

# Quality Account

2021-22



Ella getting 'glittery' during a play session at Helen & Douglas House

  
Helen & Douglas House  
your local children's hospice

# Our Vision

Every life a full life,  
every death a  
dignified death

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# Our Vision, Mission and Values

## 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 in, and around Oxfordshire, until their 19th birthday.

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

# Our Vision, Mission and Values

## Who we are and who we serve continued.

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, in schools and in community settings.

Paediatric palliative care outreach (nursing and medical) is provided within Oxfordshire and the 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.



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



Welcome to this year's Quality Accounts.

I take great pleasure in presenting to you 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 all the formal and informal aspects of quality, safety and patient experience in a single document. 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.

Despite the various pressures we faced this year, bed occupancy remained above 70% throughout the year, with three months reaching 100% occupancy. This has required immense dedication and perseverance of the whole care team in working tirelessly to support children and families, at a time they needed our service the most. We have seen lots of exemplary collaborative working between our staff and the local NHS Trust to facilitate step-down discharges and seamless transfers of care. Over the winter months we were very fortunate to receive some financial support from NHS England which was used to maximise our care offer to ease the pressure on secondary care services.

Our community and family support workers have kept in regular and close contact with the parents of children we support. We saw an astounding 48% increase in contact time with children and families compared with last year. Activity packs and gift packs were also sent to families as an additional way of building and maintaining strong relationships. Staff across the care 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 had great contribution in local and regional teaching and training sessions. Collectively these resources have provided opportunity for better joined-up working, increased regional competence in the delivery of palliative care and increased the prominence of Helen & Douglas House.

Several student nurses from Oxford Brookes University have completed their training placements with us this year, and in March we were joined by two senior medical paediatric trainees who chose to undertake their placement with us. We have also committed to developing the competence and level of skills of our staff. This includes, supporting two Nursery Nurses through the Nursing Associate qualification, and a further two are expected to qualify this coming year. After 20 months of limited contact with other colleagues, in January of this year we held a much-needed virtual all staff conference. This was an amazing opportunity for staff to engage with other colleagues and find out about all the exciting projects and wonderful achievements across the organisation.

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

This year we fully refurbished our garden and garden room to enhance the experience that families receive. Being able to enjoy quality outdoor space is integral to a child and family's holistic care. We are also pleased to welcome our volunteers back, whom we value greatly. We are very excited for the year ahead as we roll out a new 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 celebrating our 40th anniversary and 40 years of Children's Hospice provision.

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 and pleased to have been of service to people who have sought our help in this time.

Clare Periton



Chief Executive Officer

Date: June 2022



## Part 2 - What We Have Achieved

### Patient Safety

**To maintain or increase our incidence of incident reporting and excellence reporting.**

To develop a high reporting culture, recognising the opportunities to learn from our near misses and concerns by developing systems that are a reflection of good practice and quality care, while appreciating the human factors elements of people working within a system.

To ensure that staff feel safe and comfortable reporting incidents, promoting the growth of the service, and appreciating the non-punitive nature of reporting.

To celebrate the good work that happens every day, when our staff engage in a safe and quality service delivering excellent care as standard to our families and children.

#### Update:

We are confident that we have a high reporting culture across the organisation. Within the clinical service, we have introduced a quarterly newsletter with a focus on sharing learning from incidents that have been reported and analysed within the preceding months.

There is a programme of regular training days for Clinical Teams. Reported incidents and any patterns will influence the content of the training sessions.

2021/22 has seen an adoption of Good Practice reporting and this has been embraced by the clinical service with peers submitting reports of Good Practice of colleagues.

### Clinical Effectiveness

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

Reflect on how we access families that meet the criteria of our services and continue to offer a suite of services that meet differing requirements and offer choice. Continuing to offer breaks and support to those families who regularly engage with us and finding ways to support those who may be hard to reach.

Ensuring that our teams have the resources to work together to offer seamless care for our families and are confident to assess the family need in line with our services.

#### Update:

Our new strategy has a focus on increasing our reach. This includes all areas of the service. We have demonstrated an increase in accepted referrals to all teams.

A specific role has been appointed in the Outreach service that includes a focus on engaging with referrers across the region and building partnerships with voluntary and statutory organisations.

## Part 2 - Priorities for Improvement & Statements of Assurance from the Board

A mapping project of palliative care services in Oxfordshire has enabled some gaps in the provision of paediatric palliative care to be recognised.

The organisation has built on an Equality, Diversity and Inclusion Plan which includes ongoing exploration of any barriers to specific communities accessing care. We have also reviewed and improved data collection on EDI for the children we serve.

### Patient Experience

**To extend our current model of bereavement support to families that have not previously had contact with our service.**

Our model of bereavement support is both practical and emotionally supportive and encompasses the entire family from before death, at the point of death and beyond. Effective bereavement support improves long-term outcomes for families.

We will engage with other service providers (such as local NHS services) to promote and optimise the use of our little room (cold room) 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

A volunteering strategy has been developed to include the delivery of bereavement support, enhanced by volunteers. We have funded and are recruiting for a new post, Head of Family Support, to increase capacity in the current team and support the new model of delivery. Two new Bereavement Groups have been launched, offering programmes of support to newly bereaved parents and then a group to offer ongoing support. The first two programmes have been evaluated and have been very well received by parents.



We continue to offer post-death care to children and their families immediately after death. We have been able to offer a service to a number of families who have experienced sudden, unexpected loss of a child who had not been previously known to our services.

## Part 2 - Priorities for Improvement & Statements of Assurance from the Board

### Nadia's Story - Family Story

I've got three children, who each mean the world to me – Alisha, Zaky and Rayyan. And I lost my little boy Zayn in 2017. Zayn had a disease called Niemann-Pick which attacked his nervous system and slowly robbed him of everything - he'll be forever four years old. And always in our hearts.

