

## **Richard House Trust**

# Richard House Childrens Hospice

## **Inspection report**

Richard House Drive

Beckton London E16 3RG

Tel: 02075110222

Website: www.richardhouse.org.uk

Date of inspection visit:

01 June 2016 02 June 2016 08 June 2016 21 June 2016

Date of publication: 06 September 2016

#### Ratings

Overall rating for this service	Good •	
Is the service safe?	Requires Improvement	
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 1, 2, 8 and 21 June 2016 and was unannounced. The service was last inspected in February 2013 and at that time was meeting the regulations we looked at.

Richard House is an independent charity and provides specialist care for babies, children and young adults who have life-limiting, life-threatening or complex health conditions. In addition they provide a range of support services to parents, siblings and the wider family. This is provided through a 4 bed residential respite unit and a day play and activity unit. At the time of our inspection there were four children receiving respite care in the residential unit and approximately 350 children and young people were registered to use one or more of the services offered by Richard House.

The service had a registered manager. 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 and associated Regulations about how the service is run.

Children, young people and their families told us that Richard House was a happy place to be and that they enjoyed the time spent there. They and staff had fun together and there were lots of play and activities that were based on their preferences and needs.

Families told us staff understood their emotional needs and focused on their wellbeing as well as the wellbeing of their family member. There was a family support team which provided pre and post bereavement counselling for patients, friends and relatives. They also provided a children's counselling service if needed. There was a dedicated room where families could spend time with their loved one after they had passed away to privately say their goodbyes. This was available up until the time of the child's funeral if families wished it.

Although parts of the systems for ensuring children and young people's safety were robust others were not and this placed them at risk of not always being safely cared for.

The provider's recruitment process was robust and ensured that staff and volunteers were suitable to work with children and young people. Safeguards ensured that young people who were unable to make decisions about their care had their human rights protected.

Families were happy with the quality of food provided and their children's nutritional needs were met. However, although vegetarian meals were available halal meals were not and we have recommended that catering arrangements be reviewed to facilitate people receiving meals that meet both their preferences and their cultural and religious needs.

Staff were clear about their roles and responsibilities. Children and young people received care from a multi-

disciplinary staff team who received effective training and good support from the management team. A system of competency based assessments ensured staff had the required knowledge and skills to effectively meet the complex needs of those who used the service. The staff team worked closely with other professionals to ensure that children and young people were supported to receive the healthcare that they needed.

Children, young people, their families and staff were asked for their feedback about the service. There was a clear management structure and staff, children and young people and their families felt comfortable talking to the management team about any concerns. They felt that any issues or concerns they raised would be dealt with. The provider had a positive approach to using complaints to improve the quality of the service. Each complaint was investigated and, where necessary, appropriate action taken to improve the service provided.

Children and young people received a person centred, individualised service. They and their family members were consulted and involved in planning their care and supported to make decisions on how they were cared for and what they did.

The service was committed to deliver good care and to work collaboratively with partners to deliver and inspire better care for those affected by life limiting illness. Staff worked closely and in partnership with external health and social care professionals and other organisations to improve the service provided.

People's cultural and spiritual needs were respected and care and support was provided in line with their culture and traditions. Staff had received training and were aware of different religious and cultural practices and the chaplain told us that they could call on religious workers of different faiths for support when needed.

Systems were in place to ensure that children and young people received their prescribed medicines safely and appropriately. Medicines were administered by staff who were trained and competent to do this.

There were systems in place to monitor and improve of the quality of the service provided. Governance systems had been reviewed and strengthened to assist the service to achieve its aim of being a leading provider of children's palliative care services.

We found one breach of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. You can see what action we told the provider to take at the back of the full version of the report.

## 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 provided was not always adequately safe. Equipment used was safe but hot water temperatures were not checked to ensure that they were within a safe range other than as part of a 6 monthly service. Risk assessments and safety plans were not always individualised or sufficiently detailed and therefore did not adequately safeguard children and young people.

Staffing levels were based on individual's complex needs and enough staff were available to provide the support that children and young people needed.

