

Alexander Devine Children's Cancer Trust

Alexander Devine Children's Hospice Service (Headquarters)

Inspection report

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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?	Good ●
Is the service responsive?	Good ●
Is the service well-led?	Good ●

Summary of findings

Overall summary

Alexander Devine Children's Hospice Service was founded in 2007 and provides support across Berkshire and surrounding counties to children and young people from 0-19 years who have a life-threatening or life-limiting condition. Care is offered through hospice at home and in the community.

There was a registered manager at the service who registered with CQC on 16/07/2013.

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.

At the time of the inspection the service was supporting 86 children and families, 15 of which were suffering a recent bereavement. The bereaved families continued to receive support from the service.

Hospice staff worked in partnership with local NHS Foundation Trusts and other services across health and social care to deliver integrated care to children and their families. Staff worked within children's community teams to provide palliative care support and advice. Care was delivered in a variety of settings including at home, in hospitals or schools, depending on the individual needs of the families.

Children and young people who used the service were safe. Staff received safeguarding training and all staff we spoke with told us they would not hesitate to report any concerns they had to the relevant authority. Safe recruitment procedures were in place to ensure only suitable staff were employed.

Staffing levels were appropriate for the service and the service ensured it did not offer over and above what they could deliver.

Staff completed a thorough induction programme to enable them to carry out their roles and responsibilities. Palliative care and end of life training for all staff ensured children, young people and their families received compassionate and caring support. Bereavement support was available where this was identified as a need.

There were safe systems in place to manage medicines in the community. Practice was supported by robust professional guidance and policy to ensure the safe management of medicines.

There was a holistic approach to children, young people and their families, with social and spiritual needs given equal importance as the physical needs. Diverse cultural requirements were met by the service and any specific requirements following the death of a child addressed.

Where a specific need was identified in terms of dietary requirements, liaison with the relevant healthcare

professionals was sought.

We saw children and young people received care and support in a personalised way. Complex medical needs were managed well by staff who were trained to deliver specialised care and support. Children and young people said they felt safe with staff. Families reported staff knew their child or young person well and were reactive to their complex needs. Parents told us on-going bereavement support allowed them to adjust to their loss and helped them come to terms with their loss, enabling them to care for their other children.

Children, young people and families had their needs fully assessed, planned for and met by the service.

The service employed a play specialists who were able to work with families and children to engage with them positively, including supporting of social activities to promote the development of relationships.

There was a clear management structure, and staff said they were proud to work for the service. Staff were fully committed to the children and families they supported. Families felt comfortable talking to managers about any concerns or ideas they had for improvements. There were systems in place to ensure the continuous improvement of the quality of the service provided.

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.

Children and young people were protected from harm. Staff had received training in safeguarding and told us they would not hesitate to report any concerns.

Recruitment procedures were robust which ensured only suitable staff were employed.

Risks were well managed and reflected the complex needs of those who received care.

Medicines were managed safely and effectively by highly skilled professionals

Is the service effective?

Good ●

The service was effective.

Children and young people were supported to eat and drink and where additional input was required this was addressed.

Staff had effective training and support to carry out their roles. Parents felt staff were skilled to meet the children and young people's needs.

Staff understood the importance of gaining consent before care was carried out.

Is the service caring?

Good ●

The service was caring.

Staff were kind and compassionate and treated children, young people and their families with dignity and respect.

Parents told us the service supported the whole family, they told us ongoing care was invaluable.

Support was offered to families who were bereaved. Contact was maintained if this was the family's wish.

Is the service responsive?

The service was responsive.

Staff had an excellent understanding of children and young people's complex ways of communicating and responded to verbal and non-verbal ways of communication.

A complaints procedure was in place and families knew how to raise any concerns.

Children and young people were supported to engage in play and activities that met their individual needs.

Good ●

Is the service well-led?

The service was well-led.

Staff felt valued, listened to and supported in all areas.