Rayyan is now the same age Zayn was when he passed away. And, like him, Rayyan needs around-the-clock care. Rayyan has a different rare condition, Infantile Epileptic Encephalopathy. It causes terrifying seizures and means he needs help every second of every day.

I am Rayyan's sole carer, and I do everything for him. He can't sit up, talk, walk or feed himself. But, as his mum, the thing that breaks my heart the most is seeing Rayyan fit like he does. He has seizures every day – and sometimes they can go on for hours. They've been so bad at times that I've had to give him emergency medicine and even be admitted to the hospital.

Helen & Douglas House look after Rayyan like he's one of their own.

Rayyan has been coming to Helen & Douglas House since 2018. He loves it so much. The support and specialist equipment enables him to do things at the hospice that are simply impossible at home, like crafting or having a bath.

But, it is the staff and the incredible care and support that make Helen & Douglas House so special. Every member of the team – from the volunteers on reception to the nurses and doctors - is wonderful in their own way. They always have time to talk and support me, in a way that no one else does. Working at the hospice isn't just a job for them.



*'Caring for Rayyan is exhausting, both physically and mentally. But I don't have to cope on my own as, thankfully, Helen & Douglas House are always there for us.'*



I'd be lost if Helen & Douglas House wasn't there. This is why I'm doing everything I can to help them be there for children like Rayyan and their families – now and always. And that's why I'm sharing my story and asking for your support.

Being at Helen & Douglas House is like having a weight lifted off my shoulders. I can go to bed at night and simply sleep, or spend time with my other children, knowing that Rayyan is safe. I wouldn't leave him anywhere else.

I don't know what the future holds for Rayyan or how long he has left in this world. But I do know we couldn't cope without Helen & Douglas House.

### 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 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. There is no nationally agreed outcomes framework for children's 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.

### 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.

### 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.

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 referral from external agencies, partners and self-referrals.

### Finn's Story - Sibling Story

Finn Morrisroe has been part of the Helen & Douglas House siblings club for over 10 years. His brother, Patrick, has a life-limiting Neurological condition with severe epilepsy. He was cared for by Helen & Douglas House for 11 years, until his 19th birthday. We continue to support his siblings. Finn told us this,

*'Laura organises lots of fun sibling group activities including trips, outings and, since lockdown, online quizzes.'*

*Our family have enjoyed many activities organised by the siblings group. A few years ago Niamh and I 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. We also took part in an Escape Room in Oxford which was amazing. We all joined the online quizzes during lockdown which were lots of fun. We have really enjoyed being members of the siblings group because of the fun activities and trips which have been organised. The group also provides a good opportunity to meet and talk to other children in similar circumstances to us, discuss how we are feeling and just have fun.*

*Helen & Douglas House has helped our family in so many ways. It has provided us with a safe space to create happy family memories. It has also enabled us to go on holiday abroad, spending time together knowing Patrick is well cared for. We have had the opportunity to talk with professionals who helped us when we were feeling anxious.'*