Children and young people received their prescribed medicines safely and when they needed them.

The recruitment process was safe and effective. Staff and volunteers were appropriately checked to ensure that they were suitable to provide care and support to children and young people.

#### **Requires Improvement**



Good

#### Is the service effective?

The service was effective. Children and young people received support from a skilled, experienced and knowledgeable staff team. The team was able to meet their assessed needs, preferences and choices.

Staff competency was monitored and tested to ensure that they could provide the right care and support to meet the very complex needs of those who used the service.

Children, young people and their families were involved in making decisions about their treatment and care needs.

Safeguards were in place to ensure that young people who were unable to make decisions about their care had their human rights protected.

Children and young people's nutritional needs were met. This included those who were unable to receive their nutrition orally. However meals were not available to meet both their preferences and their cultural and religious needs.

Richard House staff worked with other healthcare professionals
to support children and young people to receive the healthcare
they needed.

#### Is the service caring?

Good



The service was caring. Children, young people and their families were treated with kindness and their privacy and dignity were respected.

Relatives valued and appreciated the support their whole family received from the different services offered by Richard House.

If wanted the family support team provided support and counselling to the whole family for up to two years after the loss of their child. This could continue indefinitely when needed.

A special dedicated suite was available where bereaved families could spend time with their loved one to say their goodbyes privately. This could be used for those that had passed away at the hospice or elsewhere.

#### Is the service responsive?

Good



The service was responsive. Children and young people received an individualised person-centred service based on their specific needs, choices and preferences.

There was a wide range of activities on offer which relatives, children and young people enjoyed and benefitted from.

Young people approaching adulthood and their families received support and guidance from the hospice transition team to assist them in the transition to adult services.

#### Is the service well-led?

Good



The service was well led. Families were happy with the way the service was managed and with the quality of service.

People used a service that recognised the importance of good governance and was developing and changing its governance systems to ensure that a safe and good quality service was provided.

Children and young people used a service that was continuously developing and improving to ensure that they received the best possible care where and how they wanted this.



# Richard House Childrens 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 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 1, 2, 8 and 21 June 2016 and was unannounced. The inspection team consisted of two inspectors, a pharmacist inspector and a specialist advisor.

Before our inspection, we asked the provider to complete a Provider Information Return (PIR). The PIR 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 the information we held about the service.

During the course of the inspection we spoke with, either in person or on the telephone, one young person who used the service and 16 relatives. We also spoke, in person, to 22 members of staff including the chief executive, registered manager, human resources officers, cook, head of care, practice development nurse, family support service staff, transition team manager and staff, activity coordinator and play staff, a student nurse and three nurses. Sessional support was provided to Richard House by a range of professionals as part of service level agreements with their employers. We talked to four of the people who provided this service, a consultant paediatrician, a pharmacist, an occupational therapist and a chaplain. We spent time in the inpatient and activity units, observing care, support and activities and joined a multi-disciplinary meeting. We spoke, by telephone, to the chair of the board of trustees.

We looked at seven people's care records and four medicines records. We looked at other records relating to the management of the hospice including three staff and two volunteer recruitment records. We also looked at duty rosters, accident and incident reports, complaints, compliments, health and safety, maintenance, governance and quality monitoring records.

## **Requires Improvement**

## Is the service safe?

## Our findings

Families were confident their child was safe using the services provided by Richard House. This included both the residential unit and sessional activities. One relative told us, "I don't feel worried when [my child] is there." Another said, "[My child] is happy when there and I feel comfortable leaving them. They know how to treat them."

The service had a risk management policy which gave clear guidance to staff about how to complete a risk assessment. However, we found that some risk assessments were detailed and addressed risks comprehensively but others did not. For example, in the personal safety section of one young person's file there was a clear management plan to manage epilepsy as safely as possible. For another young person we saw that prior to their admission concerns and issues about their care had been raised and action taken to ensure their safety whilst at Richard House. Other risk assessments seen did not address all individual risks and omitted individual detail. For example, for one child their risk management plan included a list of possible triggers for agitation and restlessness. The recommended response was, "Just calm [the child] and change activity." There was not any guidance as to how to calm them.

