

## East Anglia's Childrens Hospices

# Quidenham Children's Hospice

### Inspection report

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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

Quidenham 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 at Quidenham.

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.

Quidenham Children's Hospice is housed in a converted building in the peaceful grounds of a monastery. The in-house short break service is housed in a two storey building and includes shared areas for relaxation, play and meals, single bedrooms and a kitchen. There are bathing facilities and facilities for families to stay.

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

This comprehensive inspection took place on 8 March 2016 and was unannounced. On the day of the inspection no young people had stayed the previous night. We met three young people and their families who arrived during the afternoon 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 2 years.

The young people we met were very happy to be staying at the hospice. We saw from their body language and their interaction with staff that they were comfortable and relaxed with the staff. Parents were effusive in their praise of the staff and of the service they and their children received. They told us how much the care and support provided to them and their child meant to them.

There was a very strong 'person-centred culture, which recognised and supported the holistic needs, preferences and goals of each individual child and each of their family members. Everything that happened was based on meeting those needs, preferences and goals. The service 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 the family needed support.

We saw that there were warm caring relationships between staff and the young people and also with their parents. There was a lot of laughter and fun. Staff were well-trained to meet the complex and specialised needs of the young people in their care. Staff treated every young person with care and compassion and with respect for their privacy, dignity and independence. A wide range of methods was used to communicate with each young person in the way that enabled the young person to make choices about their everyday lives.

Staff had extremely good, caring and respectful relationships with parents. Parents were grateful for the attention staff paid to detail and felt staff knew them and their children well.

There were systems in place to make sure that young people were kept as safe as possible. There were enough staff on duty to support each young person in the way they needed and preferred to be supported. Pre-employment checks had been carried out to make sure that staff and volunteers were suitable to work in this environment. Staff had been trained to recognise and report any incidents of harm and medicines were managed safely. Any potential risks to each young person had been assessed and guidance put in place so that staff knew how to minimise the risks.

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 applies 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.

Young people and their extended families were cared for by a highly motivated, dedicated and well supported staff team. A wide range of age-appropriate activities, outings and events were organised and young people were supported to pursue and develop their own interests. The service was as fully responsive as they were able to be to the needs and goals of the young people and their families. Families valued the events and therapy sessions which were arranged and which they were encouraged to attend both during their child's life and following bereavement.

Holistic, detailed needs assessments were undertaken so that staff were fully aware of the 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 service was managed very effectively by a dedicated registered manager who was extremely passionate about their work; about the young people and their families they provided a service to; and about their staff team. The whole staff team learnt from any mistakes and were constantly striving for excellence.

Everyone involved with the service was encouraged, in a number of both formal and informal ways, to give their feedback about the hospice and the service it provided. Numerous compliments had been made about the service, the management and the staff team. Parents were aware of how to raise any issues if they needed to and felt comfortable doing so. 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.

## 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 a service 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 exceptionally kind and compassionate staff in a way that respected their privacy and dignity.

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

The spiritual and religious needs of young people and their families were well supported.

### **Is the service responsive?**

The service was very responsive.

Outcome-focused, 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.

An exceptionally wide range of age-appropriate activities, outings and events were arranged to suit young people and their families. Young people were encouraged and supported to develop skills and interests.

Complaints and concerns were welcomed, encouraged and responded to well.

**Outstanding** 

### **Is the service well-led?**

The service was well-led.

The service was fully inclusive and empowering of young people and their families and was managed very 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 well with a wide range of external healthcare professionals, developing partnership working and mutual support.

**Good** 

# Quidenham 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 an expert by experience. An expert by experience is a person who has personal experience of caring for someone who uses this type of care service.

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.

We spoke face to face with one young person, one relative and three foster carers. We also spoke with three relatives over the telephone. We spoke with staff (three care staff, one nurse, a chef and one duty manager) and the registered 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 registered 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, "Yes, [name's] definitely safe here with the staff". They explained how critical it was for their child that staff recognised immediately if the child was not well. They had confidence that staff at Quidenham were able to do this so would keep their child as safe as possible. Another parent said, "I am so relaxed when [name] is there. I know [they are] safe. It gives me sleep, helps to keep me focused, keeps me going."

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] safe here. Any needs he needs they can do it here. They're on the ball and we've no worries about this place at all." 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 need to do so.

Staff told us, and the registered 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. A member of staff told us, "We worked through scenarios. Safeguarding covers such a wide area, for example, the internet." 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. This training had been arranged for all staff during 2016.

