

The Forget Me Not Children's Hospice Limited

Forget Me Not Children's Hospice

Inspection report

Russell House
Fell Greave Road
Huddersfield
HD2 1NH
Tel: 01484411040
www.forgetmenotchild.co.uk

Date of inspection visit: 24-25 October 2023
Date of publication: 17/01/2024

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

Ratings

Overall rating for this location

Outstanding 

Are services safe?

Good 

Are services effective?

Good 

Are services caring?

Outstanding 

Are services responsive to people's needs?

Outstanding 

Are services well-led?

Good 

Summary of findings

Overall summary

Our rating of this service stayed the same. We rated it as outstanding because:

- The service consistently had enough staff to provide highly individualised and personalised 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 to a high standard. Staff assessed risks to children and young people, managed and acted on them and kept clear and concise care records. They managed medicines well. The service managed safety incidents well and always learned lessons from them.
- Staff provided innovative and proactive care and treatment. Staff consistently gave children and young people enough to eat and drink and gave them pain relief when they needed it in response to individualised plans. Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked efficiently as a team for the benefit of children and young people. Staff provided a truly holistic approach to care. They advised children, young people and their families on how to lead healthier lives, supported them to make decisions about their care, and had access to good information. Key services were available seven days a week.
- Staff were consistently committed to treating children, young people and their families with compassion and kindness. Staff respected their privacy and dignity, found innovative ways to meet their individual needs, and helped them understand their conditions. They provided strong, caring and respectful emotional support to children and young people, families and carers in a personalised way. They worked in active partnership with children and families, ensuring children and families felt like they mattered.
- The service used innovative approaches to providing planned care to meet the needs of local people. They were proactive in developing person-centred pathways with other service providers. They consistently worked to understand and take into account children, young people and families individual needs in order to deliver care that met these needs. The service made it easy for people to give feedback. They engaged families and children in regular service reviews and learning events. People could access the service when they needed.
- Leaders were dedicated to providing a compassionate, inclusive and highly effective service. They ran services well using reliable information systems and consistently supported staff to develop their skills to succeed in the delivery of a high-quality service. Staff shared an understanding of the service's vision and values and were inspired to strive to deliver a service they were proud of. Staff felt respected, supported and valued. They were focused on providing best practice to meet the needs of children, young people and families receiving care. Staff were clear about their roles and accountabilities. The service was committed to seeking constructive engagement with children, young people, families and a wide range of local organisations and community groups to plan and manage services. All staff were empowered and committed to improving services through a systematic and embedded approach. Innovation was celebrated.

However:

- The service did not have a direct link with specialist mental health crisis services.
- The service did not have health promotion leaflets readily available.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	Outstanding 	Our rating of this service stayed the same. We rated it as outstanding. See the summary above for details.



Summary of findings

Contents

Summary of this inspection

Background to Forget Me Not Children's Hospice

Page

5

Information about Forget Me Not Children's Hospice

5

Our findings from this inspection

Overview of ratings

7

Our findings by main service

8

Summary of this inspection

Background to Forget Me Not Children's Hospice

Forget Me Not Hospice is a nurse and therapy led service which provides support to children with life-shortening conditions, their families and families of those living with the loss of a child across West Yorkshire. Services are provided from a purpose-built hospice environment, families homes and in hospitals across West Yorkshire. Service provision can start during pregnancy and continue for as long as there is a therapeutic need.

Services include nursing and medical care, hydrotherapy, music therapy and counselling, end of life care and bereavement support. Services provided by the care team are provided to the children and families in the Russell House hospice environment or within their own home. Services provided by the family support team are provided within Russell House, homes or local community venues.

The service was registered for the treatment of disease, disorder or injury and had a registered manager in place.

We last inspected the service in 2015 when it received a rating of 'outstanding'.

How we carried out this inspection

The inspection team included three inspectors, regulatory co-ordinator and a specialist advisor with a background in paediatric nursing and end of life care. During our inspection we spoke to trustees, staff across the organisation, families and carers, and observed interactions with children. We reviewed sets of clinical notes and policies. We observed meetings with other agencies. We spent time in Russell House where the inpatient and day care was provided.

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

Outstanding practice

We found the following outstanding practice:

- The hospice had pioneered a highly specialist perinatal service in response to an identified need based on experience, local evidence and national literature. The service demonstrated a significant understanding of the devastating impact of perinatal deaths and stillbirth and the support that would benefit families at this time. The service was working in collaboration with local hospitals to make this support more widely available.
- The hospice had launched a sudden death in childhood service and were leading the way in partnership with the local police to support families in dealing with the devastating effects of sudden and unexpected death of a child.

Areas for improvement

Action the service SHOULD take to improve:

- The service should ensure they meet their own provider compliance rate for safeguarding training.
- The service should consider identifying direct links with local specialist mental health crisis services.







Summary of this inspection

- The service should consider ensuring provision of health promotion leaflets.






Our findings

Overview of ratings

Our ratings for this location are:

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

Hospice services for children

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

Is the service 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.

Staff received and kept up to date with their mandatory training. The mandatory training completion rate was 87% at the time of inspection which was below the service's target of 95%. This was due to bank staff. The service had made provision for bank staff to be offered bank shifts to allow them to complete training. Managers made sure that any bank staff not up to date with training for example, tracheostomy care, would not be booked for a bank shift that required this kind of clinical care.

The mandatory training was comprehensive and met the needs of babies, children, young people and staff. There was a clinical educator role dedicated to providing training and monitoring training compliance. Ten key competencies were delivered to staff over a six-month period by the clinical educator. This role was vacant at the time of inspection, however, there was a person identified to fill this post in December 2023. The training responsibilities were being overseen by an identified member of the clinical team in the interim.

The service had an education framework in place. This identified core training that all staff including volunteers, estates and housekeeping staff should complete along with specific additional training requirements for individual roles. There was a learning needs analysis completed in 2021 to ensure all staff were able to access required training and were able to identify any additional training to support development.

Clinical staff completed training on recognising and responding to children and young people with mental health needs, learning disabilities and autism.

Managers monitored mandatory training through 1:1 supervision sessions with staff. Training needs were shared to the clinical educator. Face to face training sessions were booked in advance with the clinical educator. These could be completed in a group session or individually depending on the needs of each staff member. All staff held a copy of their own training competency booklets. Staff also received notifications electronically through the training provider when e-learning training was due to expire.



Hospice services for children

Safeguarding

Staff understood how to protect children, young people and their families 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.

Staff received training specific for their role on how to recognise and report abuse. All staff who worked with children received training to level three. This was in line with national guidelines for safeguarding children. Safeguarding children level three training was 90% compliant. This was below the provider target of 95% compliant. We understood there were some shortfalls in bank staff completing training, however, staff had been given additional bank shifts to support completion of training. We saw evidence of a safeguarding training session taking place for staff during our inspection. Volunteers all received level two.

There was a safeguarding policy in place that stated the required level of training for each job role within the service. The organisational mandatory training framework also clearly outlined the training and levels applicable to each job role.