## Part 4 - Overview of services

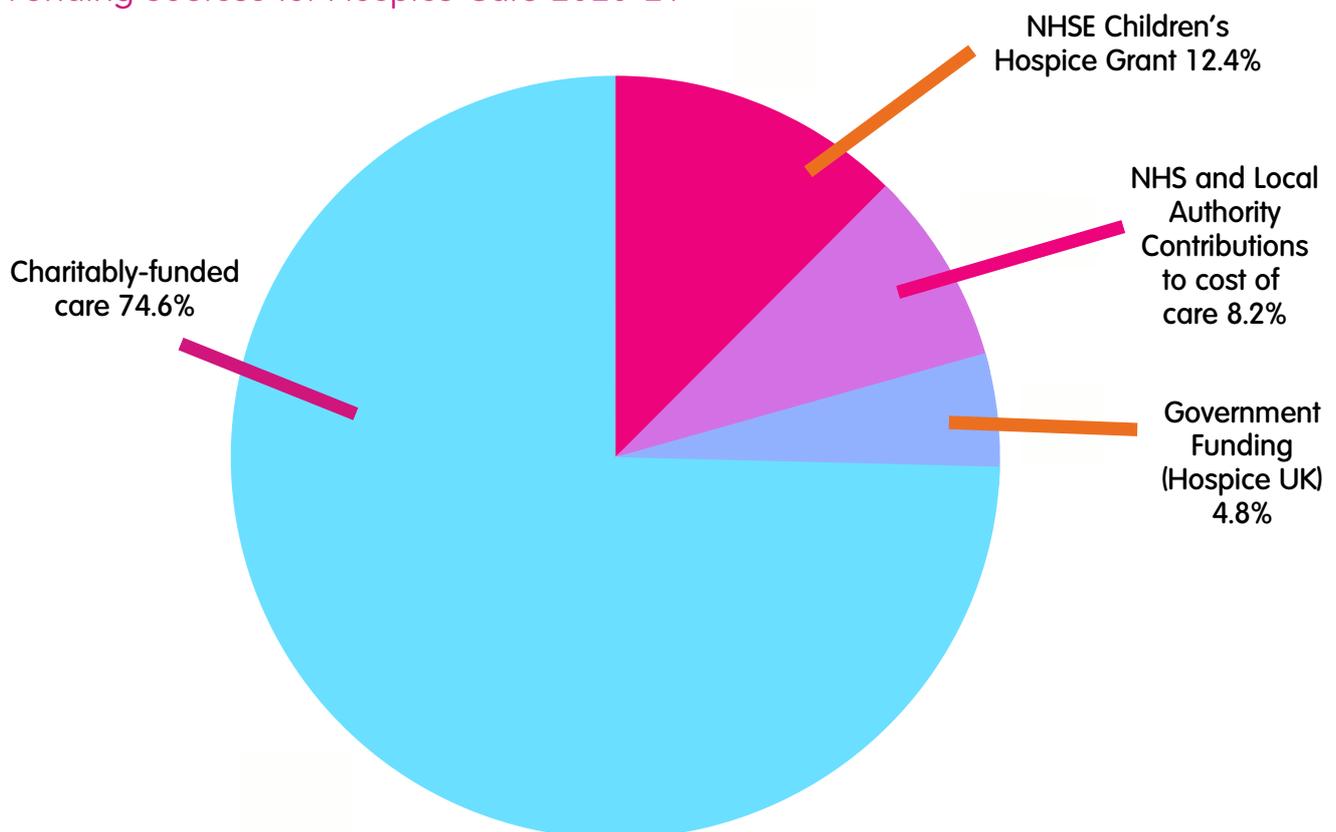
### Financial considerations

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, lottery and negotiated contributions from public sector/statutory bodies. For the year 2021-22 public sector contributions to care only represented 20% of the hospices' total expenditure on care services (patient care, family and bereavement support).

Government funding (hospice UK) – Covid-19 support money was available from December to March, to relieve pressures on local secondary services. We used this funding to maximise our bed capacity and community support.

### Funding Sources for Hospice Care 2020-21



### 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, and have continued to manage personal data in line with this legislation. 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.

## Part 4 - Overview of services

### Clinical coding error rate

Helen & Douglas House was not subject to the Payment by Results clinical coding audit during 2021/22 by the Audit Commission.

### Participation in national clinical audit

In 2021-22 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 clinical governance lead maintains oversight of the programme and results with learning areas for improvement are presented to the clinical governance committee and sent to staff through internal communication channels. This provides transparency, better understanding and ownership of findings and recommendations. 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 2021/22. 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. We are incredibly fortunate that Helen & Douglas House has remained open throughout the year, and this can be largely attributed to our very dedicated and conscientious care team who have meticulously adhered to IPC measures.

Personal Protective Equipment, hand hygiene and cleaning of near patient equipment were all audited twice during the year. In addition to this, the IPC Lead Nurse completed an IPC knowledge audit in February 2022, to identify any areas for training and improvement.

## Services we provide



**Supportive stays**



**Outreach**



**Symptom Control**



**End of life care**

**Community and family support services**



**Transition**

### MHRA and patient safety alerts

All care 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 relaxation of Covid-19 protective measures/ testing were implemented after a risk assessment by the senior nursing team.

### Research

Helen & Douglas House have been involved in a number of research projects in the last year. These have focused on understanding and improving patient and family experience of receiving care, including pain management, support for children with feeding tubes, and spiritual care needs. We believe that our patients have an equal right to care based on the experience of their own peers. This is likely to be safer and to better meet their individual needs.

We have worked with the Academic Health Science Network on a patient safety project relating to gastrostomy feeding and supporting parents to maintain their confidence with practical procedures relating to feeding.

The PARAMOUNT study concluded this year, which has led to the creation of a 'pain tool' which is in the final stages of development.

Helen & Douglas House were also involved in the multi-centre Diamorphine Paediatric Palliative Evaluation of feasibility of Randomised control trial (DIPPER) study looking at how best to conduct pain studies in children with palliative care needs.

To address some of the needs identified in the DIPPER study, we were privileged to be involved in the formation of the Collaborative Paediatric Palliative Care Network (CoPPAR). This project, based at Martin House Research Centre, seeks to bring together children, families, clinicians and scientists in a network that supports taking research forward collaboratively. Helen & Douglas House are proud to be one of six main hosting centres and looks forward to taking forward several collaborative projects relating to spirituality, outcome measures, staff wellbeing and symptom management.

Doctors, nurses, trustees and parent representatives from Helen & Douglas House have had significant input into several articles published in peer-reviewed journals in the last year.



### Education

Throughout the year the medical team regularly contributed to regional teaching, including John Radcliffe Hospital Grand Rounds, the Thames Valley Paediatric Conference and prominence at the Dying Matters week enhancing awareness across all ages. We also delivered virtual-focused teaching to identified sub-groups and continued to run our twice-yearly informal regional network education evenings around pain control, ethics and law. A new initiative of an hour delivered virtually every 6-8 weeks designed as an introduction to palliative care has also been well-received. Each of these regional meetings and teaching sessions provides an opportunity for networking, increased the prominence of Helen & Douglas House and contributes to better joined-up working and delivery of world-class palliative care for the children and families that we support.

The medical team also regularly contributed to national teaching, through organising and delivering teaching to trainee doctors developing higher-level paediatric palliative care skills (APPM GRID/SPIN teaching), Project Echo (national multi-disciplinary team monthly teaching) and both chairing and submitting abstracts to the Royal College of Paediatrics and Child Health national conference palliative care session.

After becoming a registered centre for palliative care SPIN (Special Interest Development) for doctors, we are now supporting two medical registrars in developing their skills.



### Incident/Excellence Reporting

This section gives an overview of the incidents and excellence reported in Helen & Douglas House in 2021/22.