Staff spoke of an open, supportive workplace culture that encouraged their views and input.

There were systems in place to monitor safety and drive improvements throughout the service.

The trustees and managers were accessible to families and staff.

Good ●

Alexander Devine Children's Hospice Service (Headquarters)

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.

The inspection took place on 28 and 29 September 2016 and was announced. The provider was given one week's notice that we were coming to ensure senior staff were available to access the documents we required to carry out our inspection.

The inspection team included one adult social care inspector, one registered nurse specialist advisor and an Expert by Experience. An Expert by Experience is a person who has experience of using or caring for someone who uses this type of care service. This was the first inspection at this location. We reviewed the information we held about the service and notifications we received. A notification is information about events which the service is required to send us by law. We reviewed the Provider Information Return (PIR). A PIR is a form that asks the provider to give some key information about the service, what the service does well and any improvements they plan to make.

We spoke with eight parents of children and young people who used the service. We observed three children who received care. We spoke with the Chief Executive Officer (CEO) the registered manager, the quality and governance lead, five registered nurses, a member of the fundraising team, a member of the care team, the play specialist and the person who donated land to build the inpatient unit.

In addition, we reviewed nine care plans, minutes of meetings, recruitment files, supervision records, staff

training records, policies and procedures, and audits carried out. We also had the opportunity to visit the inpatient unit which is due for completion in 2017.

Is the service safe?

Our findings

Staff had exceptional skills and the ability to recognise when children and young people did not feel safe. One mother told us, "I know [name of child] is safe with [member of staff] as they are very skilled and caring. They ensure we have a thorough handover before I go out, [the member of staff] has learnt to interpret how [name of child] is and safely adapt their feed and medicines accordingly so they get the best care."

Another comment from a mother who had two children that the service supported told us, "I feel very safe in leaving my children in [member of staffs'] care; they are like part of our extended family and sometimes know them better than the family. [The member of staff] knows what signs to look for if one child is becoming unwell, I would trust [the member of staff] to take appropriate action swiftly if I was not here". We found safe practice was supported through continuous engagement with children, young people and families.

Risk management was underpinned by policy and procedure which included a comprehensive home risk assessment and lone worker policy that protected staff working in the community. The service used effective ways to manage risk and keep children and young people safe. For example, we saw comprehensive and personalised care plans which took account of all presenting risks above and beyond more traditional risk assessments. In particular, we found there was a child with a risk of fractures during their moving and handling regime. We found that staff would use specific techniques for the child during the procedure to protect them. We found another child had significantly impaired body temperature control and was at risk of hypothermia. We saw risk assessments addressed this to allow the child to lead as normal a life as their condition allowed. In addition, activity care plans included a risk assessment based on the need for each child and young person.

Children and young people received medicines in their homes. This practice was supported by robust professional guidance and policy to ensure the correct and safe administration of medicines. Medicines were mostly prescribed by the child or young person's lead consultant and facilitated by their own GP. Where routine or as required medicine, including rescue medicine were required during a care visit, a dedicated medication administration record chart (MAR) would be completed. This would be transcribed by the service's registered nurse and countersigned by the Alexander Devine Children's Hospice Service doctor. For palliative care medicines, a symptom management plan was written by the Alexander Devine Children's Hospice Service doctor or palliative care consultant from the relevant hospice. The medicine would then be prescribed by the child or young person's GP. The medicine would be kept in a locked box within the home. The team were able to access symptom control advice 24 hours a day via on-call palliative consultants based at the relevant hospice/hospital local hospital.

Staff told us and records showed staff training had been completed in medicines management and staff were competency-assessed.

The staff had a comprehensive awareness and understanding of potential abuse which ensured they could

recognise cases of abuse. Staff knew what to do to make sure that children and young people in the community were protected. This was demonstrated when we spoke with a member of staff who told us they had recently reported to the manager a bruise they had seen on a young person's body whilst delivering care. This was investigated and was found to be a bruise the child had sustained when they fell. This demonstrated staff awareness of safeguarding and a high level of understanding to make sure children and young people were safe.

