

Helen & Douglas House

Helen and Douglas House

Inspection report

14A Magdalen Road
Oxford
OX4 1RW
Tel: 01865794749
www.helenanddouglas.org.uk

Date of inspection visit: 18 July 2023
Date of publication: 24/11/2023

This report describes our judgement of the quality of care at this service. It is based on a combination of what we found when we inspected, information from our ongoing monitoring of data about services and information given to us from the provider, patients, the public and other organisations.

Ratings

Overall rating for this location

Outstanding 

Are services safe?

Good 

Are services effective?

Good 

Are services caring?

Outstanding 

Are services responsive to people's needs?

Good 

Are services well-led?

Outstanding 

Summary of findings

Overall summary

Our rating of this location improved. We rated it as outstanding because:

- We found a service that was leading the way nationally in educating third parties on the complex needs of paediatric palliative care. Leaders encouraged innovation and participation in research. Staff working for the service produced numerous pieces of legislation and were members of national committees related to paediatric palliative care.
- There was an exceptionally strong focus on multidisciplinary working, with the service developing multidisciplinary teams whenever there was an opportunity for shared learning. Staff were committed to working collaboratively and took a clear, coordinated and holistic approach to ensure seamless care.
- Staff repeatedly went above and beyond to find ways to make a difference to children and their families. Staff went above expectations to establish and meet children's individual needs and were passionate about the care they delivered. We found an exceptionally caring culture with whole staff buy in to promote dignity, respect and understanding. Staff developed positive, trusting relationships with children and their families and did everything possible to ensure that last requests could be achieved.
- The service provided safe care, environments were safe and clean with enough staff to provide safe and effective care. Staff developed holistic care plans informed by a comprehensive assessment. They provided a range of treatments suitable to the needs of children and young people and in line with national guidance and best practice. Staff engaged in clinical audit to evaluate the quality of care they provided.
- The service met the needs of all children and young people who used the service – including those with protected characteristics. Staff helped children with communication, advocacy and cultural and spiritual support. The service treated concerns and complaints seriously, investigated them and learned lessons from the results, and shared these with the whole team and the wider service.
- The service was well led and governance processes ensured the hospice ran smoothly. Leaders had the skills, knowledge and experience to perform their roles, had a good understanding of the services they managed, and were visible in the service. Staff felt respected, supported and valued and knew and understood the provider's vision and values and how they were applied in the work of their team.
- However:
- Managers acknowledged that due to an influx of new staff, not all staff had completed all mandatory training. This was mitigated in an action plan that ensured the completion of training was prioritised by all staff, and safeguarded children and young people by ensuring there were always staff on shift that had completed the mandatory training.
- Staff were very knowledgeable about the children they looked after and how to support children, young people and their families in an individual, personalised way. This was reflected in the level of detail in patient care plans. However, this information had not been transferred onto risk assessments.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	Outstanding	

Summary of findings

Contents

Summary of this inspection

Background to Helen and Douglas House

Page

5

Information about Helen and Douglas House

5

Our findings from this inspection

Overview of ratings

7

Our findings by main service

8

Summary of this inspection

Background to Helen and Douglas House

Helen and Douglas House is a hospice based in central Oxford. The service provides supportive stays, symptom management, end-of-life and counselling and bereavement services to children, young people and their families.

The service opened as Helen House in the 1980s and at the time was the world's first children's hospice. The service merged with Douglas House in 2004 to provide care for young people and bridge the gap between children's and adults end-of-life care services. Douglas House closed in 2018, however Helen and Douglas House continue to provide services for up to 8 children and young adults up until their 19th birthday inhouse, and also provides community support for children and young people in their own homes.

The service is registered to carry out the following regulation:

- Diagnostic and screening procedures
- Treatment of disease, disorder or injury

This was the first inspection of this service using the acute framework. When this service was previously inspected in 2017, hospices were inspected using the adult social care inspection framework.

How we carried out this inspection

This was an unannounced inspection that took place on 18 July 2023. The inspection was carried out by a CQC Inspector and a Specialist Advisor with specialism in end-of-life care and paediatric services. The inspection was overseen by Operations Manager Jonathon Parry-Hall.

We inspected all areas of the service, spoke with staff, children and families and interviewed the senior leadership team.

You can find information about how we carry out our inspections on our website: <https://www.cqc.org.uk/what-we-do/how-we-do-our-job/what-we-do-inspection>.

Outstanding practice

We found the following outstanding practice:

- We found a service that was leading the way nationally in educating third parties on the complex needs of paediatric palliative care. Staff working for the service were involved in the production and development of numerous pieces of legislation and research studies. The staff were passionate about driving legislation and guidance to improve care for children looked after in all organisations, not just their own.
- Effective communication was at the heart of multidisciplinary working, with the service developing multidisciplinary teams whenever there was an opportunity for shared learning and ensuring seamless care across organisations, charities, third parties and families.

Summary of this inspection

- Staff developed positive, trusting relationships with children and their families that lasted beyond the period of time children were in their care. Feedback from families was overwhelmingly positive, we were provided with numerous examples of staff exceeding expectations. There was a fundamental buy in from staff to go above and beyond to promote children and young people's dignity, respect and understanding, independence and support to enable children to achieve goals and accomplishments before they passed.

Areas for improvement

Action a service SHOULD take is because it was not doing something required by a regulation but it would be disproportionate to find a breach of the regulation overall, to prevent it failing to comply with legal requirements in future, or to improve services.







Action the service SHOULD take to improve:

- The service should ensure all staff are up-to-date with mandatory training requirements. (Regulation 18)
- The service should ensure where risks are identified, mitigations are documented and personalised. (Regulation 12)






Our findings

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Hospice services for children	Good	Good	 Outstanding	Good	 Outstanding	 Outstanding
Overall	Good	Good	 Outstanding	Good	 Outstanding	 Outstanding

Hospice services for children

Safe	Good 
Effective	Good 
Caring	Outstanding 
Responsive	Good 
Well-led	Outstanding 

Is the service safe?

Good 

Our rating of safe improved. We rated it as good.

Mandatory training

The service provided mandatory training in key skills to all staff. However, not all staffing groups met the training completion target due to an influx of new starters.

Mandatory training was comprehensive and met the needs of children and young people. Staff had their own e-learning homepage with dashboard in order that they could monitor training progress. The service provided staff with a suite of training that was a mix of e-learning and face to face. Topics included Control of Substances Hazardous to Health, Equality and Diversity, Health and Safety and Manual Handling. Staff also received 4 in-house clinical training study days per year. Each study day was repeated to enable all staff the opportunity to attend and consisted of a rolling programme of clinical skills.

Managers monitored mandatory training and alerted staff when they needed to update their training. Managers emailed alerts if team members are not up-to-date. Managers also produced a monthly training report based on the HR Data Dashboard which contained information regarding mandatory training completion. Every quarter, managers reported training completion figures to trustees alongside an education report.

Managers reviewed service performance, incidents and safeguarding referrals in order to steer training requirements to better support children and young people. For example, managers were organising training in paediatric suicide support for families and sudden trauma death training in response to a national increase in suicides and mental health concerns in young adults.

During staff probation, mandatory training was reviewed by managers at 3 and 6 months. If training was not completed by 6 months, then there was an opportunity to extend probation until training was completed. This ensured all staff signed off probation were fully compliant and up-to-date with training requirements.



