

Acorns Children's Hospice Trust

Acorns Children's Hospice in Birmingham

Inspection report

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Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Outstanding 

Is the service caring?

Outstanding 

Is the service responsive?

Outstanding 

Is the service well-led?

Outstanding 

Summary of findings

Overall summary

Acorns Children's Hospice in Birmingham is registered to provide care and treatment to children and young people, aged between 0 and 18 years, who have a life-limiting illness or condition. Acorns provide a range of services within its hospice; day care, short breaks for children, support into adult services, end of life care, and care after death. Specialist nursing care is provided at the 10 bed hospice. The provider; Acorns Children's Hospice Trust runs three hospices in the West Midlands. They share some staff expertise and teams, such as the hospice wide Transition Team, and Asian Liaison Officer.

This comprehensive inspection took place on 2 March 2016 and was unannounced. There were five children staying in the hospice on the day of the inspection with a further two children attending for day care.

There was a registered manager 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.

Children and young people we met were happy and relaxed in the company of staff. Parents we spoke with told us they were very happy that staff kept their child safe. Staff had been trained and knew how to recognise and report any concerns about potential harm or abuse. Within the hospice appropriate safeguards were in place to chaperone visitors to keep children safe. There was regular review of accidents, incidents and concerns to promote the safety of children and young people. Arrangements were in place to promote the safety of staff working alone within the community. Staff were aware of risks specific to each child's care, safety and medical condition and how to manage these.

Appropriate checks had been undertaken to ensure only suitable staff were recruited to work with children and young people. Staff had the specialist skills to care for children and young people's needs. Arrangements were in place to increase staffing levels where children and young people's needs increased and parents had access to out of hour's support for help in emergencies.

Staff had received training and support to manage children and young people's medicines. The arrangements in place for managing medicines were safe.

Staff were highly trained and had the specialist skills to support children and young people. There were strong links with other organisations to ensure children and young people at the end stage of their life benefitted from high quality palliative care. Staff and external professionals expressed a high level of praise for the expertise and commitment of staff. There was a strong focus on developing and supporting staff to take on specialist lead roles to ensure children and young people had the care they needed.

Staff had been trained in and understood the importance of gaining young people's consent to their care

and treatment. We saw young people had been involved in decisions that affected their care or treatment. Parents' consent and decisions regarding their child's care had been sought.

Children and young people had a choice of meals and staff knew what to do if there was a concern about eating or drinking enough. Staff worked with parents and community services to maintain children's eating and drinking if their condition deteriorated.

Where children or young people needed end of life care advanced care plans were in place. Parents were provided with explanations and choices regarding their child's care and support needs. Wishes in relation to end of life care were discussed and planned for. These reflected personal choices and preferences about how their care and treatment should be met and included the arrangements for managing symptoms or pain.

Parents and family members support needs had been considered and met. Bereavement support, complementary therapies and sibling support had been highly complimented. There was an excellent awareness of children and young people's spiritual, religious and cultural needs so that they and their families had the support they wanted, before, during and after death. Families had additional practical and emotional support via the use of trained volunteers and befrienders.

There was a clear commitment to providing the best quality care to the child and young person and their extended family. Parents and external professionals told us staff were always keen to help, thoughtful, considerate and kind. We saw many examples of compassionate care and staff treating children, young people and their family with respect.

We saw children and young people enjoyed a variety of play and activities during their respite stays at the hospice. They had access to a hydrotherapy pool, specialist sensory room and computer technology. A variety of outings and events had been arranged to ensure children and young people had fun and stimulating opportunities.

A complaints procedure was available and there was technology for children to communicate feedback on their experiences. These were monitored by the management team to ensure any learning could take place.

Everyone we spoke with was consistently positive about the way the hospice was managed. The experiences of children, young people and parents had been used in a positive way to develop the support services available to them. Families had access to specialist staff in the hospice and support within their own home. Young people approaching adulthood had been well supported with their transition into adult services. There were excellent links with antenatal services so that care and treatment could be planned without delay for babies who had life-limiting or life threatening conditions.

There were strong links with other specialist organisations to share learning and expertise and this had led to developing their services further. We saw they had been creative, innovative and had positively increased the number of families they had reached. The systems in place to check the quality of the service were consistently applied. These included checking their service against recognised standards for end of life care for children. Management and staff were highly motivated and committed to continual improvement to meet the changing needs of children and families.

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

The service was safe.

Children and young people were protected from potential harm or abuse by staff that had been trained in recognising and reporting abuse.

Risks to the safety and welfare of children and young people were identified and managed to keep them safe.

Staffing levels were planned to ensure children and young people were cared for by staff in the right numbers and with the right skills to meet their needs.

The arrangements for managing children and young people's medicines were safe.

Good 

Is the service effective?

Outstanding 

The service was effective.

Staff were skilled in paediatric palliative care and had specialist lead roles with strong partnership working with other organisations. The training, development and support to all staff and volunteers enabled them to carry out their roles effectively.

Young people had been involved in decisions about their care and treatment by staff who understood the importance of gaining their consent. Parents' decisions regarding their child's treatment and end of life care had been sought.

Children and young people were provided with a choice of meals and drinks. Staff liaised with parents and community services to maintain children's eating and drinking.

Children and young people had access to specialist advice and support, including medicines and equipment for their care, symptom and pain management. Symptom and pain management could be planned and provided without delay at the hospice or via out of hours support.

Is the service caring?

Outstanding 

The service was caring.

Staff were kind and compassionate and treated children, young people and their families with dignity and respect. Parents felt staff listened to them and showed concern for the whole family's wellbeing.

There were some excellent examples of 'targeted' volunteering whereby families had additional practical and emotional support this included the use of 'befrienders'.

There was an excellent awareness of children and young people's spiritual/religious and cultural needs so that they and their families had the support they wanted

Children, young people and their parent's wishes in relation to end of life care was discussed and planned for.

Is the service responsive?

Outstanding 

The service was responsive.

There was an excellent understanding of the diversity of children and their families and a variety of flexible services had been designed to respond to their needs.

Transition arrangements were well established to support young people moving into adult services.

Excellent links with antenatal services were evident to ensure families of unborn babies had early involvement with the hospice.

Children and young people had access to a wide range of activities, outings and events suited to their needs and age.

There was a positive approach to receiving and managing concerns or complaints which were used to improve the quality of the service.

Is the service well-led?

Outstanding 

The service was well-led.

There was a positive and inclusive culture with a range of opportunities for parents, children and young people to share their views about the quality of the service.

Management had a clear vision and strategy to increase the

services on offer to children, young people and their families. They had promoted a flexible, accessible and consistent service to meet the specialist needs of children and young people.

