

Haven House Children's Hospice







Quality Report

The White House
High Road
Woodford Green
Essex
IG8 9LB
Tel: 020 8505 9944
Website: www.havenhouse.org.uk

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This report describes our judgement of the quality of care at this location. It is based on a combination of what we found when we inspected and a review of all information available to CQC including information given to us from patients, the public and other organisations

Ratings

Overall rating for this location	Good	
Are services safe?	Good	
Are services effective?	Good	
Are services caring?	Good	
Are services responsive?	Good	
Are services well-led?	Good	

Mental Health Act responsibilities and Mental Capacity Act and Deprivation of Liberty Safeguards

We include our assessment of the provider's compliance with the Mental Capacity Act and, where relevant, Mental Health Act in our overall inspection of the service.

Summary of findings

We do not give a rating for Mental Capacity Act or Mental Health Act, however we do use our findings to determine the overall rating for the service.

Further information about findings in relation to the Mental Capacity Act and Mental Health Act can be found later in this report.

Overall summary

Haven House Children's Hospice provides overnight respite care for up to six children and young people aged from birth to 18 years who may have complex needs associated with life-limiting or life-threatening conditions. They also provide some day care. Haven House will accept initial referrals from anyone in the community who knows a child with a life limiting condition or life-threatening conditions. Additionally, they provide community and day therapeutic and nursing services in the home or at the hospice.

Haven House offers a multi-professional approach to the health, social care and education of children who attend the service. At the time of our inspection, there were currently 387 children including siblings open to the services and they and their families accessing their provision in a variety of ways. Parents were able to negotiate with Haven House about the most suitable and convenient time for their child to receive support. This could be provided as half days, overnights and in some situations blocks of time to allow parents time to have a holiday or visit family abroad.

In addition to the respite care offered to children at Haven House, there was support for parents and siblings. This support ranged from a specialist toy loan library, complimentary therapies for adults including Reflexology and Rejuvenessence (head and facial massage designed to help relaxation), a bereavement team and an expert parent programme designed to give training and confidence to parents caring for their children. The family flat provided adjacent accommodation for parents and siblings to stay so they could be near their child or young person. The flat incorporated the Butterfly Suite as a specially adapted cold room to provide end of life and post death care.

The 'Hospice at Home' service was registered with Care Quality Commission (CQC) with the aim of providing families with choices when their child was nearing the

end of their life and they wish them to die with them at home. Additionally, Haven House had nurses with neonatal experience to support babies with complex needs associated with their conditions. The hospice had a registered manager in post. A registered manager is a person who has registered with the CQC to manage the service. Like registered providers, they are 'registered persons'. Registered persons have a legal responsibility for meeting the requirements in the Health and Social Care Act and associated Regulations about how the service is run. The charity had seven retail shops.

We inspected this service using our comprehensive inspection methodology and the inspection was announced. The inspection was 10 and 11 March 2020.

To get to the heart of patients' experiences of care and treatment, we ask the same five questions of all services: are they safe, effective, caring, responsive to people's needs, and well-led? Where we have a legal duty to do so we rate services' performance against each key question as outstanding, good, requires improvement or inadequate.

Throughout the inspection, we took account of what people told us and how the provider understood and complied with the Mental Capacity Act 2005.

Our rating of this hospice stayed the same. We rated it as **Good** overall.

- The service had enough staff to care for children and young people and keep them safe. Staff had training in key skills, understood how to protect children and young people from abuse, and managed safety well.
- The service controlled infection risk well. Staff assessed risks to children and young people, acted on them and kept good care records. They managed medicines well. The service managed safety incidents well and learned lessons from them. Staff collected safety information and used it to improve the service.

Summary of findings

- Staff provided good care and treatment, gave children and young people enough to eat and drink, and used special feeding and hydration techniques when necessary. Staff assessed and monitored children and young people to see if they were in pain and gave them pain relief when they needed it.
- Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked well together for the benefit of children and young people, advised them and their families on how to lead healthier lives, supported them to make decisions about their care, and had access to good information. The service could deliver palliative, respite and end of life services seven days a week.
- Staff treated children and young people with compassion and kindness, respected their privacy and dignity, took account of their individual needs, and helped them understand their conditions. They provided emotional support to children and young people, families and carers.
- The service planned care to meet the needs of local people, took account of children and young people's individual needs, and made it easy for people to give feedback. People could generally access the service when they needed it.
- Leaders ran services well using reliable information systems and supported staff to develop their skills. Staff understood the service's vision and values, and how to apply them in their work. Staff felt respected,

supported and valued. They were focused on the needs of children and young people receiving care. Managers and staff were clear about their roles and accountabilities. They had the right skills and abilities to run a service providing high quality sustainable care.

- The service engaged well with children, young people and the community to plan and manage services and all staff were committed to improving services continually. They strived for excellence through consultation, research and reflective practice.

However, we also found the following issues that the service provider needs to improve:

- During our review of patient records, we found the use of two electronic systems and paper records during the transition lacked a cohesive approach. Senior leads acknowledged it had taken longer than expected to transfer records but told us that this was because they were creating updated care plans.

Following this inspection, we told the provider that it should make other improvements, even though a regulation had not been breached, to help the service improve. Details are at the end of the report.

Nigel Acheson

Deputy Chief Inspector of Hospitals

Summary of findings

Our judgements about each of the main services

Service

Hospice services for children

Rating

Good



Summary of each main service

We rated this service as good overall because we rated safe, effective, caring, responsive and well led as good.

Summary of findings

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Good 

Haven House Children's Hospice

Services we looked at

Hospice services for children

Summary of this inspection

Background to Haven House Children's Hospice

Haven House Children's Hospice is operated by Haven House Foundation. Haven House is a six bedded children's hospice located in Woodford Green, Essex. The hospice was established in 2003 and provides specialist holistic support to life limited children and young people (CYP) and their families in the ethnically diverse boroughs of Waltham Forest, Redbridge, Havering, Barking and Dagenham as its core areas, as well as supporting CYP in Enfield, Haringey, Barnet, Camden, Islington, West Essex and East Hertfordshire. Haven House aimed to provide specialised support from diagnosis to death from antenatal diagnosis to post bereavement care. There were currently 387 children including siblings open to the hospice's services and they and their families accessed provision in a variety of ways.

Haven House Children's Hospice provides services for 0-18 year olds, both in the hospice and in the community. The hospice was originally designed as a respite and short stay centre for life limited children in the local community. However the hospice has evolved to meet families' needs with a more responsive service offered to families both at hospice site and in the community through the Hospice at Home team. Community support was launched in 2015 in response to family requests for more choice for end of life care in the community and evolved to provide therapeutic support to children unable to leave the home. The hospice worked closely with NHS colleagues to provide 24/7 access to specialist paediatric palliative care for children known to the service. The following services were currently available:

On site services included:

- Short breaks and respite
- Specialist neonatal link nurse
- Education and training for families, professionals and staff
- Step-down care
- Crisis support
- End of life care
- Play therapy
- Transition support
- Symptom management
- Counselling
- Family Support
- Dads' group
- Music therapy
- Physiotherapy
- Therapeutic Yoga
- Teenage Cancer Group
- Buddies Sibling Support Group
- Stay and Play
- Memory Day
- Pastoral and Spiritual Support

Hospice at Home Services included:

- Respite in the home
- Play therapy
- Therapeutic yoga
- Music Therapy
- End of Life Care
- Symptom Management
- Physiotherapy
- Specialist outreach nurses

Our inspection team

The team that inspected the service comprised a CQC lead inspector, other CQC inspectors, and a specialist advisor with expertise in children's hospice care. The inspection team was overseen by Carolyn Jenkinson, Head of Hospital Inspection.

Summary of this inspection

Information about Haven House Children's Hospice

During the inspection, we visited the inpatient units and attended two home visits. We spoke with 25 staff including registered nurses, specialist outreach nurses, music therapists, counsellor, play specialists, health care assistants, pharmacist, yoga therapist, reception staff, trustees and senior managers. We spoke with six parents as a high proportion of the children and young people were non-verbal. During our inspection, we reviewed 18 sets of patient records. There were no special reviews or investigations of the hospice ongoing by the CQC at any time during the 12 months before this inspection.

The accountable officer for controlled drugs (CDs) was the registered manager.

Activity (number of patients who used the service) for the period November 2018 to October 2019:

- Children 0 to 3 years: 105
- Children 4 to 12 years: 130
- Children 13 to 17 years: 80

- Adults 18 to 65 years: 11

Track record on safety for the same activity period:

- One never event
- Three serious incidents
- Zero incidence of hospice acquired methicillin-resistant Staphylococcus aureus (MRSA)
- Zero incidence of hospice acquired methicillin-sensitive Staphylococcus aureus (MSSA)
- Zero incidence of hospice acquired E-Coli
- Zero incidence of hospice acquired Clostridium difficile (c-diff)
- Nine complaints
- 52 compliments

Services provided at the hospice under service level agreement:

- Physiotherapy service
- Pharmacy service

Summary of this inspection

The five questions we ask about services and what we found

We always ask the following five questions of services.

Are services safe?

Our rating of safe stayed the same. We rated it as **Good** because:

- The service provided mandatory training in key skills to all staff and made sure everyone completed it.
- The hospice had clearly defined and embedded systems and processes to keep people safe from abuse and staff demonstrated understanding of safeguarding processes and awareness on how to escalate and report safeguarding concerns.
- The service controlled infection risk well. Staff used equipment and control measures to protect patients, themselves and others from infection. They kept equipment and the premises visibly clean.
- Staff completed and updated risk assessments for each patient and removed or minimised risks. Staff identified and quickly acted upon patients at risk of deterioration.
- The hospice ensured they had enough staff with the right qualifications, skills, training and experience to keep patients safe from avoidable harm and to provide the right care and treatment.
- Staff kept detailed records of patients' care and treatment. Records were clear, legible, stored securely and easily available to all staff providing care.
- The service used systems and processes to safely prescribe, administer, record and store medicines.
- 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. When things went wrong, staff apologised and gave patients honest information and suitable support.

However, we also found the following issues that the service provider needs to improve:

- During our review of patient records, we found the use of two electronic systems and paper records during the transition lacked a cohesive approach. Senior leads acknowledged it had taken longer than expected to transfer records but told us that this was because they were creating updated care plans.

Good



Are services effective?

Our rating of effective stayed the same. We rated it as **Good** because:

Good



Summary of this inspection

- The service provided care and treatment based on national guidance and evidenced-based practice. Managers checked to make sure staff followed guidance. Staff protected the rights of patient's subject to the Mental Health Act 1983.
- Staff gave patients 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 patients' religious, cultural and other needs.
- Staff assessed and monitored patients 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 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.
- All those responsible for delivering care worked together as a team to benefit patients. They supported each other to provide good care and communicated effectively with other agencies.
- Key services were available seven days per week to support timely patient care.
- Staff gave patients practical support and advice to lead healthier lives.
- Staff supported children and young people to make informed decisions about their care and treatment. They followed national guidance to gain patients consent. They knew how to support patients who lacked capacity to make their own decisions or were experiencing mental ill health.

Are services caring?

Our rating of caring stayed the same. We rated it as **Good** because:

- Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and took account of their individual needs.
- Staff provided emotional support to children, young people, families and carers to minimise their distress. They understood children and young people's personal, cultural and religious needs.
- Staff and management were fully committed to the visible person-centered approach. They all used creative ways to make sure that children and young people had accessible, tailored and inclusive methods of communication.
- Staff supported and involved children, young people and their families to understand their condition and make decisions about their care and treatment.

Good



Summary of this inspection

- Staff were able to provide examples of where they had ensured patient's needs were met in the last days and hours of their lives.

Are services responsive?

Our rating of responsive stayed the same. We rated it as **Good** because:

- 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.
- 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. They coordinated care with other services and providers.
- People could access the service when they needed it and received the right care promptly.
- The service treated concerns and complaints seriously, investigated them and shared lessons learned with all staff. The service included children, young people and their families in the investigation of their complaint.

