

East Anglia's Childrens Hospices

Milton Children's Hospice

Inspection report

Church Lane
Milton
Cambridge
Cambridgeshire
CB24 6AB

Tel: 01223815115
Website: www.each.org.uk

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Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Good 

Is the service caring?

Outstanding 

Is the service responsive?

Outstanding 

Is the service well-led?

Good 

Summary of findings

Overall summary

Milton Children's Hospice is registered to provide care and treatment to children and young people, aged between 0 and 19 years, who have a life-limiting illness or condition. The hospice offers a wide range of services, which are delivered in the way that meets the needs of each young person and their family and in the place that suits the young person and their family best. This can be in their own home, in hospital or at the hospice in Milton.

Services are offered from diagnosis to end of life and throughout bereavement and include the young person's extended family, such as grandparents. Receiving care from East Anglia's Children's Hospices (EACH) does not mean that the child's death is imminent. Many of the children and young people who use the service live long and active lives but need additional care and support. The provider's website states that the service is available 365 days a year.

Milton Children's Hospice building is an old rectory set in its own peaceful grounds next to the church on the outskirts of the village of Milton. The original house has been converted and extended a number of times over the years. The house 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. At the time of the inspection the service had adjusted the number of young people staying for respite to four to ensure that the service provided was safe and of high quality.

The provider, EACH, runs three hospices in East Anglia. The three hospices work very closely together, sharing knowledge and expertise as well as sharing some staff teams, such as the Symptom Management Team (previously known as the True Colours team) and the Well Being Team.

This comprehensive inspection took place on 16 and 25 February 2016 and was unannounced. On each day of the inspection there were two young people staying for a short break.

There was a registered manager in place. A registered manager is a person who has registered with the Care Quality Commission (CQC) to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 and associated Regulations about how the service is run. The registered manager had been in post for 10 years.

The young people we met were happy at the hospice and they were relaxed and comfortable with the staff. The service had received numerous compliments about the care and support provided to young people and their families. Parents told us how much the care and support provided by the hospice staff meant to them, their child and their extended family. They were effusive in their praise of the staff. The staff team looked for solutions and used creative approaches to support each child and their family.

The service had a very strong person-centred culture. Everything was based on the needs, wishes and goals of the individual child and their family and how those needs, wishes and goals could be recognised, supported and met. The staff team strived to give each child the best life, and if and when it came to it, the best death they could have. Staff supported families before, during and after a bereavement for as long as the family wanted support.

Outstanding care was provided by compassionate and enabling staff who treated the young people well, respected their privacy and dignity and encouraged them to be as independent as possible. We saw that the young people and the staff supporting them had warm, caring relationships and there was a lot of laughter and fun. Staff were creative and used a wide range of methods to communicate in the best possible way with each young person. Staff's relationships with parents and other family members were equally caring and respectful. Parents were pleased that staff knew them and their child well.

The service was safe because there were enough staff on duty to support the young people in the way they needed to be supported. Pre-employment checks had been carried out before staff started to work at the hospice and staff had been trained to recognise and report any incidents of harm to the young people in their care. Any potential risks were managed so that the risks were minimised, whilst ensuring that young people were enabled to be as independent as possible. Action had been taken to ensure that medicines were managed safely.

Staff showed that they understood and worked within legislation relating to young people and/or their parents giving consent to their care and treatment. Staff used different methods with each young person to enable them to make choices about their everyday lives.

The CQC monitors the operation of the Mental Capacity Act 2005 (MCA) and the Deprivation of Liberty Safeguards (DoLS), which apply to care services. This legislation applied to young people over the age of 16 and staff working with this age group had an understanding of the principles of the MCA and DoLS. This meant that the rights of young people not able to make their own decisions about aspects of their care were protected.

Children and young people were supported by a highly motivated and well trained staff team. The service provided a very wide range of opportunities for therapy sessions, activities and outings and each child's hobbies and interests were encouraged and widened. Events and sessions for families were organised regularly, which families appreciated and valued. Staff went 'the extra mile' in a number of ways, including sourcing funding for family holidays.

Holistic, detailed needs assessments were undertaken so that staff were fully aware of each young person's and their family's needs, wishes and goals. Young people and their families were fully involved in the planning and reviewing of their care. Detailed information was available to staff so that each young person received the care and support they needed in the way they preferred.

Young people's nutritional needs were met by a catering team who worked hard to ensure that each young person and every family member had the food and drink they preferred. Young people's healthcare needs were monitored and staff involved external professionals when required.

The hospice was managed very effectively and was constantly striving for excellence. Young people, their relatives, the staff and other healthcare professionals were encouraged to give their views about the hospice and put forward their ideas for improvements. The provider's complaints procedure was well advertised and relatives said they felt comfortable to raise any issues with the management team. An effective system was

in place to monitor and audit the quality of the service being provided. There was a homely, friendly and open culture in the hospice.

The hospice staff worked in partnership with a wide range of other services and healthcare professionals, all of whom praised the service that was provided to each young person and their family.

Please note that the summary section will be used to populate the CQC website. Providers will be asked to share this section with the people who use their service and the staff that work there.

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

Good ●

The service was safe.

Young people were protected from avoidable harm by a staff team that had been recruited well and trained to recognise and report any concerns.

Young people staying at the hospice or receiving care and support elsewhere in the community were kept safe by a sufficient number of staff on duty.

Risks were assessed and managed well so that young people were protected as well as being enabled to be as independent as possible. Equipment designed to keep young people safe was available when required.

Is the service effective?

Good ●

The service was effective.

Staff were trained and supported well so that they had the skills and knowledge to deliver effective care and support to the young people in their care.

Staff were aware of and worked within legislation relating to young people's consent to care and treatment, so that the rights of young people were protected. Staff supported young people to make choices about their everyday lives.

