

Milton Children's Hospice

Quality Report

Church Lane
Milton
Cambridge
CB24 6AB
Tel: 01223 815100
Website: www.each.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		Outstanding	☆
Are services safe?		Good	●
Are services effective?		Good	●
Are services caring?		Outstanding	☆
Are services responsive?		Good	●
Are services well-led?		Outstanding	☆

Overall summary

Milton Children's Hospice is operated by East Anglia's Children's Hospices (EACH). The service has six single patient rooms and one single bedroom suitable for a baby. Facilities include therapy rooms, a hydrotherapy pool and an education centre. There are facilities on site for families to stay and there are a number of offices, a library and meeting rooms.

The service provides a range of physical, emotional, social and spiritual support services including end of life care, symptom management, short breaks, psychological

and family therapy interventions. It also provides children, young people and their families with support for emotional, physical health and wellbeing through counselling, music therapy, art therapy, specialist play, hydrotherapy, physiotherapy, occupational therapy, practical help in the family home through the 'Help at Home service', spiritual care and family information.

Summary of findings

The provider, EACH, runs three hospices in East Anglia. The three hospices work very closely together, sharing knowledge and expertise as well as sharing therapy and nursing teams to meet service demand.

We inspected this service using our comprehensive inspection methodology. We carried out the short-notice announced inspection on 9 January 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.

Services we rate

Our rating of this service stayed the same. We rated it as **Outstanding** overall.

We found outstanding practice in relation to hospice care for children and young people:

- Staff repeatedly went the extra mile in their care and were committed to find ways to make a difference to children and their families. Staff went above and beyond expectations to establish and meet patient's individual needs and were passionate about the care they delivered. Staff were highly motivated to offer care that was kind and promoted dignity. Staff recognised the totality of people's needs and supported the emotional needs of children and their families and children and their families emotional and social needs were seen as being as important as their physical needs. Relatives felt truly cared for and that they mattered.
- Leaders promoted a positive culture where challenge was welcomed. Every member of staff we spoke with told us they were proud to work for the service and that the leadership team were accessible, approachable and actively sought their input. The service had formed effective working relationships with other care providers, local faith leaders, community organisations and charities providing national guidance. The service had taken a leadership

role in the local healthcare environment to meet the needs of the local population through the development of the managed clinical network and hosting the regional palliative care network. This ensured that the service had strong links with external stakeholders and influenced decision making in the sector.

We found areas of good practice in relation to hospice care for children and young people:

- The service had enough staff to care for patients and keep them safe. Staff had training in key skills, understood how to protect patients from abuse, and managed safety well. The service controlled infection risk well. Staff assessed risks to patients, acted on them and kept good care records. They managed medicines well. The service managed safety incidents well and learned lessons from them.
- Staff provided evidence-based care and treatment, gave patients enough to eat and drink, 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 patients, supported them to make decisions about their care, and had access to good information.
- Children's individual needs and preferences were central to the delivery of tailored services. The service had developed a truly holistic assessment model which placed children and their families at the centre of care planning. Children and their families were asked what they wanted to achieve while being under EACH's care and staff were passionate about ensuring these goals were achieved and that children and their families were engaged with the care planning process. The service planned and provided care based on patient and family needs and had found innovative ways to improve access for non-emergency admissions. The service strived to ensure they were inclusive and welcoming to patients and their families from all faiths. The service had developed innovative teams to assist patients in need such as the symptom control team and the long-term ventilator community outreach service.

Heidi Smoult

Deputy Chief Inspector of Hospitals

Summary of findings

Our judgements about each of the main services

Service

Hospice services for children

Rating

Outstanding



Summary of each main service

Milton Children's Hospice is operated by East Anglia's Children's Hospices (EACH). Hospice services for children was offered at Milton Children's hospice. We rated the service as outstanding overall. The service was rated outstanding in caring and well-led, and good in safe, responsive and effective.

Summary of findings

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Outstanding



Milton Children's Hospice

Services we looked at

Hospice services for children.

Summary of this inspection

Background to Milton Children's Hospice

Milton Children's Hospice is operated by East Anglia's Children's Hospices (EACH). It is one of three hospices operated by EACH, one in Ipswich and one in Norfolk. EACH provides support for children and young people with life-limiting or life-threatening conditions, and their families and carers, across the counties of Cambridgeshire, Norfolk, Suffolk and Essex.

Milton Children's Hospice building is an old rectory set on the outskirts of the village of Milton. The original house has been converted and extended a number of times over the years. The hospice building offers six single bedrooms all of which have direct access to bathroom facilities. There is also a single bedroom suitable for a baby. There are shared areas for relaxation, play and

meals as well as therapy rooms, a hydrotherapy pool and an education centre. There are facilities on site for families to stay and there are a number of offices, a library and meeting rooms.

The service provides a range of physical, emotional, social and spiritual support services including end of life care, symptom management, short breaks, psychological and family therapy interventions. It also provides children, young people and their families with support for emotional, physical health and wellbeing through counselling, music therapy, art therapy, specialist play, hydrotherapy, physiotherapy, occupational therapy, practical help in the family home through the 'Help at Home service', spiritual care and family information.

The hospice has had a registered manager in post since January 2018.

Our inspection team

The team that inspected the service comprised a CQC lead inspector, two other CQC inspectors, and a specialist advisor with expertise in children and young people's palliative care. The inspection team was overseen by Fiona Allinson, Head of Hospital Inspection.

Information about Milton Children's Hospice

The service is registered to provide the following regulated activities:

- Treatment of disease, disorder and injury.

During the inspection, we visited the hospice and its facilities, including the care floor, bedrooms, clinic and therapy rooms, and outdoor facilities. We spoke with 18 members of staff, including registered nurses, therapists, support staff, senior managers, the librarian and trustees. During our inspection we spoke with two patients and relatives and reviewed three sets of patient records and medication administration 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 service has been inspected four times, and the most recent inspection took place in February 2016 which found that the service was meeting all standards of quality and safety it was inspected against.

Activity from October 2018 to September 2019: the hospice provided care to 136 patients under the age of 18.

Track record on safety

In the reporting period from October 2018 to September 2019:

- The service reported no never events.
- The service reported no serious incidents.

Summary of this inspection

- The service reported no incidences of healthcare associated MRSA.
- The service reported no incidences of healthcare associated Clostridium difficile (C. diff).

Track record on complaints

In the reporting period from October 2018 to September 2019:

- The service reported one complaint.

- The service reported 38 compliments.

Services provided at the hospice under service level agreement:

- Maintenance of medical equipment
- Pharmacy
- Safeguarding professional advice
- Infection prevention and control specialist advice.

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:

Good



- The service provided mandatory training in key skills to all staff and made sure everyone completed it.
- Staff understood how to protect patients from abuse and the service worked well with other agencies to do so.
- 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.
- The design, maintenance and use of facilities, premises and equipment kept people safe. Staff were trained to use them.
- Staff completed and updated risk assessments for each patient and removed or minimised risks.
- The service had enough nursing and support staff with the right qualifications, skills, training and experience to keep patients 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.
- Staff kept detailed records of patients' care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.
- The service used systems and processes to safely administer, record and store medicines.
- The service managed patient safety incidents well. Staff recognised incidents and near misses and reported them appropriately. 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. Managers ensured that actions from patient safety alerts were implemented and monitored.

However:

- The service had low safeguarding training rates. The service had until April 2020 to meet their training targets and told us that extra study days had been put on to ensure staff would be trained by the target date.
- The service had not had an infection control audit completed as part of their service level contract with a local trust since 2017.

Summary of this inspection

Are services effective?

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

- The service provided care and treatment based on national guidance and best practice. Managers checked to make sure staff followed guidance.
- Staff gave patients enough food and drink to meet their needs. 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.
- Nurses and other healthcare professionals worked together as a team to benefit patients. They supported each other to provide good care.
- Staff supported children, young people and their families to make informed decisions about their care and treatment. They knew how to support children, young people and their families who lacked capacity to make their own decisions.

Good



Are services caring?

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

- Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and went above and beyond expectations to meet their individual needs and wishes. Children, young people and their families were truly respected and valued as individuals. Staff were passionate about delivering care and strived to build supportive and trusting relationships with patients and their families.
- The service provided targeted emotional support to children and their families through their extensive wellbeing team consisting of counsellors and therapists. Staff provided emotional support to children, young people and their families to minimise their distress. They understood children and young people's personal, cultural and religious needs. People's emotional and social needs were seen as being as important as their physical needs.

Outstanding



Summary of this inspection

- Staff supported and involved children, young people and their families to be partners in their care. Staff ensured that they understood their condition and made decisions about their care and treatment. They ensured a family centred approach.

Are services responsive?

Our rating of responsive went down. We rated it as Good because:

- Children's individual needs and preferences were central to the delivery of services and managers planned and organised services so they met the changing needs of the local population.
- Facilities and premises were innovative and met the needs of a range of children who used the service.
- 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.
- The service was accessible and promoted equality. The service championed holistic and individualised care for all patients, particularly those who were receiving end of life care.
- People could access the service when they needed it and received the right care promptly.
- 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.

However:

- The service had a number of cancellations for planned short breaks. Between October and December 2019 there were four instances of short-break cancellations by the service. The service were in the process of a service-redesign to reduce short-break cancellations.

Good



Are services well-led?

Our rating of well-led improved. We rated it as **Outstanding** because:

- We saw that there was compassionate, effective and inclusive leadership at all levels. Leaders within the service demonstrated the high levels of experience, capacity and capability needed to deliver excellent and sustainable care. There was an embedded system of leadership development and succession planning.