There were strong links with specialist palliative care professionals and providers to share best practice and expertise so that children and young people had high quality palliative care.

There were robust auditing systems in place to ensure the quality of the service was constantly monitored and actions were in place to constantly drive improvement.

Acorns Children's Hospice in Birmingham

Detailed findings

Background to this inspection

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

This inspection took place on 2 March 2016 and was unannounced.

The inspection was carried out by one inspector, a member of the CQC medicines team and a specialist advisor. The specialist advisor was a Paediatric Palliative Care Liaison Nurse, qualified and experienced in working within a hospice within the field of palliative care.

We reviewed information the provider had sent to us which included notifications of significant events that affect the health and safety of children/young people who used the service.

We used a number of different methods to help us understand the experiences of children, young people and families who used the service. We spoke with six families of children and young people. We spent time with children and young people observing the care and support being delivered. We spoke with a young ambassador [YA] from Acorns; a young person who has had experience of using the services of Acorns. They represent 'the voice' of young people within the service with a view to influencing the services provided. We spoke with a Parent/Carer Champion; [PCC], a parent who uses the services of Acorns and has been trained to support other parents. They represent the views of parents and families in order to influence the services provided.

We talked with 15 staff. This included, nurses, healthcare assistants and team leaders from the family support team, transition team, Asian Liaison Officer, volunteer manager, volunteers, sibling support worker,

quality and governance lead, safeguarding lead, head of care services and director of care services. We viewed 11 children and young people's care and treatment plans and medication records. We looked at a range of quality assurance audits, clinical audits, meeting minutes for different teams and departments, and staff training and development records. We also looked at the feedback from external professionals who had attended palliative care training days provided by the provider. We looked at a variety of written feedback from parents and children to include testimonies from parents, feedback from support groups and young people's feedback from sibling groups they attended. We received written comments from external healthcare professionals and looked at a range of documents which related to the management and governance of the service to include impact statements; [reports on how the services provided had impacted upon people receiving them].

Is the service safe?

Our findings

Parents were consistently positive in their comments about the safety of their child. One parent told us, "My child is safe at Acorns; the staff understand the risks associated with her condition and manage these really well". Another parent told us, "It's a big thing leaving your child; it comes down to confidence that the staff can look after them properly and I have no worries about that".

Staff and volunteers were aware of the reporting systems to use regarding concerns of potential or actual abuse. A staff member told us, "I had training in safeguarding children and I know how and when to report concerns". We saw all staff had access to and were able to tell us about child protection procedures. We found there was a clear framework for all staff which included what to do if a child or young person disclosed abuse. Staff were aware of the risk of bullying and how to report and act on this. Information leaflets were available for children and their families in the information packs. These provided clear child friendly information using words and pictures to inform children and young people about their right to be protected.

The director of care services was the designated safeguarding lead and chaired the safeguarding steering group. They showed us documentary evidence that confirmed all safeguarding concerns involving a child or young person had been reviewed. Links with other statutory agencies such as safeguarding children's boards, Clinical Commissioning Group [CCG] and the National Society for the Prevention of Cruelty to Children [NSPCC] were also evident which confirmed that any child protection risks were shared so that appropriate investigation and action could be taken. We saw staff had attended additional 'Prevent Awareness' training. This focused on the needs of vulnerable groups of children. The director of care services was able to provide examples to us of how this training and multidisciplinary working had assisted to protect vulnerable children. The safety of each child and young person was taken into account. We saw appropriate safeguards were in place to keep children and young people safe because staff chaperoned all visitors.

Environmental risk assessments for the facilities and the clinical equipment children and young people needed to use were in place. Medical equipment in use at the hospice was regularly checked and tested for safety. This was carried out on a daily basis to ensure equipment such as oxygen was available to respond to emergency situations. The systems for the reporting of accidents and incidents were viewed and found to be robust.

Some children and young people were supported to move with the aid of specialist equipment; instructions were in care plans to do this safely and we saw staff followed these when supporting children. Children and young people were able to safely take part in activities such as using the hydrotherapy pool because staff were trained and assessed as competent to safely support children in the pool. The provider had two other hospices with jacuzzi or hydrotherapy pools which children and their families could access for "Family Splash Days". One parent we spoke with told us, "My child loves the pool and it is safe because the staff are trained to support her needs whilst in the water. We would never be able to take her swimming normally so this is fantastic for her".

A physiotherapist worked as part of the staff team and assessed the support children and young people needed to keep them safe. This included safe positions for eating, sitting, sleeping or supporting children or young people to move with the aid of specialist equipment. The physiotherapist supported children and young people to access the hydrotherapy pool safely. Each child or young person had a 'Going out information sheet' which demonstrated risks had been considered and planned for which included the equipment they needed and the number of qualified staff. We saw individual risk assessments specific to each child or young person's needs were in place. One staff member was supporting a very young child who had a tracheostomy [a tube to help breathing]. The child also required regular suctioning, (clearing breathing airways) and close monitoring for sudden changes in their condition. We saw the child was being supported by a nurse and a health care assistant, (HCA). The HCA was able to describe what care interventions the child needed and how they monitored and responded to these. They were able to recognise the signs of deterioration and how to seek medical attention from the nurse. They told us, "There's a nurse and myself working with [child's name] and we will work with him all day and monitor his condition". We saw the risks associated with the child were recorded in their care plan and the frequency of interventions was detailed. The child's parent told us, "My child needs constant monitoring there is always a nurse and care assistant with him, they have been fantastic".

We saw staff had a handover at every shift where they discussed each child and young person's needs and staff were allocated to work with individual children or young people to meet their needs. A parent told us, "Before each visit to Acorns staff contact me and go through any changes so they have an up to date plan, also when we arrive we can discuss any issues". We saw staff were well informed and knew how to manage each child's needs on the day. Some staff provided home based support to children and their families. A staff member told us, "We have a lone worker policy in place and we carry out risk assessments of the home environment".

Parents told us they had no concerns regarding the staff arrangements at the hospice. One parent told us, "I've got no concerns about staffing; there's always staff to talk to us or to care for our child". A young ambassador who had used Acorns the services at the hospice told us, "I remember there was always enough staff to look after us, take us out or do activities. At night staff came to check on you". We observed staff were available to supervise and care for children and young people. We saw staff worked with individual children some of whom required one to one or two to one support from staff. We saw a high level of interaction with children and young people; using the sensory room, playing games with staff, listening to music and watching DVD's. Staff were attentive and playful with children and young people who we saw responded to staff contact with smiles and gestures. Staff we spoke with were confident the safety of children and young people could be managed effectively by the staffing levels. A staff member told us, "We do have extra staff if we have children or young people who require extra staffing support".