Staff could give examples of how to protect babies, children, young people and their families from harassment and discrimination, including those with protected characteristics under the Equality Act.

Staff knew how to identify adults and children at risk of, or suffering, significant harm and worked with other agencies to protect them. Staff could give examples of when potential risk of harm had been identified and when a safeguarding referral had been considered.

Staff knew how to make a safeguarding referral and who to inform if they had concerns. There was a clear process defined within the policy. There was a named safeguard lead within the service. There was a safeguard log within a specific safeguard folder and a log within individual children's electronic records.

Safeguarding governance meetings were held three monthly with the safeguard team. Regular in-house safeguarding supervision was available for all staff. We saw evidence of peer supervision that included topics such as modern slavery and county lines.

Safeguarding referrals were all reviewed by the service to ensure best care was provided and the service was able to respond to changing needs of individuals.

Cleanliness, infection control and hygiene

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

All areas were clean and had suitable furnishings which were clean and well-maintained. We observed clinical areas, play areas, communal eating areas and bedroom areas. All areas were cleaned to a high standard. We observed regular cleaning practices throughout the inspection. We saw bedroom doors clearly marked with 'I am clean' labels.

Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. We heard that a deep clean was done weekly and curtains throughout the building were washed weekly.



Hospice services for children

We saw details of a recent PLACE audit carried out by two parents. This had identified there was no internal window cleaning schedule. We saw a clearly dated action plan with an identified lead to ensure this was put in place within two months of the audit completion.

We observed staff following infection control principles including the use of personal protective equipment (PPE). There were hand gel dispensers around the building and on entering at the main reception. Staff wore scrubs which were provided by the service and laundered on site.

Clinical staff took responsibility for carrying out hand hygiene audits.

Staff cleaned equipment after patient contact and labelled equipment to show when it was last cleaned. We heard that play areas were cleaned in between children and families using the areas. Soft play equipment could be fully removed and disinfected.

There was an up-to-date infection prevention and control policy that included links to guidance, for example, cleaning and decontaminating children's toys.

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 design of the environment followed national guidance. The building was easily accessible from the car park. Priority parking spaces were given to families using the service. There was level access throughout the building and lift provision where needed. The service had commissioned an accessibility audit which ensured a focus around the accessibility of the Hospice. We saw evidence of regular review of the environment and suitability to meet children's needs, for example a recent audit had taken place that had identified some grab rails were not optimally positioned and had been moved accordingly. The outdoor garden area was reviewed annually by the Royal Society for the Prevention of Accidents (RoSPA).

Staff carried out daily safety checks of specialist equipment such as the resuscitation trolleys and the hydrotherapy pool. The environment was maintained by the onsite maintenance team and repairs prioritised according to need. There was a monthly compliance tracker that alerted staff when specialist checks were due, for example, hoist servicing. We saw one check that was overdue, however, there was a date recorded for completion of this service within three weeks of the due date.

The service had suitable facilities to meet the needs of children, families and those close to them. Rooms were organised and designed in a way to be opened up to accommodate larger family and friends' groups to allow for larger social gatherings at appropriate key times important to the individual child. There were indoor soft play and sensory play areas, a cinema room, a music room and a hydrotherapy pool. There was an outdoor garden and play area adapted to meet the needs of all children and families using the service.

The service had enough suitable equipment to help them to safely care for patients. All bedrooms and communal play areas were equipped with suitable hoist facilities. There were sensor mats installed at external doors. There was a wheelchair accessible swing in the garden area. We saw evidence of a monthly mattress audit.



Hospice services for children

Clinical waste was clearly labelled, and staff disposed of clinical waste safely. Hazardous products were clearly marked and locked away according to guidelines. Control of substances hazardous to health (COSHH) risk assessments were completed annually.

Assessing and responding to patient risk

Staff completed and updated risk assessments for each child and young person and removed or minimised risks. Risk assessments considered patients who were deteriorating and in the last days or hours of their life.

Staff followed NICE (National Institute for Clinical Excellence) guidance to identify children or young people at risk of deterioration and escalated them appropriately. There was a policy in place for the management and escalation of an unwell or deteriorating child. This gave guidance for community and hospice settings.

Staff were proactive in completing comprehensive risk assessments for each patient on admission or arrival using appropriate tools that followed national guidance. We reviewed records and saw risk assessments were reviewed at least three monthly. We heard that a review would be done sooner if there was a change to presentation.

Staff we spoke to explained there was a constant reassessment of risks as children's conditions change. We saw evidence that families were involved in discussing risk and making plans for responding to risk with their children. We were told about parallel planning for children arriving at the hospice for end-of-life care to support families with a range of possible circumstances.

The service did not have 24-hour access to mental health liaison and specialist mental health support, however, would support families to navigate the system to access appropriate support.

Staff shared key information to keep patients safe when handing over their care to others. One foster carer told us that detailed and clear care plans had been shared. We saw a nurse transfer letter was used for children being transferred to hospital.

Handovers were held twice daily at shift changes and included all necessary key information to keep patients safe. For each individual the handover included the child's situation, background, daily update, plan for day and issues to escalate. The handover also identified allergies, nutrition and hydration needs and advanced care plans or ReSPECT documents in place. A ReSPECT document is a Recommended Summary Plan for Emergency Care and Treatment that creates a summary of personalised recommendations for a future emergency.

Nurse staffing

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

The service had enough nursing and support staff to keep patients safe. Staff had a range of qualifications, skills and experience. There were no vacancies at the time of inspection.

Managers calculated and reviewed the number of staff required each shift using a dependency scores toolkit devised by the service that took into consideration dependency of each individual child. Care coordinators were responsible for ensuring dependency scores were accurate and up to date. A booking administrator used the toolkit to safely allocate respite slots matching requested dates against staffing levels according to dependency of each child. The dependency score toolkit was used to further determine the number of children that could be allocated a day care place.



Hospice services for children

Managers were clear that staffing levels would need to be adjusted according to changing needs of children. The service staffed the hospice for comfort and safety during the day and for safety at night. There were adjustments within daily staffing that could be made, for example, we saw on the rota there was capacity for the nurse in charge to take on additional care responsibilities. Staffing rotas clearly identified which staff had care responsibility for which child at any point through the shift. We heard the clinical members of the leadership team would provide additional support in an emergency. The daily handover allowed for escalation of concerns regarding staffing levels on a daily basis.

The number of nurses and care staff matched the planned numbers. A member of senior management and a senior care coordinator were on call out of hours for support or advice. There was a planned rota.

The service had reducing turnover rates. In January 2022 turnover rates had been high. Turnover rates had fallen consistently from 34% to 23% during 2022. We saw managers had carried out a thorough review of turnover rates taking into consideration local and national comparisons, reasons for staff leaving and improvements that could be made to retain staff.

The service had low sickness rates. Sickness rates had reduced in the six months prior to inspection from the previous six months.

Managers did not use agency staff as they were aware of the need for continuity for children. The service employed bank staff who were familiar with the service.