Staff received safeguarding training and staff we spoke with were able to demonstrate they understood the procedure to report any concerns they had to the relevant authority.

We observed high level infection control measures from all team members within each child and young person's home. The team had their own alcohol-based hand gel and we observed prompt and appropriate hand hygiene and use of protective clothing after carrying out personal care and nursing interventions. The staff team could describe how they ensured appropriate infection control equipment were used in the home for example sharps bins and contaminated waste disposal bags.

The service followed safe recruitment procedures. Pre-employment checks were carried out before staff were invited for an interview. In addition the service had an occupational health contract with the local NHS trust to ensure the correct safeguards were in place around qualified nurses' fitness to practice. Attention to robust recruitment procedures ensured the service only employed the right people with the right skills to meet the needs of the service. Staff we spoke with told us, "We make sure we deliver a safe and effective service protecting children young people and their families from any form of harm or abuse".

Is the service effective?

Our findings

The model of service delivery through partnership working with the NHS ensured effective collaborative working within the community. We found the service offered continuity of support for children, young people and their families. Alexander Devine registered nurses worked directly with the children's community nursing team, and other nurses from the NHS. In addition the service contracted sessional workers from the local NHS Trust to provide medical support.

Staff had a thorough induction that gave them the skills and confidence to carry out their role and responsibilities effectively so that children and young people had their needs met and experienced a good quality of life. On-going clinical skills and associated medical equipment training were based on best practice guidelines and integrated within annual appraisals. Staff were supported to develop their confidence in care delivery through a robust competency framework. In addition, registered nurses were encouraged to maintain their own portfolios and the service had integrated learning opportunities to support the new Nursing and Midwifery Council (NMC) revalidation process.

One member of staff told us, "The learning culture is second to none." The effectiveness of the service was enhanced by the on-going support for staff from induction to supervisions and annual appraisals. Another member of staff we spoke with told us, "It's been lovely, I can ask for support, the registered manager has been amazing, knowing I can talk to them is great. If I need to fulfil a competency then I work alongside a nurse; this is observed practice".

Staff completed a programme of mandatory training which included moving and handling, equality and diversity, health and safety, safeguarding, The Mental Capacity Act 2005 (MCA), Deprivation of Liberty Safeguards (DoLS) and infection control. Protected staff training time was respected to ensure required competencies were achieved.

The service had creative ways of training and developing their staff that made sure they put their learning into practice to deliver care to meet everyone's individual needs. For example, the service had organised specific training in exploring people's spiritual care. Staff told us the training had created a positive impact on how they supported children, young people and their families who had diverse cultural backgrounds.

One member of staff told us, "I have had advanced training in two subjects in the field I lead in since I began. As well as mandatory training I have had additional training in spirituality and bereavement. There is a budget and they find funding if it's thought to be beneficial".

Staff we observed had extensive paediatric palliative care experience. One member of staff had completed a Master's degree in complex and palliative care for the child and young person. The play specialist had specific qualifications and extensive experience in distraction therapy. One parent we spoke with described how the play specialist had transformed their child's negative behaviour and fear around wound dressing into a positive experience that the child no longer feared. "[The staff member] is completely responsible for

[my child's] change in behaviour, which has been such a relief for us as parents and for [our child]. [The staff member] came every time a dressing change was needed, which was daily for some time, and used fantastic distraction and then was able to reflect with [my child] and turn the fear into trust".

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people who may lack 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 interest and as least restrictive as possible.

Young people over the age of 18 can only be deprived of their liberty to receive care and treatment when it is in their best interest and legally authorised under the MCA. The application procedures for this in hospices are called the Deprivation of Liberty Safeguards (DoLS). The registered manager was familiar with the DoLS legislation and was aware of how to make an application.