A healthcare professional told us, "I think sometimes communication could be better but I can see things are improving. When I identify risk, it gets taken on board and people are working on it."

People were cared for in an environment where the premises and equipment were appropriately maintained. Records showed that equipment was serviced and checked in line with the manufacturer's guidance to ensure that it was safe to use. Gas, electric and water services were maintained and checked to ensure that they were functioning appropriately and were safe to use. The records also confirmed that appropriate checks were carried out on hoists, and fire alarms to ensure that they were in good working order. Systems were in place to ensure that equipment was safe to use and fit for purpose. A fire risk assessment was in place and staff were aware of the evacuation process and the procedure to follow in an emergency.

However, records showed that night time fire drills had not been held, there was not a record of which staff had been present for a fire drill and there were not any personal emergency evacuation plans for individuals. We discussed this with the provider and they carried out a night time drill and started a record of staff that had been present. They also spoke to the local fire service and arranged for a fire safety inspection which took place before our inspection was completed. Action had been taken as a result of the visit based on the advice given. We also found that hot water temperatures were not checked to ensure they were within a safe range and that although the registered manager told us that staff checked water temperatures by hand they did not measure hot water temperatures before bathing or showering children and young people. This placed children and young people at risk of scalding if a water temperature control valve was faulty.

The above issues show that although parts of the systems for ensuring children and young people's safety were robust others were not and this placed them at risk of not always being safely cared for. This was a breach of Regulation 12 HSCA (RA) Regulations 2014 Safe care and treatment.

From our observations, discussions and from looking at staff rotas we found that staffing levels and skills mix were sufficient to meet people's needs and to provide personalised and individual care. Relatives told us that there were enough staff to care for people safely. Staff also felt that staffing levels met people's needs. .When asked if they have enough time to give personalised care. One nurse responded, "As a whole, yes, mainly one of the reasons I stay here." Another said, "Yes, enough, one-to-one per child so they have personalised care."

Staff in the day activity unit told us that that there were enough staff available to run activities. One member of staff said, "We're always evaluating whether it's [number of staff] worked. We have two family support staff on activities and have family support volunteers." This was a nurse led service and a consultant paediatrician visited at least one day per month as part of a service level agreement with a local acute health trust. The paediatrician told us that the arrangement had been shown to be satisfactory for two reasons. Firstly a high level of nursing care was provided and secondly there was 24/7 access to a paediatric specialist at Great Ormond Street Hospital.

Staff had received safeguarding training both via e learning and face to face training and confirmed that safeguarding was discussed both at staff meetings and one to one meetings with their line manager. Staff knew what to do if they suspected or saw any signs of abuse or neglect and told us that they did not have any concerns about the way people were cared for and treated. They were clear that they would report anything of concern and confident that action would be taken. One member of staff told us, "If you see something that needs reporting you won't be punished." People who used the service were protected from the risk of abuse, because the provider had taken reasonable steps to identify the possibility of abuse and prevent it from happening.

The provider's recruitment process ensured that staff and volunteers were suitable to work with children and young people who need support. This included prospective staff completing an application form and attending an interview. We looked at three staff files and found that the necessary checks had been carried out before they began to work with people. This included proof of identity, two references and evidence of checks to find out if the person had any criminal convictions or were on any list that barred them from working with children and young people. Nurses' registration with the Nursing and Midwifery Council was also checked to ensure that they were allowed to practise in the United Kingdom. There was evidence in staff records to confirm that they were legally entitled to work in the United Kingdom. A similar process was followed for volunteers. They completed an application form, attended an interview and two references were taken. If the person was going to work directly with people who used the service checks were again made to find out if they had any criminal convictions or were on any list that barred them from working with children and young people. The provider followed safe recruitment practices and this help to safeguard children and young people.

There was an emergency business continuity plan and major incident procedure and this had been reviewed and updated in March 2016. This was a detailed document which included information of where back up records were stored, shut off points for gas, electricity and water and emergency alternative accommodation. Staff had received emergency training and were aware of the procedure to follow in an emergency. Systems were in place to keep people as safe as possible in the event of an emergency arising.