Outstanding



Summary of this inspection

- The service had a clear vision for what it wanted to achieve and a detailed 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 and national plans within the wider health economy.
- Staff felt respected, supported and valued. They were focused on the needs of children, young people and their families receiving care. The service promoted equality and diversity in daily work and provided opportunities for career development. The service had an open culture where children, young people and their families and staff could raise concerns without fear. Leaders had a shared purpose, strived to deliver and motivated staff to succeed.
- There were high levels of satisfaction across all staff groups and staff repeatedly told us that they were proud to work for the service. Staff we spoke with shared a common focus on improving the quality and sustainability of care and people's experiences.
- 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 good systems to identify risks, plan to eliminate or reduce them, and cope with both the expected and unexpected.
- The service collected reliable, detailed data and analysed it to drive forward improvements. 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. Data or notifications were consistently submitted to external organisations as required.
- There was consistently high levels of constructive engagement with staff and people who used services, including equality groups. Rigorous and constructive challenge from service users, their family and staff was welcomed. The service took a leadership role in its local health system to identify and proactively address challenges and to meet the needs of the local population.
- All staff were committed to continually learning and improving services. Staff actively shared learning throughout teams. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation and participation in research.

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	 Outstanding	Good	 Outstanding	 Outstanding
Overall	Good	Good	 Outstanding	Good	 Outstanding	 Outstanding



Hospice services for children

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

Are hospice services for children safe?

Good



Our rating of good 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.

Nursing staff received and kept up-to-date with their mandatory training. The mandatory training was comprehensive and met the needs of children, young people and staff. The mandatory training included infection prevention and control, data security and protection, fire safety, moving and handling, oxygen management, safeguarding children level 3, resuscitation/anaphylaxis, and food hygiene.

The service's training programme ran from April until the end of March each year. The service set a target of 90% for the completion of all mandatory training modules, the services overall compliance rate across the modules was 87% as of January 2020. The service met the 90% target for four out of the eight topics which were: Food hygiene, data protection, oxygen management and fire training.

However, the target of 90% was not yet met for safeguarding children level three (68% overall compliance rate), infection control (71% compliance rate), Resus/Anaphylaxis (85% compliance rate) and moving and handling children (85% compliance rate). Leaders within the service told us that staff were on target to meet the 90% compliance rate by March 2020 and this was being achieved by providing more training sessions.

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

Managers monitored mandatory training and alerted staff when they needed to update their training. The services mandatory training compliance levels were reported in the service's clinical governance meetings. Staff received email reminders from the education department when their mandatory training was due.

Safeguarding

Staff understood how to protect patients from abuse and the service worked well with other agencies to do so. Staff knew how to recognise and report abuse. However, not all staff had completed mandatory safeguarding training.

There were clear safeguarding processes and procedures in place for safeguarding vulnerable adults and children. The service's safeguarding children and young people policy, dated March 2019 set out responsibilities of staff and contact details of local authority referral. The policy also covered child sexual exploitation (CSE) and female genital mutilation (FGM).

Nursing staff received training specific for their role on how to recognise and report abuse, however not all staff were currently up to date with their training. Staff received safeguarding training appropriate to their role in line with the intercollegiate document for children and young people (2019) and adult Safeguarding (2018): Roles and Competencies for Health Care Staff.



Hospice services for children

The service set a target of 90% for completion of safeguarding training. At the time of our inspection the data submitted showed the compliance across each role was as follows:

Nursing staff:

- Safeguarding children level 3: 60% (9 out of 15 staff)
- Preventing radicalisation training level 3: 53% (8 out of 15 staff)
- Adult safeguarding level 2: 6.5% (1 out of 15 staff)

Care assistant staff:

- Safeguarding children level 3: 75% (6 out of 8 staff)
- Preventing radicalisation training level 3: 75% (6 out of 8 staff)
- Adult safeguarding level 2: 12.5% (1 out of 8 staff)

Other staff (which included therapy staff):

- Safeguarding children level 3: 75% (6 out of 8 staff)
- Preventing radicalisation training level 3: 75% (6 out of 8 staff)
- Adult safeguarding level 2: 37.5% (3 out of 8 staff)

Volunteers:

- 82% (14 out of 18 volunteers)

Service leaders provided evidence that staff who had been unable to attend safeguarding training had been booked onto courses at the organisation's other sites in February and March 2020 to ensure all staff were fully compliant by the service's end of March 2020 deadline.

The service had introduced an e-learning adult safeguarding training package for staff in January 2020. Senior leaders told us that they have given staff three months to complete this training by the end of March 2020 deadline.

Staff could give examples of how to protect 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. We saw that safeguarding concerns were discussed, and reporting was encouraged in the service's local multidisciplinary team meetings.

Staff told us that they attended two safeguarding supervision sessions per year where feedback was provided on safeguarding referrals submitted by the service.

The service had a service level agreement with a local community NHS trust to provide professional safeguarding advice and training.

Staff knew how to make a safeguarding referral and who to inform if they had concerns. Staff told that they would speak to their line manager and the service's safeguarding lead if they had safeguarding concerns. The service's safeguarding lead was trained to level 3 in safeguarding children which was the same level as all clinical staff.

Cleanliness, infection control and hygiene

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

All areas in the hospice were clean and had suitable furnishings which were clean and well maintained, including the bedrooms, treatment area, playrooms and bathrooms. However, some of the service's bedrooms had carpet which are harder to keep clean than hard flooring. We saw that the service had a cleaning schedule for the carpets and a programme in place to replace them.

Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. We

saw that each area had a completed daily, weekly and monthly cleaning schedule. Cleaning

schedules included soft furnishings, doors, windows, blinds, hard surfaces, toys and equipment.

Staff cleaned equipment after patient contact and labelled equipment to show when it was last cleaned. Staff used 'I am clean' stickers to indicate that equipment and rooms had been cleaned. Staff told us that they tried to clean toys after every patient contact in addition to having a cleaning schedule for all toys.

The service had no incidences of healthcare acquired infections in the last 12 months. The hospice had a local infection control lead, as well as an infection control specialist adviser, which was provided under a service level agreement (SLA) with a local NHS trust. We saw



Hospice services for children

under this agreement; the service undertook infection control audits of the service. We reviewed the results of an audit from 2017 and saw the service performed well for cleanliness and actions were put in place to address areas of non-compliance. We were however concerned that no repeat audit had been completed since 2017.

We reviewed the results of the services latest hand hygiene audits from November to December 2019 in which the service performed well. All staff were seen to wash their hands when necessary in accordance with the World Health Organisation (WHO) Five Moments for Hand Hygiene guidance.

Staff followed infection control principles including the use of personal protective equipment (PPE). We saw staff followed hand hygiene best practices, such as remaining 'bare below the elbow' and washing hands after each episode of patient care.

Environment and equipment

The service had suitable facilities to meet the needs of children and young people's families. The service had considered the age range and cognitive abilities of children and young people being cared for in the hospice when designing the environment and facilities. The service had a separate room for teenagers with access to state-of-the-art gaming technology and had a large sensory room with a range of equipment to suit different cognitive abilities.

The service ensured children staying overnight were kept safe. The service used 'safe-space' cots and beds that lowered to the floor so that children who were at risk of falls during the night were protected.

The service had enough suitable equipment to help them to safely care for children and young people. Each inpatient bedroom was equipped with suitable equipment and had access to a bathroom. There was suitable hoisting equipment available for children and young people who required assistance to transfer throughout the building including in the pool areas, bedrooms, bathrooms, therapy rooms and the "teenagers den". The service had adaptable baths and shower rooms to ensure that children and their families could wash with ease.

Staff carried out daily safety checks of specialist equipment. During our inspection we checked

resuscitation equipment and saw this was checked in line with policy. Emergency grab bags were easily accessible, and all consumable items contained in them were in date.

There were processes in place to ensure that equipment was maintained and serviced. We checked a number of pieces of electrical equipment and all had evidence of electrical safety testing and maintenance testing. We saw that the service kept an electronic database of equipment with servicing compliance details.

Staff disposed of clinical waste safely. The service had a waste segregation system in place and we found separate bins and bags in place throughout outpatient clinics. Staff disposed of waste appropriately and followed the policy that was in place. Sharps bins were correctly assembled, dated, labelled and not overfilled.

Staff stored control of substances hazardous to health (COSHH) materials appropriately in locked cupboards which ensured patients and the public could not access substance.

The design of the environment followed national guidance. The environment had been designed with patients and their families in mind. The art therapy room could be accessed without entering the care floor so that patients and their families could use the room discretely. The care floor had step free access and had been built to ensure easy access for wheelchair users.

Access to the hospice was via secure key card access, which restricted access to facilities, particularly overnight when there was limited reception staff.

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 children and young people at risk of deterioration.

Staff completed risk assessments for each patient on admission, and reviewed this regularly, including after any incident. There was effective risk assessment, action planning and reviews in place for children and young people. Staff completed risk assessments for each patient on admission and reviewed them regularly.



Hospice services for children

Comprehensive risk assessments were carried out for all patients and care plans were in place for each child or young person. Risk assessments included skin integrity, pressure ulcers and falls.

A holistic need assessment (HNA) was completed for each individual patient, and this was reviewed annually or if there was a significant change. All patients were reviewed by a multi-disciplinary team (MDT).

Staff could access patient's electronic records which were completed contemporaneously and allowed for alerts to be put in place for key safety issues for example if a patient had any allergies or safeguarding concerns.

Staff shared key information to keep patients safe when handing over their care to others, including between each shift. Shift changes and handovers included all necessary key information to keep patients safe. We attended the services daily stand up session where staff discussed their availability, key events and the planned care of each child or young person. This meeting was attended by all staff including nurses, therapy staff and clinical nurse specialists. Following the stand-up session there was a daily planning meeting attended by the multidisciplinary clinical team. This meeting discussed the children and young people's clinical care in detail and assigned actions to staff.

We saw that staff undertook a comprehensive and holistic review of the needs of children and young people during the daily planning meeting. Staff told us that this meeting could occur at the bedside if the child or young person or their relatives wanted to be involved with daily care planning.

Staff knew about and dealt with any specific risk issues. Staff identified and responded to changing risks to children and young people receiving end of life care by having members of the services symptom control team perform daily reviews. Children receiving end of life care received a review weekly by the services managed clinical network consultant.

