting

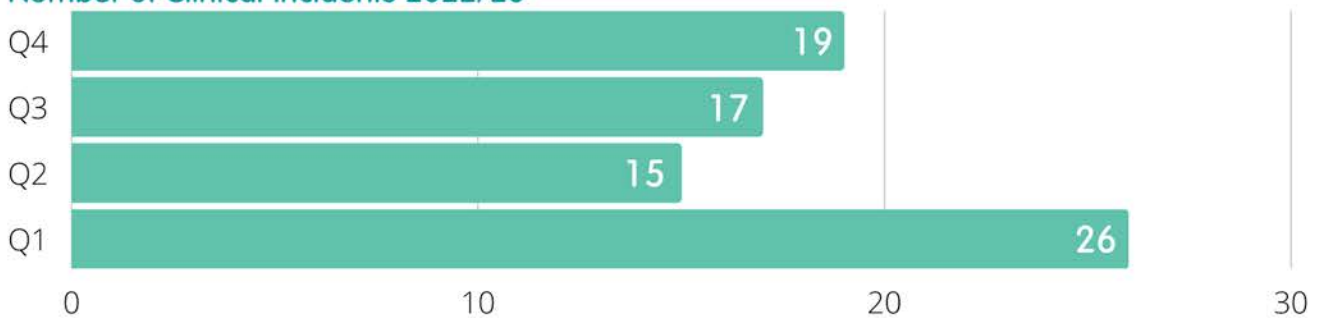
This section gives an overview of the incidents reported in Helen & Douglas House in 2022/23. At Helen & Douglas House we ensure that we place quality and safety of care at the centre of all we do. Every incident is reported through an electronic system and an alert is immediately sent through to Clinical 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.

Type of incident

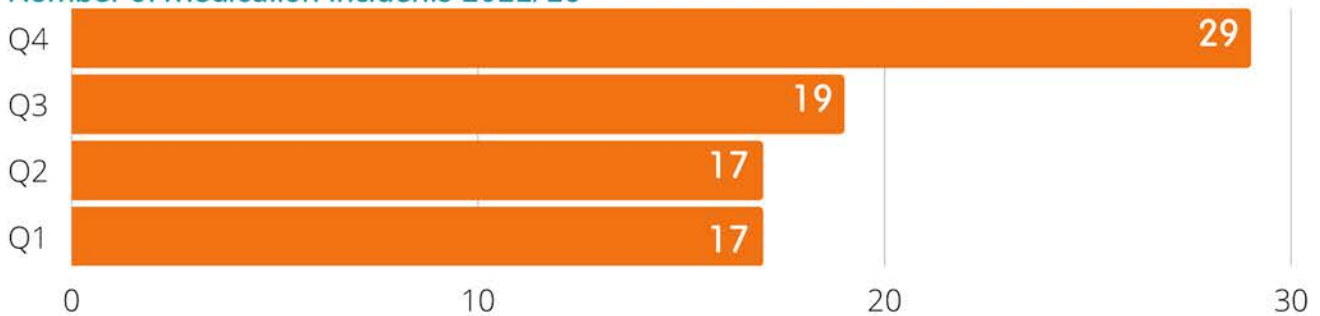
Incident data shows a healthy reporting culture at Helen & Douglas House. We have separated drug-related errors from clinical incidents as they are our highest reported category. This year there was a total of 77 clinical incidents reported and 82 drug related errors reported. None of these relate to 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 increase the 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.

Charts showing the number of drug-related errors per quarter

Number of Clinical Incidents 2022/23



Number of Medication Incidents 2022/23



Although there has been an increase in the number of drug-related errors in quarter 4, we analysed this and it is in proportion to the increase of bed nights of care we delivered.

The table shows the number of incidents in the top five categories:

Incident Category	Number
Other Drug and Medication Incident	25
Prescription Error	13
Omission	11
Device/Equipment Issue	11
Communication Involving Families	7

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.

Safeguarding

Helen & Douglas House maintains safeguarding policies which are in line with current legislation and adhere to the inter-collegiate 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 (CDOP).

Equality, Diversity and Inclusion Strategy

Our biggest equality, diversity, and inclusion news for 2022-23 has been our participation in the National Centre for Diversity's Accreditation in Diversity. All staff were sent a Fairness, Respect, Equality, Diversity, Inclusion and Engagement (FREDIE) Survey in June 2022 and in response to the survey results, we were assigned an action plan from our Diversity Advisor from the National Centre.