Good



Are services well-led?

Our rating of well-led stayed the same. We rated it as **Good** because:

- Leaders were committed and passionate about patient care and provided a high-quality sustainable service. They had the skills and abilities to run the service and clearly understood and managed the priorities and issues the service faced. Leaders were visible and approachable for patients and staff. They supported staff to develop their skills and take on more senior roles.
- The service had a child-centred vision and had developed a clear strategy with all relevant stakeholders. The vision and strategy were focused on sustainability of services and aligned to local plans within the wider health economy.
- Staff felt respected, supported and valued. They were focused on the needs of patients receiving care. The service had an open culture where patients, their families and staff could raise concerns without fear.
- Leaders operated effective governance processes, throughout the service and with partner organisations. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.

Good



Summary of this inspection

- Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact. They had plans to cope with unexpected events.
- The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements. Data or notifications were consistently submitted to external organisations as required.
- Leaders and staff actively and openly engaged with patients, staff, equality groups, the public and a wide range of local organisations to plan and manage services. The views of patients and stakeholders were considered before changes were made and they collaborated with partner organisations to help improve services for patients.
- The service was focussed on service improvement and sharing best practice externally. All staff were committed to continually learning and improving services.
- The service worked in partnership with other organisations to make sure that they were following current practice and providing a high- quality sustainable service.






Detailed findings from this inspection

Overview of ratings

Our ratings for this location are:

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

Hospice services for children

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

Are hospice services for children safe?

Good 

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

Mandatory training

The service provided mandatory training in key skills to all staff and made sure everyone completed it.

Mandatory training modules included documentation and record keeping, duty of care, equality and diversity, fire safety, handling information and information governance, health and safety, infection prevention and control (level one and two), conflict management, dignity and privacy, anaphylaxis awareness, understanding the Mental Capacity Act (MCA), consent, counter fraud, food hygiene and safety, manual handling and moving people and inanimate objects, prevent radicalisation, risk assessments, basic life support for adults and paediatrics, fire safety, understanding anxiety, understanding low mood and depression and understanding self-harm.

The training was delivered via an accredited e-learning platform and some modules were face to face. Although the human resources (HR) department monitored mandatory training compliance, staff received email reminders when training was due to expire. Data provided by the service showed the overall staff compliance rates by department were: care team (100%), community and wellbeing team (100%), finance team (100%), human resources (HR) team (100%), housekeeping (99%) and income generation and marketing (IGM) team (99%).

The hospice organised an annual training week where staff received protected time to update their mandatory training skills, including Basic Life Support (BLS), manual handling and safeguarding. The topics covered during the week were chosen in response to specific challenges where a knowledge gap had been recognised and covered new legislation or practice developments.

The care team had a dedicated education lead nurse who had the responsibility for ensuring learning needs were identified and staff were supported in achieving these. Training was also delivered in focused internal and external study days in conjunction with regular team meetings and skills sessions.

Safeguarding

Staff understood how to protect children and young people' from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.

The service had comprehensive systems to keep people safe. Mandatory training included safeguarding training and all staff were 100% compliant for safeguarding adults (level one and two) and children (level one to three). This was in line with the standards set out by the intercollegiate document, Safeguarding Children and Young People (CYP): Roles and Competencies for Healthcare Staff (2019). The hospice had two safeguarding leads of which one had completed level four training and the other had their training booked.

The hospice had a clear safeguarding policy and process which staff were aware of and knew how to access. Staff knew how to make a safeguarding referral and who to inform if they had concerns. Safeguarding leads told us

Hospice services for children

they had good working relationships with multi agency safeguarding hubs (MASH). All staff received quarterly safeguarding supervision by an appropriately trained member of the senior nursing team. Senior staff accessed safeguarding supervision through an external consultant. The safeguarding committee met quarterly with representation from all the departments and included discussions on policy reviews, and areas of development.

The hospice had an implementation plan with named leads for each action point to address the upcoming legislation change from Deprivation of Liberty Safeguards (DoLS) to Liberty Protection Safeguards (LPS) for CYP over 16 years. For example, staff had received training in the team away day in February 2020. The anticipated launch for LPS was September 2020.

Body maps were completed for CYP at each admission and the hospice kept the last five body maps to ensure there were no incidences of suspicious marks. The electronic database had a flagging system which allowed staff to use red flags to highlight safeguarding concerns.

Staff received managing challenging behaviour training to ensure they could deal with anticipatory situations. Staff also received training in autism and disability (levels one to three) during regular corporate inductions. Staff were trained to use communication aids for nonverbal patients and best interest decision making was embedded.

Safety was paramount in the hospice and the recruitment and induction of volunteers and staff was structured. Disclosure and Barring Service (DBS) certificates and checks were all in date for all staff. The hospice completed necessary checks for volunteers which included references, passports, DBS and qualifications if working in a hospice role. Volunteers also completed the necessary mandatory training (dependent on the role) either online or face to face during induction.

Staff gave us an example where the hospice had advocated for a nonverbal young person by ensuring the child or young person had the right to express their sexuality whilst acknowledging the safeguarding risks. The child or young person was placed in the hospice for three months by the local authority. The hospice worked with the multidisciplinary team to change perceptions and referred them to work done by Together for Short Lives and the sexuality alliance. Staff received training in

sexuality awareness with additional drop in sessions and pastoral care was offered to staff where there were mixed emotions. The child or young person was given private time to respect their privacy and dignity and appeared to be happy and parents had supervised visits.

Where the service had CYP patients on the end of life pathway, staff received a pre-brief to discuss their emotions, immediate debrief on the day followed by a formal debrief after.

The chaperone policy had been recently reviewed and was in date. The hospice had a two person Intimate Care Policy and visitors were always supervised.

Cleanliness, infection control and hygiene

The service controlled infection risk well. Staff used equipment and control measures to protect children and young people, themselves and others from infection. They kept equipment and the premises visibly clean.

During our inspection, we reviewed all patient areas which included the inpatient care environment, activity room, sensory room, holistic care centre, treatment rooms and sluice. All the areas we inspected were visibly clean, tidy, and clutter free. Bathrooms including showers and toilets were cleaned and checked daily. We checked a sample of bathrooms/toilets in each area and saw the checklist had been completed fully and found the areas to be visibly clean.

Waste management and removal, including those for contaminated and hazardous waste was in line with national standards. There were waste disposal bins in appropriate locations and those we checked were not overfull.

The hospice employed housekeeping staff who were available seven days a week including six hour shifts on Saturday and Sunday. We saw evidence that the housekeeping cleaning checklist was completed daily. The checklist included all bedrooms and bathrooms, toilets, staff rooms, butterfly suite and family flat. Data provided by the service showed there were zero incidences of healthcare acquired infection in the last 12 months.

Staff had access to personal protective equipment (PPE) which included sterile gloves in different sizes and

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aprons. The hospice had numerous alcohol dispensers in all the areas, and we observed staff request all visitors including the inspection team to use them. We observed staff washing their hands during home visits. Handwashing facilities with posters for cleaning your hands were seen throughout the service. Staff we observed were bare below the elbow (BBE) and adhered to infection control related aspects of the uniform policy.

During the inspection and considering the recent international viral outbreak, reception staff asked the inspection team appropriate screening questions regarding travel and exposure to anyone with a positive diagnosis. Staff instructed us to use the alcohol gel before signing in the visitor's book.

Staff used single use disposal medical devices where possible and no items were sent out externally for reprocessing. All reusable medical devices were decontaminated in line with manufacturers recommendations.

The hospice completed hand hygiene and infection control audits quarterly. Results for quarter four (Q4) 2019 showed the hospice achieved an average compliance of 93% and a significant proportion of staff who achieved a score of 90% were new starters. The hospice developed an action plan to achieve 100%. This included emailing senior nurses to support new starters on their shifts, emailing all staff of the audit results and offering hand hygiene drop ins sessions across the organisation as part of the charity's response to the recent virus outbreak.

Musical instruments were cleaned after use and soft toys were cleaned weekly. The hospice completed a deep clean annually. Staff were aware of the expectations regarding toy cleaning and we observed staff clean toys and surfaces between use. Activity areas were visibly clean and organised.

Although the hospice had toy cleaning checklists, clarification around the sign off process was required. For example, does signing the checklist mean all the toys have been cleaned or just those that had been used? We raised this with senior leads who acknowledged the feedback and told us it would be addressed. Following the inspection, the hospice submitted their revised toy cleaning schedule which provided the necessary clarity regarding the cleaning of the toys used, and the room and balls from the ball pit.

Environment and equipment

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

The hospice was set within four acres of protected woodland making it perfect for all year round outdoor activities. The charity organised several events on the grounds which included the summer festival and the Sparkle Walk.

The hospice underwent major refurbishment and improvements in 2018 and 2019. This included the new interactive discovery room, improvements to the car park and a new screen in the nurses' station to provide information. Service development included input from child or young persons (CYP) and their families. For example, the hospice installed a bigger lift to facilitate transport of incubators for neonates and a tracking hoist to the ensuite shower in the teenage bedroom to maximise privacy and dignity. The hospice had relocated the bereavement suite which allowed bereaved families to have more privacy as well as safeguard other CYP when there were lots of visitors to bereaved families.

Following a health and safety inspection of the playground which was completed in August 2018, the hospice reviewed the report and incorporated the findings into the playground improvement plans. The project had been created in consultation with parents, families and CYP and was due to be completed by the end of May 2020. The new playground would include a wheelchair swing, a sunken trampoline, a basket swing and lawn games. The surrounding area would be fully accessible with an all-weather surface which ensured that CYP could have the benefits of fresh air and fun whatever the weather. There were plans to build a new external barn structure to replace the marquee for outside activities once planning permission had been granted.

The improvement plans also included creating a new flexible kitchen which staff could use during office hours and at other times, it could be used for parents' meetings, buddies/siblings' groups, teen hub, counselling and family activities. The redesign included a protected space to use solely for preparing meals for the CYP in the hospice. The doorway between the two kitchens would be blocked to improve security and to provide storage.

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The kitchen improvements would create a space which would allow the facilities team to be relocated on the ground floor. Other planned improvements included the first floor staff room, rolling programme of redecoration and lighting upgrades, use of more wall art and murals and a digital information screen in the nurse's hub.

The hospice had three entrances, one for staff, one for visitors and one for families all of which were bright and visibly clean. The visitors' entrance was in the holistic care centre which was a welcoming space for patients and families with accessible toilet facilities. Entry was restricted and staff were present on the reception desk to monitor visitors who were asked to sign in and out. The visitors entrance area displayed a notice board with photos of all the team members and other information such as safeguarding leads.

The family entrance had its own lobby and seating area which had a television, range of toys, sensory equipment, books and magazines, seating, panic alarm and specialist seating. The notice board had information on sepsis, safeguarding, survey results and a 'tell us what you think' section.

The Holistic Care Centre allowed the hospice to provide a broader range of specialist services to an increasing number of local life-limited children. This included new consultation facilities for clinicians including children's specialist hospitals to meet with local life-limited children, bringing care much closer to home. The centre had multi-training space for staff, volunteers, local groups and Haven House Buddies (siblings of unwell children); confidential assessment areas for parents and children; a dedicated room for music and other therapy sessions, physiotherapy and complementary therapy services. The waiting rooms and clinic rooms were child friendly with toys, books and other resources appropriate for different ages.

The sensory garden, located behind the holistic care centre, was a haven for wildlife with plants and flowers designed to attract insects for wildlife hunts and games. The garden had a water feature, loungers and sensory equipment designed to make music. This area was also used by families staying in the family flat as it was tranquil, peaceful and private.

The café was bright and visibly clean with access to the garden which had ample seating. The café had range of seating available for all ages with access to a hot and cold drinks machine, a television and WIFI access.

