

Ellenor Lions Hospices

Ellenor Dartford

Inspection report

St Ronan's View
East Hill Drive
Dartford
Kent
DA1 1AE

Tel: 01322221315
Website: www.ellenorlions.org

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Ratings

Overall rating for this service	Good ●
Is the service safe?	Good ●
Is the service effective?	Good ●
Is the service caring?	Outstanding ☆
Is the service responsive?	Good ●
Is the service well-led?	Good ●

Summary of findings

Overall summary

The inspection took place on 19 and 20 July 2016. 48 hours notice of the inspection was given because the service was an office from which care was delivered and we needed to be sure that the manager and staff were available.

Ellenor Dartford provides a hospice at home service for babies and children from birth to young adults who have a life limiting condition. The service operates in Bexley, Dartford, Swanley, Gravesend and West Kent. Children's nurses provide nursing care for the child in their own home and support and advice for their family members. Respite care is provided for children in their own homes to support family members. Cancer care is provided for children, who live in Dartford, Gravesend, Swanley and Bexley, so children can receive chemotherapy in their own homes, reducing the need for hospital visits. The location was used to hold meetings, children's clubs and therapies. The service was providing services to 110 families in the community at the time of the inspection. The provider 'Ellenor' also operate an in-patient ward for adults with palliative care needs at Gravesend.

A registered manager was in post. A registered manager is a person who has registered with the Care Quality Commission 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 service recognised that some young people saw themselves as adults and had established a transitional pathway which enabled them to receive age-appropriate respite care on the in-patient ward at the providers adult hospice in Gravesend. Young people received support from nurses whom were known to them and undertook activities that they enjoyed during their stay, making it a positive and valuable experience.

The service provided end of life care in partnership with other professionals. Children and young people were enabled to experience a comfortable, dignified and pain-free death in the place of their choice. It had received a large number of compliments concerning the kind, compassionate and outstanding caring manner of the staff team.

The needs of the child or young person, their carers and siblings were all taken into consideration when staff provided them with psychosocial, spiritual and therapeutic support. This holistic approach was seen as a key to the child's well-being. This included bereavement counselling, music and play therapies and support from the chaplain.

Children and their family members were involved in planning their care and treatment. Children and young people were supported to write their own advance care plans which contained their individual wishes with regards to their care. Staff went the 'extra mile' to ensure children's wishes were realised and parents and carers were supported when they needed it.

Staff received training in safeguarding adults and children and knew how to recognise and report abuse and to help protect children and young people and keep them safe.

There were enough nursing and health care assistants available to meet the needs of children, young people and their carers. Comprehensive checks were carried out on all staff at the service, to ensure that they were fit and suitable for their role.

Assessments of risk were individual to children's and young people's specific needs and identified how risks could be minimised. Accidents and incidents were investigated and the results were used as opportunities to make improvements to the service to help ensure children and young people's safety.

There were safe systems in place for the ordering, storage and disposal of medicines. Only staff who had been trained and had their competency assessed were responsible for the administration of medicines.

New staff received a comprehensive induction and training to ensure they had the skills and knowledge to support children and young people with long-term illnesses or who needed end of life care. The service promoted and encouraged staff to further their learning and development and had developed paediatric specific training days in conjunction with another children's hospice.

Children and young people had access to the specialist health care support from medical and nursing staff. There were good working relationships and communication with other health care professionals involved in the child's care to ensure their health care needs were effectively monitored and met.

Staff understood their roles and responsibilities in relation to the Mental Capacity Act 2005 (MCA). This provides a legal framework for making particular decisions on behalf of young people over 16 who may lack the mental capacity to do so for themselves.

Children, young people and their carers benefitted from a service that was responsive to their individual needs. The nursing service enabled children and young people with complex needs to remain at home with their family and so avoid hospital visits and /or admission. The respite service was personalised as children and young people were cared for in their own home and enabled parents and carers to have a break or spend time with their siblings.

The service prioritised building links with other children's hospices and palliative care networks in order to develop and improve the care and support they could give to children, young people and their families. Children, young people and their families were able to make their views known and there were clear processes in place to make a complaint or raise a concern. When complaints had been received, these had been investigated and used as lessons learned to improve the service.

The service was led by a strong management team, who led by example. There was an open culture where staff felt safe and well supported. The views of families were regularly sought and used to drive forward the service. The service had a clear direction of the areas in which it intended to develop further to meet the needs of the local community. Education and research was seen as key to making improvements in the lives of children with palliative care needs.

Records were held on an electronic system so they were available to all health professionals involved in the person's care to ensure continuity of care.

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.

There were sufficient numbers of trained and experienced staff to meet children's and young people's needs. Checks were carried out on all staff who were employed by the service to ensure they were suitable.

Staff were trained in safeguarding adults and children and knew how to report any concerns.

Assessments were made of potential risks to children and young people and control measures were in place to minimise their impact.

Medicines were managed safely and procedures were in place to promote good infection control.

Is the service effective?

Good ●

The service was effective.

Children and young people received care from a staff team who understood how to give effective care.

