

Noah's Ark - The Children's Hospice

Noah's Ark Children's Hospice

Inspection report

3 Beauchamp Court
10 Victors Way
Barnet
EN5 5TZ

Tel: 02084498877
Website: www.noahsarkhospice.org.uk

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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 6 and 7 December 2016 and was announced. We last inspected this service on 4 December 2013 when it met all the regulations we looked at.

Noah's Ark Children's Hospice is a charity that offers support to children and young people who have a life-limiting or life threatening illness. They operate in the five North London boroughs of Barnet, Camden, Enfield, Haringey and Islington, and also in Hertsmere, a borough council in Hertfordshire.

Noah's Ark provides care for the children and young people affected by illness. This support is community based and is provided by a range of staff including family link workers, social workers, music drama and movement therapist, play workers and home support volunteers, through support groups such as sibling groups and parent groups. There are also over 70 care volunteers who support children in their own homes or through group activities. Overall 450 volunteers support Noah's Ark providing support for administration, retail and fundraising.

Noah's Ark also offers specialist carers who are able to provide direct care to children and young people. They also employ paediatric nurses who support and train the specialist carers. This is the part of the service which is regulated by the Care Quality Commission (CQC). At the time of the inspection they were providing specialist care to approximately 80 children and young people, whilst supporting an additional 150 children and young people with services not regulated by CQC, and a further 180 bereaved families.

Currently the service is community based. However, there are well progressed plans to continue raising funds and start building a hospice which will house the community teams and a small residential unit to provide end of life care for children and young people who might require this service.

Anyone in the community is able to refer themselves or any child or young person under the age of 19 to the service. Noah's Ark can provide tailored care which includes medical, emotional and practical care. They provide an out of hours on-call service to families and their staff so they can be accessed in an emergency.

The service had a registered manager in post who was the Director of Care. 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.

Parents were positive about the support they received from Noah's Ark, this was in terms of the direct support for their children and for the support provided to the entire family which alleviated pressure on them.

Staff were trained to provide end of life care to children and young people in line with their wishes and those of the family. The service was able to offer bereavement support to parents after the death of a child.

The provider completed a range of checks prior to recruitment of volunteers, staff and trustees to make sure they were suitable to work with children and young people. There were policies and procedures in place to make sure children and young people were kept safe. The service had a designated lead for safeguarding children at risk. Staff we spoke with knew what action they needed to take to ensure children and young people were protected from harm.

Staff received an induction programme and subsequently, dependent upon their role, extensive training. They were also encouraged to source training they felt they required and to remain registered with their professional body. Staff told us they received support from their peers and managers through a variety of informal and formal mechanisms.

The needs of children and young people were constantly reviewed and care provided on that basis. Health needs were reviewed by the provider including making sure children received medicines in emergencies.

Parents told us the service was caring. They valued having the continuity and consistency of the same member of staff visiting them and knowing they could access advice if there was an emergency.

Staff were able to tell us how they ensured children and young people were provided with dignified care. They were also able to tell us about maintaining confidentiality and the circumstances of when information had to be shared for the well-being of the children and young people they were working with.

Care was personalised and reflected each child's and young person's diverse and changing needs. Plans for care showed how children and young people were engaged in a range of activities at home and in the community, and ways their independence could be promoted.

Staff received training and were aware of the issues relating to the Mental Capacity Act 2005. There were mechanisms in place to ensure care was provided with the consent and agreement of either the parents and/or the young people themselves.

Senior managers within the organisation had an open and inclusive approach. They welcomed challenges from their staff team and trustees. Parents were asked for their feedback about the service and they told us they felt able to raise issues or concerns. There was a rolling programme of audits to monitor the quality of the service. Any incidents and accidents were reviewed to consider any learning or changes that needed to take place to improve the service.

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. The provider had undertaken recruitment checks of people applying to work at the service to ensure only those suitable were employed. People knew how to make sure children and young people who used the service were kept safe, and what action to take if they were concerned.