Managers made sure all bank staff had a full induction and understood the service.

Medical staffing

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

There was a service level agreement in place with a local hospital allowing for registered medical doctors to provide perinatal, neonatal and paediatric input into the care of the children. This included perinatal, palliative and end of life care. Doctors supported development of detailed care plans, advanced care plans and complex symptom management. Doctors provided regular input to the hospice and worked an agreed number of hours per year. Staff told us they were always available for consultation. Doctors told us they would be available for consultations in the hospice environment, at homes or for perinatal support when families attended the hospital for other planned appointments and during birth where possible or requested.

Records

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

Patient notes were comprehensive, and all staff could access them easily. We reviewed four sets of notes and found clear evidence that care was personalised to the child and where indicated involved the young person in decision making. There were clear care plans for specific needs, for example we saw detailed personalised care plans for a child with type one diabetes.

The record system had clearly identified flags for any children subject to child protection plans or safeguarding actions.



Hospice services for children

We saw evidence of detailed autism adjustments, behavioural needs plans and communication needs within the records. Each individual also had clearly identified social and spiritual needs or choices identified.

When patients transferred to a new team, there were detailed transition plans documented and shared. We saw examples of documentation for when children transitioned to adult services or when transfer to hospital was necessary.

Records were stored securely. Retention and destruction schedules were kept for all records. Spot checks were carried out on records by managers to ensure compliance with record keeping policy.

Medicines

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

Staff followed systems and processes in line with Nursing and Midwifery Council (NMC) and Royal Pharmaceutical Society guidelines to prescribe and administer medicines safely. There was an up-to-date policy in place that clearly outlined the roles of prescribers and staff administering medications. The policy had been adapted from a local NHS trust policy, medicines management toolkit and together for short lives (2014) guidance to ensure it met the needs of the service specifically. The policy gave guidance for staff responsibilities where children and parents wished to administer their own medication whilst in the care of the service. Children and parents were asked to demonstrate competencies to determine the level of support by staff in administration of medicines. Staff followed processes for safe management of medicines within children's homes.

The service had non-medical prescribers (NMP's) in post. Training was supported for staff who wished to become NMP's. There was a clear NMP framework and policy in place that was in line with the Royal Pharmaceutical Society's Prescribing Competency Framework (2019) and relevant NMC standards. The prescriber for each day was clearly named on the shift handover sheet.

The service also had a Controlled Drugs Accountable Officer.

The hospice doctors reviewed medications for symptom control alongside regular reviews through external outpatient appointments. Doctors provided support for the advanced nurse practitioners in the most complex cases.

Staff completed medicines records accurately and kept them up to date. All children had paper drug charts. We saw evidence of correct completion of these.

Staff stored and managed all medicines and prescribing documents safely. Staff would check any open medicines on a weekly basis. We saw all medicines were in date and correctly labelled. There were locked controlled drugs cabinets, and any controlled drugs were entered into a child's own controlled drug register. We heard that staff had expressed concern about how to safely carry treatment charts around. An improvement action had been put in place allowing individual children's charts to be stored in tote bags that would be taken wherever the child was within the hospice building.

Medicines were disposed of appropriately within the service using denaturing kits. The medicines management policy outlined the guidance for disposal of medications.

Staff followed national practice to check patients had the correct medicines when they were admitted, or they moved between services. When children attended for respite, they brought their own medication. There was a clear process outlining responsibilities of staff for medicines reconciliation.



Hospice services for children

Staff learned from safety alerts and incidents to improve practice. During our inspection we heard that an administration error had re-occurred on more than one occasion. There was an action plan in place for this. We saw the required action communicated through the shift handover sheet.

We saw evidence of the service using case examples of medication related incidents from other services to inform their own learning and practice.

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.

Staff knew what incidents to report and how to report them. There were a number of policies in place that gave guidance on what to report as an incident. For example, the medicines management policy set out medicines incidents. The leadership team told us there had been some recent work with staff to improve understanding of incident reporting.

During the quarter July to September 2023 there had been an increase in staff reporting of concerns, incidents and near misses in line with the service's policy following the staff awareness training. This had supported leaders to identify areas of practice that could be improved. For example, we saw there had been an increase in reporting of medication incidents. Investigation of these incidents had enabled staff to articulate difficulties they were experiencing and for these issues to be resolved.

The service had no never events.

Managers shared learning with their staff about never events that happened elsewhere. We saw evidence of incidents from other services that were used to inform the service's own practice and learning.

Managers told us there had recently been work carried out to improve staff understanding of duty of candour. This was following an incident reported where duty of candour had not been followed. We saw evidence of two care reviews following incident reports where staff had been open and transparent, providing the family with a full explanation.

Staff received feedback from investigation of incidents, both internal and external to the service. We reviewed a recent incident form and saw that individual staff had received feedback. We heard that staff were empowered to be part of investigations and in finding solutions. Managers explained how they were careful in the language they used to support a 'no blame' culture and to seek system improvements to reduce the risk of human error.

Managers investigated incidents thoroughly. We reviewed incident investigations and saw evidence of engagement of families in these investigations.

Managers debriefed and supported staff after any serious incident. All staff we spoke to told us that they felt supported by managers and there were always opportunities for support.

Is the service effective?



Hospice services for children



Our rating of effective went down. We rated it as good.

Evidence-based care and treatment

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

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. The policies we reviewed referred to national guidance such as Together for Short Lives, NICE guidelines and the Royal College of Nursing guidance.

The service had strong connections with local and national specialist groups. The service were the founding members of the West Yorkshire hospice collaborative. This allowed sharing of best practice. Staff were proactively supported and encouraged to acquire new skills, use transferable skills and share best practice.

Managers ensured staff followed guidance through 1:1 appraisals and supervision. The service carried out regular audits. There was a clinical audit policy in place that stipulated engagement in all relevant local and national audits to drive quality forward. We saw evidence of audits completed between July and September 2023. Actions were clearly identified following audits.

The service provided evidence-based therapies such as eye movement desensitisation and reprocessing therapy (EMDR) to support with processing trauma memories, art therapy and music therapy.

Nutrition and hydration

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

Staff made sure babies, children, young people, families and those close to them had enough to eat and drink, including those with specialist nutrition and hydration needs. Families and carers told us that they were also catered for appropriately whilst visiting around mealtimes.

The service employed a dedicated housekeeping and catering team who ensured all dietary requirements were met. Staff told us that they would check the dietary needs of the children and families attending daily. They were able to provide options to meet any individual needs and preferences, for example, halal or pureed food. We also heard that the team would check dietary needs directly with families when there had been unplanned admissions or attendance.

Staff fully and accurately completed children's fluid and nutrition charts where needed. Staff recorded children's weights on a regular basis.

Staff would work with clinicians from other agencies providing specialist support such as dietitians and speech and language therapists as indicated.