Staff confidently made use of the MCA and used ways to make sure children and young people were involved in decisions about their care so that their human and legal rights were upheld.

Records reviewed demonstrated clear documentation for consent to care. Clear evidence was seen with regard to advance care planning. We found best interest discussions documented with parents and the medical teams involved. The decisions to refuse treatment clearly documented ceilings of care and emergency intervention signed by two including one consultant.

The service ensured children and young people were protected from the risk of poor nutrition. Where swallowing problems and other medical conditions affected their health, care needs were regularly monitored and reviewed and relevant professionals were actively involved. Each child and young person had a nutritional care plan that documented in detail how and what the child and young person could eat and drink. We saw one child was enteral fed. A dated feeding regime was documented by the hour detailing when the feed is to be given and by which route, volume and speed. It included when rests were to be given and how to adapt the feeding schedule if adverse symptoms occurred. We saw evidence of regular input from the local dietician.

Many of the children and young people the service supported were dependent on enteral feeding as maintaining effective nutrients was fundamental to their well-being. Staff ensured the care plan was followed on a day-to-day basis. Communication with the child and young person's family was essential to ensure any changes to diet or any problem observed was reported. The service had access via the children's community team to the child and young person's dietician.

Blended diets are becoming increasingly used by families in the community. Blended diets consist of regular foods blended to a consistency that can be easily passed through a feeding tube. Staff we spoke with told us parents reported that this process 'normalised' the tube feeding experience. The service had adapted and developed a policy outlining principles of best practice and a risk assessment to support staff, children and young people in the giving of blended diets. The service engaged with other professionals as appropriate, in particular the dietician. Conversations took place with the family in relation to nutrition and hydration at the end of life and were seen as a key priority.

One parent told us, "My child has complex needs and they know what to do. [My child] is PEG fed and they follow the dietician's plan. I am confident they [staff] have the knowledge to change the plan short term if circumstances change. Staff have had training specifically around my child's needs for example, with

feeding and physiotherapy".

Is the service caring?

Our findings

A comment from one parent was, "I sense that people care about us, [staff]. People look out for each other, not just the care staff but the fundraisers too".

Families said they valued their relationships with the staff team and felt that they often go the 'extra mile' for them when providing care and support. One parent told us, "It works great. Our nurse works in hospital and at home, which is great for us when [my child] is in hospital. The nurse has had training specifically around my child's needs, for example with feeding and physiotherapy. They look after my child's siblings and we also have the play specialist who works mainly with the siblings. When [my child] was very poorly the Alexander Nurse talked to the siblings about end of life care. They look after the whole family I am very satisfied with the level of service." This demonstrated that care is proactively planned taking into account the needs of the family as a whole. Family support was seen as key to children, young people and their families' wellbeing.

The Alexander Devine Children's Hospice Service had developed the end of life pathway to support the care of children and young people at the end of life. The pathway included support for the whole family at the time of death and extended to support during bereavement. A member of staff told us, "End of life care is incorporated in advanced level care plans. We provide support with NHS colleagues and other hospices. It always depends on what the families want". One parent said, "We have an advanced level care plan which includes end of life care, which we have talked about. We have discussed our wishes."

One family told us, "The managers are lovely. I am more than happy to recommend Alexander Devine to anyone. They look after my whole family".

One child the service supported was only fed intravenously through a catheter directly into their venous system. Apart from the child's parents, the child could only be left with someone who was trained in intravenous feeding. A member of staff from the Alexander Devine hospice was the family's only means of support as they were trained in this area. Visits were planned several times a week to give the family much needed respite so they are able to pick up their other child from school or go shopping. The Alexander nurse attended hospital visits with the child in order to keep abreast of the child's changing needs. The parent commented, "[The staff member] has been my rock 24/7, we would be lost without them. [The staff member] looks after my child 'my way', to give us a little bit of quality time together as a family." This demonstrated families received care from staff that were compassionate, understanding, enabling and who had a distinctive skill in this aspect of care.