Staffing levels were determined by the level of care and support the children, young people or their families required.. This helped to ensure families received the level of support they required when they were in greatest need.

The provider made sure there were systems in place to manage children's medicines in an emergency and to prevent risks associated with cross infection.

The provider had arrangements to identify potential risks to people and put measures in place to mitigate against the risks.

Good 

Is the service effective?

The service was effective. Staff had an intensive induction period and received regular training. There were a number of measures in place so staff felt supported in their roles.

Staff were aware of the Mental Capacity Act 2005 and how it may impact on their work. Staff sought consent from children, young people or their families before providing care.

The provider worked with other healthcare professionals to ensure the needs of children and young people were effectively met.

Good 

Is the service caring?

The service was caring. Parents told us staff were caring, they particularly valued the support the service provided to the whole family.

Regular staff meant children and young people received care

Good 

that was consistent. Staff were able to promote the young person's independence.

The service was able to provide compassionate end of life care, which took account of families' diverse needs.

Is the service responsive?

Good ●

The service was responsive. The provider ensured that the needs of children and young people were comprehensively and continually assessed so their current needs were being met.

Activities were arranged for children, young people, siblings and parents to help reduce social isolation.

Parents told us they knew how to make a complaint and the service used learning from complaints to help improve the overall quality of the service.

Is the service well-led?

Good ●

The service was well-led. There was a clear management structure in place and the provider created an open and transparent culture within the service so staff, people using the service, relatives and others could express their views about the service.

Accidents and incidents were monitored and there was a rolling programme of checks and audits to help improve the overall quality of the service.

The provider actively sought feedback from children, young people, parents and from other stakeholders to help them understand the quality of the service being delivered.

Noah's Ark 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 6 and 7 December 2016 and was announced. We gave the provider 48 hours' notice of the inspection as the service is community based and we needed to be sure staff would be available to speak with us. The inspection team consisted of a lead inspector and a specialist advisor. Our specialist advisor had experience of palliative and paediatric care.

Prior to the inspection we looked at 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 considered the information included in the provider information return (PIR) which was completed comprehensively. 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.

During our inspection we spoke with eight members of staff which included nurses, activities co-ordinator, a specialist care worker, a social worker and the registered manager. We accompanied a social worker on one of their visits and were able to directly talk to a parent about their views of the service. We attended a 'Pathway' meeting which was a multi-disciplinary meeting to review care plans, reflect on complex cases and deliver group supervision.

We looked at records relating to the running of the service and its governance arrangements. We also looked at computer and paper records relating to six children or young people who used the service. We reviewed staff recruitment and training records for eight members of staff, which included records for volunteers and information held about the trustees.

After the inspection we talked over the telephone with seven parents of children who receive a service from Noah's Ark.

Is the service safe?

Our findings

Parents consistently told us how much their children enjoyed receiving a service from Noah's Ark. This included "She [their daughter] beams when the carer comes in," and from a parent whose child uses Eye Gaze (communication tool for the young person) saying how the child had said how much "she loved the carer." Parents told us they were comfortable leaving their children with staff from Noah's Ark and one parent said, "They [staff] know what they are doing and really keep up to speed with what my daughter needs."

We checked the provider's recruitment processes to make sure only suitable staff, including volunteers were employed by the service. The files we looked at contained completed application forms, proof of identity and address, two references and criminal records checks which were renewed every three years, in line with good practice recommendations. Additionally we saw checks with professional bodies such as the Nursing and Midwifery Council and the Health and Care Professionals Council were undertaken and staff were encouraged to remain registered with their professional body to ensure their continued suitability to practice.

As a charity we noted Noah's Ark had a board of trustees who were responsible for the management of the service. The registered manager told us they had a policy of chaperoning trustees whenever there were events that children and young people attended. Additionally the service had completed criminal records checks and taken up references for all trustees. This was following a recent organisational review of the service which highlighted some areas for improvement. The organisational review was initiated by the Senior Management team of the service and was undertaken by an external consultant.