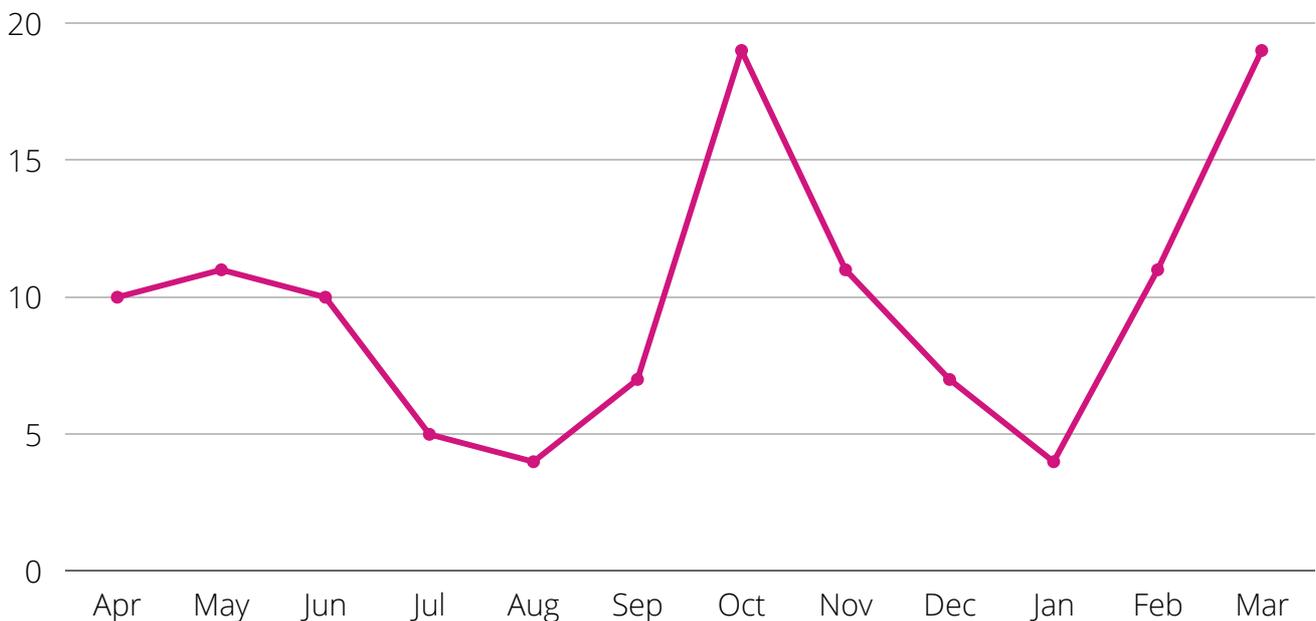
“Care organisations might improve their ability to learn from past experience by studying not only what goes wrong (i.e. incidents), but also by considering what goes right, i.e. by learning from everyday clinical work”. (Mark. A Sujan et al, 2017).

Since October 2021 we enhanced our incident reporting to include excellence reporting. This is used to demonstrate that safety is not merely the absence of negative events and learning from excellence is as equally as important as learning from incidents. At Helen & Douglas House we ensure that we place quality and safety of care at the centre of all we do.

### Type of Incident

Incident data shows a healthy reporting culture at Helen & Douglas House. This year a total of 118 clinical incidents were reported and 20 excellence reports. None of these relates to a serious incident. Drug-related incidents remains our highest single area of reported incidents, accounting for 34% of the total number of incidents. We have also noted that the months of October and March saw a higher number of incidents (see graph below), however all the data includes excellence reports too. This has been highlighted and reviewed at our Clinical Governance Committee and Medicines Management Committee. In the coming year we will be exploring ways to separate incidents from excellence reports. The data has been analysed for trends and themes with a resulting action plan to increase levels of skill and competence of clinical staff.

### Number of clinical incidents reported per month during 2021-22



## Part 5 - Incident/Excellence Reporting

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

Category	No. of Incidents
Drug Related Incident/Adverse Drug Reaction	44
Information Governance	13
Communication	12
Device/Equipment Issue	7
Risk of Injury (potentially serious)	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.

We are on a journey of learning from excellence. This year we have embedded the capturing of excellence and staff are more empowered to report on it. 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. Themes that have arisen this year are excellence in:

- Being proactive and thorough in the process, enabling timely and efficient transfer of care.
- Staff willingness to embrace tasks outside their usual area of work to support their colleagues.
- Dealing with challenging situations with dignity and compassion.

### 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 an average of 88% 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.

### Equality, Diversity and Inclusion Strategy

During this year we have reinforced our focus on how we will strive to imbed equality, diversity and inclusion (EDI) in our organisation. We have established an EDI steering group who are committed to building a diverse and inclusive workforce that reflects and understands the families we support, ensuring all staff and volunteers are valued and can contribute to and celebrate diversity. This will be supported through work we are doing towards gaining an 'Investors in Diversity' accreditation. There is also an EDI designated lead on the trustee board. Whilst acknowledging we have made some progress; we also recognise we are on a journey.

### 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 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.

### Freedom to Speak Up

As recommended by Sir Robert Francis in his 'Freedom to Speak Up Review', we have two Freedom to Speak Up (FTSU) Guardians from within the charity. 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. We also have a designated lead on the trustee board for Freedom to Speak up.

The role of the FTSU Guardians' is to be available for staff to speak to, in a safe environment about patient safety, any other concerns, as well as listening to those who have experiences to share, both positive and negative where lessons can be learnt.

### Patient Experience

We maintained contact with families we did not get to see in person, by sending them play and sensory packs, gift bags. This was to maintain the strong relationships we have and to remind them of the support we could offer.

Our vision remains the commitment to enrich the lives of all we care for, children and their families and we believe this is reflected in the comments we receive from our families.

Many families have still accessed inpatient care for end-of-life care, symptom control and a little further into the pandemic, supportive care for families who are demonstrating the need for additional care at a time when respite was very limited.

With this in mind, we have continued to adapt our service but have been delighted to be able to continue offering overnight stays and day care stays throughout this last lockdown, introducing testing for children and their visitors to ensure that we are as COVID-19 safe as we can be. We have received some great responses to our service, to the care that is delivered and to the additional support we have offered.

In January 2022, we re-introduced in-house experience feedback questionnaires to capture feedback around specific themes of care delivery. These questionnaires are given to every child/family after a stay with us to ensure we give every family the opportunity to provide feedback. The theme from January to April 2022 explored communication.