The service used creative ways to make sure that children and young people had accessible, tailored and inclusive methods of communication. We observed a child who could not communicate verbally but was able to demonstrate unhappiness and pain or discomfort by sounds. We observed staff skilfully recognise they were becoming distressed. Staff responded in line with the care plan and the child became settled and

made sounds associated with happiness.

Another child we observed with severe cognitive impairment was thought on occasions to be able to choose with eye pointing. This approach was used by the child's school teacher. We observed staff very patiently support the child to select the music they wanted to listen to. We saw the child appear to make their choice clear using eye movements, which the staff followed. This demonstrated that staff were highly motivated and inspired to offer care that was kind and compassionate. We found staff were determined to overcome any obstacles to achieve the highest possible level of care.

We observed the staff worked with the entire family, not just the child or young person receiving care and support. We saw documented evidence of how the play specialist had worked with siblings within families facilitating fun times for them away from the needs within their home. We observed the play specialist working with a child encouraging the child to make choices and lead the supportive play session. This demonstrated staff acknowledged the importance of allowing the child to dictate the play session at their own pace.

All care was carried out in the home with various levels of adaptation. We observed one child who required a bath on returning home from school with two members of staff. The staff used all methods available within the home to provide privacy. We heard the sensitive way staff spoke with the child, encouraging and reassuring them and introducing fun into the care intervention. On all occasions that we joined the staff team in people's homes, staff introduced us and asked if the child and young person was happy for us to visit and join in. This ensured children and young people that received care were afforded privacy, choice and control with regard to their care intervention.

We reviewed a care plan for a child who received end of life care at home. The care was shared between the Alexander care team and the local community children's nurses. This was supported by another hospice staff team where the child received intermittent respite care over the previous two years. The records clearly documented a good understanding of the child's and family's wishes taking into account the needs of the siblings. There was a comprehensive symptom management plan in place written by a medical consultant in paediatric palliative care. Anticipatory medicines were documented to be in the home provided by the local children's community nurses. There was an on call rota specifically for the family on the front of the records and placed in the home sharing 24 hour on call cover with the local community team and providing an out of hours contact for a consultant. Daily contact with the family was carried out together with planned twice weekly 'play visits'. The Alexander Devine Children's Hospice Service Doctor had seen the child at home. This demonstrated that care was proactively planned in conjunction with the family and the wider members of the professionals involved in supporting the child and family towards the end of life.

Staff confirmed that on-going post bereavement care and support could continue with bereaved families for as long as the family wished. Several staff had attended bereavement training in addition to mandatory training.

Bereavement services were tailored to individual needs and were provided over a significant period of time after death. This was evidenced by confirmation that the service was continuing to support 15 families following the death of their loved one. The service displayed a butterfly logo on care notes to identify bereavement in a family. This ensured staff were prepared when contacting the family and avoided any discussions about the deceased child or young person that could cause unnecessary upset to the family.

Is the service responsive?

Our findings

Children and young people received a very responsive service. Comments from one family were, "From our referral to the service being set up took less than one week. We were in hospital when the referral was made; within a week of being at home the play specialist was visiting".

Care within the service addressed a range of needs. These included support for children and families from diagnosis, respite care, crisis and emergency care, assessment and symptom management, end of life care, family support, and on-going bereavement support. The service aimed to meet the varying and changing needs of the diverse population offering total care, physical, emotional, cultural and social care. Joint working with NHS colleagues also achieved this. Care was delivered in home, hospital or school, dependent on the individual family's needs. The service had processes that supported fast-track referrals and emergency respite for family crisis.

The service strived to be known as outstanding in providing person-centred care based on current practice. For example, we saw evidence of the staff team being individually trained by an acute physiotherapist to support the mobility needs of one child. In addition, for one child who had epilepsy which was very complex, care was only ever provided by a qualified nurse who knew the child's needs very well. The service was flexible and able to adapt and alter their provision of the care package according to the needs of the child or young person.