Staff had access to 24-hour support if they had concerns over a child's care, including concerns over their mental health. Staff could receive medical advice out of hours through the organisations managed clinical network.

In the event of a transfer to hospital patients were accompanied by a member of staff in the ambulance until a family member was able to attend.

Nurse staffing

The service had enough nursing 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 and agency staff a full induction.

The service had enough nursing staff and support staff to keep children and young people safe. Staff told us that they felt they had enough time to spend with their patients and that staffing levels were safe. Managers organised staffing to ensure that end of life care was delivered as a priority. The staffing establishment was calculated to ensure there was a minimum of two nursing care staff per shift in the hospice building including a minimum of one registered nurse.

Managers accurately calculated and reviewed the number and grade of nurses, nursing assistants and healthcare assistants needed for each shift in accordance with national guidance. The service reviewed staffing levels and short break bookings daily at the service's stand up sessions prior to handover. Staff resource issues across the three hospice locations were considered weekly by the central panel meeting and the locality multi-professional meetings (LMPM) and tri-site meetings were arranged to organise cover for staffing across the locations when needed.

The service organised staffing to ensure that end of life care delivery was a priority. This meant that at times short breaks were postponed to ensure that end of life care patients received safe care.

When the hospice buildings were closed staff were allocated to a 'standby' rota in the event of urgently needing to open the building for end of life care. Nursing care staff were also allocated to an 'on-call' rota when there was end of life care needed in patient's homes.

The service had low and/or reducing vacancy rates. The service had a vacancy rate of 5.7 whole time equivalents (WTE) for registered nursing staff. The vacancies were managed by utilising the services pool of bank staff.



Hospice services for children

Service leaders told us that they had a rolling advert out to fill these roles on a number of different forums but they struggled to fill registered nursing vacancies due the location of the hospice. The hospice was in an area where housing was typically more expensive than other hospice sites and there were competing for staff with large hospital trusts nearby.

The service ensured that they would only operate when there were sufficient staff numbers to ensure patient safety. The service had two unplanned closures between October and December 2019 due to staff shortages/sickness. Leaders told us that they prioritised end of life care and would prevent closures of services where children or young people were receiving end of life care. Closures would be prevented from utilising staff from other hospice sites.

Managers limited their use of bank and agency staff and requested staff familiar with the service. The service had a small pool of bank staff which consisted of four registered nurses and one healthcare assistant. All bank staff were offered regular shifts equating to 7.5 hours a month to give them the opportunity to be familiar with the service and ensure their competencies were up-to-date. The service had not used any agency staff from October 2018 to September 2019.

Managers made sure all bank staff had a full induction and understood the service. There was an induction programme in place for all new bank staff. Managers told us bank staff that worked in the hospice worked regular shifts and were familiar with the processes and procedures.

The service had a sickness rate of 3.4% for registered nurses for the period July 2019 to September 2019.

Medical staffing

The service did not have any medical staff directly employed by the organisation. The service had access to general medical advice through a service level agreement with a local GP surgery.

Medical advice and support was provided out of hours through the services managed clinical network. The managed clinical network was hosted by EACH and provided access to specialist palliative care advice. The team consisted of children's palliative care trained consultant paediatricians and nurse consultants.

Records

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

Patient notes were comprehensive, and all staff could access them easily. We reviewed three sets of patient records and saw that patient records were clear, comprehensive and provided a detailed record of the child or young person's care. Records covered a patient's emotional, social, spiritual, physical health, mental health, learning disability, and behavioural needs. Records contained, where relevant, patient pain management plans, patient-specific information such as health passports, advance care plans, end of life plans, advance directives, and risk assessments.

Patient holistic need assessments (HNAs) were comprehensive, thorough, patient-centred and completed to a high standard. These included patient preferences, social and psychological needs of the family, as well as wider family goals and wishes. We saw the service reviewed all HNAs with each family, and reviewed the progress of any previously agreed goals annually or if there are any significant changes with the child or family.

Records were stored securely and when children and young people transferred to a new team, there were no delays in staff accessing their records. The service used an electronic records system that was used widely across primary care services in the region. The system allowed the patient's GP to see the hospice entries including clinical updates, symptom management and advance care plans if the GP service also used the same system. The service shared updates and records with other providers as appropriate through secure email or post where providers did not have access to the electronic records system.

Medicines

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

Staff followed systems and processes when safely, administering, recording and storing medicines. The service stored all medicine in a locked clinic room, which authorised staff had access to.



Hospice services for children

The service did not keep a large stock of medicines. The service only kept a stock of common home remedies, such as paracetamol. All patients would come with a supply of all their prescribed medicines. The service had appropriate facilities for storing patient's own supplies of medicines. We saw staff stored each child's medicines in separate, clearly labelled boxes, and secured these in a dedicated cupboard with access restricted to the nursing team.

Staff stored and managed medicines and prescribing documents in line with the provider's policy. We reviewed three patient medication administration records and saw that these were completed in line with the providers policy.

Staff followed current national practice to check patients had the correct medicines. Controlled drugs are prescription medicines that are controlled under the Misuse of Drugs legislation (and subsequent amendments). The service had a controlled drugs accountable officer and a service lead for the safe and secure handling of medicines. The service did not hold stocks of any controlled drugs, however had appropriate storage arrangements and records to safely store when a child attended the service with controlled drugs. We reviewed the storage of a patient's controlled drugs during our inspection and saw that these were stored and documented in line with legislation.

Registered nurses and healthcare assistants with additional training administered controlled drugs and had assessed competencies to do so. The services Matron and clinical nurse specialists were available to check doses and administration of controlled drugs.

Staff reviewed patients' medicines regularly and provided specific advice to patients and carers about their medicines. On admission staff completed a medicines reconciliation form for patients which was then checked by a second member of staff for accuracy and signed. The service had an arrangement with a local pharmacy to procure prescription medicines. Specialist pharmacist advice and support was sought from the local community NHS trust through a service level agreement (SLA).

Should the service need medicines prescribed the services Consultant nurse and Matron were non-medical prescribers. This meant that patients received the appropriate prescription without any delay.

Staff monitored the temperatures of treatment rooms and medicines fridges daily. We saw that any temperatures which exceeded policy were escalated to senior staff to rectify.

The service had systems to ensure staff knew about safety alerts and incidents, so patients received their medicines safely. There was a system in place to ensure that medicines alert or recalls were actioned appropriately. A medicines management group met regularly to discuss any medicines incidents which had been reported. These were reviewed and monitored, so that lessons could be learnt, and improvements made if necessary. All medicines information was circulated to staff via a newsletter 'Medicine Matters'.

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 and reported incidents clearly and in line with policy. Staff told us they reported incidents using the services electronic reporting system. The electronic system notified service managers who could proceed to investigate.

The service reported no never events or serious incidents from October 2018 to September 2019. A 'never event' is a serious patient safety incident that should not happen if healthcare providers follow national guidance on how to prevent them. Each never event reported type has the potential to cause serious patient harm or death but neither need have happened for an incident to be a never event. Staff we spoke with were aware of what incidents would constitute a never event or serious incident and how to report them should they occur.

Managers investigated incidents thoroughly. Children, young people and their families were involved in these



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investigations. Staff told us that they were encouraged to take part in incident investigations. Patients families were encouraged to be involved in the incident investigation process, where appropriate.

Staff understood the duty of candour. They were open and transparent, and gave children, young people and their families a full explanation if and when things went wrong. The service had a duty of candour policy dated August 2018. We reviewed the policy and saw that it was comprehensive, in date and referenced national guidelines and policy. Staff were aware of the policy and spoke about the importance of being open and honest when something went wrong.

Staff met to discuss the feedback and look at improvements to children and young people's care. We saw that incidents were discussed as an agenda item in the service's locality multi-professional meeting (LMPM). In this meeting we could see examples of actions and improvements taken following incidents including issuing a leaflet to parents to ensure medicines were correctly labelled prior to an admission.

There was evidence that changes had been made as a result of feedback. For example, staff told us of a change to the process for checking medicines in and out, because of a previous incident.

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

The service provided care and treatment based on national guidance and evidence-based practice. Managers checked to make sure staff followed guidance. Staff protected the rights of children and young people subject to the Mental Health Act 1983.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. The service had an extensive library. The

service's librarian reviewed best practice journals and shared relevant information on national guidance updates to clinical staff. The librarian ensured that all new and reviewed policies were in line with national guidance by reviewing articles, guidelines and book chapters. We reviewed several of the services policies and saw that they referenced national guidance, reflected best practice and were within their review date.

The services library and information service was used by other services nationally and had an extensive range of peer reviewed journals, relevant articles and books written on areas such as end of life care, grief and sibling support. The services librarian produced a monthly bulletin that was sent to all staff which focussed on specific topics and articles that staff would find helpful and to share best practice in the sector. These bulletins were shared with other services if they were members of the EACH library ensuring that best practice and learning was shared across the health sector. The service's library participated in Health Education England's NHS library benchmarking scheme. The provider's library scored 90% for 2019 when benchmarked against NHS libraries.

The service ensured it was following the Every Moment Matters guidance by the National Council for Palliative Care, published in March 2015 by ensuring that patients were supported to make advance care plans and directives. These ensured that children and young people received the care and treatment they wanted when they were no longer able to contribute.

The provider influenced national policy and legislation changes by proactively working with national charities who set standards and guidance for the sector. Staff within the service were frequently invited to speak at national events and advise other services on best practice.

The service was actively engaged in several research projects and had a comprehensive research programme and plan. The service had conducted a study on delivering long term ventilation (LTV) for children and young people in a hospice. The study was looking at the LTV practice standards and as a result developed and delivered a training model project.

The service had also conducted a study in buccal opioid use for pain and dyspnoea (difficult or laboured breathing) for children with palliative care needs during



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end of life care. The study was assessing the effectiveness, advantage and disadvantage of buccal opioid for breakthrough pain and dyspnoea in end of life care. Buccal administration involves placing a drug between the gums and cheek, where it dissolves and is absorbed into the blood stream.