The activity room was well organised and had a wide range of toys with dress up, arts and crafts with aprons and gloves. The room had a height adjustable table, clinical and domestic waste bins, assistive technology area, access to garden for activities and play, drug cupboard to store children's own medicines for day care respite and a call bell/alarm. The dining room was bright and visibly clean with a menu board, wipes, hand towels and specialist seating.

The estates and facilities team had an annual planner which was comprehensive and included all the environment and equipment checks, details of when the next service was due and planned dates for engineer visits. The estates and facilities team tracked progress monthly. The hospice had contracts with third party providers for the annual servicing and maintenance of children's beds, annual monitoring and servicing of the generator and support for water management. A third party contractor completed the Lifting Operations and Lifting Equipment Regulations (LOLER) inspections of hoists and lifting equipment, laundry servicing and repairs.

The inpatient care rooms were personalised for each child and had a call bell. We checked various items of equipment such as the automated external defibrillator (AED) and hoists and found they had been safety tested and were all within service date. The equipment store rooms were well organised with secure access and we saw evidence that equipment was routinely, and regularly serviced and calibrated. We saw evidence that Control of Substances Hazardous to Health (COSHH) items were locked away. The staircases throughout the hospice were painted with vibrant rainbow colours.

Fire extinguishers were stored securely and in date throughout the hospice. Although senior leads told us that fire drills were challenging given the complexities of the CYP, the hospice completed fire drills every six months. After each drill, feedback sessions took place to discuss improvements and the report was shared with

Hospice services for children

the health and safety committee. During the inspection, we observed the weekly fire alarm checks and we saw evidence of the completed checks recorded on the database.

Assessing and responding to patient risk

Staff completed and updated risk assessments for each child and young person and removed or minimised risks. Staff identified and quickly acted upon patients at risk of deterioration.

Each child had an emergency care plan completed by the palliative care team at a local children's hospital, ambulance directive and a symptom management plan. All CYP with a diagnosis of epilepsy had a seizure diary and were checked every 15 minutes at night due to the risk of Sudden Unexpected Death in Epilepsy (SUDEP). On each admission, parents were asked further questions on the child's recent health including any factors which may make an unplanned or emergency transfer more likely. The resuscitation status of all children was handed over at each shift, with special attention to children who had personalised resuscitation plans. Staff were able to view Advance Care Plans (ACP) on the electronic database.

The hospice had a policy for resuscitation, Do Not Attempt Resuscitation (DNAR) and anaphylaxis which was in date. The policy was comprehensive and included guidance on ambulance transfers, emergency equipment, how and when to use ACP, documenting decisions for resuscitation, the process to follow in event of cardiac arrest and managing anaphylactic reactions. The service managed deteriorating children through increased staff to children and young people (CYP) ratios and by using monitoring tools such as Paediatric Early Warning Scores (PEWS) which was introduced if there was a deviation from the baseline observations taken at every admission. Staff told us that CYP with PEWS in place had one to one care.

All staff had adult and paediatric basic life support skills training and appropriate emergency equipment was available throughout the hospice. Clinical care staff always had access to an automated external defibrillator (AED). Staff received extensive training on managing and identifying deterioration in CYP including training on Spotting the Sick Child, aggravated risk factors and sepsis. Haven House ran a nurse rotation project in conjunction with the local hospital paediatric ward to

offer staff the chance to develop their acute skills and confidence. Individual risks were identified at the care planning stage when diagnosis, medical needs and history were extensively documented to allow staff to understand the needs of the child. Resuscitation status was also discussed at the care planning stage and updated when appropriate.

When a child's condition changed, parents or their nominated representative were informed immediately. If there was a risk of deterioration in the child, a transfer to hospital via blue light ambulance was protocol where a staff member accompanied on the transfer bringing all the child's documentation and care plan. During the inspection, we saw evidence where a CYP was escalated for transfer to the hospital as they were unwell, and a staff member accompanied the parent and child. If a transfer wasn't required, staff could access medical and senior nursing support 24/7 from the palliative care teams at the local specialist children's hospitals. Medical reviews were also available through the supporting GP practice.

Staff had good awareness of lone working arrangements. Staff had work mobiles and tablets which were password protected and lone working safety devices. Staff told us that for initial visits, staff would go in pairs for home visits.

An external contractor provided regular and routine security patrols, site inspections and provided and maintained remote assistance/emergency call devices.

Nurse staffing

The service had enough nursing and support staff with the right qualifications, skills, training and experience to keep children and young people safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix, and gave bank and agency staff a full induction.

Haven House was a nurse led unit and currently employed 24.2 whole time equivalent (WTE) care staff which comprised of registered nurses and trained healthcare support workers. Senior leads told us that staffing was arranged around the needs of the CYP patients.

The hospice based the need for a healthcare support worker or a nurse by assessing the CYP's dependency

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considering the physical, social and emotional needs. A score of red, amber or green was calculated and used to determine the level of staffing support a child needed before the staffing for the shift was determined.

Each shift had a minimum of one nurse which was increased in line with dependency with a float member of staff. Senior nurse support was always available on the clinical floor during working hours to ensure safe staffing levels in the event of staff sickness. The clinical nurse manager responsibilities included safe staffing, ensuring staff were competent and liaised with families.

There was an on call system between 5pm and 8am for all staff who were Band 7s and above. Senior nurses on call typically worked one night shift once a week and one weekend every five weeks. Support was provided via phone or staff could come in if needed. The Director of Care was included in the 24/7 senior nurse on call rota and covered short notice shift cover if required. Staff told us families who received hospice at home services were given the on call contact numbers.

Between October 2018 and November 2019, the sickness rate was 12% for health care support workers, 2.2% for administration staff and Band 6 nurses, 3.3% for Band 5 nurses and 1.1% for allied health professionals. The current vacancy was 0.6 whole time equivalent (WTE) for Band 5 nurses.

The service maintained a staff bank of 20 regular nurses and healthcare support workers to allow flexibility. Bank staff worked an average of 2.5 shifts a month each, and substantive staff also filled bank shifts if they wanted to. The service completed quarterly audits on the use of agency and bank staff to ensure that necessary safety checks had been completed and quality of care delivered was not affected. The service used a small number of agency staff. Between October 2018 and November 2019, the number of hours worked by agency staff was 2081.

The service employed a wide variety of allied health professionals who complimented the nursing team to provide holistic care. Examples included music therapists, yoga specialist, counsellor and play specialists.

Two reception staff covered the main reception desk Monday to Friday 9am to 5pm. Volunteers provided cover on Saturday mornings once a month to support the yoga clinic. Between October 2018 and November 2019, the

organisation had 527 volunteers across all the areas. Although visitors were limited after 5pm, staff told us that visitors would buzz at the security gates to get access into the hospice grounds after which a staff member would meet them at the visitor's entrance. The care team were aware of the CYP parents and families and so were able to tailor visiting hours to family's needs.

Although the lead neonatal nurse had recently resigned before the inspection, the service had recruited two outreach nurses who were due to start in March. The hospice had several experienced neonatal nurses and senior leads were keen for all staff to have a good understanding of neonatal palliative care. The hospice had recently secured funding for a joint nursing post with a local NHS hospital to support with identifying CYP with palliative care needs and rapid discharge pathways.

The hospice had also trialled a rotational post with a local NHS hospital for eight months and was in discussion to replicate the rotational model with other NHS hospitals for a shorter rotation of four weeks. Senior leads told us they had a good working relationship with the Pan London neonatal palliative care lead nurse.

Medical staffing

The service could easily access medical staff with the right qualifications, skills, training and experience to keep patients safe from avoidable harm and to provide the right care and

treatment.

Although the hospice was a nurse led unit, the hospice had access to medical support when required. The local GP practice completed medical reviews and responded to hospice calls as necessary and CYP patients could be registered at the practice as temporary residents. The family GP was crucial to the hospice at home service and when managing CYP patients at end of life, supporting with symptom management and certification of deaths.

The hospice had 24/7 on call support from the palliative care teams from specialist children's hospitals and liaised with local paediatricians who case managed many of the CYP patients on the hospice's caseload. The hospice worked closely with the local Paediatric Oncology Shared Care Unit (POSCU) and received responsive support and advice when required.

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Records

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

The hospice used an electronic database for records and paper based notes. During the time of the inspection, the hospice was transitioning to another electronic database which would allow the service to be paperless.

We reviewed 18 patient care records including paper records which we found were stored securely. Records were comprehensive and included ACP and DNACPR where appropriate and risk assessments which were fully completed. The care plans included a wide range of information such as past medical history, allergies, nutrition and pain assessments, daily routines including sleeping, resuscitation status, emotional needs, spiritual needs, sexuality and social needs. Records showed evidence of person centred care with full involvement of the families and the multidisciplinary team, detailed observations and entries were dated, signed and legible.

The hospice completed record keeping audits every six months which involved reviewing 10 patients' records including both the paper notes and electronic notes. Results for paper based records in November 2019 were: confidentiality (100%), entries were signed clearly (90%), use of black ink only (60%), all entries were legible (50%) and the CYPs name recorded on every page (30%). Results for electronic records were: notes were signed off (60%), documentation standards followed (20%) and DNACPR recorded accurately (10%). The hospice reiterated the expected standards for documentation to all staff and delivered an education session on nursing notes standards during the training week in November 2019.

The hospice completed a re-audit in one month's time which showed that although some improvements had been made, further work was required. Results for paper based records were: confidentiality (100%), entries were signed clearly (90%), use of black ink only (80%), all entries were legible (100%) and the CYPs name recorded on every page (70%). Results for electronic records were notes were signed off (40%), documentation standards followed (50%) and DNACPR recorded accurately (10%).

The action plan included further training in the team away day and for the assessment nurse to focus on DNACPR status at care plan updates and encourage use of advance care plans.

We reviewed the results for the DNACPR audit for Q4 2019. The audit reviewed the records of CYP with a DNACPR and results showed 100% compliance for appropriate documentation, accessibility, staff awareness, capacity and decision making. The audit also reviewed 10 random records of CYP known to the service to ensure the records documented full resuscitation details. Although results showed there was good compliance with DNACPR record keeping, for most children full resuscitation was recorded only in the paper records and not on the electronic database. However, as the hospice was transitioning between two electronic systems, staff were reminded to check paper records for resuscitation status until the transfer of records to the new database was completed.

The senior management team acknowledged it had taken longer than expected to transfer records but told us that this was because they were creating updated care plans. During our review of patient records, we found the use of two electronic systems and paper records lacked a cohesive approach.

Senior leads told us that the use of ACPs was relatively new in London. The hospice was part of a pilot project run by a local children's hospital which started in July 2019. The pilot included the use of ACPs with DNACPR in a document called ReSPECT. The hospice had identified suitable candidates for the pilot by working with families and some staff had received training.

However, one of the patient's records we reviewed was for a child who was part of the pilot and had a DNACPR document which we couldn't find. Although staff could not locate the DNACPR in the ReSPECT document, staff involved in the patient' care were aware there was a DNACPR in place and the resuscitation status had been referenced in other documents such as the emergency plan. We raised this with senior leads as we were not sure if the document had been misplaced during the transition.

The hospice raised this as a critical incident and completed an investigation report. Care staff established that the ReSPECT page had not been completed as the ACP was never finalised. Furthermore, staff contacted all

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the other healthcare providers involved in the child's care who did not have a record of the DNACPR on their files either. This included the palliative care team at the local hospital, GP, consultants at other hospitals, community children's nursing (CCN) team and the school. The hospice contacted the parents and discussed the ACP on the phone and agreed to meet with the parents the next morning to review the document and obtain signatures. The care team were advised to monitor the CYP patient closely overnight and utilise PEWs if required to enable staff to call the parents at any sign of deterioration. The next day, the staff member visited the family home and completed the ReSPECT document with both parents. The care team shared the ACP and ReSPECT documents with all the healthcare professionals involved in patient's care. During the inspection, we observed the weekly senior nurses meeting which included a discussion on the pilot and the difficulties in identifying a suitable date with the children's hospital to review the pilot.