We have introduced FREDIE Champion roles across the organisation to advocate for, and actively weave FREDIE through all that we do at Helen & Douglas House. This included the creation of a calendar of events, with highlights including mindfulness sessions for Mental Health Awareness week, our first International Women's Day panel, and Race Equality Week guest speakers.

A FREDIE Hub on Sharepoint was established as a mechanism to communicate internal news, and calendar events, and share webinars, recordings, and articles. Our staff are sharing their stories, sharing what makes them unique and bringing their whole self to work. We have read stories of experiences of mental health, chronic illness, and religious festivals. We heard our first soundscape around our experiences with race and racism. We have an action plan and have set targets.

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 that may result in moderate or serious harm. 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. We have invoked the Duty of Candour once this year.

Freedom to Speak Up

Within the organisation, we have two Freedom to Speak Up (FTSU) Guardians. We endeavour to become an organisation where there is a strong speaking-up culture, where employees are listened to and lessons are learnt, so our services can improve. The role of the FTSU Guardians is to be available for staff to speak to, in a safe environment, about patient safety and any other 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 Nationals Guardian's Office.

Our Freedom to Speak Up Guardians have spent time increasing their awareness throughout the organisation, including visits to the organisation's shops, 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 Nationals Guardian's Office every quarter.

Patient Experience

Our vision is to remain exceptionally committed to 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 in service delivery that may have surfaced as a result of the pandemic. With the relaxing of Covid-19 restrictions, we were able to support more families with in-patient care for end-of-life care and symptom control and offer supportive stays to as many families as possible.

In February 2023 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 we communicate with 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 overleaf for a summary of what families told us:

Patient Experience continued.

Current families: Survey sent to 150 families and had a 40.6% response rate

- 82% said their overall experience was 'very good'.
- 78% said we adapted our service to meet their needs during the pandemic.
- 66% of families who responded told us their child had stayed in-house within the last 12 months.
- 95% of families told us their child was 'always' treated with respect and dignity by staff.
- 82% of families told us we had staff available 'all of the time' to support with their child's personal care and nursing care needs.
- 85% of families told us they were 'always' kept informed about their child's care and treatment.

Feedback on facilities:

- Family flat: Family flat: 36% said exceptional and 25% said excellent.
- Garden: 61% said exceptional and 25% said excellent.
- Bathrooms: 41 % said exceptional and 28% said excellent.
- Food: 33% said exceptional and 31% said excellent.
- Play activities: 36% said exceptional and 25% said excellent.
- Education provision: 36% said exceptional and 25% said excellent.

Bereaved families: Survey sent to 72 families and had a 16.6% response rate

- 92% of respondents said their overall experience of our service was 'Very good' (highest rating).

Experience of families who had used our services prior to their child's death:

- 100% said they were 'always' treated with respect and dignity by staff.
- 100% told us that there was 'always' enough help available to meet their child's personal care and nursing care needs.
- 88% told us that their child's pain was relieved 'completely, all of the time'.
- 78% said they were 'always' kept informed about their child's condition.

All respondents whose child died in Helen & Douglas House responded 'yes definitely' to having enough help and support from the staff team at the actual time of their child's death.

We asked families that had stayed with us if we gave them the time and space to just be a parent and to make precious memories together. 88% said 'yes, definitely'.

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, in the form of an in-patient stay, day stays and, community and family support services. We take great pleasure in sharing feedback from families.

Part Six - Review of quality performance

Patient feedback continued.

Current families:

- 'Everyone is very welcoming and so supportive.'
 - 'Helen House is amazing and we wouldn't cope without the support they give.'
 - 'Always accommodating to our needs. Polite and professional and empathetic.'
- 'We wouldn't be where we are today without it. We are one of the lucky families that have the support of Helen & Douglas.'
- 'As a family we receive so much support from Helen & Douglas House. Our son loves coming to Helen House, so much so that it is a task to get him to come home. My daughter also has received so much support and thrives at the sibling's activities. We are a happier family with Helen & Douglas House in our lives.'
- 'I think the service you offer is amazing and all the staff do their very best to help families despite difficulties such as the pandemic/ staffing etc.'
- 'Nowhere else can parents find people who can care for their child like you do.'
- 'We know we have 24-hour access to advice and support. This has helped us to stay at home and not go into hospital on many occasions. Like how closely the doctors work with his neurologist.'
- 'Their care is exemplary and everyone does their best for us.'
- 'Bent over backwards to provide support in an extremely challenging situation.'
- 'We have been supported by Helen House for over 15 years. They have enriched our lives, helped us understand our son's condition, and understand that life can still be good. They have been there for us in the good and the bad times. The staff are fantastic, so understanding and supportive of our child and our family. We always felt cocooned in safety when we stayed, like everything was all right. When we did have concerns, these were addressed quickly and effectively.'



