

Haven House Foundation

# Haven House Children's Hospice

## Inspection report

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## Ratings

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

# Summary of findings

## Overall summary

This inspection took place on 31 August and 1 September 2016 and was announced. The service was last inspected on 11 December 2013 and at that time was meeting all the regulations we looked at.

Haven House Children's Hospice provides overnight respite care for up to five children and young people aged from birth to 19 years who may have complex needs associated with life-limiting or life-threatening conditions. They also provide some day care. Haven House will accept initial referrals from anyone in the community who knows a child with a life limiting condition or complex health conditions which are likely to shorten their life.

Haven House offers a multi-professional approach to the health, social care and education of children who attend the service. At time of our inspection, they provided respite support to approximately 100 children and their families, the majority of whom received up to 20 days of care yearly. Parents were able to negotiate with Haven House about the most suitable and convenient time for their child to receive support. This could be provided as half days, overnights and in some situations blocks of time to allow parents time to have a holiday or visit family abroad.

In addition to the respite care offered to children at Haven House, there was support for parents and siblings. This support ranged from a specialist toy loan library, complimentary therapies for adults including Reflexology and Rejuvenessence (head and facial massage designed to help relaxation), the Butterfly suite used as accommodation for children which allows parents to stay in adjacent accommodation so their can be near their children, a bereavement team and an expert parent programme designed to give training and confidence to parents caring for their children.

There were also a number of services being developed to support families. The 'Hospice at Home' service has recently been registered with CQC with the aim of providing families with choices when their child was nearing the end of their life and they wish them to die with them at home. Additionally, Haven House had also employed a neonatal nurse to support babies with complex needs associated with their conditions.

The service had a registered manager in post. A registered manager is a person who has registered with the Care Quality Commission (CQC) to manage the service. Like registered providers, they are 'registered persons'. Registered persons have a legal responsibility for meeting the requirements in the Health and Social Care Act and associated Regulations about how the service is run.

Staff, volunteers and trustees all held a shared vision to provide high quality care for children and young people with life limiting conditions. In order to achieve this staff were highly trained and supported to undertake their roles.

Care that was offered to children and young people was personalised and reflected their needs. Care plans were comprehensive and constantly reviewed so they were up to date. Practical and emotional support was

provided to children and their families throughout their contact with Haven House, this included after the death of a child.

Children and young people had their health care needs met by professionals within Haven House and by community health and social care professionals. There was evidence professionals worked with each other in the interests of the child. The provider met the nutritional needs of children and young people and ensured they received their medicines as prescribed. There were appropriate infection control measures in place.

Staff used a number of communication methods to seek consent from children and young people. Where this was not possible, measures were in place to make sure their rights were protected and decisions about their care and treatment made in their best interests.

Parents told us they felt their children were safe at Haven House. Staff knew what action to take if they consider any young person was at risk of harm. There were a number of checks in place to make sure only suitable staff and volunteers were recruited. Staffing levels were sufficient to meet children's needs.

The care that was provided was characterized by compassion and warmth. Staff were knowledgeable about the children they were caring for and ensured the care maintained the child's privacy and dignity. Haven House were mindful of the different spiritual and cultural needs of people, and these could be accommodated during the provision of care and after a child's death.

Haven House had a commitment to providing high quality care. There were a number of measures in place to actively seek parents' views and to act on comments and suggestions made. In addition, there were internal measures to monitor and audit the service, to learn from any incidents and accidents and to anticipate any future difficulties and take action to minimise them.

Senior managers provided strong leadership. Staff and parents were positive about the role of senior managers and how they were open and approachable. Senior managers were constantly monitoring the service and considering ways it could be improved for the existing children and young people who used the service, but also ways they could support more children in the community.

## The five questions we ask about services and what we found

We always ask the following five questions of services.

### Is the service safe?

The service was safe. Parents were confident and positive about the service and felt their children were safe at Haven House. Staff, volunteers and trustees had undertaken training to ensure they could keep children and young people safe. They were knowledgeable about what they should do if they suspected children were at risk from harm. The provider had undertaken appropriate checks to make sure only suitable people had contact with children.

Staffing levels met the needs of children and young people using the service. They were constantly under review to make sure they met the needs of the changing population of children receiving respite care.

There were procedures in place to ensure the safe storage and administration of medicines. Nurses continued competency to administer medicines was regularly reviewed. The home was clean and hygienic.