We saw there was an on-call system for staff to seek management support if there was an emergency or a child's condition deteriorated. The registered manager told us, "We look at staffing levels and skill mix to ensure they are right for the child; sometimes we can plan in advance sometimes we have to increase staffing if there is a child in need of acute end-of-life care or a family crisis". We saw day care was offered for two children each day, in addition the outreach team supported families in their home or visited children in hospital. We found the dedicated teams had the staffing levels which provided these specific benefits to children young people and their families. The staffing structure also enabled psychological, social, emotional and bereavement support to be provided as well as support to transition into adult services. These services were further complemented by social workers, volunteers and complementary therapy staff. In addition we saw housekeeping, catering and maintenance staff complimented this structure.

Recruitment procedures were implemented for all staff and volunteers. These included a disclosure and

barring check, [DBS] a police check to ensure staff were suitable to work with children and young people. Nurse registrations were also checked and updated. A staff member told us, "I had a police check, showed proof of my identity and health as well as my qualifications". Volunteers helped to support and complement the care children and young people and their family's received. The team leader for the volunteers worked across the three hospice sites and confirmed that full recruitment checks were in place for all volunteers. We discussed recruitment practices with the director of services and we found their procedures were appropriately implemented.

Medicines were prescribed by a team of two nurse prescribers and a GP who visited daily to manage individual children's healthcare and medicine requirements. We were told that if advice from a pharmacist was needed then the team would contact the community pharmacist or specialist pharmacists at the local children's hospital. Medicines were available which were supplied by a local pharmacy. Nursing staff had access to local community pharmacies for out of hour's medicine requirements. We observed the administration of medicines by one nurse who took the medicine and the prescription chart to the child to ensure the correct medicine was given. The chart was then signed for the administration of the medicine. This followed the nursing and midwifery council [NMC] guidance for the safe administration of medicines. There were no set medicine administration times. The times of administration were designed to be specific to the individual child. This was a very child centred approach. However, there had been an incident where a child had not been given the morning medicines which had not been noticed until the afternoon. Lessons had been learnt from this and nursing staff now ensured medicine charts were checked regularly to prevent this happening again. We checked the medicines prescribed on two prescription charts. We noted there was clear recording of the prescribed medicines which also included additional instructions for safe administration.

Pain treatment guidelines were accessible and available for staff to follow. A separate chart was used to record what pain relief had been given with the reason why documented. The effect of the pain relief was evaluated and recorded on the same chart. We were shown a clear system for managing the ordering and supply of medicines. Medicines were checked for accuracy when a child was admitted to the service. This was undertaken by two nurses who checked what medicines were prescribed and ensured that the doses were accurate and current. The medicine administration chart was also checked and signed by either the GP or one of the nurse prescribers.

Processes were in place to check medicines were within their expiry date and suitable for use. Expired and unwanted medicines were disposed of safely and correctly. Medicines were stored securely in locked cupboards in a locked treatment room. Only authorised staff had access to the treatment room. Prescription pads were securely locked away with a copy kept of what had been prescribed on each prescription for audit trail purposes. The storage and recording of controlled drug medicines which require extra security storage arrangements were stored securely and recorded correctly according to safe practice. Controlled drugs were managed safely which included sending quarterly incident reports to the local Controlled Drug Local Intelligence Network [CDLIN]. Daily temperature records were available which recorded the temperatures for the medicine refrigerator and the medicine room temperature. This ensured that medicines were stored within safe temperature ranges. Arrangements were in place to enable children or parents to look after and self-administer their own medicines following a risk assessment.

Medicine incidents were reported using a specific medicine incident form with arrangements in place to ensure they were investigated. They were discussed at monthly medicine management meetings as well as at three monthly meetings between the medical director and the nurse prescribers. This helped to ensure lessons were learnt. We were shown minutes of recent medicine management meetings which also included what action was taken on any medicine safety alerts to ensure safe practice was followed. In the event of an

anaphylactic reaction (a severe allergic reaction), there was no provision for the availability of emergency treatment packs. We were told this subject had been widely discussed and that children usually brought in their own emergency medicine supply if needed.

Is the service effective?

Our findings

Parents told us they were confident in the staff who cared for their children. Staff were described as being professional and knowledgeable about children and young people's needs. One parent told us, "They understand [child's name] needs and they meet them very well, I have no concerns". Another parent said, "There's nurses, specialist nurses, a physiotherapist; we've had support from all of them at different times".

Nurses had been actively supported to achieve accredited training in paediatric palliative care; [end of life care], and held a higher education qualification to provide specialist palliative care to babies. There was a dedicated nurse with special responsibility for the delivery of antenatal and neonatal care at each of the provider's three hospices. These staff had the skills to ensure they could support parents with decisions regarding their child's care and treatment options. Their links with the local neonatal units had enabled staff to offer compassionate removal of breathing equipment within the hospice. This provided parents with a choice around the preferred place of death or in some cases a longer period of palliative care and symptom management. Staff supported families alongside hospital medical consultants so that an end of life plan could be put in place before extubation took place. This had enabled staff to provide palliative care to babies at the hospice sometimes at short notice. The rapid discharge plan enabled staff to gather essential information about the child and family's needs in preparation for end of life care being delivered. An external healthcare professional told us this training had enabled staff to develop the skills necessary to care for babies who required end of life care at very short notice. They highly praised the high quality palliative care which provided babies with an alternative to hospital care. They told us they had a strong partnership working with the provider on a regional drive to improve palliative care services.

Nurses told us they had specialist training in pain and symptom management and the GP's supporting staff, children and young people had also undertaken additional training in end of life care. Children and young people were cared for by a range of highly qualified professionals. This included the provider's medical director responsible for overseeing children or young people receiving end of life care.

Staff told us the training opportunities were excellent and included additional training specific to the needs of children and young people. Nurses informed us that when a child or young person required greater technological support they had training to manage the equipment required. One nurse explained that additional pre-admission training took place with regard to relevant ventilators a child would need. We saw nursing staff supporting one child who had very complex medical needs and who required a high degree of technological support. The nurse confirmed they had training in managing the child's specific equipment and their condition. The child's parent told us, "They have been excellent; they worked with the hospital nurses and since we have been here they have managed [child's name] really well".