Ella, who is cared for by the hospice, took part in our Bubble Rush fundraising event

Part Six - Review of quality performance

Bereaved families:

- 'I couldn't think of any point of our time where anything was unliked. Helen & Douglas House is amazing.'
- 'They not only supported me but my family.'

• 'Helen House for us was from home to home.'

- 'With all interaction the staff were very caring and couldn't do enough. All our sons symptoms were addressed and managed and we couldn't be more grateful that he was kept comfortable and for the compassion shown.'
- 'Welcomed us in even during the middle of the pandemic when most were not being admitted. So grateful for this.'

• 'Despite all the restrictions we were provided with pain management and some respite stays which we desperately appreciated.'

- 'Following the sudden death of our daughter we didn't know where to start or where to turn, Helen & Douglas really helped us through this time from supported with registering her death to funeral support and giving us time to come to terms with her death, spending every minute with her after her death and being supported by staying in the family apartment.'
- 'Helen House allows parents to be just parents, not carers. It is extremely exhausting as families trying to do both. At the same time allowing your child to die with love and support desperately needed'.

• 'Helen & Douglas House was a safe haven for us when our son was dying. It allowed us to be parents again and it was so good to be out of the stressful hospital environment.'



Lily-Mae was cared for at the hospice for four years. At the end of her life, we cared for and supported her whole family in a place they felt at home.

Activity Report

Referrals

This year we accepted 87 new referrals - 38% increase from last year.

225 community and family support referrals.

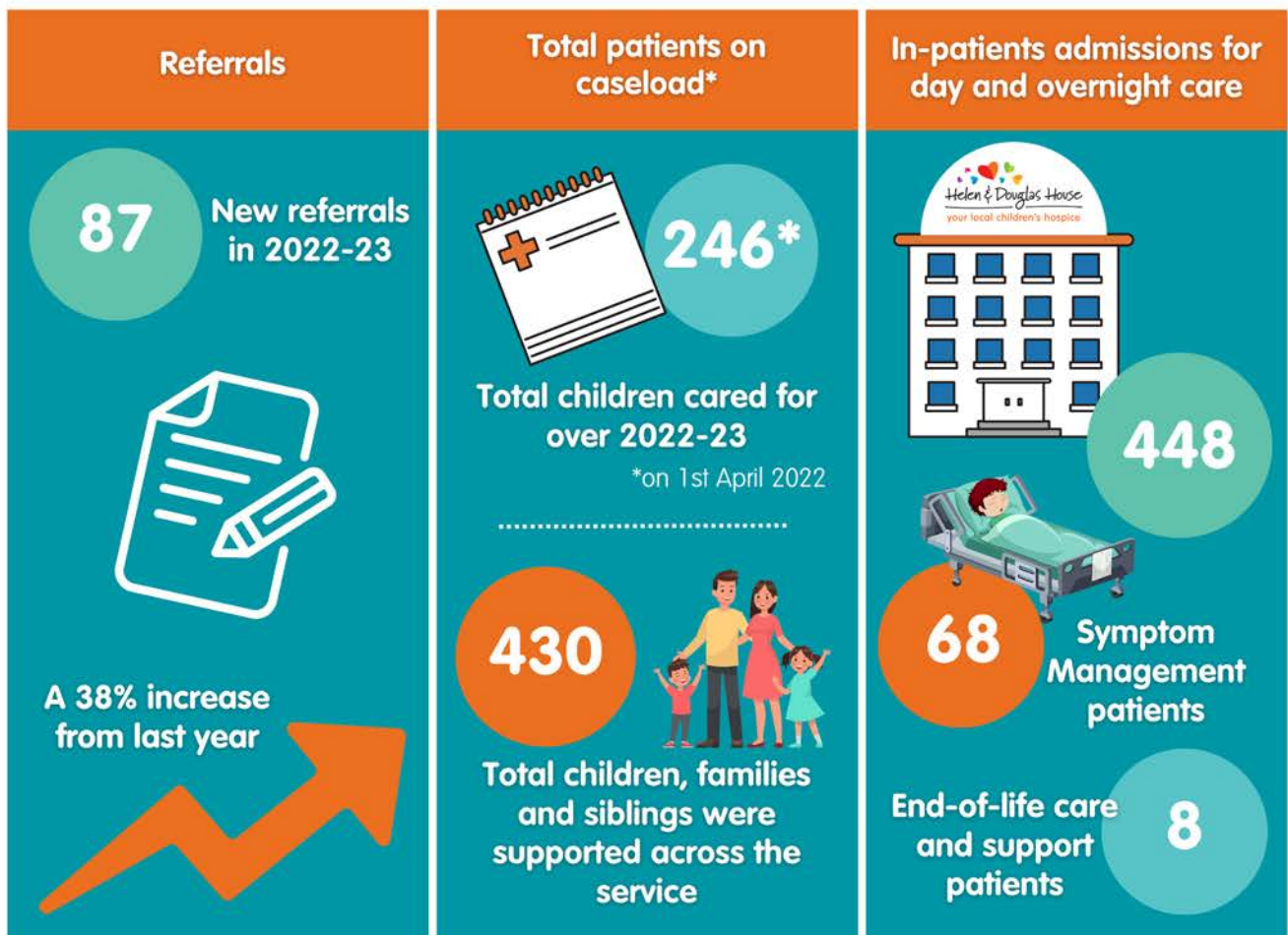
We supported 246 children this year. A total of 430 children, families and siblings were supported across the service.