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 a short break 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 medicines; nutrition; mobility; and travel as well as any risks identified as specific to the child. For example, how to keep the child safe from avoidable harm at night.

A parent whose child had died told us how much they appreciated the steps taken by the staff to make sure their child's body was safe at the hospice. The room their child was lying in was kept locked when they weren't there. When the hospice closed for a few days, which meant there were no staff in the building at night, the registered manager had assured them that the building was secure. They said the registered manager had even alerted the fire brigade so that in the event of an emergency they would know there was a child in the building and which room they were in. This parent told us, "It meant a lot to us to know that [name] was safe."

Equipment had been put in place to make sure that children and young people were supported in the safest way possible. For example 'safe-space' cots and beds had been provided so that children who were at risk of harm during the night if they slept in a regular bed or cot were protected. Mattresses could be placed at floor level if that was safer for a particular child. Suitable hoisting equipment was available for young people who required assistance to transfer, for example from their chair to their bed. We saw that equipment was checked regularly and maintained to ensure it was in a safe condition.

The provider had systems in place in case of emergencies. For example, fire safety systems, water and electrical equipment were checked regularly as required. There was a generator on site to provide a supply of electricity if the main supply was not available. Parents were aware that young people staying at the hospice might need to return home in the event of an emergency which meant the young people were not safe. The registered manager said this had happened very infrequently. They quoted one occasion when the telephone network had not been available, which meant that staff would not have been able to contact any emergency services if they needed them. One young person had had to go home.

We asked about the staffing in the hospice. On the day of our visit we saw there were sufficient staff on duty to fully meet the needs of the three young people who arrived for their short break. One of the staff told us, "There are always enough staff to run the shift safely. Things are always put in place to ensure safety." Another member of staff said, "There's enough staff – we're flexible. [There are] extra staff on duty if a child needs additional staff." There were also enough staff to meet the needs of the young people who were receiving a service at home.

Staff told us that recruitment procedures were rigorously followed. One member of staff described the recruitment process. They said they had completed an application form and had two interviews. References had been sent for and a criminal record check carried out through the Disclosure and Barring Service (DBS). They said, "I wasn't allowed to start [working at the hospice] until they'd all been returned." The registered manager told us that the same rigorous procedures, including references and a DBS check were followed for all volunteers who spent time at the hospice. This included volunteers who did not have direct access to the young people using the service. This demonstrated that the provider had a robust system in place to ensure that only staff and volunteers 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, "They deal with the medicines OK. They're checked every time we fetch [name] in. They go all through it in case of changes." Another parent said they were "happy" with the way staff managed their child's medication needs.

Nursing staff told us that they completed regular training on medicines administration and were supported to learn techniques such as administering via nasogastric tubes. We saw that there was a medicines policy and a range of standard operating procedures covering all aspects of medicines management.

We saw that as part of the checking process, families were asked to confirm which medicines had already been given that day to avoid duplication. We also saw that where it was unclear how a medicine should be given, there was a process for resolving the discrepancy. Medicines, including those which need to be stored in refrigerator, were stored safely. 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.

The hospice had a range of over-the-counter medicines available, and there was an arrangement in place with a local GP who visited regularly and could be contacted in an emergency. There was a nurse prescriber

who could issue a prescription if needed. The hospice group had access to specialist pharmacist advice via a service level agreement with Cambridgeshire Community Services NHS Trust. We saw they had reviewed medicines incidents and identified areas for action. For example they identified that a number of incidents were linked to stock discrepancies, so they introduced a nightly check of the stock against the MAR charts

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, "I'm very confident about the nursing care. They really understand tubes, oxygen, medicines". Another parent felt the staff were well-trained. They explained, "At check-in they always check feeding and water regimes and medicines very thoroughly and any changes are implemented immediately. They check labels and expiry dates on everything too." A third parent told us, "Staff understand and are perfectly well trained. We have no concerns at all."

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 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." The registered manager told us, "Education is an important part of working here."

There was an education centre attached to another of the provider's hospices in Milton, 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 all three hospices. The member of staff who managed the library sent information and resources to staff whenever it was requested.

All new staff received an induction pack and 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 had completed the induction program designed for their role within six months. Staff 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 kitchen, 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. Staff told us they had e-learning (on the computer) and face-to-face training. Other topics included neo-natal pathway, end-of-life, resuscitation and positive handling (for caring for young people whose behaviour challenged the service). Senior staff carried out observations of staff practice and completed competency assessments in certain topics to ensure that standards were maintained. One member of staff said, "I'm definitely offered what [training] I need."