The provider had a system in place to record, monitor and learn from accidents, incidents and near misses. For example, these were reported on and discussed at quarterly clinical and community engagement meetings. This group reported to the board of trustees and this enabled the board to be aware of and oversee high level risks and the action taken to minimise these.

Medicines were stored safely and securely. The medicines room was entered by means of an electronic key and all of the cupboards in the room were locked. The keys to the medicines room and to the cupboards were kept by the senior nurse on duty for a particular shift. The medicines room was well organised and tidy, with separate cupboards for controlled drugs and general medicines. Medicines requiring cool storage were stored appropriately and records showed that they were kept at the correct temperature to ensure that they remained effective. Controlled drugs were also safely stored and managed appropriately. There had not been any controlled drug incidents reported in the last 12 months.

Systems were in place to ensure that children and young people received the correct medicines and doses as prescribed. Prior to each child and young person's stay in the hospice nursing staff obtained an up to date medicine list from their GP to ensure that they had the correct details. Medicines were brought in by relatives or carers prior to each residential stay. All medicines brought into the hospice were logged on a section of the medicine administration record (MAR) with the quantity brought in and returned recorded. We saw a stage one medicine reconciliation was completed by nursing staff prior to a child's admission and this was checked again on admission. Stage one medicines reconciliation is a check of the medicines that an individual is prescribed on admission against current information to make sure they get the medicines they have been prescribed when they are admitted and that the doses are correct. This was good practice as it ensured the person received the correct medicines on admission and that any changes since the previous admission had been recorded. Doing this in advance and then double-checking on admission was safe practice.

People received their medicines safely and consistently as prescribed. Medicines were administered by qualified nurses. When necessary they completed additional training to enable them to safely administer specific medicines or to administer medicines via different routes. For example, medicines for the management of epileptic seizures or medicines administered via a tube directly into the stomach.

Records showed children and young people got their medicines when they needed them. There were not any gaps on MAR and any reasons for not giving medicines were recorded. Any allergies were recorded on MAR chart to ensure that nursing staff were aware of these. The hospice had access to specialist pharmacist support and advice by means of a service level agreement with the local acute trust. In addition to telephone advice a clinical pharmacist visited weekly and reviewed and checked MAR. Each month senior staff met with pharmacy staff to discuss medicines management issues. Any medicines incidents were reviewed and the development of new policies and procedures discussed. The trust produced pharmacy bulletins to highlight any important medicine management issues and these were shared with staff.



## Is the service effective?

## Our findings

Families told us that they were very happy with the care provided and felt that staff were skilled and competent. One relative told us that their child had very complex needs and that this had meant that they had always stayed with their child as although the nurses were very well trained they had not able to carry out all of the necessary tasks. However, nurses had now received specialised training and in future would be able to meet all the child's complex needs. This relative added that they had confidence in the nurses and in future would not stay with their child.

There was a comprehensive training programme in place for staff and a practice development nurse had been in post since February 2016. Their remit was to work with the head of care on training and in particular ensuring staff competency. Training was provided on line and face to face. Some senior nursing staff were qualified to train staff in specific skills and other training was provided by external facilitators. For example, the physiotherapist or community nurse specialists. Nursing staff told us they received the training they needed to keep their clinical skills up to date, and to develop the skills, knowledge and expertise needed to effectively care for the children and young people who used the service. One nurse told us, "The monthly team day is used for reinforcing learning from training and we also have days for face to face training."

The process for monitoring, recording and testing staff competency had been reviewed and was now formalised and more robust to ensure that their skills and knowledge were up to date. New starters received a competency book to complete with details of the competencies they already had. If nurses were newly qualified or not experienced in children's palliative care they were given a workbook to complete. The practice development nurse was aware of the need for flexibility to accommodate a variety of complex needs and was working with staff and the management team to achieve this. The service was looking at options such as linking with other hospices to do joint or rotational training and to share best practice.