Inpatient admissions

We had 448 patient admissions to Helen House. The admissions break down as follows:

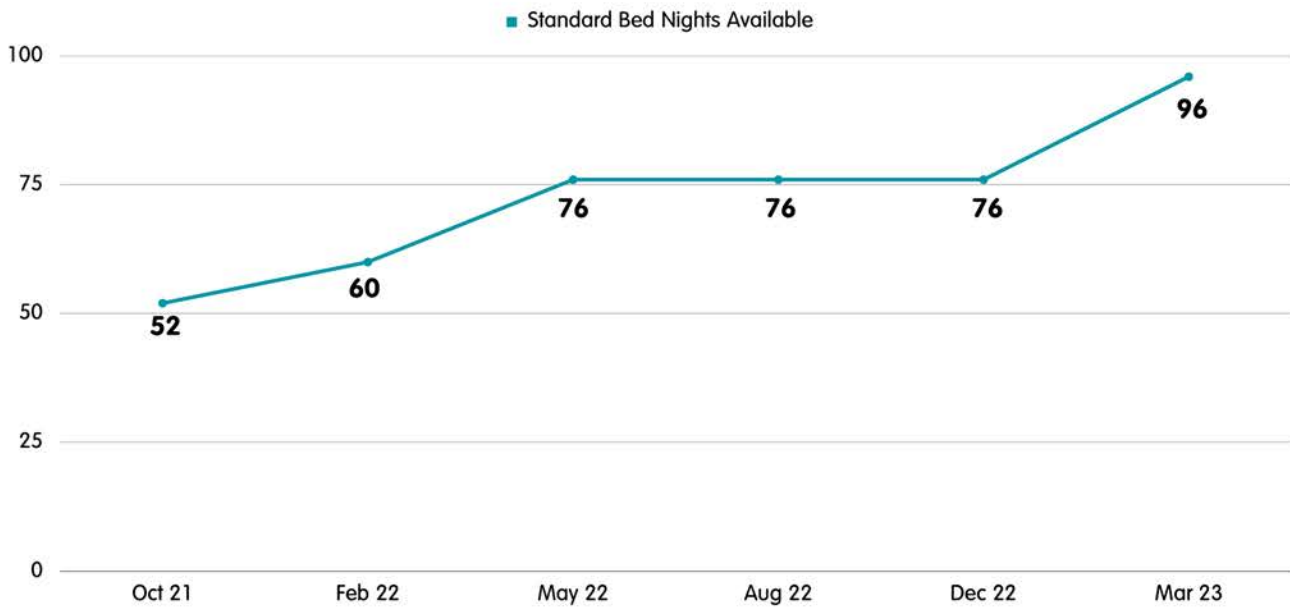
Supported 68 children with symptom management.

Supported 8 children with end-of-life care and support.



Standard bed nights available

From March 2022 to March 2023, the standard bed nights available increased by 60%. This allowed us to provide planned episodes of care and remain as responsive as possible to the changing needs of other children at the same time. 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. The graph below shows the gradual increase of bed capacity over the last 12 months.