A member of staff told us, "The training is brilliant, for everything you need." They said that staff were able to do training, such as gastrostomy (tube feeding directly into the stomach) training as often as they felt they needed to. They explained that they undertook research and training and then a member of the provider's education team of staff had to "sign us off as competent". Staff explained that some procedures, such as

tracheostomy suctioning were "child-specific" so staff had to undertake training for each young person who had a tracheostomy in place. A parent told us how much it meant to them that the staff on duty were always "the right staff, right qualifications and skill-fit" to meet the whole family's needs.

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.

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. Daily internal meetings were held to ensure that information was cascaded to all staff, including information about the young people who were staying at the hospice, those who were arriving later in the day for their short break and any events that were taking place during the day.

Staff told us they felt very well supported by the registered manager, the senior staff and each other. One member of staff told us, "The nurses are all fantastic at giving you the support you need." Another member of staff said, "I can talk to anyone. We support each other more than we realise." All staff received regular supervision from their line manager. The registered manager told us that all line managers had undertaken training in supervising staff to ensure that they provided effective supervision.

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. The nurses were knowledgeable 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 being taken out in the hospice's transport or using a hydrotherapy pool at another venue.

Staff showed that they had a good understanding of consent and the need to give every young person opportunities to make choices about their daily lives. Staff told us they used a range of methods to communicate with each young person, including sign language, picture cards and hand-held computers. They told us that for young people who were not able to give their consent, staff consulted their parents and decisions were recorded. We saw that staff knew each young person well and were good at knowing how to support the young person to make their own decisions. 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).

Quidenham 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 registered 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.

The young person we spoke with was very positive about the food they were given at Quidenham. They told us they really only liked one particular food. When they arrived for their short break they were clearly very pleased that the chef had made this favourite food ready for them. Parents made very positive comments about the food. 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. One parent said, "The food was amazing, really nice and they always checked what we wanted. They made sure we had drinks and snacks and everything we needed." The registered manager told us that the chef had researched and provided Lithuanian food for a family who were missing their Lithuanian food.

The chef told us that menus were written based on which children would be staying in the service, day visitors and families. Menus were nutritionally balanced and included the likes, dislikes and medical requirements of the young people and their families. They said that a lot of the young people who stayed or had day services at the hospice did not eat as they were given food by means of a tube. However, the chef made sure that young people who did eat were given the food they liked. The chef said, "Today, one of the young people likes finger food so the menu will be adapted."

Each young person'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 told us they 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 demonstrated that they knew each young person's dietary needs and preferences very well. They told us that one young person liked a particular combination of food but it had to be arranged on the plate in a certain way or they would not eat it. The chef told us they checked the computer system and spoke with the nurses daily to make sure young people's medical needs and their preferences had not changed. The chef told us they had accessed a course at the local hospital so that they could provide a ketogenic (high-fat, adequate-protein, low-carbohydrate) diet to help a young person's medical condition.

The provider had systems in place to make sure that the healthcare needs of the young people were met. Parents told us that they dealt with almost all of their child's medical appointments when their child was at home. However, 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. 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.

Parents told us they were confident that arrangements were in place for their child should an emergency

happen whilst the child was at Quidenham. One parent said, "They take [name] to [hospital] when needed, they call the GP if needed and always contact us straight away. ...[we] know [name's] looked after." Another parent explained that "small things can make a huge difference not only to [name's] well-being but also to [their] health." They said it was "crucial" that attention was paid to how their child's health and care needs were managed. They had confidence that staffs' attention to detail would ensure that nothing was missed and their child would remain in good health.

## Is the service caring?

### Our findings

We saw the three young people as they arrived at Quidenham for their short break. They were full of smiles and obviously very happy to see the staff and very happy to be staying there. Their body language and the way they interacted with the staff showed that they felt comfortable and relaxed with them. Staff were equally welcoming to the parents who brought the young people in. One parent told us, "[It's an] excellent service. We've been going for several years. [Our child] always smiles and claps [their] hands when we arrive. [Name] is happy to be there."

Parents consistently described the staff in terms, and with inflection in their voices, that told us they thought the staff were outstanding. The words and phrases they used included "just amazing"; "approachable"; "lovely"; "caring"; "helpful"; and "dedicated". One parent said, "I am very happy with the staff and would recommend Quidenham to others. I couldn't manage without them." Another parent told us, "All the staff are amazing, brilliant, so nice, professional and friendly. Even the receptionist is really lovely and very helpful when you ring."

