

Acorns Children's Hospice Trust

Acorns Children's Hospice in the Three Counties

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

This inspection took place on 25 April 2016 and was unannounced.

Acorns Children's Hospice in The Three Counties is registered to provide care and treatment to 10 children or young people, aged between 0 and 18 years, who have a life-limiting illness or life threatening condition. Support is also provided for families of the children and young people who use the service. There were five children staying in the hospice on the day of the inspection with a further one child 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.

Staff had received training to support children and young people in receiving their medicines. We identified some shortfalls in the management of medicines although there were no indications children or young people had been placed at risk. The registered manager and staff were responsive to the medicine issues we found.

Children and young people were happy and relaxed in the presence of staff. Parents told us they had no concerns about their child's safety and were confident staff had the knowledge to keep their child safe. Staff knew how to recognise and report possible harm or abuse and would have no hesitation in speaking out if they witnessed abuse.

The leadership team had arrangements in place to make sure the planning of the numbers and skills of the staff team were effective and safe in meeting the specialist needs of children and young people. When children and or young people's needs changed and or there was an emergency there were contingency arrangements to be able to increase the staffing numbers.

Children and young people received personalised care to meet their specialised needs from a staff team who had access to on-going training and support.

There was a strong focus to source initiatives in helping the staff team to be the best they could be in their varying roles. This included individual staff taking on specialist link roles to ensure best practice guidance was implemented and specialist skills were shared amongst the staff team. We heard how these initiatives had had significant impacts upon children and young people as their complex medical needs, symptoms and pain were well managed and staff were trained to meet these specialist needs. The medical arrangements and support was provided without delay at the hospice or children and young people's own home.

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.

We saw staff cared for children and young people with compassion and kindness which was a pattern which was consistent in the way services had been developed. Staff consistently reported they felt proud to work at the hospice and had formed supportive and caring relationships with children, young people and families. Parents told us how amazing and fantastic the different groups of staff had been in helping them through the tough times as well as sharing moments of happiness.

Advance care plans around end of life care were used to make sure good preparation where choices could be made with consideration of the support families would need to share their views. Parents and family members appreciated the bereavement and support services offered to them. We saw the different services provided support for all family members.

Staff worked in close partnership with a wide range of other professionals and services so children and young people received consistent care. Staff responded positively and inclusively to children and young people's changing needs. This way of working had made real differences for families in supporting them through different stages of their child and young person's lives. This included young people being well supported with the changes in services as they approached adulthood.

There were excellent links with antenatal services so 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 things to do for fun and interest. There was a great awareness of children and young people's spiritual, religious and cultural needs so they and their families had the support they wanted, before, during and after death. Families had additional practical and emotional support from trained volunteers and befrienders.

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

Everyone we spoke with were consistently positive about the way the leadership and staff team were inclusive in how they involved children, young people and parents in influencing and directing their own services to meet their needs. This included developing roles so children, young people and families used their own first hand experiences in different aspects of service delivery which included checking the quality of the services offered.

The leadership and staff team were highly motivated and committed to continual improvement to meet the changing needs of children, young people and parents. Partnerships had been formed with other specialist organisations to share learning and expertise. This also helped the leadership and staff team to meet their vision of every child and young person with life limiting and life threatening conditions should be able to access the specialist care and support they need.

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

Requires Improvement ●

The service was not consistently safe.

The arrangements for the management of medicines were not consistently safe.

Children and young people were protected from abuse because the staff had received training in how to identify and report possible abuse.

Risks were assessed and managed effectively to promote children and young people's safety.

There were sufficient numbers of staff employed to ensure children and young people received the care and treatment they needed.

Is the service effective?

Good ●

The service was very effective.

Children and young people had access to specialist care and treatment from staff and volunteers who had appropriate knowledge and skills. Staff had specialist link roles as a way of sharing best practices in various subjects relevant to palliative and end of life care.

Different initiatives had been developed so parents were able to support each other and be involved in training as their experiences were seen to be an effective way of sharing knowledge with the staff team.

Young people were supported to be 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's food tastes had been taken into account to ensure they enjoyed their food as a way of supporting them to meet with their nutritional needs.

Children and young people's health and wellbeing was supported by complementary therapies and medical care to ensure their symptoms and pain were well managed.

Is the service caring?

The service was very caring.

Children, young people and their families were provided with compassionate care which ensured their privacy

The leadership and staff team showed they cared about the difference they could make to the lives of children and young people who used the services. They had developed different practices so children and young people could as independently as possible communicate their feelings and be involved in the services offered.

Children, young people and families had access to an excellent range of resources to support different faiths and beliefs during their treatment and following the death of a child or young person.

Outstanding 

Is the service responsive?

The service was very responsive.

Children and young people received personalised care and support because of the development of services which were flexible and responsive to their particular needs. Young people moving into adult services were well supported by the transition arrangements which were well established.

Links had been made with local hospitals to create relationships with antenatal services so the families of unborn babies had options of hospice care.

Children and young people had access to things to do for fun and interest which were suitable for their individual needs and age.

Staff worked with other organisations and the local community to meet the individual requests and individual needs of the children and young people.

The leadership and staff team consistently listened to and acted upon feedback received from children, young people and their families. This resulted in improvements in care.

Outstanding 

Is the service well-led?

Good ●

The service was well led.

Children, young people and families were placed at the heart of all services offered and staff applied the organisation's vision of reaching out to everyone.