Hospice services for children

Service leaders evidenced action plans to ensure all staff completed mandatory training. This was in response to an influx of new staff in the months prior to inspection, which meant completion rates did not meet the 85% target. The plan outlined a schedule and protected time for ensuring staff had completed mandatory training, which since inspection has been achieved. During this period, managers mitigated risks by ensuring there was always staff on site that had completed training.

Safeguarding

Staff understood how to protect children, young people and their families from abuse. Staff had training on how to recognise and report abuse and they knew how to apply it.

Staff received training specific for their role on how to recognise and report abuse. Staff received level 3 training in safeguarding children and adults in accordance with 'Intercollegiate Document Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff' (2019) guidelines. The completion rate for nurses was just under the 85% target, at 84%, however managers ensured every shift had staff onsite that were up to date with their level 3 training in order to mitigate any potential risk.

Staff could give examples of how to protect children, young people and their families. Staff we spoke with understood their role and responsibilities in recognising and reporting signs of harm and abuse. Staff advised us they were not only safeguarding the children and young people they cared for, but also friends and family members of people who used the service. Staff gave us an example of a modern slavery referral and how they worked with social workers and the Home Office to remove the person from their place of residence and ensure their safety.

The services safeguarding lead was trained to level 5, staff knew who the safeguarding lead at the service was, how to report a referral to the local authority and demonstrated how to access the services safeguarding policies. Staff attended a quarterly safeguarding steering group where policy and training, as well as recent examples of referrals and learning were discussed. Staff we spoke with advised they appreciated the group, as it gave them an opportunity to discuss concerns and support other members of the team in emotional situations.

The service was a part of the Oxfordshire Safeguarding Children's Committee, the local Child Death Overview Panel, as well as the Buckinghamshire, Oxfordshire and Berkshire Health Advisory Group which was a multidisciplinary meeting for all safeguarding leads across integrated care boards, local NHS trusts and ambulance services.

Cleanliness, infection control and hygiene

The service controlled infection risk well. They kept equipment and the premises visibly clean.

Ward areas were clean and had suitable furnishings which were clean and well-maintained. We visited all areas of the service and noted it to be visibly very clean, open and uncluttered. All furnishings were wipeable and met Department of Health 'Health Building Note 00-09: Infection control in the built environment' standards. The bedroom corridor was protected by a specialised door that provided a "Clinical Bubble" to further protect children and young people from infectious diseases.

The service generally performed well for cleanliness. We observed staff demonstrating good hand hygiene practices that followed the World Health Organisation '5 Moments For Hand Hygiene' guidelines. We also observed staff encourage children and young people to wash their hands effectively where appropriate. We also observed staff cleaned equipment before and after patient contact.



Hospice services for children

Staff followed infection control principles including the use of personal protective equipment (PPE). We observed staff using a variety of PPE, for example aprons, gloves and masks where appropriate and noted staff completed donning and doffing of PPE in accordance with best practice. PPE was available in a variety of sizes in accordance with Health and Safety Executive standards.

Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. The service used a cleaning daily checklist to ensure all areas of the service were clean and tidy. Items included; emptying bins, topping up hand towels. All areas of the checklist had been signed off for the week prior to inspection.

The service had cleaning processes in place for all toys and play equipment. Only one of the two play team members had completed their Infection Prevention and Control training. This was due to an influx of new staff and the service had an action plan to ensure completion of training was prioritise.

Environment and equipment

The design, maintenance and use of facilities, premises and equipment kept people safe. Staff managed clinical waste well.

The service had suitable facilities to meet the needs of children, young people and their families. Since Douglas House was closed in 2018, the service used the building for offices and back of house services. Helen House was the main building where clinical services were provided. The main entrance was secure with staff swipe card access. The welcome area displayed a tapestry showing the history of the hospice. The building consisted of 2, 2 bedroom flats available for families on-site, a staff scrubs area and patient paper storage, offices for the community team, siblings' team and social workers, school classroom, arts and crafts activity area, a play area and 3 playrooms, conservatory, nurse's station and dining area. The patient bedroom wing could be isolated and included wet rooms, bathrooms, the sluice, medicine and equipment storage and the spa. The bereavement suite was located at the back of the building and had direct access to outside areas. The service had a cold storage bedroom, and another that was adaptable.

The service had enough suitable equipment to help them to safely care for children and young people. Ceiling hoists were fitted in all areas where personal care was provided including bedrooms and bathrooms. The service had a range of commodes, bathing chairs and moving and handling equipment to support children and young people depending on their mobility needs. We observed staff check equipment was calibrated before use.

The service created an annual environmental audit of all areas of the service including organised events and retail outlets in order to ensure the physical environment met all health and safety standards. There were action plans from this audit to ensure compliance with legislation.

The facilities and estates team kept up-to-date records of all water, spa, equipment, appliance and building testing and servicing, including testing of legionnaires to ensure the environment met safety standards.

All children and young people had a personalised fire evacuation plan, staff were aware of these and knew their responsibilities in the event of a fire. The service provided evidence of fire alarm and equipment testing to ensure all systems were ready in the event of a fire.

The services equipment log detailed each item of equipment, the date of purchase, serial number to ensure all items could be tracked and details of when the item required replacement.



Hospice services for children

We checked the services consumables and noted all stock was in date and there was a rotation system to ensure items closer to their expiration date were used first.

Staff disposed of clinical waste safely. Staff stored clinical waste in a secured area and had a contract with a third party for destruction and disposal.

Assessing and responding to patient risk

Staff identified and quickly acted upon children and young people at risk of deterioration.

Staff used a nationally recognised tool to identify children or young people at risk of deterioration and escalated them appropriately. Staff completed paediatric early warning scores for every child, these were regularly checked, and staff understood systems and processes for escalation when children deteriorated, or when there was the potential for deterioration. The paediatric early warning score is a system that enables the early recognition of sick patients and management of any deterioration. It includes taking vital signs such as heart rate, respiratory rate, blood pressure, oxygen saturation and temperature.

Staff developed a tool to support the contextualised assessment of paediatric patients with medically complex palliative care needs. The tool would allow the child's situation to be put into detailed context. This could then be shared between clinicians to support a response that included families and supported the child's best interests in a timely manner. The tool was presented at the recent 'Together for Short Lives' conference, shared with local care providers and the service was in the process of teaching it to staff at the local NHS hospital paediatric critical care unit.

Staff knew about and dealt with any specific risk issues. Staff were trained to care for and respond to the complex needs of children and young people attending the service, including; sepsis, airway management, oral suction and enteral tubes. Staff received face to face training in paediatric basic life support and at the time of inspection, all clinical staff were up-to-date with this training.

We checked all emergency equipment and trolleys and noted there was documented evidence these were checked daily, battery powered equipment was fully charged and ready for use, trolleys were securely locked and there was a sufficient number of trolleys and equipment to support the amount of children seen on-site.

Where appropriate, all children and young people had advanced care plans including evidence of discussions regarding resuscitation. These were clearly produced in conjunction with children, young people and their families. Where there was a decision not to resuscitate, care plans included all legal documents and reviews.