Young people's nutritional needs were met by a staff team dedicated to providing food that young people enjoyed. Young people's healthcare needs were met by staff who involved external healthcare professionals when required.

Is the service caring?

Outstanding ☆

The service was very caring.

Young people and their families were supported by kind and compassionate staff in a way that respected their privacy and dignity.

Staff showed they cared about the young people they were supporting and about their families. They used a range of methods to communicate with each individual.

The spiritual and religious needs of young people and their families were supported in whichever ways each young person and their family wanted.

Is the service responsive?

Outstanding 

The service was very responsive.

Outcome-focussed, goal-based, holistic needs assessments were carried out to ensure that the service could meet those needs. Care plans in place for each young person using the service were detailed and gave full guidance to staff on how the young person preferred their needs to be met.

A wide range of activities, outings and events were arranged to suit young people and their families.

Complaints and concerns were encouraged and responded to.

Is the service well-led?

Good 

The service was well-led.

The service was inclusive and empowering of young people and their families and was managed well.

The management were visible and approachable and supported everyone using the service and the staff. Quality checks and audits were carried out to make sure the service continued to improve.

The staff worked extremely well with a wide range of external healthcare professionals, developing partnership working and mutual support.

Milton Children's Hospice

Detailed findings

Background to this inspection

We carried out this inspection under Section 60 of the Health and Social Care Act 2008 as part of our regulatory functions. This inspection was planned to check whether the provider is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008, to look at the overall quality of the service, and to provide a rating for the service under the Care Act 2014.

This inspection was carried out by an inspector, a pharmacist inspector and a specialist professional advisor (SPA). The SPA was a qualified paediatric nurse with a range of experience of providing services, mainly for children and young people.

Prior to the inspection we looked at information we held about the service and used this information as part of our inspection planning. The information included notifications. Notifications are information on important events that happen in the service that the provider is required by law to notify us about.

In December 2014 the provider completed a Provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make. We discussed this with the registered manager, who gave us updated information about the service.

We spent time in the shared areas of the service where we observed how staff interacted with the young people who were staying at the service and the young people who were participating in the sibling day.

We spoke with two young people, two family members, three care staff, two nurses and the manager. Following the visit we spoke with two more relatives and one healthcare professional on the telephone. Three other healthcare professionals wrote to us to tell us their views about the service. We looked at care records relating to two young people as well as some other records relating to the management of the hospice. These included complaints and compliments and some of the quality assurance audits that had been carried out. The manager sent us some further information after the visit.

Is the service safe?

Our findings

Parents of the children and young people who used the hospice service were confident that the service was safe for their children. One parent told us, "Oh yes, I know he's safe. I trust them totally." Another said, "[Name's] definitely safe there. I've never had any concerns. I'm really happy with the care he receives there."

One parent told us that they had managed to go on holiday for the first time in several years while their child was being cared for at the hospice. Another parent described a similar experience. They said, "We have total confidence [in the service]. So much so that we even went abroad for four nights."

Staff demonstrated that they had a good understanding of keeping children and young people safe. They showed that they would recognise if a child was at risk of, or suffering from avoidable harm or abuse. They were fully aware of different forms of abuse and the signs and symptoms to look out for. One parent said, "[Name's] absolutely safe there... there's never been an issue with the way they treat her." Staff knew the procedures to follow if they had any concerns. They knew where to find contact details for external agencies, such as the local authority children's safeguarding team, should they have needed to do so.

Staff told us, and the manager and records confirmed, that they undertook safeguarding and protection of children training each year. Staff who had direct contact with the children and young people attended compulsory in-house 'safeguarding supervision meetings' at least three times a year. These sessions were facilitated by an external provider and gave staff the opportunity to discuss any general concerns. The hospice had a named member of staff for safeguarding with whom staff could discuss any issues. The provider had recognised that staff also required training in safeguarding adults, as some of the young people who used the services were aged 18 and over. Records confirmed that this training had been arranged for all staff during 2016.

Staff across the service had also been trained to recognise signs of emerging safeguarding problems so that they could consider early intervention to benefit the young person and their family.

There were systems in place to reduce risks to children and young people and their families who used the hospice services. Assessments of any potential risks to anyone who used the services had been carried out and guidelines put in place so that any risks would be minimised. Risks to children and young people who stayed at the hospice for respite care were reviewed each time the child came to stay and updated when there had been any changes. Staff knew about the risks to each child they were supporting. Risks included use of the hydrotherapy pool; medicines; nutrition; mobility; and travel.

Equipment had been put in place to make sure that children and young people were supported in the safest way possible. For example we saw that new ceiling hoist tracking had been installed in bedrooms and bathrooms so that children could be safely transported between these rooms. 'Safe-space' cots and beds had been provided so that children who were at risk of harm during the night if they were sleeping in a regular bed or cot were protected. In one bedroom there was a mattress at floor level surrounded by a large

tent that could be zipped up at night to ensure that certain young people would feel comfortable and be as safe as possible. We saw that equipment was checked regularly and maintained to ensure it was in a safe condition.

We asked about the staffing in the hospice. Some of those we spoke with said that staffing levels could have been improved and that sometimes there were not enough staff. On the day of the inspection we saw that there were sufficient staff on duty to fully meet the needs of the two young people staying at the hospice. One of the senior staff stated, "Yes, there are enough staff." We saw that one young person with very complex needs was supported by at least two members of staff at all times. The manager confirmed that the amount of services provided was based on the staffing available. For example, she said that current staffing levels meant the hospice limited the number of children and young people staying for a respite break to four at any one time. This meant that the provider had worked within staffing constraints to ensure that each young person and their family received the service they needed and which kept them safe. There were also enough staff to meet the needs of the young people who were receiving a service at home. A healthcare professional told us, "The staff have always endeavoured to ensure the safety of accepting the referral, and re allocate staff around to support skill mix, and the safety of the service."