Staff were trained to ensure that they had the skills and additional specialist knowledge to care and support children and young people with a long-term illness or at the end of their lives.

Staff understood their responsibilities in relation to the Mental Capacity Act 2005, how to gain children and young people's consent and act in their best interests.

Children and young people's nutrition and hydration needs were assessed and shared with relevant staff to ensure they were met.

Is the service caring?

Outstanding ☆

The service was very caring.

Staff showed kindness, compassion and empathy to children, young people and their family members in difficult situations.

People valued their relationship with the staff that went the 'extra mile' to meet children and young people's needs.

The service was highly complimented for enabling children to remain with their families and for valuing each individual member. Providing holistic support to children, young people and their family members, was key to the service. The range of support available included specialist therapies, counselling, bereavement and support groups, which continued after the death of the child or young person.

Young people's needs in respect of their age and disability were understood by staff and met in a caring way.

Is the service responsive?

Good ●

The service was responsive.

Support for children and young people was personalised and reflected their choices and preferences.

Children and young people were given opportunities to engage in activities and interests that were important to socialise with their peers.

The service was developing links with other professionals and the community in order to improve and develop the service for the benefit of children, young people and carers who used it.

People were encouraged to give their views and raise concerns. When complaints had been received, they were used to drive improvements in the service.

Is the service well-led?

Good ●

The service was well led.

The service had an open culture and the management team disseminated the vision and values of the service to the staff team and placed children and young people at the heart of the service.

Emphasis was placed on continuous improvement of the service and best practice. There were robust systems to ensure quality and identify any potential improvements to the service.

Clinical networking, education and research were prioritised to ensure the service delivered and helped develop best practice in children's palliative care.

Ellenor Dartford

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 checked 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. At our last inspection on 7 February 2013, we found the service was fully compliant with legal requirements.

This inspection took place on 19 and 20 July and was announced. The inspection team consisted of an inspector and a specialist advisor who was a children's palliative care nurse.

Prior to the inspection we looked at previous inspection reports and notifications about important events that had taken place at the service. Before the inspection, we asked the provider to complete 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. This helped us plan and inform our inspection.

We accompanied staff on two home visits and spoke with the children's parents. We also attended a meeting with a school nurse at a special school, where the service supported three children.

During the inspection we were not able to speak to any children due to their age and level of understanding. We spoke with a visiting consultant in paediatric palliative care, six children's nurses, one student nurse, the head of respite services, five respite support workers, a play therapist, a medical secretary, a fundraising officer, two volunteers, the chaplain, the head of 'well-being', the health and safety officer, the head of support services and a human resource assistant. Members of the management team we spoke with included the registered manager, the director of patient care and the head of children's services. We also obtained feedback from four commissioners of the service.

We attended the weekly multi-disciplinary team meeting and looked at a range of records including eight children's care records; six staff recruitment records; the staff training programme; staff rotas, medicines and safeguarding policy; health and safety records; risk assessments and audits; compliments and complaints logs and quality assurance questionnaires.

Is the service safe?

Our findings

The service received feedback from parents via their quality assurance systems that children were in safe hands when being supported by the service. One had relative commented, "The respite care team are so friendly and I didn't feel worried leaving my son with her at all". Staff prioritised children and young people's safety at every point of contact. When interacting with a child, staff took into consideration the child's experiences of medical care and interventions and communicated in a sensitive manner to help the child feel safe and secure in their presence.

The children's safeguarding policy clearly set out different types of abuse and detailed how a staff member, the child/young person or anyone involved in their care could raise any concerns with the local authority. There was a flow chart which gave guidance in which circumstances the local authority and/or police or medical services needed to be contacted. The contact details of each local authority which was covered by the service were available to staff so there would be no delay in seeking their advice and support. All staff had received training in safeguarding children and adults at induction and via yearly updates. This training included discussing scenarios to ensure staff knew how to relate the safeguarding policy to day to day practice in order to keep children safe. Safeguarding was a scheduled topic at each weekly multi-disciplinary team meeting to ensure it was always at the centre of how the service operated. A commissioner told us that two members of staff had attended a training day on child sexual exploitation (CSE). CSE is a form of sexual abuse that involves the manipulation and/or coercion of young people under the age of 18 into sexual activity in exchange for things such as money, affection or gifts.

Staff understood their responsibility to discuss any concerns about a child or young person's welfare with a more senior member of staff and to report them to the head of service who was the safeguarding lead. The safeguarding lead demonstrated they had contacted the relevant professionals when they had received concerns and when risks to the child's safety had increased. If staff had any concerns about poor practice at the service, they understood they could report them using the guidance in the service's whistle-blowing policy. This policy ensured staff protection in raising their concerns.

Risks to children and young people's safety were appropriately assessed, effectively managed and regularly reviewed. These areas of risk included any potential hazards in the environment, and in relation to nutrition, medicines, falls, behaviours that may challenge others and specific health care needs. Staff understood the control measures in place to help minimise the identified risks. For example, one child had limited movement and was at risk of their mobility deteriorating. A very descriptive and detailed plan was in place with pictures to guide staff on how to position and support the child to stretch, to aid their movement and mobility.