Risk assessments were in place for each child and young person receiving a service. These were comprehensive and reviewed regularly to make sure they continued to be appropriate.

Good 

### Is the service effective?

The service was effective. Personnel throughout the organisation had received comprehensive training. Specialist training was also available to staff to enhance their knowledge and understanding of specific areas.

Staff were able to access support for themselves through their line managers, peers and external bodies. This meant they were better able to support the families they worked with.

The provider tried to ascertain the views of children and young people. If this was not possible there were safeguards in place to make sure their rights were protected.

Children and young people had their health needs met by staff or community healthcare professionals. This included good nutrition and hydration.

Good 

### Is the service caring?

Good ●

The service was caring. People told us staff were warm and compassionate. We saw staff provided care to ensure children and young people had privacy when receiving personal care.

The needs of the whole family were considered by Haven House both whilst the child received respite and when they moved into adulthood. There were also services available if a child or young person died.

There were a number of measures in place to make sure a child's death was managed in as dignified a way as possible and in line with the parents and young person's wishes. A bereavement team were available to offer emotional and practical support after the death of a child.

### Is the service responsive?

Good ●

The service was responsive. Assessments of children's needs new to the service were comprehensive. Care plans were personalised and written specifically for each child. The care plans were reviewed regularly to ensure they met the child's needs.

Staff were knowledgeable about the children at Haven House. This meant the care provided was in line with the needs of the child or young person.

The service encouraged people to comment or complain about the care provided. In this way they were continually monitoring the service and trying to drive improvements.

### Is the service well-led?

Good ●

The service was well-led. People were positive about senior managers within the service.

Staff, volunteers and trustees had a shared vision of the service and were committed to providing high quality care.

There were a number audits and processes in place to review the service. Staff and parents views were continually sought to try and make improvements in the service.

# Haven House Children's Hospice

## **Detailed findings**

### Background to this inspection

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

This inspection took place on 31 August and 1 September 2016 and was announced. We gave the provider 48 working hours' notice of the inspection. We did this because we wanted to be sure there would be children for us to meet during the summer holidays. We also needed to be sure senior managers and staff would be available to speak with us on the day of our inspection. The inspection team consisted of a lead inspector and a specialist GP advisor. Our specialist advisor had experience of palliative and paediatric care.

Prior to the inspection we reviewed the information we held about the service, including the statutory notifications we had received. Statutory notifications are what the provider has to send to the CQC about significant events that occur at the service. We also reviewed the information included in the 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 looked at the Annual Quality Accounts which services' commissioned by the NHS are required to complete which gives information about the quality of the service.

On the day of the inspection, we spoke with two parents of children using the service. This was because in general children were not able to verbally communicate with us and we were therefore reliant on families to tell us what they thought of the service. We used the Short Observational Framework for Inspection (SOFI). SOFI is a specific way of observing care to help us understand the experience of people who cannot talk with us.

We spoke with a 13 members of staff, which included registered nurses, care assistants, a music therapist, the facilities manager, the registered manager, and the Chief Executive Officer. We looked at care records for four children including their medicines records. We also looked at records for five members of staff including two volunteers. We were also supplied with and requested additional information about the running and governance of the service. We attended a multi-professional meeting to consider new referrals to the service.

The following day over the telephone we had contact with a further seven parents and one young person who receives a service from Haven House. We also had additional feedback from four representatives from the local Clinical Commissioning Group (CCG) including a safeguarding lead and a paediatric dietitian.

## Is the service safe?

### Our findings

We received many positive comments from parents about the service their children received from Haven House. One parent told us, "Staff are lovely. Took me a long time, but now I've got complete confidence in them." Someone else said "100% needs are taken into account, I feel he's really well looked after." Another parent summed the comments when they stated, "We love this place."

Parents told us they had confidence in the care provided and felt their children were safe from harm and abuse in the care of staff. One parent said, "When I leave my daughter here, I feel she is in safe hands" and another said, "I feel he's really well looked after."

The provider had taken steps to ensure children and young people were as far as possible, protected from harm. All staff and volunteers received safeguarding children and young people at risk training which was refreshed regularly. Staff and volunteers had completed safeguarding training dependent upon their roles and responsibility ranging between Level 1 to 4. This is nationally recognised stages of training with Level 1 being a basic course to raise awareness and Level 4 being able to undertake investigations of abuse, if necessary.