The provider took measures to protect children and young people from the risk of harm. There were safeguarding policies and procedures in place which guided staff through the processes. Also staff had access to support via a 24 hour on call system if they were concerned about the welfare of children or young people. The service had a designated safeguarding lead that attended additional training and was a member of the Barnet Safeguarding Children Health Group which had links with the local safeguarding board which help to ensure the service was up to date with current and best practice.

Staff we spoke with knew what responsibilities they had to safeguard children and young people. They told us they received regular training which was refreshed annually. We checked training records and saw everyone within the organisation had at least completed a basic safeguarding course, including administrative staff, trustees and volunteers. The provider had also used an audit framework from the Children Act 2004 to ensure they had measures in place to promote and safeguard the welfare of children.

We saw the provider did not maintain a waiting list. Instead children' and young people's needs were constantly reassessed and each individual was given a priority status. In this way, the provider was using their staffing establishment to maximise support for children and young people in the greatest need. Parents said they were aware of this system of priority rating and knew if the service was temporarily removed it was because another family was in crisis.

Medicines were managed safely, although in general the staff did not prescribe or administer medicines. Instead children and young people received their medicines from their GP or hospital consultant. Staff would only assist parents to administer medicines in emergencies. We saw there were clear written guidelines in place for administration. In addition, we saw there was an 'emergency medication administration risk assessment' for each child or young person. The competency of staff to administer medicines was checked annually by the Registered Nurses (RN's) who worked for Noah's Ark. We discussed with the registered manager how the competencies of RN's were checked. The registered manager told us nurses accessed external training and competence assessments. In addition, there were discussions with Children's Hospices across London (CHaL), to consider a shared system to check RNs' competencies across the services.

There were adequate infection control measures in place to minimise the risks to people. Staff had all received training regarding infection control and this was refreshed regularly. We were shown a Noah's Ark red rucksack which staff took with them on visits in the community. The rucksack contained infection prevention and control equipment such as gloves, aprons and sanitising gel. Staff told us they could easily obtain additional items when necessary.

The provider had systems in place to identify and manage possible risks to people using the service, staff and others. Each potential risk was assessed and reviewed regularly and measures were put in place which outlined the action required to minimise the risk. For example, plans were in place to manage risks associated with a gastrostomy tube (way of feeding through a tube inserted directly into the stomach) or the use of two members of staff for moving and handling to ensure the task was completed safely. Information pertaining to risks was rated before and after a change of management plans to assess if the plans were effective. In this way the risk of reoccurrence was minimised.

Is the service effective?

Our findings

Staff received the training they needed to undertake their role. One member of staff told us, "If you're unsure about something you can request training or source it yourself and they will arrange it for you." We spoke with two new members of staff who told us about their induction into their new roles. This had included training with other new staff from CHaL, accompanying staff in their different roles, shadowing more experienced workers and being introduced to the policies, procedures and systems of the organisation.

The provider had identified mandatory training for all staff which included first aid, fire training and moving and handling. Additional training was provided to staff dependent upon their role within the organisation, for example, seizure management and tissue viability were offered to clinical staff, whilst an additional course, symptoms management, was offered to RN's. The provider kept a record of all the training undertaken and ensured staff received regular updates so care was provided in line with current and best practice.

Staff were positive about the support they received from their team and senior managers. A member of staff said, "Really look after each other, very supportive of each other, everyone is so approachable." Another new staff member told us their manager was always available to them, "but I feel comfortable talking to others in the team." In addition to the informal support there was a range of other meetings that staff could use to discuss issues of concern or for additional support. Staff had the opportunity to meet with their line manager on a one to one basis. At these meetings, there were regular discussions about the ongoing needs of the families they were working with, and the caseload of staff was adjusted accordingly. In this way the provider was ensuring their staff had their work reviewed and the support they needed to do their work effectively.