Staff were proud of their work, achievements and knew how their roles contributed to making a difference to the care they provided.

There was strong leadership and systems were in place to monitor the quality of the services to reflect continuous improvement and development of services offered to children, young people and families.

Acorns Children's Hospice in the Three Counties

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 25 April 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 in the field of palliative and end of life care.

Before the inspection, the provider completed a Provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make. We reviewed information held about the service including statutory notifications and enquiries relating to the service. Statutory notifications include information about important events which the provider is required to send us.

We asked the local authority and the clinical commissioning team if they had any information to share with us about the hospice services provided to children and young people. In addition to this we asked Healthwatch if they had information to share with us. Healthwatch are an independent consumer champion who promote the views and experiences of people who use health and social care. We used this information to help us plan this inspection.

We used a number of different methods to help us understand the experiences of children, young people and families who used the services. We spoke with two parents on the day of our inspection and a further five parents by telephone following our inspection. We spent time with children and young people and saw

the care and support provided by the staff team at different parts of the day. We looked at seven children's care and treatment plans, advance care planning and medicine records.

We met and spoke with 14 staff on the day of our inspection. This included the registered manager, director of care services, quality and governance lead, manager of sibling services, chair of spiritual care group, a GP, nurses, student nurse, healthcare assistants, physiotherapist and student occupational therapist and staff who provided a range of services. A healthcare professional also shared their views and experiences of being involved with the care and support provided to children, young people and parents by staff at the hospice. Following our inspection we spoke with the medical director by telephone.

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 saw a variety of written feedback from parents and children including testimonies from parents, feedback from support groups and young people's feedback from sibling groups they attended. We also saw 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

Staff told us that two nurses checked all medicines for accuracy when a child and or young person came in to the service. However, we saw examples of two medicines not written up accurately in accordance with the doctor's instructions. This meant staff were not following Nursing and Midwifery Council [NMC] guidance on standards for medicines management and which increased the risk that the child or young person may be given their medicines differently to what the prescriber intended.

Staff reported medicine incidents using a specific form and they discussed the incidents at monthly meetings. No record was kept of any thorough investigation, discussion or action plan. This meant that there was no evidence of learning from the incident and we could not be assured that the risk of the incident happening again was reduced.

The hospice had a framework for checking the competency of healthcare assistants each year. However, there was no similar method in place for checking the competency of nurses working within the service. This meant that the management team could not demonstrate how they knew their nurses could look after children and young people's medicines safely. The lead nurse assured us that this would be something that would be put in place as a priority.

We saw in the event of an anaphylactic reaction (severe allergic reaction), there was no emergency treatment pack available. Staff told us children and young people usually brought in their own emergency medicine if needed. However, there was no risk assessment available to show the risk of not having a treatment pack available. This was discussed with the medical director who told us they were currently considering their position in regards to having emergency treatment packs available following our inspection. We saw this had also been discussed at a 'prescribers group' meeting with an agreed action of carrying out a risk assessment.

A nurse prescriber (a nurse who had additional training to be able to prescribe medicines) and a GP visited daily to manage individual children's and young people's healthcare and medicine requirements. If staff needed advice from a pharmacist then the team would contact the community pharmacist. A community pharmacy provided medicines for children and young people including those required in an emergency.

We checked the medicines prescribed on four prescription charts. We noted that there was clear recording of the prescribed medicines including additional instructions for safe administration.

Nurses gave people their medicine when they needed it and not at set administration times. This was a child and young person's centred approach to meeting their needs.

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. Staff locked away prescription pads securely with a copy kept of each used prescription for audit trail purposes.

Medicines that require additional controls because of their potential for abuse (controlled drugs) were stored securely and monitored according to safe practice.

Throughout our inspection we saw many examples where children and young people's body language and facial expressions showed they were happy and looked comfortable in the presence of staff.

Parents spoken with us shared their thoughts on how their children's safety was promoted. One parent told us, "I trust them (staff) implicitly as they are all very knowledgeable so I know [child's name] is safe, if I did not [child's name] would never be left at Acorns." Another parent said, "To be honest I could not praise them (staff) enough as I know [child's name] is being well looked after when I go home and is safe so I can relax." Professionals who shared their comments with us similarly believed children and young people were safe in the care of staff at the hospice.

Information about keeping safe was available in a suitable format for children and young people to access. We saw in one leaflet phrases, such as, 'respect our views' and 'listen to us' which reflected the positive attitude taken by the organisation to promote the human rights of children and young people within the services they received.

Staff understood their role in promoting children and young people's safety. Staff told us how they would recognise and report abuse, and we saw they had regular training to ensure they were up to date with the procedures in place to report safety concerns. In addition to this there was a 'safeguarding steering group' which helped to drive through consistent approaches from all staff when working with other professionals around the issue of abuse. This also provided a management overview in relation to abuse.

There were effective procedures in place to record and report abuse which included working with other professionals in line with the 'Working Together to Safeguard Children' guidance. This formed part of the practices whereby the leadership and staff team worked closely with various organisations, such as, the National Society for the Prevention of Cruelty to Children NSPCC and the local safeguarding boards. We spoke with the staff member who was the designated safeguarding officer for the organisation who told us about some of the benefits of close partnership. One of the benefits was to increase other professionals' understanding of how the subject of abuse could have added impacts for children and young people with life limiting and life threatening conditions.