Staff we spoke with were knowledgeable about the types of possible abuse and what action they were required to take if they thought anyone was at risk of harm. Haven House had a designated safeguarding children's lead trained to Level 4. The designated safeguarding lead also had close links with the local authority so they were up to date with current practice.

We saw there were guidelines for staff and volunteers for safeguarding children at risk and whistle-blowing policy and procedures. Haven House had also produced a one page summary for staff and volunteers. It was a step by step guide telling them what they were required to do if they suspected children or young people were at risk of harm. This summary was accessible and displayed throughout the home for ease of reference.

We checked Haven Houses' recruitment processes to make sure they were thorough and that only suitable staff or volunteers were employed. The staff and volunteer files we looked at all contained an application form, notes from interview, proof of identity and references from previous employers. There were also Disclosure and Barring Service (DBS) checks. We noted DBS checks were renewed every three years in line with best practice. There were also additional checks for nurses with the Nursing and Midwifery Council (NMC) to ensure they were suitable to practice.

We noted Haven House as a charity had a board of trustees responsible for the running and management of the hospice. As the trustees may have some direct contact with children and young people, they had also received regular safeguarding children at risk training and been DBS checked.

From observations we saw there were enough staff to meet children and young people's needs. The staff included a skill mix which included nurses, healthcare assistants and a play co-ordinator. There were



additional support staff available which included the registered manager and educational lead. We checked the staff rota from a number of weeks and saw the level of staffing was maintained although the skill mix was sometimes altered due to the needs of the children and young people receiving respite care. For example, there were occasions when the nursing level was increased if the needs of the children required more clinical interventions. The registered manager told us about high staff turnover approximately 18 months ago, although they had always managed to recruit to vacant posts. We were told if there were shortfalls in the staff rota, they used either their own staff or bank staff. Only in rare circumstances did they use agency staff. In this way, children and young people were cared for by staff that were familiar to them, this was particularly important when providing personal care.

Medicines were managed safely. We saw medicines were stored in locked cupboards in bedrooms. Controlled drugs were stored in a separate room which was locked when not in use. We saw there was a log specifically for the administration of controlled drugs, in line with pharmaceutical guidelines which recorded the usage of these medicines. There was a policy for the administration of medicines which was strictly adhered to. These included trained nurses only administering medicines, with their continued suitability and competence to administer regularly reviewed by their managers.

We observed the administration and recording of medicines and found it was completed in line with the hospice's policies. Our checks of stocks of medicines confirmed these had been given as prescribed. Haven House had previously identified a number of medicines errors which were attributed to the community pharmacist. Haven House had subsequently changed the community pharmacist supplying to them, and the number of errors had fallen. The provider had protocols in place to ensure the safe disposal of medicines either on site or by arrangements with the local pharmacist.

The hospice was clean and hygienic throughout. We saw there were a number of infection control measures in place. This had included regular audits to ensure staff were following proper infection control protocols. For example there had been a recent hand washing audit in July which had identified some areas for improvement and action had been taken. The cleanliness of the building was also reviewed and we saw evidence of regular deep cleaning of the premises. The provider used an independent infection control advisor to maintain high standards and make sure the service was up to date with current best practise.

For each young person we saw there were a number of risk assessments in place, aimed at identifying and reducing potential risks. Within each care plan we saw there was a potential 20 sections identifying the child or young person's needs. Each section contained sub-categories, for example, personal safety was divided into mobility, moving and handling and transfer, with each section assessed and given a numerical total and a rating based on a traffic light system. These risk assessments were reviewed regularly. In this way the provider was assessing current needs and delivering care on that basis.

The provider recorded all accidents, incidents and near misses and ensured action was taken to prevent reoccurrences. The managers reviewed all incidents immediately and put measures in place to prevent repeat incidents, such as changing care plans. The registered manager gave us an example of how a young person had almost missed their planned respite care as an email had not been printed out. Measures had been put in place to prevent this happening again. Incidents were reviewed quarterly by the trustees responsible for Clinical Governance.

## Is the service effective?

### Our findings

A parent told us, "[Staff] Know what they are doing, even if they're new and learning." Staff told us they were provided with the training they needed.