There was a clear procedure to record and respond to any accidents, incidents or near misses such as if there was a medicine error or if a child developed a pressure ulcer. A record was made of the event, together with the details of what had happened, who was affected and of the immediate action taken. These events were investigated and the service used the results as opportunities to assess current practice and initiate improvements. For example following a medicine error, at the Friday Fun club, a specific member of staff

had been allocated to administer medicines.

Staff said there were enough of them available to meet the needs of children and young people. The staffing rota was consistent and reflected the staff on duty on the days of the inspection. There was a separate rota for children's nurses and health care assistants who provided respite care. The service covered a large geographical patch so nurses were split into two teams to help reduce travelling times and ensure consistency of care. Staffing levels for the respite service were determined following the assessments of each individual child or young person. A mixture of full time and flexible health care assistants were employed to meet the changing needs of the client group. Health care assistants were employed to cover seven days a week and evenings so as to be available for carers when they required them. Nurses were available for core hours between 8am and 6pm during the week and one nurse was on call each day and so available for advice outside these hours, with the support of a manager if needed. If a visit was requested by the family for reassurance or in a child's or young persons' last few hours, the nurse attended their home. They were also allocated to support the person and their family overnight if needed. Therefore, there were sufficient staff available to respond flexibly and appropriately to meet the needs of the child or young person and people who were important to them.

There were robust recruitment procedures in place for staff and volunteers, which included a clear monitoring system to ensure that all checks were completed before staff started employment. These checks involved applicants completing an application form, including a history of their previous employment, attending an interview and gaining suitable character and/or work references as appropriate and a Disclosure and Barring Service (DBS) check. The DBS helps employers make safer recruitment decisions and helps prevent unsuitable people from working with people who use care and support services.

Disciplinary procedures were set out in the service's policy and in the staff handbook. They included the expected standards of staff performance and behaviours and what performance and behaviour may lead to disciplinary action. The service had followed these detailed procedures to ensure that staff working at the service were of good character and had the necessary skills and knowledge to carry out their duties.

The service had a comprehensive paediatric medicines policy which set out responsibility of the child or young person's carer to safely keep and manage their medicines. The policy covered all areas of the management of medicines in a child's home including the storage and transportation of medicines, administration of medicines, what to do if there was a medicines error and the use of specialist medicines such as those at higher risk of misuse and therefore in need of closer monitoring. There were separate policies on self-administration, medicines administered intravenously (directly into the child's or young person's blood stream) and syringe drivers (a system which allows medicine to be administered by slow release over a period of time). Health care assistants had separate guidance on the oral administration of medicines.

Staff had completed training in medicines management and their competency had been assessed to ensure they knew how to administer medicines safely. Health care assistants said the training and support they received with regards to the management of medicines gave them the skills and confidence necessary to keep children and young people safe. Children's and young people's medicines records contained a list of the medicines they had been prescribed, the reason for their administration, any side effects and information about the different strengths of medicines available. The service had introduced and was piloting a new prescription chart for symptoms management with the aim of managing children and young people's symptoms more effectively.

Is the service effective?

Our findings

Relatives and professionals said that the staff had the skills and knowledge to effectively support, advise and care for children and young people and their families. Feedback from relatives to the service focused on the staff's skills, professionalism and knowledge. Comments included, "Ellenor have been a lifeline to us. A constant support helping fight our corner, liaising with medical professionals and helping with pain management. Couldn't be without you"; "With the input of Ellenor nurses, the doctors listen more"; and "The nurses are brilliant. Helpful, knowledgeable and always doing what they can to help". A commissioner told us, "The service trains staff to a high standard to care for children so they can remain in their own home and it reduces the need for them to access hospital services."

Children and young people were supported by a multi-disciplinary team that included medical and health care professionals. The team met weekly to discuss and share information about the children and young people they supported, and updates were given on relevant training and networking meetings. External speakers were regularly invited to attend to share their knowledge and ways of working and at the time of the inspection this included an epilepsy nurse who spoke about specialised diets for children with epilepsy. Information was also effectively shared between staff members. These meetings helped in sharing relevant information to ensure consistency of care and for staff learning and development.

Children and young people's health care and medical needs were assessed and recorded in their plans of care. This included guidance for staff about how to support children to regulate their body temperature, breathing, any pressure areas and specific medical conditions. For example, one child was at risk of epileptic seizures. Their care plan included how to recognise when a seizure was happening, what circumstances increased the risk of a seizure taking place and the specific action to take if the seizure lasted for specific period of time.

Staff played a key role in partnership with other health care professionals to ensure children and young people were supported to receive on-going health care support. Each child remained under the care of their doctor and their specialist consultant. The staff team prioritised developing strong relationships with other professionals involved in a child's care. Professionals told us that the staff team was stable, contacted them for advice as appropriate, communicated effectively and were always willing to work with them for the benefit of the child and their family members.

