

Acorns Children's Hospice Trust

# Acorns Children's Hospice in the Black Country

## Inspection report

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## Ratings

Overall rating for this service

Good ●

Is the service safe?

Requires Improvement ●

Is the service effective?

Good ●

Is the service caring?

Outstanding ☆

Is the service responsive?

Outstanding ☆

Is the service well-led?

Good ●

# Summary of findings

## Overall summary

Acorns Children's Hospice in the Black Country 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 provides a range of services within its hospice; 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 or within children and young people's own homes. 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 22 February 2016 and was unannounced. There were four children staying in the hospice on the day of the inspection with a fifth child visiting for the day.

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.

We saw the children and young people we met were happy and relaxed in the company of staff. Parents told us they were very happy that staff kept their child safe when working with them within their own home or the hospice. 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 recruited safely to ensure that children and young people were cared for by suitable staff. There were enough staff on duty who had the specialist skills needed to make sure children and young people's needs could be met safely. Staffing levels were increased to respond to children's and young people's rapidly changing needs. Separate staffing arrangements were available to ensure children and young people cared for in their own home received consistent support 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. We identified some shortfalls in the administration and storage of medicines. Corrective action was taken on the day but we found the monitoring of processes needed to be improved to ensure that medicines were administered and stored safely.

We saw positive risk taking which enabled children and young people to take part in everyday play activities that were important to them. Staff were well informed about the risks to children and young people and we saw staff were trained in managing risks specific to each child's care, safety and medical condition. Risks

had been considered and planned for which included the use of the specialist equipment children and young people needed to keep them safe.

Parents and external professionals spoke highly of the specialist skills of staff which meant children and young people received the care they needed either in the hospice or their own home. Staff were highly trained and supported in their development of specialist skills and there was a strong working partnership with other organisations to support children and young people at the end stage of their life.

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

There was a choice of meals for children and young people 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.

Young people and their families were fully involved in the planning and reviewing of their care so that their choices, preferences and goals were known and planned for. This included the arrangements for medicines and equipment to manage symptoms and pain. Medical support was planned and provided without delay at the hospice or in the child's own home.

Everyone we spoke with described staff as kind, patient, good listeners and always keen to help. We saw many examples of compassionate care, thoughtfulness and respect. There was a clear commitment to providing the best quality care to the child and young person and their extended family. Parents said they were involved in decisions and 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. Parents and family members valued the bereavement and support services offered to them. 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.

The management team had consistently developed its services to increase the options available to families. We saw families had greater choices of the services they wished to use with access to specialist staff in either the hospice or 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.

Parents reported their children enjoyed a range of activities, outings and events at Acorns. They were happy that access to the jacuzzi and specialist equipment meant their child had pleasurable experiences.

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.

Everybody we spoke with was consistently positive about the way Acorns was managed and run. We saw they had actively engaged with parents, children and young people to ensure they shaped their services in the way people wanted and needed them. 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 not always safe.

Procedures were not always followed to ensure that medicines were managed safely.

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.

Children and young people were cared for by staff in the right numbers and with the right skills to meet their needs both in the hospice and in their own homes.

**Requires Improvement** 

### Is the service effective?

The service was effective.

Staff were skilled in paediatric palliative care and had specialist lead roles. Partnership working ensured staff had the specialist skills to support children and young people.

Young people had been involved in decisions about their care 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.

Symptom and pain management was planned and provided without delay at the hospice or in the child's own home.

**Good** 

### Is the service caring?

The service was caring.

Staff were kind, compassionate and treated children, young

**Outstanding** 

people and their families with dignity and respect. The use of targeted volunteers provided a valuable befriending service as well as practical support.

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?**

The service was responsive.

Families had a variety of flexible services 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.

**Outstanding** 

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

The service was well-led.

There was a positive and inclusive culture with a range of opportunities for parents, children and external professionals to feedback about the way Acorns was managed.

There was a clear vision and strategy to increase the services on offer to children, young people and their families. A flexible, accessible and consistent service was promoted.

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

**Good** 

# Acorns Children's Hospice in the Black Country

## 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 22 February 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 qualified and experienced in working as a nurse within a hospice and the community and within the field of palliative care.

We did not request a provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make. The provider had sent a PIR for one of their other locations and information from this was taken into account when we inspected the service and made the judgements in this report.

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 seven 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 18 staff. This included, nurses, healthcare assistants, physiotherapist, and team leaders from

the family support team, transition team, hospice at home team, volunteer manager, volunteers, sibling support worker, quality and governance lead, safeguarding lead, head of care services and director of care services. We viewed the accommodation and facilities, six children'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 spoke with Acorns Asian Liaison Officer. We 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

Medicines were prescribed by a team of nurse prescribers and a GP. We were told that if advice from a pharmacist was needed then the team would contact the community pharmacist or specialist pharmacists at Birmingham Children's Hospital.