After the inspection, we reviewed the investigation report and found it was comprehensive. Although further investigations were needed to determine why the documents had not been completed and why no other healthcare professionals had a record of the DNACPR, the hospice had put together an action plan with identified learning from this incident. The action plan included refreshing staffing training for ACPs and DNACPRs. We observed senior nurses discuss the implications of the incident in the morning handover with staff. All staff were reminded to be vigilant when checking CYP during admissions and reminded to check that each child had a personalised resuscitation plan or DNACPR.

The risk and governance lead started auditing the records on day two of the inspection for all children with personalised resuscitation plans and DNACPR to ensure safety and compliance. Although the transition between the electronic systems did not contribute to this incident, the hospice had plans to review their timelines for the transition and to assess the suitability of the new system to ensure it was fit for purpose.

Medicines

Staff followed systems and processes when safely prescribing, administering, recording and storing medicines. Staff reviewed patient's medicines

regularly and provided specific advice to patients and carers about their medicines. The service ensured children and young people received their medicines as intended.

The hospice had a service level agreement with a local NHS hospital who provided 24/7 on call pharmacy support and advice through a medicine's safety officer and a consultant pharmacist.

The hospice had implemented a weekly pharmacy clinic led by the pharmacy technician (medicines safety officer) and the lead nurse for medicines management following feedback from families who found the previous arrangements inconvenient. The weekly clinic had improved the safety of medicines management in the hospice for CYP and was more convenient for families.

We attended the pharmacy clinic and found there was a thorough review of all the medications required during the respite stay. The care plan was recorded on the electronic database as it had been on paper notes previously. Parents brought in all the medications the CYP was taking and the latest letter from the GP. Medicines reconciliation was completed in the clinic in advance of planned admissions. If the child or young person suffered from seizures, the seizure plan was checked, and the feeding regime was shared with the care team ready for admission. All medication was reconciled before and after respite stays and any discrepancies were investigated using the clinical incident reporting system.

The Director of Care was the accountable officer for controlled drugs (CD) and attended London wide Local Intelligence Network (LIN) meetings. The service completed CD audits every quarter to ensure checks and processes supported a safe working environment. Results for Q4 2019 showed the service met all the CD check standards. This included security, stock checks and record keeping. The CD keys were stored in a secure safe which had to be accessed with a number code. Staff told us the CD cupboard was checked daily and the hospice did not keep any CDs as stock but stored the patient's own CDs. We checked the CD cupboard during the inspection and found it was empty. The hospice had two authorised witnesses to destroy CDs when needed.

During the inspection, we found all drug cupboards and the drug fridge were locked and the keys were kept with

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the nurse in charge. CYP patients' medications were locked securely in their rooms. Oxygen cylinders were appropriately stored in the storage areas within the hospice and all the cylinders we checked were in date.

Staff told us medication was transcribed by senior nurses and was always counter signed by another trained nurse. Qualified nurses checked medication charts to ensure all medications had been given and we saw that all medication charts included records of allergies. During the inspection we observed staff discuss medications during handover. Staff told us they did not take any medications with them on home visits as all the necessary medications were at the CYP homes.

Staff told us the daily fridge temperature checks used to be completed three times a week before February 2020. However, the revised compliance checklist now included daily fridge checks. The daily checklists included checking the resuscitation bags, resuscitation equipment, oxygen cylinders, rooms, fridge and emergency exits. We reviewed the daily checklist and noticed that the fridge temperature checks had been omitted. We raised this with the senior nurse who addressed this immediately. Although the risk and governance lead completed audits on the completion of the daily checklists and shared the findings with staff and the clinical nurse manager, senior leads acknowledged more oversight was required on checklist compliance to ensure there were no gaps.

There were three resuscitation grab bags and the hospice had reviewed the contents and locations of the bags within the past 12 months. The grab bags were located on the ground floor, second floor within in-house care and at the staff entrance. The community staff checked the grab bag at the staff entrance. As this was a recent change, more time was required to ensure the process was fully embedded.

Each grab bag had a tamper tag and staff completed daily checks to ensure the tag was intact and that the suction equipment was working. We saw evidence of the daily checklists being completed for the grab bags. We broke the seal for one of the grab bags and found the contents were intact and single use patient resuscitation equipment and medications were in date. Although staff carried out full checks on the contents weekly, we found the weekly sign off sheet was inconsistently completed. We raised this with senior leads who acknowledged the

lack of oversight and told us they would address this. Following the inspection, the hospice amended the audit schedule to ensure the compliance checklists included the weekly sign off sheets.

The hospice considered requests for the administration of off license medication carefully to ensure patient safety. Although these requests were infrequent, the service had a defined process for dealing with these safely which included administration in line with the prescription and obtaining letters from the consultant responsible for the child's care. Detailed discussions were held with families during the pharmacy clinic regarding therapeutic doses prescribed by the consultant/GP. The service had fully trained paediatric nurses to administer medicines. All new starters completed a medicine competency assessment which included a supervised drug administration round observed by the pharmacy technician. The hospice was currently working in collaboration with other hospices to form a standardised competency document for benchmarking.

All CYP were cared for at a ratio of 1:1 which allowed for close observation for any potential adverse reactions. For responsive or emergency transfers, discharge coordination was managed in advance of an admission to the hospice or on discharge from hospice to another care unit. This coordination involved an assessment of the patient's own drugs, liaison with local pharmacists, GP, specialist team around child such as epilepsy nurse or another medical professional.

The medicines safety officer worked closely with the governance and risk lead nurse to support staff with learning from medicines related incidents and produced a quarterly report for clinical governance board, commissioning reports and board of trustees. We reviewed the quarterly report for October to December 2019. The report included top three messages, review of all medication incidents, action plan, national and local concern and controlled drugs.

Patient group directions (PGDs) allow some registered health professionals (such as midwives) to give specified medicines to a predefined group of patients without them having to see a doctor. The hospice used to have a PGD for pain relief which included information on inclusion criteria, exclusion criteria, referral arrangements

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and what to do if treatment is declined. Although the specialist outreach nurse who used the PGD had recently left the hospice, the service had secured funding for two nurses to complete the nurse prescribing course.

The hospice was a founding member of the Joint Pharmacy Performance Meeting with three other children's hospices to share best practice and learning from medication related incidents. National alerts were shared with staff and families and recommended action taken immediately. Examples given included drug recalls and replacing T34 ambulatory syringe pumps.

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. When things went wrong, staff apologised and gave children, young people and their families honest information and suitable support. Managers ensured that actions from patient safety alerts were implemented and monitored.

Never events are serious patient safety incidents that should not happen if healthcare providers follow national guidance on how to prevent them. Each never event type has the potential to cause serious patient harm or death but neither need have happened for an incident to be a never event.

Between November 2018 and October 2019, there was one never event reported at the hospice. There were three recorded serious incidents between November 2018 and October 2019, of which one resulted in no harm and two in low harm.

We reviewed the root cause analysis (RCA) reports for two incidents for May and June 2019. The reports included detailed descriptions of the incidents, staff involved, chronological timeline of events, staff statements, root causes, staff debrief summary and an action plan with dates. Where necessary, the hospice organised professional debriefs to allow staff time to reflect and discuss the incident. We reviewed the professional debrief report for the incident in June 2019 and found that each theme identified was discussed in detail with lessons learnt noted.

The hospice had recently changed to a new electronic system to report incidents. Staff were aware of their responsibilities for reporting incidents and were able to explain how this was done. Staff told us they received individual feedback for incidents they had reported and after investigations had been completed.

Incidents were discussed at the monthly clinical risk management meetings and the weekly senior nurses' meetings. Learning from incidents was shared with staff at the daily handovers and safety huddles.

The hospice arranged morbidity and mortality debriefs in a range of different formats. Debriefs could be professional, responsive or internal pre-briefs and with/without clinical and emotional focus. For example, staff could receive responsive debriefs at the end of their shifts with emotional and wellbeing focus. Staff also received quarterly clinical supervision and safeguarding supervision.

The hospice had a duty of candour policy to aid staff in navigating the process when an incident occurred. Senior leads told us that mandatory training included duty of candour and learning from incidents is discussed at regular team meetings. Staff were aware of their responsibilities in relation to the duty of candour. All staff we spoke with were aware of the principles of openness and accountability when things go wrong.

Safety Thermometer (or equivalent)

The hospice displayed information on the clinical safety and quality improvement notice board at the nurse's hub which was updated monthly. Results for March 2020 showed that so far, there were zero incidences of hospice acquired infections and zero incidences where staffing wasn't safe.

Are hospice services for children effective?

(for example, treatment is effective)

Good 

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

Evidence-based care and treatment

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

Policies and procedures were readily available for staff. Policies referenced national guidelines from organisations such as the National Institute for Health and Care Excellence (NICE) and Royal Colleges. For example, the policy for resuscitation, DNAR and anaphylaxis guideline was based on guidelines from the Resuscitation Council, British Medical Association and Royal College of Nursing. We reviewed four policies and procedures and found them to all be version controlled and in date.

The hospice followed NICE guidelines. For example, 'end of life care for infants, children and young people with life-limiting conditions: planning and management' (NICE clinical guideline NG61). The service looked at whether they were compliant with all aspects of the guidance. The current compliance score against the NICE guidance for End of life care for infants, children and young people (NG61) was 88%. The service was prioritising further implementation of advance care plans, education and information around organ donation.

The hospice used audits to ensure that service design was effective and met the needs of the local population. For example, the You're Welcome standard ensured the service and facilities were tailored for the specific needs of young adults. Targeted audits provided the hospice with an overview of how the service design met the needs of CYP and helped to provide targets and priorities for improvement.

The content of the expert parent training programme was based on the national guidance and accepted good practice. The programme provided education for parents and carers and it was designed to empower them and give them the confidence to manage the child's conditions. It also aimed to encourage families to find ways to work more collaboratively and effectively with health and social care experts. Previous sessions covered a broad range of topics such as aspects of clinical care, legislation in the field of caring for children with disabilities, behaviour management, epilepsy and resilience. Parents who had attended these sessions reported feeling better equipped and having greater confidence in their ability to manage their child's care.

They also felt more confident in dealing with professionals and therefore more empowered to take an active role in the planning and delivery of their child's care.

The hospice provided evidence based holistic therapies such as music therapy, physiotherapy, therapeutic yoga and specialist play therapy and therapy was delivered usually in 10 week blocks as required.

Nutrition and hydration

Staff gave children and young people 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 patients' religious, cultural and other needs.

Since the last inspection, the hospice had introduced a protected mealtime policy to ensure privacy and dignity at mealtimes for children and young people (CYP). There was a communal eating area and supportive equipment such as adapted cutlery, plates with sides and non-slip mats were available.

As part of meeting a child's physical needs, nutrition and hydration were prioritised to ensure needs were met at every stage in the palliative journey. Staff were in regular contact with the palliative care team at the children's hospital and the nominated dietitian for the child. The hospice provided nutritious meals taking into account the cultural and religious needs of children and young adults.

This included outsourcing the provision of nutritionally balanced meals which allowed staff to cater for soft, pureed and blended diets as well as halal, vegetarian and kosher meals. Where CYP and families preferred fresh diets, catering staff cooked individual meals according to the child's tastes. The staff were Food Hygiene Certified and following a recent unannounced local authority food hygiene inspection, the hospice was awarded a score of five stars.

Staff offered water and snacks in between meal times as needed. Food intake was always documented which meant parents and carers were able to see what their child had eaten at each meal.

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All staff were trained to provide enteral feeds and the feeds were always administered in accordance with advice from the prescribing dietitian or speech and language therapist (SALT). When necessary, liaison and input was also sought from local certified clinical nutritionists (CCN) teams, community dietetics and SALT. There were multiple catering options offered for orally fed CYP.