Staff also had access to an external counsellor if there were particularly issues they felt they were unable to discuss with their line manager. Additionally there were larger forums for staff to participate in. These included a 'Pathways' meeting which was a multi-disciplinary meeting and team meetings which were available to anyone in the wider organisation including volunteers and shop staff.

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

Whilst children and young people received support at home and were generally under 18 years old, they did not come under the remit of DoLS. However, we needed to check staff were still acting within the MCA framework. We saw staff had received training on the MCA during their induction period and were aware of its implications for children and young people. Staff told us they always tried to establish the young's

persons consent before providing any care. If children and young people were not able to give verbal consent, then their care plans described to staff how certain actions could be interpreted. For example, one care plan described how a child would put their hand over their mouth to indicate they were not hungry. Where appropriate, parents had also signed consent forms for their children to receive personal care from staff at Noah's Ark.

The provider supported children and young people with their communication needs and tried to ensure they understood the individual's communication methods to make sure care and support was provided according to their wishes, preferences and consent. Each individual's care plan had a section devoted to communication methods which recorded how the child or young person could most effectively make their needs known. For example, some used Makaton (a language programme using signs and symbols to help people to communicate), eye contact or yes/no buttons to make their needs known. Staff had received training in the various communication methods used by children and young people so they were able to understand what was being said to them.

The provider worked with healthcare professionals in order to achieve the best outcomes for children. A community healthcare professional told us how the service worked well with them and were always prompt at making referrals when they considered it necessary. Noah's Ark kept in regular contact with healthcare professionals particularly those who had lead responsibility in a child's life. As the needs of children and young people were changeable, the provider had a policy of updating themselves at least every three months by contacting lead professionals. We saw the service also maintained contact with specialists such as those working at Great Ormond Street so the service could best meet the needs of children and young people.

The nature of the service provided by Noah's Ark meant that staff did not usually become involved in ensuring children were supported to eat and drink sufficiently, as this was undertaken by their parents. However the service did ensure all care staff had the necessary knowledge and understanding about nutrition and food hygiene to support people with eating and drinking if this was necessary. Some staff were involved in gastrostomy feeding and were appropriately and regularly trained to maintain these skills. The service had responded to requests from families to consider 'blended diets' for children and worked with paediatricians to ensure this was done safely. Staff were alert to changes in children's and young people's welfare and if they had concerns they would raise these with the appropriate healthcare professionals.

Is the service caring?

Our findings

Parents were positive about the support they received from Noah's Ark. Some comments we received included, "Absolutely amazing. They are here when no one else is around", and "They are my support, they are my only family here." Other comments included, "Don't know how we would have coped without them" and "They are so, so good at what they do."

Additionally many parents stressed the positive impact that support from Noah's Ark had on the entire family. One parent told us, "They create a nice and relaxing environment for my whole family", and another said, "They understand my children and that indirectly helps me." Noah's Ark provided a range of services which were viewed positively by families, this included a parents' group which allowed parents to share experiences and a siblings group which gave brothers and sisters an opportunity to engage in social activities and understand they were not alone in their experiences. Noah's Ark were also able to offer transport to activities to increase participation and had advocated with external organisations in order to benefit children and young people, this had included negotiating the use of a hydrotherapy pool.

Staff we spoke with knew how to maintain a person's privacy and dignity. They were able to give us examples of making sure doors and curtains were closed prior to providing personal care and being mindful of the environment before asking a young person if they want to go to the toilet. In a further example, a member of staff said they always had an extra tee-shirt with them so they could change, as some young people did not want to be associated with the logo shirts of Noah's Ark and being out in the community with a member of staff rather than a family member. We also discussed issues of confidentiality with staff and they were able to tell us what it meant and the times when they would not be able to keep certain information confidential such as when they needed to ensure a child's or young person's safety.