Staff completed risk assessments using a recognised tool. Staff reviewed physical, personal and social areas of care and produced risk assessments including risks associated with medication, seizure management, distress and pressure ulcers. Risks were regularly reviewed and changes to practice made and communicated to staff where appropriate. Whilst documentation in care plans was very detailed and staff knowledge of patient's preferences and care needs was exceptional, risk assessments were taken from a generic bank and therefore, the assessments themselves were not personalised. Knowledge of risk was also not always transferred into every assessment.

Staffing

The service had enough staff with the right qualifications, skills, training and experience to keep children, young people and their families safe from avoidable harm and to provide the right care and treatment.



Hospice services for children

The service had enough staff to keep children and young people safe. We saw staff rotas for the week of inspection and the month post inspection. The rota showed shifts were divided into early, late and night. All shifts were accounted for including where staff were taking annual leave. The service had a team of bank staff to cover shifts in the event of staff sickness. The service had 2 level 4 consultants and 1 level 3 consultant, who were specialists in paediatric palliative care, paediatric specialist trainees, GPs and associated specialists. As well as 3 community outreach nurses, 2 social workers, 3 counsellors, a siblings and bereavement family support team as well as nurses, nurse associates and care support workers.

Medical, nursing and support staff were directly employed by the service. There were service level agreements in place for specialist staff including schoolteachers, spiritual leaders, and pharmacists.

The manager adjusted staffing levels according to the needs of children and young people. Staff rotas were published 6 weeks in advance. They were planned around expected case load which were reviewed by management at the weekly huddle every Monday. The rota was split into symptom management, end-of-life or supportive stay using colour coordination to denote whether it was a support stay, first stay or urgent stay. Staffing was based around the availability of skill set and the child's requirements.

At the time of inspection, the service was staffed to support 4 beds. Managers had plans in place to recruit to staffing vacancies. There were 2 clinical nurse vacancies out for post and 1 band 5 nursing vacancy. Managers had plans to increase nursing roles available in order to develop the service, including another youth and transition worker to support families to be prepared for a move from paediatric to adult services, as well as increasing the sudden death end-of-life team, in response to an increase in suicide in young people. The service recently employed a clinical lead midwife specialising in antenatal care and support for families whose unborn babies have a life-limiting condition. The service had 10 new members of staff in the 12 months prior to inspection, which impacted their training completion rates.

The service enlisted support from a large number of volunteers in various areas, performing reception duties, working in retail, fund-raising as well as volunteering in clinical areas. The recruitment of volunteers included a comprehensive interview process together with criminal record/barring and vetting checks.

Records

Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.

Patient notes were comprehensive and all staff could access them easily. On the day of inspection, 4 children were receiving care at the service. We viewed the records for all 4 children and found care plans and medical notes were detailed and personalised to the child's needs including spirituality, behaviour and agitation. There was clear evidence care plans were written in conjunction with children, young people and their families. The most recent records audit showed the service passed.

When children and young people transferred to a new team, there were no delays in staff accessing their records. The service was introducing the same records system that was used at the local NHS trust. This would ensure consistency of information and ease of data transfer. The service was in the process of moving records from paper into an electronic format and therefore, records were a mix of paper and electronic. Patient notes, risk assessments and care plans were



Hospice services for children

kept in purple folders and consultant notes were kept in orange folders. There was a clear process for uploading information onto the new system and staff understood how to combine the 3 systems, ensuring information was not missed or poorly documented until the service could transfer fully into 1 e-document. Advanced care plans were stored on both electronic and paper records, the most recent audit of care plans showed the service passed.

Records were stored securely. Paper documents were stored in secure locked files away from public areas. Where electronic records were used, we noted devices were password protected and staff locked screens before they moved away from the device.

Medicines

The service used systems and processes to safely prescribe, administer, record and store medicines.

Staff followed safe systems and processes to administer and store medicines safely. Training records documented staff competencies in medicines management, including the use of controlled drugs and syringe drivers. Allergies and the child's weight were clearly documented in all medicine's records. Staff ensured prescription doses were appropriate to a child's weight rather than age in accordance with best practice guidance. The service had systems in place to store medicines safely and securely. Staff used a stock rotation system to ensure medicines closer to their expiration date were used first. Staff checked refrigerator temperatures daily and understood actions to take if temperatures fell out of range.

The service used controlled drugs, which are "Drugs that are subject to high levels of regulation as a result of government decisions about those drugs that are especially addictive and harmful". The service had a Home Office License as required by the Misuse of Drugs Act 1971. Staff were aware of their role and responsibility regarding the storage, prescribing, preparation, administration, documentation and destruction of controlled drugs, all of which met national standards. The service was a part of the controlled drugs local intelligence network that included local NHS trusts and the Police, the network was used to share good practice and learning from incidents.

Staff followed national practice to check patients had the correct medicines when they were admitted or they moved between services. Staff completed medicines care plans that included checklists for use when children and young people transferred between services.

Staff learned from incidents to improve practice. The results of the most recent audit for medicines management were; Standard Operating Procedures 100%, Patients own medicines 100%, Administration 100%, Prescribing 100%, Purchasing and supply of stock medicines 91.7%, Storage and destruction of medicines 80%. In response to the last result, managers implemented protected time to ensure medicines were stored and destroyed correctly. Also, staff undertaking medicines tasks now wore red tabards to signal to other staff that they were not to be disturbed. Managers had also developed a medicine training day to refresh training and medicine errors were included in this training.

Incidents

The service managed patient safety incidents well. Staff recognised and reported incidents and near misses. Managers investigated incidents and shared lessons learned with the whole team and the wider service.

Staff knew what incidents to report and how to report them. Staff we spoke with understood their responsibility in reporting incidents including near misses. We found an open and honest incident culture where staff felt able to raise concerns without fear of repercussions. Staff advised us they looked at incidents and near misses as a learning opportunity rather than a chance for blame.



Hospice services for children

Staff understood the duty of candour. They were open and transparent, and gave children, young people and their families a full explanation if and when things went wrong. The duty of candour refers to a duty on providers to be open and transparent with people receiving care. The duty of candour requires registered providers and registered managers to act in an open and transparent way with people receiving care or treatment from them. Staff we spoke with understood the requirements of duty of candour. In the 12 months prior to inspection, one incident at the service met the duty of candour threshold.

Staff received feedback from investigation of incidents. All clinical incidents were analysed by the senior clinical team before being closed. We saw the incidents log and noted investigations were thorough, actions were recorded, there was evidence that learning was disseminated at staff meetings and via newsletters, and any emerging themes were noted.

Managers used their relationships with external agencies as an opportunity for learning from incidents. We were given examples of learning from a local pharmacy and an incident regarding a child's at home medicine. Managers organised a shared staff initiative with the local NHS paediatric intensive care unit and another local children's hospice. Staff at the 3 services swapped shifts in order to understand ways of working and ensure learning from incidents was shared.

The service had no never events. In the 12 months prior to inspection the service did not report any never events. A never event is a serious incident or error that should not occur if proper safety procedures are followed.

Is the service effective?

Good



Our rating of effective stayed the same. We rated it as good.

Evidence-based care and treatment

The service provided care and treatment based on national guidance and evidenced-based practice. Managers checked to make sure staff followed guidance.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. We reviewed 10 policies and noted they were all in date and referenced appropriate national standards and legislation. The service had systems in place to provide an umbrella view of policies, each policy was assigned to a lead who ensured it was reviewed and up-to-date. Once a policy was renewed, staff were notified and had to sign off to state they had read and understood the policy.