There was an education lead to support training opportunities for all staff and the staff we spoke with said they were supported with their clinical practice. This had enabled some of the staff team to take on specialist lead roles which included respiratory, resuscitation and moving and handling. Staff told us this allowed them to share their skills and expertise regarding children's specific conditions and how to manage these. We saw health care assistants (HCA) had additional training in enteral feeding, (feeding through a

tube into the stomach). Their training and competencies had followed a recognised training course and included shadowing, monitoring and assessment before they were competent to undertake this task. We were told there was a rolling programme to further develop competencies in airway suctioning and tracheostomy care to equip staff with the skills needed. The provider had already achieved this at one of their other locations. There were nurse prescribers at the hospice who had been trained to prescribe medicines for children and young people when they needed them. This ensured children and young people could receive their medicines without unnecessary delay. The registered manager and staff worked in partnership with other organisations, such as Together for Short Lives to develop their practice and contribute to the development of best practice in their service. We saw examples of networking with groups outside of the hospice including the respiratory and tracheostomy meetings and workshops staff had attended.

The provider had a team of physiotherapists who supported children and young people to access the hydrotherapy pool providing chest physio or advice about mobility or positions for eating or sleeping. This ensured there was a consistent care approach for children and young people provided by staff who had the right skills and training to meet those needs.

Parents told us they had been provided with 'Face To Face' training equipping them to support other parents of children who have a life limiting condition or whose child had died. This showed the provider recognised parents as an important resource for supporting other parents. We spoke with a parent who had undertaken this training. They told us the 'Face To Face' training had given them the skills to use their own experiences in a positive way. One parent said, "It's about being a befriender and being able to offer support to another parent, it might be emotional support or practical, or just a listening ear". This initiative showed the provider had recognised the experiences of parents could be used in a positive way to inform their delivery of care to children, young people and their families.

There was a structured and planned induction process for all staff and volunteers. This included an overview of the organisation, its values and vision, training in key areas and familiarisation with equipment. Staff had a mentor to support them through this process. One staff member told us, "The induction is very thorough and you get training as well as a lot of support". We saw the provider had links with universities and had students on work placements. One nursing student on a placement told us they felt very supported by the staff and had learned a lot about communicating with children and young people and managing end-of-life care and death. Having students demonstrated the provider's commitment to sharing their expertise and best practice.

Staff and volunteers told us there was a good culture of training and they had regular supervision in which to reflect on their practice. A volunteer was very complimentary about their role and support, they told us, "I have never felt so affirmed and supported within an organisation, Acorns is my second family". All staff had access to support or counsellors following significant incidents. One staff member told us, "I have regular support and can discuss my practice and the support or training I need". All staff said they had an annual appraisal in which to review and plan their learning and development.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf must be in their best interests and as least restrictive as possible. The MCA applies to children age 16 years and over. We checked whether the service was working within the principles of the MCA. We found young people were involved in decisions; a young ambassador who had moved on to adult services spoke with us about their time at Acorns. They said, "The staff listened

to us and things like bedtimes and treatments were agreed with us". Parents told us they were always involved in any decisions affecting their child's care or treatment. We saw consent had been sought from parents of younger children for their care, treatment and activities the child may undertake whilst at the hospice such as use of the hydrotherapy pool or taking children out in the transport provided. We found from speaking with staff they had a good understanding and application of the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards. For children under 16 years of age the MCA does not apply. Instead a child needs to be assessed whether they have enough understanding to make up their own mind about the benefits and risks of treatment; [the child's ability to give consent]. This is termed 'Gillick competence'.

During our visit we observed staff worked in an age appropriate way when seeking consent from children and young people; explaining to the child first and asking them if they were happy to participate. A young ambassador who had used the service told us, "Staff generally asked us kids rather than telling us, there was no real rules and we could say no". One staff member told us about a young person who disliked the treatments they needed to have. We saw explanations had been given to the young person and that they had agreed to a compromise so that staff provided the treatment at times they were more comfortable with. Other staff were able to describe where young people refused the use of leg splints or leg stretches as well as the hydrotherapy pool. Staff understood that as an adolescent, some young people made their own choices. Staff had a good understanding of managing refusals and told us this would be documented and discussed with the young person and or their parents if this was appropriate. There was evidence staff encouraged young people in decisions about their care, and tried to gain their consent. All members of the care team had training on the MCA.

Some children and young people had a 'Do not attempt cardio-pulmonary resuscitation' (DNACPR) document in place which had been discussed and agreed by the child's parents and palliative care consultant. Some children with a DNACPR in place had a comprehensive advanced care plan [ACP]. One parent told us, "Yes my child has an ACP so that if they deteriorate there is a plan in place about their treatment; I discussed this with the consultant and staff". Parents told us their child's care and treatment was reviewed at every visit so all staff had a clear understanding of this.

All of the children and young people we saw on the day were supported with their nutrition by feeding through a tube into the stomach. The hospice team liaised with parents and community services, such as the dietitian, speech and language therapist and community paediatrician to maintain children and young people's eating routines. We saw children and young people's nutritional needs were assessed and care plans included details of their support needs such as food and fluids. Specialist diets were provided and there was a choice of food. Safe eating positions were supported by the physiotherapist who assessed for the correct positioning of a child or young person when eating. The provider told us in their provider information return, (PIR) that professionals met to discuss a child's condition, including their hydration and nutritional status where a concern was identified. This allowed staff to act quickly to provide advice and support to those children and young people whose nutritional or hydration needs were compromised. Parents told us their child's religious and cultural diets were catered for.

There were clear arrangements in place for children and young people in need of symptom control or end-of-life care. The medical director, on-call GP and specialist palliative care nurses were available to ensure children and young people received consistent health care at the hospice for pain and symptom management. Staff were able to tell us how they managed children and young people's pain and comfort and we saw care plans included details of how children and young people expressed pain or discomfort so staff would know how to identify when they experienced pain. We saw staff regularly comforted children and young people and provided reassurance particularly when care or medical tasks had to be carried out. The visiting GP provided out of hours support for symptom management and end of life care. They told us the

staff provided quality care, commitment and had made a positive difference to children young people and their families.

There were close links between Acorns and the local children's hospital. Staff attended Parallel Planning Meetings with the local hospital. Parallel planning is where a child or young person has two plans in place for different circumstances around their condition. This allows families to plan what treatments they may wish their child to receive or not should their medical condition deteriorate so that the specialist support children and young people would need to experience good healthcare outcomes is arranged.

Is the service caring?

Our findings

We saw staff interacted with children in a happy and friendly way, comforted them, reassured them and were tactile in their interactions. Children appeared at ease and relaxed in the company of staff, we saw they enjoyed playtime in the sensory room and we observed staff were able to occupy children throughout the day with play, games and sensory items. We observed lots of cuddles and tickles and children giggling in response. Staff were happy and smiling and used lots of encouraging friendly tones when speaking with children and young people.