Noah's Ark linked families to a member of staff who was their primary care worker, this meant children and young people had consistency and continuity. Parents viewed this as crucial as it was someone who understood their child and how their needs could be best met. Families were introduced to a number of staff, so if workers were unavailable due to leave or sickness, there was always someone who the child was familiar with.

The service considered children's and young people's differences when providing care. Staff received nationally accredited online training as well as CHaL training regarding diversity and differing attitudes to death. Staff were able to tell us about the different cultural and religious needs of young people and the contact they had with faith leaders in the local community. In this way the service was able to provide care that was respectful of the child's and family's needs.

Noah's Ark provided an out of hour's on-call service was available to parents and staff. The on-call service was operated by members of staff on a rota basis. Parents we spoke with said it was 'reassuring to know they could contact someone in an emergency'. Staff also told us they found it invaluable particularly as senior staff could remotely access computer records held for each child and young person so any information they required was readily available.

Children and young people were encouraged to mobilise, develop their motor skills and become as independent as possible. We heard an example where the music therapist employed by the service was working with a young person. During the music sessions, the young person had progressed from using one hand, to using both hands and then their fingers to play the piano. In another example, we heard how the service had worked with a school in encouraging a young person to walk.

If relevant, children and young people were involved in their end of life care planning process. This was conducted sensitively and in a manner which took account of their age and level of understanding. The registered manager told us she had previously worked in children's palliative care and could support advance care planning with children, young people and families. All staff had completed loss and grief training which promoted effective communication before and after the death of a child. If required the care plans showed that advance care planning was put in place in line with the wishes of the young people, relatives and professionals. The service also ran a bereaved parents' group to provide continuing support to families, as well as support to any parents in the community who experienced the death of a child. They also ran memory days which families can choose to attend as a way of remembering their children.

Is the service responsive?

Our findings

We received many positive comments from parents about how the service responded to the needs of their children and their family. This included, "You have no idea, they are fantastic and go above and beyond" and "They understand my son and I'm so grateful."

The service had an open referral policy whereby anyone could refer themselves or others to Noah's Ark. Once a referral was made a named link worker completed an assessment, the first part of the assessment was in consultation with the family and considered what support might be offered to the young person and their family. This part of the assessment is undertaken by the Family Link Team who can signpost families to other services that Noah's Ark offer such as music, movement and drama therapy or play therapy. The second part determined the urgency of the referral. All children and young people were given a priority status which was reviewed following every visit or contact with the family.

We looked at assessment records for children's and young people's needs which were held in a paper and electronic format. We saw there was a comprehensive assessment which covered 17 aspects of care including moving and handling, communication and an overview of the young person's typical day. The information was specific and up to date for each child and young person. For example, a breathing care plan for a child stated "often sounds congested and the raspy noise is normal" but went on to highlight other indicators to look out for which were indicative of early warning signs of a possible deterioration of the child's condition. Another care plan, described the signs to observe if the child was in pain, and in the parents words, 'had a sour face', and the way to alleviate the pain and discomfort was to reposition the child and for the family to administer pain relief. There was also important information such as known allergies recorded and requests for gender specific care.

In addition to the comprehensive assessment, there was also a 'pen profile' which was a one page summary which included a photograph and gave staff key information about the young person and their needs. We saw information about young people was regularly updated as staff made use of computer tablets following every visit to record and upload new information on the person's electronic records. All care staff had access to this system which was secure and could be remotely accessed. In this way, all strands within the organisation could access key information instantly.

Noah's Ark offered children and their families a variety of ways to become engaged in community activities which may not be available to them otherwise. There were children's groups divided according to the child's age, ability and needs which gave children and young people time away from their families to help them build confidence and develop friendships independently. We were given an example of a young person, who with support had for the first time been able to shop, cook and wash up. They had gone on to develop a friendship with someone in the group who they now met up with independently. We also heard about a trip to the ice-skating rink which was thoroughly enjoyed by those that attended.