Hospice services for children

Pain relief

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

Staff assessed children's pain using tools personalised to the individual depending upon the child's ability to communicate and gave pain relief in line with individual needs and best practice. Pain assessment was included in care plans for each individual. The care plans reflected how an individual would normally express pain. We saw examples of verbal and non-verbal assessment tools used including the facial assessment non-verbal tool, faces and symbols. We also heard about an individualised pain assessment tool that had been devised by one of the children attending with the support of staff. This was based on the characters of a well-known children's story series, Harry Potter whereby the character Voldemort was the worst pain and Gryffindor depicted being comfortable.

We observed staff were attentive to children and young people's needs and pain relief was managed in a timely way.

Staff prescribed, administered and recorded pain relief accurately. Anticipatory medicines were prescribed accordingly.

Patient outcomes

Staff monitored the effectiveness of care and treatment. They used the findings to make improvements and achieved good outcomes for patients.

The service carried out a range of appropriate audits and repeat audits. We saw audits completed by managers and staff including, for example, hand hygiene, record reviews, content and discussion of advanced care plans. Staff had recently been asked to take an increased role in completing audits to encourage better understanding and ownership. Families and external agencies had also completed audits such as environmental audits. We saw actions that had been taken to improve the environment.

The service had developed an outcomes framework to support consistency in the way that data was captured and used to evidence quality or demonstrate areas for improvement. The framework supported continual improvement in line with the services vision.

Outcomes for patients were positive, consistent and regularly exceeded expectations. We saw evidence of an annual family survey. We reviewed notes from a focus group. This group had been formed as part of service development work to support a new co-produced strategy. This demonstrated that patients had the opportunity to be consulted on experiences and staff had the opportunity to reflect upon care provided to families and consider improvements.

The service had recently introduced the use of recognised scores for anxiety and mood. These scores were completed at entry and exit into each tier of therapeutic support offered. At the time of inspection these scores were not collated and used as an outcome measure, however, staff told us that this was due to start.

We saw an outcomes star used for music therapy with children. This was used to rate certain characteristics such as emotional wellbeing and relating to others. We saw data for 2023 that evidenced the positive effect of music input on children's health.

Managers shared and made sure staff understood information from the audits. We reviewed care team minutes that demonstrated information was shared and staff were provided with opportunity to raise questions through meeting forums or separately with managers or identified individuals, for example, the pharmacist following a medication audit.



Hospice services for children

Competent staff

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

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of babies, children, young people and their families. The team was made up of nurses, midwife, advanced clinical practitioners, doctors, therapists, family support workers, sibling support worker, community engagement officer, bereavement support practitioners and counsellors.

Managers gave all new staff a full induction tailored to their role before they started work. There was an induction flow chart, managers guide and toolkit in place. New staff worked with managers to identify transferable skills from previous roles and gaps in skills. Skill gaps were included in an action plan completed during the induction.

Managers supported staff to develop through yearly, constructive appraisals of their work. We saw compliance was 100%.

Managers supported staff to develop through regular, constructive clinical supervision of their work. All care team staff had access to safeguarding supervision, managerial supervision and clinical supervision. The family support team also had access to external clinical supervision with a registered supervisor depending upon field of practice, for example with an external peer registered with the British Association for Counselling and Psychotherapy.

Medical staff with service level agreements did not receive direct supervision within the service, however, were due to start peer review sessions in 2024 to support their development in line with the service development.

A clinical educator supported the learning and development needs of staff. At the time of inspection, a new member of staff was due to start in this role. The responsibilities had been covered by another member of staff in the interim.

Staff told us they were able to access team meetings, caseload catch ups, peer supervision and case reflection.

Managers identified any training needs their staff had and gave them the time and opportunity to develop their skills and knowledge. Staff told us they were supported to attend additional training and were supported to identify and meet their own training needs. We heard all staff had recently completed Makaton training. The continuing development of staff skills was recognised as integral to ensuring high quality care.

Managers made sure staff received any specialist training for their role. There was an onsite training room for use to support staff training. For example, scenarios would be set up for staff to practice their responses. Additional external training would be sought as needed, for example, a health condition that staff were not familiar with.

We saw processes in place for managers to identify poor staff performance promptly and support staff to improve. For example, audits, incident reporting, supervision and 1:1 sessions.

Managers recruited, trained and supported volunteers to work within the service. All volunteers had five main competencies including safeguarding that they needed to achieve.

Multidisciplinary working

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



Hospice services for children

Staff held regular and effective multidisciplinary meetings to discuss patients and improve their care. Handovers were held at each shift change. In addition to handovers, there were multidisciplinary team (MDT) meetings, caseload review sessions, peer supervision and time for reflection on cases. We saw evidence that the MDT worked well together within the hospice to provide good holistic care. All staff we spoke to had a clear understanding of each other's roles and how they worked together to provide holistic care. The MDT were committed to working collaboratively together to support children, young people and families to be part of that team and to receive seamless care.

Staff worked across health care disciplines and were committed to working collaboratively with other agencies to ensure the best care for patients. The MDT included a range of professions and roles including a midwife, doctors, family support workers, community engagement officer, bereavement practitioners, music therapist and physiotherapists. There was also an arrangement in place with a local pharmacy service for support with medication management. One doctor worked in a unique and innovative role across the hospice and local hospital neonate service. We heard this allowed for very close collaboration between the services, improving hospice referral rates and quality of care for families.

We heard that staff worked well with other agencies. During the inspection we saw evidence of innovative multiagency working with a local hospital trust through observation of a meeting regarding best practise in caring for babies once they had died. We also heard from carers about positive multiagency working with specialist diabetes nurses and a children's hospital involved in a child's care. We spoke to a member of local authority staff who told us the service had been committed to joined up and multi-agency working throughout one child's care.

Staff were aware of mental health needs of children and their families and those close to them. Staff supported the mental wellbeing of children and families they worked with through the holistic services they provided. Staff had knowledge of local specialist support services and would support access to appropriate assessments or seek referral through the support of GP's as needed. However, there was no evidence of a direct link to specialist services, for example, mental health crisis teams.

Housekeeping and estates staff had close working relationships with the care team and were kept updated daily about any unplanned or urgent admissions. This allowed for sensitivity when working in areas of the building and ensured the care team could continue to focus on providing good care.

Seven-day services

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

Care was provided by the care team 24 hours a day, seven days a week both in the hospice and in children's homes. There was an on-call facility for staff to access extra support out of hours. There was always one senior member of staff and one member of the care team available. The service made sure staff on call were able to reach the hospice within one hour of being called.

The family support team provided evening and weekend support tailored to the individual needs of the family. There were appropriate systems in place to support out of hours working to ensure people could access the support in a way and at a time that suited them.

Health promotion

Staff gave children, young people and their families practical support to help them live well.



Hospice services for children

Staff assessed all children and young people when admitted and provided support for any individual needs to live a healthier lifestyle. Staff also supported the families of children with life shortening conditions and bereaved parents to live healthy lifestyles, for example, walking groups, support with daily activities allowing relaxation and leisure time for family members. Staff were proactive in supporting individual family members to identify and achieve their own goals. Staff identified specific health promotion needs through the initial assessment process and would signpost to appropriate services or social prescribers locally. However, we did not see any evidence of health promotion leaflets readily available.

Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

Staff supported children, young people and their families to make informed decisions about their care and treatment. They used appropriate communication methods to gain children and families' consent. They knew how to support children, young people and their families who lacked capacity or were not able to make their own decisions. They used agreed personalised communication tools to prevent restricting liberty.

Staff understood how and when to assess whether a patient had the capacity to make decisions about their care. There was a consent policy in place that provided guidance.

Staff we spoke to were clear about the decision-making process and importance of gaining consent with children and young people. We heard decision making was managed by talking to all professionals involved, families, carers and children. The children and young people remained central to all decision making. Disagreements regarding care provision would be immediately addressed and continue to include the children and young people until an acceptable outcome for all was agreed.

Children and young people had all the information provided to them in a way that they could understand. If consent was not possible families were fully involved to ensure the young person's cultural and social needs and wishes were taken into account.

Staff clearly recorded consent in the patients' records. We saw consent forms had an option to be provided in different languages. There was a process in place for medication administration for those families and children who were less able to consent. For example, where children and families wished to administer their own medication, this was agreed through a standard process to determine the competency of each child or parent.

Staff understood Gillick Competence and supported children who wished to make decisions about their treatment. For example, we heard about a teenager who did not want a room camera on at nighttime. This had been discussed and agreed with a clear plan put in place.

Staff supported children and their families to complete advanced care plans. We saw evidence of review of advanced care plans when appropriate, for example transition between services or changing needs.

Is the service caring?



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



Hospice services for children

Compassionate care

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

During our inspection we saw that staff were discreet and responsive when caring for children and their families. We observed all staff across the organisation took time to interact with patients and those close to them in a respectful and considerate way. We heard that families were made to feel like they were the only family the staff were working with at any moment in time. One person we spoke to explained how they had nearly cancelled an appointment to access the service due to anxiety, however expressed how easy the first appointment had been stating 'I immediately felt like I'd known them ages'.

We spoke to families and carers who told us they had received excellent care from the service. One family expressed feeling 'absolutely over the moon' with the support they have been able to access. We consistently heard that all staff across the organisation treated children and their families well and with kindness. One person expressed gratitude that the chief executive officer was always able to give time to families. There was a strong visible person-centred culture. Relationships between families, children and carers who used the service were strong, caring, respectful and supportive.

Staff followed policy to keep patient care and treatment confidential. We saw evidence of records checks providing assurance that electronic records were viewed appropriately. We saw evidence in notes stating information could not be shared with some family members, for example, complex safeguard scenarios.

Staff understood and respected the individual needs of each baby, child and their family and showed understanding and a non-judgmental attitude when caring for or discussing individuals with mental health needs. We saw that all individuals were treated equally.

Staff understood and respected the personal, cultural, social and religious needs of patients and how they may relate to care needs. We heard that all staff across the service had an understanding of the needs of the local population. The service employed a member of the family support team specifically to work with and support staff working with South Asian and Eastern European families. There was a developed knowledge base that recognised the specific cultural, social and religious needs of this population group.

Emotional support

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

Staff gave children, families and those close to them help, emotional support and advice when they needed it. Staff across the organisation demonstrated a clear understanding of the changing needs of children, young people and their families including wider family and friends. Staff were clear that emotional needs would change and fluctuate over time. The service responded to this by ensuring the door was never closed for individuals to access the service. This meant that individuals could re-access support in a planned way at any time in the future. For example, staff recognised that a new pregnancy a number of years into the future may trigger worries and concerns from previous experiences.

During our inspection it was clear that the support offered was to the baby, child, young person and their family, wider family and friends. For example, we saw and heard positive examples of care that had been provided to fathers. We heard that staff understood the different experiences that different family members had and clearly saw each as an individual whilst also working with families as a whole unit. We heard about support that was offered for friends of children and young people in a sensitive and timely way. We heard examples where staff would go the extra mile. For



Hospice services for children

example, we heard about two children who were able to hold their birthday parties within the soft play area of the service. One eight-year-old had been unable to have a birthday party previously due to seizures. The safe environment of the hospice made this possible. We also heard about an annual memorial gathering within the cinema room for a group of teenagers to remember their friend.

We saw memory trees in the garden area and a memory wall inside the building for individuals to remember their loved ones. We saw some memory squares had been positioned at heights suitable for younger siblings.

Staff supported children and families who became distressed and helped them maintain their privacy and dignity. Staff we spoke to were able to explain how they would support individuals. We heard examples of the use of signage around the building, for example, if a baby had passed there were discreet but clear 'footprint' pictures on entrance to the building and on doors leading to the designated 'snowflake suite'. This ensured all staff were aware and allowed families to maintain their privacy and dignity. The snowflake suite also had a separate entrance that could be used privately. Funeral directors also had an additional separate entrance. Privacy and dignity were embedded in the team culture throughout all staff groups including management, administration, care staff, housekeeping, and estates.

Staff told us they undertook training on breaking bad news. During our inspection we heard staff consistently talk about children, young people and families with empathy.

Staff understood the emotional and social impact that a person's care, treatment or condition had on their wellbeing and on those close to them. We saw evidence of a range of therapies for children and families to express and explore emotions and cope better with the challenges they faced. We saw evidence of support groups for siblings, mothers, fathers, grandparents and friendship groups. We heard examples of families being supported to meet others in similar situations. This had been done discretely and with confidentiality maintained, however was done in a way that families were able to then build their own invaluable support networks to help manage the social and emotional impact of their experiences.

The service was a multi faith organisation with a commitment to discuss and plan children's care with religious and spiritual needs in mind. Chaplaincy support could be outsourced as needed. We heard that all staff would be accessing a new training module 'opening the spiritual gate' from January 2024 to support better understanding of spirituality and religion.

Understanding and involvement of patients and those close to them

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

Staff made sure patients and those close to them understood their care and treatment. We heard staff clearly articulate care plans and families we spoke to were clear about their involvement with the service and their options. Staff found innovative ways to support families. For example, we heard staff had supported young people to attend concerts. We heard one father had wanted to watch a football match with his son. This was made possible by staff within the hospice environment. The father had watched a match with his son dressed in a team outfit. Staff took time to understand the memories that families wished to make and considered ways to support memory making during pregnancy in case this was not possible afterwards.



Hospice services for children

Staff talked with patients, families and carers in a way they could understand, using communication aids where necessary. We saw examples of how staff communicated using communication aids and language that was mutually understood. We reviewed care records and saw clearly documented evidence of children's and families preferred method of communication and specific communication needs.

Patients and their families could give feedback on the service and their treatment and staff supported them to do this. Families told us that staff were approachable and that they were kept involved in their care. Children, families and friends were able to leave feedback on their care after each visit to the service. There was an electronic friends and family survey at the reception where visitors would also sign out.

Staff supported and empowered children and families to make advanced decisions about their care. We saw advanced care plans were reviewed and updated at appropriate times.