Care and support needs were planned proactively in partnership with each child or young person and their family. Staff used individual ways of involving the whole family so they felt consulted, empowered, listened to and valued. Comments from one parent included, "It felt like a huge weight was lifted from me to know [my child] was getting direct support at home and my younger child was able to have some of my time back, and as siblings they could be helped to learn to play together again". This meant the family had an enhanced sense of well-being brought about via the responsiveness of the service.

Staff had specific skills to understand and meet the needs of children, young people and their families in relation to their emotional support and the practical assistance they needed with day-to-day life. One parent told us, "The staff have been so helpful since the beginning. I referred myself and the response was very quick. I know if [my child] is going through a bad patch I could ask for more help and they would do all they can to provide more input". This demonstrated the service's flexibility and responsiveness to individual needs and preferences in finding creative ways to enable children and young people to live a life as full as possible.

The service was nearing completion of an inpatient unit. Comments from one parent were, "When we were talking about the new build, my child's sibling, who is six years old, came up with the idea of a wheelchair accessible tree house. They [staff] actively encouraged [my child] with the idea and got [my child] to draw a picture with their ideas on it. It has now been submitted to the architects and we are so proud".

The service supports children and young people in the community. For example, care was delivered in a

variety of settings such as at home, hospital or school. In addition, the service facilitated respite visits. For example, staff would take a child or young person out whilst parents spent time at home with the other children. This was organised for several families who were supported by the service. This gave the parents a much needed break. Comments received from a parent were, "I know I would be a very different mummy, I would not be well without the care and support from the service. We had really dark moments; the service has been the glue we needed to get through. It's impossible to express how grateful we are". Other comments were, "My child has after school care so they [staff] have to be there to meet [my child] at home. They follow the care plan and [my child] goes to bed at the usual time. They were very flexible when I had an operation and were helpful in getting [my child] out of the house." The feedback from parents who use the service demonstrate outstanding levels of support in meeting the needs of the whole family.

The service actively sought solutions to make sure children and young people had as few restrictions as possible and not miss out on social activities. One example of this was that the service arranged transport to take a child to their nursery. We observed handover between school transport care staff to the Alexander staff and from a parent to Alexander staff for two children. This included both the children's health status and general well-being. This demonstrated communication was effective between staff that provided care and other parties important in the person's life.

The comprehensive set of care plans we saw were personalised to the needs of each child or young person. For example, where tracheostomy care was required, care plans would be specific to the care and support provided. In addition to physical support, the service ensured that emotional support was reflected in the care plans and was of equal importance. For example, what makes me happy/sad was included in the care plans. Staff we spoke with were able to tell us what made each child or young person happy and upset without referring to the care plan. This demonstrated staff knew the children and young people they supported extremely well. There were robust systems in place to make sure that any changes to care plans were communicated to those that need to know at all times of the day or night. For example, on call consultants based at the local hospital.

The service took a key role in the local community and actively built further links. Children, young people and their families were encouraged and supported to engage with services and events that would have a positive impact on their quality of life. For example, the service offered VIP days for families to a nearby theme park for children. In addition, 'Hospice on the Road', 'Kids in Action' and Christmas Parties. These were additional activities to ensure children and young people were involved in the community.

The organisation worked in partnership with local NHS Foundation Trusts and other services across health and social care to deliver integrated care to children and their families. Staff worked within children's community teams to provide palliative care support and advice. The Alexander Care team worked closely with GPs and other professionals to support quality care. We found a coordinated approach to care which ensured gaps in care were prevented.

Input from other services and support networks were encouraged and sustained. The service demonstrated that an integrated approach facilitated an effective service for children, young people and their families. For example, the service worked collaboratively with children's community nursing teams, child development centres, local and tertiary paediatric units and neighbouring hospices.