Staff told us, and records confirmed, that recruitment procedures were rigorously followed. These procedures included the volunteers who worked at the hospice. One volunteer we spoke with told us they had completed an application form and provided proofs of identity. They said that even though they did not get directly involved with the care of the young people, references had been sent for and a criminal record check carried out through the Disclosure and Barring Service (DBS). The manager said, "No-one [potential new staff or volunteers] comes over the threshold until the DBS is back." The manager also explained that some staff applying to be employed were not always of the high quality that the hospice wanted to employ. This demonstrated that the provider had a robust system in place to ensure that only staff suitable to work with children and young people and their families were employed.

We checked how children's and young people's medicines were managed. Parents told us that medicines were managed well. One parent said, "Medicines are given at the right times and they [the nurses] are strict on us taking labelled medicines in." Another parent told us that at every visit staff checked that each of their child's medicines was the same, including the same dose, as on their previous visit. Any changes were recorded on the medicine administration record (MAR) charts and in their child's notes.

We looked at the MAR charts for children and young people who used the service. The MAR charts showed that children were getting their medicines when they needed them. Staff were signing the MAR charts correctly to show when each medicine had been given. There were no gaps on the MAR charts and any reasons for not giving children their medicines were recorded.

Medicines prescribed to each individual child were brought into the hospice by their family and returned with them when they left. The provider had a robust policy in place to verify the correct medicines and doses were being administered. We noted that this medicines reconciliation was not recorded on the MAR chart. MAR charts were reused each time a child was readmitted for care, which in some instances led to unclear charts when doses of medicines had been altered.

Medicine instructions were transcribed by a nurse on to the MAR chart. However there was no evidence these were checked by another member of staff to ensure this had been done correctly. This does not follow the recommended guidance in the medicines toolkit produced by Together for Short Lives (the UK charity for children expected to have short lives). This guidance includes that the transcription process must be independently checked by another registered healthcare professional before medicines are administered.

On the second day of our inspection the manager told us that the service had reviewed their policy and practice and had undertaken a further risk assessment. The result of this assessment was that their practice was safe and we found no evidence that it was not safe.

We saw medicines were stored securely. Medicines requiring cool storage were stored appropriately. Records showed that they were kept at the correct temperature, and so would be fit for use. There were no controlled drugs on the premises at the time of our visit but we saw that facilities were available for secure storage and record keeping.

We were satisfied that the provider had systems in place to ensure that medicines were managed safely and that the children and young people who used the service received their medicines safely and as they were prescribed.

Is the service effective?

Our findings

Parents told us that the staff had the skills and knowledge to meet their child's needs. For example, one parent told us that the nurses had been able to change their child's nasogastric feeding tube "in seconds", which nurses from another service had not been able to do. They said this "really really helped" their child. Another parent told us that the staff were "brilliant" at managing their child's respiratory support and they also said, "We know they [the staff] are well enough trained to act quickly if she were ill." One parent said the staff at the hospice all knew their child well: "Her history, her medicines, her care, everything about her."

The provider had a range of systems in place to ensure that all staff, including volunteers, had opportunities to undertake all the training they required so that they were fully equipped to carry out their role. The provider had an education team, which worked across all the provider's services, and the team had produced a training plan for all staff. The provider stated their vision was, "To promote the philosophy of lifelong learning, in an innovative and inspiring way; enabling the development of skills, knowledge and values, which will enhance the specialist palliative care provided to children, young people and their families." There was an education centre attached to the main hospice building, which housed a large library. The library contained a very wide range and a huge amount of resources to support everyone who used or worked at the hospice.

Records confirmed that all new staff received induction training when they started work. In their training plan the provider stated that, "Induction provides an introduction to the essential key areas of practice to ensure new staff and volunteers are supported to provide competent and safe practice." All staff and volunteers had completed the induction program designed for their role within six months. Staff and volunteers confirmed that their induction had been informative and robust.

Further training was on-going and staff received refresher training at the intervals required for each topic. Staff, including staff not involved in direct physical care such as housekeeping and maintenance staff, told us they had undertaken training in a range of topics. Training considered 'mandatory' by the provider included moving and handling; fire safety; food safety; safeguarding; and infection control. Senior staff carried out observations of staff practice and completed competency assessments in certain topics to ensure that standards were maintained.

The provider had a team of nurses (the Symptom Management Team), which was led by a Nurse Consultant. Part of this team's role was to provide specialist clinical advice to the nurses working in the hospice and in the community. Nurses were expected to complete self-assessments of their own competence in particular areas of practice, such as medicines administration, as well as receiving training and support from senior staff. A hospital consultant said, "The Symptom Management team provide a 24 hour on call service which supports families in managing palliative and end of life care at home. This team is excellent, a good team of experienced, highly competent Clinical Nurse Specialists."

A volunteer who worked as part of the administration team told us that the manager of the administration team was very good at making sure that particular pieces of work were given to members of the team who

had the skills to complete them. This manager also provided training based on the individual's interests to enhance the skills and knowledge of volunteers in the team.

The provider had a number of ways to ensure that communication across the service was as effective as possible. The provider's Director of Care produced a newsletter, 'Care Matters', which all staff were required to read. This newsletter gave staff updated information on everything to do with the organisation, including new or revised policies and procedures. It also included external information such as changes or additions to nationally recognised good practice. Every morning at Milton Children's Hospice there was a meeting, known as 'the stand-up meeting', which was attended by all heads of departments and chaired by the duty manager. The manager told us that "the drive is about planning and pre-empting", which this daily meeting addressed. Plans for the day across all areas of the service were discussed, so that all departments knew what was happening. This included which children and young people were staying and what events were taking place. This meant that, as far as possible, there were no surprises, such as a sudden requirement for an early lunch if a young person had an appointment to attend.