Parents consistently described staff in positive terms, "We have had a fantastic experience; they really have looked after our daughter". Another parent said, "Staff are absolutely lovely, take great care of our child and when she comes home she is always clean and fresh and perfectly happy". Parents told us they had good relations with the staff and always felt they could approach them with any concerns. A parent told us, "The staff has been fantastic; they are so caring and really keen to help". We observed a staff member taking the time to support a family in preparation for a meeting about their child. We saw staff interacted with the parents listening and being receptive to them. The parent told us how thankful they were staff had supported them at meetings and had explained options to them.

There were well established support networks in place which enabled staff to support children and their families on both an emotional and practical level. Following our visit we spoke with a parent who used the outreach team. They told us, "The outreach support has been fantastic; they visit us regularly between respite stays, spend time with my child and provide emotional support to me, they really love [child's name] and have really looked after us all in the family".

We saw the care and support offered to children and young people and their families achieved very positive outcomes and promoted their quality of life. We spoke with one nurse who told us she was, "Proud of the care on offer to children and their families". They spoke about the impact the outreach team had on a family's wellbeing and we saw many examples of how this service made a real difference. Parents talked about using the time to 'catch up on some sleep', 'complete some housework', and 'prepare meals for the rest of the family'. One parent said it had been over twelve months since they had been able to spend time together as a family. Another parent whose child went into hospital told us, "As soon as the staff knew they visited my child in the hospital, spent time with her, did fun things it was really good for her and me". We saw from records the numbers of families using this service had increased giving a greater degree of choice over the support families wanted to use. A parent supported by staff whilst their child was in hospital reported, "Having Acorns there has made a difference to me and the rest of the family. I was able to pick up my other child from nursery and spend some time with him. It was so good to be able to leave the ward today; I have been in so much pain with my back, the rest has helped". These examples showed the outreach team were making a real difference to the child and their family.

Outreach services included providing complementary therapies to the child and young person and or their parents. We saw from one parent's testimony the positive impact this had on them and their child who was receiving end of life care at home. Complementary therapies had been provided to both the parent and

child over a number of weeks. These included Indian head massage, reflexology and aromatherapy and the parent had continued with this support following the death of their child. We saw the family had particularly expressed their gratitude regarding the benefits to the young person. They described the value of these visits as being able to build lasting positive memories of their child's last few weeks. The parent stated how much they had enjoyed it and had never expected that it would have been of so much benefit. We saw extremely positive feedback from the community children's nursing team who worked with this family. They commented on the, 'Fantastic service' and the immense benefits to [child's name] physical and emotional well-being.

The provider had developed a dedicated approach to the needs of children, young people and their families which included the recognition of their ethnic, cultural and religious needs. A percentage of families were from black and ethnic minority groups, with a number of families from the South Asian community. There was a strong and active Asian Mothers' Support Group (AMSG) with an Asian Liaison Officer who worked across their three hospice sites. We spoke with the Asian Liaison Officer who was able to show us a wide variety of documented feedback from parents. These captured the positive impacts particularly for mothers who attended the (AMSG). Mother's expressed how their feelings of isolation and language barriers had been responded to in a caring and compassionate way. This had enabled them to build positive supportive relations with other mothers. The group had provided emotional and practical support via a range of regular opportunities to share in social events such as trips and days out. Mothers had reported this had led to strong feelings of inclusion. We saw from parents testimonies that these reflected the positive emotional support and the level of kindness, compassion, and sensitivity shown to families at different stages of their journey. Mothers spoke of feeling, 'inspired by other parents', 'learning from them', and having a 'sense of being understood by others and feeling it was ok to talk about their feelings'. We also saw comments that showed the value of friendships that had subsequently developed.

There was a diversity champion and steering group who met to ensure staff had the systems and structures in place to provide for families. We saw staff recognised and celebrated a wide range of cultural and religious events and worked with children and young people and their families to meet their religious and cultural needs. For one young person their dream to be baptized had been fulfilled by staff including the Asian Liaison Officer, physiotherapist and volunteers and 'pool spotters' who had facilitated a baptism using the hydrotherapy pool because no other place was equipped to meet the young person's needs. We saw the testament of the family which included the following statement on behalf of their child; "Acorns had made their dream possible". We found children, young people and their families experienced care that showed respect for their diverse needs; age, culture and religion and offered a flexible range of options which families could choose from.

A sibling support group was well established and held on a regular basis. This initiative recognised the need to support the siblings of children and young people who had a life limiting condition or siblings who had lost a brother or sister. We saw a range of varied activities, events, trips and days out had taken place. The feedback from siblings attending the group was very positive. We saw comments from siblings showed they enjoyed these opportunities and how it helped them to cope with their feelings. A parent told us, "My children love attending the group, they have fun, have made friends and they get attention". The support networks in place for children, young people and their families had been sustained for many years. More recently the provider had won the Diversity Champion Award 2016 which was in recognition of the quality of care and support offered to children and young people across their services.

We saw there was an extensive and creative dedicated team of volunteers who supported children, young people and their families in social, emotional and practical ways. There were some excellent examples of 'targeted' volunteering. Some trained volunteers undertook work with children within the sibling groups as

well as taking on a 'befriending role' with individual children and young people. We saw one young person being supported in games and activities by their befriendeer and they looked comfortable and relaxed. A parent old us, "The befrienders are a great idea, my child loves time with hers".

Parents said that staff were receptive to their needs and that there was no restriction on visiting times. Parents told us that could stay overnight with their child, or during the day until they had settled in. One parent told us their child did not like respite care but had day care which, 'worked better for me and her'.

The environment was conducive to respecting the privacy and dignity of children and young people. Staff attended to children's needs in the privacy of their bedrooms. Bathrooms and toilet areas were easily accessed and privacy screens were used to promote privacy. Adolescents had the use of pendants so that they could call for assistance when they wanted which promoted their privacy and independence. We saw bedrooms were personalised to individual children and young people; one had bedding in their football team colours which provides a personal touch for children and young people coming away from home. Separate age appropriate lounge areas for young children and adolescents meant they could spend quality time with their peers in a suitable environment.

Care plans were personalised and child centred, containing children's and young people's needs as well as their preferences; favourite food, activities, toys and routines. Parents confirmed staff went through the care plan with them at each visit to the hospice or before their visit to capture any changes. Parents were involved in making decisions and planning their child's care. Some parents we spoke with told us they had discussed advanced care planning [ACP] for their child in the event that their health deteriorated. Personal choices were captured in the advanced care plan so that decisions about treatment and care for end of life were clear. The ACP's showed a collaborative approach with staff and other external healthcare professionals being involved regarding decisions. The provider had implemented the 'Collaborative Advance Care Plan' which provided a personalised approach to achieving the goals of each child, young person and parents when talking through end of life care decisions. The Collaborative is a group of NHS and private sector organisations with the common goal of delivering the best possible care to children and young people with life limiting and life threatening conditions. Staff told us a child's end of life care was explained to families to ensure they were fully involved in this process and interpreting services were provided to families to aid communication and understanding. End of life care was supported by the nursing staff, the GP and medical director to ensure a child or young person experienced a pain free and comfortable death.