Children and young people were protected against the risks of discrimination. One example was the comprehensive resources to meet the spiritual care needs of children, young people, families and staff. We saw these were accessible and made available. The chair of the spiritual care group told us how the staff team's awareness of spiritual care had been raised to enable them to understand it in a wider context to encompass each person's beliefs. One parent we spoke with told us they were amazed at the amount of different items available to meet people's different faiths and said, "Acorns makes sure everyone is included no matter what their backgrounds are."

Parents spoken with told us they had been involved in identifying and managing risks to their child's wellbeing and safety alongside other professionals when staying at the hospice. One parent told us, "The staff are keen to learn from me about [child's name] needs and presentation when they become unwell." We also spoke with the staff member who had the responsibility for managing the admissions of children and young people at the hospice. They told us staff communicated with other professionals, such as doctors, to make sure children and young people's current needs and risks were shared on admission together with any changes if the child or young person had used the services previously.

The risks to each child or young person's safety and wellbeing had been considered when staying at the hospice. We saw examples where staff had identified risks associated with supporting a child or young person to move. Systems were in place to make sure the risks associated with the use of specialised equipment had been assessed and plans were in place for staff to follow. These systems helped to ensure the risks to each child and young person from avoidable harm could be managed and were reduced. We saw examples of how staff practices when using specialised pieces of equipment considered each child and young person's safety and dignity.

Parents we spoke with told us how their child or young person could continue with different activities they enjoyed doing because of the support provided by staff. One example parents consistently told us about was how their child or young person was supported to use the hydro pool. One parent said the hydro pool, "Has so many benefits for [child's name] as they enjoy being in water but we want to know they are safe at the same time which without staff support this would not be the case." Another parent told us how they felt unable to use community swimming pools as they felt other people would make judgements about their child if they became unwell. A further parent said staff had supported their child's needs so they were able to enjoy the benefits of being in water in a safe way and were not disadvantaged from having fun. We saw safety measures for each child and young person who used the hydro pool had been considered which included any specialised equipment they needed together with what staff support was required. The physiotherapist told us about 'taking fully ventilated children in to the pool, having done risk assessments of course'. They also spoke about the 'family splashes' which were offered at the weekends which were also confirmed to us by parents as times where families could have fun together.

Children and young people were cared for in a safe environment. The hospice environment was spacious and accommodated specialist equipment which was required to keep the children and young people safe. Children and young people were not restricted to only the indoor hospice environment. The entrances and exits to the hospice were locked to make sure staff could monitor who entered and exited the building. Children and young people could access safe spaces within the hospice's grounds and could request to leave the hospice grounds.

We saw when incidents occurred they were reported and investigated appropriately. This included making sure actions were taken to review any specialist equipment which might reduce risks of the incident happening again. For example, we saw where one incident had prompted staff to review the equipment needed for a child or young person to meet their unpredictable needs when they were using the hydro pool. Staff were kept informed of incidents and the actions necessary to prevent re-occurrence via daily hand overs and staff meetings. We consistently heard from staff that they believed incident reporting and the methods to share actions taken to be 'good.'

Parents we spoke with told us they believed there were enough staff on duty to meet their child's individual needs whilst they stayed at the hospice. One parent said, "There are always staff here when we arrive, during the stay staff are allocated to [child's name]. I think staffing is well organised and definitely makes sure children are safe. I have no qualms about leaving [child's name] at Acorns as I know they will be safe and cared for." Another parent told us, "What can I say, they (staff) are always there when I need them both at the hospice and to visit us at home, to just pop in when [child's name] is ill." During our inspection we saw children and young people's individual needs were responded to in a timely way without any unreasonable delays. For example, we saw a staff member assisted one young person with their drink and each time the young person wanted their drink the staff member provided this to them. The staffing numbers ensured the young person had the support they needed to assist them in a safe and unhurried manner to finish their drink. We also saw when two staff were required to support a child or young person to move with equipment. This support was provided without any undue rushing which could place a child or young

person at risk when using equipment.

Staff we spoke with told us staffing levels were planned and managed to meet the needs of children and young people. One staff member told us, "There are enough staff, if we are ever short the manager would act upon this." Another staff member said, "Children don't have to wait to have their needs met, there are enough staff so they are safe too." The staffing planner reflected what the registered manager had told us about how they ensured sufficient staffing numbers and skill mix of staff to keep children and young people safe. During the day of our inspection we saw there was a good mixture of skills between the staff team and volunteers which enhanced the safety aspect when meeting the individual needs of children and young people. For example, we saw nurses were on hand to focus upon medicines and children and young people's health needs. There were physiotherapists whose responsibilities included improving and/or maintaining children and young people's physical health to a level where their safety was not compromised whilst they enjoyed their lives. There were also on-call arrangements and staff spoken with told us they never felt their safety and/or each child or young person's safety was at risk in the day, evening or through the night as there were procedures in place for any unforeseen emergency.

Staff said and records confirmed background checks had been completed on staff and volunteers before they had been appointed. These included checks with the Disclosure and Barring Service to show that they did not have criminal convictions and had not been guilty of professional misconduct. We noted in addition to this, other checks had been completed including obtaining references from their previous employers. These measures helped to ensure new staff could demonstrate their previous good conduct and were suitable people to be employed to provide care to children and young people who used the hospice services.

Is the service effective?