There were various meetings where staff could also discuss the needs of children, young people and their families or issues about the running of the hospices. These included staff 'handover' meetings where information was communicated from one staff group to the next team coming on duty. There were also at least 10 team days per year for the whole care directorate. Part of the team days were dedicated to training. For example, the plan for the July meeting was to focus on competency and there was an action plan in place to ensure that all staff had the necessary competencies to support the children and young people who used the service. When children and young people are booked for a stay in the respite unit the skills that staff needed to support them were recorded to ensure that nurses with relevant competencies were on duty.

Staff received supervision, including clinical supervision (one-to-one meetings with their line manager to discuss work practice and any issues affecting children and young people who used the service) and also an annual appraisal of their performance. They felt well supported by management and other staff. One nurse told us, "Yes I'm supported by my managers and we all try to support each other within the team." When asked if they felt supported in their role another non nursing member of staff said, "Yes, definitely. We have a big meeting on the first Monday of the month and catch-up meetings on other Mondays. Can chat with line manager."

On occasions it was necessary to use agency nurses to provide care and support and an agency staff handbook had been created with an orientation form completed by the senior nurse on shift to ensure that the necessary guidance and information had been passed to them. As far as possible regular agency nurses were used and one agency nurse had already had their competencies signed off.

All of the above ensured that staff were well trained and competent to carry out the duties required to safely and effectively support children and young people and to meet their very complex needs.

Catering was provided by an external catering company which had been providing the catering service for 14 months. There was a file in the kitchen containing the children and young people's dietary needs and the chef had a list of the children with allergies and pictures of the food they are allergic to. Some children and young people needed to have their food pureed and others were unable to take food orally. When this was necessary the nutrition section of their care plan included a summary of feeding methods and a copy of their hospital food guidelines/feed plan. The chef pureed different foods separately to try to make the meals look as nice as possible and so that people had the opportunity to enjoy different tastes.

The care team met with families to plan individual menu's one week prior to admission for respite. There was a nutritious and varied four-week menu with four choices and jacket potato available. Breakfasts were made to order for the children as requested by care staff. There was not any catering staff on duty in the evenings and at weekends and chef left food in one of the fridges which care staff heated up if needed. Families were happy with the quality of food provided but said that although vegetarian food was available there was not any halal food provided. Relatives told us the food offered was good but that the service would benefit from kitchen staff being available at weekends and from halal food being offered. One relative said, "The worst thing is the lack of the halal food for the children." Another told us that no halal food "was an issue" and that quite a lot of Muslim families used the service. The registered manager told us that frozen halal meals were available but this was not the case during the inspection and one of the freezers was in fact broken.

Children and young people's nutritious needs were identified and they received nutritious meals. However, we have recommended that catering arrangements be reviewed to facilitate them receiving meals that meet both their preferences and their cultural and religious needs.

Richard House was a nurse-led service, i.e. there was no resident doctor. However, there was 24/7 access to a paediatrician at Great Ormond Street Hospital. Children and young people had access to health professionals. For example, a consultant paediatrician from the hospital visited the service as did an occupational therapist. Individual care files contained guidance from healthcare professionals and specialist services working with them. They also contained a care plan detailing the action to be taken in the event of an emergency arising and confirming the basic life support that should be provided until the emergency service arrived. Richard House staff liaised with other healthcare professionals to support children and young people to remain as healthy as possible. One relative said, "They help with advice and health."

Staff understood how to obtain consent from children and families and how to use different communication methods to obtain consent. When asked how they would obtain consent from a child or young person one nurse said, "Talk to them, tell them what you are doing in a language they understood, look at their body language, whether they're happy with what you are doing." Another told us, "Even if the child cannot speak ask them before giving day to day care. It's all about knowing the children. They will let you know." Consent was discussed with parents and legal guardians prior to their child using the service and any required consent forms signed.

The transition to adulthood team worked with young people from the age of 14 and their families. Part of this was around assessing their capacity to make decisions about their care and treatment, supporting relatives to accept changes as their child approached adulthood and liaising with professionals to make decisions about what was in the person's best interest.