There was a comprehensive training and development prospectus for staff and volunteers. The provider had banded training specific to people's roles. For example, Band E referred to staff and volunteers who had no access to patient information but were still required to undertake eight courses including first aid and infection control. Staff in Band A were those who provided hands on clinical care and were required to undertake a total of 24 training courses. The developmental prospectus outlined the frequency training needed to be refreshed and this was monitored by line managers. Some of these courses were specific to roles such as bereavement training or specialist equipment training. The providers' training was further supported by Children's Hospices across London (CHaL) which is made up of six independent children's hospice charities who work and support each other. CHaL members combined to provide a shared induction programme for new staff and volunteers. In addition, Haven House employed a 'practice educator' whose role it was to provide much of the in-house training and to source external specialist courses for staff.

Staff were supported to undertake their roles and to consider their professional development. Staff received formal one to one sessions with their line managers on a monthly basis, this was confirmed by staff we spoke with. In addition, there were clinical supervision sessions every two months, quarterly team meetings and full organisational learning days three or four times a year. We were also told about the use of external counsellors who were available to staff and volunteers if they felt they required additional support outside the organisation. We spoke with a member of staff who had used this service, they told us it had been 'easily available and they had found it to be really beneficial.'

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. 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, hospices and hospitals are called the Deprivation of Liberty Safeguards (DoLS).

The MCA applies to people aged 16 and over who are unable to make all or some decisions for themselves. We checked whether the service was working within the principles of the MCA. Staff we talked with had all received MCA and DoLS training as part of their mandatory training, and were able to tell us how they supported young people to make decisions for themselves.

Staff and volunteers were aware about how to seek children and young people' views and consent about their care and when to involve parents in making decisions about the person's care and treatment. They used a range of communication methods to seek consent and to support the care provided to children and

young people. Staff were knowledgeable about how individual children communicated, this included non-verbal communication through body language and facial expressions. We also saw picture symbols used to show a child what activity was being planned next and their facial reaction carefully gauged to seek if they were happy with the activity or not. Staff told us about the use of Makaton and Picture Exchange Communication System (PECS), both of which are symbol based communication methods. A member of staff also told us about the increasing use of iPads for communication and how they had been "really, really effective" for one young person who they had previously found it difficult to communicate with.

Children and young people had their nutritional needs assessed prior to care being offered. This included information being gathered from appropriate healthcare professionals who knew them from the community or from hospitals. We received positive feedback from a community dietitian who said, "The staff are very helpful and approachable. They also take on recommendations and guidelines that are given." We saw that within care plans, there was a section that highlighted nutritional needs and outlined how to support children and young people. This included the seating position, equipment required and how fluid was to be given.

For those children and young people who were able to have food orally, there was sufficient choice and a list of likes and dislikes recorded for each child. An external catering company supplied Haven House with microwavable meals which catered for a variety of people's dietary needs including pureed or soft meals. The company was also able to cater for food based on religious requirements or preferences such as Halal meat or vegan meals. Some parents provided meals for their children to eat whilst receiving respite care and Haven House were easily able to accommodate this arrangement. Additionally, there was a kitchen for the use of parents to make meals and snacks for themselves if they were staying at Haven House for any period of time.

A number of children and young people received feeding through percutaneous endoscopic gastrostomy (PEG) feeding, which is a tube feeding directly into the stomach. Staff were well able to manage PEG feeding, although consideration was given to children and young people being given opportunities to taste food in their mouths, where it was considered safe to do so, in order for them to have the sensation of food.

Children and young people's health and social care needs were managed and supported by a range of staff. On site there were nurses, healthcare support workers, music and play therapists and physiotherapist. A consultant paediatrician from Great Ormond Street (GOS) also visited Haven House on a weekly basis. This meant Haven House staff were able to seek medical advice when necessary, but also children and young people under the care of GOS were able have any outpatients appointments locally.

Haven House provided a suitable and appropriate environment for children and young people. It was bright, child friendly and equipped with toys and activities suitable for children and young people. There was a sensory room which included projected animations on the floor which were interactive, as well as equipment for moving and handling such as hoists and specialist baths. Outside there was a sensory garden, swings, ground level trampoline and an adventure play area suitable for children in wheelchairs. For young people, a 'buddy hut' had recently been acquired which was equipped with computer games and various board games. There was also a cinema room with a large screen which could be adapted for films and DVD's.