Staff and volunteers told us they felt very well supported. They received regular supervision and opportunities to attend meetings. 'Locality meetings' were held twice a year for all staff to attend and every member of staff had an annual appraisal at which they identified their goals for the coming year. The manager told us that consultations were available at any time to all staff with the nurse consultant, psychologist or family therapist if the staff member wanted to book one. Staff could also request a "peer-reflective session", for example if they had experienced a difficult shift. One member of staff said, "I get supervision every four to six weeks with [line manager]. She's good at giving advice and making suggestions. I can go to her at any time if I need anything. Or the managers. I feel I could go to any of them."

This showed us that the provider had taken steps to ensure that staff had the knowledge, skills, confidence and support to provide effective care to the children and young people who used the hospice service.

We looked at the ways in which the provider ensured that staff understood and worked within the requirements of relevant legislation and guidance relating to consent to care and treatment regarding children and young people. One of the nurses spoke with us about '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). For the majority of the children and young people who used the service their parents were their legal guardians. We noted in care records that parents had signed their consent to various aspects of their child's care, such as using the hydrotherapy pool or being taken out in the hospice's transport.

Staff told us that they always consulted the children and young people and gave them every opportunity to make choices in their daily lives. They described a range of resources that they employed to communicate with children and young people who found communication difficult. These included picture boards, iPads, and sign language such as Makaton. Parents told us, and we saw that staff knew each child well and knew ways in which to support the child to make their own decisions. For example, when telling us about one young person with very complex needs staff said, "We offer [name] two pieces of toast, one with jam and one with something else and he will take the one he wants." Staff told us that children were encouraged to be as independent as possible and never had to do anything they did not want to do.

The Mental Capacity Act 2005 (MCA), which applies to people aged 16 and over, provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf

must be in their best interests and as least restrictive as possible.

People can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in care services are called the Deprivation of Liberty Safeguards (DoLS).

Milton Children's Hospice offered a service to young people up to the age of 19. We checked whether the service was working within the principles of the MCA. Staff, especially those involved in looking after young people in that age group, demonstrated sufficient knowledge of the principles. All staff had undertaken some training in the MCA and DoLS and the manager told us that further training for all staff was in the training plan for early 2016. This meant that young people who lacked capacity to make their own decisions had their rights protected.

Parents made very positive comments about the way staff dealt with their child's nutritional needs. One parent told us that their child "can be really difficult" about food. They told us, "The staff do really well and encourage her. They are firm with her and they put up a sign 'I'm eating, leave me alone' so she doesn't get distracted." This showed that staff had considered not only the child's nutritional likes and dislikes but other influences, such as the environment, on the child's eating habits. Each child's nutritional needs had been assessed and their likes and dislikes recorded in detail in their care records. Special diets were provided for children and young people who needed them. Nursing and care staff passed this information on to the chef. The chef also had access to the computerised care records so that they could check each child's needs, preferences and any allergies to certain foods.

The chef told us how much they enjoyed working at Milton Children's Hospice. They said, "It's just wonderful, I absolutely love it. I get to cook so many lovely things. Sometimes I might have three, four or five different meals to cook." They explained that they attended the staff handover every morning so that they could "pick up whatever I need to know in advance." They told us they had recently been on a training course at the local hospital to ensure they knew how to meet one young person's particular dietary needs. The service had excellent links with dieticians and other external professionals, such as the enteral feed (directly into the stomach) nurses, who supported them with information and advice about young people's special dietary needs.

Menus were re-written every three months. The chefs from all three of the provider's hospices met to discuss the menus, ensuring that they provided the children and young people with a nutritionally balanced diet. However, the chef said that the children and young people could "have whatever they like, within what they're allowed." They said they always checked, both in the child's care records and with the nurse on duty to make sure the food was suitable. Children often came to the dining room to help prepare their own food, such as pizza.

'World food days' were planned into the menu. The chef explained that at the time of the inspection the service was celebrating Chinese New Year. At lunchtime there was Chinese food on the menu and everyone had a fortune cookie at the end of the meal. The chef told us that they provided Venezuelan food when a family from Venezuela was visiting.

On the first day of the inspection lunch was a very busy, social occasion. The young people staying for respite, the young people attending the sibling day, staff and volunteers all ate together. Young people who needed support to eat their meal were given the support they needed and staff made sure that each young person had the food and drink they wanted. There were choices for each course.

Parents told us that they were offered food and drinks whenever they visited. There was accommodation in the building for parents to stay and all meals were provided. They could eat with everyone in the dining room or choose to eat on their own if they preferred. The chef said that it was "fine" if families wanted something different to what was on the menu; it would be provided. The chef also made sure that the snack trolley was well-stocked so that there were always things for families to snack on. The chef said, "It's my job to make sure that families stay healthy."

The day-to-day healthcare needs of the children and young people were met by the staff when the young person was staying at the hospice. The service had excellent working relationships with a range of external healthcare professionals. Parents told us they were confident the staff would look after their child even if the child became ill. There was a doctor on call for the hospice throughout the day and night and the symptom management team also had on-call nurse specialists to support parents and the hospice staff. The expertise of other healthcare professionals, such as a dietician, was called on when required.

One of the staff told us that they had used non-verbal signs for pain with one young person who did not use words to communicate. This had led to the staff identifying that the young person was in pain. The young person's treatment had been changed and the pain relieved. This meant that the provider had systems in place to ensure that the children and young people they were supporting remained as healthy as possible.