The service had a full catalogue of audits that covered clinical and environmental topics. We viewed the annual audit schedule and noted it to be comprehensive and up-to-date. Each audit resulted in an action plan and managers retained oversight in order to ensure actions were followed up, reviewed and retested.

Nutrition and hydration

Staff gave children, young people and their families enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for children, young people and their families' religious, cultural and other needs.



Hospice services for children

There was an exceptional culture of understanding the importance of eating and drinking well during palliative care, not only for physical and mental health, but as an opportunity for children to have accountability and social interaction. Staff truly understood the holistic benefits, and used innovative methods and positive relationships to encourage those who were reluctant or had difficulty in eating and drinking.

There were excellent links with dietetic professionals and staff were aware of individual preferences and patterns of eating and drinking. These preferences were sustained over time as health allowed. Staff understood the importance of collaborative working to ensure children and young people received care based on evidence and research. Staff working at the service were leaders in their fields and were members of national medical societies specialising in nutrition and hydration. This demonstrated that children and young people at the service were receiving the latest treatment and understanding regarding their nutritional intake in order to receive the best outcomes. For example, staff co-chaired the British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and Association for Paediatric Palliative Medicine (APPM) Joint session on 'Nutritional support in life-limiting conditions: Working together to support safe & comfortable feeding'. The service supported a number of children and young people on ketogenic diets, consuming low amounts of carbohydrates and replacing them with fat to help your body burn fat for energy. Ketogenic diets are commonly used to support a number of chronic illnesses. Staff understood how to support these children.

Staff made sure children, young people and their families had enough to eat and drink, including those with specialist nutrition and hydration needs. Coffee, tea, cold drinks and snacks were available 24 hours a day, seven days a week. Children, young people and their families were encouraged to help themselves. Families advised that mealtimes and the quality of food and choice were exceptional, that food was restaurant quality, fresh, varied and could be adapted or changed to ensure individual needs were met. Staff went out of their way to meet their preferences, including providing specific brands of foods and purchasing takeaways for families unused to western cuisine. Staff gave children and young people regular surveys specifically regarding the quality of their food that included free flow text to write any changes they would like to make. Opinion regarding nutrition and hydration was also included in the annual family feedback survey, in the most recent survey, 64% of families said the food was exceptional or excellent.

Staff fully and accurately completed children and young people's fluid and nutrition charts where needed and used a nationally recognised screening tool to monitor children and young people at risk of malnutrition. We viewed the fluid and nutrition charts for all 4 children receiving care on the day of inspection. We noted the records were fully completed and detailed including risk assessments where required. Staff understood the importance of monitoring input and output and described the escalation process if input was less than recommended.

Pain relief

Staff assessed children and young people regularly to see if they were in pain, and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.

The service was actively involved in numerous research studies in the assessment and treatment of pain in children and young people on palliative care. These included; The DIPPER study that reviewed oral morphine versus transmucosal diamorphine. The Children's Palliative Outcomes Score study into pain management, staff from the service also contributed to National Institute for Health and Care Excellence Standards NICE NG61 and the quality standard QS160 into end-of-life care for infants, children & young people. Staff involvement in research and development ensured they were aware of cutting edge pain relief technology, methods and training and could in turn provide these services and techniques to the children in their care.



Hospice services for children

Staff assessed children and young people's pain using a recognised tool and gave pain relief in line with individual needs and best practice. The service used several nationally recognised pain scale tools, to assess pain levels in children and young people. Usage was based on the child's age and ability to communicate. We observed staff using a Lego face scale, with pictures of a Lego head from happy to sad and angry, children and young people could point at the face that most appropriately communicated their level of pain. The service supported children and young people manage chronic pain via the use of the spa and physiotherapy in accordance with World Health Organisation guidelines.

Children and young people received pain relief soon after requesting it. We observed staff regularly checking pain levels of the children attending. When a child communicated they were in pain, staff administered pain relief in a timely manner.

Competent staff

The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of children, young people and their families. Managers provided staff with a catalogue of clinical competency training to ensure the complex levels of care required by some children and young people attending the hospice were met. Managers had systems in place to provide oversight of staff competencies and ensure staff with the appropriate skills were allocated appropriately via the clinical skills framework. The framework was divided into job titles, the requirements for each job, as well as skills required for job progression.

The education team directly supported staff, the teams plan included; simulation training and competencies for syringe drivers and advanced care plans. The professional nurse advocate was a new post within the service to support "a continuous improvement process that aims to build on the personal and professional clinical leadership of nurses, enhance the quality of care for patients, and support preparedness for appraisal and professional revalidation."

The service not only supported the learning and development of its own staff but was committed to supporting third party services as well. Managers organised a Compassionate Collaborative Care Group which included paediatric palliative care educational evenings every 6 weeks. These were attended by staff from hospices and hospitals across the region. Medical staff contributed teaching material to the Improving Palliative Care for the World's Children perinatal module. A member of staff travelled to Eastern Europe to provide training to hospice staff. Staff ensured there was joined up working across the region which supported children and their families as they moved across services. Staff demonstrated a caring culture that they not only wanted to support children under their service, but all children receiving palliative care.

Managers gave all new staff a full induction tailored to their role before they started work. New staff recruitment documents were stored online and included schedule 3 requirements for example, vetting and barring documents. The HR team had responsibility for ensuring staff did not commence a shift until recruitment checks and mandatory training were completed. Recruitment processes were currently manual, however the service was reviewing installing a digital application tracking system. Once the recruitment process was finalised, staff completed a 6 week induction followed by 6 month probation. Staff objectives created during induction were signed off and finalised by HR.

Managers supported staff to develop through yearly, constructive appraisals of their work. All staff had received an appraisal in the 12 months prior to inspection. Managers reviewed staff objectives every quarter to ensure they were up-to-date and accurately reflected the working practices of staff.



Hospice services for children

Managers made sure staff attended team meetings or had access to full notes when they could not attend. Team meetings were held monthly, staff could access them via videoconference if they were unable to attend in person. Minutes were also available for staff to access if they were on annual leave.

Multidisciplinary working

Staff worked together as a team to benefit children, young people and their families. They supported each other to provide good care.

There was an exceptional, embedded culture of multidisciplinary working. Managers and staff actively sort opportunities to share learning, guidance and best practice within the service, the community and outside agencies. There was 'buy in' from all staff to work as a unified unit to provide holistic, unified care with the child at the heart of it.

Staff held regular and effective multidisciplinary team meetings (MDT) to discuss children and young people and improve their care. We observed a clinical education meeting and noted there was good communication throughout, all members of staff were given an opportunity to speak and contribute to discussions.

Staff provided us with examples of numerous multidisciplinary meetings that demonstrated joined up, holistic working for the benefit of the children and young people under their care. The service held a weekly full MDT every Wednesday. This included staff from all disciplines and was a full review of child and young people's physical, mental and social health. These meetings were used to ensure all staff were aware of who is leading each aspect of care to ensure joined up working. We were provided with numerous examples of where the service developed multidisciplinary groups and meetings in order to ensure seamless care and shared learning across services. For example, social workers and the director of clinical services attended 'Child in Need' and strategy meetings with specialists from third parties, for example, Great Ormond Street Hospital. Medical consultants worked collaboratively with children's disease-specific specialists, for example, oncologists and neurologists at the local NHS trust. These ensured children and young people treated at the service received cutting edge treatment in collaboration with the country's leaders in specialisms and paediatric palliative care. Staff organised virtual MDT meetings where large groups of external agencies were included in conversations, for example, the Child Death Overview Panel, which included members of the local authority, coroners and local NHS representatives.