Health care assistants supported children and young people with eating and drinking in their own homes or when attending a club or event at the service. Their nutritional and hydration needs were assessed and recorded in detail in their care plans. This included what they liked to eat and drink, their ability in feeding themselves, dietary requirements, any specialist support and equipment needed, and if they suffered from nausea and sickness. If food was provided by the service, the nurses gave information about children's dietary requirements to the catering team. Young people were asked about their food choices and what food they would like to see on the menu. Children or young people with more complex nutritional needs were referred to a dietician or speech and language therapist who advised on the consistency of a person's diet and fluids, to aid their swallowing. Some babies and children were unable to care for their own oral

hygiene. Mouth care was provided to prevent any mouth problems from arising which could reduce their ability to eat and drink. Therefore, children and young people had access to the specialist support they required to ensure they had adequate nutrition.

Staff told us that they had excellent supportive working relationships with their colleagues and that there was good communication between nurses, health care assistants, therapists and office staff to ensure the effective care of children and young people. One staff member told us, "It is the most rewarding job. The team work so well together and everyone supports each other so well. Everyone lifts each other up at difficult and emotional times". Staff said the service considered their safety when lone working. There was a system in place so that they could contact the service if they felt any risk to their safety and staff reported this worked well and made them feel safe. Formal supervision for all staff was well established and staff said that it was an effective way of supporting them in their roles. Supervision included group clinical supervision and individual supervision. This meant children and young people were receiving care and treatment from a staff team who were supported and encouraged to further their development.

Staff said there were opportunities to reflect on their practice and to talk and gain support from other members of the staff team. The chaplain was available to offer periods of reflection and spiritual support and staff valued their presence and contribution. Reflective practice is where staff personally and critically reflect on their work, on what they are doing well and what they need to do better, to ensure continuous learning. Debriefing sessions took place after a death of a child and case discussions had been introduced for children or young people with more complex needs.

'Schwartz rounds' were held where staff came together to talk about the emotional and social challenges of caring for children and young people. These were open to care and non-care staff and the majority of staff had reported these to be positive learning experiences. Members of the staff team had attended as panel members to share their experiences. One staff member described the meeting as "Emotional and thought provoking, making me value my colleagues even more" and another staff member said, "The panel members were very clear and passionate about their experiences, and it was great that they were all so different". Each session looked at a different issue such as 'I didn't know what to say' and 'The patient who made a difference to me'. This gave staff the opportunity to share their stories and offer support to one another.

New staff received a comprehensive staff induction programme which had been developed by the service according to staff's individual roles. Staff told us that during their induction they felt very welcomed and supported by the staff team. All roles included shadowing an experienced member of staff, understanding the roles and responsibilities of different team members and undertaking training that was essential for their role such as safeguarding, infection control and health and safety. There was a specific programme for volunteers which included the impact of illness and loss, customer care and confidentiality. Staff were trained and their competency assessed in relevant medical procedures. For nurses this included the use of syringe drivers and for health care assistants to use of emergency medicines and medicines administration, oxygen therapy and monitoring, techniques to clear a child's airway and feeding via percutaneous endoscopic gastrostomy (PEG). A PEG is a tube that feeds directly into a person's stomach.

Ensuring that staff received the appropriate training for their development was a priority of the service. Staff described the staff training programme as 'excellent' and told us they could make suggestions about the training they required for their role. The service had invested in 'train the trainer' to enable their own staff to be qualified to train staff in a number of areas. There was an on-going, classroom based programme of training for staff which helped embed their knowledge through the use of scenarios. This was monitored to ensure that staff kept up to date with the skills and knowledge they required. Staff had received training in

palliative/end of life care, bereavement, and conflict resolution. Planning was in place to make sure that nurses were able to revalidate their registration with the Nursing and Midwifery Council. This process ensures that registered nurses can demonstrate that they can practice safely and effectively.

Health care assistants were encouraged to complete level three Health and Social Care Award with a speciality in long-term conditions. This is a nationally recognised qualification which is work based and achieved through assessment and training in which the participant must prove they have the ability to carry out their role to the required standard. Nurses were supported to attend study days internally and externally to further their development. The clinical nurse specialists were attending further training. One nurse was undertaking a Postgraduate Diploma in Palliative Care that was nationally recognised as of a high standard and involved research in children's palliative care. A health care assistant was completing a level five Assistant Practitioner Diploma in which the service was leading. These qualifications benefitted children and young people as they enabled staff to become more skilled in their roles.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of young people over the age of 16 who may lack the mental capacity to do so for themselves. The Act requires that as far as possible young 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 the best interests and as least restrictive as possible. All staff had received training in the MCA and had a sound knowledge of their roles and responsibilities in relation to this legislation. Staff understood that when a young person had the capacity to consent, they had the freedom to make their own decisions and that a person's capacity to consent could change. For children under 16 staff gained parents consent, but also gained children's consent when they believed the child understood what was involved in their care and treatment. During home visits staff gained children's verbal consent when undertaking nursing tasks. There was a very clear consent process in place for gaining children and young people's consent and this was documented within children and young people's records and care plan.

Is the service caring?