Staff also at times supported the healthcare needs of young people living in their own homes. One family told us they had had a crisis in the middle of the night. By the time they arrived at the hospital accident and emergency department, a nurse from the hospice service was already there and had alerted the staff. One family member said, "The nurse had arranged everything. It was amazing and unbelievable." This demonstrated that the service ensured that the healthcare needs of the children and young people were met.

Is the service caring?

Our findings

The young people we met were not able to put into words what they thought about the staff. However, we saw from their body language and the way they interacted with the staff that they were very comfortable and relaxed with them. One young person happily cuddled up close to the staff member who was supporting them while they watched a film together. The young person behaved like any young person their age would with someone they liked and enjoyed being with. One parent said, "[Name] loved it from the first time she went there. It was clear very quickly to us that she was very comfortable there. Now she asks 'when am I going next?'." The young people in the 'sibling group' were also comfortable with the staff and the volunteers, chatting happily and having fun with them. We saw that staff were without exception kind, caring and compassionate in all their dealings with the young people, their families and each other.

Parents consistently made very positive comments about the staff and their attitude and commitment to the work they did. When we asked them to describe the staff they used words such as "brilliant", "so kind and understanding", and "amazing". Their comments included, "I think the staff are angels, they are honestly, they're great"; "Staff are amazing, friendly, you can talk to them"; "The staff are definitely kind and compassionate"; and "I don't think the staff there are appreciated enough. We can't thank them enough." One parent told us, "I think they're really good, they don't treat her like a sick child." Another parent described how the staff had guided them through their child's illness and eventual death. They said, "They guided us, they didn't push us. They're very caring. They don't just think of the child, they think of the whole family."

Some of the parents told us they had only had support at home and had not used the respite service. They were full of praise for the staff who had come to their home. One parent said, "All the staff have been lovely. There's always two staff and at least one is a familiar face that we've got to know." Parents who used the respite service also said that each time their child was admitted the admission was done by a member of staff who they had met previously and who knew them and their child. They said, "The staff know us quite well and we know them."

The hospice had received numerous thank you cards and emails. One parent had written, "To the amazing, fantastic, dedicated, focussed and caring care team. Thank you very much for all your hard work." Another wrote, "Thank you all for everything you do for us, you are angels!" Parents made it very clear that the service supported the whole family. One parent said, "They treat us very good as a family. They always offer for us to stay as a family. They offer us meals and they're very welcoming." Another parent told us, "I get a break and [our child] really enjoys it there."

We saw that one young person who had come to the 'sibling day' was very comfortable with the staff and seemed to be really enjoying their day. This young person's parents told us that it was two years since their bereavement but the young person "still loves coming to sibling days." They described how much the staff had helped their child to develop and, although still rather shy of strangers, their child had hugely gained in confidence and self-esteem. Another parent explained how much it meant to them that their older son was able to attend events such as sibling days at the hospice. They said, "He loves it. It gives the siblings a day

that's all about them. I really like that they do it; it makes our older son part of the hospice as well." A third parent said, "Just wanted to say a big thank you for the opportunity to bring [name] to Milton at the weekend - she had an amazing time, as did the rest of us. We had the opportunity to take [sibling] out and do something just for her, which [husband] and I worked out, we have never done with both of us before. All the staff were just lovely, and made us all feel really welcome."

Healthcare professionals used words such as "Patient-centred", "passionate", "engaged", "absolutely caring" to describe the staff. One said, "They are a team who care for the whole person, family, friends and the staff around them. From what I have witnessed this is always with compassion, supportive, inclusive, they listen, all at a very high standard."

A student nurse who had been on a placement at the hospice wrote a 'thank you' card to the staff. The student wrote, "You included me as part of the team, joked with me and shared your experiences with me. I am so grateful for the time you have all taken, never once making me feel I was in the way. You are all very special people and have made my first experience of nursing a valuable and enjoyable one."

Whenever possible, staff found ways to involve children and young people in planning their care and support and making decisions about the care and support they wanted from the staff. Staff used individualised techniques to enable each young person to communicate their wishes. We saw that the two young people staying at Milton were given every opportunity to make choices about their care. They were supported by staff to make decisions about what they wanted, and staff confirmed that each child was as fully involved in directing their care as they wanted to be. For one young person who did not use words to communicate we saw that staff used a variety of methods to enable them to make their choices. Staff also checked to ensure, as far as they could, that the young person had understood the choices.

Parents told us that they had been fully involved in planning the care and support their child, and they as a family, required, right from the start. They said their views were always listened to and included. Parents were also involved in any changes to the planned care. Parents who used the respite service told us that they talked in detail with the staff about their child's care every time they brought their child to stay. One parent, whose child received care at home, told us that staff "come round once a year and we go through all [name's] needs." They said that staff found out from them whether what they and their child wanted from the hospice had changed. Staff had been creative in offering other ideas for them to think about. They also stressed that "there's always someone there to speak to if I need to. It's fantastic."

Bereaved parents told us that they had been fully in control in planning for the death of their child. They had welcomed ideas and guidance from the staff but had felt they were the ones who had made the final decisions. Staff had supported them to make decisions at appropriate times in their child's life, such as putting an end-of-life care plan in place. Their wishes following the death of their child had been respected by staff and they had also been supported when they had changed their minds about certain aspects of the support they wanted. There was no limit to the time that bereaved families were supported. The support was personalised and based on the needs of each individual within each family. The manager told us how grateful they were to Muslim families who had really helped the staff understand Muslim children's immediate needs after death. This meant that staff had then been better equipped to offer an appropriate, individualised service to each family.