At handover meetings, staff routinely referred to the psychological and emotional needs of children, young people and their families. Staff talked about ensuring the child's voice is heard during handover meetings and referenced their psychological as well as physiological needs. The service had holistic needs assessments and care plans in place that addressed the psychological and emotional needs of patients and their families.

Nutrition and hydration

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

Staff made sure children, young people and their families had enough to eat and drink, including those with specialist nutrition and hydration needs. Each child or young person had a comprehensive nutrition care plan in their electronic patient record. We saw that these were regularly reviewed. This covered all nutrition and hydration needs, including any allergies, preferences, method of eating and drinking, and desired quantities.

We saw that nutritional needs were discussed with children or young people and their families approaching the end of life in line with the National Institute for Health and Care Excellence Guidance, NG61.

The hospice worked with dieticians in the NHS when a child had been prescribed nutritional supplement plans.

The hospice had children and young people using their services who had different feeding devices. The service had standard operating procedures in place to ensure feed was delivered safely and the service ensured staff were competent in using different devices.

The services catering team prepared freshly made meals on-site and provided children and their families with hot

and cold food options. The patient's nutritional plans were shared with the catering team who catered for all types of dietary requirements including vegetarian, vegan, soft, gluten free and religious requirements.

Pain relief

Staff assessed and monitored 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 and young people's pain using a recognised tool and gave pain relief in line with individual needs and best practice. Staff used pain scores with children and young people to determine if they required pain relief. For children and young people with communication difficulties, staff supported them to communicate with communication aids.

We saw in the records we reviewed that each child or young person had a pain assessment and management plan in place. Additionally, the service ensured that the child and young person had access to non-medical pain relief including using hydrotherapy and physiotherapy techniques to alleviate pain.

The service managed the pain of children and young people who were approaching the end of their life by ensuring they were reviewed regularly by the service's symptom management team. The service's nurse consultant and the managed clinical networks consultant reviewed end of life care children and young people on a weekly basis, including those who wished to be cared for at home.

Children and young people received pain relief soon after requesting it. Relatives we spoke with told us that staff always responded quickly if a child or young person was in pain. We saw that administration was recorded in a timely manner on the medicines administration charts we reviewed.

Patients were required to attend the hospice with their own medicines as the service did not routinely stock a large range of medicines. The service did hold a supply of common pain relief medicines including paracetamol and ibuprofen.



Hospice services for children

If a child or young person required different medicine or their supply had run out, the service had developed a service level agreement with a local GP and an arrangement with a local pharmacy service to obtain medicines. The service had a service level agreement in place with a local trust to obtain specialist advice for medicines.

Patient outcomes

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

Managers and staff carried out a comprehensive programme of repeated audits to check improvement over time. Audits included documentation, medication management and hand hygiene. We saw that audit outcomes were reviewed by clinical staff and senior leaders and associated action plans were monitored and discussed at the quality and safety group meetings.

Managers and staff used the results to improve children and young people's outcomes. The service used patient and family reported outcome measures to improve services. During our inspection, we reviewed two internal audit reports, a controlled drugs procedures audit from May 2019 and a nutrition care plan audit from November 2019. We saw that each report showed the service performed well in these areas as well as identifying areas for improvement. The audits had detailed action plans which had actions assigned to named members of staff. Each audit contained a re-audit date for when the audit required repeating. The service reported the results of audits and progress with their associated action plans at the quality and safety group meetings.

The services therapy team set therapeutic goals for patients and reviewed these regularly.

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 clinical educators supported the learning and development needs of staff. The organisation had an educational lead and individual clinical educators for

each site. The service's clinical educators identified specific training needs the teams had and provided specialist training to support this. This included contacting the local trust's diabetes nurse to provide training as a new patient with an insulin pump was being treated within the service. Specialist study days had taken place for long-term-ventilation, female catheterisation and subcutaneous injections.

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of children, young people and their families.

Managers gave all new staff a full induction tailored to their role and their experience before they started work. Each new starters skills and experience were assessed in order to build an individualised induction programme. Care staff were supernumerary for the first four weeks of their role to allow them to observe staff and have their competencies signed off. All new staff were allocated a mentor and met with their supervisor bi-monthly to ensure they were supported in their new role.

Managers supported staff to develop through yearly, constructive appraisals of their work. The service provided data that showed that as of September 2019 100% of nursing staff, allied healthcare professionals, healthcare assistants and other non-qualified staff had received an appraisal in the previous 12 months.

Managers supported nursing staff to develop through regular, constructive clinical supervision of their work. All clinical staff had quarterly supervision meetings with their manager in addition to their annual appraisal.

Managers made sure staff attended team meetings or had access to full notes when they could not attend. The service held four annual away days for teams where information on complaints, incidents and bespoke training was provided.

Managers identified any training needs their staff had and gave them the time and opportunity to develop their skills and knowledge.

Staff had the opportunity to discuss training needs with their line manager and were supported to develop their skills and knowledge. Training needs were discussed as part of annual appraisals and quarterly supervision. One member of staff told us that the appraisal process had helped them transition into an educational role.



Hospice services for children

Managers made sure staff received any specialist training for their role. A member of staff told us how the service had supported them to enhance their skills and funded a foundation course on hydrotherapy. The service included a whole day of training on end of life care as part of mandatory training to ensure all staff were able to meet the end of life care needs of patients. This included training by local funeral directors and morticians to ensure that staff understood every part of a patient's end of life care.

Managers identified poor staff performance promptly and supported staff to improve. Staff told us that performance would be discussed as part of their supervision meetings and that if there were performance issues identified then staff would be supported with additional training and mentor support.

Managers recruited, trained and supported volunteers to support children, young people and their families in the service. Volunteers completed a two-day training and induction programme, which covered topics including safeguarding, information governance, manual handling, bereavement support and palliative care awareness, as well as a tour of the hospice's facilities. Managers supported all volunteers in their role and undertook a minimum of four supervised shifts with each volunteer, each year.

Multidisciplinary working

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.

Staff held regular and effective multidisciplinary (MDT) meetings to discuss children and young people and improve their care. The services staff were committed to working collaboratively and demonstrated a holistic approach to planning people's care during weekly MDT meetings. We saw that these meetings were well attended and had representation from nursing and therapy teams.

The service worked alongside the doctors in the managed clinical network who provided expert advice when required.

The service held multi-professional reflective practice groups where staff presented topics which were discussed by the group. The group allowed staff to view a topic from different multi-professional perspectives.

Staff worked across health care disciplines and with other agencies when required to care for children, young people and their families. Staff we spoke with told us they felt the service had a truly multidisciplinary approach and spoke about how they worked closely with different healthcare professionals including physiotherapists, occupational therapists, art therapists and nurses.

We saw the service had developed effective working relationships with other healthcare providers,

including local NHS acute trusts and community trusts, GP surgeries, social services and other hospices. Physiotherapists and occupational therapists told us how they work closely with NHS community therapists to ensure they were providing therapy that the community physiotherapists couldn't and that the therapy complimented that which was already received. The music therapists told us that they work with support networks in schools to determine how they can best support patients and their siblings.

The services lead arts therapist provided examples of close working with external agencies including working closely with a school's special educational needs co-ordinator to help a profoundly disabled child communicate through chiming. Staff told us about physiotherapists working with the long-term ventilation team to help children and young people have hydrotherapy sessions.

Seven-day services

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

Staff could call for support from doctors and other disciplines, 24 hours a day, seven days a week. The Provider's clinical management network provided out of hours advice and support. The hospice had developed a service level agreement with a local GP surgery to provide staff and families with specialist medical advice or reviews when necessary.



Hospice services for children

Service leaders planned service provision to meet the needs of patients. The service prioritised end of life care and ensured that a provision of 24 hours a day of care, seven days a week could be provided in the event of a child needing end of life care.

Symptom management advice was provided 24 hours a day, seven days a week, by the Symptom Management Nursing Service.

Staff had access to a safeguarding advice line, which was available 24 hours a day, seven days a week, should they require specialist safeguarding advice.

Health promotion

Staff assessed each child and young person's health when admitted. The service completed a holistic needs assessments (HNA) for every child and family referred. This looked at the patient's clinical condition in addition to the family's overall wellbeing. The service had more targeted wellbeing assessments for families and children who raised concerns around wellbeing as part of their HNA. Referrals to appropriate therapies were discussed at the services locality multi-professional meeting (LMPM) and systemic meeting.

The service had relevant information promoting healthy lifestyles and support. The service offered a range of support to meet the wellbeing needs of patients and families. Emotional and wellbeing support included social opportunities for families to come together and meet others, for example at sibling activity days, coffee mornings and male/female carers nights. The service provided patients and their families goal-based therapy support through counsellors, music therapists, art therapists, play specialists and spiritual care advisors.

There were health promotion materials displayed throughout the hospice which signposted children or young people and their families to support services and charities.

Consent and Mental Capacity Act

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

Staff understood how and when to assess whether a child or young person had the capacity to make decisions about their care. Staff we spoke with understood the importance of consent when delivering care and treatment to children and young people. We observed staff seeking consent from children and young people prior to examination, observations and delivery of care.

Staff understood how and when to assess whether a child or young person had the capacity to make decisions about their care. When children, young people or their families could not give consent, staff made decisions in their best interest, taking into account their wishes, culture and traditions. Nurses we spoke with understood 'Gillick competence' (a term used in medical law to decide whether a child under 16 years is able to consent to their own medical treatment, without the need for parental permission or knowledge).

Staff clearly recorded consent in the children and young people's records. We saw consent was documented in patient records for medical interventions.

Mental Capacity Act and Deprivation of Liberty training completion

Staff received and kept up to date with training in the Mental Capacity Act and Deprivation of Liberty Safeguards. Staff received Mental Capacity Act and Deprivation of Liberty Safeguards training. As part of the mandatory training staff completed modules on mental health, consent, safeguarding, best interests' decisions and deprivation of liberty. Care and nursing staff completing level three face-to-face training and senior managers completed level four training on the Mental Capacity Act and Deprivation of Liberty Safeguards. All other staff who had contact with children or young people and their families completed level two face-to-face training.