# Patient Experience

Here is some of the feedback from these forms:

*'As always, every staff member was fantastic with (name). All her care and medication needs were explained to me, and I've gone home knowing everyone is on the end of a phone.'*

*'Very good care and professional manner'.*

*'There was always someone there to listen and support me when I needed it'.*

*'Excellent care and advice, the team went above and beyond to try to help (name) and treat her symptoms and condition'.*

*'As always, the medical team took time to explain and share their thoughts and suggestions, very reassuring'.*

*'All staff were considerate, caring and attentive. (name) visibly improved throughout her stay and this was a pleasure to see. All the family were cared for. Dr Charlotte's advice as always was thorough and carefully considered and invaluable- giving us the confidence, reassurance and knowledge we needed to return home knowing that the support is there if we need it'.*

*Patient feedback: 'best of the best'.*

We have seen an increase in our contact with families, and this has enabled us to ensure that the families who really need our support are offered it, in the form of inpatient stays, day stays and community and family support services.

It is with real pleasure that we can share this feedback from families and professionals:

*'Thank you all for looking after M. He has really enjoyed all the activities - Eddie the dog, the spa, working with the school teacher, music and his walks in the garden'.*

*'You have been amazing through such a difficult time for our family, but especially for all the care & support you have given to us. We cannot thank you enough'.  
(Use of the little room).*

*'Best day ever'.*

*'The food is lovely; this is the first time I am enjoying a hot meal in five weeks'. We didn't realise how much we needed Helen & Douglas House until we got here, and feel we are so much more comfortable here. The staff have been so accommodating that they have made it home from home'.*

## Patient Experience continued.

'When things were tricky for us, having what is essentially (child)'s extended family with us, in the form of the care team, who know her so well and who know just what to do to meet her needs and soothe her worries was priceless'.

'THANK you for making a medically fragile child smiling and smiling and smiling and keep smiling still just looking at the memories of this day. This was a magical day to remember x Thank you'.

'Beautiful video and thoughtful bundle of gifts. We loved watching the emotional service together, sharing our love and tears with each other and feeling part of the extended Helen House family. We have all enjoyed the glitter, planting the seeds, blowing bubbles and reflecting with the tree'.

'I am so thankful for the support we have had from Helen & Douglas House. We don't know how we would have coped without it'.

'We had a lovely stay at Helen & Douglas House this Friday night and all worth it coming down all the way from Milton Keynes. Me and my husband had a very relax relaxed night and so did our daughter with all the love and care from staff'.

'We felt so much more comfortable and at ease at Helen House which meant we could enjoy our precious time with our child without any wires, lines or alarms. This allowed us to be a family in the vital last moments. Even the floorplan of the building felt welcoming and positive'.

'We didn't realise how much we needed Helen House until we got here, and feel we are so much more comfortable here. The staff have been so accommodating that they have made it home from home'.

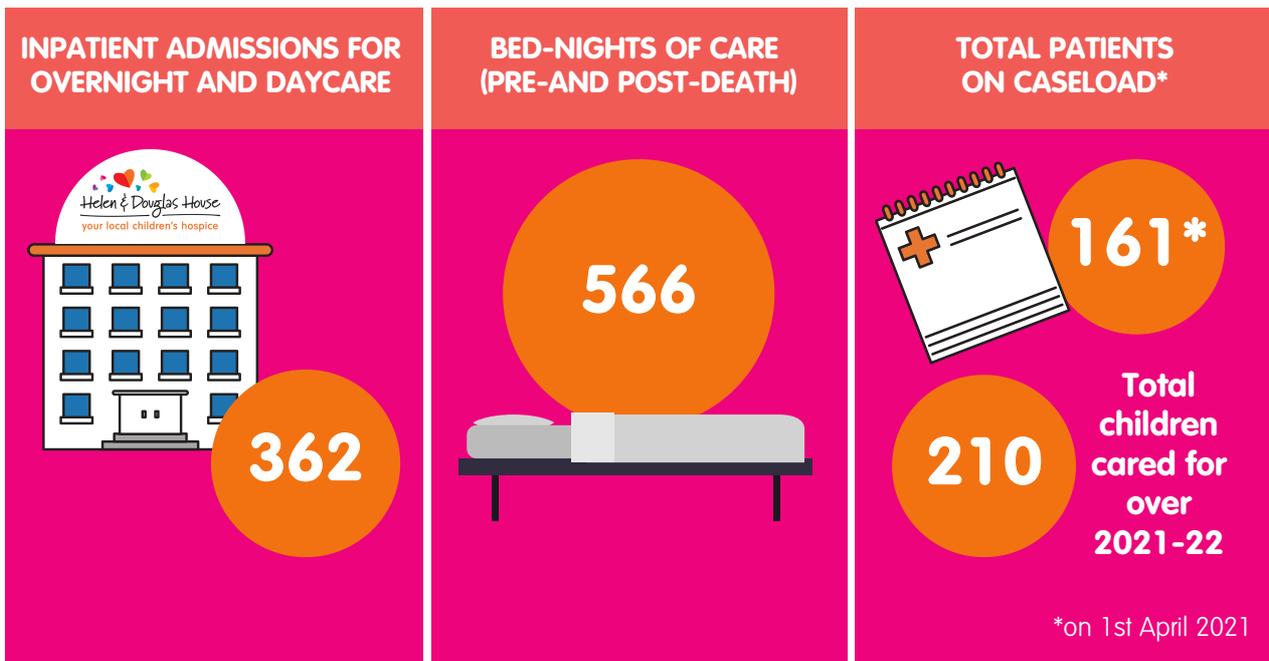
'The Forget-me-Not group was just what we needed, we feel connected to the other parents already and the three Mums have met for coffee. Your support has made a significant difference in giving us the strength to cope with the loss of our daughter'.