We saw that staff treated all the young people with respect, compassion and genuine warmth. Staff crouched down to speak with each young person at their level, made eye contact and communicated in whichever way the young person found easiest to understand. Staff told us that they utilised a range of methods to communicate with each individual and we saw this in practice. One young person with very

complex needs was known to sometimes react suddenly and in particular would throw whatever they were holding. Staff worked with this young person at a safe distance from other children, but without excluding the young person. They did not raise their voices or react in a negative way when things were thrown and continued to show the young person they were enjoying working with them.

Is the service responsive?

Our findings

The manager told us about the 'open referral system', which meant that a young person could be referred to the hospice by anyone, including their family. An assessment of the young person's clinical needs was then carried out by the hospice staff. They consulted any other healthcare professionals involved with the young person, such as their GP and hospital consultant. The young person's family, and whenever possible the young person themselves was fully involved in the assessment. If the young person's clinical needs met the criteria to be offered a service, the whole family, including extended family such as step-siblings and grandparents became eligible to receive a service. During the panel meeting, one member of staff complimented another member of staff on the assessment they had completed. They said, "It gives a real feel for the family and it's good to see the family's goals made paramount."

The manager said that over recent months the service had adopted a goal-based, outcome-focussed approach to care. A holistic needs assessment of the whole family was undertaken. This enabled the service to identify which of the young person's and family's goals they could work towards, and which they could work towards with external partners. Each young person who used the service had a detailed, personalised care plan in place. These were developed from the original assessment and were reviewed regularly to ensure they contained up to date information and guidance for staff. For young people who used the respite service, their care plans were checked every time they stayed at the hospice and any amendments documented. All the parents we spoke with told us how impressed they were that their child's care was reviewed every time they took them for a respite stay. One parent said, "The staff go through everything about [name], all the care plans, every medicine [name] takes. They make sure everything is still the same or make a note of any changes." Another parent told us, "We've been fully involved in the care plans. We go through them each time and tell them about her current schedule, but we don't dictate what they do with her."

Each young person had worked with staff to create an 'all about me' board. These were full of pictures, photographs and single words or short sentences, which gave a completely personalised picture of each individual young person.

Parents confirmed that they were completely in control of the service that they and their child received. Some had chosen to have overnight stays. Others had chosen to have care at home or day care at the hospice. Some parents had used other services, such as family therapy, the hydrotherapy pool or bereavement counselling. One parent who had never been parted from their child said, "It's my choice. The staff have been brilliant and very patient with me." They explained that to begin with they would only go to another room in the hospice. However, over a long period of time they had gained sufficient confidence in the staff to leave their child for day care and travel into the town to have lunch. One parent told us how the staff "go out of their way to help." They explained they had to go to an appointment on a day when their child was not at the hospice. The staff went to their home and stayed with their child. Another parent told us, "We were offered extra care when [name] was really poorly."

Care records we looked at reflected in detail how and where each young person and their family wanted to

receive their care and support. One parent said, "A lot of the staff know [name] very well. They recognise when he wants to move on, needs a different activity or doesn't want to go to the dining room." Care records included as much detail as possible about the young person and their family including their life histories, preferences, likes and dislikes and their hopes and goals for the future. The manager confirmed that the staff "are looking far more widely at what each family member needs, not just short breaks." The manager told us that the service was developing a 'resilience model' of support. This was based on the premise that the majority of people were resilient and that strengthening their resilience was one of the most effective ways of supporting them.

The service believed that holistic care of each individual assessed as being eligible to receive services from the hospice was of the utmost importance. A range of professionally trained therapists, including activity coordinators, were employed to make sure that the hopes, goals and aspirations of each young person and each of their family members were met as far as the service was able to. Staff understood people's cultural diversity and beliefs and recognised that these might have influenced the support they chose. Staff had the knowledge and expertise to be able to suggest other services that might be appropriate for some families. The service had developed strong links with a range of other service providers to ensure that more targeted intervention, such as mental health services, were available to the small percentage of people who needed this intervention. The manager told us that the sibling days gave staff good opportunities to informally assess if they felt any of the siblings were in need of additional help.

Families gave us numerous examples of the individualised service that the hospice had provided for them and their child. One parent told us that the staff "went above and beyond." Staff had sourced charity funding and arranged for the whole family to spend time at Centre Parcs. While they were there, staff "came and checked out we were OK." Another child's sibling had told staff how much they wanted to take their sister on holiday to Disneyland, Paris. Again, staff sourced funding and assisted the parents to arrange the trip for the whole family.

As well as responding to individual needs and preferences, staff had organised a wide range of activities and events. The manager told us, "It's all about meeting their individual needs (within the framework of safe practice)." These had included 'EACH fest' in 2015 when the whole hospice site "was given over to" a weekend of activities centred around the needs of older children and included a 'sleep-over'; the Fitzwilliam Museum in Cambridge opened its doors on one day every summer, exclusively for EACH families; and sibling days arranged in each school holiday provided a "fun, social event and opportunities for peer and therapeutic support" for siblings aged over five years. There were female carer and male carer groups and a mother and toddler group met at the hospice once a month. Outside venues were booked if it was felt the event would work better away from the hospice building. A member of staff told us it was wonderful to see how some parents made friends with other parents and continued those friendships outside the monthly groups.

Many of the parents had written to the hospice to express their gratitude for individual events. Comments included; "[Child] and I would like to say a big thank you for a lovely party. We had a wonderful time and were very appreciative of all the help"; "I wanted to say what a wonderful party you put on for all the children and their families on Saturday! It was so special, [sibling] absolutely loved his Lego and [lead child] was clutching on to his Mr Tumble bag and cheering all the way in the van! It was lovely to see the other families.....enjoying themselves"; and "Just wanted to say that we have had an amazing day - thank you so much for inviting us to take part. The film was brilliant and the workshops before the film and after were such fun. The special guests were very special indeed! Thank you again.....We will never forget today - it was very special."