The service held monthly care team meetings to ensure effective communication around clinical updates, service development and any new and revised policies and procedures. In addition the service had monthly multidisciplinary team meetings which were attended by the doctor to review the services caseload.

The service demonstrated that spirituality was an integral dimension of good quality palliative care. The service recognised that each child and young person had a unique cultural background which had specific spiritual issues. They also acknowledged life-threatening illnesses were a physical but also a spiritual event. In addition the service recognised that understanding the diverse needs of different families was essential due to the significant amount of Muslim families the service supported. In response to this and to ensure staff were fully conversant with different belief systems, training was organised that allowed staff to feel prepared and confident when supporting families from different backgrounds.

A presentation titled 'Illness and Death from a Muslim Perspective' was given by one of the Muslim parents. Feedback from staff confirmed they felt more confident and comfortable addressing issues of spirituality and cultural care with families and children. The service had recently cared for a Muslim family at the end of life. Staff reported they had a greater understanding of the cultural and spiritual values of the family. This enabled them to attend to the child's nutritional needs and to respect the many visitors to the home. In addition, the training provided staff with confidence in what to expect at the funeral and how they could continue supporting the family in the days following the death, at the funeral and in the months ahead.

Written comments from a Muslim family following the death of their child included, "I was thinking of you today, when we called you came straight away and because of your care and compassion [my child's] last few days were more bearable. I just wanted to thank you from the bottom of my heart. I'm so grateful to you for being there for [my child]."

On-going bereavement support is by way of, a phone call to the family within a week, a home visit, a card sent at the time of birthday or 1st anniversary, groups, forums and sibling days.

The service valued the opinion of those using the service and welcomed comments and suggestions about the care and service from children, young people and their families. Children and families were encouraged to be involved in the care planning process and given the opportunity to provide feedback. In addition the service regularly undertook a satisfaction survey to support improvements and developments within the service. A parent's forum provided a comprehensive avenue for feedback and discussions for service development.

We saw evidence of many compliments about the service families had provided. One in particular was, "When [my child] is in your care we feel confident that they are being nursed and looked after to the highest standards. At one point [my child] was experiencing pain and distress and one of the first questions we were asked was around pain management. This was the first time we had been asked this question proactively and it showed an understanding of the importance of quality of life. Although our time has finished our smiles will never fade. Thank you for all the laughs and memories."

The service had not received any complaints.

However, the service saw concerns and complaints as part of driving improvement. On-going improvement was seen as an essential part of providing the service to people. Feedback from families was valued and the responses to the matters raised were dealt with in an open, transparent and honest way. One member of staff told us they had made a suggestion to improve communication with the lead managers in Community Continuing Care Needs. They confirmed the suggestion led to an improvement in the service and the way care was prioritised.

Is the service well-led?

Our findings

Families we spoke with told us the service was well-led and said they were able to easily contact the management. They said the service was focused on meeting the needs of children, young people and their family and that staff were kind and genuinely passionate about the service they provided.

The organisational health of the service was addressed using a business plan that met the needs of the people who worked within the service as well as ensuring a robust financial state. For example, the organisation was committed to providing strict financial governance arrangements and a fundraising strategy to ensure a constant, sustainable and effective service.

The organisational values and principles of practice provide a rich philosophy where open and honest communication is valued. Workshops exploring the model of Myers Briggs Type Indicator (MBTI) had been undertaken within the service. This type of training explored personality types and how people perceive the world and make decisions. This demonstrated the organisation encouraged and explored proactive ways in which to promote self-development for staff who worked within the organisation.

Team building exercises were undertaken at each meeting to promote good communication and team support. This extended to the fundraising team to ensure both care and fundraising work together achieved the same goal.

The charity was directed by a Board of trustees led by a Chairman who was the Co-Founder of the charity and had an MBA in Business. The organisation was led by the Chief Executive who had experience in social care. The senior management team consists of the Co-Founder, Chief executive and three heads of departments who reported to the Board of Trustees. The service worked towards and achieved recognition with quality accreditation schemes. The service was recognised by the Landmark Trust and had received an award for recognising 'a deserving team'.