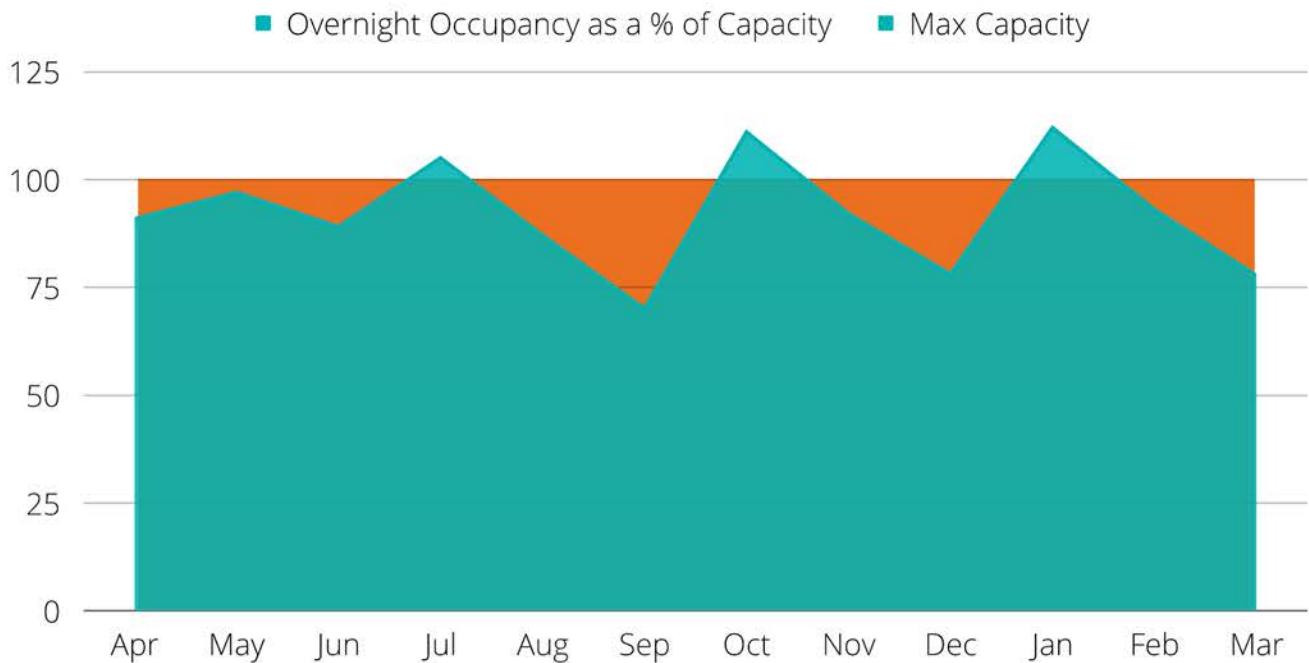
We provided a total of 889 bed nights of care this year. That is a 54% increase on the previous year.

There was a total of 968 bed nights available throughout the year, which means 91% of these bed nights were occupied to provide care for children. In the previous year, we provided care for children for 82% of bed nights available.

Service capacity

Bed occupancy has varied over the financial year, with July, October and January representing particularly exceptional months for the organisation. October was a particularly outstanding month, with the team working incredibly hard to facilitate two end-of-life children staying in the hospice for a long period of time. September, December, and March were our lowest occupancy months, due partly to increased staff sickness, complex patients and the inducting of new staff.

A chart showing bed occupancy over the last 12 months



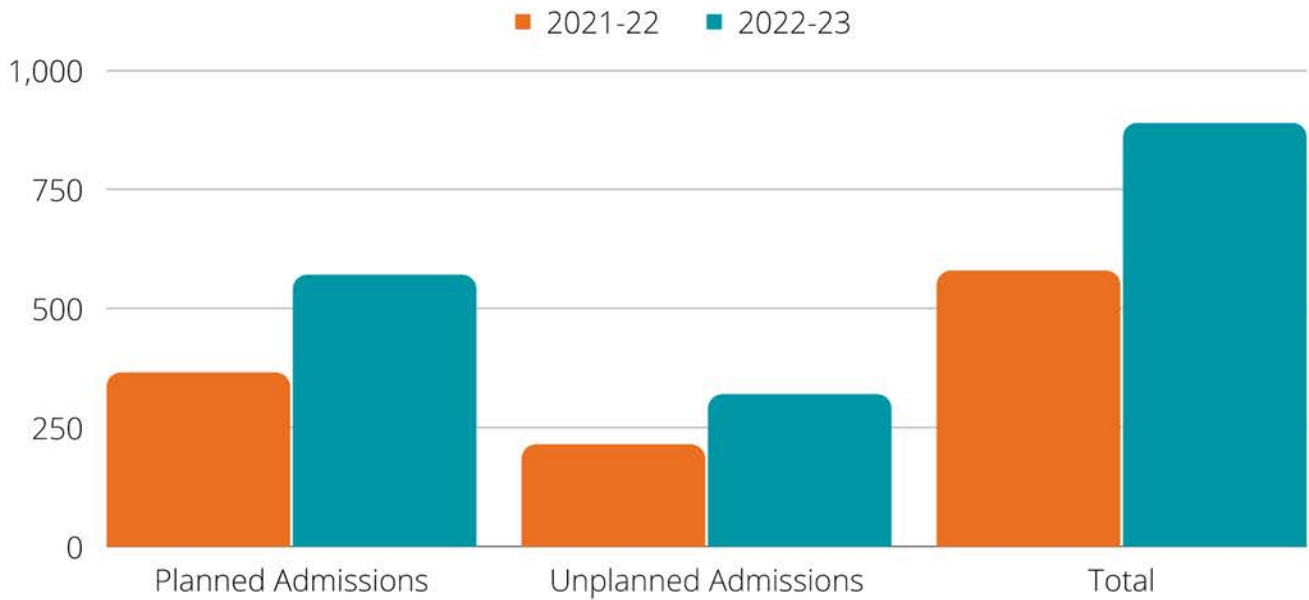
Breakdown of bed nights:

The table below shows a comparison between the number of each bed night activity provided over the last two years. All of our core service offer had a significant increase; we provided a substantial increase in first stays and end of life care.

Activity	Year 2021-22	Year 2022-23	Comparison
First Stay	15	29	Increase by 93%
Little Room	45	49	Increase by 8%
Symptom Management	133	207	Increase by 56%
End of Life	31	63	Increase by 103%
Supportive Stay	342	541	Increase by 58%
Social Emergency*	5	0	Decrease
Step Discharge*	8	0	Decrease

* Social emergencies and step discharges were a service innovation to support Covid-19 pressures on the healthcare system. They do not form part of our current core service offer.

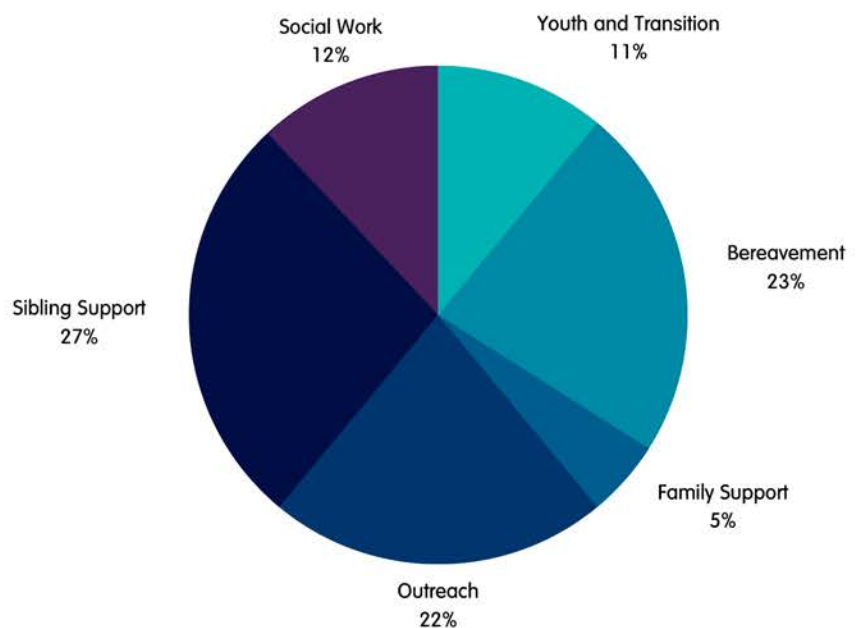
A chart showing bed occupancy over the last 12 months



Community and Family Support Services

The CAFSS team had 4036 hours of contact with patients and families this year. That is a 4% decrease from the previous financial year. This translates to roughly 14 hours of contact time per child. The breakdown of those hours is depicted below, showing a fairly even distribution between sibling support, bereavement, and outreach. All teams saw an increase in face-to-face activities and visits this year as Covid restrictions have lessened. The number of contacts for the CAFSS team was 4934 this year. That is a 15% decrease from the previous year. This is possibly due to the fact that we are now able to offer more face-to-face contact in-house.

- No of Outreach face-to-face contacts – 157
- No of telephone and email Outreach contacts – 726
- No of face-to-face sibling contacts – 373
- No of family support face-to-face contacts – 57
- No of family support other contacts (call/email) – 245
- No of BV parents have we supported – 143



Care 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.