Parents told us they had huge amounts of confidence in the way the staff cared for their children. One parent told us, "[Staff are] pleasant, helpful and efficient. There's always one-to-one and you know [name's] looked after." Another parent said that Quidenham was the only service they accepted because they knew the staff were very well trained and could meet the extremely complex needs of their child.

Young people who had attended a 'youth event' had included comments about the staff in their evaluation of the day. The comments included, 'The person running it was kind'; and '[name of staff member] was fantastic and made good jokes'.

We saw that staff were without exception kind, caring and compassionate in all their dealings with the young people, their families and each other. Staff knew each young person well. They knew the details of their care as well as details of their likes, dislikes, preferences and goals. One parent told us, "[Staff are] all very good. They've coped with [name] very well. Staff understand [name]. Staff know what [name] does if [name's] worried or wants to go to bed."

Staff treated each young person with complete respect. Staff made sure they were at the young person's level, sitting down, on their knees or on the floor, when they talked to them. They gave the young person their full attention, making the young person feel that they really mattered. A parent told us, "They always do the things he likes, they know and understand him very well." Parents said that staff made them feel that they mattered too. They said, "They make you feel like you're the only family" and, "They do it so well. They're very good at making you feel you're special and an individual."

The registered manager explained that it was equally important to look after families. For some parents their time at the hospice was the only time that they were the ones being cared for. They really appreciated the accommodation, having their meals cooked and being looked after. A parent told us, "If you need to stay, they look after you too, as well as your child. Even do the washing!" In the PIR the provider wrote, 'Holistic

care for the whole family is planned and delivered at all times. For example, a family stay caring for all six of them so that parents got a break from everyday stresses and strains.' A member of staff said, "Knowing that you're supporting families is rewarding in itself."

Staff told us they looked after each other. As an example, they told us about the support experienced staff gave to newer staff who were experiencing their first bereavement. One member of staff said, "We work as a team. No-one is made to do things they're not comfortable with."

One parent explained they had not used the short break service. Their baby had died in hospital and had gone to Quidenham so that they could "spend time to say goodbye." They had been amazed at the caring and compassionate way they had been treated by the staff. They found it difficult to put into words just how much the care and support they received had meant to them. They told us, "They really looked after [name]. They kept him clean and washed his clothes. Even though he had died they still really cared for him."

Parents who used the short break service were full of praise for the staff. They told us how important individual members of staff had been to them. One parent said, "[Name of staff member] was on duty for a large proportion of [name's] stay, which was excellent as [they] knew [name] well and was able to hand over details of [name's] care to other staff."

The service ensured that young people and their families had support available to meet their emotional, spiritual and religious needs. This included making sure that the times of Mass and contact details of the local priest from the convent were available for a Catholic family whose child was dying. Staff were trained to be aware of the cultural needs of young people and their families and to ensure that when a child died those needs were met in a sensitive and culturally appropriate way.

At the time of our inspection the hospice was not actively providing end-of-life services as none of the children and young people they were supporting were at that stage of their lives. However, families told us how they had felt supported to make decisions about end-of-life care for their child.

We spoke with bereaved families who were grateful for the compassion, empathy and patience shown to them by the staff. One parent told us they had been given information throughout the time they were supported by the hospice staff, as and when they needed it. For example, they were introduced to the idea of attending a bereavement group and they said how much the bereavement group had helped them.

Young people and their families were fully involved in the planning of their care and in making choices and decisions about their care. Staff told us they used a range of personalised methods to communicate with each young person. In this way they made sure that the young person was enabled to make choices about their everyday life. One member of staff said, "Each child has their own way of communicating." Staff told us the methods included showing the young person two choices; using yes and no flash cards; picture cards; sign language; and objects of reference. The details of the methods most successful for each young person were described in their care plan. Staff gave us an example where they showed one of the young people a plastic glove and the young person knew the staff were asking them if they needed any personal care. Parents were sure that their children were given every possible opportunity to make choices and decisions for themselves. One parent told us, "They don't just give [name] a toy that they know he likes, they offer him choices, he decides." Another parent said, "[Name] definitely chooses for herself, she uses signs. She likes to go out, especially to the zoo."

Staff were extremely skilled at ensuring that young people's privacy and dignity were respected and that young people were encouraged to be as independent as possible. We saw that the young people were offered personal care very discreetly and they were supported to do as much as they could for themselves.

Families were also offered privacy in the accommodation provided for them. Staff spoke about and to the young people and their families with the greatest respect and admiration.