Seven-day services

Key services were available seven days a week to support timely patient care.

The service was open 24 hours a day, seven days a week. Staff could call for support from doctors. Medical staff worked in-house 9am to 6pm Monday to Friday. The service used an out of hours on call system when medical attention was required outside these hours and over weekends.

Therapy and support services based their hours according to the requirements of the children and young people being cared for. Educational support was provided by Oxfordshire County Council and was available 3 days a week from 9am to 3pm.

Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

Staff supported children, young people and their families to make informed decisions about their care and treatment. They knew how to support children, young people and their families who lacked capacity to make their own decisions.



Hospice services for children

Staff confidently made use of the Mental Capacity Act 2005 and used innovative ways to make sure that children were involved in decisions about their care in order that their human and legal rights were sustained.

Staff understood their role and responsibilities regarding following the requirements of the Mental Capacity Act 2005 (MCA). The MCA provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that, as far as possible, people make their own decisions and are helped to do so when needed. When they lack mental capacity to make particular decisions, any made on their behalf must be in their best interests and as least restrictive as possible.

We noted staff with appropriate competencies carried out capacity assessments. Where these found young people did not have capacity, there was evidence that decisions were made in their best interests and were most likely to be in accordance with their known personal and cultural preferences.

Staff understood their role and responsibilities regarding Deprivation of Liberty Safeguards (DoLS). DoLS is the procedure prescribed in law when it is necessary to deprive of their liberty a resident or patient who lacks capacity to consent to their care and treatment in order to keep them safe from harm. Applications under DoLS complied with legal requirements and staff evidenced those under the order were supported in the least restrictive manner.

Staff mostly kept up-to-date with training in the Mental Capacity Act and Deprivation of Liberty Safeguards. Due to an influx of new staff, nurses, nurse associates and child and family support service registered staff did not reach the 85% training completion target for Mental Capacity Act and Deprivation of Liberty Safeguards training. In response, managers developed an action plan to prioritise training completion. Part of the plan included ensuring there was always staff on shift who had received training in the Mental Capacity Act and Deprivation of Liberty Safeguards.

Staff demonstrated they understood the principles and requirements of gaining consent and knew how to access the consent policy if they had a question or concern. We viewed records for all 4 children in attendance on the day of inspection, and noted all consent forms were completed and signed by an appropriate person. Staff understood how to support and document young people consenting using Gillick Competency. The Gillick Competency is an assessment to support whether a child (a person under 16 years of age) is able to consent to their own medical treatment, without the need for parental permission or knowledge.

Is the service caring?



Our rating of caring improved. We rated it as outstanding.

Compassionate care

Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and took account of their individual needs.

We found a staff culture that was highly motivated and inspired to offer care that was kind and compassionate. Staff were determined in overcoming obstacles to achieve goals and final requests for children, young people and their families in imaginative and resourceful ways. Managers supported staff to 'buy in' to this approach in order that it could be sustained.



Hospice services for children

Children, young people and their families said staff treated them well and with kindness. Children, young people and their families valued the relationships they had built with staff, and as a result felt cared for and that they really mattered.

The inspection team was inundated with examples of staff going ‘the extra mile’, especially regarding ‘Make a Wish’ requests. For example; staff arranged for llamas to be brought into the garden where a child and their family were able to walk and feed them. Staff set up a fair ground including rides. Children’s television characters and presenters as well as famous footballers have also attended the site. One child’s ‘Make a Wish’ request was to see their imprisoned sibling before they passed. Staff worked with prison officers to ensure the visit could take place in a safe and controlled manner. Families told us how much these final wishes meant to their children and to themselves and how the memories of these events enabled them to “Look back and smile, even though xxx is no longer with us. We are so grateful for the time we spent there knowing xxx got to fulfil a dream”. Staff understood the importance of creating individual experiences to give children in their care a sense of achievement, but also to demonstrate to families that there were positives in a situation that could seem dire.

Not only did the service support the children they cared for, they provided support to whole families. Staff decorated a private room and provided catering for a couple with a child in attendance in order that they could celebrate their wedding anniversary. Managers ensured beds were available for a family with multiple children using the service. This enabled the parents to go out for a meal and explore Oxford by themselves, which they had been unable to do for 20 years.

Staff were discreet and responsive when caring for children, young people and their families. Staff had an in-depth appreciation of people’s individual needs around privacy and dignity. Staff cared for children and young people in a respectful and considerate way. We observed a child wishing to leave an activity after getting distressed. Staff supported them to leave the area quietly and quickly so as not to draw attention, but also provided comfort. Staff understood and acted on signs and signals where families and friends required private time together, staff were on hand without being obtrusive.

Staff understood and respected the personal, cultural, social and religious needs of children, young people and their families and how they may relate to care needs. Staff we spoke with understood their role and responsibility in providing holistic care. For example, staff arranged for a child whose religion was Muslim to access a virtual Hajj when they were unable to make a pilgrimage. Staff made appropriate arrangements where early burial was required due to cultural preference and ensured religious rights post death were adhered to.

Emotional support

Staff provided emotional support to children, young people and their families to minimise their distress. They understood children and young people’s personal, cultural and religious needs.

The service provided outstanding end-of-life care where children and young people experienced a comfortable and dignified death. Staff also cared for and supported friends and family with empathy and understanding.

Staff undertook training on breaking bad news and demonstrated empathy when having difficult conversations. All staff received training to support patients and families in emotional situations. The bereavement team attended additional specialised training throughout the year which enabled them to better support families. Training topics included; Trauma including PTSD and stress, Conflict Management including patients, families and medical professionals and support for parents with rainbow babies. Rainbow babies are a terminology used to describe a baby born subsequent to a miscarriage, stillbirth, or the death of an infant from natural causes.



Hospice services for children

Staff gave children, young people and their families help, emotional support and advice when they needed it. Staff received training in starting difficult conversations that included responding to signs and clues as to when a child, young person and/or their family were ready to have difficult conversations. Support was available for all family members including parents/carers, siblings and grandparents. Telephone support was available 24 hours a day, seven days a week. A consultant was always available if families required medical advice or support.

Staff provided us with numerous examples of how they supported children, young people and their families to learn to appreciate that although their child was receiving palliative care, there were good memories and positives that could bring the family together. Staff helped siblings feel acknowledged when their families focus may not be on them and also supported families in accepting their child was nearing the end of their life.

The service had a dedicated team that provided bereavement support to individuals, couples, and groups. The team developed a bereavement standard that included touch points throughout the end-of-life pathway to ensure children and families were regularly supported. The bereavement team “Walked alongside” parents and supported them to register the death, find a funeral director etc.

The service was part of the Thames Valley Network that developed a holistic care framework to support families facing the death of their newborn infant. It provided integrated ongoing support throughout pregnancy, delivery, the postnatal period and bereavement care. The bereavement team was also involved in developing a pilot for a bereavement triage tool, designed to improve tailored support plans.

The bereavement team ran a monthly bereavement group for those in the first year of bereavement and a bi-monthly group for the second year onwards. There was no end date as to when bereavement support would end, and staff tailored the level and type of support to each individual within a family.