We had a provider engagement meeting with CQC in September 2022. Following this, we were informed that CQC had not found evidence that they need to carry out an inspection or reassess our rating at this stage.

The last comprehensive inspection of Helen & Douglas House was on 6 June 2017. Our service was rated 'Good' overall.

We remain engaged with keeping updated with CQC's new methodology and framework due to be rolled out in the coming year.

Commissioner Quality Assurance visits

We have different contracts and reporting requirements with five commissioners. We had regular engagement, including quarterly quality reporting through electronic means, such as Microsoft Teams and email. We have not had any requests for quality assurance visits but would warmly welcome them.

Complaints and compliments

We have received many compliments over the last year including letters, cards and emails. We have not had any formal complaints this year. We always respond to feedback from service users in a timely manner.

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 some of our stakeholders.

'I wanted to take the chance to say a massive thank you to each and every one of you. I hadn't had the chance to visit Helen House before this or the privilege to see the amazing work that you all do. Having known the family since they arrived in the UK and seeing them on their first day at Helen House, the positive impact that you provided for them at such a difficult time was huge. You created a safe haven for them where they had space to process such a tragic prognosis and provided the care and support they needed. The garden was a favourite of both the family's and (child's), particularly after spending such a long time in hospitals. Your care and compassion is outstanding' (Social worker, Oxford County Council).

Part Seven: What Others Say About Us

Complaints and compliments continued.

'I wanted to thank you for your help and support over the years. You really are such an inspiration and it has been a real pleasure to work with you' (Director of Programmes & Professional Engagement, Together for Short Lives).

'Thank you so much for your excellent presentation at the Palliative Care study day. It is always so helpful to have an update on symptom management and the rationale behind decision-making. We really appreciated you taking the time to come and talk to us, thank you' (Paediatric Nurse Specialist, Oxford University Hospitals).

'Consultant provided support from Helen House for a child who was dying on our ward. On the morning she got the phone call, she came straight to the ward along with a nurse from Helen House, and provided support for the team and the family. She gave a detailed care plan for the escalation of comfort care - which was then needed later that evening. When there was uncertainty about symptom relief overnight, she was available on the end of the phone with advice for the team. Without a doubt, she helped that boy be much more comfortable in his final hours. With this, she was invaluable to both the team on the ward and to the family of the boy. THANK YOU.' (Excellence Reporting Core Team, Oxford University Hospitals).



Fundraising is one of ways we generate income to run the hospice

Just wanted to say a big thank you to everyone who organised the talk. Was incredibly informative and interesting. It was a very powerful and moving set of slides. We had no idea Helen & Douglas House were such pioneers in the area. Truly inspiring stuff to see (Scientist, Abbot Diabetes Care).

As we all continue to respond to and adapt service to meet the increasing complexity of children with life-limiting conditions, it is really valuable to work in close partnership with colleagues. By working together, we are able to enhance the quality of care for children and young people. In particular, the outreach medical support from Helen & Douglas House has ensured children and their families can be cared for in the place of their choice. (Director of Clinical Services, Alexander Devine Children's Hospice).

Sensory Room

The sensory room at Helen House is one of the most engaging and interactive spaces we have. This year we decided to move it to a larger space, to make it more enjoyable, to better support the multi-sensory experience of the children and to enable more children to access it at the same time. The room has specifically been designed taking into consideration all of the children that use the hospice and their varying needs. Our sensory room helps children improve their visual, auditory and tactile processing, as well as fine and gross motor skills.

Some of the exciting features of the sensory room include:

- The waterbed - provides a comfortable, safe and relaxing space for children to have time out of their chairs.
- A variety of lights - including a bubble wall, fibre optic cascade and infinity mirror. The settings on these allow us to interact with the children by changing colours and speeds. Children who are able to can control this themselves using cause and effect.
- A large, interactive, tactile mural is full of bright colours and textures for children to feel. The interactive panels allow children to turn lights on or off, change colours, sounds and play games.
- Floor padding on one side of the room - children have a soft place to play and interact. The floor without padding allows children in wheelchairs or beds to easily access the room.
- Large projector - children can watch their favourite TV shows, movies or listen to music.

Refurbishment of discussion room

We completed a whole refurbishment of our discussion room at the front of Helen House. This room is now a calming and serene space for multi-purpose uses; for parents and their visitors to be able to relax, and is also used as a private space for internal and external meetings. There is a computer station set up to allow ease of access to electronic information when this is required.