# Activity Report

## Referrals

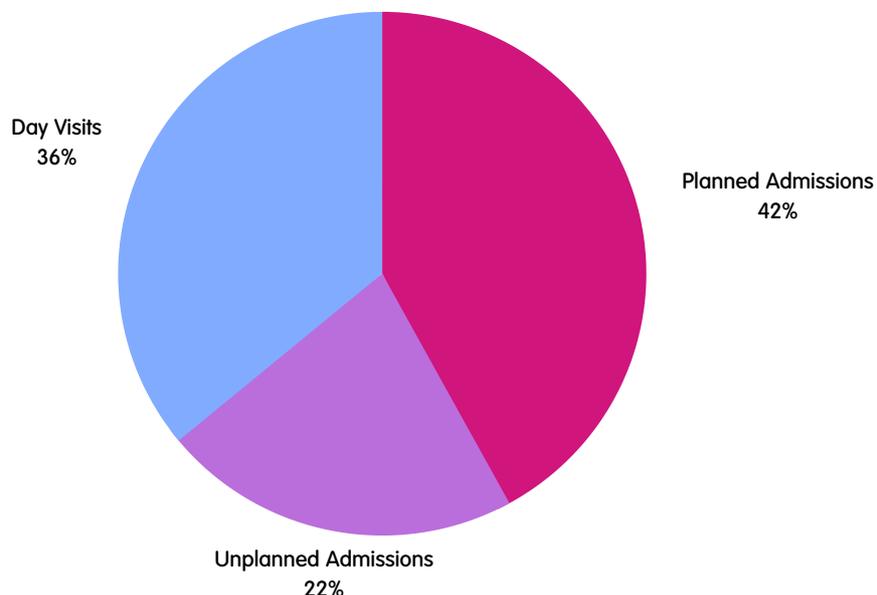
This year we accepted 63 new referrals and 269 Community and Family support referrals.

We supported 161 children, a 62% increase from the previous financial year.

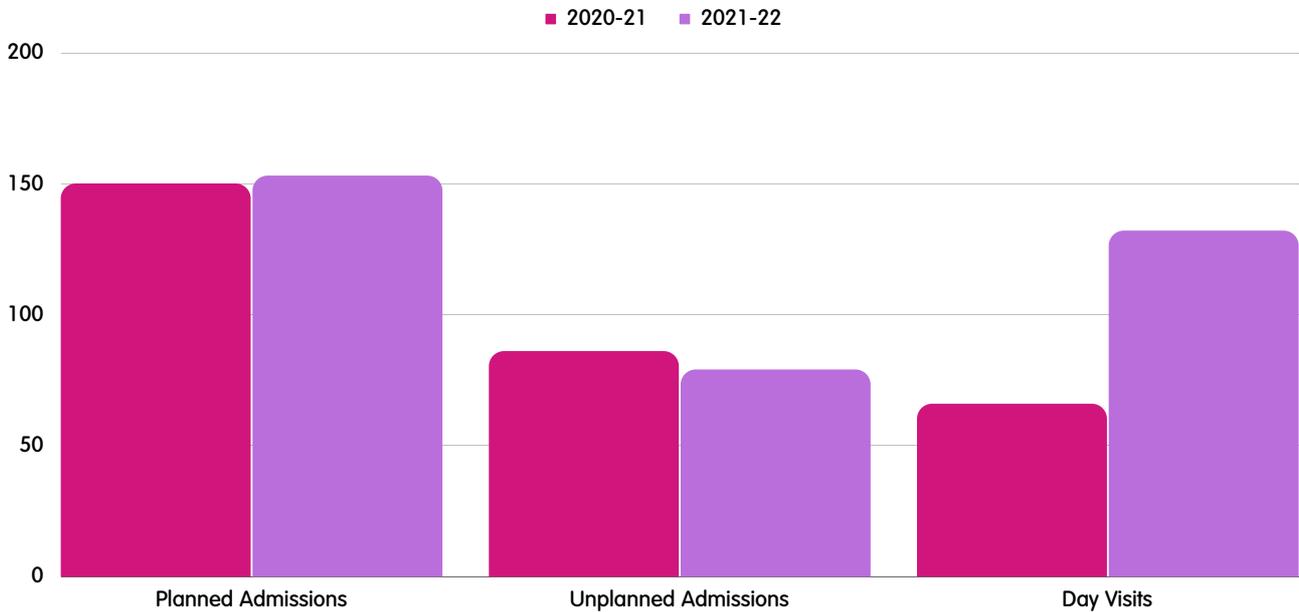


## Inpatient admissions

We had 362 patient admissions to Helen House, an increase of 22% from the previous year. The admissions break down as follows:



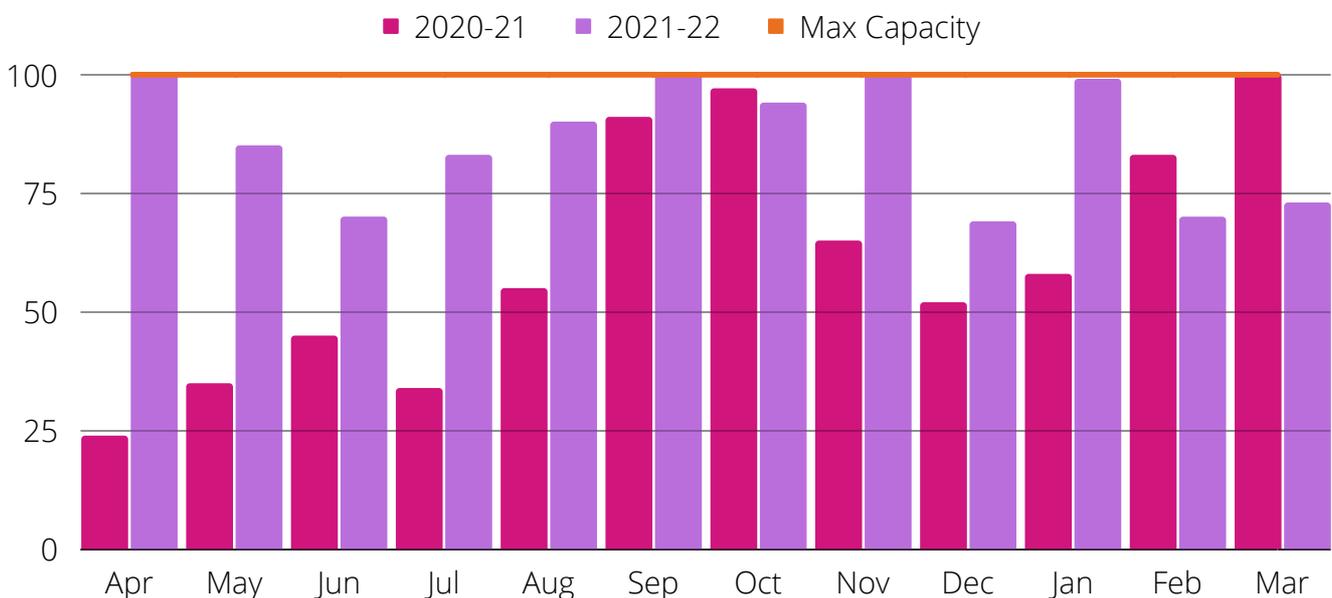
Whilst planned and unplanned admissions seem to have stayed relatively stable, we have seen a 50% increase in day cases:



Although we saw a significant increase in the number of day visits, the number of bed nights of care decreased by 12%.

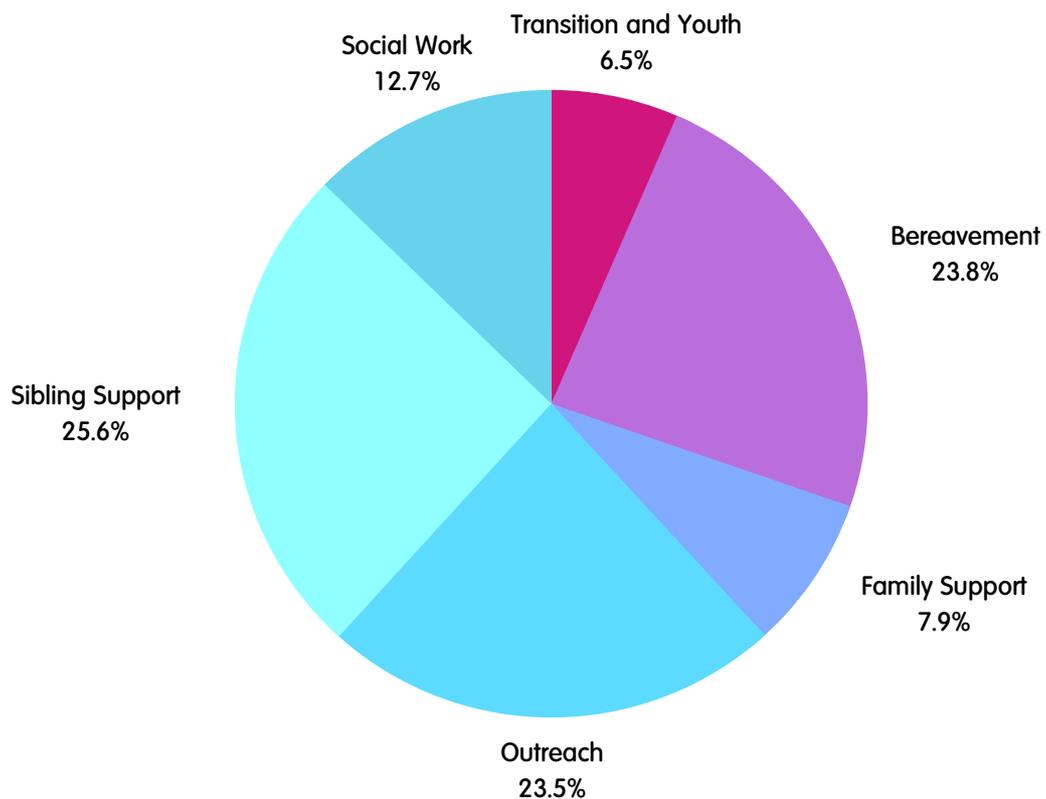
## Service capacity

During the last 12 months, we saw bed capacity recover significantly from the year before. We reached 100% capacity in April, September and November, whilst maintaining at least 70% capacity throughout the year except for the month of December (69%).



## Community and family support services

The C&FSS team had 4200 hours of contact with patients and families this year. That is a 48% increase from the previous financial year. This translates to roughly 16 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.



The number of contacts for the C&FSS team was 5775 this year. That is a 35.3% increase from the previous year.



## Part 6: What Others Say About Us

### 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 for injury for children (0-18years). Specialisms include: diagnostic and screening procedures, learning disabilities, physical disabilities and sensory impairments.

Our current registration status is unconditional.

In line with CQC's current methodology, we have not had a full comprehensive inspection this year. However, we did engage in a Direct Monitoring Activity with CQC in January 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 Care Quality Commission have published the following statement on their website: 'We have carried out a review of the data available to us about Helen and Douglas House on 3 March 2022. We have not found evidence that we need to carry out an inspection or reassess our rating at this stage. This could change at any time if we receive new information. We will continue to monitor data about this service.'

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

### Commissioner Quality Assurance visits

We have different formats of communication and contracts with commissioners. We had continuous engagement through electronic means, such as Microsoft Teams and electronic mail. We have not had any requests for quality assurance visits but would warmly welcome them.

### Complaints/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 have continued to work closely with the local hospital, community services and other children's hospices, as we truly value them.