The service had educational resources to support them with their decision making for deprivation of liberty safeguards. There was an eLearning module and policies and procedures for staff to follow should either a standard or urgent authorisation need to be made.

There were no occasions in the past year where an application had been made to deprive a young person of their liberty.



Hospice services for children

Are hospice services for children caring?

Outstanding



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

Compassionate care

Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and went above and beyond expectations to meet their individual needs and wishes. Children, young people and their families were truly respected and valued as individuals. Staff were passionate about delivering care and strived to build supportive and trusting relationships with patients and their families.

Feedback from people who used the service, those close to them and stakeholders was positive. Relatives told us that staff went the extra mile and that the care provided exceeded their expectations. We spoke with one relative on the day of our inspection who told us that they could not believe all the effort staff had gone to for them and that they had felt like part of the EACH family from day one.

On the day of our inspection we saw staff going the extra mile by making arrangements for a vow renewal ceremony for the relatives of one of the children at the hospice. Relatives of the child told us that they had wanted to renew their vows as the child hadn't been at their wedding and felt they were missing from the pictures. Staff within the service had sourced volunteer professionals from local businesses to ensure the family's day was special. This included sourcing local florists, a photographer, hairdresser and Celebrant. Staff had decorated the care floor with flowers, electric candles, bunting and chair covers. The service's kitchen staff had made and decorated a cake for the occasion. The child wanted the renewal to be star themed, so staff had found different ways to incorporate stars within the decorations including decorating the child's wheelchair with stars and lining the aisle with stars.

Staff were highly motivated to offer care that was kind and promoted people's dignity. We saw that staff consistently put the patient and their family's needs at

the forefront of care. Staff were discussing the vow renewal during the daily handover and were keen to ensure that support was provided to the family following the renewal. Staff were aware that the family had been excited for the service and wanted to ensure additional support was put in place the days after the service in case the family experienced a come down of emotions. We observed staff discuss different members of the family and how best to support them as individuals following the renewal.

Other examples of staff going the extra mile included organising a magic circle magician to perform for a child at the end of their life, Walt Disney to send a representative with an advance copy of the new Mary Poppins film so a child could view it before they died and two young people to go ice skating in their wheelchairs for the first time. The service organised an annual festival called EACH Fest where they had musicians perform, silent discos and entertainers.

The service offered a 'help at home' volunteer service, where families could receive help and support with a variety of tasks, including everyday household chores like shopping, cleaning, gardening, decorating or help to move home.

Relationships between people who used the service, those close to them and staff were strong, caring, respectful and supportive. One relative told us that staff were fantastic, had made them and their family feel so welcome and that they had felt comfortable living in the hospice for an extended period of time while their child was being cared for. Staff were visibly excited and compassionate when discussing ways they try to meet individual needs of children and young people and ensured that they enjoyed their interactions with the service.

Leaders within the service promoted strong, respectful and caring relationships between staff and patients and their families. Staff told us that they were encouraged to get to know patients and their families as individuals and we saw that staff were praised for building supportive and trusting relationships with children and their families. We observed that staff were praised through exceptional reporting in the service's locality multi-professional meetings (LMPM) for getting patients and their families to open up about their needs so that appropriate care plans and therapy input could be put in place.



Hospice services for children

Staff recognised and respected the totality of people's needs. Staff tried to ensure they offered person-centred care and support to patients and their families. We saw that discussions on different ways of helping families were encouraged in the services locality multi-professional meetings. For example, staff suggested offering overnight accommodation at the service to a family whose child was being treated at a nearby trust. The family did not live close to the trust so would benefit from having somewhere to stay locally.

Children and their families emotional and social needs were seen as being as important as their physical needs. Staff completed holistic needs assessments (HNA's) for every child and their family which detailed the social needs and emotional impact the child's condition was having on the family. Staff within the service were passionate about ensuring that children and their families social and emotional needs were met and were given the time to discuss these at length to find solutions with the multidisciplinary team at the service's LMPM and systemic meetings.

Staff were discreet and responsive when caring for children, young people and their families. Staff took time to interact with children, young people and their families in a respectful and considerate way. Staff were compassionate when discussing children in their care and spoke highly of all children in their care. All interactions we observed between staff and patients and their families were respectful and demonstrated kindness and compassion. Staff had built a strong rapport with patients and their relatives. One relative we spoke with told us they were overwhelmed by the care and love shown to their family by staff.

Children and young people who had died at the service or who died in the community or local neonatal unit would continue to be cared for with dignity and respect whilst awaiting funeral arrangements. Families could spend time with their loved ones after they had died in a private space and the service accommodated families who wished to have their child stay at the hospice until their funeral by using specialist cooling equipment.

Emotional support

The service provided targeted emotional support to children and their families through their extensive wellbeing team consisting of counsellors and

therapists. Staff provided emotional support to children, young people and their families to minimise their distress. They understood children and young people's personal, cultural and religious needs. People's emotional and social needs were seen as being as important as their physical needs.

The service was truly holistic. Staff ensured they supported the patient and their family as a whole at every available opportunity. Children and their family's individual needs and preferences were always reflected in how care was delivered. The services holistic needs assessment (HNA) included sections on the psychological wellbeing of the family and spiritual needs. We viewed completed HNAs and saw that this section was detailed and looked at the children and young person, their siblings, parents and wider family members and discussed their emotional needs.

The service had created a "six-step assessment psychological assessment" to assess the psychological needs of families and to determine input from the services wellbeing team. The assessments were discussed at weekly "systemic" meetings where the therapy team would discuss their needs and allocate therapy support. The service offered a range of therapy support to children and their families including counselling, group sessions, art therapy, play specialists, bereavement support and music therapy.

The service supported innovative techniques to provide emotional support and had recently introduced hypnotherapy sessions for children and their relatives with plans to increase sessions.

Staff always took children's personal, cultural, social and religious needs into account, and found innovative ways to meet them. The service ensured that children and their families religious needs were met by the team of chaplain and faith leaders available to support families 24 hours a day, seven days a week. The service had engaged with religious groups within the community to ensure that services delivered could be aligned to religious traditions and that support could be offered from different faith groups.

Staff recognised that children and their relatives needed to have access to and link with their support networks in the community and supported children to do this. Staff within the service were aware that children living with life



Hospice services for children

limiting illnesses could experience social isolation and planned services to ensure that siblings and children's friends and peer group could attend the hospice and take part in sessions. Staff were aware that as children got older their social needs may change and tried to ensure that there were designated spaces for children to socialise and interact with their peer groups that were age appropriate, such as the teenage den. The service organised specific events to try and ensure children's support networks were encouraged and supported such as pizza and gaming nights.

We saw feedback from a bereaved parent that spoke about how they appreciated that their network of family and friends were welcomed into the hospice while their child was receiving end of life care. They said the sensitivity of staff and the opening of the hospice to all those who that the family wished to be involved made the difficult time bearable.

Staff gave children, young people and their families help, emotional support and advice when they needed it. Relatives and patients valued their relationships with staff and felt they often went the extra mile for them when providing care and support. Relatives we spoke with told us how the service made sure they supported all the members of the family and gave examples of how children siblings had been supported with art therapy and how staff had taken the time to get to know siblings' preferences and worked around them. For example, one sibling didn't like to be asked questions, so staff would try and ensure the sibling was being supported without asking him direct questions. Relatives felt truly cared for and that they mattered.

The service ensured that support was provided to families after a child had died. For example, we saw the multidisciplinary team discussing providing further therapy support to a bereaved sibling for an extended period after the child had died. The service hosted an annual memory day which offered bereaved families the opportunity to come to the hospice and celebrate the child that had died. The service additionally offered families to come to the service and celebrate their child or young person on marked occasions such as the anniversary of their death or birthdays.

We saw that staff signposted to other organisations and local charities that could provide additional support to patients and their families. Staff were passionate about ensuring families accessed all the support that was available to them.

Staff undertook training on breaking bad news and demonstrated empathy when having difficult conversations. Staff told us that they had received training on difficult conversations as part of their quarterly nurse carer days.

Staff understood the emotional and social impact that a child or young person's care, treatment or condition had on their, and their family's wellbeing. Staff identified children and young people and their relatives who would benefit from an emotional wellbeing review in the services local locality multi-professional meeting. The service undertook exceptional reporting to celebrate good practice and staff successes. We saw that staff encouraging open discussions about emotional support with relatives was viewed as a success to be celebrated by leaders in the service.

The service ensured staff were supported following traumatic events or a child's passing. The service's chaplain held remembrance sessions for staff and families. These focussed on remembering the child and mindfulness of the staff who had cared for them. The service held a number of mindfulness sessions for staff including guided relaxation sessions, colouring and garden walks.

Understanding and involvement of patients and those close to them

Staff supported and involved children, young people and their families to be partners in their care. Staff ensured that they understood their condition and made decisions about their care and treatment. They ensured a family centred approach.

Staff made sure children, young people and their families understood their care and treatment. Children and their families were seen as active partners in their care. We spoke with the parent of a child staying at the hospice who told us that all the staff had explained the care and treatment clearly and that "without a doubt they have been so involved" with their child's care planning.



Hospice services for children

Staff were fully committed to working in partnership with people. Families were invited and encouraged to attend the daily planning meetings where the multi-professional team considered and planned for the patient and their whole family's needs for the day.

Care plans included one-page profiles to ensure each child's individual preferences were specified and understood by staff.

Staff empowered children and their families to have a voice and realise their potential. During each holistic needs assessment the staff set goals with patients and their relatives to ensure that the care being delivered was person-centred, met the needs of the whole family and ensured that all relatives who wished to be involved could be.

Staff talked with children, young people and their families in a way they could understand, using communication aids where necessary. We observed staff explaining to patients and their family the care and treatment that was being provided. During handovers staff always had a conversation with the patients and parents and took their views into account when discussing and planning care and treatment.