We observed the administration of medicines by two nurses and noted the medicine administration chart was signed before the medicines were given. We were told this was normal practice. This does not follow the Nursing and Midwifery Council (NMC) guidelines for safe practice as it is not safe practice to sign for administration of a medicine when it has not been given. We were told that if the child refused the medicine the nurse would cross out their signature as an error.

Medicines were checked by two nurses for accuracy when a child was admitted to the service. The medicine administration chart was also checked and signed by either the GP or one of the nurse prescribers, (Nurses who had been authorised to prescribe). However, we found inaccuracies in three of the records we viewed. For example the names of some medicines did not match the name on the medicine container. This was because medicines often have different names. These differences had not been noted or changed on the charts to ensure the same name was recorded. We also found that additional instructions for the safe administration of medicines were not always recorded onto the medicine administration records and the form or strength of the medicine was not always written. This increased the potential of a medicine administration error.

Prescription pads were securely locked away with appropriate checks in place. However, we found one prescription pad which had not been securely stored with the other pads in line with national guidance. The NHS Business Authority Guidance "NHS Protect" provides guidance to staff members in all roles and healthcare settings who handle or issue prescriptions. If blank prescription pads are not handled appropriately this could lead to misuse and could cause harm by individuals obtaining medicines that they are not entitled to receive. On making a nurse aware it was immediately stored securely.

Temperature records were available for the medicine refrigerator. However we noted nine records between January and February 2016 which documented that the refrigerator temperatures were not within the recommended safe storage range for medicines. There were no records available to show what action was taken to ensure medicines were stored safely. We found vaccines stored in the refrigerator which would not be safe to use if they had been incorrectly stored at the wrong temperature. We also found a medicine in the refrigerator that had gone past its seven day expiry date and therefore was not safe to use. On informing a nurse the medicines were removed from the refrigerator and destroyed.

The times of medicine administration were specific to the individual needs of the child or young person. This was a child centred approach. Arrangements were in place to enable children or parents to look after and self-administer their own medicines following a risk assessment. These arrangements offered choice and independence however we were told that it did not happen very often.

Medicines were stored safely and securely in locked cupboards in a locked treatment room. Only authorised staff had access to the treatment room. Controlled drug medicines which required extra security storage arrangements were stored securely and recorded correctly according to safe practice. A named accountable officer ensured the required checks for controlled drugs were in place and reported to the local information networks.

Medicine incidents were reported with arrangements in place to ensure they were investigated. They were discussed at monthly medicine management meetings and at three monthly meetings between the medical director and the nurse prescribers. We were shown minutes of recent medicine management meetings which included what action was taken on any medicine safety alerts to ensure safe practice was followed. However, it was not clear what monitoring took place following any changes to ensure safe practice continued.

Medicine information was displayed for learning in the staff conference room. Of particular note was the development of a 'Medicine of the Month' notice board. This was designed for staff, parents and children and young people to read about a particular medicine. It was well displayed with good information available to learn about the medicine.

Pain treatment guidelines were available for staff to follow. These showed a visual face to show differing levels of pain. This enabled staff to determine the level of pain and whether a child or young person required pain relief, where they could not communicate this. In the event of an anaphylactic reaction (severe allergic reaction), there was no provision for the availability of emergency treatment packs. We were told this subject had been widely discussed and children and young people usually brought in their own emergency medicine supply if needed. However, there was no risk assessment available to show the risk or benefit to not having a treatment pack available.

Monthly checks were evident to ensure every time a medicine was removed stock levels were maintained to ensure children and young people had the medicines they needed. However a recent incident had occurred where a medicine had run out on a Sunday. The on call nurse prescriber rectified this and we were told that lessons would be learnt and staff would in future check weekend supplies. We saw improvements had been made following a medicine error. Staff told us they checked medicine charts three times a day to prevent children missing their medicines.

One young person; [an ambassador for the service] told us, "When I first went [to the hospice] I was very young and very scared. Looking back now as an adult I am massively impressed at how they made me feel safe; it's having confidence in the staff". Parents were consistently positive in their comments about the safety of their child. One parent told us, "When we were at our most vulnerable staff made us feel safe in their hands". Another parent told us, "I can leave my daughter with staff both in the hospice and in my own home; I have 100% confidence in them doing everything necessary to keep her safe".

All the staff we spoke with were aware of how to report concerns of potential or actual abuse. A staff member told us, "Everyone who works here, volunteers included undergo safeguarding training. We all have regular updates and opportunities to discuss the procedures and the manager checks our understanding". Procedures related to child protection were available. We found there was a clear framework for all staff which was aimed at minimising uncertainty about recognising and reporting concerns. One staff member told us, "We are very aware of our responsibility to protect the safety of children". Another staff member told us, "We have had training on what to do should a child or young person disclose abuse". We saw information leaflets were available for children and their families in the entrance hall and information packs. These provided clear child friendly information using words and pictures to inform children and young

people about their right to be protected. During our visit we observed appropriate safeguards were in place to keep children/young people safe because staff chaperoned all visitors. The director of care services was the designated safeguarding lead and chaired the safeguarding steering group. We saw documentary evidence that this enabled them to monitor and review all safeguarding concerns involving a child or young person. 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. Additional 'Prevent Awareness' training had taken place which focused on the needs of vulnerable groups of children. The director of care services was able to provide examples of how training and multidisciplinary working had worked to protect children.