Staff supported patients to make informed decisions about their care. Staff explained to us that they would share all relevant information with families and support decision making. They would work with children and young people to help them understand decisions they needed to make and would support informed decision making for the whole family.

Patients gave positive feedback about the service. For example, 'the care Forget Me Not gave not just our son but, myself, his dad and his sisters meant so much. We made so many more memories in those final days.'

Is the service responsive?

Outstanding



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

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.

Managers planned and organised services so they met the changing needs of the local population. The service was available to all children with a life shortening condition, children requiring end of life care and families. The support services were available for families beyond death of the child. The service was clear there was never a closed door for families. There was clear recognition that families' needs would change over weeks, months and years and that families could re-access services at any time. The service recognised there was a high percentage of families from a South Asian and Eastern European background in the area. They worked closely with the local community to engage with these families and manage barriers to accessing services such as cultural beliefs.

The service worked flexibly to provide support within the hospice environment, the families own home and community locations to suit the family's needs. The service provided day and overnight respite.

Family support was not limited to those where children had been supported by the service. For example, there was a joint collaboration with the local police force enabling referral for families of children where sudden unexpected death in childhood (SUDIC) had occurred. This initiative had been led by the hospice in response to recognition of this being an unmet need locally.



Hospice services for children

The service also provided perinatal midwifery support. This work was led by the hospice in response to a recognition that babies health conditions can be identified much earlier on than at birth and that often life changing information is shared within a short appointment requiring life changing decisions to be made. Staff were proactive in working with the local hospital trusts to develop this service and be leaders nationally for this initiative. In reach work was done within the local hospital trusts' maternity departments to promote the role of the hospice where there was a known health condition with an unborn baby. Staff would work with families during the pregnancy offering support to manage difficult decision making and to deal with other people's responses. This was provided equally to all family members. Staff were experienced and skilled and recognised that family members would experience the same situation in many different ways and that support should be tailored to each individual within a holistic family approach.

The service offered support to families whose baby had died before, during or shortly after birth. This was offered through bereavement support or immediately through the use of the snowflake suite. This was a quiet apartment with separate access providing a comfortable space for families and loved ones to be able to say goodbye in their own time with as much or as little support as required. This facility was available up until the funeral.

We heard that the service was aware of a strong evidence base for occupational therapists to be able to provide support not only for equipment but for sensory and complex needs. The forward plan included bringing occupational therapy into the service's core business. The service recognised there was an evidence base for trauma informed support and used this to underpin their work with all children, carers, family members and friends. The service had made links with two local universities to support their use of best evidence and be at the forefront of developing further evidence base. One piece of work related to sudden death in children. The second piece of work was a perinatal literature review.

Facilities and premises were appropriate for the services being delivered. The hospice building was in a quiet accessible location with ample parking and enclosed garden areas. Priority parking was given to families and there were separate entrances depending on reason for visit. For example, for funeral directors or for those accessing the snowflake suite. All rooms were fully equipped with suitable hoist facilities and height adjustable beds or cots including in the snowflake room to allow for women after caesarean section.

There was a garden area with level access throughout and wheelchair accessible swings. There was a range of activities including musical instruments and spaces available within the garden.

There were soft play areas for smaller children and babies, sensory areas and spaces for older children and young people to use with family or friends. For example, a cinema room with an ice cream cart stocked with ice lollies.

The service had systems to care for children and young people in need of additional support, specialist intervention, and planning for transition to adult services. Staff told us there was a robust system in place to support young people to transition to adult services. We saw evidence of clear pathways and communications with all stakeholders.

Managers monitored and took action to minimise cancellations. Spaces were offered to others when there was a cancellation to make best use of resources.

Meeting people's individual needs

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



Hospice services for children

Staff supported children, young people and their families living with complex health care needs. The service was able to provide the necessary care to meet all of their needs. Each care record we reviewed demonstrated an overview of the individual needs and preferences of the young person and family members. We saw evidence of social needs, physical health needs, communication aids and adjustments. There was clear evidence of family involvement. For example, one care record included sibling support and music therapy.

We also saw white boards in bedrooms with personalized information such as likes and dislikes or preferred activities and timetables to guide staff at the point of care. We heard about one child who had been supported to attend school where health had allowed. We heard evidence from an external agency that this intervention had supported significant social and personal development.

We heard that staff would access specific training should there be a gap in skills to meet the individual needs of any one clinical presentation.

The service offered practical support as well as emotional support for families. The family support team told us about examples of practical support within a family home such as preparing meals allowing the family to have quality time together. We heard clearly that respite care would be provided as a themed event such as a cinema night for a young person rather than 'respite for parents'. This supported access to the service as the experience was made to be positive.

Staff worked with other services and providers to coordinate care. We heard one example of clearly coordinated care for a young child where health, social care and education services had been involved. Staff explained how they had been proactive in this care provision. We heard one example from an external agency where staff had gone above and beyond in supporting a transition of care. There had been difficulties in seeking suitable equipment which had been resolved by hospice staff to ensure the transition happened in a timely way.

Staff understood and met the information and communication needs of children and young people with a disability or sensory loss.

The service had information leaflets available in languages spoken by the children, young people, their families and local community. We saw the front entrance door had a poster with greetings in a range of languages.

Managers made sure staff, children, young people and their families could get help from interpreters or signers when needed. During our inspection we saw evidence of interpreter provision to meet the needs of an Arabic speaking family.

Children, young people and their families were given a choice of food and drink to meet their cultural and religious preferences. Daily menus were provided which included Halal options to cater for the religious needs of families who require them. We heard that housekeeping staff would review daily attendances and cater according to individual needs. Shopping was done by housekeeping staff to meet individual needs.

Staff had access to communication aids to help children, young people and their families become partners in their care and treatment.

Access and flow

Babies, children, young people and families could access the specialist palliative care and therapy services when they needed them and received the right care promptly.



Hospice services for children

The service did not have a waiting list. Babies, children and young people required prompt care and support. The service had a process for acute transfers from hospital and an urgent discharge pathway to meet the wishes of families with a baby or child nearing the end of life who did not wish to spend final hours in hospital. The service worked with local agencies and hospitals to promote the service to ensure timely referral and support could be received. We saw one example of a concern raised where appropriate pathways had not been followed causing additional distress, however, this had been thoroughly reviewed and additional education provided for staff regarding urgent transfer processes.

There was a fortnightly referral panel for family support and therapies. This involved the multidisciplinary team to ensure full consideration of all referrals. Any referrals that required earlier input, for example pregnancy support, would be reviewed more quickly. The family support team operated a tier system to support flow through the service.

Managers monitored cancellations and worked to offer vacant appointments, care and support to others to make best use of resources.

Staff did not accept end of life transfers to the hospice at night as this was not felt to be appropriate.

Staff supported patients when they were referred or transferred between services. For example, young people transitioning to adult services were supported. We heard examples of recent transition plans.

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 service included children, young people and their families in the investigation of their complaint.