Our findings

Without exception, parents we spoke with told us they had total confidence in the abilities of the staff in meeting their child's individual needs. One parent talked about how staff did more than just meeting the health needs of their child with medicine and treatment. They said staff also had the skills and awareness to instinctively know when children needed a hug which the parent believed was as effective as any other treatment or care. Another parent said their child had a specific health condition which the hospice medical staff had more knowledge about than external professionals. They said staff, "Having that experience and wealth of knowledge" made a difference to their child's quality of life.

The comments we received from a paediatric consultant were very positive as they believed the services families with children who had life limiting illnesses was, 'fabulous.' One of the reasons they confirmed this with us was due to staff accepting emergency referrals which can be critical in a child or young person's care. They were equally positive about the respite care children and young people were offered which was a 'lifeline' for many families. They thought the respite care supported families whose children had complex medical needs to have a break knowing nurses were part of the staff team which provided added reassurance for families.

New members of staff and volunteers received structured and planned induction and training which we consistently heard from staff was very good in helping them to be effective in their roles. We heard from the leadership and staff team there was a strong culture of sourcing, arranging and encouraging training so that staff were as effective in their roles as they could be. This included staff having access to an education lead and co-ordinator. Staff told us the education lead supported them to make sure they were up to date with best practices when providing palliative and end of life care and treatment to children and young people. Staff also told us they were supported by their colleagues and believed they worked well as a team. One staff member told us, "This is an incredibly happy place but when a child dies we do feel the sadness this brings. We are strong on supporting each other so we can carry on supporting children." We heard how there were two weekly debrief meetings which provided staff with support following the death of a child or young person. A new initiative was to also use these meetings as a 'time to reflect' for the staff team to discuss clinical issues.

The provider told us in their PIR, 'Locally Acorns is part of the West Midlands Paediatric Palliative Care Network with active membership of many sub-groups. Acorns works closely with the national body Together for Short Lives on a number of practice groups and developments with active membership of a number of key forums ensuring we maintain up to date current practice.' In addition to these opportunities we found there was a culture which had developed which supported the staff team to continually provide high quality care and treatment. The registered manager told us about how staff were encouraged to 'take on' lead roles so they could broaden their knowledge in specialist subject areas, such as respiratory care and resuscitation to share their skills with their colleagues. One staff member told us what this meant for them, "It provides excellent opportunities for us all to learn, develop and share our knowledge as a team. I find it a great way to learn about a child's specific needs and increase our knowledge as we do provide some very specialist care to children."

Parents we spoke with talked to us about how they knew staff had the knowledge and skills required which included how to manage the additional specialist needs for children and young people with life limiting illnesses. For example, when a child required airway suction (clearing breathing airways) this was done with confidence as told by to us by one parent. Another parent talked about how they, "Absolutely knew" staff had been trained in specialist care. This gave staff the knowledge and skills to meet their child's specific needs and they were, "Really relaxed [child's name] is being taken care of with all the essential equipment, by staff who really do know what they are doing." A further parent told us how the community staff team had really used their knowledge to help them as they had had, "A tough year and they were really great."

Parents and staff spoken with told us how the role of the physiotherapists were invaluable in providing advice and support around meeting children and young people's particular needs. This included providing advice about and guidance around physical health conditions, using the hydro pool, chest physio or advice about supporting children and young people to move or positions for eating or sleeping. The physiotherapist told us physiotherapist students had spent time at the hospice and they had received some positive feedback and an award for 'best mentors.' In addition to this staff who had interests such as gardening brought these skills to enable children and young people to develop their own interest and have fun. One parent told us the different experiences of activities were beneficial as they provided therapeutic fun and interest for children and young people.

We saw and heard from parents and staff how volunteers were used creatively and effectively alongside staff to support children, young people, their siblings and families. One parent we spoke with told us, "The volunteers do an amazing job and they really know how to communicate with children. We have seen this and it works beautifully for children bringing a lot of joy to them." During our inspection we saw a volunteer 'befriender' chatting with one child. The 'befrienders' had been trained to undertake their roles and we saw how the 'befriender' effectively put their training into practice. They knew how to effectively use a mixture of verbal and sensory communication which was understood by the child. We saw the child clearly enjoyed the time they spent together as they smiled and used their hands to join in the activity.

We heard from parents how they had been successfully included in making sure the services offered were effective in meeting the needs of children and young people with a life threatening condition. One example provided was the 'Face to Face' training which was provided to parents to assist them in further developing skills in sharing their own experiences to benefit and support other parents. One parent told us they felt this was a "Brilliant idea" as unless you have been through the experience of one of your children living with a life threatening condition you would not be able to "Truly understand." In addition to this we heard about how parents had been invited to staff training days to provide staff with parent's direct experiences. One example was where one parent had joined a training day to talk about blended diets as a method of effectively meeting children's needs.

Throughout our inspection we saw and heard many examples of how staff had effectively met the individual care and treatment needs of children and young people. Staff practices had positive impacts for how well children and young people's needs were met, such as when using individual aids and equipment to achieve positive wellbeing for each child and young person. For example, we saw staff were confident and competent when they supported children and young people at lunchtime and teatime who required particular assistance so their nutritional needs were met. This was also confirmed by one parent who told us their child was, "Really fussy" with their food but staff knew how to make sure their meals were "Just right" for them to eat and enjoy.