The safety of each child and young person was taken into account on each visit to the hospice. One parent told us, "There was a thorough assessment at first and they looked at everything; the clinical equipment my child needed, his health conditions, how they should be managed and so on. I was happy that my child was still able to do some things such as swimming in the jacuzzi because despite all his needs, they made it safe". We saw risk assessments specific to each child or young person's needs were in place. Staff we spoke with were able to give a full account of children's safety needs. One staff member told us, "I did additional training in suction which means I can support children who have a tracheostomy [a tube to help breathing]". We observed this staff member attending to a child who required suction and saw they followed the child's care plan to keep them safe. The physiotherapist who worked as part of the staff team told us, "We work collaboratively with the child's community occupational therapist so that when a child comes in we can maintain consistent safe care".

Risk assessments were in place which related to one child's needs and the risk to their fragile bones. We saw staff positioned the child in line with their risk assessment to help reduce the increased risk of fracture. Another staff member explained how they supported a child with epilepsy and we saw a written protocol was in place to guide staff on the actions to take if the child had a seizure. A range of clinical risk assessments were completed and reviewed regularly in the children's care plans. Staff supported children and young people to move with the aid of specialist equipment and we saw instructions were in care plans to do this safely. We observed staff followed these instructions carefully with their colleague as they supported a child to move. A parent talked about how the facilities at the hospice allowed their child to be cared for safely outside of a hospital environment. "Today [name of child] has had his first bath since August 2015 when he had his operation". The child gave us a 'thumbs up' for his day at Acorns and the care he had received; a second 'thumbs up' with a smile; told us he loved his bath.

Staff told us that they were confident they were well informed about risks. One staff member said, "We have a staff handover at every shift where we are informed about each child's needs and any changes and how we are to manage them. We also have access to their care plan and read the risk assessments". We observed a staff handover and saw each child or young person was discussed in detail and issues related to their health and their safety were reviewed. We saw 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. Children and young people were able to safely take part in activities such as using the jacuzzi because staff were trained and assessed as competent to safely support children in the jacuzzi. The provider had two other sites with hydrotherapy pools which children and their families could access for "Family Splash Days". One parent told us, "Being in the pool is something that can't be done safely anywhere else; it's fantastic we can enjoy this with our son". Individual risk assessments were completed for families who received home-based care including assessment of the home environment and any family risks.

Systems were in place to ensure 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.

Parents were very happy with the staffing arrangements at the hospice, one parent told us, "There is always an allocated staff member when we arrive, sometimes two who meet us at every visit; they always have time to talk to us". Another parent said, "The children are never unsupervised; enough staff to care, nurse and play with them". A young ambassador told us, "There was always enough staff to look after us during the day and sometimes at night children had staff sit with them or outside their door if they were poorly". Staff were confident the safety of children and young people could be managed effectively by the staffing levels. A staff member told us, "We have 24/7 management support; some children require one to one, some children require two to one if they have complex care needs". We saw there were the appropriate levels of staff to enable the specific needs of children and young people to be met without compromising their safety. We saw children were tended to by a variety of staff depending on their specific needs which showed there was a clear system for allocating nursing and care staff to each child. The registered manager told us, "Staffing levels are based on the needs of the child; if a child was in need of acute end-of-life care or a family were in crisis we increase the staffing accordingly". We also heard pre-planned respite care could be re-arranged to accommodate children and families in an emergency situation thus ensuring staffing levels met children's safety needs.

We found there was a good skill mix on duty on the day of the visit. Some of the team had taken on extended roles such as music therapy and all staff were responsible for supporting activities and play. We observed there was sufficient staff to provide children and young people with a high level of interaction. We saw children engaged in arts and crafts sessions, using the sensory room and playing games with staff. We saw extensive outreach services were provided to meet children's and family's needs in community settings. The hospice at home, the family support team and the outreach team each had a designated team of workers who told us arrangements were in place to promote their safety when working alone within the community. An out of hour's on-call team to support children and families was also available. The staffing structure allowed children/young people and families to receive psychological, social, emotional and bereavement support 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 robustly implemented; one staff member told us, "I had a police check and my nurse's registration was checked". We saw volunteers helped to support and complement the care children and their family's received. The team leader for the volunteers told us, "All volunteers go through the same recruitment checks so that we know they are suitable to work with children and families". A volunteer told us, "I do voluntary tasks in people's homes; practical things like gardening or decorating but I had to have a police check and training before I started". We discussed recruitment practices with the director of services and we found their procedures were robustly implemented.