The care team had a dedicated nutrition working group who worked with staff and lead nurses to ensure a cycle of continuous improvement and audit. The hospice completed nutrition and hydration audits every six months. Results for February 2020 showed the hospice met most of the standards which included governance and service design, food provision (which covered facilities, services, environment), information available to families and CYP, staff and training, management of nutrition at end of life and best practice in delivered care.

Pain relief

Staff assessed and monitored patients 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 hospice managed the pain of children and young people who were approaching the end of their life effectively. The hospice recognised that one pain assessment tool may not work for all children. Staff assessed patients' pain using recognised tools and gave pain relief in line with individual needs and best practice. The hospice used Individualized Numeric Rating Scale (INRS), Faces Legs Activity Cry Consolability Revised (FLACC-R) scale and Faces Pain Scale for pain assessments in line with guidance from a specialist children's hospital. We observed discussions on FLACC-R pain scores during the morning handover.

Care plans were paperless and could be adjusted to include a process to isolate the correct pain assessment tool for each individual child. The pain link nurse ensured that staff were confident to select the appropriate pain management tool for the complex caseload and assessed and treated if indicated.

Patient care records showed us that children and young people had pain assessments and pain management care plans. Medicine charts showed that staff recorded if 'as required' medicines were given for pain relief.

Patient outcomes

Managers monitored the effectiveness of care and treatment of patients and used their findings to make improvements to the service.

The hospice used a system of key performance indicators (KPI's) and audits to ensure the quality and effectiveness of the service remained high and were developing better impact assessments to understand the value of the service.

The hospice actively participated in many local, national and sector specific clinical networks which allowed the service to develop their practice and rapidly respond to new safety alerts. The service benchmarked against other children's hospices through formal networks, national standards and guidance.

The hospice followed the Hospice UK audit schedule and supplemented this through benchmarking with other similar settings. The service developed audits in response to new national or local guidance and in response to local incidents if a trend emerged, or if a risk was assessed as needing more effective monitoring. The audit schedule for 2019/2020 was comprehensive and covered several subjects which included infection control, hand hygiene, safeguarding, recordkeeping, medicines management, CDs, resuscitation status, complaints, referral time, staff feedback, family survey, emergency consent and contact, nutrition and hydration, mandatory training, agency staff and MCA and DOLS.

Audit findings were shared with staff and reported into the quarterly clinical governance committee meetings and the monthly clinical risk management meetings. The hospice used the audit results to make improvements to patient care.

The hospice identified an increasing number of CYP presenting with behavioural needs or autism with 98% of CYP identified as having a learning disability. In response to recent guidance on Closed Cultures issued in July 2019, the hospice completed a closed culture risk assessment in November 2019 as they recognised the high inherent risk of developing a closed culture with

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many non-verbal CYP. We reviewed the results and found the action plan included mitigations, actions needed and dates of completion. The hospice closely monitored this risk and had a large emphasis on staff training. As a result, staff attended study days and workshops on sexuality awareness, autism and disability awareness, challenging behaviour and positive behaviour management. Work in this area remained a priority and was included as one of the priorities for improvement this year. The hospice had plans to repeat the assessment in November 2020.

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.

The service completed thorough checks when accepting a new agency staff member which included receiving copies of their registration, Disclosure and Barring Service (DBS) checks and competencies prior to them arriving for a shift. Agency staff received a local orientation to unit, including the location of resuscitation equipment, fire and evacuation plans and overview of policies was completed and documented.

The hospice had an agreed operating procedure with each agency to ensure that the service had the correct and necessary staff information before accepting staff cover. The service had good working relationships with their staffing agencies and regularly engaged with them for visits to ensure they understood the specialist working environment and send appropriate candidates when requested. The service used staff from a small pool who were familiar with the hospice and had worked for the hospice previously.

Bank staff followed the safer recruitment process which included application, shortlisting and interview stages all underpinned by the service's equal opportunities policy. Following the successful interview and checking process candidates were invited for a morning induction meeting which included an in-depth tour, skills self-assessment and policy reading session. Two further shadow shifts were offered to ensure they were familiar and confident with the setting if needed. Substantive staff and bank staff received regular checks to ensure their registrations are still in date.

Staff induction took place four times a year and all new starters met the chief executive officer and the senior management team (SMT). We saw the agenda for the staff induction programme for February 2020 which included meeting the CEO and SMT, safeguarding, autism and disability awareness training, grief and loss awareness, fire, health and safety, finance overview, HR and staff wellbeing, introductions to various teams and overview of children's palliative care.

During the six month probation period, new staff completed three progress interviews with the educator in which learning progress and needs were discussed. Staff were invited to complete the core competencies and extended competencies which included skills from the Royal College of Nursing (RCN) Palliative Care Skills framework. Completion of the competencies included theory, practical and assessment stages which were assessed by lead nurses. Although the expectation was for new starters to complete the competencies within six months, there was flexibility for some competencies such as Bilevel Positive Airway Pressure (BiPAP or BPAP) which took longer to complete.

New starters were supernumerary for two weeks and the education lead checked progress against the competencies before staff came off the supernumerary status. Healthcare support workers received an intensive support package of competencies to enable them to safely and effectively care for children with complex medical needs.

The hospice completed quarterly audits on temporary staffing to ensure the calibre of temporary staff helped ensure CYP receive high quality and safe care. The audit identified five separate records for bank staff and five for agency staff who had worked in the hospice in the last month. Results for Q3 2019 showed that the hospice had 36 shifts filled by bank staff (17 staff) and no agency staff in November 2019. Results showed that 100% of bank staff were compliant with mandatory training, competencies and had valid professional registrations.

Data provided by the service showed that the appraisal rate for all staff groups was 100% in the last 12 months. Staff received monthly clinical supervision through an external provider and data provided showed that 100% of staff received regular clinical and management supervision. Staff we spoke with told us they had regular one to ones with discussions on development. For

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example, we spoke with one healthcare assistant who started as a housekeeper but had completed a diploma in health and social care and achieved all the required competencies.

The management team and the human resources (HR) department had a close working relationship to ensure that managers were aware when competencies were due for renewal. Senior leads supported staff with their revalidation and the education lead monitored revalidation. The hospice had a strong nursing leadership and the Director of Care and clinical nurse manager regularly carried out visits out of hours. The educational lead organised skills sessions to address any identified gaps.

The hospice delivered study days to local professionals to raise the awareness of paediatric palliative care. This included grief and loss awareness and piloting the introduction of advance care planning in partnership with London Children's Palliative Care network.

Multidisciplinary working

Doctors, nurses and other healthcare professionals worked together as a team to benefit children and young people. They supported each other to provide good care.

Staff worked closely with the palliative care team at a specialist children's hospital, which meant staff had up-to-date symptom management plans to look after the child and keep them comfortable.

Each child was looked after by a team of healthcare professionals led by one of the experienced nurses during their stay. The nurse had overall responsibility to ensure the child's care plan was up-to-date, liaise with professionals to ensure they had all the relevant medical information and kept in regular contact with the parents to offer support and advice where needed.

Handovers took place twice daily, once in the morning and once in the evening. We observed the morning handover and saw there was discussion around overnight issues, advice on the viral outbreak (COVID19) and reinforcing handwashing, thorough discussions on each patient, day care admissions and reminders to complete the daily checklists. Attendees included nurses, healthcare assistants, students and the governance and risk lead.

We reviewed the minutes for the weekly panel meetings between August 2019 and November 2019. We found there was consistency in the format and structure of the meetings. Attendees included the interim clinical nurse manager, specialist outreach nurses, lead for community and wellbeing team, statutory partnerships and data manager, care administration manager and the governance and risk lead. The meeting agenda included a review of the action log, new referrals, internal service referrals, update from statutory partnership managers, update on red flags and recently bereaved families. The action log included a named lead with updates and date completed.

The music therapist spent half a day working at a local NHS hospital as statistics showed that 20% of neonates that used neonatal intensive care unit (NICU) or aspecial care baby unit(SCBU) also used hospice services. The music therapist worked closely with the nurses at the hospital and had a good working relationship with the wider multidisciplinary team which had resulted in increased referrals from the hospital to the hospice. Senior leads told us that the hospice had been recognised for having the first neonatal link post in London and this was due to be cited in a neonatal textbook.

Seven-day services

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

The hospice offered a range of community services on the weekdays. This included group yoga/music/play, toy home loan, family support, buddies support counselling and step-down care.

Responsive end of life care at home and therapeutic services such as physiotherapy, music, yoga and play were available in the community seven days a week. Although home respite was available on weekdays, families could have the option of weekends if required.

The hospice had access to 24/7 specialist palliative care advice from a specialist children's hospital.

Health promotion

Staff gave practical support and advice to children and young people to help them lead healthier lives.

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The support for physical needs extended to families and carers as the hospice offered complementary therapies to relieve stress and had plans to improve the grounds and facilities to provide exercise opportunities for families. Staff signposted families to services for targeted support such as smoking cessation and drug and alcohol misuse.

Therapeutic yoga (Yoga for the Special Child) was a unique yoga method that had changed and improved the lives of children with special needs around the world. This style of yoga was gentle and therapeutic and consisted of a comprehensive programme of yoga techniques designed to enhance natural development. A session included a series of yoga poses to increase body awareness, flexibility, strength and control of gross and fine motor skills. The sessions were specifically designed in a way that met the individual requirements of children and young people with varying needs.

Consent and Mental Capacity Act

Staff supported children and young people to make informed decisions about their care and treatment. They followed national guidance to gain patient's consent. They knew how to support patients who lacked capacity to make their own decisions or were experiencing mental ill health.

Staff understood the relevant consent and decision-making requirements of legislation and guidance, including the Mental Health Act, Mental Capacity Act 2005 and they knew who to contact for advice. The hospice obtained consent at the point of entry to the service and information was shared with the GP.

Staff understood how and when to assess whether a patient had the capacity to make decisions about their care. Staff we spoke with demonstrated a good understanding of when a person might lack capacity to consent to care or make significant decisions about their treatment. Where patients lacked capacity to make decisions regarding their care and treatment, we found that discussions with patient's relatives or those close to them were recorded within the patient notes. The opinions and wishes of patient relatives were considered when making decisions.

When patients could not give consent, staff made decisions in their best interest, considering patients'

wishes, culture and traditions. In the records we reviewed, mental capacity assessments had been completed where patients had been identified as lacking capacity. We saw evidence of resuscitation status of children in records.

Are hospice services for children caring?

Good 

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

Compassionate care

Staff always treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and proactively took account of their individual needs. There was a strong, patient-centred culture from all levels of staff.

The following was representative of feedback from families and carers: "If it wasn't for Haven House, I think we'd be completely different parents", "staff are very caring and always there to listen", "they helped us make lots of memories", "We would be lost without you", "thank you for everything you did for us on our last night together, you made it very special" and "it would not have been possible without you".

The family experience survey results for July 2019 showed that 99% of families said they strongly agreed/agreed that their child was safe when accessing Haven House services and 100% strongly agreed/agreed that staff treated their child with dignity and respect. The results showed 90% of families felt Haven House improved their child's quality of life and 93% of families agreed that the hospice planned their child's care to meet their individual needs. Although, 73% of families stated that Haven House considered the needs of the wider family.

Staff told us each child had their own dedicated carer for the whole shift who followed the care plan to ensure the child was being looked after just like at home. Between November 2018 and October 2019, the hospice received 52 compliments. The following was representative of compliments received: "I really enjoyed our stay at Haven House. Please extend my greetings to all the nurses and carers", "The support the family have got from Haven

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House was incredible”, “Thank you and all the care staff, as always, for the work you all do” and “All the staff are so good at Haven House, it is a very special place and we were moved by our visit.”

We observed a home visit and observed staff involve the extended family. Staff showed their understanding to the nonverbal patient’s “noises” and communicated effectively with the patient. Staff told us they saw the patient’s ability, not their disability. The family told us that staff listened to the family and described the hospice as a “god send”.