We saw children and young people were supported and encouraged to drink and eat their meals at lunchtime and teatime. Children and young people were seen to enjoy their meals and were eager to be

supported by staff. Staff involved children and young people when helping them by using their preferred method of were assessed so staff had information about their likes and dislikes to meet their child's specific needs. Communication so a child or young person was supported to go at their own pace when eating and drinking. Specialist diets were provided for and there was a choice of food. Parents said meals were consistently good and they were able to join their child as they wished. Parents we spoke with also told us their child's nutritional needs

The PIR confirmed, 'Information regarding eating and drinking gained from family and or child/young person as part of care plan. If complex issues with parents' permission, team link with community services e.g. dietician, speech and language therapist, community paediatrician to formulate a comprehensive feeding plan including safe swallow advice. Care team are trained to deliver naso-gastric and gastrostomy feeds.' We saw and heard from staff about these professional partnerships which they believed supported children, young people and parents to gain advice and guidance so their nutrition and health needs were met in the best possible way. In addition to this staff told us about how by 'parallel planning' was beneficial to children and young people. ('Parallel planning' is where a child or young person has two plans in place for different circumstances around their health conditions). Staff told us by having different plans in place children and young people's individual needs in aspects of their care and treatment could be planned for more effectively. Parallel planning' also enabled and empowered families to realistically plan what treatments they may wish their child to receive or not should their health needs deteriorate.

There were assessment and monitoring tools in place which were used to enable staff to identify changes in children and young people's health and wellbeing. There was access to appropriate health, social and medical support. Nurses and physiotherapists were employed by the provider and local General Practitioners [GP's] visited the hospice on a daily basis. In addition to this there was a system in place to gain out of hour's medical support if it was required so children and young people's health needs, such as the management of their pain and symptoms were effectively met.

Staff and GP's had access to support from the medical director. We spoke with the medical director who showed us they were passionate about their role and responsibilities in having an overview of children and young people's end of life care and treatment. We also spoke with a GP who confirmed the medical director would always make themselves available to them to discuss a child or young person's end of life care which included any complex symptom management issues. The medical director and GP's had regular set meetings where they used this time for training and discussing complex matters around a child or young person's care and treatment to make sure their practices remained effective.

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 interest and as least restrictive as possible. People can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in care homes and hospitals are called the Deprivation of Liberty Safeguards (DoLS).

Staff spoken with showed they understood how the Mental Capacity Act (2005) and DoLS (applicable to children over the age of 18 years old) affected their caring roles. For example, staff knew for children under the age of 16 years old each child needed to be assessed as to whether they had sufficient understanding in order to make their own minds up about the benefits and risks of their treatment. Staff and the information we had received in the PIR confirmed, 'Young people who wish to refuse treatment and who have mental capacity to make that decision would be supported along with their parents if in agreement.' We saw

children and young people's rights were protected. Where appropriate staff sought consent from children and young people. Care records contained information detailing who had parental responsibility for children and young people who should be included in best interest decisions. One parent told us, "They (staff) make sure we are always involved whether it be around our preferred choices and or crucial decisions, they (staff) are really great when it comes to being inclusive."

Is the service caring?

Our findings

One young person showed us they liked the staff by putting their 'thumbs up.' A child used their eyes and facial expressions by smiling in acknowledgement they were happy to be with a staff member. Parents we spoke with consistently told us they had formed strong relationships with staff who they saw regularly and who they thought were highly caring individuals. One parent told us, "I would say care is second to none" and "Staff are absolutely amazing." Makes a huge difference to family life and the daily grind." Another parent said, "Staff are very caring, they love the children. They are all wonderful." A further parent told us how a staff member from the community team had helped them with a particular problem and they, "Couldn't do without her."

We saw caring relationships had been formed between children, young people and staff. One example of the staff team's caring attitudes was highlighted when we saw staff checked with children and young people whether they were warm enough before they went outside. Staff did this in an unrushed manner taking into account each child and young person's preferred communication methods, such as using body language, eyes and gestures to gain their views. Children and young people responded positively to staff who they had become to know well. Another example which reflected how staff involved children and young people with their choices was when they asked them what they wanted to do for fun. We saw a staff member showed respect to a young person's choice of what they wanted to do and patiently supported them to achieve their choice of activity.

The leadership and staff team told us how they kept children, young people and families at the heart of all the services they provided. We saw and heard from staff how this ethos had enabled new initiatives to be continually developed which supported children and young people to express their views and be actively involved in their care and decision making. One such initiative was the idea known as 'real time reporting.' This idea was about involving children, young people and families to be involved in their care and what makes a difference to them. A survey could be accessed electronically, such as by hand held computers and mobile telephones. Careful thought had gone into making sure children and young people could use this technology. This included consideration to children and young people who used a form of signing and pictures to express themselves, such as Makaton.

Staff we spoke with showed they knew the children and young people very well. We consistently heard from the staff team how they were passionate about caring for not only the child or young person but the whole family. One staff member told us, "We put the child and their family at the heart of all that we do." Another staff member said, "It is all about children and how we can with them make life as good as it can be. We help and support families to make memories, it is such a privilege." Parents we spoke with also confirmed the culture of the staff team was to care for the whole family whether their child or young person was staying at the hospice or received care from the community. One parent told us, "They look after the whole family, cup of tea and a chat when I become emotional. They understand the bigger picture and the journey we as a family are traveling, makes a real difference to us." Another parent said, "It's a special place for the whole family, love being there. Staff are nice and friendly and we all feel relaxed and at home."