Staff understood the emotional and social impact that a child or young person’s care, treatment or condition had on their, and their family’s, wellbeing. The service had recently offered 10 families the opportunity to record a bespoke song about their child who had passed. There were also plans to expand the services remembrance and celebration events by working with an interfaith minister to cater to all religious preferences.

Understanding and involvement of patients and those close to them

Staff supported and involved children, young people and their families to understand their condition and make decisions about their care and treatment. They ensured a family centred approach.

Staff made sure children, young people and their families understood their care and treatment. Each child was allocated a member of staff who acted as their key contact. It was the responsibility of staff to touch base with families and provide regular updates. Staff photos were displayed throughout the unit and included their job role. Families advised they appreciated being able to put a name to a face and knowing who was on shift when they were visiting.

Staff talked with children, young people and their families in a way they could understand, using communication aids where necessary. We observed staff explain what care they were going to provide, why they were doing so, what feelings the child may expect and any risks or side effects using clear and simple language. Staff gave children and their parents the opportunity to ask questions and during care regularly checked in that the child was well. Staff received specialised training to support children who may experience difficulties with communicating their wishes.



Hospice services for children

Staff supported children, young people and their families to make informed decisions about their care. We viewed the care plans of all 4 children being cared for on the day of inspection and noted plans were written with input from both the child and their parents, rather than staff completing them on their behalf.

Patients gave positive feedback about the service. Comments included; “We were spoken to so well all the way through the process which placed us at ease in a terrible situation. I was blown away by the kindness shown to us by the staff”. “We can’t even begin to communicate what a gift the Helen House has been to us during this time”. “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”. “We always felt cocooned in safety when we stayed, like everything was alright,” and “Staff bent over backwards to support us”.

Is the service responsive?

Good



Our rating of responsive stayed the same. We rated it as good.

Service delivery to meet the needs of local people

The service planned and provided care in a way that met the needs of local people and the communities served. It also worked with others in the wider system and local organisations to plan care.

Services were planned and organised so they met the changing needs of the local population. The service provided support to children and young people living in; Thames Valley, Buckinghamshire, Oxfordshire, Berkshire, Northamptonshire, Bedfordshire, Wiltshire and Gloucestershire. The service was expanding the community outreach team in order to support children and young people who wished to pass away at home.

The service used over 500 volunteers to support the organisation with various activities including; pianists, bakers and gardeners.

Facilities and premises were appropriate for the services being delivered. We viewed all areas of the service and noted bedrooms were bright and airy and children’s bedding was used. Two out of 8 bedrooms had direct access into the garden. The conservatory led to the gardens and had doors wide enough to allow beds access into all outdoor spaces. The garden was bright and open and included musical instruments, a wheelchair accessible swing and play equipment. There were sheltered areas in order that families could enjoy outside spaces in the rain and a separate area for teenagers with indoor space. The bath had lights and bubble jets, the sensory room had light’s, bubbles and an interactive television. We noted there was children’s artwork used as decoration throughout the unit and that communal spaces were arranged to provide private areas for families to spend time together, whilst still being included in activities. The bereavement suite had 2 entrances, 1 via the unit and 1 directly outside. The suite was used during the COVID-19 pandemic as a visiting area as it could be isolated and deep cleaned pre and post families visiting. The areas inside the suite were adaptable depending on the needs and family dynamic of the people using it. Families appreciated access to the flats and said “Having a family flat to stay in is very helpful to our family as it gives us some much needed reset and some quality time with siblings”.

Refurbishment plans included; creating a teenage suite, updating the family flats, redecorating the bereavement suite, creating a flexible family space, increasing access to the garden and adding en-suites and direct outdoor access to all 8 bedrooms.



Hospice services for children

Meeting people's individual needs

The service was inclusive and took account of children, young people and their families' individual needs and preferences. Staff made reasonable adjustments to help children, young people and their families access services.

Staff understood meeting the information and communication needs of children and young people with a disability or sensory loss. The service had a bronze Makaton award. Makaton is a unique language programme that uses symbols, signs and speech to enable people to communicate. Two nurses and the play leader were Makaton champions, as champions they developed the words of the week. Each week Makaton signing was displayed based on a theme, the theme for the week of inspection was 'holiday' which included how to sign for 'bucket', 'spade' and 'beach'. Staff and families advised us they appreciated the displays and had improved their knowledge of Makaton as a result.

Managers made sure staff, children, young people and their families could get help from interpreters or signers when needed. The service had access to an interpretation service 24 hours a day, seven days a week. Staff described how they supported a Ukrainian family, who did not speak English. The family were staying with UK hosts, however, the hosts left the country. Therefore, staff moved the family into an on-site flat. Their child died on-site and staff were then able to help the family take them back to Ukraine to be buried.

Children, young people and their families were given a choice of food and drink to meet their cultural and religious preferences. We observed a mealtime and noted there was a range of meal choices available. Staff chatted with children and their families and supported children to eat in a dignified manner that was unrushed. We observed staff playing a 'Mr Tumble' game to support a child to take a drink. The catering team could make any food requested by children, young people and their families for either physical or cultural reasons. For example, the team routinely gave smoked salmon to a child who enjoyed the flavour and the consistency was appropriate for a soft diet. Another child was treated to a small chocolate bar every time they consented to taking their medicine. Staff supported Muslim families to observe fasting during the month of Ramadhan. Staff also bought in meals from a local African takeaway for a family not used to western cuisine.

Staff organised a range of different activities to support the social needs of patients and their families, including; visits from pets as therapy dogs, teenage social weekends where they ate takeaways and played computer games, individual meet ups tailored specifically to mums, dads and siblings.

The service held annual remembrance events for bereaved families and noted several families had built strong relationships following these events.

Staff ensured when children died on-site, they did everything possible to meet their personal needs and preferences. For example, the bereavement suite included a sound system, staff ensured the child's favourite music was always playing, families advised us they appreciated this. Families said the suite gave them, "Time together as a family, we will hold these precious moments forever. The kindness of the staff and making sure his music was always playing, I will never forget."

Staff also provided families with personal diaries in order they could document their own experiences and memories. Staff displayed a picture of Winnie the Pooh outside the bereavement suite to show when it was in use. This ensured staff did not enter the suite unnecessarily.

The service had good links with local faith leaders and was able to access representatives from most religions in a timely manner.



Hospice services for children

Access and flow

People could access the service when they needed it and received the right care promptly.

Children and young people could either be referred privately or via their GP for respite care, or directly from their local NHS trust. Referral was either via telephone or electronically via the website.

Staff demonstrated that care planning started during the referral process and ensured families needs were included. Referral information included a history of the family, their social/economic dynamic, in order that staff could sign post to appropriate financial initiatives, and whether sibling support would be required. Goal setting and education planning were also arranged in conjunction with the teaching service in order to ensure lessons mirrored what was being learnt at school.

The services eligibility criteria was based on the 4 priority categories as defined by Together for Short Lives. These were; 1) Life-threatening conditions for which curative treatment may be feasible but can fail. Examples: cancer, irreversible organ failures of heart, liver, kidney. 2) Conditions where premature death is inevitable. Examples: cystic fibrosis, duchenne muscular dystrophy. 3) Progressive conditions without curative treatment options. Examples: batten disease, mucopolysaccharidoses. 4) Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to deteriorating health. Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.