## Is the service effective?

### Our findings

Every parent we spoke with commented that their child received excellent care from skilled staff. One parent said, "The staff are amazing; highly skilled and lovely people". Another parent told us, "Their expertise keeps my child safe; both in our home and in the hospice they know her well and understand her needs". Another parent said, "My child has complex needs; a life threatening condition. The staff are amazing; his needs can change rapidly, there is a whole team around us to support us". Feedback from young people told us they were happy with the care they had received.

Training was provided to make sure that staff had the specialist skills to care for the children and young people. Staff were able to describe all the specialist training they had attended. One staff member told us, "The training opportunities are excellent; we cover all the clinical care needs, use of specialist equipment as well as training specific to our roles". Staff had additional training specific to the needs of children and young people. For example the provider had sourced specialist training in preparation for a child arriving with new equipment. A nurse told us, "The hospice is taking more children and young people requiring greater technological support. Where this is the case we increase the assessment visits and source more specialist training for the team to learn about managing all the equipment". We saw a child arrived for their second assessment day. The parent of the child told us, "I'm very confident they can care for him safely and manage his equipment".

There was an education lead to support training opportunities for all staff. 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 had also received additional training in the use of airway suction (clearing breathing airways) whilst others were trained in enteral feeding (feeding through a tube into the stomach). This enabled HCA to take on more advanced roles in the care to children and young people. We saw a HCA supported a child with their enteral feeding and airway suctioning. One HCA told us, "I did my training for enteral feeding and suctioning, then my competency was checked before I could do it independently". The staff member was able to describe to us both processes and the importance of them and we saw they were able to carry out these processes as they had described to us. A nurse told us, "I am one of three nurses at the hospice who has been trained as a nurse prescriber; I can prescribe medicines for children and young people when they need them". This ensured children and young people could receive their medicines without unnecessary delay.

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, children and young people. This enabled staff to provide palliative care at the hospice or the child's own home. An external healthcare professional told us this training had enable staff to develop the skills necessary to care for babies who required end of life care at very short notice. The person highly praised the staff who they believed provided high quality palliative care which provided children and young people to have an alternative option as opposed to going into hospital. They also confirmed they had received feedback from parents who highly valued the care offered.

Nursing staff also had specialist training in pain and symptom management and the GPs supporting the service had additional training in end of life care. It was apparent from speaking with staff that they worked in partnership with other organisations and attended external networking groups that included the respiratory and tracheostomy meetings. This had helped to contribute to the development of best practice in their service.

We saw the provider had developed their own 'Face To Face' training with parents who they recognised as an important resource for supporting other parents with children who have a life limiting condition or whose child had died. One parent told us, "The 'Face To Face' training equips us to use our own experiences in a positive way to support other parents; just having someone to talk to, someone to re-direct you is so important. It breaks down barriers because we can relate to each other as parents with similar experiences".

There was a structured induction process for all staff and volunteers. This included an overview of Acorns, 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, "I had a good induction over several weeks which covered the whole of the service. I felt well prepared for my role". All of the staff confirmed they had regular supervision in which to reflect on their care and clinical practice. Staff also told us additional support was available in groups following significant incidents or access to counsellors. One staff member told us, "The emotional nature of our work can be intense and at times we need support, I've always found that to be strength here". One volunteer told us, "We get a lot of support from our manager, there's good communication. We have different roles we have been trained for like befriending or helping at groups or doing tasks in someone's home, it makes a big difference to families".

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".

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'. We saw staff were aware of taking into account a young person's level of understanding to make up their own mind about their care or treatment. One staff member told us, "I can think of two occasions where a young person under the age of 16 years refused their treatment and we have looked at a compromise". The director of care services who was able to provide examples of where they had provided alternative treatments and implemented this. This was good practice in encouraging young people of this age in decisions about their care. We observed staff worked in an age appropriate way when seeking consent from younger children and young people; explaining to the child first and asking them if they were happy to participate. Consent had been sought from parents of younger children for their care, treatment and activities the child may undertake whilst at Acorns, such as use of the jacuzzi or taking children out in Acorns transport. A parent told us, "I am always involved in any decisions affecting my child and staff always ask for my permission". Another parent said, "Kids need a normal life and experiences; I gave permission to wrap him up warm and take him outside, the risks were discussed with me and I agreed to that". All members of the care team had training on the Mental Capacity Act.

We saw 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, "I have discussed ACP if my child's condition deteriorated but don't need one yet". Parents told us their child's care and treatment was reviewed at every visit so that all staff had a clear understanding of this.

Mealtimes were a relaxed and social affair with children and young people, their family and staff all sitting and eating together. Children were offered a range of food choices. One child responded with a smile and giggles, to indicate their choice of meal. The staff member knew what food the child enjoyed and we saw the child's likes and dislikes had been captured in their eating plan. The staff member told us, "It is lovely to help [name of child] eat as she is a foodie and really enjoys her meals". Most of the children and young people we saw on the day were artificially fed with their own nutritional feeds via feeding through a tube into the stomach (enteral feeding). The hospice team liaised with parents and community services such as the Dietician, Speech and Language Therapist and Community Paediatrician, to maintain consistent standards of care regarding children and young people's eating routines. Where children and young people required prescribed nutritional additives these were in place and the times of their meals were known by staff. Eating plans we saw contained safe swallow advice and details about how the child should be supported. We spoke with the hospice physiotherapist who told us they assessed a child for correct positioning, the equipment staff should use and the pace of mealtimes. Multidisciplinary team meetings were held to discuss a child's condition, when eating and drinking became a concern. This allowed staff to act quickly to provide advice and support to those children and young people.