## Is the service caring?

### Our findings

Parents were happy with the care provided by Haven House and this was reflected in the many positive comments we received from them. It included, "Everything is good about here, they really look after our daughter," "Staff are lovely and understanding and that's for me too," and "She [their daughter] loves this place and doesn't want to come with us when it's time to go."

The interactions we observed by staff and volunteers was characterised by a warm and caring approach. For example, we saw staff move a child from a chair to bed, this task was completed with patience and empathy and with staff constantly verbally reassuring the child in calm tones. Whilst the vast majority of interactions were caring we did see one interaction which was not very good. This happened as a young person was supported by two members of staff who swapped over part way through the young person eating their lunch. There was also a discussion between the two staff about whether the young person's pad was dry or not, close enough for the person to overhear. We discussed this with the registered manager who acknowledged this interaction could have been better and agreed to remind staff of their responsibilities. The registered manager also told us, they had already considered more protected mealtimes for children and young people so they were not disturbed whilst eating.

Parents were supported to be fully involved in the care of their children even whilst they were receiving respite care. We met with a parent who was dropping their child for day care; we noted some time was spent talking with staff about how care should be delivered by staff. We also met with another family who had chosen to spend the day with their child at Haven House. The parents we spoke with all said they were kept informed of any issues that arose with their child, and a parent over the telephone told us, "If there is anything at all, then they ring you up straight away."

Staff maintained privacy and dignity when providing personal care. We observed staff moving children into their bedrooms or a bathroom before providing personal care and ensuring doors were closed before they started. Staff and volunteers had a knowledge and understanding of the issues surrounding confidentiality and were able to tell us how it worked on a day to day basis. For example, the times they needed to share health information with other professionals.

Haven House offered support to the whole family, so they in turn were better able to care for their child. A parent summed it up when they told us, "They provide for parents as well." There were complimentary therapies including Reflexology and Rejuvenessence for parents, family days out designed for the whole family to attend and a sibling groups to provide fun and support. There was also a toy library which loans out specialist toys for children with complex needs.

When a child or young person is nearing the end of their life, Haven House are able to support parents and families so they feel less isolated. In a small number of situations this involves working with children and young people themselves about their wishes for their own deaths. The 'Butterfly suite' a bereavement suite adjacent to the family accommodation designed so that parents can be close to their child whilst still receiving support. A bereavement team offers support ranging from help with funeral arrangements to

counselling. Haven House also holds an annual memory day, which people chose to attend if they wished.

The provider is mindful of different faiths and customs and these can be accommodated. Staff and volunteers told us they had knowledge and experience of a range of religions. If unsure they were able to access information about practices and rites. There was also contact with various faith groups to continuously consider how care could be provided more appropriately. These measures ensured wishes for end of life care could be met. For example, staff knew for some religions it was important that a burial needed to happen soon after the death of child or young person, and they could work with funeral directors to ensure this happened.

Haven House provided a range of advice and information for parents and carers so they are better able to look after children and young people. There is an expert parent programme, designed to give parents the knowledge and confidence to care for their children. Haven House also arranges and hosts a series of workshops throughout the year regarding specific medical conditions. We saw there was a range of information available throughout the home and that the provider employs a family liaison worker who signposts parents to information that may be beneficial to them such as benefits advice and local resources.

## Is the service responsive?

### Our findings

A young person who uses Haven House told us how it met their needs, "I get to do a lot of artwork, whatever I want. They take me out, cinema, walk to the shops and get me take-aways."

Parents were also positive about the support provided to them, one said, "They listen to what you say, and they really do listen." Another parent told us about the confidence they had to leave their child with the service so they could spend valuable time with their other children who often missed out.

We attended a weekly multi-professional meeting where new referrals to the service were assessed and to determine the needs of the child or young person. Once established Haven House would be able to provide a service, a thorough and comprehensive assessment of the person's needs was undertaken which included information from parents, hospitals and schools. We saw each care plan was divided into 20 sections which covered physical, social and psychological support needs including for example breathing, play and end of life care. There were detailed instructions on how to care for children such as checking a child every fifteen minutes throughout the night.

Care was personalised to each child coming into the service. Bedrooms were adapted to suit the child receiving respite even for a short period. Additionally, given some children had significant disabilities, time was taken to establish their likes and dislikes based on the five senses, for example, smells the child liked and disliked, and noises that appeared to relax them. Care plans were regularly reviewed whenever an episode of respite care was to be offered, and parents were consulted about any changes.