Two beds were always reserved for symptom management and/or end-of-life care. This was to enable a child to attend at short notice instead of having to pass away at a hospital facility.

When children and young people deteriorated, staff followed hospital transfer criteria that had been developed with the local NHS trust and followed legislative guidance. The document was detailed and included review of; resuscitation status, ongoing diagnostic tests, discussing extubating expectations with families, pretransfer planning including fluids and medicines.

The service was supporting the development of the Managed Clinical Network. This reviewed transfers from the paediatric intensive care unit where the child was leaving the trust to pass away in a preferred setting. There was evidence of how the teams work together to ensure smooth transfer of children between services.

Staff supported children, young people and their families when they were referred or transferred between services. Staff from the transition team regularly supported children aged 14+ and their families to understand and prepare themselves for the move between children's and adult palliative care services. Families were supported to seek further guidance regarding changes and were provided numerous opportunities to discuss any concerns with the transition team prior to their child turning 19.

Learning from complaints and concerns

It was easy for people to give feedback and raise concerns about care received. The service treated concerns and complaints seriously and included children, young people and their families in the investigation of their complaint.

Children, young people and their families knew how to complain or raise concerns. Children, young people and their families were provided a 'Complaints, Concerns and Suggestions' leaflet as part of their admission. Families we spoke with advised they felt able to raise any issues with staff and the management team. The service had not received a formal complaint in the 12 months prior to inspection.



Hospice services for children

The service clearly displayed information about how to raise a concern in patient areas. Complaints leaflets were displayed throughout the service and information on how to raise a complaint or concern was available on the services website. The service had recently redesigned the 'Complaints, Concerns and Suggestions' leaflet using branded colours, to make them more noticeable.

Managers investigated complaints and identified themes. Managers acknowledged feedback and made changes accordingly. For example, a parent of a child cared for at the service for several years but who had since passed, requested their bereavement support take place in-house. This was in order that the sibling, who enjoyed their visits to the service, could reconnect with staff, the environment and their memories of the hospice. Bereavement counselling did not take place onsite. Although information regarding support services was included in the literature provided to families, in response to this request, managers included bullet points of what the service is able to provide and where in order to make the information easily accessible.

Managers shared feedback from complaints with staff and learning was used to improve the service. Meeting minutes demonstrated learning from complaints, concerns and feedback was an agenda item on monthly all staff meetings. The services digital strategy included an introduction of real time feedback, this was to ensure a quicker turnaround of change.

Is the service well-led?

Outstanding



Our rating of well-led improved. We rated it as outstanding.

Leadership

Leaders had the skills and abilities to run the service. They understood and managed the priorities and issues the service faced. They were visible and approachable.

Leaders had the skills and abilities to run the service. The managerial team worked together to ensure all areas of the service were monitored and reviewed. Each member of the team had clear roles, responsibilities and objectives, and staff we spoke with understood who to report to dependent on their concern. Staff advised us the leadership team was friendly, approachable and had an open-door policy. All staff advised us they felt able to speak with the leadership team regarding areas of concern.

The services head of professional development ensured appropriate staff were recruited and competencies were evidenced. This was for the whole team including managers. Managers were open and honest regarding areas where they required further support and were proactive in organising training to fill any gaps in knowledge or experience. Two members of the managerial team were attending a leadership course and further safeguarding qualifications.

The managerial team and senior members of staff were leaders in national committees. For example, both medical consultants were on the National Association for Paediatric Palliative Medicine (APPM) Executive committee. The medical director and medical consultant were part of the NHS South East Children and Young People Paediatric End-of-life Care Team. A manager was an active member of the Managed Clinical Network. The medical director was also the clinical lead for Children and Young People's Palliative and End-of-life Care for Buckinghamshire, Oxfordshire and Berkshire Integrated Care Board for the South East Region (NHSE).



Hospice services for children

Vision and Strategy

The service had a vision for what it wanted to achieve and a strategy to turn it into action. Leaders and staff understood and knew how to apply them and monitor progress.

The services strategy was a continuous document that was reviewed and discussed at monthly team meetings as well as staff conferences. Managers attended a strategy review meeting every 6 months to review progress and make changes.

At the time of inspection, the service was 18 months into a 3 year strategy. The strategy was focused on developing services including enhancing the community and therapies teams and bridging the gap between children's and adult's services, especially for children with learning disabilities. Staff we spoke with were particularly passionate about the introduction of therapy services.

There was staff buy in to the services vision and values and all staff we spoke with understood future plans for the service and wanted to support and be a part of that vision. The services values were developed in consultation with staff, were printed in all marketing leaflets and formed part of the appraisal framework.

Culture

Staff felt respected, supported and valued. They were focused on the needs of patients receiving care. The service promoted equality and diversity in daily work, and provided opportunities for career development. The service had an open culture where patients, their families and staff could raise concerns without fear.

In the years since the closure of Douglas House and the introduction of 10 new members of staff, the managerial team put a lot of effort and focus into improving the culture of the service. More experienced staff described there used to be 3 separate cultures, those working in Helen House, Douglas House, and community services. Staff advised us the teams were now working as 1 unified unit. This was supported by a focus on staff mental health and well-being awareness. Managers developed a well-being newsletter providing information on the signs and symptoms of anxiety and depression, staff anonymously wrote stories regarding their own experiences of mental health. Staff were able to volunteer to become mental health first aiders, they met quarterly to review methods for how staff mental health could be improved, in response to this, the team created a wallet sized checklist that included reminders to take breaks, keep hydrated and enjoy outside spaces.

The service joined the Fairness, Respect, Equality, Diversity, Inclusion and Engagement (FREDIE) hub to promote learning equality and diversity amongst staff. Initiatives included; a lunch and learn session with a transexual guest speaker and internal events to celebrate Pride month. On International Women's Day managers organised a panel to share stories about living abroad and living with chronic illness. Staff were able to join the Menopause Network Group that was supported by the medical team to aid diagnosis and included a session by a national medical specialist.

The staff forum had representatives from across the organisation including retail to bring issues and concerns to the forefront. Recent topics of discussion included; the cost of living crisis, in response, HR put together a pack that included cost saving tips and contact details of local and national support initiatives. After viewing the minutes from this forum, the exec team found funds for a staff bonus. The staff recognition group was also created specifically to support and celebrate staff and gave managers an opportunity to demonstrate their appreciation of the team.



Hospice services for children

We observed a workforce that overwhelmingly enjoyed the work they did at Helen and Douglas House. Staff advised us they felt like managers truly cared about them and they went home knowing they had made a difference in the lives of not only the children they cared for, but their families and friends as well. One member of staff became teary describing how much she loved her job; another advised us it was “A dream to work here”. These opinions were reflected in the recent staff survey that demonstrated positive results across the board.

Governance

Leaders operated effective governance processes, throughout the service. Staff had regular opportunities to meet, discuss and learn from the performance of the service.

The services senior management team was comprised of a chief executive officer, registered manager, nominated individual and medical director. This team oversaw the day to day running of the service and reported to the board of trustees.

The senior clinical team including medical staff, met weekly to discuss incidents, complaints and feedback and safeguarding referrals. We viewed minutes from the last 3 senior clinical meetings and noted all incidents were reviewed and updated. Service updates were also reviewed following the CQC inspection domains of safe, effective, caring, responsive and well led. This fed into the monthly managerial meeting.