At the time of our inspection no children or young people were receiving end of life care. Nevertheless staff showed us and told us with passion and empathy how they showed care, respect and dignity at this time in a child and young person's life. This was confirmed to us by staff and the PIR which stated, 'Children can be cared for in a cool special bedroom after they have died. Cultural and spiritual needs are followed. Individual faith and religious needs are followed and are guided by family. Resources are available to support the delivery of religious and spiritual care after death and links in the local community of religious leaders of all faith for support at this time.' Families were able to stay at the hospice and or visit their child whenever they wished. Staff continued to provide after death care to the child or young person until their funeral. We heard from one staff member how they were incredibly proud of their colleagues as they had seen how they had spent time with a child after they had died and read to them.

Practices were in place to ensure children and young people experienced a comfortable and pain free death. This included regular assessment and reviews by nursing and medical staff and personal choices were respected in line with each child or young person's advance care plan. One parent told us how they had they had found the idea of advance care planning to be "Harrowing." However, with the care and support from the family support team and transition worker (the transition team help young people and parents with the move across to adult services) had made a, "Huge difference" which assisted them to talk about end of life care for their child and it was, "Not as bad" as they had thought it would be. Parents told us their child's care and treatment was reviewed at every visit and they had the information they needed. The leadership and staff team had embraced the newly developed '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.

We heard examples which highlighted the significant impact to parents' feelings and memories due to the caring approaches of staff and the opportunities the two 'special bedrooms' provided families. The family were supported by staff to make memories and share their feelings. For example, one parent finished a book they had been reading with their child as they stayed in one of the 'special bedrooms' for nearly two weeks after they had died. The family also bought in a record player the child had given one of their parents for Christmas and played their child's favourite record. The child's siblings were not forgotten as they were helped to write down their thoughts and feelings to place in the coffin, collected small pieces of hair and took finger print impressions to keep to incorporate into jewellery. The family team worker supported the family to discuss their child's funeral. This included what they wanted to say and the practical arrangements of registering their child's death. We saw some of the things the family had said had made a significant difference. One of these was they felt so grief stricken they may have missed the opportunities of making memories they really valued.

There was a strong sense of caring about the feelings of siblings which showed siblings' feelings were not overlooked. For example, on the sudden death of one child, time had been arranged at an outdoor centre for the child's bereaved siblings and peers who had developed close friendships with the child. The event supported them to have a safe place to express their feelings of loss. During the time together children were involved in activities, such as creating 16 tiles which they painted and made friendship bracelets to represent their memories and friendship with the child who had died. This also helped children to share their common bond of experiencing the death of a brother or sister. There was an belief in the staff team that without the support, this group of children had they may not have been able to positively express their grief which could have a negative impact on their wellbeing and their lives in the future.

There were other initiatives set up to meet the diverse needs of different groups of people. This included a

group for grandparents, an oncology group, family support days and bereavement groups. We also heard how the needs of young people over the age of 10 had been recognised by increasing the number of opportunities for them to come together to consider options for the future and learn new skills. The leadership and staff team were continually looking at how they could support parents to ensure their diverse needs could not only be met but were empowered to continue with the networks of support they had formed. We heard from staff that the groups set up to support parents had continued to exist with friendships made as parents shared the joys and sorrows of their journeys. More recently the organisation had won the Diversity Champion Award 2016 which was in recognition of the quality of care and support offered to children and young people.

The leadership team promoted a culture of caring and keeping children, young people and their families at the heart of the services by creatively exploring ways of involving them in the services offered. This included siblings having their own forum, magazine and a bereavement group. A member from the family support team spoke about the on-going support offered to bereaved families and the contact maintained if this was what the family wanted and for as long as they needed it. The positive outcomes from the bereavement group were varied. They included, supporting parents to tell their story in a safe environment and lessened the sense of isolation described by bereaved parents. We attended the post bereavement group meeting where the members of the team reviewed the last meeting with bereaved parents and prepared for the next meeting. We saw and heard how thoughtful consideration had led to some very personalised approaches being put into action by this team. For example, following each group meeting every parent received an individualised letter setting out what they spoke about or reflected on. In addition to this the team offered parents on-going support in their bereavement for three years which was another example of a caring organisation who were committed to offer individualised end of life services.

Children, young people and their families' privacy was promoted. We saw private and confidential information relating to the care and treatment of children and young people was kept secure. Children, young people and their families had access to private spaces within the hospice environment. Young people were able to use pendants so they could call for support when they needed this which helped to maintain both their independence and privacy. We saw this in practice as staff showed respect when one young person wanted time alone.

Is the service responsive?

Our findings

We heard from parents we spoke with how staff had gone the 'extra mile' and should 'polish their halo's daily' due to how they responded to the individual needs of not only the children and young people but their families as well. One parent told us, "Without the excellent support and advice from staff who understood the whole family's needs we would have struggled so much, we would not have been able to cope." Another parent said, "Having a much needed break is wonderful and they (staff) are so accommodating when I need some respite. They (staff) will always offer advice and support whenever we need it, which is so very valuable to us." A healthcare professional's comments were equally positive and they confirmed staff had been very accommodating and responsive to the needs of children, young people and families. They concluded that the 24 hour access to advice from the nurses and doctor who specialise in palliative care including the outreach services had supported better palliative care services.