We observed a home visit for an end of life patient and observed staff manage symptoms in line with the symptom management plan. Parents described staff as extremely caring, responsive and respectful to their child’s needs. Parents told us they valued the respite service and the emotional support offered to siblings as part of the buddies’ group.

Emotional support

Staff provided a high level of emotional support to patients, families and care givers to minimise their distress. They understood patients’ personal, cultural, physical and religious needs.

The service had a wellbeing team of experienced and fully trained staff to support families by providing counselling. Bereavement counselling supported the whole family which included mums, dads, brothers, sisters and grandparents in line with the service’s holistic ethos. Counselling offered the time and space to discuss concerns and consider issues that may prevent parents from getting on with their day to day life. The sessions were a safe and confidential place to talk and the service worked extensively with families who were finding it hard to come to terms with their child’s diagnoses and what that meant to them. Counselling was available on a one to one basis, as a couple and extended to family members. One parent who had used the counselling service told us they found it extremely helpful.

The hospice considered spiritual care to be an essential component of holistic care and worked with local faith groups to provide spiritual support as needed. A local faith leader was on the Board of Trustees to ensure that spiritual support was prioritised.

Staff were confident to speak with families about their spiritual needs and the facilities catered for all faiths. There was a dedicated quiet prayer and reflection room. The hospice took special care to provide support for groups with very specific needs. This included rapid access to religious support for the travelling community and anticipatory planning of death certification to facilitate early burial for the Jewish and Muslim population.

The family support worker offered support and advice to families by appointment when needed. This included advice and information on social issues, liaising with professionals from other agencies, completing grant applications and support with benefits.

The bereavement team looked after children from end-of-life through to death and supported the entire family to ensure they had the opportunity to create positive memories of their child while staying at the hospice. The support for the family and siblings continued for however long the family needed it. Each summer the service organised an annual memory day for all bereaved families to celebrate their child’s life and to provide continued emotional support with their journey in grief and loss.

As part of the 2018 refurbishment, the Butterfly suite was redesigned to be more comfortable to enhance privacy and dignity. This included the provision of a double bed following feedback from a young person on an end of life pathway who wished to be close to their family members. The suite was a private space for family and friends to use to grieve in an appropriate and dignified environment before the funeral.

Understanding and involvement of patients and those close to them

Staff supported and involved children and young people, families and carers to understand their condition and make decisions about their care and treatment.

Staff were fully committed to working in partnership with patients who were approaching end of life, their carers and their families, and those close to them to be active partners in their care. Choice and the voice of the child was always sought when understanding and identifying a CYP’s needs and staff were confident using different

Hospice services for children

communication tools to facilitate this as appropriate. A recent upgrade of the Lifelites eye gaze technology facilitated communication, allowing staff to champion independence in CYP.

Staff provided us with numerous examples of where they had gone the extra mile to ensure patients' needs were met in the last days and hours of their lives. Staff gave the example where a CYP patient wanted to stay at home with the family for Christmas but was needle phobic. Staff liaised appropriately with specialists at the children's hospital and provided support with intravenous medication which allowed the patient's wish to be fulfilled.

Staff supported patients to make informed decisions about their care. We saw evidence in the records we reviewed of discussions between end of life care staff and patients, and their families, including discussions around do not attempt cardiopulmonary resuscitation decisions, and decisions about patients' preferred places of care. Staff told us how this had to change sometimes due to the changing needs of the child or young person, however they worked closely with the families to ensure their needs were met. We found in some cases where staff had had discussions with families about resuscitation plans and families told staff they didn't want to discuss it yet, staff did not always document this. We raised this with senior leads who acknowledged this and understood the importance of having an audit trail.

Staff supported and involved patients, families and carers to understand their condition and make decisions about their care and treatment. Monthly coffee mornings took place and provided parents and carers with the opportunity to meet with other families who had similar life experiences and challenges. The parents decided which topics they wanted to include. As well as coffee mornings, the service offered several family events throughout the year. These included a summer pantomime, family picnics, Christmas parties and multi-faith festival celebrations.

Staff made sure patients and those close to them understood their care and treatment. For example, the hospice had introduced a monthly Dad's group to share experiences and challenges as well as have fun. On the weekend before the inspection, the hospice had piloted a

dad's group for music therapy which had been successful. Staff had arranged this having received feedback from mothers that the dads were anxious about joining in activities with the child.

The service recognised that learning to care for a child with a life-limiting condition could be challenging. Families could stay together at the hospice where the nurses and healthcare support workers provided support and training to help build parents' confidence as part of step-down care.

Staff recognised that people need to have access to, and links with, their advocacy and support networks and they supported people to do this. The family support worker assisted and signposted families appropriately when they needed support with advocacy, benefit advice or funeral payments. Family support was an integral part of the multidisciplinary team at the hospice.

We attended a home visit for a music therapy session and observed compassionate and caring interactions between the therapist and child. The child was non-verbal but was able to communicate through sound and the child was offered a choice of instruments. We spoke with the family who told us they were happy with the interventions and valued the support networks for families and buddy sessions for siblings. Parents said using the service was the best decision they ever made.

Haven House Buddies was a support group for siblings to meet other brothers and sisters of children with life-limiting illnesses or those who have experienced bereavement. The groups were divided between Juniors (aged 5-11) and Teens (12-18). Children were able to discuss common fears, joys and concerns and for some, share their feelings around grief. Junior buddies had outings arranged which included the zoo, aquarium, fire station and theatre. Teen Buddies had outings arranged to museums, theatre, outdoor adventure day trips and dance/drama workshops. The following was representative of feedback from families and carers: "Buddies helps me so much because I realise that there are other children who understand how I feel every day" and "Buddies has given me so many opportunities to meet and socialise with people who have gone through the same experiences as me, and has helped me cope with many of my problems and fears." Parents valued the support offered to siblings and said staff met the needs of sibling of different ages and requirements.

Hospice services for children

Are hospice services for children responsive to people's needs?
(for example, to feedback?)

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.

All families received a welcome pack that included information about local transport, local amenities and helpful information about the local community. The hospice had recently carried out full resurfacing of the driveway which provided more suitable drop-off and parking facilities for parents. The hospice was awaiting approval for a planning application to provide an additional 8 parking spaces adjacent to the main building to improve accessibility for families. Part of this project included installing clearer directional signage for those coming into the hospice.

Staff ensured the child had fun staying at the hospice, attended school and parents could also stay in the fully equipped family flat. The family suite included the Butterfly Suite which had an adjacent lounge. All furnishings had been selected to create an environment to be a 'home from home', rather than a clinical environment whilst still maintaining infection prevention and control standards. The family accommodation was comfortably furnished and included a fully operational kitchen and dining area with air conditioning throughout. There were televisions in the private lounge areas, free access to WIFI, soft lighting and a selection of toys and games for younger family members. The family suite was regularly used for step down support from hospital.

The hospice offered respite for day and overnight care which helped parents get a break from caring 24 hours a day. Between November 2018 and October 2019, there were 566 respite admissions. Once the child was accepted for respite care, parents had the opportunity to

discuss all their child's needs including medication, feeding, sleeping, seizure management, bathing and dressing. This meant the care plan helped staff get to know the child and understand their needs before their stay. Nursing staff monitored each child every 15 minutes whilst asleep to ensure they were comfortable and safe. This meant parents could get a good night's sleep knowing that the child was being properly looked after.

The toy home loan was a free lending service of specialist toys for children with complex medical needs and life-limiting conditions. The vast toy library included many objects that light up such as plasma globes and hand-held ultraviolet light tubes which helped stimulate movement, communication, learning and development. There was also a selection of toys designed to relieve stress and support the development of focus, attention, and active listening. The toys could be delivered and collected from families and loaned for up to three months.

The hospice had a dedicated sibling space called 'The Buddies Hut' which was a chalet building located a short distance from the main building. It was regularly used for emotional support particularly for the sibling groups.

The café provided an accessible space in the heart of the main hospice building which parents and families regularly used for drop-in sessions and coffee mornings. The space could also be booked for other events such as family celebrations and parties.

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 patients access services. They coordinated care with other services and providers.

In 2018, the hospice had introduced the community and wellbeing team which allowed the service to fully respond to a child and family's holistic needs. The hospice had plans to expand the team to include a chaplain and further therapeutic support. The hospice was currently negotiating a service level agreement with a local NHS paediatric psychology service to provide specialist psychology support.

The hospice had a counsellor who provided both one to one and couple counselling once a week. The sessions

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offered a safe, confidential space to discuss sensitive information and was offered to extended family including grandparents. Referrals were received either from CYP and families using the hospice service and from hospitals for families who had experienced stillbirths. Families were offered up to 12 sessions. Senior leads told us discussions were taking place to increase counselling sessions to two days a week.

The sibling support worker provided therapeutic support for siblings as the hospice recognised that siblings can sometimes experience and deal with confusing emotions and at difficult times, communication between adults and children can become challenging. The sessions could be a one off or a series of regular individual sessions, family sessions if the child was under five years and telephone support.

The hospice supported families with creating memories which included offering a silver fingerprint pendant and a page within the memory book. Families were welcome to write poems or tributes in memory of their child and include special pictures and photos. An artist designed the page and entered it in the memory book which was kept in the prayer and reflection room. Each year, the hospice held a service of remembrance (memory day) for bereaved families. The day was about celebrating the child's life and parents could share their stories if they wanted to.

The hospice had a bespoke sculpture called the Tree of Recognition which offered a unique and meaningful way to mark an occasion or celebration, to remember a loved one. The sculpture was in the holistic care centre ensuring that dedications to loved ones were displayed every day of the year. Each leaf was engraved with a personal message and was displayed on the tree with a donation fee for either one or two years. At the end of the display period, families were given the option to renew the leaf or have the leaf as a special keepsake.

The nursing team provided bereavement support both before and after for bereaved families and carers. Staff visited families at home to provide support after a child had died. The support was wide ranging from practical help with funeral arrangements to creating memories for each family. For example, staff organised an outing to the beach for a family who had a CYP in the end of life care pathway and staff were praised for their attention to detail.

Play activities were fun, multi-faith, age appropriate, creative and tailored to meet the child's emotional and developmental needs. From sensory stories to messy play, the child could play with scarlet coloured spaghetti, jade green jelly, fuchsia coloured foam or strawberry scented rice. The play co-ordinators and healthcare support workers spent time with children to create artwork by blending colour and materials as well as helping them to explore texture with their hands and feet through mixtures of smooth, stretchy and stimulating resources. Children could explore the world through sensory stories and activities in the specially-adapted sensory room.

The Haven House Teenage Cancer Group was formed in October 2016, following patient feedback that it would be nice to meet others with a cancer diagnosis in a less formal setting than a hospital. The group met monthly and was a great way for young people with cancer to have fun and make friends as they can sometimes feel isolated, particularly during the treatment phase of their disease, where they can be absent from school for long periods of time. One member described the group as a "mini family" where they could relax, have fun and just be themselves as everyone around them understood what they were going through. The play team had also started a 'Little Oncs' group on a monthly basis for younger oncology patients.

Music therapy was an established health profession which used the medium of music, in a therapeutic relationship with the child. In one-to-one sessions the therapists used music and their voices to respond to the child at their level. Interactions were led by the child and during the sessions, the child had the freedom to express themselves in whatever way they could, with the therapists responding to any cues in a sensitive and validating manner. Music therapy was also available to siblings where song writing, and composition was used for self-expression and as a safe outlet to explore emotions.

Staff told us that the hospice had recently trialled joint music therapy sessions with physiotherapy for a child who was in pain. The combined appointment was for a block of six weeks and had been successful. The yoga specialist offered groups sessions, hospice at home sessions and had trialled joint sessions with music therapy which had been successful.

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Senior leads told us that families were previously able to book respite six months in advance. However, in order to provide families with more flexibility, the hospice allowed families to make bookings one year in advance.