The monthly managerial meeting was attended by the senior leadership team and reviewed training, completion of audits and performance.

There was also a monthly clinical heads forum that had a flexible agenda focusing on specific requirements of the service. We viewed minutes from the 3 most recent meetings and noted topics included; research, capacity planning, referral processes and data protection.

The monthly community and family support services team meeting was used as an opportunity to ensure senior managers were aware of issues and concerns raised by people who used the service and ensure grass root concerns were escalated accordingly.

The care team met bi-monthly to review the effectiveness of the day to day running of the service. This meeting was supported by an external midwife to provide assurances of effective working practices.

All of the above fed into the quarterly clinical governance meeting where agenda items included; infection control, policy updates, a review of risk registers, clinical quality and compliance as well as regulatory compliance. A report from these meetings was presented to the board of trustees.

Management of risk, issues and performance

Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact.

Managers understood the risks associated with the service. The 3 biggest risks to the service were staffing, medicine incidents and an increased patient complexity, especially regarding mental health services. There were action plans and mitigations in place for these risks as well as all those on the services risk register.

Staff working on the floor, were aware of risks associated with the service. Staff felt they could escalate identified risks to the senior management team and were kept informed of progress against risks at monthly all staff meetings.



Hospice services for children

The senior clinical team reviewed the risk register on a quarterly basis and produced a report based on the progression of action plans which was reported to the board of trustees.

Part of the action plan into reviewing patient acuity, was a review of the admissions process in order to ensure the most effective staff skill mix. Managers were also increasing the number of staff teaching days to improve staff competency.

The service benchmarked itself against National Institute for Health and Care Excellence guideline NG61 End-of-life care for infants, children and young people with life-limiting conditions: planning and management. At the time of inspection, the service was 94% compliant, this was an improvement on the 2022 score due to the introduction of the in-house physiotherapy service. Managers had plans to expand in-house therapies in order to become 100% compliant.

The month prior to inspection, the service benchmarked itself against the End-of-life care for infants, children and young people quality standard (QS160). This demonstrated the service was continually analysing itself against national quality standards and ensuring any gaps were addressed via an improvement strategy.

The service contracted an external auditor to review the performance of the service. We viewed the report and noted it stated; “We have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on Helen & Douglas House’s ability to continue for a period of at least twelve months”.

Information Management

The information systems were integrated and secure. Data or notifications were consistently submitted to external organisations as required.

Managers appointed an external data protection officer to review the service and ensure compliance with data protection requirements. In response, managers created an action plan to improve staff understanding of data sharing with trusts and a manager was completing a digital apprenticeship in data science to streamline data software.

The service had a Caldicott Guardian and Deputy Caldicott Guardian (who were responsible for protecting the confidentiality of people's health and care information and making sure it was used properly) who led the monthly information governance meeting. This meeting reviewed the annual data protection toolkit as well as audits of screen locking and password protection safeguards. Minutes from the meeting noted there were gaps in communication methods as evidenced when telephone systems went down.

Managers and staff understood their responsibilities in meeting the requirements of Care Quality Commission (Registration) Regulations 2009: Regulation 18, which states that “Providers must notify CQC of all incidents that affect the health, safety and welfare of people who use services”. Staff completed mandatory training in General Data Protection Management and Cyber Security. In the 12 months prior to inspection, the service did not have any data protection breaches.

Engagement

Leaders and staff actively and openly engaged with patients, staff, the public and local organisations to plan and manage services.

Managers organised regular surveys and discussion groups with children, young people and their families including food surveys and staff uniform surveys after a query from a family member. All surveys were available in a range of formats including picture and easy read to ensure children with limited writing and communication capabilities could



Hospice services for children

respond. The service recently completed a bereaved family survey, specifically to gain feedback from families who experienced a bereavement in the previous 12 months. The survey included questions regarding the physical environment, level of support as well as whether families felt their child passed in the best place for them. The services refurbishment plans were based on these families' opinions of the environment. The family working group had been reinstated since the COVID-19 pandemic and was used to shape the service. Discussions included review of room temperatures, feedback about when and what type of information families wanted at each stage of their journey and reminders of the various services the hospice provided.

The service held monthly organisational all staff meetings, managers produced regular clinical newsletters that were sent to staff via email and posted on notice boards. The chief executive officer sent a bi-weekly update via email, this was used to inform staff of key events across the service as well as updates regarding the strategy and business updates.

The service engaged with the public via their retail services to advertise specific initiatives within the service.

The service engaged with numerous local and national organisations to support not only the children and young people receiving care at Helen and Douglas House, but also children receiving palliative care nationally.

Learning, continuous improvement and innovation

There was an culture within the service of continually learning and improving services. Leaders encouraged innovation and participation in research.

We found a team that was passionate about developing care, standards and national guidance for paediatric palliative care using innovative, holistic methods. Staff were enthusiastic regarding their active role in developing research and on national committees and understood the importance of sharing learning across national organisations.

The service went above and beyond to lead and develop working with nationally agreed agencies to embed an outcomes framework, based on the Together for Short Lives priority categories, in order that nationally, paediatric hospices could monitor outcomes. This was in response to the fact there is no nationally agreed outcomes framework for hospice care for children and young people.

Managers and staff provided numerous examples of where they worked with national agencies to write and produce legislation and guidance, for example the Association for Paediatric Palliative Medicine. Staff from the service were also involved in teaching the principles of legislation and palliative care to other agencies and care providers including the local university and NHS ambulance service.

Staff at the service were involved in numerous development and research projects and were leaders in the field of paediatric hospice services. For example, the services medical consultants contributed several chapters to the Healthcare Professionals Guide 'Children & Young Person's Advance Care Plan'. Staff delivered the session on palliative care at the Lily Foundation annual conference in late 2022. One consultant presented their work on acrania (antenatally diagnosed congenital skull defects) at the European Association of Palliative Care conference in Rotterdam. Another consultant chaired the Association for Paediatric Palliative Medicine session at the Royal College of Paediatrics and Child Health conference and jointly hosted with the Paediatric Gastroenterology Group, focussing on feeding difficulties related to gut failure. Staff also presented at the recent Together for Short Lives conference and the chief executive officer delivered a plenary session on children's hospice care. The service was also involved in a project with local integrated care systems to create virtual wards to support palliative care in the community.



Hospice services for children

Staff working at the service developed a contextualised assessment tool that was being adopted at local NHS trusts. Staff were co-chairs at the British Society for Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) and Association for Paediatric Palliative Medicine (APPM) joint session at the RCPCH conference. Staff were part of the DIPPER study that reviewed oral morphine versus transmucosal diamorphine and developed the Children's Palliative Outcomes Score study into pain management. Staff contributed to National Institute for Health and Care Excellence Standards NICE NG61 and the quality standard QS160 into end-of-life care for infants, children & young people. This demonstrated that children and young people at the service were receiving the latest treatment and understanding regarding palliative care in order to receive the best outcomes.

The hospice was closely linked to the local NHS trust to provide collaborative children's palliative care services. This meant children would receive palliative care sooner through a much simpler transfer process.

The service was heavily involved in educating not only its on-site staff, but staff working with other providers. Staff at this service were leaders in their fields and not only following legislation and guidance but supporting the development and expansion of understating of paediatric palliative care.