When a child or young person died they could rest until the time of their funeral in the facilities provided. At the time of our inspection both of the special bedrooms were in use for children who had died. We did not view these rooms but discussed the facilities available. The special bedrooms operated on a cooling system allowing the child or young person to lie at rest until the time of their funeral. Staff personalised these rooms with cots or beds, and favourite toys and possessions. A private entrance was available and the privacy of families was protected by the use of a symbol to show the room was in use. A separate access was available to allow funeral cars to arrive in privacy. Families had a private garden where their privacy could be protected. The self-contained facilities enabled families to live in the accommodation to spend as much time as they wished with their child. We saw there was no time limit on families which enabled extended family members the opportunity to visit and express their final goodbyes. These facilities offered a family-friendly environment.

Staff described how they supported family members to 'build treasured memories'. Memory boxes were created in which families could keep important mementoes of their child. This could include photographs, hand and foot print pictures, and locks of the child's hair. One staff member we spoke with was supporting

bereaved parents on the day and spoke with compassion and empathy. We heard how they continued to care for the child after their death and support their parents and extended family.

We saw the religious and cultural needs of children and their families were respected and met in a culturally sensitive and dignified way. Parents could care for their child's body before burial or cremation. The 'special bedroom' had an arrow marking the direction of Mecca for Muslim families. We saw the hospice had purchased white sheets specially bought from Muslim shops so families could wrap their child's body as part of their religious rituals. Religious artefacts for use by families were available for all faiths. Families had access to Asian newspapers, T.V channels audios and tapes showing their religious and cultural needs had been considered. Families were able to access bereavement counselling as well as support groups for bereaved parents, grandparents, and siblings.

We saw the support to families included help with practical arrangements; arranging the funeral, registering the child's death or liaising with family or other professionals. We saw from a range of compliments from bereaved families that they highly valued the facilities and the compassion shown to them during this period. One quote read, "All her most treasured possessions were around her and she was surrounded by flowers". A quote from a staff member showed the level of empathy and respect for bereaved parents; "The time and care they gave to [child's name] and the dignity she was shown in death and during her life was a privilege to witness and be part of". Bereaved parents valued the compassion shown to them prior to and after the death of their child. Staff described the feedback from the bereaved parents of a baby who had been receiving end of life care read; 'The family have said they have been overwhelmed by the support offered by Acorns'. Following the death of their baby both parents hugged and thanked the nurse for their care and compassion and stated they could not have emotionally coped if they had not been present throughout the night with them. The parents spoke about how this had enabled them to spend precious hours building lasting memories, holding and bonding with their child.

A memorial garden was available to families to visit and lay an inscribed stone in memory of their child. Memorial days were arranged so that families could visit and celebrate the lives of the children and young people who had died. Bereaved parents continued to be included in significant events and cared for by staff whilst they wanted this.

There was a comprehensive range of information available to families provided in their 'family information packs.' This informed them of the services offered and the booking procedures. There were dedicated rooms which were used for complementary therapies offered to children, young people and their extended families. These facilities ensured therapies could be delivered in privacy to promote a sense of well-being.

Is the service responsive?

Our findings

Parents were consistently positive about how staff responded to their needs. One parent said, "I was initially introduced to Acorns following the diagnosis of my child with a life threatening illness. They phoned me and visited us then we used their day care and progressed to respite care. It's been a great resource for us".

Each child or young person had an allocated key worker who met the family, discussed their needs and goals and explained the options available to them. Information from other professionals involved with the child such as children's' community nurses, consultants or the child or young person's school were involved in this process. Collaborative working with external professionals helped ensure the child's medical, social and emotional and educational needs were identified. We saw the assessment process included a focus on the needs of the whole family which enabled staff and the family to identify their goals and the services they may wish to use.

Care plans were detailed and personalised to the child or young person and contained up to date information so that the child and young person's stay could mirror that provided at home. There was information about how children communicated. Staff understood children and young people's complex ways of communicating and responded to their verbal and non-verbal communication and gestures. A student nurse told us what they had learnt during their placement, "One of the most important things I will take away with me is how to communicate with children and young people who have no verbal communication". We saw staff used Makaton signing where this was the child or young person's chosen communication method.

Staff used care plans to guide them in delivering personalised care. For example we saw they followed 'rest times' for a young child on their bed and placed their favourite cuddly toys within reach. Another young child enjoyed time in the sensory room, and a third child's 'favourite' DVD was played for them. Staff demonstrated they knew the needs and preferences of the children and young people they were caring for and one staff told us, "Today we have [child's name] and he is very active and mobile, he likes the cars, big toys and lots of space". We saw when the child arrived staff occupied them in this way and they were visibly happy. The needs of older children and adolescents were addressed in an age appropriate way. Planned admissions with their peers, dedicated adolescent trips and activities were arranged with them. Separate lounge areas with age appropriate play equipment, computer games and music were evident for children and adolescents. Signage around the hospice was in picture and Makaton form to support young people in identifying areas.

Staff attended daily handovers in which the medical, personal care and well-being of each child and young person was discussed. Staff told us they were allocated to a child or young person and read the care plans to ensure they were familiar with the child and young person's needs and how these should be responded to. We saw a staff member attending to a child where their needs had changed since their last visit. The staff member was able to tell us about these changes and we saw they carried out the support to the child in the way it was described in their care plan.

Parents confirmed that out of hours support was in place to support them and their child in the community when not using the respite facilities. They had regular contact with their allocated outreach support worker and an on-call facility was available to seek help in an emergency. Where a child or young person or family needed additional support emergency respite and end of life care were given priority and responded to. For babies being transferred from hospital to the hospice for end of life care, the rapid discharge plan was used to ensure all the information needed to support the child and parents when moving from one care setting to another was in place. Attendance at planning meetings at the hospital ensured the effective sharing of information. This included parents' views so children's needs were prioritised and planned for. For example where a child was ready for discharge from hospital they were redirected to Acorns. We spoke with one of the visiting GPs. They told us the out of hours support ensured that children and young people had access to symptom and pain management without delay. We saw there was a holistic approach focused on the needs of the child and their family.