We saw snacks, fresh fruit and drinks were available in the dining room for children and young people. Families we spoke with told us they could self-cater using the family accommodation facilities. Religious and cultural dietary requirements were well met. Families told us staff liaised with them about their child or young person's dietary needs at each visit to the hospice. One parent said, "It's amazing how often children change their minds about food; I tell the staff [name of child] is no longer eating certain foods and they make a list of it".

Routine health care checks such as general health checks, progress checks, weight- monitoring, and immunisations continued whilst children and young people stayed at Acorns. When a child became ill they could be seen by the GP who visited daily. There were clear arrangements in place for children and young people in need of symptom control or end-of-life care. Acorns medical director, on- call GP and specialist palliative care nurses were available. This ensured children and young people received consistent health care either at the hospice or their own home via the hospice at home team for pain and symptom management. The GP told us they visited daily as part of the supporting GP team to the hospice and provided out of hours support for symptom management and end of life care.

There were close links between Acorns and the local hospital. Staff attended "Parallel Planning Meetings" with the local hospital to review children and young people whose care was being redirected, (moving out of hospital). This was a very innovative approach enabling staff at Acorns to proactively plan and collaborate so that children and young people had the specialist support they needed to experience good healthcare outcomes. Parallel plans for children and young people help to ensure they have a care plan which identifies their needs alongside a care plan which identifies how their care is to be delivered should their medical condition deteriorate. Acorns had a team of physiotherapists who further supported children and young people by assessing their needs. For example we saw the physiotherapist provided guidance on children's needs in relation to accessing the jacuzzi, providing chest physio or advice about mobility or positions for eating or sleeping. This ensured there was a consistent care approach to the healthcare needs of children

and young people.



## Is the service caring?

### Our findings

We saw from their smiles and responses to staff that children and young people were happy to interact with staff and were comfortable and relaxed with them. One young person on arrival at Acorns [for their second visit] broke out into a big grin; the child's mother told us, "He is definitely pleased to be here, look at that grin he is so happy". We saw staff were caring and considerate in their approach; and understood the importance of listening to children. A staff member told us, "We get to know the child first and it's important we can understand their feelings, some children are anxious or they may be in pain or uncomfortable so we need to be able to identify this".

We saw staff engaged with children in a happy and friendly way and were tactile. One staff member held a young child on her lap during lunchtime, the staff member said, "She enjoys cuddles and feeling close". In the sensory room we saw staff sat with children and stroked and massaged them and children relaxed with this interaction. Another child was being cared for on their bed and we saw throughout the task staff interacted with them; reassuring them and making them comfortable.

Parents consistently described staff in positive terms, "Fantastic staff, really look after us". "They are very kind and considerate, always willing to listen and support me". "At times I would be lost without them". One parent summed up the general consensus in saying, "I've used a lot of the services at Acorns; hospice at home, respite breaks, sibling group, and I see all the staff as 'Acorns'; they all represent Acorns and all show how much they care".

Staff were able to tell us how they managed children and young people's pain and comfort and we saw this was recorded in their care plans. This included details of how children/young people expressed pain or discomfort so that 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 tasks had to be carried out.

All of the parents we spoke with shared positive experiences about their relationship with staff. One parent told us, "After my child was diagnosed we were in turmoil, the first contact we had was from a family support worker who was so kind and understanding, ever since then they have been at the end of the phone whenever I have needed them". Parents told us staff were receptive, compassionate and 'went out of their way to help'. We saw written compliments from one parent thanking staff for all the support and practical help they gave following an incident with their car. Staff had arranged with various people to provide practical help to the family. The parent stated they had not only been listened to but their difficulties had been speedily addressed by the kindness of the staff. Feedback from parents confirmed staff worked hard on their relationships. One parent commented, "Hospice at home have been really brilliant. They become part of our home and were not intrusive; they talked to him constantly about things he likes".

We saw there was a range of ways in which staff supported children and their families on both an emotional and practical level. A strong feature of the service was the variety of support available via the well-established support networks. A staff member told us, "We care for the child and their family; families need

lots of different support at different points in their journey". Following our visit we spoke with a parent who used the hospice at home, respite breaks, and sibling group. They told us "Acorns has been brilliant; they have helped with medical appointments, talking to professionals, getting equipment but more so it's the importance of knowing someone is there to help you and family members through".