Patients, relatives and carers knew how to complain or raise concerns. Families told us they felt comfortable to approach staff. Information on how to raise concerns was displayed in public areas and on information leaflets. We saw a recent introduction of an apple tree on a wall in a communal corridor. The tree had magnetic leaves for families and children to put on comments, concerns, changes they would like to see and positive feedback. There were also brief questions asking for feedback when people signed out using the electronic device at the main reception.

Complaints information gave details of external agencies that could also be approached if a complaint was not resolved by the service satisfactorily.

There was a complaints policy in place with complaints pathways available for staff to access and follow. There had been no complaints received by the service during the quarter July to September 2023. However, we saw evidence during this period of a concern raised by other agencies and through an internal incident form was investigated thoroughly. Follow up actions were identified.

We reviewed one complaint response. We saw evidence that a thorough investigation and review of care had been completed with actions taken. For example, staff had received additional training regarding duty of candour.

Is the service well-led?

Good



Our rating of well-led went down. We rated it as good.



Hospice services for children

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 patients and staff. They supported staff to develop their skills and take on more senior roles.

There was an established board of trustees in place. The trustees we spoke to were clear about their role in maintaining an oversight and seeking assurances of safe care provision and financial sustainability through attendance at committees and board meetings. The service had a senior leadership and management team. The roles were clearly understood across the leadership and management structure. There had been changes to the leadership and management team prior to our inspection and it was recognised by the team that they had further developmental work to undertake. We saw clear priorities for ensuring sustainable, compassionate, inclusive, and effective leadership. For example, a leadership development framework had been developed in 2022. This set out the expectations of leaders and a plan to develop a leadership programme throughout 2024. This work was being done in preparation for the launch of the 2025 vision and strategy in recognition of the current leaders being those who would take forward the new strategy and vision. We heard examples of how members of the senior leadership team had been able to progress through the organisation and had been supported to complete relevant training to ensure they had the skills and abilities to run the service. We also heard how staff within roles across the organisation were supported through initiatives such as apprenticeships and a scheme for advanced nurse practitioners in conjunction with the local university. The service were looking at how to expand their offer of apprenticeships and placements further through a more structured, long term partnership with the University and other local providers.

Staff and families we spoke to told us that the leadership team were visible and approachable within the organisation. We heard from clinical leaders about a recent change to ensure they based themselves within the main clinical team area to remove any perceived divide between the staff downstairs and the management upstairs. We heard from trustees about their work on a 'day in the life'. Trustees told us they would attend for a day to work alongside a member of the team to fully understand the roles of all staff.

All leaders and trustees we spoke to understood the challenges to the quality and sustainability of the service provision. The challenges to the organisation were clearly articulated as retaining a suitable workforce and financial pressures. The team told us there were plans to look at further work with a local university to provide opportunities for staff development that would in turn support staff retention and attract staff to the organisation. Leaders were also clear that to maintain a funding base a more diverse income would be needed. We heard about several projects that were aimed at protecting the future of the organisation for the benefit of the local community that it served. For example, participating in research, national events, sudden death in children work.

All senior leaders had a clear understanding of the values and strategy for the service and worked well together. Leaders understood the challenges to the sustainability of the service and the importance of maintaining a high-quality service.

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 vision and strategy were focused on sustainability of services and aligned to local plans within the wider health economy. Leaders and staff understood and knew how to apply them and monitor progress.

The service had a 'trailblazer' strategy in place that was due to come to an end in 2025. This was a five-year strategy. Leaders recognised that it had not always been possible to maintain focus on this strategy due to changes beyond their control. For example, the pandemic in 2020 forced changes to service provision and funding arrangements. However,



Hospice services for children

leaders and staff had maintained focus on delivering pioneering care to children and families throughout pregnancy, childhood and loss. Leaders recognised there had been a lot of change since the launch of the trailblazer strategy and there were new challenges ahead. We heard that work on re-setting the future was underway with the development of Thrive-25 that would be the vision for the coming ten years. We heard that national guidance and local information had been used to begin to create the foundations for this strategy. For example, learning from the most recent Hospice UK study along with reflections and learnings from the pandemic, families and their needs and how these are different from the creation of the trailblazer strategy ten years previously. An outline strategy had been developed that aligned to the local needs with the wider social and economic landscape very much in sight. We heard about a whole organisation event that was planned to take place following our inspection that was aimed at sharing the outline strategy and would be the starting point for involving staff, families and stakeholders in the further development of the future strategy. All staff we spoke to were aware of this plan.

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.

We heard about the 'Our people promise' that set out the services vision of delivering pioneering care to those who needed it and the promise made to staff to support them to achieve this delivery. This included working to attract and retain the best staff, ensuring staff were supported and felt valued, aided in their growth and development and that staff were always well enough informed to act as advocates for the organisation.

All staff we spoke to told us they felt valued and respected. All staff expressed how much they enjoyed working for the organisation. The staff survey results showed staff were proud to work at the organisation. Staff told us they felt well supported. We heard examples of how the wellbeing of staff was supported, for example, through resilience sessions, debrief sessions and regular one to one sessions with line managers. There was a wellbeing coordinator in place to offer extra support or advice to staff as needed. All staff and leaders we spoke to recognised that the work could impact each other in different ways. The service had won a local business award for the wellbeing package provided to staff.

During our inspection we heard and observed clearly the culture focussed on putting the needs of babies, children, young people, families and extended family or friends at the centre of everything they did. We saw that staff were skilled in meeting the complex needs of the child or young person whilst also understanding and meeting the needs of the family in a holistic way. The staff told us their aim was to co-produce life changing moments through giving families choice and being an advocate for children and families.

The recent staff survey had identified that staff felt they needed to be listened to more. We heard that this had been explored with staff. Issues around communications and sharing information had been identified. In response to this there had been some staff listening events and engagement between staff and trustees. Senior leaders recognised there was still work to do and whilst a speak up guardian was identified there was more work to do in formalising this process. The senior leadership team were committed to developing their emerging initiative to create a speak up culture within the organisation. We heard that this would include integrating a range of speak up channels across the whole organisation. We were told this would also include 'listen up' and 'follow up' principles. Staff told us they could approach senior leaders for support or advice and to speak openly. We heard that senior leaders would be visible and would work in a clinical role as part of the care team to support any additional needs.

The service recognised when staff had gone above and beyond. The service held quarterly all staff update events to celebrate success. These were held in a hybrid fashion for staff to attend in person or online and were recorded for those



Hospice services for children

unable to attend to access the content later. Staff away days were held offsite annually to celebrate success and provide wider strategic updates. The senior leadership team would send letters to staff to recognise outstanding work at the time. Staff celebration events were held offsite annually for all staff to attend. Long service was recognised at one, three, five and 10 years. The chief executive officer would ensure each staff member received a handwritten personalised card. Bi-weekly bulletins also shared successes.

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 service had a clear governance structure that placed children and families at the centre of everything they did. For example, we heard that every board meeting would be started with a family story to ensure the focus was always on the aims and purpose of the service. If a family felt able to attend this would be encouraged. The time would be spent hearing the story and reviewing what had worked well and what could be changed.