There was a strong sense of partnership which had been developed and sustained over the years by the leadership and staff team working with children, young people, parents and external professionals. We saw this had been effective in responding to each child and young person's needs so these could be met with the best possible outcomes achieved. For example, one parent told us how staff had learnt from them the signs and symptoms of when their child could be experiencing pain and were always responsive in the actions they took if this was the case. Another parent said staff linked up with their child's school so their educational needs continued to be met alongside their goals and aspirations. This 'joined up' way of working had helped to achieve a personalised way of assessing each child and young person's needs to form the comprehensive care plans which we saw. These care plans held a variety of assessments which included the important home routines of each child and young person. One staff member told us, "Care plans are a very good source of information for all of us, especially when a child comes to us for the first time and/or when their needs change."

Staff attended daily group meetings (handovers) in which the medical, personal care and well-being of each child and young person was discussed. We attended one handover and found information was shared which included any changes to a child or young person's needs so staff were able to provide consistent and responsive care. One staff member told us how these meetings were an important part of sharing and gaining knowledge to inform their practices.

Parents we spoke with told us how important it was to them for their child to be able to have fun and share their interests with staff which had huge impacts on their quality of life and created special moments. We saw and heard how staff had worked hard with charities to achieve this. For example, one parent told us how a local rugby team had been involved in activities at the hospice and we saw signs of this displayed in the hospice environment. In addition to this their child spent time with their dad watching a rugby match described by the parent as, "[Child's name] dad's time." We also heard from parents how volunteer 'befrienders' had made a difference in supporting their children to have fun and interesting things to do, such as play on games consoles and talking with children about things which particularly interested them.

Parents consistently told us a great deal of thought had gone into the resources to provide opportunities for

fun and play for their child to make these personalised and responsive. This included having a variety of spaces within the hospice environment to make sure they responded to the different age groups. Parents we spoke with believed the hydro pool was a fantastic facility which the whole family could enjoy and was an excellent way of spending quality time together while having fun. Parents also appreciated the therapeutic benefits of their child being in water which included how it could relieve joint pains and help with moving limbs. There was also the sensory room with equipment and aids for each child and young person which could be controlled by children making noises or using switches or touch and light sensors. One parent described to us how this had real benefits in their child's sense of wellbeing.

We saw and heard from staff and parents how services which had been developed, supported and responded to the needs of children and young people when they stayed at the hospice and when they were at home. For example, one staff member told us how they were involved with a home extubation [when a child is taken off the ventilator] of a child who was in hospital and the parents wanted them to die at home. This was a great achievement as it provided parents with other choices around the preferred place of death of their child other than in a hospital or hospice.

In the PIR we were informed, 'When a child is staying at Acorns for end of life the care process is explained clearly to the family and child (if appropriate) with the nurse caring for the child, the GP and medical director. Families who require an interpreter will have the opportunity to use the interpreting services available to Acorns, so they have clear understanding of what is happening and the plans for their child. This service is available 24 hours.' We also saw and heard from staff who told us end of life care was individual to each child and young person to meet their cultural and religious needs. This approach enabled staff to respond to the cultural and religious customs of each child, young person and their families, such as any arrangements for the post care of a child's body.

The leadership team had taken note of best practice research and was enthusiastic about offering care in a personalised and responsive way. In the PIR it stated, 'Acorns has also developed an 'End of life policy and Rapid Discharge Process' whereby information can be sought quickly and ensuring all information gained. Outreach workers will also go out to the hospital or home to meet the family and child and discuss options.' We heard from staff how this worked in practice when responding 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 three Acorns hospices. We heard from professional staff had forged positive working in partnership relations with local hospitals. 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.

We heard about the exceptional support families received not only when their child stayed at the hospice but when at home. The community team is made up of experienced staff from health and social care fields who offered social, emotional and psychological support to the whole family which continued after the death of the child or young person. They also provided a 24 hours a day, 365 days a year service by having an on-call member of the team so a family's needs could be responded to. Staff members all had key roles which included, 'transition worker' and 'adolescent worker' in order to respond to the varying needs of children and young people.

Parents described to us how staff had been 'outstanding' in responding to the whole family's needs at times of transition for their children into adult services and school. One parent described this time as a "Scary" one but staff had made it less so in order for them to be able to voice the best possible outcomes for their child in regards to their future. Another parent said they were still meeting with the staff member who had supported them and felt they were, "Supporting me more than anything" which they really valued. We read

other positive examples of how the community team had responded to families which had significantly impacted on their emotional and psychological wellbeing. For example, for one young person staff believed due to the on-going support provided they had become more independent. This had supported the young person to take some control over their own decisions which would impact on them throughout their life.

We saw the leadership and staff team from the organisation's three hospice locations worked together for the sole purpose of ensuring children and young people's needs were responded to in the best possible way for them. We heard how each child and young person's care was centred on them and also took into account the whole family's needs. For example, one child who had been spending a lot of time at a children's hospital outside of the Worcester area was now receiving their care and treatment at another Acorns hospice which was nearer to the hospital.

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 if they ever needed to. One parent told us, "I have absolutely nothing to complain about but lots of compliments to give. I can't fault the care."

We saw that complaints that had been made had been appropriately investigated and written feedback provided to the complainant. We saw there were arrangements in place for sharing complaints and developing actions. For example, we saw action had been taken in regards to the two complaints which had been made to reflect the lessons learnt to ensure improvements were made. We saw in the PIR and heard from parents we spoke with an extensive number of compliments had been received. These were helped to shape and develop the services in line with the positive feedback from children, young people, families and external professionals.