Our findings

The views of carers, relatives and professionals were that staff were kind, caring and compassionate in the support they provided. Relatives we spoke with could not speak highly enough of the support the service had given their child and family. Compliments about the outstanding caring nature of the service included, "Our Ellenor nurse is warm and caring, and always happy to see him, putting his mind at rest with any questions he might have, and including him with all she does with and for him"; and, "The staff are incredible and genuinely care about their patients/families!" They said that staff knew their child well and treated them and all the family with compassion and respect. One relative feedback included, "All the nurses in the team that I have met are very supportive and are always up to date on my child's care so there is always someone for me to talk to. I do not feel that any question I have to ask is considered silly and I am always treated respectfully".

The service had received a large number of compliments. The themes of these compliments included people appreciating the individual care their child received from the service as well as its holistic approach in supporting the whole family. The service was described as "compassionate" and "professional" which are both part of the service's aims and vision. The comments indicated that constant reassurance provided by staff had given many families the strength to continue. One person stated, "My life would be very difficult if I didn't have the Ellenor team. They are always there for me either face to face or a phone call away".

Children and young people were supported at the end of their life to have a comfortable, dignified and pain-free death. They and their carer/parents were fully involved in planning their care which included symptom and pain management plan, and prescription chart and a 'Just in case box'. A just in case box contains palliative care medicines that it is anticipated a child or young person may need at the end stages of their lives. Discussion with the child/young person and their family members included their views, wishes and preferences with regards to their care and support. These 'advance care plans' set out what was important in the future and included the preferred place of death, spiritual and family support and decisions about which treatments would be preferred or declined. Advance care plans were stored on a data base and regularly reviewed to ensure they contained the most up to date information.

Staff had supported young people to write their own advance care plans and be fully involved in the control of their own lives. One child wrote in their plan they would like white horses and a carriage to transport their coffin at their funeral. The service had supported the family to approach a charity so their child's wish could be realised. Another child had requested they wished to have as many days out as possible and to spend their last days at their local hospital. Staff remained involved in the child's care when they moved from home to the hospital ward. They attended the child and their family at the times when this was requested. Staff also worked in partnership with the hospital nursing staff and gave them support during and after the death of the child. This included ensuring the families wishes were met, by being involved in a practical way in ensuring the child's body was removed from the ward in a dignified manner and returning the child's possessions to the family. Ellenor nurses also involved the hospital chaplain with the family. Therefore, the service ensured that children and young people's wishes were realised and offered continuous support to the child and those who were important to them.

Staff had gone the 'extra mile' to support children, young people and their family members. One person feedback to the service, "The Ellenor team visit is always inspiring, encouraging and comforting. I was also happy that they remembered my baby's birthday even while in hospital and they even sent her a birthday card right in the ward. I was very grateful about this". The service's on call system meant that nursing staff could respond immediately, at any time of day or night, to requests from family members to attend them at home if they had any immediate concerns or in their child's last hours. Staff gave examples of how they had given support in a caring, compassionate and individual manner, based on the child's and families wishes. On some occasions they attended to the child and on others they stayed at the family home, just to be there for the family and to give them the reassurance and confidence to focus on their child's needs in their last hours.

A number of families had shared their experience of the outstanding care they had received from the service with the public, through the local newspaper. One family described how the nurse had visited them before school, so their child could attend because they did not like missing school lessons. They said that to help their child's class understand their condition, the nurse had visited the classroom to explain this to the children and teachers. Another family reported, "My daughter loves the team from Ellenor. They are one of the family. They help with so much, all the day to day stuff that makes a family life run. We couldn't live life without them. The support we get is as a whole family".

The service prioritised the well-being of the child or young person as well as their family members. A commissioner told us, "Ellenor also support effective bereavement care, informed by a greater understanding of grief and loss". Parents and carers had given feedback about their high satisfaction with the counselling and bereavement support in a survey in 2016. Counselling and bereavement support was available for relatives and close friends. People were offered up to 12 weeks of support by a counselling team of staff and volunteers. One parent who had lost a child lived a long way from the service and found it difficult to attend counselling sessions. The service found a private room that could be used so they had less to travel. A bereavement group had also been set up, led by a member of staff, where people could explore their feelings in an informal setting and gain support from others with similar experiences. There was also a bereavement group specifically for fathers to help them with grieving.

The service employed a specialist music and a play therapist to support children who were affected by their or their siblings diagnosis and by the impact this had on their lives. A music therapist supported children with communication difficulties, with lowering their anxiety and increasing their self-esteem. A play therapist supported children with exploring painful feelings and distressing experiences that they may not be able to say with words, through play. A play and music room was available at the service that was used for that purpose. The therapists worked closely together and with other staff members. They took time to meet the child and their family members in different settings to assess their needs and the best ways of working to benefit the child. Feedback from parents and carers was that there was a high satisfaction with this service. One person feedback, "Our son has had play therapy, which really helped him. The extra support was just what we needed".