Some of the families who used the hospice 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 the provider's three hospice sites. This had enabled staff to respond to parents' feelings of isolation and to support families where English was not their first language. There was very good evidence that staff recognised and responded to mothers' needs in a caring and compassionate way and had built positive relationships with families. People using the AMSG had been actively supported in both an emotional and practical way via a range of regular opportunities to share in social events such as trips and days out. People told us 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. These included; "Being part of the Asian Mothers' Group has given me the confidence to develop and extend my life". "I've made a lot of new friends... I love to attend meetings and be with these women. They understand my situation and give me strength". 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.

There was a diversity champion and steering group who met to ensure they had the systems and structures to provide for families. We saw in addition to the support groups they recognised and celebrated a wide range of cultural and religious events. 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.

The provider had worked to overcome obstacles to families accessing or using their services. Some children and young people had their care delivered in their own home via the dedicated hospice at home team. We saw from records the flexibility of this service had increased the numbers of families accessing the services. This had given a greater degree of choice over the support families wanted to use. A parent we spoke with told us, "It's an excellent service, gives us the choice of care in our home and helped us to get the services we needed". Families were able to access and contact the team when they needed out of hours support. Parent testimonies captured the impact on families which included: "Helps to have some normality in your life and also helps to recharge your batteries". "Acorns has helped me to feel how normal life is after a long stay in hospital, you have changed our life".

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. One quote said, "It was nice to talk about my sister, because it was sad". Another quote said, "It's good to be with others who understand how you feel". A parent told us, "The sibling group gives kids a chance to express themselves; it's also a way of them building relationships with the staff, being part of that 'bigger family.'"

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. A volunteer working with a family had recognised the distress of a mother who had been unable to visit her child's grave. The volunteer manager allocated a volunteer to drive the mother to the cemetery on a regular basis in order to visit her child's grave. The volunteer manager told us, "We work in a variety of ways; practical tasks in the family home, assisting families with domestic tasks, gardening, cleaning, basically whatever the family needs we try meet their needs and put a volunteer in". Some trained volunteers undertook work with children within the sibling groups as well as befriending roles with individual children and young people; supporting them to engage in activities, play and fun events.

Parents said staff were receptive to their needs; one parent told us they had stayed several times until their child settled because it was 'so difficult to leave him'. We saw there were no restrictions on visiting times. Parents told us staff accompanied them to hospital appointments, advocated for them if needed and liaised with services to ensure the child had the equipment and support they needed at home.

We saw each child had a personalised care plan which identified their needs. These were child centred and built up a clear picture of the child and their needs as well as details of the child and young person's favourite food, activities, toys and routines. Care plans were reviewed at each visit to the hospice; parents we spoke with confirmed staff, 'went through everything in case there were changes to the child's routines'.

The environment was conducive to respecting privacy and dignity of children and young people. We saw that when staff were attending to children's needs they did so in the privacy of their rooms. In the evening when supporting children and young people to bathroom areas we saw privacy screens were used across the corridors to promote privacy. Adolescents had the use of pendants so that they could call for assistance when they wanted which protected their privacy and independence.

Some parents we spoke with told us they had made decisions about their child's future treatment. They said they had discussed advanced care planning [ACP] for their child in the event that their health deteriorated. Decisions about treatment and resuscitation were clear in the ACP's we saw. These were of a high standard and showed a collaborative approach between staff and other external healthcare professionals providing palliative care. There was a multi-disciplinary approach, [MDT] which included input from local hospitals or community professionals so that there was good communication and involvement regarding decisions. Advance care plans were reviewed as the child's condition changed. Staff told us a child's end of life care was explained to families. Nursing staff, the GP and medical director were involved in this process. Interpreting services for families were available to aid communication.

When a child or young person died they could rest until the time of their funeral in the facilities provided. The special bedroom operated on a cooling system allowing the child or young person to lie at rest until the time of their funeral. We heard from staff how they personalised the room for each child or young person; cots or junior beds for infants with their favourite toys and possessions. The room was softly furnished and presented as a bedroom with seating for family members. Staff explained that the surroundings could easily be altered for older children and young people. A private entrance was available so that families could access without going through the main hospice areas. We saw the privacy of families at this time was addressed by the use of a symbol to show the room was in use therefore alerting people to respect the family in the accommodation. 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 them to live in the accommodation self-catering or meals could be provided. These facilities enabled families 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. An external health professional described the hospice as being able to offer a much more appropriate, family-friendly environment as opposed to a hospital for children and young people who needed end of life care.

The religious and cultural needs of children and their families were respected and met. 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 provided religious artefacts for use by families so that these could be accessed without delay. Whilst families stayed with their child; they had access to 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. A bereaved parent stated, "It's good to know when you feel like you've got nothing, there was Acorns". There was a memorial garden which families could visit and lay an inscribed stone. Memorial days were arranged so that families could visit and celebrate the lives of the children and young people who had died. We saw bereaved parents continued to be included in significant events.