Is the service well-led?

Our findings

Parents, children and young people consistently made positive comments about the support they were offered from all the staff working across the different teams which had enhanced the care and treatment they received. One parent told us, "The services are fantastic and the staff are absolutely marvellous as they really do shine in all they do for us. We would have struggled so much without the support in the tough times they are always there." Another parent said, "When times are tough it means a lot to know there is Acorns with the staff who are absolutely amazing and totally know what they are doing. It says a lot about the management of an organisation." A further parent told us, "When I need a break there is always Acorns."

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. The registered manager was fully supported by the chief executive, director of care services, medical director and team leaders for the outreach and family support services. We found the registered manager showed they had an accountable and responsible leadership style. For example, they were responsive to the medicine issues we identified and improvements would be made.

There was a clear structure to the organisation with a board of trustees and layers of senior managers, managers, staff and support services. Staff spoken with liked working at the hospice and were motivated to provide a good standard of care to people. We saw many examples where staff worked as a team and communicated with each other and understood their roles and responsibilities. For example, we spoke with the manager of the sibling services and they showed they were passionate about the achievements made to support children and young people to direct and champion their own care and support. This included linking in with a theatre where families were involved in performances and were able to have 'whole family time out' and 'make memories.' The theatre staff were also able to gain experiences of children and young people living with life threatening and life limiting conditions. This was one example but we consistently heard from staff how proud they were of the high standards of care, treatment and support they provided. They all had a sense of how they could contribute to the overall care of children, young people and family's and were "Proud" of the work they did.

We saw and heard how the leadership team showed they valued their staff teams and helped them to learn, develop and share best practices within palliative and end of life care for children and young people. This was confirmed by staff and volunteers spoken with as they enjoyed their work, wanted to continue to strive to do better and shared examples with us of how they felt valued. Another example was the experiences staff gained from students spending time at the hospice. We spoke with a student nurse who told us they had received a very good induction to the hospice and had worked mostly with their mentor. They told us, "I was made to feel part of the team" and very well supported by the whole team, their mentor and the lead for education. They said there was a caring and homely element to the hospice environment and 'children were treated as part of the family and with respect as are the staff.' They also felt the palliative care offered was person and family centred and fun.

The organisation's vision, mission and values emphasised the strength of the feelings of the leadership and

staff teams who we spoke with during our inspection. The vision was, 'Every child and young person living in our region that is life limited or life threatened and their families should receive the specialist care and support they need.' We heard from a healthcare professional how families were provided with a quality service after the death of their children which reflected the organisations vision. The healthcare professional confirmed children and families who lived in another area were able to benefit from using the 'special bedrooms' at the hospice and families were able stay in the flat so they could be close to their children. We also saw information was available to people on the organisations website about the services offered. This included video presentations delivered by parents and children informing the public about their experiences and the value of the services provided. Regular newsletters were also published updating families on all events. These examples showed the leadership team across the three hospices had a variety of ways of reaching families who might benefit from their services to ensure no family would be discriminated against.

Parents we spoke with consistently told us how the staff had great knowledge and experience about the added impact for their child in having palliative and end of life care needs. One parent told us how the staff's knowledge and skills were, "Exemplary" and they, "Really know their stuff." We saw how the leadership and staff team used their knowledge and experience to influence and share best practice with health and social care providers and professionals to promote good practice through presenting training and learning events. We saw the feedback from these events had been reviewed and comments from attending professionals showed they valued the work and expertise of the staff team. One comment read, 'I think the support offered by Acorns is fantastic and invaluable to families and children in this area, especially the variety of support offered for the entire family.'

We saw and heard how children, young people and families influenced and shaped the services which were offered. For example, the development of roles and groups to encourage and support families to access services, such as the 'Asian Mothers' Support Group' and 'Asian Liaison Officer.' Staff told us this initiative offered support to families where English was not their first language and had responded to parents' feelings of isolation. These initiatives had been sustained over a significant period of time and they had grown in the amount of families supported to which reflected how successful this initiative had been.

We saw and heard about the strong emphasis on keeping children, young people and families at the heart of all the services by involving them in a variety of roles within the services offered. For example, young ambassadors (children and young people) and parent/carer champions were involved in public presentations and the providers' monitoring visits. We saw how a visit to the hospice to look at the quality of care had involved a young ambassador to ensure palliative and end of life services offered were developed and improved with the inclusion of people who had first-hand experience of using these. We also heard and read how the leadership team were also considering adopting the practice of using 'experts by experience' when undertaking visits to look at the quality of care by finding further methods of capturing experiences of children, young people and families.

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 leadership team used feedback to improve their services and we saw planning ahead was in place for the next five years to ensure the hospice services developed to meet the needs of people in the community and improved services for the future. This included consultation with children, young people, families, staff, volunteers and other professionals so services remained relevant to everyone who used them.

We saw and heard from the leadership team how they had incorporated research and evaluated different organisations best practices for children and young people with life threatening and life limiting conditions.

For example, the standards framework from the charity 'Together for short lives.' These standards were used by the leadership to benchmark their services by to ensure they were up to date with best practices in order to guide and inform their work. Parents we spoke with all believed the services they received had made a significant impact on their lives as a family and that of their child. One parent said, 'Without the support from understanding and caring staff the journey would have been so tough. We know they are always there to help you to cope.' Another parent told us, "The value of this service means even in my darkest times I know Acorns will be there to support us all."