The service also offered a number of family days out during weekends and holidays. These days out were free with transport and volunteers arranged if necessary, and gave families an opportunity to meet with

each other in a social setting. All these groups were designed to help reduce social isolation and for children and young people to engage in activities they may not otherwise experience.

The provider was continually adapting the service they provided to children and young people so they could be responsive to needs. In one example, they had increased the number of children's groups. In a further example the Home Support Volunteer Service had supported a parent to attend a local toddlers group with their child by providing transport and by attending the group with them. In this way, the service was listening to the needs of families and changing their needs accordingly.

Noah's Ark had a complaints procedure which outlined in detail how to complain and how complaints would be dealt with and the timescales for each stage. Noah's Ark website also directed people to an abridged format of the complaints form. Parents we spoke with told us they knew how to make a complaint and felt they would be able to raise issues directly with staff. We saw the provider kept a log of the complaints received and the action taken to resolve the complaint. We noted the provider had received no complaints during 2016 thus far.

Is the service well-led?

Our findings

Noah's Ark had a clear management structure in place. As a charity, Noah's Ark had a board of trustees who were ultimately responsible for the governing and direction of the service. The trustees held a full board meeting every quarter and there were also sub committees covering areas such as care, finance and governance. The hospice had a 'parent forum' whereby parents have electronic access to trustees at any time and the opportunity to have face to face meetings with trustees throughout the year. In this way there was two way communications between those providing the service and those receiving support which helped to provide an effective service.

The day to day running of the service was undertaken by the director of care and the chief executive officer. Staff told us they and other managers within the service were open and inclusive. One member of staff told us, "It's an open door policy and we are encouraged to share." We heard managers effectively tell their staff team, "we are open to challenge". Managers are open to feedback which had included 360 degree appraisals (which solicits feedback from staff at different levels within the organisation) so they could make improvements to the way they managed their teams. The provider had also started to extend this value of openness to the parents of children who used the service, for example, they had parents on interview panel for new staff.

The provider had systems in place to monitor the quality of the service and make any necessary improvements. We were shown a schedule of audits undertaken in previous months and those planned for the future. For example, we saw there had been an audit of the information detailed in the nutritional plans for each child; an audit ensuring written consent for care was sought for young people over the age of 16 and an audit of medicines management. In addition, the provider considered national reports of findings that may be relevant, for example the operation of Kids Company, and any possible implications for the provision of the service at Noah's Ark.

We saw the provider had ensured staff recorded every incident, accident and near miss. Each incident was documented and outlined the issue. For example, a child being accompanied by an adult volunteer had missed their arranged transport after an activity day. The incident had prompted a change of protocol to ensure the risk of reoccurrence was minimised. Information gathered was regularly reported to the trustees and reviewed as part of their governance procedure.

People's views about the service and its future direction were continually sought. The provider had based plans for the further development of the hospice on the needs of the local population. We were provided with a report which outlined the strategic intent of the provider for the next three years. The registered manager told us about the 'Big Think' which was a questionnaire sent to parents and other interested stakeholders about their views of the design of the new hospice building.

There were many other ways in which feedback was sought from parents and young people using the service. Parents were asked to reflect on certain children's sessions before and after they took place, and also children were asked about their views through the 'crocodile group'. We discussed feedback

mechanisms with the registered manager who told us they were continually seeking different ways to gather information from children, young people and their parents who may find it difficult to communicate to them verbally.

Noah's Ark had developed links with their local and wider communities. There were approximately 70 care volunteers who support children and young people in the child's own home or through group activities. Overall Noah's Ark is supported by over 450 volunteers working in areas of administration, retail and fundraising. In addition, the provider worked with a number of universities to support student social workers and nurses on placement. They were also a member of CHaL who worked together to share training, resources and knowledge across London. In this way the provider was helping to develop a service that met the needs of the children and young people living in North London and ensured quality end of life care for people in this age group.