Following the death of a child or young person staff continued to support the family with compassion and care. An important part of this was supporting the family members to 'build treasured memories'. Staff explained they offered families the opportunity to create memory boxes 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. When staff spoke with us about their involvement in supporting families they spoke with compassion and empathy; one staff said, "It's a privilege to care for the child and their family and we do this following the child's death". The empathy and bond between the child and staff continued after death, we heard from staff how they continued to visit the child, care for them and to sit with them showing their compassion.

We saw from a range of compliments from bereaved families they highly valued the compassion shown to them when their child died. Parents had determined the preferred place of death for their child. Within the hospice or at their own home staff supported children and young people at the end of their life to have a comfortable and dignified death. The wishes of the family were paramount as reflected in the compliments we saw from parents. One parent had informed staff they could not have coped with their child dying at home and they were extremely grateful for the support they had received from staff.

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 we spoke with told us their initial contact with the hospice was either in their own home or in the hospital their child was staying in. Staff presented options of the different services they could offer to support parents and their child. One parent said, "It was a great relief; I needed help with my child but also support for my other children and me. The effect of looking after a child with a life limiting condition can be huge on a family so hearing about the services available was great".

Each child or young person had an assessment of their needs which included information from other professionals involved with the child such as children's community nurses, consultants or the child or young person's school. Collaborative working with external professionals helped ensure the child's clinical, social and emotional and educational needs were identified. There was a focus on the needs of the whole family so that their goals and the support they might need were also identified.

Children' and young people's care plans were detailed and personalised for them. We saw during our visit staff updated care plans at each visit to the hospice. This ensured care plans contained up to date information so that the child/young person's stay could mirror that provided at home. There was information about how children communicated and we saw staff responded to children's verbal and non-verbal gestures and communication. For example staff used Makaton signing or asked children to eye point when making choices. We saw staff used the care plan to guide them in delivering a child's care. We saw favourite activities such as, 'toys that dangle', 'being in the water' and the 'sensory room' and 'Princesses (especially in Frozen)' were recorded. We saw the child was supported to spend some time playing with musical toys and had time in the sensory room which helped ensure person /child centred care and routines were kept to. The needs of older children and adolescents were addressed. Planned admissions with their peers, dedicated adolescent trips and activities were addressed. 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.

We attended one of the daily handovers and observed the medical, personal care and well-being of each child and young person was discussed to ensure staff had up to date information on how to respond to their care and treatment needs. We spoke with a visiting GP who told us two GP's from the local practice covered out of hours to offer support for staff when providing end of life care. Multi-disciplinary team (MDT) meetings and attendance at planning meetings at the hospital ensured the effective sharing of information. This included parents' views so that children's needs were prioritised and planned; for example where a child ready for discharge from hospital was redirected to the hospice. We saw there was an inclusive approach focused on the needs of the child and their family. This ensured the services Acorns could offer were coordinated to suit the child and family needs and could include a number of services from Acorns; respite care, hospice at home and access to support groups.

Parents told us staff were always responsive to their needs; there was regular contact between them and families via the on-call facility and the hospice at home staff who visited their home when they needed additional support or when there was a significant change in their child's health. All the parents we spoke

with told us they were fully involved in reviewing their child's care. One parent said, "Each time we have respite the staff go through everything; his medicines, bumps and bruises, sleep, eating, and anything else".

There were many examples of a proactive and responsive approach to children and young people's needs. A child using the local hospital was visiting the hospice with a view to using the service. We saw this was possible because the hospice staff had been trained to manage the specific lifesaving equipment the child required. This meant the child could receive the specialist care they needed outside of a hospital environment. The parent told us how this had been a significant improvement for their child's continued wellbeing.

The management team had evolved and developed its provision to children and young people and had worked in partnership with other agencies and hospitals. We saw evidence of multi-disciplinary working within the wider health community. For example, one child was using the hospice's 'step down' bed and this 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 and fostering to work collaboratively on a care package to support the child's discharge from the hospice. We saw evidence that staff were providing support and training to the child's main carer in meeting the child's care and treatment needs.

There was a well-established hospice wide Transition Team who worked across the three Acorns locations. We spoke with the staff from this team and with a young ambassador and their parent to explore the support offered from the transition team to move into adult services. We heard the young person had been involved in meetings between health, education and social care professionals so that they could explore the options available to them. We heard this had included support to access further education as well as support with community services they could utilise. The person told us they were very happy with their transition. The parent told us it had helped enormously as Acorns staff had co-ordinated everything, supported them throughout and advocated on their behalf.

The management team had developed an end of life policy and rapid discharge process whereby information could be sought quickly to respond to parents of babies who required neonatal care. There was a dedicated nurse with special responsibility for the delivery of antenatal and neonatal care at each of the hospice's locations. We heard from professionals that the staff team had forged positive partnership working with the local women's hospital. This 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. Staff attended weekly planning meetings at the hospital and therefore they were proactive in planning for babies and coordinating support alongside hospital services to focus on the parents and child's needs. Staff could respond to end of life emergencies. A hospital healthcare professional described an excellent working relationship with staff which had been established over a number of years. They confirmed that end of life care for babies could be arranged and organised without delay in response to their needs. They had not experienced any referrals being declined. Staff we spoke with were able to describe how their staffing arrangements were adjusted to accommodate emergency referrals at short notice and provide the specialist care babies needed. An external professional described a willingness by staff to collaborate and work together to accommodate the needs of parents. For example where babies who needed compassionate extubation; [when a child is taken off the ventilator] staff could provide specialist end of life care at Acorns at a time when parents were ready for the ventilator to be switched off.