The activities room was equipped for numerous different activities for all age groups of children and young people who used the service. An activities board was available, giving care staff ideas of activities they could do with the young people currently in residence. To assist care staff, the activities staff had prepared trays of equipment for particular activities that the young people might have been interested in. When we visited, the Chinese New Year and year of the monkey was the theme for the month. The trays included all the items needed, for example to make a Chinese mask or a Chinese lantern. One of the activities staff told us they planned ahead for the young people who would be coming in, based on what they liked doing. They contacted some of the older children prior to their stay and arranged what they wanted to do, such as a cinema trip or taking them bowling. At Christmas, staff took three young people on the train to Audley End to meet Father Christmas. On Christmas Eve, one of the young people had suggested they held their own X-factor talent contest, which had proved to be great fun. This member of staff said, "The service is good, there's always a lot on offer, very varied."

A sensory room, complete with a water bed, soft play equipment, lighting and sensory objects was available and had recently been fitted with a full ceiling hoist tracking system so that every young person would have full access to all areas of the room. A newly purchased interactive floor projection system, which responded to young people's gestures and movements was in use in the communal day room. Staff told us how brilliant it was and how much pleasure it gave the young people, especially those with complex needs, as they could lie on the floor and create their own pictures, designs and light movement. Specialist board games, which therapy staff used with some individual young people to work through certain issues in their lives, such as chronic illness or bereavement, were available in the library.

The provider had a complaints procedure that was available to anyone who wished to make a complaint. The procedure was advertised on notice boards throughout the hospice building and on the provider's website. However, young people's families told us they had never had any reason to complain. They all said they would be more than comfortable speaking to any of the staff or to the manager but had not had to. Comments included; "I can't think of anything that I'm not happy about. I have no criticism at all"; "There are staff I'd be comfortable speaking with if I had a problem, but it's all been very positive"; "I think they do a fantastic job. There's nothing they could do better"; and "We've never had any problems. I'm really happy with the care [name] receives there." Healthcare professionals said they had never had to raise any concerns but they were sure the staff would listen if they did have the need to raise anything. One said, "I feel the team would be happy to discuss a concern or review a process that could be improved."

The manager reported that they had received very few complaints, but issues that had been raised had been investigated and responded to within the timeframe detailed in the procedure. For example, there had been some concerns raised about the number of cancellations of respite stays. On investigation the provider had found that there had been far fewer cancellations than families and other professionals had perceived. Nevertheless, the provider had considered ways of ensuring that cancellations happened as rarely as possible. Every effort had been made on each occasion to only take this course of action if staffing available meant that the service would not be safe or would not be of the quality the hospice aimed to provide. The staff team had worked hard to make sure that in all cases an alternative service was provided and the original request fulfilled as soon as possible. In another complaint one family had said they felt that their initial visit to the hospice had been very rushed. The manager said that lessons had been learned and the way visits were organised had been changed to ensure that families would not feel that way. This showed that the provider had systems in place to ensure that any issues raised were addressed.

Is the service well-led?

Our findings

Our discussions with everyone involved with the hospice confirmed that the service was inclusive and empowering. It focussed firmly on responding to the needs and goals of each family and each individual family member. Staff and management went out of their way to ensure that everyone was fully involved in the service provided to them and to ensure that the service was of the highest possible quality. Families told us their views were always sought, and acted on whenever possible.

Healthcare professionals said that regular reviews were undertaken of the work they and the hospice staff did together and their opinions and ideas were actively sought and encouraged. One told us that staff were "approachable to discuss changes and new ideas." The service demonstrated that it sustained improvements and was constantly striving for excellence. One member of staff told us, "We're making changes all the time. Not because things are bad, but making it more and more child-friendly, even more child-orientated." They told us, for example, how the furnishings in the main communal area had been changed around to meet the needs of the young people staying at the service and to make the area more welcoming.

Families told us how much they depended on staff support through the most difficult times of their lives. Their praise of the service included: "It's brilliant. I love it. It's the only care I use because I really trust them"; "We couldn't have managed without it"; and "For us it's been a revelation. It's really nice to know we can drop her off and she's going to be fine." One parent wrote, "Thank you all for all your amazing support and an absolute life line for us as a family." Another wrote, "Thank you for all the support and care over the last year. It is greatly appreciated by us all." A bereaved family who were still heavily involved with the hospice told us, "The biggest thing for us: it didn't just stop when [name] died. The hospice is still very important to us."

One family explained that they did not initially accept any services from the hospice "because 'hospice' means end of life." But they had learnt that there was so much more offered than end of life and their child loved going there for respite stays. They said, "In a nutshell, we've benefitted and [name's] really enjoyed it." Another family told us, "Nothing is too much trouble. EACH is very special to us. We try and support the hospice whenever possible and we spend time raising awareness because we weren't aware [of the diverse services that the hospice provides]."

Staff and volunteers told us how much they enjoyed working at Milton Children's Hospice. One member of staff said, "It's a good team of staff." A volunteer said, "I love it. It's such a nice environment. I really enjoy it." When we asked what they thought was good about the hospice, they said, "The people here [staff, managers, visitors, young people]. It's the most positive place I've ever worked. Everyone is always so upbeat, friendly and welcoming." They added, "It's the little things that make you think this is really nice. We get a birthday card and present. At Christmas we all get lunch, which is served to us by the director and senior managers. It's nice to feel appreciated." A member of staff told us, "The service is really good, very varied, very supportive of families and very accommodating and flexible."

There were systems in place to make sure that staff and volunteers had the support they needed and received feedback about their work. One volunteer said, "I absolutely feel supported, very much so. I could go to anyone." Staff told us about their individual supervision sessions with their line manager. Other staff described the management as being "supportive" and "available". Staff were encouraged and supported to report incidents. A 'no-blame' culture had been developed so that staff felt comfortable reporting and lessons were then learnt by the whole team. A member of staff reported that they had used the whistle blowing policy to raise a concern. This member of staff said they had "felt supported throughout" and that they had been "fully included" in the process.