The hospice had developed the neonatal care provision in partnership with the local NHS neonatal unit. The hospice provided music therapy to infants which was called the 'Wiggles and Rhymes' group. This allowed for a soft introduction to the hospice for life limited infants and their families and celebrated their abilities. The service had plans to explore antenatal classes for mothers who had received a life limited diagnosis during pregnancy and targeted coffee mornings.

As most CYP using the hospice's service were non-verbal, the service had a multidisciplinary communication and behavioural support working group dedicated to constantly improving and promoting communication tools and strategies. The hospice worked closely with parents and schools to ensure staff fully understood the voice of the child. The hospice promoted equality and diversity and catered to different religious and cultural needs through the provision of specialist diets, links with faith leaders and an understanding of different beliefs systems.

The service provided face to face and a telephone interpreting service in partnership with the local CCG. The hospice's website had the option to translate all the information into other languages. We reviewed this function on the website and found that families could choose from 104 languages. Examples included Swahili, Welsh, Italian, French, Hindi, Tamil, Arabic and Urdu.

The hospice had recently worked in partnership with the local hospital, CCG and child death overview panel to repatriate a baby on an end of life pathway to support a single parent. The parent's wish was for the child to spend their final times in their country of origin and when the time came, have a burial next to other family members.

The complementary therapy service was led by volunteers and was offered to parents of children receiving care at the hospice. This included a holistic facial massage which was non-invasive and restful, Reiki and beauty therapy days.

Access and flow

People could access the service when they needed it and received the right care in a timely way.

Referrals were responded to in accordance to the referrals management policy. The hospice aimed to respond to emergency referrals within 12 hours and routine referrals in 24 hours. The hospice had an admission criterion and all referrals were reviewed in the weekly panel meetings. The referral could request the in house care services, hospice at home services or a mixture of both. Where a referral was accepted, the assessment nurse completed the assessment review for the child. Staff told us that the family had a right to appeal if a referral was not accepted. In areas where contracts were in place, families could receive up to 20 nights of support and for families outside of the area, there was room for negotiation as five charity funded nights were available.

We reviewed the referral management and response times audit results for Q3 2019 which looked at a random sample of ten records. Of these, 100% of referrals were responded to with a plan for next steps within 24 hours and 90% of referrals were reviewed within 5 days.

The hospice at home service was set up in response to family's requests for end of life care at home. The hospice at home service provided children who would not have been able to access care if going to the hospice was the only option and had been well received by local commissioners who had subsequently agreed to partly fund this service. The service included a rapid discharge pathway to enable CYP to die at home in their preferred place of care. The hospice at home service was led by the specialist children's outreach nurses and provided services such as respite, play, music therapy and end of life care at home to over 30 children and young people.

The hospice worked closely with the child's GP and the specialist teams that the children are known to. The medicines administration records were reconciled with GP records and this process usually resolved any discrepancies that might exist in relation to the child's prescription. All communication was logged on the care database by staff members. Any secure email exchanges were also uploaded to the child's file as an associated document.

Between April 2018 and March 2019, the hospice provided 31,989 hours of care, 379 children received support including 49 siblings, had 527 volunteers in a range of

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roles to support the hospice, received pledges for support from 100 local businesses, 571 home visits and 610 therapy sessions. Of these therapy sessions, 371 (61%) was music therapy, 198 (32%) was physiotherapy and 41 (7%) was therapeutic yoga. The current caseload for the hospice at home service was 57 CYP patients.

CYP could receive a block of 10 music therapy sessions (each lasting 30 minutes) either individually in their homes or as group sessions and involved families. At the end of the 10 weeks, parents received a report which was also saved on the patient's care records. The report included positive outcomes and recommendations. Families also had the option to extend the sessions if needed. Music therapists contacted the families ahead of the home visits to confirm the sessions. With the recent viral outbreak (COVID-19), staff completed an initial screening with families prior to carrying out home visits. The service contracted an external provider for the physiotherapy service using a service level agreement. Accessing physiotherapy involved an initial assessment of the child's physical needs to identify the level of input required. Following the assessment, physiotherapy sessions worked towards improving/maintaining the child's joint range of movement, muscle strength, balance and co-ordination to maximise function. If it was felt that the child may benefit from a piece of specialist equipment to either aid function or support postural management, additional assessments for this would be completed.

Handovers took place twice daily, once in the morning and once in the evening. A separate huddle took place after the handover. The hospice had a low transfer rate with eight unplanned or unexpected transfers in the last year out of 282 admissions (0.03%). All unplanned transfers were treated as clinical incidents and reportable to the clinical governance board to ensure that the underlying causes were understood and to determine if there was any learning to bring forward.

The hospice recognised that transition can be a time of uncertainty for young people and their families. The hospice aimed to support families to ensure a transparent, reliable and positive transition to adult support services. There was a dedicated transition link

nurse who worked closely with the parents, the child (age 14+) and professionals to ensure all care was coordinated to enable a smooth transition once the child reached their 18th birthday.

Although the biggest challenge identified was the adult respite provision, the hospice had good working links with local adult hospices and facilitated opportunities for CYP to attend youth engagement events with them. For example, a young adult group (YAG) had been set up to introduce young people to adult palliative care and the group met monthly. The hospice signposted families to the local adult's respite and specialist schools which accepted CYP patients until 25 years.

The hospice was part of the North London Regional Action Group on Transition and organised workshops in collaboration with the Council for Disabled Children and expert parent transition education workshops. The hospice was also involved in an upcoming conference on transitional care in May 2020 with local adult hospices, local hospitals and other community providers.

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, investigated them and shared lessons learned with all staff.

The hospice had a complaints policy which was in date and stated that formal complaints should be acknowledged within two working days and a formal response provided within 20 working days. The service completed investigations for each complaint and scheduled meetings with individuals when necessary. There was an escalation process if the response was unsatisfactory and learning was disseminated with staff members involved as well as the wider team to prevent recurrence.

The hospice received nine complaints between November 2018 and October 2019 of which, five complaints were upheld. The service resolved 100% of the complaints by the target date in line with the complaints policy.

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The service encouraged CYP and their families to provide feedback and displayed information on how to do this on the notice boards for parents and the parent page of the website. Each family also received a welcome pack which included information on the complaint's procedure.

Staff told us they would try to resolve concerns at the time they were raised with support from the senior staff as required. The clinical nurse manager or deputy nurse would contact families within 24 hours of a concern being raised.

Complaints were analysed quarterly, and the results were discussed at the clinical governance board, trustee board and meetings with CCG commissioners. Previous analysis suggested improvements were required in communications and use of temporary staff. The hospice addressed this by introducing an electronic handover procedure and improved the home communication feedback forms. The hospice reduced the use of agency staff and increased the staff bank pool.

Are hospice services for children well-led?

Good 

Our rating of well-led stayed the same. We rated it as **good**.

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 in the service for children and young people and staff. They supported staff to develop their skills and take on more senior roles.

The charity was governed by a Board of Trustees who had the responsibility for the overall health and strategic direction. The Trustees gave their time and expertise for free, attending Board meetings and supporting sub-committees. The hospice had 11 Trustees and kept a record of their appointment dates including the second term and the date due to retire as part of succession planning. Current trustees included experts in business, human resources (HR), law, healthcare, a local faith leader and a bereaved parent. The hospice completed

skills analysis audits annually and when individual trustees left to ensure the board had the appropriate skills which was representative of the community served. The hospice was currently engaged in the recruitment process for at least two new trustees with expertise in finance as the current Chair and Treasurer were due to retire in 2021.

Trustees completed a supervised shift in care as part of their induction and ongoing every three years. Operational staff were invited to Trustee meetings to ensure that Trustees had a good understanding of the issues affecting the whole charity and to improve overall knowledge and communication.

Board meetings took place five times a year and the Trustees told us they received board papers and committee reports at least one week before the board meetings. The board meetings dates were organised in advance and Trustees were given the opportunity to input into organisation development days.

The senior management team (SMT) were based within the hospice and were experienced within their given specialities and were highly visible. Staff we spoke with told us managers were supportive and approachable, and felt their concerns were listened to. Staff described the SMT and Trustees as friendly. Staff demonstrated awareness of the trustees as they had worked shifts in the care department, attended family events and away days. Staff told us that senior leads had an open door policy and the CEO completed regular walk arounds in the care environment including a night shift to understand the service. The CEO also led the Dads' support group.

Although the senior management team attended the Trustee Board meetings to present on matters such as strategy, the trustees also met separately. The Trustees told us the senior management team were responsive to challenge and Trustees received key information ensuring there were no surprises. For example, Trustees were made aware of serious incidents and the learning outcomes at the time they occurred. The SMT met weekly and the Chair and CEO met monthly.

Care meetings with senior care staff took place weekly. We reviewed the minutes for February 2020 and found there were discussions on the viral outbreak (COVID19), safeguarding, upcoming inspection, funding, updates on meetings with commissioners and parent engagement.

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The hospice had daily huddles for sharing learning from incidents and to discuss staffing. For example, we observed the huddle on day two of the inspection where staff were made aware of the DNACPR incident. Senior leads told us they wanted to increase the frequency of team meetings to quarterly. Staff told us that since December 2019, there had been three team meetings. The hospice organised team away days and we reviewed the agenda for the away day in February 2020 which included updates on the viral outbreak (COVID19), palliative journey, safeguarding supervision, Deprivation of Liberty Safeguards and Liberty Protection Safeguards and caseload management.

Vision and strategy

The service had a vision for what it wanted to achieve and a strategy to turn it into action, developed with all relevant stakeholders.

The charity was currently in the final year of its existing Vision 2020 strategy and in the process of undertaking a comprehensive review of all their operations including voluntary and statutory income generation and services/models of care. This included a full stakeholder review with the children and young people (CYP), families, external referrers and commissioners. The hospice anticipated finalising and launching a new three year strategy by April 2020.

The new strategy was closely aligned with the needs of the local areas as the hospice had close working partnerships with the local Clinical Commissioning Groups (CCGs) and sustainability and transformation partnerships (STPs). Senior leads told us the old strategy had focused on the respite model, but families wanted more therapeutic support. Therefore, the new strategy focussed on an individualised model of care. The hospice had geographically mapped all the CYP on their caseload on an interactive map against all the contracted areas and were having discussions with commissioners in other areas identified to formalise contracts.

The values had been reviewed and updated following consultation with staff and in partnership with the trustees, CYP and their families. The values formed the framework for how the service delivered their services

and included four key areas: respectful, safe, compassionate and professional. During the inspection we found the values were visible and displayed throughout the hospice.

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.

Staff we spoke with told us they felt supported by their managers and colleagues. Staff said there was great team work and they felt listened to if they raised concerns. The hospice had a 'staff shout out board' where staff could acknowledge the contributions of their colleagues. In the fundraising building, staff would ring a bell when they had a success with raising funds.

Staff we spoke with "felt lucky and proud to be here" as the teams were friendly and supportive. All staff including the senior management team were involved in fundraising.

Staff completed a training module on unconscious bias to enhance their knowledge and understanding of equality and diversity within the workplace. The hospice organised bi-annual organisational learning days (OLDs) for all staff which included training on the awareness of learning disabilities core skills, understanding the Hindu and Catholic faith and encouraged team bonding. The hospice worked in partnership with the local adult hospice, NHS colleagues and bereaved parents to deliver a conference on 'The Importance of Faith, Culture and Spirituality at End of Life'.

Staff were encouraged to seek additional qualifications by attending internal and external study days to widen their knowledge and skills as they undertook their continuous professional development. Examples included support with the multi-disciplinary Advance Care Planning (ACP) Collaborative and Pain Assessment. Staff learning was assessed during regular 1:1's between staff and their line managers.

The hospice had an internal improving working lives group which included representatives from every

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department across the charity. The group consulted with staff, raised issues for staff well-being and drove forward ideas on how to improve everyone's working life and environment.

Staff told us that the introduction of the Community and Wellbeing Team meant staff didn't feel that they were working on their own. Staff were able to liaise with each other directly as everyone sits in one office together instead of through emails. Wellbeing sessions were organised for staff which included lunchtime yoga sessions. Staff had free access to the Employee Assistance Programme (EAP) for extra support to help reduce stress, anxiety and improve their wellbeing.