Information about young people and their families was treated in complete confidence. Information was shared, with us and with other professionals, on a strictly 'need-to-know' basis. Each family chose which professionals were allowed access to their computerised records. A healthcare professional told us they felt it was beneficial for families to allow other professionals access to their records. They fully respected each family's decision and knew that staff at the hospice did too.

Staff spoke about young people and their family members in a compassionate and caring way. A wide range of trained, skilled and experienced staff, including play therapists, an art therapist, a music therapist, counsellors and psychologists were on hand to support families. The staff team constantly checked, with the family and with each other, that they were meeting the holistic needs of the young person and their whole family in the way the young person and their family wanted.

Staff made every effort to ensure that young people staying at the hospice for a short break kept in contact with people who mattered to them, as much as they and their families wanted. They encouraged parents to contact the hospice whenever they wanted to. One parent said, "I call morning and night, just to find out what sort of day or night [name] has had. I know [they are] very well looked after and I always apologise for calling. But they understand and I am always greeted very warmly." Another parent told us, "When [name] is there I phone every morning and evening, no problems at all, never feel like I am being a pain."

Advocacy services were available if a young person or their family needed independent support. The registered manager said that parents were always told about the advocacy service offered by Together for Shorter Lives. They also told us that members of the staff team were available to act as an advocate for a young person or their family. A healthcare professional told us about a keyworker scheme that some staff were involved in, in which the keyworker acted as "an advocate for the child and family."

## Is the service responsive?

### Our findings

The provider had an '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.

A fully personalised care plan was developed for each young person, based on the information in the original assessment. The care plan addressed the holistic needs of each individual 'lead child' and their family. 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. One parent told us how pleased they had been at the staff's attention to detail. They said, "Before [my child] came here for the first time, the occupational therapist came to our home and took videos and photos of everything – sleeping position, tubes, all the things that need to be right." The planned care was based on the goals each individual in the family wanted to achieve and the outcomes they wanted from the service. It was agreed by the young person and their parents. One healthcare professional told us, "I've really noticed how holistic they are in their approach to the child and their family."

Young people had been involved in developing a 'one-page profile' about themselves, entitled 'All about me'. The profiles were very personal to each young person and included lots of pictures, photographs and words to describe what they wanted other people to know about them.

Care plans were reviewed regularly or when the young person's needs changed. For young people who had short breaks at the hospice, their care plans were reviewed in detail each time they arrived for their stay. A member of staff sat with each child and/or their parent and went through the detail of every part of the care plan with them. Any changes were noted so that amendments would be included in the care plan. In this way detailed, up to date guidance was available so that staff could deliver the care and support each young person needed in the way they preferred. Parents had confidence that the care plan would be followed by the staff. One parent told us, "[My child] has two-hourly feeds, which is very demanding, but they always follow the care plan. I don't need to worry." Another parent, when talking about food for their child, said, "They have a list of what [name] likes in his file, no problem at all."

Staff told us that care plans were "definitely useful" and were referred to all the time by the staff. One member of staff said, "[The care plan] gives a good picture of the child and their needs. Gives the most up-to-date information you can have. It's one of your main tools; you have to go by the care plan." A parent confirmed that staff followed the care plan. They said, "They're very good. They keep the routines, they go through the care plans, we give them every detail." This parent explained that they had "a book that everything goes in. They [the staff] can read how [name's] been and what's been happening."

We saw that one young person's admission was carried out by a member of staff and the young person's parent. A second member of staff engaged the young person in an activity of their choice. Another young person was fully involved in their admission. We noted that the member of staff addressed their questions initially to the young person to make sure their thoughts and wishes were taken into account. One parent was excited that their child had started to stay at the hospice. They told us, "It felt good to get things in place. The booking staff were brilliant, we talked for 20 minutes about what needs to happen." For young people who received a service at home, reviews of their care plans took place regularly, dependant on the service they were receiving.

Parents told us they were completely in control of the service they and their child received from the hospice. Through the assessment, care planning and review process they were able to decide on the service they wanted and what they did not want. One healthcare professional told us how important the service was. They said, "Families who receive short breaks appear to benefit greatly from the service both in house and at the child's home and it is a very needy service that the children and families require."

Parents, healthcare professionals and the registered manager gave us numerous examples of how they felt the staff team had 'gone the extra mile' to provide a truly person centred service to young people and their families. Examples included; one young person was offered a bath at the hospice three times a week for several months while their parents were moving house and having their bathroom adapted. Twenty-four hour care in their own home was provided for one young person so that their parents were enabled to take up an important opportunity that included a night away. Another young person was offered an emergency short break when one of their siblings was admitted to intensive care in a hospital abroad. This enabled both parents to be with their other acutely sick child. One healthcare professional told us, "The service is set up to be holistic but as individual staff they really think outside the box. The staff are very knowledgeable about and good at linking up with other services. This extends to transition [when young people move to adult services]."