Staff supported children, young people and their families to make advanced decisions about their care. Advance care plans allowed patients and their families to make a plan for future health and personal care if they should lose their decision-making capacity. The advanced care plans we viewed on inspection captured patients and family's values and wishes and enabled them to continue to influence treatment decisions even when they could no longer actively participate.

Children, young people and their families could give feedback on the service and their treatment and staff supported them to do this. Children, young people and their families gave positive feedback about the service. We saw the service undertook a family satisfaction and experience survey in October 2019. The service invited each family who used the service in the previous six months to complete an online survey. The survey asked six questions based on their care they received from the hospice.

We reviewed the results of this survey and saw thirteen families responded to the survey. Of these, 85% of families thought the service had listened to their needs

and 85% of families felt the service had responded to their needs. 77% of respondents said they would recommend the service to other families. We reviewed the feedback from service users who would not recommend the service and saw that the concerns raised were around access to short breaks and not the quality of the care provided.

Feedback comments from the survey included:

- "I knew my child would be so well looked after with all his complex needs"
- "Care is always exceptional"
- "fantastic support from the symptom management team"

We saw that the service had put in place actions to address any areas where they did not feel they performed well including following up any concerns with individual families and to discuss findings with the Care Operational Leadership team to compare across localities how short breaks were being offered to ensure fairness and equality.

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

Good



Our rating of responsive went down. We rated it as **good**.

Service delivery to meet the needs of local people

Children's individual needs and preferences were central to the delivery of services and managers planned and organised services so they met the changing needs of the local population.

Children's individual needs and preferences were central to the delivery of tailored services and managers planned and organised services so they met the changing needs of the local population. The service prioritised end of life care for children and young people. The service had developed processes to enable flexibility to meet the changing care needs and priorities of care for patients. The service prioritised end of life care and had staff on standby to care for end of life patients in the event of a hospice closure.



Hospice services for children

The service had innovative approaches to providing person-centred pathways of care that involved other service providers and charities. The service had adopted a needs-based approach and performed holistic needs assessment (HNA) for each patient to ensure they met the child or young persons needs. The service discussed each patient's HNA at the locality multi-professional meetings (LMPM) and decided how to ensure they worked together with local charities and healthcare providers to enable children and their families to meet their goals and access services.

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. During our inspection we

observed a home visit with one of the service's long-term ventilation (LTV) community outreach teams. This team worked across the provider's three locations, with an LTV clinical nurse specialist (CNS) and LTV nurse primarily based out of each hospice location. This team attended children and young people in the community who required long term ventilation support, and provided them and their families with help and support on the operation and function of the child's ventilator. The team had trained teaching assistants in schools to care for children, so they could attend school among their peer group.

During our observation of a home visit we saw the team systematically addressed all the child's needs and provided expert advice and support where required. The LTV community outreach team explained how they aimed to meet all of the needs of the local children and young people they worked with.

The services were flexible and could be offered in an environment of the children and their families choosing. The service promoted informed choice when providing information on what services were available and where children could receive them. All staff were trained to deliver care and support in the hospice, home, hospital or other community setting depending on the families' choice.

The service had a transition planning process and transition lead to ensure that children transitioning to adult services were supported. The transition lead worked closely with adult healthcare organisations to allow children to visit organisations prior to transitioning.

Facilities and premises were innovative and met the needs of a range of children who used the service. There was a designated bedroom with a cooling system and the service had specialist cooling equipment, to allow families to spend time with their children/loved ones after they had died. Managers told us this service was particularly valued by bereaved families and that children would often stay at the hospice until their funerals at the wishes of their families.

The service had a wide range of toys and equipment designed for children of all ages and abilities in mind. The service had a vast outdoor play area with specialist equipment including a wheelchair swing. There was a fully equipped sensory room with bubble tubes, fiberoptic lights, a heated water bed, jelly pads and projectors.

The service had a range of onsite accommodation for parents and relatives to stay at the hospice including sofa beds in the children's bedrooms and separate apartment-style rooms located away from the care floor with washing and dining facilities.

People's individual needs and preferences were central to the delivery of services. Activities and events were organised to support differing groups including siblings, mums' nights, dads' activities, grandparent support groups, child support groups, teenagers and bereavement support groups.

The service held pizza nights for teenagers in the services "den" which was an environment designed for teenagers with access to gaming technology, a cinema screen, a football table and a large seating area. Staff told us that they would invite the children and young people's peers to these to try and reduce the social isolation.

There were innovative approaches to providing person-centred pathways of care which involved consulting with the local population. There was a scoping exercise underway at the time of inspection to better understand the needs of the ethnicity and diversity of the population around Peterborough. Leaders told us this would inform how to better deliver services locally.



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Meeting people's individual needs

The service was inclusive and took account of children, young people and their families' individual needs and preferences. There was a proactive approach to understanding the needs and preferences of different groups of children and to delivering care in a way that met these needs. Staff made reasonable adjustments to help children, young people and their families access services.

The service was accessible and promoted equality. The service championed holistic and individualised care for all patients, particularly those who were receiving end of life care. The service had care co-ordination teams, who reviewed the families regularly and brought any changes to be discussed to the locality multi-professional meeting (LMPPM) and considered how best the family can be supported.

Each child and their family received a holistic needs assessment (HNA) from a member of the nursing teams which covered the care needs of the child as well as social and wellbeing needs of the wider family. Individual goals were set in conjunction with the family and staff worked towards achieving these, reviewing them annually. We reviewed a number of HNAs as part of our inspection and saw that these were truly holistic, detailed and placed the child and family's individual needs at the centre of any care planning.

There was a proactive approach to understanding the needs and preferences of different groups of children and to delivering care in a way that met these needs. The organisation had a lead chaplain who offered emotional, spiritual, religious or pastoral support to patients, relatives and staff of all, any or no faiths. The hospice had a private spiritual area which had religious texts for patients and their families to use. Service leads actively sought input from religious leaders in the community and had access to leaders from different faiths who would come in and speak with patients and their families and perform religious rituals. Staff told us that the local imam had put them in touch with women who prepared deceased bodies in line with Islamic traditions and that they had attended the hospice and met with families to provide guidance on Islamic traditions.

The service had commissioned a study to look into the population needs of one of its localities to try and ensure

that services were accessible to all equality groups. We saw that needs of population groups were discussed in the service's clinical governance committee meeting minutes and how populations with higher rates of deprivation have a higher incidence of children and young people with life limiting conditions and how they could ensure access to services in the deprived areas in their locality.

The hospice was equipped to meet the needs of children and young people spending time with their families. Activities included specialist play, art therapy, music therapy, use of the sensory room and hydrotherapy pool. Staff told us that one of children staying at the hospice had enjoyed family swims with their sibling in the services hydrotherapy pool.

Staff used transition plans to support young people moving on to adult services. The service started planning for children and young people's transition to adult services five years in advance. We saw that the service had an electronic transition planner saved to the child or young person's electronic record. The planner could be amended by anyone in the organisation and outside agencies with access to the electronic system. The service wrote to healthcare providers when the young person was 13 to give them the opportunity to contribute to transition planning. The service worked closely with a local adult hospice and had held joint event days for young people transitioning into their services. Event days were for patients and their families and had included barbeques, complimentary therapies and virtual reality experiences.

The service ensured they marked a child or young person transitioning to adult services with bespoke goodbye events with young people and their families. Examples of some of the events include tea parties, cinema trips, pottery sessions and bowling.

Staff had access to communication aids to help children, young people and their families become partners in their care and treatment. Managers made sure staff, children, young people and their families could get help from interpreters or signers when needed. The service had access to a face to face and telephone translation services for families for whom English was not their first language. The service could also access a sign language interpreter, when needed.



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Children, young people and their families were given a choice of food and drink to meet their cultural and religious preferences. The service had an onsite catering team who took pleasure in ensuring that children and their families had access to nutritious meals that were inclusive and met the diverse needs of service users.

Access and flow

People could access the service when they needed it and received the right care promptly. However, the service had a number of cancellations for planned short breaks. Between October and December 2019 there were four instances of short-break cancellations by the service. The service were in the process of a service-redesign to reduce short-break cancellations.

Managers made sure children, young people and their families could access services when needed. Referrals could be made by professionals or directly by the child's relatives. We saw that referral forms were available on the services website. When referrals were received they were considered by the service's central panel to decide if the referral met the services eligibility criteria. Any referrals requesting 'same day admission' or 'urgent' were reviewed by the hospice leadership team and would not wait for the central panel meeting. We attended the weekly central panel meeting during the inspection, and saw staff discussed the child or young person's needs, the needs of the family and also discussed capacity of the unit and safe staffing. Once it had been decided to accept the referral, the information was taken to the locality multi-professional meeting (LMPM) to organise and prepare for completion of the holistic needs assessment (HNA).

Nursing teams had a caseload of children who they saw frequently and could discuss children and their care needs at LMPM meetings to decide with the operational management team what care planning could be offered. This could include access to hospice facilities and therapy sessions, such as hydrotherapy, art or music therapy, or the facilitation of planned short break stays.

The service prioritised end of life care patients and ensured they met the demand for this care by diverting staff from other sites to the hospice or community if a

child was receiving end of life care. We saw feedback from a patient's families about how the service had opened to ensure that their relative received end of life care in their chosen place.

Healthcare professionals and children's families could access clinical advice and support out of hours from the service's managed clinical network if the patient was known to EACH. The managed clinical network was hosted by EACH and provided access to specialist palliative care advice. The team consisted of children's palliative care trained consultant paediatricians and nurse consultants.

Managers worked to keep the number of cancelled planned short break to a minimum. The service had no waiting lists for targeted wellbeing interventions but did have instances of hospice closures and cancelled short stays.

The amount of planned short break care available was based on staffing levels and other demands on the service such as end of life care provision. Managers arranged additional staffing from one of the other EACH hospice locations where necessary. To reduce any impact to staff, managers offered staff overnight accommodation, use of pool cars and reduced working days to the affected staff.