The play therapist employed at the time of the inspection had been in post for six months and was making further developments to established play therapy services. They gave an example of where they had worked with a parent and child to teach them how to play therapeutically through the use of play sessions, videos, reflection and discussion. As the child had benefitted from this interaction, the parent's confidence had grown and they had used the new skills they had learnt to play with all their other children in this effective way. As a result of this positive experience, the play therapist had planned to further their work with parents to help them develop the skills they needed to support their child's emotional well-being through play.

Young people's needs in respect of their age and disability were understood by staff and met in a caring way. Young people, with support from the children's nursing team, could access the in-patient ward at the provider's hospice in Gravesend. The service had recognised that some young people wished to receive care and support away from their home environment and with their peers. Two friends had received respite care at the same time with the theme of a sleep-over, with DVD's. Therefore, the young people were able to undertake an activity which was desirable for people in their age group. They were supported by nurses from the children's team who knew how to care for them in a way that respected their privacy, dignity and specific needs as teenagers.

A chaplain was available to give support to families and staff. They were supported by a team of volunteers. Their aim was to make connections with people of any faith or no faith, to offer a listening ear and give spiritual support. The chaplain demonstrated they were passionate and dedicated to their role and they conversed with people in a relaxed and engaging manner. The chaplain had contacts with spiritual leaders of other faiths from the local community, who they could call on when needed. As they took the time to get to know people well, they had often been called upon to direct children's funerals.

To help parent, carers and siblings through the grieving process the chaplain arranged a number of memorial services and participate in a number of events throughout the year to celebrate children's lives. These family memorial days were open to anyone who had lost a loved one and included crafts and activities for people and children of all ages. This included painting a stone, writing on a star, placing a light on a tree, drawing pictures and planting daffodils which everyone could participate in. This ensured that adults and children could remember and celebrate the lives of their child, grandchild, sibling or friend who were no longer with them.

Ensuring that staff supported people in a caring and compassionate manner was embedded in the service. The values of consideration and compassion were demonstrated by nursing staff, health care assistants, volunteers, and office and support staff showing that they were part of the culture of the service. Volunteers explained that when parents visited the service they greeted them and let the parent take the lead in whether they wished to talk further and explained that some relationships with parents had developed over time. One volunteer spoke passionately about a child whom they had known since they were a baby and the positive and caring relationship they had developed with the child and their family. This had a positive impact on the child and their family.

When visiting a family their main focus was on the child and their needs, but they also included the parents and their siblings, asking how they were feeling and responding in a compassionate manner. Staff showed genuine interest in the child and their family and were passionate about their roles. One staff member explained how a parent had a lack of trust of health and social care professionals. They described how they had spent time building a relationship with this parent and that there was good communication between them, which benefitted the child. Another staff member explained that, "Palliative care is about giving the best and not about the quantity. It is about the quality and making a difference".

Nurses and health care assistants were positive, friendly, cheerful and sensitive in their engagement with children and family members. For example, one child had spent the majority of their life in hospital and was fearful of new people. When taking the child's heart rate the nurse ensured the child was comfortable and secure with their parent. They then spoke to them and gently placed their finger on their chest. The nurse then showed the child their stethoscope and let them play with it before placing it gently on their chest. The health care assistant moved away from the child when this medical procedure was taking place so the child would not associate them with the experience. This showed how staff strived to remove the fear that children, young people and adults may have of healthcare professionals.

Parents and carers were given a welcome pack which included clear and comprehensive information about the service. There was also information on the service's website about the children's hospice service including therapies, what to expect at end of life, advance care planning, carers' courses, and the youth group. The dates of all upcoming events, such as family memorial days and carers courses were displayed at the service and on the website, so they were accessible to people who used the service.

Is the service responsive?

Our findings

One relative told us, "I just have to ask for help and it arrives". Another relative said that the support from the service has changed their experience of having a child with a life-limiting condition into a positive one. A family had shared their experience of the outstanding responsiveness of the service with the public, through the local newspaper. "The medical team at hospital told us our son was brain damaged and unlikely to survive. We wanted our son home with us from hospital so we asked if that was possible. It was then the hospital team mentioned Ellenor. Our son has just enrolled at a local nursery: a milestone. We are so grateful to Ellenor for helping him get there and for every single thing they've done for us".

Commissioners were complimentary about the responsiveness of the service. One commissioner told us, "Ellenor have evidenced they have prevented the children in their care from being admitted into hospital through the interventions they have put in place in the home". Another commissioner commented that, "Ellenor provides specialist nursing care in their home, for children and young people with life-limiting and life-threatening conditions to enable them to access and receive holistic, community-based care, including all care at the end of their life. The flexibility of Ellenor's approach is particularly valued".

The service offered a home nursing service for children and young people with cancer who were undergoing active treatment at their specialist hospital, which was located in central London and Surrey. This was responsive to families' needs to maintain as normal a life as possible. It enabled the child to receive treatment in the comfort and familiarity of their own home from a nurse who they knew well. It also prevented long travelling times and complex childcare arrangements for families who also cared for other children.