## Part 6: What Others Say About Us

I am delighted to take this opportunity to say a huge thank you to Helen & Douglas House on behalf of Paediatric Critical Care in Oxford. Your contribution to our service is immeasurable, and without you, we would not be a complete service - it's that simple. Helen & Douglas House never let us down. They are always there to provide support, guidance and friendship - that's really important to us when looking after families and children who are facing sad, frightening and distressing times - making really challenging decisions. The wisdom and guidance that Helen & Douglas House provides not only sustains the families but the staff enable us to do the best possible job we can when looking after these families. Wherever a child is on their journey towards the end of their life, Helen & Douglas House are always there for them and for us - for that, we are entirely grateful. **(Alison from Paediatric Critical Care, Oxford University Hospitals)**

From the Electronic Records system, we can see your involvement with (child) and his family in his last few days and wanted to thank you for the care you gave him and the helpful documentation you have provided. We acknowledge this is a rare event to occur on the wards but from the sounds of things you treated him and his family with a lot of compassionate care that they will be incredibly grateful for. **(Nurse, Oxford University Hospitals)**

I want to take this opportunity to acknowledge the real benefits and value that we have found at Alexander Devine, in our close working relationship with you all at Helen & Douglas House. In particular our work with Andrea, Emily and the CNS team and the collaborative partnership that supports the children and families that we all care for. I know that this partnership will go from strength to strength and will really make a difference to the children and families we look after. **(Helen Bennett, Alexander Devine Children's Hospice)**



Lily-Mae was cared for by the hospice during her life. In her final hours we also cared for and supported her whole family in a place they felt at home.

## Part 7: Service Improvements

### Supportive stays

During this year we reviewed our booking process as we are no longer in a position to offer planned respite to support our families. Helen House continues to deliver stays for symptom management and end-of-life care. We consulted with families to ask them if they would like to be offered a supportive stay, at short notice, when safe staffing and capacity allowed. This was very well received, and we have seen a significant increase in our bed occupancy since this was introduced. The aim of this was to introduce a more efficient and equitable way of allowing families the chance to have a supportive stay. We will continue to monitor and review this process to ensure we are reaching as many children as possible and families that need these stays.

### Stay and play

We have extended our services to include stay and play days, which enables the whole family to come and spend the day with us. It gives families the opportunity to use our facilities and meet other families. It is also a chance for families to become familiar with our environment and experience what we have to offer. We provide a hotel-like experience for the day where families are served hot meals and are looked after in a comfortable environment.

### Sensory spa bath

We have refurbished the whole bathroom and installed a sensory bath, with mood lighting, choice of a family's own music to create their own spa experience.

### Electronic Patient Records

In July of 2021, Helen & Douglas House started to migrate from paper care records to electronic records. Whilst this programme is in its infancy, there has been great benefit in being able to have interoperability with the local NHS trust. In March 2022, a nurse has been seconded for six months to project lead the next phase of this exciting transition.

### Outreach

During this past year we have introduced a skill mix within our Outreach Nurses team. Outreach Nurses started to undertake additional training to enhance care and support given to children, with the aim that both Band 7's have Advanced History Taking and Assessment Skills with the addition of a non-medical prescriber later this year. Skill mix has also been introduced to Sibling Support.

### Bereavement support

We have created two bereaved parent support groups:

Forget Me Not group to parents who have been bereaved 6-12 months. These groups are held monthly for 6 months and the Butterfly Group for parents bereaved over 12 months, meeting alternate months. Each session of both groups has a different topic and provides **(Continued.)**

## Part 7: Service Improvements

**(Continued.)** strategies and tools for parents to manage their grief, start to build their lives around their grief and develop informal peer support networks.

All bereaved parent support groups, Network Saturday and Siblings Groups are now back to face to face rather than virtually. We continue to offer a blended approach to individual/couple's support with their choice of support being delivered via a virtual session, telephone session, walk and talk session or visits to clients/parents/child/young people's homes and schools. Doug's Den has been refurbished and is being used for activities for teenagers to socialise and enjoy the space.

### Garden

We have now completed a whole refurbishment of our garden and garden room. It has instruments, water features, a roundabout and swing, sensory board. We have refurbished the play train which is now the garden room, to make a comfortable and tranquil space for parents to be able to relax whilst their child is being looked after by our care team. This is also used as a private space for external meetings.

### Managed Clinical Network

Helen & Douglas House has worked in partnership with other Hospices within the Thames Valley region to develop a proposal to secure funds for a managed clinical network (MCN) to deliver Children's Palliative Care. An MCN is a self-supporting group of professionals working together to ensure cross-speciality sharing of patients and expertise. This is a recommendation of NICE guidance 2016 and the Health and Social Care Act. The aim is to ensure that all children within the Integrated Care System footprint have access to 24/7 specialist palliative care, in the place of their choice.

### Makaton

We have achieved a bronze award in Makaton awarded by The Makaton Charity. This demonstrates our ability to communicate effectively with children and young people with learning or communication difficulties, to improve outcomes.



Nurse Siobhán  
teaching Makaton

### Statement of Assurances from the Board

The Board is assured that the treatment and care provided at Helen & Douglas House is of high standard, in an environment of continuous quality improvement and learning, to reach the best outcomes for the children, young people and families we support.

The Board has approved and supports our three-year strategy to ensure we continue to deliver a high quality, safe and effective service provision. The strategy has been developed in line with recent research on the prevalence of children and young people with life limiting and life-threatening conditions.

Our Clinical Governance Committee has representation from the Trustee board. Two are Clinical Trustees, both retired paediatricians and one is a Parent Trustee who also chairs the Clinical Governance meetings. Input from our Trustees is highly valued as it ensures there are clear lines of responsibility and accountability. Helen & Douglas House has a detailed Clinical Risk Register which is regularly updated and monitored by the Clinical Governance Committee.

The Board have maintained oversight of adaptation of services and compliance with all Covid regulations and requirements. A recent Board review has led to the recruitment of another Trustee to include nurse representation on the Board.

Helen & Douglas House  
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Helen & Douglas House  
your local children's hospice