In addition the service had been invited to speak at a number of events and conferences including the Thames Valley Business Awards and the first End of life Conversation event with Reading Borough Council in recognition of the organisation's achievements and quality of care and support they have provided.

The service had appointed a quality and governance lead to guide areas of improvement, which was continually monitored through a comprehensive review and audit processes. The service's clinical governance lead, supported by an engagement and active trustee group, managed the quality of care.

The service worked in partnership with other organisations to share best practice and ensure high quality care was underpinned by consultation, research and reflective practice. The service is able to care for children and young people with complex care packages. This was achieved with the strong links the service had established with the NHS. The service defined quality from the perspective of those who used it. Involvement with staff and external stakeholders was consistent.

There was a sustained and monitored emphasis on striving to improve. Strong foundations on which to

further develop the service and maintain a supportive environment for children, young people and their families were addressed. This was evidenced in the development of the inpatient unit due for completion in 2017. The CEO had a clear vision of hospice services needed for children and young people in the area and strived to put this into practice. Strong values and vision from senior staff shaped the way the service provided outstanding care to children and young people.

Comments from a visiting professional were, "Everybody seems to share the same core values which are testament to great leadership".

Staff understood their role and appreciated what was expected of them. They told us they were happy in their work and were motivated and had confidence in the way the service was managed. One member of staff told us, "The registered manager has confidence in their own ability which rubs off on the rest of the team". The registered manager had 20 years' experience in children's palliative care, both in clinical and educational practice. They held a first degree in palliative care and a Master's degree in advanced practice. At the time of the inspection, they were completing a PhD. The registered manager told us and felt that this would further enhance the care and support we provide to families.

Staff told us, "The best thing about working for Alexander Devine is the team we all care for and support each other and help each other learn and develop. I came with no clinical skills. The team have been amazing in taking the time to teach me and make sure I am safe. They always make sure they have the time to teach". Another staff member said, "I have clinical supervision every two months, more if I need it. The sessions are well planned and very productive. This is what you need when you work with very sick children and young people. You need to be able to reflect and process the sad and challenging times to keep providing the best care".

Staff we spoke with told us, that the small size of the organisation significantly contributed to information sharing and peer support. There was unanimous praise for the two lead managers the general manager and the clinical governance manager. One member of staff commented, "It's a small team and we work in the same building. Knowing all the staff is lovely. It's cohesive and supportive. This place is all about learning". Other comments were, "I've never worked for a manager so committed. People feel confident because of their experience. I can't think of anything similar anywhere else".

We were told, "There is a culture of openness and I definitely feel I have the opportunity to shape things". The open and learning culture extends from those delivering care to the senior management team. Monthly organisational meetings were held to enable an exchange of updates and for everyone to raise issues or concerns. This in turn enables constant feedback from staff in a supportive environment. One family told us, "The managers are lovely. I am more than happy to recommend Alexander Devine to anyone. They look after my whole family".

Families were regularly involved with the service in a meaningful way to drive continuous improvement. The service encouraged comments and feedback about the care provided. This was achieved by way of user involvement feedback, for example, parents' questionnaires, parents' forum, postcards, and Survey Monkey. Survey Monkey is an online survey.

Integrated governance and quality assurance underpinned the service which was supported by comprehensive risk management, audit and quality improvement programmes. Care delivery was robustly supported by continuous monitoring and audit of the quality of the service. Annual audits allowed the service to act on findings from individual audits. We saw monthly audits which were undertaken and any shortfalls could be addressed. We did not find evidence of any concerns that had been identified whilst

carrying out monthly audits.

The registered manager was aware when notifications of events had to be submitted to us. A notification is information about important events that have happened in the service and which the service is required by law to tell us about. A notification only had to be submitted if a child or young person died whilst staff were in attendance and providing care and support.