We reviewed data on the number of unplanned closures of the hospice from October to December 2019. There were three planned closures overnight and two instances of unplanned closures due to staff sickness. Between October and December 2019 there were four instances of short break cancellations by the service. This was comparable with the other hospice sites the provider had.

The service had received poor feedback around cancellations and availability of short breaks offered as part of the family satisfaction survey. 31% of participants (out of 13 families) rated the service as poor, the survey looked at reasoning for this and saw that there was dissatisfaction among families when the service had limited the episodes of care that children could receive or had reduced the number of overnight stays a child could receive. The service had analysed the responses and were implementing new ways of working to increase capacity



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to deliver end of life and urgent care simultaneously with short breaks to reduce the number of short break cancellations and improve patient and family satisfaction.

Managers were aware of the cancellations, monitored them and had a programme of improvement in place to address the concerns. The service was in the process of a service redesign to try and reduce the number of cancelled short breaks. The service recently implemented holistic needs assessments looked at providing families with the specific care and input they needed including allocating short breaks. The service previously provided short breaks on an ad hoc basis and were trying to ensure the service went to those families who were in need and had this highlighted in their assessments.

Managers in the service were acutely aware of the impact cancellations had on families and were committed to reducing them. In order to prevent cancellations in the event of an end of life care patient, service and clinical leads had trained and upskilled care assistants to be able to take responsibility and care for children with stable care needs, allowing the registered nurses to focus giving end of life care and urgent care.

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.

Children, young people and their families knew how to complain or raise concerns. Families we spoke with told us they knew how to make a complaint or raise concerns, however had felt no reason to do so.

The service clearly displayed information about how to complain. Leaflets were available throughout the service and the provider had a dedicated section on their website which contained contact details for those wishing to raise compliments or concerns.

The service had received one formal complaint from October 2018 to September 2019 which was managed and resolved under the services formal complaint procedure.

Staff understood the policy on complaints and knew how to handle them. Staff supported families to make complaints and had access to policy and procedures to guide them in managing complaints. Staff told us they always tried to resolve any issues or complaints with families at the time they were raised. Concerns and complaints were logged on the services electronic incident reporting system to ensure managers were aware and could investigate.

Managers investigated complaints and identified themes. Complaints and concerns were reported as part of the service's balance score cards where the complaint outcomes and any learning were detailed. Managers shared feedback from complaints with staff and learning was used to improve the service at the services quarterly team days. Complaints were logged and investigated in line with incidents in the service and investigation outcomes were discussed at the weekly locality multi-professional meeting.

The service had an up to date complaints policy which included staff roles and responsibilities. The complaints policy stated that complaints would be acknowledged within three working days. There was no set timeframe for complaints to be investigated and closed by. Managers told us that they contacted the complainant advising them how the complaint would be investigated and how long it was expected to take. At the end of the process a letter was sent to the complainant explaining the conclusions of the investigation and what the complainant could do if they were unhappy with the outcome.

Complaints were investigated locally by the service manager and the matron. The hospice chief executive had overall responsibility for the management of complaints.

The service had received 38 written compliments from October 2018 to September 2019. Compliments were shared with staff through the services balance score cards. However, we saw many more expressions of gratitude during the inspection. These included compliments about how the whole family feeling cared for not just the patient, how care was focussed and individual, how caring the staff were and how patients and their families were treated with dignity and compassion.



Hospice services for children

Are hospice services for children well-led?

Outstanding



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

Leadership

Leaders at all levels had the skills and abilities to run the service. They understood and managed the priorities and issues the service faced. They were highly visible and approachable in the service for patients and staff. They supported staff to develop their skills and take on more senior roles.

We saw that there was compassionate, effective and inclusive leadership at all levels. The executive leadership team consisted of the acting chief executive officer (CEO), acting director of care, director of finance, director of income generation, director of workforce and corporate governance and head of marketing and communications. The acting CEO and acting director of care had been in post for six months, but both had previously been working in the organisation in deputy roles. At a local level, the service had an established local operational leadership team made up of the service manager, clinical lead (matron) and a well-being lead.

Despite there being a number of senior staff in acting up roles, there was an embedded system of leadership development and succession planning. The service had a plan in place to appoint to these roles permanently and were working with the board of trustees to ensure that the appointments were appropriate. The service had advertised the role and had a recent round of interviews for the chief executive role. During this interim period the executive team had hired a human resources consultant to come in and listen to staff to ensure they felt supported and to highlight any areas of improvement for the interim team. The acting CEO was supporting those in other interim positions and had a wealth of experience in the hospice sector and leadership roles.

The executive leadership team was accountable to the EACH board of trustees, who had a range of relevant

expertise to contribute to the service. The trustees told us that they had a good working relationship with the executive team and that they felt their support and expertise was valued.

Trustees ensured they met their governance responsibilities by sitting on the service's various boards such as the clinical governance committee, finance and income generation committee and safeguarding board. The trustees held quarterly meetings with a set agenda that included training, matters for decision and matters for information. The trustees we spoke with had a good understanding of quality and care and the challenges the organisation faced. Trustees performed care quality visits at the organisation's various sites to increase their understanding of quality and ensure they had oversight of the care provided.

All staff we spoke with told us that the senior leadership team were visible, approachable and supportive. Staff told us that you could raise concerns or feedback with the service's leadership team and they felt confident that action would be taken.

New starters within the organisation had a meeting with the acting CEO as part of their induction. One member of staff told us that the acting CEO had encouraged them as a new starter to raise concerns and voice any improvements they felt could be made. One member of staff told us that the senior leadership team made them feel like they were all working towards a common goal and allowed them to make a real difference to children and their families.

Staff told us that communication from the executive leadership team was regular and clear. Staff told us that the executive team did annual management executive briefs where the team came and spoke to staff about finances, the strategy and highlighted good practice. These sessions provided the opportunity for staff to provide feedback to the executive team.

All leaders within the service demonstrated the high levels of experience, capacity and capability needed to deliver excellent and sustainable care. Leaders within the service had vast experience and expertise developed from working in the palliative care sector and wider health economy.

Leaders within the service had a deep understanding of issues, challenges and priorities in their service, the wider



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organisation and the children's hospice sector. These included funding, staff recruitment and future service demand. A culture of continuous improvement and service development was embedded throughout the service. The leadership team had worked to mitigate some of the recruitment challenges by introducing a programme of education to upskill care workers to allow them to take on some nursing responsibilities.

There was an embedded system of leadership development. The service had implemented leadership schemes including a progression framework for nursing staff.

Vision and strategy

The service had a clear vision for what it wanted to achieve and a detailed 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 and national plans within the wider health economy. Leaders and staff understood and knew how to apply them and monitor progress.

The service had a clear vision which was to 'aspire daily to lead the way in providing world class care for children with life-threatening conditions' and that 'every child deserves support, alongside their families, whenever and wherever they need it'. Alongside this the service had a mission statement 'to improve the quality of life and wellbeing of every child and family under their care, by providing individual and comprehensive services at all times'.

The service had four core values:

- Empathy and understanding – understanding the views and feelings of others is central to our work relationships and how we interact daily.
- Commitment to quality – we consistently employ our best efforts and strive for the highest standards in everything that we do, always looking for ways to improve.
- Open and respectful – we operate in an honest and participative way. Welcoming constructive feedback and different views, we understand the power of words and behaviour and hold ourselves accountable for maintaining a positive and considerate work environment.

- Make it happen – we are empowered to and take responsibility for getting things done.

Staff within the service were aware of the vision and strategy and felt committed to achieving them. Families, staff, volunteers and external stakeholders were engaged in the development work. Staff were expected to provide examples of how they demonstrated the values as part of their annual appraisal process.

There was a rolling five-year provider strategy reviewed by the Board annually. There was a systemic and integrated approach to monitoring, reviewing and providing evidence of progress against the strategy. This was translated into annual goals and priorities which were monitored by the care strategic leadership team, clinical governance committee of the board and trustee board. We saw from minutes of the service's trustee board meetings that issues in the wider health economy and hospice sector influenced the planning of the service's strategy.

We reviewed the strategy and saw it was aligned with local plans and the wider health economy and included actions to continue and create effective beneficial partnerships with local, regional, national and international organisations. The strategy detailed how goals were to be monitored as part of the service's governance structure.

Culture

Staff felt respected, supported and valued. They were focused on the needs of children, young people and their families receiving care. The service promoted equality and diversity in daily work and provided opportunities for career development. The service had an open culture where children, young people and their families and staff could raise concerns without fear. Leaders had a shared purpose, strived to deliver and motivated staff to succeed.

The service had a person-centred culture and encouraged staff to promote patient and relative welfare at all times.

Leaders had a shared purpose and strived to deliver and motivated staff to succeed. We saw that staff championed patients and their relatives in locality multi-professional meetings. For example, a relative had requested having a



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room to put their possessions in when attending day care with their child, when discussing the request one member of staff enthusiastically said “if it makes all the difference to mum and it’s achievable, let’s do it”. We saw that leaders assigned actions to staff to make this possible.

There were high levels of satisfaction across all staff groups and staff repeatedly told us that they were proud to work for the service. All staff we spoke with told us they enjoyed working at EACH. Staff told us that managers promoted a culture of positivity and praise among staff. Managers sent weekly “good news” emails which featured praise for staff for any achievements that week.

Staff at all levels were actively encouraged to speak up and raise concerns and there were policies and procedures in place to support this process. Staff were encouraged to report incidents and raise concerns or issues, so they could learn from them and improve the service they offered. Staff provided examples of where senior management had sought their input and welcomed challenge. One member of staff told us that when they met with the acting CEO they encouraged them to voice concerns and give feedback on any improvements that could be made and valued the member of staff as a pair of “fresh eyes” into the organisation.

Patients and their families were encouraged to raise concerns and there was information available on the care floor explaining how to do so. Leaders within the service treated all concerns seriously and told us they would speak to families to try and resolve concerns as soon as possible.