The service operated a respite service whereby health care assistants or nursery nurses spent time in the family home to care for the baby, child or young person. This gave carers a period of respite and enabled them to spend time with their other children. Care staff spent a number of visits getting to know the child, their routine and family members, before caring for the child independently. Many children and young people had complex health care needs for which care staff received the necessary training. Parents and carers had confidence in the staff's skills and trusted in their ability when they handed over their child's care. One relative fed back to the service, "Our daughter has a very rare condition. The Ellenor respite team has helped us tremendously and enabled us to have some time for ourselves and share time with our son, who often gets overlooked in day to day life."

In addition to the respite service, there were a number of clubs and family drop in sessions at the service which were available to parents/carers and children. A Friday fun club was held each week which held two sessions and catered for up to five children. This offered a break for parents and carers who were able to leave their child in safe hands. Nurses and health care assistants were available to give a high ratio of support to the children and young people who attended to join in play activities including messy play. A youth group for 11 to 19 year old young people and their siblings met once a month on a Saturday to socialise and enjoy a variety of activities such as cooking, art and music sessions. Family drop-ins were held

in school holidays and gave parents and carers a chance to meet other families, to exchange experiences and share some mutual support and fun. During this time children were kept entertained with games, activities and cooking such as making cupcakes or decorating pizzas. Members of staff were available to offer support, care and guidance. In addition, in partnership with a local organisation, the service had arranged for some children who used respite services to participate in a trip to Disney.

Due to feedback from parents and carers a new venue had been found in Maidstone to hold sessions for children and young people. This is because people had responded that Dartford was a long way to travel, due to the large geographical area that the service covered. The Maidstone venue was due to begin operating in September and was piloting care for a group of under five year old children. Children, young people and their siblings were also able to access reflexology and aromatherapy at the provider's hospice in Gravesend.

There was a nurse on 24 hour call, seven days a week who provided telephone advice to respond to families' individual needs and queries. There was a clear protocol in place whereby issues could be escalated to the clinical nurse specialist, doctor or consultant. The service had recognised that there were shortfalls around clinical leadership for children and young people who did not have a consultant based at one of the specialist London children's hospitals. This was because the consultants at the service had experience in palliative care for adults rather than children. The service had responded by jointly working with one of the specialist children's hospitals and putting additional plans in place with respect to up- skilling the staff team and reviewing the referral criteria to ensure that all children and young people are under the care of a consultant paediatrician.

The service was involved in building links with the community and other professionals which had a positive impact on children's quality of life. A commissioner told us, "Ellenor are willing to work with and support other service providers such as special schools". At the special school we visited, the Ellenor nurse discussed children and young people's health care and treatment with the school nurse. A member of school staff said to the Ellenor nurse, "Thank you for your excellent support". We visited a young person with a complex condition who received nursing support from the service and also input from the local tissue viability nurse who was leading on this aspect of their care. The partnership working enabled the young person to be nursed at home. The Ellenor nurse also worked in partnership with the child's consultant at the specialist children's hospital to manage their pain effectively.

Children and young people's care and support was planned in partnership with them and/or their families. When undertaking an assessment, a nurse conversed with a parent in an informal way, gaining a lot of information about their child, their likes, dislikes and routines. They asked what the child liked to do and how the parent liked to support them. This included what signs staff should look out for to gauge if the child was happy or unhappy. This information was used to develop a plan of care. Staff had an excellent knowledge of children's individual needs and said that plans of care were easy to understand which helped them to care for children and young people. The nursing team also undertook joint home visits with staff from the child's specialist hospital.

When people were first known to the service they were given an information pack which included information about how to make a comment, compliment or complaint about the service. This set out how to make a complaint and how the organisation will respond. It included information on how to contact the ombudsman if the person was not satisfied with the response to their complaint. These leaflets were available around the service. Staff knew what they should do if a complaint was raised. Complaints were investigated and the complainant responded to in writing. The service used complaints as a learning experience if shortfalls were found which included additional training for staff in identified areas.

Commissioners told us they had not received any complaints about the service and two commissioners told us they had only received compliments about the level of care provided.

Is the service well-led?

Our findings

The service consulted with parents and carers in order to monitor the quality of care and people's satisfaction with the range of service's it provided. In 2016 people responded they used the 24 hour advice line mainly for urgent advice and that it was useful. One person responded, "I don't know what would have happened if the nurses advice had not been available". 89% of respondents were satisfied with the respite service, with a minority stating the reason for some dissatisfaction was having to pay for activities and staff not being available at the times they were requested. 50% of respondents used the family drop in service that was available. 100% of people responded they were satisfied with the support they received from the service. The reasons included, "The nurses are brilliant"; "Ellenor are really supportive and help get things done and to get my son seen by the right people"; and "Ellenor is truly amazing. I would be lost without their support".

A separate survey asked people about the effectiveness of the counsellors and therapists available at the service. This had been sent to users of the children's and adult hospice services, which were operated by the provider. 97% people responded they would recommend the service and 3% that they may possibly recommend the services. One person responded, "Two of our children have benefitted from play therapy and as a family we are very grateful that the option is available to us". The service was further developing its bereavement service and was setting up a small bereavement group for children who had been bereaved in the last three years. Therefore, the service was constantly reviewing its service delivery and making changes to improve the lives of children and their families.