Staff worked with external professionals and sourced additional funding to meet some of the goals that families were aiming for. For example, a healthcare professional told us, "I've really noticed how holistic they are in their approach to the child and their family. They are really really helpful. They find information about charity funding, for example, for driving lessons."

As well as working with external partners, additional services outside the hospice had also been provided for young people. An overnight stay for two young people had been arranged in a guest house. These two young people wanted to spend time with each other but one of them, for medical reasons, was not able to stay at the hospice. A room in their GP surgery had been booked for one young person who had no transport so that staff could deliver counselling to help the young person understand their diagnosis. A hydrotherapy pool, with the necessary temperature and levels of cleanliness and safety, had been found within travelling distance of the hospice to provide regular hydrotherapy to several young people who benefitted from the treatment.

One parent told us about their child who was diagnosed half way through the pregnancy with a serious life limiting condition. They said, "We were with Quidenham straight away. A member of staff came every few weeks and when [name] died the support stepped up." Their baby remained in hospital until they died and then went to Quidenham so that the family had time to say their goodbyes. They told us about the services that the Quidenham staff had organised for bereaved families. For example, they said, "We go every month to the 'grieving group'. We meet other parents who've lost a child. It's helped us, and it's nice helping other people." They also told us about the Memory Day held in September each year and other events including, "They hold a barbeque and evening for all the families who've lost a child."

One parent said, "The support never stops." They told us that as well as the bereavement and sibling groups they were involved in, the staff involved them in a range of other events. Staff had given them tickets to a London premiere of the film, Shaun the Sheep. It was a showing for invited children and their parents only and afterwards the children made models of the characters in the film. They were joined by three members of the royal family. Parents had also been given other 'treats' such as theatre tickets, and admission to a local zoo whenever they wanted to go.

One young person who had only had care at home from the hospice staff had had a short break at the hospice in an emergency. This parent told us the service had gone "above and beyond". The service had ensured that a member of staff who cared for the young person at home was on duty when the young person arrived and during their stay. The parent had written to the hospice: "I am writing to say how wonderfully smoothly [name's] recent stay with you went. A huge part of this was due to the hard work and dedication of [name of member of staff] whose attention to detail meant that all issues were addressed in advance."

Regular events were arranged for siblings. There was a day during each of the school holidays when siblings were invited to the hospice to take part in activities that they had chosen to do. A parent reported that one of their children who attended a sibling day had said, "I don't ever want this to end." This parent said, "[Their other children] thoroughly enjoyed it, they had lots of fun and that made me feel happy."

There was also a monthly evening activity for siblings. One parent told us, "They've been very good to [name of sibling]. [Name] really enjoys the monthly sibling night: he has to choose between Beavers and the sibling night and he always chooses the sibling night. He loves it." They also said, "When we were here with [name of lead child] the staff always made our other child feel welcome. He sat with staff and the other children doing whatever they were doing. He watched films and made models. They made us feel we were part of a family."

The staff had responded to the wishes and needs of the older children they were providing a service to. Some of the teenagers were offered weekend 'sleepovers' at the hospice. This meant they were with others of a similar age, rather than the wide age range of the young people who had short breaks. One 'sleepover' was planned for six teenagers to spend a day at the Strawberry Fair in Cambridge and have a take-away for supper "to give them normality and independence."

Young people who had attended a 'youth event' had been encouraged to write down their comments or tell staff so that they could write them down. Their comments showed that they had felt able to be honest in their opinions about each of the activities. For example, comments about air rifle shooting were 'love it'; 'liked it a lot'; and 'I did not like the gun and got a bit bored.' The comments about the whole stay were all positive and showed that the event had been a success. One young person wrote, 'I really enjoyed myself and didn't want to go home.'

One parent told us, "Nothing is too much [trouble]. They go out of their way to help you." They said that what was really special for them was when the staff made a picture of the family's hand prints, with the hand prints of their child who had died in the centre.

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. Parents told us they would know how to complain, but they had not needed to. They said they had been given a leaflet and had the registered manager's name and telephone numbers. One parent said, "They [staff] listen. You can say what you want." All the feedback we received was positive. Parents felt the

management team would be responsive to any concerns that were raised and that the team was pro-active in dealing with issues so that no-one felt they had anything to be concerned about. One parent said, "I don't think anyone's frightened to say and if you wanted to complain it would be dealt with." Another parent added, "We've had two children here and never had a complaint."