The charity prioritised the staff's mental health and wellbeing and recently trained two fully accredited Mental Health First Aiders. The Mental Health First Aiders were the go-to person for anyone who was going through some form of mental health issue. The first aider helped guide the person in distress to the relevant help that they needed.

Governance

Leaders operated effective governance processes, throughout the service and with partner organisations. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.

The hospice had made improvements to the governance structure which included the recruitment of a risk and governance lead and an interim clinical nurse manager and introduced monthly clinical risk management meetings.

The risk and governance lead nurse started in March 2019 and senior leads told us improvements had been made to the management of audits and policies. The hospice had a robust audit schedule to ensure that quality and safety processes put in place were effective in providing a safe environment for CYP and staff. Audit results were publicly available and reviewed in the clinical governance board meetings, seniors' nurses' meetings and were reported to commissioners quarterly. The clinical

governance board meetings reported into the main board meetings to ensure there was a robust clinical and internal audit programme to monitor the quality of the service and identify when to act.

External auditors had completed a financial audit last year and senior leads told us the audit didn't highlight any concerns. Between April 2018 and March 2019, the hospice generated an income of £3.93 million of which 61% was through fundraising, 20% through statutory grants, 18% from the retail shops and 1% from investments. The finance and resources committee had the responsibility for risk management and reported directly into the board.

We reviewed the monthly clinical risk management group meeting minutes for October and November 2019 and found there was consistency in the format and structure of the meetings. The meeting agenda included actions from the previous meeting, update on policies and procedures, review of quality dashboard indicators, review of the risk register, medicines management, recruitment, activity/occupancy and feedback from audit, research and education. The quality dashboard indicators included clinical incidents, concerns, complaints, compliments, serious incidents, safeguarding, Deprivation of Liberty Safeguards (DoLS) and central alerts including patient safety alerts and Medicines and Healthcare products Regulatory Agency (MHRA) alerts. The minutes for both meetings presented the agenda items in an action log format and included an 'actioned by' column.

We reviewed the quarterly clinical governance board reports for Trustee Board for April, July and September 2019 and found there was consistency in the format and structure of the meetings. The reports included a summary on clinical incidents, complaints, compliments, audits, infection prevention and control and a safeguarding update. The reports included updates for each of the three planning priorities which were patient experience, clinical effectiveness and patient safety.

The charity's annual quality account included the priorities for improvement to enhance the quality of care and progress was reported quarterly to the CCG commissioners and clinical governance board. We reviewed the quality account report for 2018/2019 which was structured in three sub sections. Part one provided details of the hospice, the values and purpose and the

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services provided. Part two reviewed the priorities for improvement which include national and in-house clinical audits. Part three included a review of quality performance, patient safety, safeguarding report, staff training, staff and family engagement and partnership networks.

Managing risks, 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. They had plans to cope with unexpected events.

The charity had an emergency and business continuity plan which was in date. The plan ensured the hospice was prepared for all eventualities such as managing emergencies, lockdown procedures, and listed details of the emergency management team for the hospice and retail shops. The hospice had upgraded their fire alarm system, aligned the positions of the loft hatches to facilitate horizontal evacuation and introduced grab bags. The yellow grab bags included foiled blankets, screwdriver set, mini first aid kit, maps of the site, wind up torch. There were three bags in total, two in the care building and one in the fundraising building. Care staff had additional emergency bags which included the necessary medication. Families staying in the family flat received a welcome pack which included information on what to do in event of a fire.

The charity had a corporate risk register which divided into governance, clinical, finance, HR and health and safety and premises. We reviewed the risk register and found risks were appropriately documented with potential impact, likelihood, total risk score, mitigation steps, risk score post mitigation and further action needed. However, we found a named risk owner was not included. We raised this with the senior management team who told us the senior lead for each area was responsible for the corresponding section in the risk register. However, the senior management team acknowledged our feedback and submitted a revised clinical risk register for March 2020 following the inspection. The risk register had been amended to include a dedicated lead who had the responsibility for the named risk.

The senior leaders identified the current risks affecting the hospice was the viral outbreak (COVID19) and getting the information technology (IT) systems where they needed to be. The clinical risk register had been reviewed following the viral outbreak alert in February 2020 and the hospice had a dedicated lead who kept staff updated and provided advice on what actions were required in line with advice from the government.

Although the hospice had reviewed the risks for the transition between the electronic records systems, considering the DNACPR incident during the inspection (refer to Records section for details), the director of care completed another risk assessment. Following the inspection, the hospice provided an updated clinical risk register which included this as a risk. The hospice also submitted the change management plan and risk assessment for the implementation of the new database having thoroughly reassessed the risks and putting mitigations in place following the incident. The action plan had a dedicated project lead and deadline for each task.

A local security company provided voluntary patrols every night and on bank holidays. Staff told us they were responsive.

Managing information

The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements.

The hospice used a mix of paper-based and electronic records. Computer stations were available so that staff could access the intranet and internet. Staff were aware of how to use and store confidential information. We found paper records were stored securely and staff locked computers preventing unauthorised access.

The hospice was in the process of transitioning from one electronic system and some paper records to another electronic system which would allow the hospice to go paperless. However, we found the use of two electronic systems and paper records during the transition phase lacked a cohesive approach. The senior management team acknowledged it has taken longer than expected to transfer records but told us that this was because they were creating updated care plans (Refer to Records subheading for more details).

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Although staff had electronic tablets to use in the community on home visits, most staff told us that the WIFI connection in the community was poor. This meant staff completed documentation in care records after the visit. Staff told us the new database was a shared notes system which meant information was easily accessible.

The hospice had appointed a Data Protection Officer (DPO) to strengthen the data protection procedures. A third party provider provided information technology (IT) support both remotely and onsite.

The clinical safety and quality improvement notice board displayed information for staff on sepsis, contact details for palliative care team, duty of candour, out of hours on call rota with contact details and advice on the recent viral outbreak. The Teen Zone Board displayed information on accessing emotional support, the NHS youth forum poster, the young people survey results and ideas envelope.

Engagement

Leaders and staff actively and openly engaged with patients, staff, equality groups, the public and local organisations to plan and manage services. They collaborated with partner organisations to help improve services for patients.

The hospice used different methods to collect feedback from CYP and their families. This included social media posts, emails, thank you cards and technology such as video calls which allowed parents to observe their CYP at any time during respite visits. The charity was working to improve its methods of obtaining feedback from CYP and families with potential investment in the 'I want great care' system.

Two of the Trustees organised quarterly family forums which were hosted at weekends to facilitate attendance. This provided Trustees with the opportunity to talk directly with families and seek their views on service development. The hospice had also introduced 'You said we did' posters to keep families better informed which we saw displayed during the inspection.

The charity engaged with stakeholders regarding site development plans, strategy development and had a stakeholder interview panel where young people were involved. The following was representative of feedback from families and carers: "I feel very privileged that we as

parents, have a say in how the future of Haven House's vision and care will be shaped"; "I feel privileged to be part of this unique combined-effort to make things work better" and "I look forward to its development".

The Director of Care and CEO were visible and approachable to parents. For example, they attended regular parent coffee mornings and spoke informally to parents at fundraising events. Communication with families included newsletters which were published quarterly and linked to a dedicated family page on the hospice's website. We reviewed the newsletter for August 2019 which included snapshot stories, feedback from children, news and updates and had information on how to get involved in events. The newsletter provided the charity with an opportunity to show the community how their support had enabled staff to care for families and make a difference in their lives.

The charity held bi-annual 'appreciation and thank you' events for their volunteers and kept volunteers informed through newsletters.

CYP and their families were encouraged and offered opportunities to raise concerns about privacy and dignity with staff and the hospice had adopted the 'Freedom to Speak Up policy' to encourage staff, CYP and families to feel able to raise their concerns. The hospice had two freedom to speak up guardians.

Senior leads told us the recent staff survey highlighted that staff wanted more flexibility in their working hours. For example, clinical staff wanted shorter shifts available as early and late shifts instead of a long day. The new e-roster allowed staff to have more flexible working arrangements and where staff worked over their hours, they were offered the option of taking their time back or being paid overtime. Staff has also highlighted inequalities in the annual leave and pension entitlement for those staff who did not fit into the NHS Agenda for Change. However, senior leads had addressed this by increasing annual leave for staff who were not part of the Agenda for Change effective from April 2020.

Haven House had entered the National Sunday Times Best Employer Awards in 2018 and was awarded a 2-star accreditation for the second highest standard of workplace engagement which represents organisations striving for the top made possible only through 'outstanding' commitment to workplace engagement.

Hospice services for children

The hospice was a member of Children's Hospices across London (ChaL), a separately registered charity and a collaboration between the six children's hospice services which supported CYP with life-limiting and life-threatening conditions and their families. The six ChaL charities helped to manage children's symptoms, give families time to take short breaks, as well as offering end-of-life care and bereavement support across all 33 London boroughs. By collaborating with other children's hospices, Clinical Commissioning Groups (CCGs), local authorities and private sector providers, the hospice aimed to improve and increase the services offered to families in need. In partnership with CHaL, the hospice had set up a successful nurse rotation programme with the local acute trust to raise awareness on paediatric palliative care and the holistic support offered by children's hospices.

Learning, continuous improvement and innovation

All staff were committed to continually learning and improving services. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation and participation in research.

The hospice actively contributed to academic research. For example, in 2019, the music therapy team produced a paper which was published in *Approaches: International Journal of Music Therapy*. The paper described the ongoing work ('Wiggles and Rhymes') with life-limited pre-school aged children and their carers in conjunction with the multidisciplinary team, and the holistic therapeutic support this offered.

A song writing project ('Our Story') with the teenage cancer group had been accepted as a paper presentation for the 16th World Congress of Music Therapy at the University of Pretoria in South Africa 2020, and the British Association of Music Therapy conference in Belfast 2020. The project had also been accepted as a poster presentation in the 'Together for Short Lives' national conference in Manchester in March 2020.

The hospice had recently introduced joint music and physiotherapy sessions for babies and younger children to improve their experience of physiotherapy using the distraction of music therapy. The project was showing promising early results and staff told us that feedback from parents had been very positive.

NHS England recognised the charity's collaborative work with the local paediatric oncology shared care unit (POSCU) in providing holistic support to CYP diagnosed with cancer. Staff from the hospice were invited to participate in a film showcasing this integrated approach to promote the aims of the NHS England's long term plan.

The hospice was shortlisted for three awards in 2019's nursing times awards for the categories: nurse leader of the year, child and adolescent services and HRH Integrated Approaches to Care. For the second year running Haven House has been shortlisted for the Queen's Award for volunteering in 2019 and the outcome was expected in May/June 2020.

Haven House made it onto the top 100 Sunday Times Best Companies Not-for-Profit List for the second year running and placed 26.

Outstanding practice and areas for improvement

Outstanding practice

- Staff went the extra mile to ensure patients' needs were met in the last days and hours of their lives. For example, the hospice had recently worked in partnership with the local hospital, CCG and child death overview panel to repatriate a baby on an end of life pathway to their country of origin at the request of a parent.
- The song writing project ('Our Story') with the teenage cancer group had been accepted as a paper presentation both internationally and nationally.
- NHS England recognised the charity's collaborative work with the local paediatric oncology shared care unit (POSCU) in providing holistic support to CYP diagnosed with cancer.
- The hospice provided holistic care tailored to the child's needs. For example, the hospice had recently introduced joint music and physiotherapy sessions for babies and younger children to improve their experience of physiotherapy using the distraction of music therapy.

Areas for improvement

Action the provider SHOULD take to improve

- The provider should continue taking steps to ensure compliance with the completion of checklists.
- The provider should continue taking steps to ensure the transition between the electronic records systems is reviewed periodically and completed without further delay.