Commissioners told us that the service gave a high level of satisfaction to children, young people and their families. One commissioner told us, "The service is outstanding and of high quality. They work well in partnership, promote excellent communication between professionals and families and the wide sector, enabling the sharing of good local practice to the benefit of families". A health care professional told us they valued the consistency and flexibility of the service to offer a respite service and a 24 hour on call system on such a consistent basis.

The management team consisted of the registered manager, the director of patient care and the head of children's services who were led by the chief executive officer. The head of children's services was based at the service and responsible for the day to day management of the staff team. The registered manager, head of children's services and the director of patient care were actively involved in clinical networks, improving service delivery, education and training. The chief executive led by example and was a strong role model. They had spent the day with the children's team which included home visits to children and families. Members of the board of trustees had also visited the team and attended multi-disciplinary team meetings.

Staff said they worked in a service where the culture was open and did not include staff bullying or harassment. One staff member told us, "The management of the service is motivational". A core team of nurses had worked at the service for many years. All staff were proud to work for the service and demonstrated their passion, commitment and enthusiasm for caring and supporting children and young people with palliative care needs. Staff meetings and team away days were held to engage staff in the

development of the service. Staff said they could make suggestions at staff meetings and they were listened to. For example, a clear career pathway was being developed by the director of patient care so staff knew how they could progress within the service. Joint working was underway to ensure that staff had access to a consultant in children's palliative care in addition to a doctor with paediatric experience.

There was a structured approach to monitoring the quality of service delivery. A comprehensive audit plan was in place which included medicines, safeguarding, staff training and complaints. A clinical nurse specialist was auditing the pain measuring tool used by the service and they gave an update about their findings at the multi-disciplinary meeting. A governance framework was in place whereby each aspect of the service, such as health and safety, clinical practice and medicines were discussed in sub groups and their findings were fed to the Board of trustees. The board meet on a quarterly basis to set and review the strategic direction of the service. The service had a strategy in place which covered the timescale from 2013 to 2018, which set out what action it intended to take to develop the service further. The majority of these improvements had been completed which included supporting carers.

The quality account for the service was published on the website. A quality account is required for NHS commissioned services and sets out the quality of the service and the plans in place to develop the service further. Proposed developments that had been achieved included developing an assessment tool and a set of criteria so that the respite provision was allocated fairly to each family; and a rebranding of Ellenor to join together the children's 'service' and adult hospice services to minimise confusion for the public and be clearer about the geographical areas that they cover. The reasons for these changes were due to a recognition by the provider that they were not caring for as many of the local population who had end of life needs as they could. This was also as a response to feedback that had been obtained from the public and other stakeholders. Therefore, there were processes for an on-going assessment and improvement of the service at all times.

The service had recognised that it could not function effectively without its support services such as the catering department and reception staff. Staff who worked at the service were asked for their views about these services and the support they gave them. Both services had received excellent feedback and any suggestions were looked into to see if they could lead to further improvements. .

Records about children and young people's care and treatment were stored electronically which gave staff and other relevant health care professionals' access to this up to date information when in the community. This also ensured that nurses who were on-call had all the necessary detailed information about a child or young person's medical, health and care needs. This meant that if a paramedic was called to Staff informed the ambulance service of any changes in children's clinical needs, a child's home, they were able to access this important information in order to help them assess what action to take in relation to the child's welfare.

The service worked in partnership with other organisations to make sure they are following current practice and providing a high-quality service. They strived for excellence through consultation, and research. Representatives from the service attended a number of clinical networks for palliative care and end of life care in relation to children which helped to agree end of life care strategies, share good practice and develop best practice initiatives. They also attended the Kent County Council Disabled Children's Provider Forum, which enables networking and information session to keep up to date with what is happening in Kent for disabled children.

Training links had been developed with a children's hospice in Kent to develop paediatric specialist end of life care training. A collaborative external neonatal event took place to increase awareness of advance care plans and to improve discharge processes for children moving home from hospital. In partnership with the

Kent and Medway Children's Palliative Care Network the service had successfully piloted and implemented a new paediatric prescription chart for symptom management. This tool was of high quality as it had been constantly reviewed and updated during its use in the community. Future partnership working was planned with the children's hospice in Kent around neonatal and infant palliative care.

In 2015 the service had received the Kent Charity Award, Children's Charity of the Year Award, Gravesham Community Award, Volunteers 'Best Group' Award and the former chief executive won the Hospice UK Lifetime achievement Award. This helped to ensure that people received support from a service that continuously learnt through experience and research, the most effective ways of meeting their palliative care needs.

The service had a separate fundraising department whose aim was to raise funds to ensure the service was able to operate as only 20-25% of the service was funded by the National Health Service. This was achieved through a chain of charity shops and a number of fundraising events throughout the year, such as a summer fayre where members of staff and the management team and participated. The parents of children and young people who used the service had been supported to raise the general public's awareness of the service to and some of their stories had been published in a local newspaper and the service's newsletter.