The refurbished Discussion Room is now a more welcoming, comfortable space

More specialist medical cover

To meet the medical demands of the service, we have employed a second Level 4 consultant. This means more children using our services will have access to specialist consultant support five days a week.

Part Eight: Service Improvements

Non-Medical-Prescriber

One of our outreach nurses successfully completed the Prescribing for Clinical Practice course. We recognise that having a non-medical prescriber within the service can promote faster access to treatment, improve quality of care, and enable greater efficiency and responsiveness to children's needs.

Physiotherapy

We recruited a physiotherapist towards the end of this year to support children and young people to support with controlling their symptoms and improving the quality of life for both the child and of his/her family. Our physiotherapist has been supporting children at any stage of their illness and working closely with the care team to provide physiotherapy alongside conventional medicine. The support our physiotherapist provides includes education and advice on things that can affect daily life, tailored exercise and physical activity advice and manual therapy. In the coming year, we look forward to expanding this offer to enable us to benefit more children.

Extending opportunity for specialist play

This year we reviewed and increased the availability of specialist play offered to children and siblings we support. Previously we had one play specialist in post. This year we recruited a play leader and another play specialist. Children and siblings in-house are now able to access specialist fun and play activities 7 days a week, with the service due to be extended into the community in the coming year.



Beth enjoying a cooking session

Expansion of family and bereavement support team

We have expanded our family and bereavement support team to further develop our service and adapt to the ever-changing needs of families. This will allow us to maximise the impact of the support we deliver. This also allows us to support more families and family members. This includes the start of building a team that will be able to provide support for families who experience sudden unexpected deaths and be able to signpost to a wide range of external services.

Expansion of sibling support team

We have increased the team by one member, to meet the increasing demand of siblings requiring support. This means more siblings will have access to support prior to and post-bereavement. Siblings now also have access to a wide range of activities including whole-day adventure activities off-site, in accordance with their preferences.

Expansion of social work team

We have now expanded the social work team to ensure that the service has a social worker present 5 days per week. This allows better access and responsiveness to the families' needs. Our social workers aim to improve children's and family's lives by helping with social and interpersonal difficulties, and promoting human rights and well-being.

Inclusion of midwifery expertise

We have expanded the expertise in the team to include a clinical lead who is a registered midwife. This is to enhance the support we can offer families before and after the birth of a child who is either known during pregnancy to have a life-shortening condition or where unexpected difficulties arise around the time of birth.

Expanding learning and development

Towards the end of this year, we employed a Head of Professional Development to lead on delivering a clinical education and professional development programme for all our clinical staff. Some of the work started so far includes mapping the current education offer across all the professions within clinical services, benchmarking against standards and other service providers, and moving towards using this mapping and knowledge to create a more comprehensive educational offer.



Harry trying camouflage face paints at Network Saturday meeting in November

Managed Clinical Network

Helen & Douglas House is an active member of the Managed Clinical Network for Children and young People's Palliative Care for the Berkshire, Oxfordshire and Buckinghamshire (BOB) Integrated Care System (ICS). The aim is to establish partnerships between statutory and charitable providers to build a system that delivers 24/7 specialist palliative care to children and families with 24/7 specialist palliative care with better choice, better access and seamless transfers of care. This is a recommendation of NICE guidance 2016 and the Health and Social Care Act.

Transition

Our new consultant specialist was awarded a 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 strategy and supporting adult clinicians with individual cases in the 19-25 year age group.

Part Eight: Service Improvements

Young people attaining qualifications

The teaching assistant has supported young people to gain qualifications in areas of their interest. The qualifications are awarded by AQA as part of the Unit Award Scheme. This has enabled young people to receive a recognised qualification and helped to boost their confidence and emotional well-being.

Collaboration with our Local Tertiary Service

We have continued to develop a number of working groups across our service and Oxford University Hospitals with the aim to improve transitions for children across both environments. This has included the ratification of procedures for the transfer of a child for compassionate extubation.

We started a new programme to give opportunities for nurses from Paediatric Intensive Care to undertake shadow shifts at Helen House so that they better understand the hospice environment. The next steps are for staff to undertake shadow shifts in Paediatric Intensive Care.



Emily with her sister at our family Easter party

Helen & Douglas House
14A Magdalen Road
Oxford OX4 1RW

Donate - Fundraise - Volunteer - Shop

www.helenanddouglas.org.uk
Fundraising@helenanddouglas.org.uk
01865 799 150



Registered with



FUNDRAISING
REGULATOR

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



Helen & Douglas House
your local children's hospice