The registered manager said, "We take concerns really seriously...We have a responsibility to follow up all concerns and make sure it doesn't happen to anyone else." They quoted two examples in which people not involved with the hospice had put identifiable photographs of young people on a social media site and on a television report. Although these matters did not officially fall within the provider's remit, the registered manager had dealt with both issues under the provider's complaints procedure and within the procedure's timescales. They had informed both families of the actions they had taken.

## Is the service well-led?

### Our findings

Our discussions with everyone involved with the hospice confirmed that the service was inclusive and empowering. It focused firmly on responding to the holistic 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.

Parents were effusive in their praise of the service they received and told us how much they depended on staff support through the most difficult times of their lives. Their comments included, "We've had an amazing journey, very sad, but amazing. We owe such a lot to Quidenham"; "I love Quidenham hospice. We're so lucky to have it"; "They're just fantastic at Quidenham"; "[Name of young person] signs 'friends'. [Name] thoroughly enjoys being here"; and "Quidenham has been a lifeline for us." Parents also told us how important it was for them that the staff team all showed how fond they were of their child and how much they enjoyed looking after their child.

Staff told us how much they enjoyed working at Quidenham. One member of staff said, "I really do love it, every day's different and there are always challenges that you can learn from." Healthcare professionals reported that the service provided was very beneficial to the young people and their families. One healthcare professional told us, "Families who receive short breaks appear to benefit greatly from the service, both in-house and at the child's home and it is a very needed service that the children and families require."

Young people, their families, the staff and other stakeholders were given a number of opportunities to provide feedback about the service and to be involved in the development of the service. One parent told us that they were involved in the regular Family Forum meetings, which were open to all families and were chaired by a parent. They said, "We can raise issues, good and for improvement and they give us an update." Regular reviews of the service offered to each young person and their family were held and families were also encouraged to give honest feedback. Written surveys were sent out by an external organisation to young people and their families who received any of the services provided by the staff team. The responses were collated into a report and an action plan developed and shared. The registered manager told us they were in the process of setting up a 'user-involvement' group so that young people would have even more opportunity to make their views and opinions known.

A member of staff told us that the provider employed an external organisation to carry out a staff survey, which meant the survey was independent. Staff felt they were able to be very honest when they responded to the survey, but also felt they could be honest with the management team at any time. They said, "People [managers] will always listen to you."

Staff understood whistle-blowing and knew that they could report poor practice if they needed to. They were aware of the provider's whistle-blowing policy and where to find a copy. They felt that they would be protected but all said they had never had to report anything. One member of staff said, "All the managers are very approachable." Another said, "We work together really well as a team. ....we all work together for the

same purpose."

There was a registered manager in post. Our discussions and evidence we found during the inspection showed us that the service was managed extremely well. The registered manager was very visible and provided excellent leadership across the whole service. Parents, staff and healthcare professionals all made very positive comments about the registered manager. One parent said, "The [registered] manager is always lovely and very approachable. I would be happy to go straight to her with anything that I wanted to." Another parent told us, "The [registered] manager does a fantastic job, she has changed things for the better, views are listened to and valued." A member of staff said, "[Name of registered manager]'s door is always open. [Name's] always supported us." The registered manager told us, "I really feel passionate about it [the service provided to young people and their families]." This passion for their work, the young people and their families and their staff team was obvious in the way they spoke about everything that happened at Quidenham. This passion was recognised by others.

Parents, staff and healthcare professionals also made very positive comments about the whole management team. One parent told us, "They know precisely what they're doing. Communication is spot-on. We are so grateful; it's a privilege to be involved with Quidenham." Another parent said, "They [the management team] are all very polite. It runs very smoothly." A member of staff explained, "I've never had a problem with management. They've always helped or pointed me in the right direction. I do just love working here, it's a really lovely place." A healthcare professional said, "Management are really really supportive of staff taking the keyworker role."

There were systems in place to make sure that staff and volunteers had the support they needed and received feedback about their work. There was a clear management structure and role accountability, which all staff were aware of. However, staff of all grades told us they all worked together as a team. One member of staff said, "We all pull together really well. Everyone mucks in." The registered manager described the delegated supervision system that was in place. Each care manager had undertaken training in staff supervision and had a team of staff that they supervised. Staff received clinical, management and safeguarding supervision and the registered manager was confident that she was apprised of any issues that arose.