Children, young people and their family had access to a range of support that was responsive to their specific needs. This included respite care, day care, outreach support and access to support groups. In addition the management team had evolved and developed its provision by working in partnership with other agencies and hospitals. We saw evidence of multi-disciplinary working within the wider health community. For example a child staying at the hospice on a 'step down' bed meant they could be cared for at the hospice over a long period of time as an alternative to care in hospital. This enabled a number of agencies; health and social care to work with the parents on a care package to support the child's discharge from the hospice. The parents of the child told us, "It has been fantastic staying here; we are nearer to the children's hospital to attend meetings and organise the support and equipment our child needs to come home, we could not be happier with how staff have helped us". We spoke with a staff member supporting the family who was able to describe the role they had; organising feedback to the hospital on the child's progress, identifying equipment needed and discussing with the family practical support at home. We found this was a responsive approach and one of partnership working with the parents and other agencies so the child had the care they needed when they needed it. These arrangements can take some time to arrange and the family told us, "Whilst he has been here they have been lovely in the way they care for him; following his routines and loving him, but they have also given us so much support we can't put into words how great they have all been". Staff we spoke with were aware of the importance of the young child experiencing child centred care for their extended stay and understood and responded to the child's needs and routines.

The management team had developed an end of life policy and rapid discharge process. This ensured information could be sought quickly to respond to parents of babies who required neonatal care and wished this to be provided at the hospice. There was a dedicated nurse with special responsibility for the delivery of antenatal and neonatal care. Staff told us this arrangement enabled them to meet with and build relationships with parents as well as offering parents the choice of where they wished their baby to receive end of life care. We heard from an external professional that the staff team worked in partnership with them and they confirmed staff shared the common goal of making the end of life care for babies as good as it could be. They described how this partnership working enabled high quality palliative care to be offered as a treatment option, outside of hospital. They also confirmed that short notice end of life referrals had never been delayed and staff had always accommodated such referrals. They praised the willingness of staff to work collaboratively and told us this had resulted in high quality end of life care provision, avoiding unnecessary intensive care.

The provider had implemented an outreach team. This new initiative provided children, young people and their families with additional support either in their own home or supporting children and families during their hospital stays. The outreach team provided a range of support as well as a visiting service to children and young people in hospital. We heard from parents who had used this how beneficial it had been to be

able to leave their child and take a break from the ward. Staff told us the outreach team also updated care plans at home and offered 'a listening ear' to the parents. One parent told us, "It's lovely when staff come to visit us; they always make a big fuss, bring presents for my child, offer advice and enquire how we are". A wide range of therapies were available to respond to children, young people and their family member's needs in regard to relaxation and general wellbeing. We saw a range of very positive feedback from external health professionals regarding the positive impact of the complementary therapies provided. One comment regarding a child who had received end of life care read, "They (staff) have provided a positive experience throughout an enormously challenging period of their (the family's) lives". We saw the Community Children's Nurses [CNN's] expressed their thanks to staff at the hospice for the additional support offered to another family in the form of providing a memory box, the offer of photographs for the family and bereavement support.

There was a well-established hospice wide transition team who worked across the three hospices. We spoke with the staff from this team and with a young ambassador. Young people were supported to explore the options available to them. They had attended meetings with health, education and social care professionals. The transition team supported them to move into adult services, access further education and utilise community services. We saw this was a gradual process so that young people were prepared for these changes. The young ambassador and their parent told us staff from the transition team had co-ordinated everything and advocated on their behalf, both described positive experiences.

We saw children and young people enjoyed a range of activities and planned events. The creative use of befrienders ensured a child centred approach so that children and young people had the support they needed to take part in activities they liked. We observed a 'befriender' supporting a child with their play which showed this approach worked well. There was a well-equipped activities room with arts and crafts and eye gaze and eye point computer games which enabled children and young people to play independently. Staff told us they planned activities around the child's known interests and we saw on the day some very young children were supported in age appropriate play with toys, teddies and DVD's. The sensory room provided a range of sound, light and touch objects to stimulate children and we saw some children enjoying this. Spontaneous and planned visits to the onsite hydrotherapy pool enabled children to both relax and enjoy fun in the water. Staff had been trained in music therapy so they could engage children in this. A range of planned events had taken place; such as a Disney weekend, a Villa football match and a visit to the Sea Life Centre. Children and young people had provided positive feedback regarding the activities they had undertaken. We also saw staff promoted opportunities for families to visit the hospice and 'test out' what was an offer. For example fun play days had been arranged to introduce new children and young people. One parent comment read, "Due to the lovely experience [child's name] had at stay and play, the family have decided they would love to use Acorns".

In addition staff arranged events suited to adolescent girls or boys so young people could socialise with their peers whilst on respite at the hospice and enjoy age appropriate activities such as music or DVD's. There had been a range of visiting local celebrities so that young people could share experiences and try their skills at being a DJ or music making. Several parents told us how much their children enjoyed their time at the hospice and how thankful they were for the effort staff put into these. We saw a wealth of compliments from parents and young people expressing their thanks for individual events which showed staff helped to make fun and special memories for the children and young people as well as their families.

A range of ways had been adopted to ensure children and young people were positively encouraged to provide feedback on their experiences. There was an excellent initiative called 'Real Time Reporting'. Using technology in the hospice children and young people could provide instant feedback about their stay and experiences. The technology had been further enhanced to provide a Makaton communication system. This

supported children and young people to use their own form of signing and or picture communication to share their experiences. The feedback captured and action taken in response to this was displayed for children, young people and their families to see. There was an active website where parents and young people had provided video testimonials. We also saw parents had their testimonials published in the form of a book in which their experiences were available for other parents and staff to read. Young ambassadors engaged in a variety of public awareness presentations describing their experiences of the service as well as informing other professionals how services could be further developed to meet their needs. One young ambassador told us, "I've been to lots of events and to training events to talk about what we need from services; the transition support, the magazines we produce are all good things that have been developed".

Families were provided with a welcome pack which included information on the complaints procedure; the format of this was suited to both adults and children. Parents told us they would be comfortable to complain but had not had cause to. We saw complaints that had been made had been appropriately investigated and written feedback provided to the complainant. We saw there was a clear system for sharing complaints and developing actions where lessons had been learnt to ensure improvements were implemented. The management team had captured an extensive number of compliments and positive feedback in their records and quality assurance audits. This showed the registered manager had robust systems for the management of people's feedback.

Is the service well-led?

Our findings

Parents, children and young people consistently expressed very positive feedback about Acorns and the support they had experienced. Parents who had used the service for a number of years told us it was an excellent provision which had continually improved and developed. One parent said, "I think it is fantastic all the things they have achieved; parents are involved, young people, staff and volunteers, everyone works hard to make things as good as they can be for the children".

We found there was a clear management structure with good organisation of the different teams whose staff understood their specific roles and responsibilities. All of the staff we spoke with across the organisation demonstrated a very caring approach and were highly motivated to provide a high quality service to children, young people and their families. The vision and values of staff put children, young people and their families at the heart of the service. We saw staff always tried to accommodate their needs, for example linking in with other external agencies to provide care for a child who needed to be closer to the hospital. All of the parents told us staff listened to them and that they had access to advice when they needed it.