We saw each child and young person had a named nurse who had specific responsibility for their care. Although we saw many examples where staff and volunteers were knowledgeable about children's needs and the level of support required. Regular meetings across the staff team ensured care was provided in line with current care needs and the entire staff team were aware of any changes.

The provider encouraged complaints and concerns to be raised so the quality of the service could be improved. Parents told us they felt comfortable raising issues and concerns with staff and felt they would be listened to and any complaints acted upon. A parent told us, "If we had a problem we'd talk to the manager, but really there isn't anything and there never has been." The service had devised a 'Tell us what you think' poster which encouraged people to contact the registered manager with any issues, complaints or compliments. In addition, there was a comprehensive complaints policy which detailed the various stages of the complaints process. There was also a compliments and complaints log which summarised comments received, and if a complaint, what action had been taken to resolve the issue.

## Is the service well-led?

### Our findings

Families, staff and outside professionals were all extremely positive about Haven House and the way it was managed. A member of staff described the registered manager as "an inspirational leader, who is also prepared to spend time on the shop floor." A local authority commissioner we spoke with said "We have a very positive and collaborative approach with Haven House," and "Feedback from frontline staff is again that Haven House is supportive and proactive."

The provider had a clear management structure with a Chief Executive Officer (CEO) based on site. We received positive comments about the CEO who was described as someone 'who took the time to listen and take steps to improve things.' There was also a Board of Trustees who were experienced, visible and supportive in their role. Haven House told us about a staff survey undertaken on behalf of Hospice UK during summer 2016. We were shown a copy of the report which highlighted high figures for communication between staff and senior management and, confidence in the management team and trustee board compared with other similar organisations.

Staff, managers and trustees worked towards a shared vision of providing the best care they could for children and young people with life limiting conditions. A member of staff summed up their view when they said "100% supported. We are all doing very different roles but focussed on one aim." We spoke with a range of staff throughout the organisation who understood their roles, responsibilities and accountability, although none were rigid and prepared to work together in the interests of children and young people. The registered manager said trustees also attended some of the organisational learning days, in this way the provider was maintaining a cohesive vision for the whole organisation.

Haven House were constantly monitoring the quality of the service children and young people received, this was established through a range of quality assurance measures. They had an audit sheet which identified staff responsible for aspects of care such as medicines management, infection control and mental capacity assessments. It also included the date the audit had been completed and when the results had been presented to the clinical governance trustee meeting. This rolling programme of audits ensured senior managers were aware of any issues and action could be taken to minimise potential risks. Haven House also had a clinical risk register, which considered possible risks to the service and measures to mitigate against the risk. For example, the possibility of insufficient staff to lead shifts which had resulted in the recruitment of additional staff and increasing the number of bank staff.

The provider was encouraging parents to continually comment on their views of the service and how it could be improved. This was achieved by using an iPad and encouraging parents to complete a short survey after every episode of respite provided. There was also a comment box for additional feedback. This type of survey allowed for rolling and continuous feed-back. For example, we were shown some of the feed-back received between June and September 2016 with a total of 43 respondents with 33 strongly agreeing and 10 agreeing 'that they were satisfied with the care their child received' and comments included, "Keep doing what you are doing," and "Very happy, first visit was brilliant."

Senior managers also employed a variety of other methods to ascertain the views of parents. This had included for example, attending various social events with slots to 'meet the CEO or manager' and there were posters which described requests from parents and action the service had taken in response. A parent told us, "They're pretty good, we asked for water coolers and they arrived pretty quickly."

Haven House has made links with the local community. They had employed a 'transitions' nurse, whose main responsibility was to assist young people from the age of 14 into adult services. The registered manager told us they offered support to families whose children died unexpectedly in the community. In particular the bereavement team had offered support, even if the children have not been known to the service previously. The provider was also in the process of developing a 'Hospice to Home' project. They had already registered with CQC to provide this type of service for parents who wished their child to die at home.

Additionally the provider worked with CHaL to share knowledge, experiences and resources across children's hospices in London. There was also close links and contacts with children's schools and the CCG's when appropriate. In this way the provider was ensuring all agencies working with a child or young person were working together in their best interests.