We saw that across the organisation there was strong collaboration and effective team working with a common focus on improving the quality of care and people’s experience. The services governance structures supported collaboration across the teams and we saw that cross-team working was praised by senior staff. Staff prioritised the holistic needs of each patient and family and used evidence-based models to ensure they were delivering the best possible care. Therapy staff we spoke with talked about how their sessions were reviewed by patients and their family and how they used this feedback to improve and individualise the care given. For example, therapy staff told us about a sibling of a patient who hadn’t engaged very well with other services but

attended a music therapy session and fed back that they particularly liked the drums. Staff created a care plan that allowed the child to use the drums as a source of communication for their emotion.

Staff unanimously told us that they worked well as a team with different healthcare professionals and providers.

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.

There were effective structures, processes and systems of accountability to support the delivery of the strategy and good quality services. The service’s local leadership team consisted of a service manager, matron and locality well-being lead and they had the responsibility for oversight of governance and quality monitoring.

The services corporate governance structure featured local level care quality safety groups, strategic leadership groups and corporate quality and governance groups which fed into the management executive group meetings (MEX). The MEX meetings fed into board committees such as the clinical governance board committee, audit and compliance board committee and HR board committee.

Local governance meetings included the services weekly central panel which reviewed admissions, incidents and complaints. These fed into the local multidisciplinary team meetings which included a set agenda to look at incidents, exceptional reporting and learning from deaths.

The local leadership team fed any concerns they had to the management executive team which consisted of the acting chief executive officer (CEO), deputy CEO, acting director of care, director of finance, director of income generation and director of workforce.

A systemic approach was taken to working with other organisations to improve care outcomes. The service was proactive within the local health economy and worked closely with adult hospices, children’s hospices, local acute and community trusts, local faith groups and



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hospice charities. The service provided best practice advice to national children's hospice charities. The service's acting CEO had been appointed as an advisor to the board for a national children's palliative care charity who advised on national initiatives and changes to policy and legislation. The services nurse consultant was the vice chair for a national nursing organisation's children and young people palliative care community group.

Managing risks, issues and performance

The service had good systems to identify risks, plan to eliminate or reduce them, and cope with both the expected and unexpected.

There were robust arrangements for identifying, recording and managing risks, issues and mitigating actions. The management executive provided oversight and scrutiny of operational risks. There was a demonstrated commitment to best practice performance management and risk management systems and processes.

The provider had an operational risk register which contained all current risks at all three hospice sites. We reviewed the risk register, which was updated in October 2019, and contained 12 active risks. Each risk entry was detailed and contained a risk rating, a risk owner, review date and target risk rating. The risks echoed what senior staff told us were the risks including the gap with adult safeguarding training, nurse recruitment and failure to deliver care.

Problems were identified and addressed quickly and openly. We saw that mitigating actions were put in place for each risk and progress against the risk was assessed. The risk register was reviewed by the clinical quality and safety group. We reviewed three sets of minutes from the group and saw that risks and gaps in assurance were discussed and escalated appropriately. The service's operational risk register fed into the board assurance framework if risks were rated as red.

Staff told us that risks were reported through the service's incident reporting system and fed into the clinical quality and safety group by the operational leadership team.

The board reviewed the corporate risks that featured in the board assurance framework (BAF) annually. Any changes to the risks during the year were reported to the

board at their quarterly meetings. The committees of EACH's board of trustees regularly reviewed the strategic risks relating to their responsibilities and operational risks.

The service monitored performance against key performance indicators (KPI) through a quarterly balanced scorecard report, which included referrals, service user experience, complaints and concerns, training, staffing, staff survey results, audit results, learning from deaths and incidents, research activity, update on service redesign and financial performance. We saw that the service measured performance by using a number of different metrics including: whether requests to deliver end of life care were met, holistic needs assessment completion, vacancy rates and staff survey results. The KPI's were red-amber-green rated to determine how well the service was achieving the metric. We reviewed two balance score cards and saw that where metrics were rated as amber or red commentary was provided including how the service were working to improve the result.

The service reviewed mortality as part of their local disciplinary meeting and had a standard agenda item for learning from deaths to ensure learning was shared. We attended one of the meetings and observed this taking place.

Managing information

The service collected reliable, detailed data and analysed it to drive forward improvements. 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. Data or notifications were consistently submitted to external organisations as required.

There were systems in place to ensure that data and notifications were submitted to external bodies as required, such as local commissioners and the Care Quality Commission (CQC). The service had engaged regularly and openly with CQC inspectors throughout the year prior to inspection.



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The services information systems were secure. The service used a secure electronic records system to record care plans and medical records for children and young people. Access to the system was restricted and staff were given individual log ins.

The service ensured that staff were aware of data protection requirements. The service provided mandatory training to all staff and volunteers on information governance processes.

The service collected data by using an internal audit programme as well as key performance indicator information. This information was reported on to the board through various committees and drove improvements throughout the service.

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 proactively collaborated with partner organisations to help improve services for children and young people.

There was consistently high levels of constructive engagement with staff and people who used services, including equality groups. Staff within the service gave examples of how they actively sought the input of local faith and community groups to ensure services were delivered in line with individual patient needs. Examples of this included engaging a group called The Muslim Sisters to assist with Muslim traditions when patients were receiving care at the hospice. The service had plans in place to start a hub within the local community to encourage hard to reach groups to access services.

The service had a quarterly family newsletter to keep families informed of events within the hospice.

Rigorous and constructive challenge from service users, their family and staff was welcomed and was seen as a vital way of holding services to account. Staff consistently told us that their feedback was sought and actioned by the senior leadership team. Staff were provided with the opportunity to give feedback at the services quarterly team days. We saw that feedback provided by service users informed operational changes and service planning.

Services were developed with the full participation of service users, staff and external partners. The service held family lunch events to provide families with the opportunity to meet with senior care leaders to provide feedback and to give advice on the service's redesign. Service user feedback had prompted the service redesign and families and staff feedback was sought in the planning of this.

Innovative approaches were used to gather feedback from patients and their families. The service had an active service user forum and palliative care group. The service actively encouraged children, young people and families to give feedback through evaluation forms, feedback suggestions box, annual satisfaction and experience survey, comments through the family section on the EACH website, comments slip in the Family Corner newsletter and social media.

The service took a leadership role in its local health system to identify and proactively address challenges and to meet the needs of the local population. The service ensured they were partnering with other organisations to ensure they were effectively meeting children's needs and sharing best practice. The service hosted the regional palliative care forum, this was responsible for developing and implementing the priorities of the managed clinical network. The regional forum was chaired by the acting director of care and attended by the medical director and nurse consultant. Leaders within the service attended the county-based palliative care networks and regional action groups for young people.

Learning, continuous improvement and innovation

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

Innovation and learning was encouraged through listening to staff and families and encouraging ideas through the ideas email inbox to the operational leadership team. Improvement was seen by leaders as the way to deal with performance and for the organisation to learn and excel.



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Staff were empowered to lead and deliver change. The service had established and hosted a managed clinical network which provided out of hours access to specialist medical support and advice, provided education and developed and promoted good practice and guidance. The service consisted of one tertiary centre and nine district general hospitals.

The services symptom management team had established a symptom management clinic where patients could attend the hospice in an outpatient setting to discuss their symptoms and be reviewed with the services specialist nurses.

Innovation was celebrated and there was a clear, proactive approach to seeking out and embedding new and more sustainable models of care. The service commissioned a university study to evaluate the well-being interventions and therapies offered by the service. The study confirmed that the service had a varied workforce, who provided a range of supportive therapies that were appropriate for supporting the needs of children with life-limiting or life-threatening conditions, and their family.

The service prioritised wellbeing and ensured that wellbeing management was placed on the same level as clinical management by having a wellbeing lead as part of the operational leadership team.

The service ensured that care episodes were truly holistic and catered to individual needs. The service's holistic needs assessments and six step wellbeing assessments ensured that appropriate therapies were provided to children and their families. Goal measuring in therapies and holistic needs assessments ensured that the service could monitor the effectiveness of their assessments and therapy input.

There was a strong record of sharing work locally and nationally. The service undertook a leadership role in various children's palliative care forums nationally and advised children's hospice charities on best practice to be shared across the sector. Staff contributed to academic research into children's palliative care. For example, we saw a number of staff had published research articles on peer reviewed scientific journals including a study on buccal opioids for breakthrough pain in children with life-limiting conditions receiving end of life care.

Outstanding practice and areas for improvement

Outstanding practice

- The service had developed an innovative long-term ventilator community outreach service, which staff and managers continually reviewed to ensure it met the needs of the children, young people and their families who used the service. The team had trained teaching assistants in schools to care for children, so they could attend school among their peer group.
- The service had developed a nurse-led symptom management out patient clinic to allow children and their families to be assessed and have their care needs addressed without having to be admitted to the inpatient.
- The service had developed a truly holistic assessment model which placed children and their families at the centre of care planning. Children and their families were asked what they wanted to achieve while being under EACH's care and staff were passionate about ensuring these goals were achieved and that children and their families were engaged with the care planning process.
- The service had formed effective working relationships with other care providers, local faith leaders, community organisations and charities providing national guidance. The service had taken a leadership role in the local healthcare environment to meet the needs of the local population through the development of the managed clinical network and hosting the regional palliative care network.
- Staff repeatedly went the extra mile in their care and were committed to find ways to make a difference to children and their families. Staff got to know children and their families as individuals and built up a strong rapport with them to enable innovative care.
- Service leaders welcomed challenge and had developed an open and transparent culture at all levels. Staff unanimously spoke about the supportive and effective leadership in place both locally and executively. Staff at all levels were committed to provide the best care and treatment for children and young people, and their families.

Areas for improvement

Action the provider **SHOULD** take to improve

We found the following areas of improvement:

- The service should consider undertaking infection control audits of the service more regularly.
- The service should ensure that staff meet the safeguarding adults mandatory training requirements.