A registered manager was in post who was experienced and skilled in paediatric palliative care. We saw the registered manager was visible and available to families and staff during the day which enabled them to oversee the delivery of care and treatment. The registered manager was supported a board of trustees and layers of senior managers, and team leaders for the outreach and family support services. There was a range of ways in which information was shared between managers within the wider organisation of Acorns so they could review their practices and where needed develop them further. For example there were designated lead people such as the safeguarding lead who attended safeguarding panels to review incidents and reflect on lessons learned. We saw these incidents had been thoroughly reviewed by the management team to ensure they had acted accordingly to safeguard children and young people.

There was a strong emphasis on continually striving to improve. There were robust systems in place to review the quality of care and monitor service delivery. We saw this included innovative and creative ways to enable people to be empowered and voice their opinions. The use of young ambassadors and parent/carer champions involved in the provider's monitoring visits and public presentations helped shape the services offered. A parent told us this provided the management team with a 'user perspective' to help with their quality assurance. We saw young ambassadors had been included in training events to ensure professionals understood their perspective when developing hospice services.

Quality assurance reports, audits and feedback from parents, children and young people was consistently captured and regularly presented to the trustees; chief executive and the director of care to help drive improvements. As part of their quality assurance medicine management was reviewed at multidisciplinary meetings. The management team used feedback to improve their services. They had standardised their 'end of life referral processes' and 'rapid discharge' procedure so that all the information needed from all the professionals involved with the child was in one place. This assisted staff to respond quickly to families in a time of crisis. We saw documentary evidence that the management team continually monitored the impact of their service and looked at ways of increasing parents, children and young people's access to services.

The records showed they had extended their services and had offered greater flexibility. This was evidenced by the increase in the number of parents, children and young people accessing the outreach services as well as the neonatal end of life care.

We found staff spoke passionately about their role and all of them spoke about the 'privilege' of working with families of children and young people with life limited and life threatened conditions. There was a clear focus on putting children and young people and their families first, identifying with them their goals and how they wished to be supported both during life and at end of life and post death. Staff were aware of the service vision and values; involvement, compassion, dignity, independence, respect, equality and safety. They demonstrated these in their practice evidenced in the extensive complimentary feedback we saw from parents, children, young people and external professionals. Healthcare professionals valued the collaborative working to ensure rapid discharge for children from hospital to the hospice as well as 'step down' facilities provided for children waiting on a support package to return to their own home.

The management team had further developed its services to offer outreach support. This initiative ensured families had a choice of how they wished to be supported. These community services had a positive impact on children and their families by ensuring they had additional support such as complimentary therapies, bereavement support, sibling groups and support groups for parents and grandparents. The Asian Mothers' Support Group and Asian Liaison Officer had responded to parents' feelings of isolation. Support to families where English was not their first language had encouraged families to access services. These initiatives had been sustained over a significant period of time. The management team produced an annual quality account. This provided information gathered from people, children and young people as well as external professionals. It captured the impact services had on children, young people and their families as well as looking at the priorities for the next twelve months. These records showed there had been an increase in the number of families using services indicating the variety and flexibility of the services offered was reaching more families.

Staff and volunteers were positive about working at the hospice and felt very involved and valued. They described their support and training as very good. Nurses had been supported to take on specialist lead roles which involved working with external professionals to ensure children's needs could be met. Staff who had a community role working in the child's home, or facilitating support groups or transition of young people, had team leaders who provided management support, direction and supervision. All of the staff from the different teams told us there were several platforms for them to communicate and share information.

The provider worked in partnership with other organisations to make sure they followed current practice and provided a high-quality service. They strived for excellence through consultation and reflective practice. The management team had developed links with health and social care providers and professionals to promote good practice through presenting training and learning events. This enabled the management team to continually review the quality of their service and share best practice and expertise. We saw these events had been evaluated and comments from attending professionals showed they valued the work and expertise of the staff team. One such comment read, "I am impressed with the site, professionalism and forward thinking I have heard about today," and "Clearly a well-established, researched service to meet all the needs of the child and family holistically".

There were creative ways to enable people to choose services voice their opinions and influence service provision. Feedback on all aspects of the service was actively encouraged, captured and used to shape the service. We saw extremely positive feedback had been captured from children and young people attending the sibling groups. This group was well established and regularly accessed by an increasing number of

children. Children reported the group enabled them to share in fun activities and make new friends whilst being able to express their feelings and learning to cope with a sibling with a life limited or life threatened condition, or the loss of a sibling. Young people had also been supported to raise awareness of their experiences via their own 'BASIL' magazine, [Brothers And Sisters in League]; an innovative way of children expressing their feelings. Attendees at support groups such as parents, grandparents and the Asian Women's Support Group identified the benefits for them as; feeling less isolated, helping them to socialise and to build their confidence by being able to share their experiences with other parents. The transition team supported young people through a robust transition pathway into adult care services. We heard they felt well supported and valued the fact staff had coordinated services and supported them to explore their options. Young ambassadors had continued to be involved with the service showing their commitment to developing best practice.

The provider had an active website in which they shared information about the services they offered. We also saw parents and children had video presentations informing the public about their experiences and the value of the services provided. Regular newsletters were published updating families on all events. Play days and day care facilities were other initiatives that showed they had a variety of ways of reaching families who might benefit from their service.

The provider had provided excellent opportunities for children, young people, families, staff and stakeholders to shape the services through a number of innovative and creative platforms. 'Real Time Reporting' enabled children and young people to provide instant feedback using technology. 'Young Ambassadors' and 'Parent Carer Champions' provided feedback as well as input into service delivery attendance at transition meetings and meetings with stakeholders. They had participated in staff induction processes to raise awareness and had a user engagement steering group. An ambassador told us how this enabled them to be actively involved in shaping service delivery. They had been actively involved in developing the provider's website. A Parent Carer Champion [PCC] told us they had participated in the providers' unannounced spot checks on the service and had training to undertake this role. They told us how this ensured their perspective of care was considered. A new initiative of 'Face To Face' training enabled parents to support families with children with palliative care needs. A parent told us they received training and supervision to support other parents during their journey.

Staff were involved with the palliative care hospice network in which hospices shared good practice and innovations. We saw examples of networking with groups outside of the hospice to further promote their expertise. Nurses took on additional training and lead roles in specific areas so that they could provide children and young people with up to date specialist care they needed. The provider had an education lead and education co-ordinator to support their staff in accessing the right training to maintain their competences in this specialist area of work.