There was an integrated governance framework document available to all staff. This set out clear roles and responsibilities of all staff. This document clearly described reporting structures. The service had a number of committees including, clinical governance; human resources and governance; audit, finance and risk; trading. Trustees with relevant backgrounds chaired these committees. We reviewed meeting minutes and saw meetings were regular with detailed discussion of key topics and action points.

There were a number of senior managers in place with operational responsibilities. External agencies provided oversight of compliance regarding health and safety.

Staff told us about regular opportunities to meet formally. We reviewed minutes from a care team meeting that provided evidence of information sharing. There was a care team meeting action tracker link within the minutes. There were visual displays and noticeboards detailing learning points for staff.

Management of risk, issues and performance

Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact. They had plans to cope with unexpected events. Staff contributed to decision-making to help avoid financial pressures compromising the quality of care.

There was an incident reporting system in place. We heard that the service had identified this system could be improved. A review of systems used by peer hospices had been completed and a new electronic system had been identified to be implemented.

Senior leaders told us work had been recently completed to raise awareness of incident reporting. Following this there had been an increase in incident reporting which had allowed for better identification of trends or repeated incidents requiring improvement work. For example, an improved checking system had been put in place following awareness that drugs had been omitted on two occasions.



Hospice services for children

We reviewed the risk register and saw the risks reflected the ones we were told about. Controls and actions were clearly outlined with review dates and person responsible for the actions. There was a risk management policy in place. The service had a risk assessment tool which leaders fed into to manage risk safely. This detailed accountability of leaders to assess risk in their own areas and feed into the overall risk management process.

The service had plans to cope with unexpected events. We heard about an annual risk management exercise completed by senior management. For example, a scenario would be set around a potential serious incident. The senior leadership team worked together to manage the fictional scenario. This included reflection to identify any gaps in skills, knowledge, team working or policies. There was a business continuity plan in place.

The service had a clearly defined succession plan in place dated April 2023. This plan ensured continuity of roles and responsibilities should a member of the senior leadership team be absent from their role. The plan outlined defined qualifications and skills required for each post and identified actions and mitigations for each aspect of an individual's role.

Information Management

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 information systems were integrated and secure.

The service used secure systems and stored records according to guidance. We saw evidence of audit demonstrating records were accessed for the intended purposes only.

The service recognised that the incident reporting system could be improved. We heard that new systems had been considered and time had been taken to speak to similar services about experiences with other systems. However, we saw that data had been collected and analysed, for example, through the staff survey and through incident reporting.

Engagement

Leaders and staff actively and openly engaged with children, young people, families, 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 service engaged well with families and children to help develop and improve services. We heard about families who had or were accessing services being involved informally as experts to give ideas on improvements to services. We saw staff had been asked to seek teenager's views to identify specific needs they had that could be better met.

The service employed a community engagement officer that had supported the service over recent years to gain a greater understanding of the specific needs of the local community, for example, families with a South Asian and Eastern European background. The service recognised that more than fifty percent of the caseload was from a South Asian and Eastern European community. The service had won a Hospice UK award for the work carried out in engaging with diverse communities to build trust and dispel myths about hospice care. This was described as bold and innovative.

Trustees told us they were aware there was a gap in user experience on the board of trustees. They had previously approached families about being involved and were continuing to explore ways to bring the user views and perspectives to the board.



Hospice services for children

Leaders told us about recent changes they had made to engage better with staff groups. Leaders and trustees had seen through recent staff survey results that staff did not feel communication was as good as it could have been. Senior leaders told us they had started to spend more time within the clinical office bases to be available to staff more often and to support better engagement. We heard that a presentation regarding the future vision and strategy proposals had been shared with staff. To support engagement of staff there were planned drop-in sessions following this and a planned whole organisation away day to ensure staff were able to hear the information, think about it and then provide feedback and take ownership of the future direction as a whole organisation. We heard that trustees had recently implemented a regular 'speed date' session with staff. This allowed staff and trustees to meet, have 5-minute conversations about key aspects of their role or concerns and feedback to be taken to the wider board meeting.

During our inspection we saw evidence of strong engagement with local organisations. We heard the service had won a Hospice UK award for community engagement.

Leaders told us about their links with the local Integrated Care Board (ICB). The service was engaging with the ICB to focus on health inequalities and local needs. We saw evidence of discussion supporting referral to the most appropriate and accessible services through breaking down of historical referral patterns that weren't always supportive of local need. The service was planning to undertake a small scale consultation at a local education event aimed at reaching families of children with special educational needs or disabilities.

The service were the founding members of the West Yorkshire Hospice collaborative that was formed during the pandemic of 2020 to look at the challenges across the region such as funding, health inequalities and engagement. They were also represented on the starting well and dying well board specific to Kirklees Place Partnerships.

The hospice was involved in collaboration work with other local hospices, independent health organisations and local NHS trust to further develop their transformation work in line with local need.

During inspection we observed a meeting with maternity and mortuary representatives from a local hospital trust. Hospice staff had driven this initiative to determine ways to better work with local hospitals and maternity departments to promote support for families who experienced baby loss around the time of birth.

Hospice staff identified key stakeholders whom they engaged with regularly as neonate teams, other hospices, Macmillan Care services, Young Lives versus Cancer, other charitable organisations, hospital consultants and other health professionals.

Staff told us that the hospice had also recently been on a number of South Asian radio stations talking about hospice care. An Asian television channel had also recorded a two hour show from the hospice garden and were due back to carry out more filming in conjunction with the hospice.

The hospice also had close links with funeral directors including those specialising in working with the South Asian community locally.

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.



Hospice services for children

Leaders were committed to encouraging improvement work and were keen to develop experts in areas of clinical practice to take forward different strands of improvement work. We heard that staff would be asked a set of questions each month about things they wanted to learn more about or changes they wanted to implement.

During our inspection we saw and heard about innovative practices. We were told the service was the first known hospice in the United Kingdom and Europe to have a midwife in post. We heard this role had developed over recent years and had become recognised within the local community and stakeholder organisations. This role enabled valuable specialist support to be provided to families from 16 weeks gestation that was not available through statutory services.

The service had been responsive to understanding the need for trauma informed care and how experiences were different for families experiencing sudden unexpected death in children. The service was involved in ongoing improvement work to support these families. We heard about collaboration work with the local police force and saw details of a recent training programme that the hospice had been involved in developing and facilitating. The service had won a national award at the national Charity Awards 2022 for their pioneering work in this area.

Where possible staff were supported to attend train the trainer courses to support in house training.

We heard that staff had been supported to continue research through further education such as Masters courses, PhD courses, speaking at conferences and joint work with a local university in the completion of a literature review on perinatal services.

The service had also co-authored an article regarding baby milk donation and were involved in further research on this topic.

The service also had links with a local university to support research around their SUDIC provision.

The service had contributed to the child death mortality report.

We heard staff had learnt from fathers who had attended and used the service for support. There was a strong emphasis on recognising the experiences of fathers and improving services to ensure all family members were included.