Our discussions and evidence we found during the inspection showed us that the service was managed well. The manager was very visible and everyone we spoke with knew members of the management team and said they were comfortable speaking with them. One parent told us, "From the way it works, and our experience, it's managed very well. Seamless." There was a registered manager in post who had managed the hospice service for 10 years. Staff felt that the management motivated and inspired staff to provide the best possible service to each child and their family.

One of the staff described how much staff appreciated that the manager had introduced a '10 minute time out' for staff to support their "emotional well-being". Staff were given opportunities to participate in a short break, which could include a walk, exercise or art therapy". Another member of staff told us that the manager made sure there were opportunities for staff to have a de-brief after a difficult shift or following the death of a child in their care.

Staff said the hospice had a very good ethos, putting young people and their families at the forefront of the service. A healthcare professional told us how the service had improved. They described the culture of the service as "open and transparent..... positive and a 'can do' attitude."

The manager had completed a CQC Provider Information Return (PIR) in December 2014 in which she described various aspects of the service. The manager also gave us information about what the service had hoped to achieve 'in the following 12 months', which was 2015. We discussed this on the day of the inspection and everything that had been planned had been achieved. Our records showed that during the 12 months before the inspection, CQC had not received any notification forms from the service, as required by the regulations. Discussion with the manager confirmed that she was aware of the regulations. Records showed, and the manager confirmed, that no reportable incidents had occurred.

The provider had a number of systems in place to carry out checks to ensure that the hospice provided a high quality service. Each area of the service had a Care Quality Risk Group, which was responsible for completing audits in that area, for example care planning or catering. Each audit resulted in an action plan and completion of actions was checked at the next audit. The lead staff member from each group then reported to an over-arching risk group, which in turn reported to the clinical governance committee and the board of trustees. The manager also completed an organisational audit plan, which was monitored by the provider's quality team.

To ensure quality in medicine management, the hospice group had access to specialist pharmacist advice via a service level agreement with Cambridge Community Services. We saw they had reviewed the medicines incident data and identified areas for action. For example, it was identified that a high number of incidents were linked to the receipt and disposal of medicines and in response to this the provider had implemented daily stock checks.

The provider had a medicines management group made up of staff from all three of their locations, which

met quarterly. This group identified work plan activity for each year and monitored progress against the plan. All medicines information was circulated to staff via a newsletter 'Medicine Matters'. The provider had a 'controlled drug accountable officer' who was part of and reported to the local intelligence network.

The provider demonstrated that they had learned from comments and criticisms. For example, they had learned from staffing issues and had made the decision to limit the number of young people staying at the hospice at any one time so that they could be sure the young people were safe. Also, they had taken on board the comments CQC made about medicine records transcription at another of their services. They had reviewed and risk assessed their practice. They did this again between the two days of our inspection and found their current practice was safe.

The management team and the staff had worked hard to develop partnerships with other agencies. All four healthcare professionals we had contact with, which included consultants and senior hospital nursing staff, made very positive comments about the excellent working relationships they had with all the staff at the hospice. One said, "[Name of manager] and staff bend over backwards. They go above and beyond to accommodate us. I'm really pleased about the way we work together." They said, "Working with the hospice staff has changed our practice for the better." Another told us, "I have experienced clear information sharing from the senior team, they are aware of the services within the hospital. They work closely with [a number of the hospital teams]." A third healthcare professional told us that the team definitely "go the extra mile". They said, "The team have always made themselves available to discuss a new referral, a family they are involved in and give advice for professionals and for families. They are a team who always think about the whole family and the journey of the child."

They told us that the holistic approach of the hospice had resulted in the staff being very pro-active in developing partnership working with a range of other services. One healthcare professional told us they were involved in "parallel-planning" with the Symptom Management Team to work out how to best support babies at home, which was "really really good". Another told us, "The Symptom Management Team has extended care into the community, supporting local services and families to care for children at home. The model of care is integrated across a number of different services including, NHS acute and community." Another wrote, "If a child is receiving end of life care from both organisations, we all maintain dialogue between ourselves, GPs and any other professional involved at the time."

One of the healthcare professionals we spoke with told us how impressed they were with the way the management and staff team worked with them and each family to provide the best possible experience to families preparing for the death of their baby. They said they had worked "in partnership" with the hospice staff for over five years and together had developed a neo-natal 'pathway'. The healthcare professional said that the hospice staff met with them weekly so that all the services involved were kept up to date with each child's, and their family's, progress. A hospital consultant wrote, "This team works very closely with my service... to provide a comprehensive integrated service which is tailored to individual children and families' needs."

The manager reported that the Symptom Management Team had worked hard with GPs who were now fully involved with the service provided to their patients. GPs attended meetings to discuss the management of their patients' care. Hospice staff also had excellent working relationships with hospital consultants, which was demonstrated by the comments we received.

As well as being responsible for updating evidence-based policies and procedures, which all staff were required to read, the library staff provided an on-line education and resource centre for a number of other hospices, other providers and individuals such as health and social care professionals. One member of staff

said, "EACH is very good at sharing resources and encouraging other organisations to use the library facilities."

One parent told us that they had helped the hospice make a video about the service, which was taken by a nurse to a hospice in Malaysia to help that hospice develop. The family had also allowed their story to be made into a story board, which was used in the hospital. This gently introduced parents, new to the realisation that their child had a life threatening condition, to the services the hospice could provide, before they had to make a decision. A healthcare professional described the story boards as "beautiful, really colourful, with the story well-written and not upsetting."