The registered manager praised all the staff and volunteers who worked so hard to make the experience of young people and their families as good as possible. For example, the registered manager said, "My team of care managers is fabulous. They all bring different things but they're all so passionate. We're meeting a big need of kids who have problems socialising."

The registered manager explained how much the organisation did to support the staff team. They said, "We're really good, we need to be, we need to look after our staff, they have a difficult job to do." Along with thorough induction, training and supervision, they gave staff full feedback about their work and praised their achievements. They worked hard to make staffs' working conditions as supportive as possible. One example was the efforts that were being made to reduce levels of sickness, which included the re-introduction of a return-to-work interview. Staff rotas had been designed to support staff as well as provide the necessary level of staffing to meet the needs of the young people and their families. Staff told us, "[The rotas are] a family-friendly scheme for staff, with a set day off each week." The hospice was closed to in-house, non-emergency short breaks on two Mondays a month. This gave staff an opportunity for supervision and to catch up with documentation, reading and learning as well as planning for the young people in their care. Staff said this worked very well for them, the young people and their families.

We asked people to describe the culture of the service. All the responses showed that parents, staff and

healthcare professionals interpreted 'culture' in different, but all very positive ways. For example, parents said, "Quidenham is like an extension to home"; "Home from home"; "Very reliable"; and "They understand the needs of the whole family." They all felt the culture was very open and completely honest. The registered manager described the culture of the service as "good palliative care and good family support for all children and their families." They felt that "most of the time we achieve it." They explained that they were continually striving for excellence and recognised that there was always room for improvement. For example, training in a universal approach to well-being, undertaken first by the well-being team, had been offered to all staff throughout the provider's services.

The registered manager told us about the keyworker scheme that operated externally to the hospice for young people and their families who had "a lot of professionals involved." They said that staff were encouraged to be a keyworker to "one or maximum two" young people. A healthcare professional told us, "The keyworker service is about finding a central point of contact, emotional support and an advocate..." They said it demonstrated that families felt the staff from Quidenham would go the extra mile for them, as "families often ask for a member of Quidenham staff. It's telling that those they ask for are those who can support them, who they can relate to."

There was honesty and transparency from all staff when mistakes occurred. The registered manager described strategies that were in place for the whole staff team, and the rest of the organisation, to learn from any incidents. One parent told us that they had confidence that the provider had learnt from incidents. They said, "There was an error [in medicine administration] once. They told me an error had occurred. Later they told me that steps had been taken and exactly what they were. I knew that they were looking at it very seriously."

The registered manager had completed a CQC Provider Information Return (PIR) in December 2014 in which they described various aspects of the service. In the PIR, the registered manager had also given 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 registered manager confirmed that she was aware of the regulations. Records showed, and the registered manager confirmed, that no reportable incidents had occurred. We found that records were maintained as required and kept securely when necessary.

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 provider told us in the PIR that the "Trustee Board has a variety of expertise; clinical, financial, business, service user and law." The registered 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 Cambridgeshire Community Services NHS Trust. 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 hospice staff worked in partnership with a wide range of other services and healthcare professionals. The healthcare professionals we contacted praised the service that was provided to each young person and their family. They were complimentary about the way staff worked with them and provided them with information when it was needed. Staff recognised that some services that families might need were more appropriately provided by their external partners.

In the PIR the provider (EACH) told us about a number of good practice schemes and initiatives that they were a member of. They participated in local as well as national and international schemes, such as the Association of Paediatric Palliative Medicine, with its associated national research group, and the International Children's Palliative Care Network. They were involved in the provision of training to University of Cambridge undergraduate medical students. They hosted the East Anglian Managed Clinical Network, which was described on its website as made up of 'health professionals and organisations working to ensure the co-ordinated and equitable provision of high quality, clinically effective services.... where clinicians from all professions and sectors place their focus on patients and services rather than being constrained by organisational boundaries.' EACH had been asked to act as a role model and help establish a community of specialist practice with children's hospices in Australia.

The registered manager told us that at some point in the future the hospice would be moving to a new, purpose-built building. They were aware that this was going to be a big challenge and that for some young people, families, staff, volunteers and other stakeholders it was going to be very hard. Some were worried that the homely, friendly and caring atmosphere of Quidenham would be lost. However, some people were very positive. One parent told us, "It will be nice when they get the new building: they're held back by their surroundings." Another parent was "looking forward to the new premises. It's [Quidenham is] a bit inaccessible during the winter on back roads and I do worry about services getting there....the move is much needed." One member of staff felt the move would be a good thing, but also said, "I hope it doesn't lose the magic that Quidenham has."