The hospice at home team supported families of children and young people where they had chosen a home death. This new initiative was responsive to the needs of children/young people and their families and clearly provided them with a choice. The parent of one child stated that end of life care at home had given them "everything they had wanted and more". Professionals told us the service was very responsive to

children's and young people's rapidly changing needs within their own home. We saw a range of compliments from external professionals where this had occurred. One professional wrote, "What a great job Acorns had done with regard to the rapid discharge from hospital and the end of life care (provided in the child's own home) for (name of child)". Another compliment from the Community Children's Nurses [CNN's], read, "Walsall CCN's grateful for the support offered last week regarding end of life care for (name of child) at home". We saw the CNN's expressed their thanks to Acorns staff for the additional support offered to a family in the form of providing a memory box, the offer of photographs for the family and resources following their bereavement.

During their stay children and young people had access to a range of activities and planned events. We saw young children in a well-equipped activities room with arts and crafts. Children had access to eye gaze and eye point computer games which enabled them to play independently. Staff told us they planned activities around the child's known interests and we saw on the day children were supported in age appropriate play; toys on the floor, messy painting and computers. 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 jacuzzi pool enabled children to both relax and enjoy fun in the water. Staff told us they organised and planned play activities. We saw staff had been trained in music therapy so that they could engage children in this. A range of planned activities and events had taken place; these included trips out and events held at the hospice for parents and children to enjoy. Fund raising projects enabled Acorns to provide opportunities for children such as a Disney weekend and we saw feedback from children and parents about how much they had enjoyed this. In addition staff arranged events suited to adolescent girls or boys so that 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 clearly showed staff helped to make fun and special memories for the children and young people as well as their families.

Children and young people were proactively encouraged to provide feedback on their experiences. A new initiative called 'Real Time Reporting', enabled children and young people to 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 give their experiences. The feedback we saw was positive from children and young people who described how much they enjoyed their stay at Acorns.

No complaints had been made by children or young people. 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

Children and young people expressed positive feedback about the hospice and the support they had experienced. One young person told us how they were involved in meetings and developments and how they wished to 'give something back' following their positive experiences. Parents consistently expressed their praise, one parent told us, "It is a brilliant place; I wouldn't cope without their help". Another parent said, "It's fantastic what they do for us, they look after the whole family as well".

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 the positive culture in the service showed staff always tried to look at how best to support them. For example we saw staff actively listened to parents concerns and looked at ways to support them. Parents told us they felt everyone was welcoming, listened to them, supported them and staff were; 'genuinely committed and went out of their way to help'.

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 by the chief executive and director of care services and team leaders for the hospice at home team, 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 that 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 and we saw that they had.

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. 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 was in one place so that staff could 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 and children/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 range of services provided.

Medicine management was reviewed and medicine management meetings were multidisciplinary. We found some aspects of medicine practices required further improvement and these had not been picked up by the provider's quality checks. 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 12 months.

Staff were passionate 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. The hospice at home manager said, "I have been here for 16 years in total and I love everything Acorns stands for; I can't think of a better organisation to work for." 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. 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 or support for end of life care in the child's own home.

The management team had further developed its services to offer end of life care from the hospice at home team. This initiative ensured families had a choice of their child's place of death and could be supported by specialist nurses from Acorns. Community services had a positive impact on children and their families by ensuring they had additional support such as 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. Records showed there had been an increase in the number of families using Acorns services indicating the variety and flexibility of the services offered was reaching more families.

Staff and volunteers told us how they enjoyed working at Acorns 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".

The management and staff team had found innovative and 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 groups 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 Acorns staff had coordinated services and supported them to explore their options.

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 Acorns provided. Regular newsletters were published updating families on all events. These initiatives showed they had a variety of ways of reaching families who might benefit from their service.

The service proactively 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. We heard from an ambassador they attended transition meetings to discuss, share and shape ideas with adult stakeholders. They had participated in staff induction processes to raise awareness and had a User Engagement Steering Group. An ambassador told us, "My motivation was to raise awareness of the brilliant things Acorns did for me and others; I want to give something back and shape the services". We heard they had been actively involved in developing Acorns website. Parent Carer Champions [PCC] actively participated in the providers unannounced spot checks on the service and had training to undertake this role. One PCC told us, "It's important that children and young people are always well cared for. As a parent doing the visits this allowed me to share and input into this, I think it is great parents have this opportunity and great Acorns have that transparency". 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.

Acorns actively participated in the palliative care hospice network which invited hospices to share good practice and innovations. We saw examples of networking with groups outside of the hospice. 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. Acorns 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.