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). This legislation 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, and whether any conditions on authorisations to deprive a person of their liberty were being met. Staff had received MCA and the DoLS training and were aware of the implications of this in their practice for some of the young people they supported and their rights to make their own decisions were respected and promoted. At the time of the inspection it was not necessary for any of the younger adults to be subject to a DoLS.

The hospice was set in its own grounds and was close to transport links. The building housed a residential unit, a day activity unit, a sensory room and rooms for meetings and consultations. The residential unit had recently been completely renovated and now comprised four large single rooms. The new bathrooms provided a wide range of facilities, including hoists to ensure that children and young people could use or be supported to use them safely. The public areas were accessible for people with mobility problems or who used a wheelchair. The gardens that surrounded the premises were well maintained and had spaces and equipment for children to play in. The environment and equipment available met the needs of those who used the service.



# Is the service caring?

## Our findings

Families all said that staff at Richard House were very caring. One relative told us, "Very, very good. They're brilliant with people like me and my son. I'm just glad there's something like that for children with complex needs, there's not many places that are as good." When asked if they thought staff were caring another commented, "Definitely. 110%. Very dedicated and passionate about what they do." One young person told us, "Staff are caring" and in a video about the service we saw that another young person had said, "Staff are very nice and do care about you the same way as your parents would."

All of the interactions between staff and children and young people we observed were caring, respectful, age appropriate and met the needs of the individual. Staff told us what they did to develop caring relationships with children and young people. One nurse said, "Give it time, can't be forceful about it, be gentle, introduce yourself, read through their care plan, do things you know they enjoy with them. I'd usually introduce myself the first time, smile." Another told us, "I started with the less complex children. By then families get used to seeing you. The more time you spend with the families and children the more you know them. The care plan might contain lots of information but there's always more to know. Time and Patience."

Staff were aware of and recognised the values of the service and employing staff with the right values formed a key part of the recruitment process. In addition to an experience and competency based interview prospective staff had to undergo a values based interview. This was carried out by a separate panel who asked questions about attitudes from a set bank of questions and topics. Successful candidates had to reach the necessary level in all parts of the recruitment process.

Some people told us they had initially been reluctant for their child to use the hospice service but were very pleased that they had visited and changed their mind. One relative told us, "I said no initially but when I did go to have a look it was nothing like I thought. It wasn't just place where sick children go to die. Life changed from that point."

Relatives appreciated the support their whole family received from the different services offered by Richard House. One relative told us, "The best thing is the support. I feel I'm not alone. It's one family." Another said, "All come and enjoy as a family, feel more pampered here." Relatives told us they had enjoyed relaxation sessions, massage and having their nails painted as part of mum's pamper sessions.

There were two self-contained flats where families could stay whilst their child was in Richard House. This meant that they could be close at hand but also have some much needed rest. One relative told us, "The flat is a good space for the family." Everyone seemed happy to be at Richard House and it was evident it was a place where relatives and children could go to relax.

People's privacy was respected and their dignity maintained. Personal care was offered discretely. Staff had a good understanding of the balance between maintaining children and young people's privacy, supporting their independence and monitoring their complex health needs. For example, one nurse told us, "For older children, offer them support but if they don't want it we can wait outside. Reassure them by saying, I'll be

outside if you need me." Another said, "We always pull the blinds and close the door in their room or the bathroom. If there's something they can do let them do it themselves. Give them positive feedback for example if turning in bed, say, 'very good rolling'."

Clear information was available about the service provided at Richard House and also about other services that people might benefit from. The information was available in leaflets, on the website, via the telephone or in face to face meetings. Each month a 'Family Matters' clinic was held. Families could make an appointment to see the pharmacist, the doctor, or a legal expert to discuss any specific specialist issues or concerns they needed advice or guidance on. Families found the advice session beneficial and one relative told us that when they had a problem the 'Family Matters' doctor had written to their GP surgery and sorted the situation out. We attended a multi-disciplinary team meeting and found that even if the hospice was unable to offer a service to a child or young person they advised on other options and supported people to make contact with other organisations.

Staff were aware of and respectful of individual cultural and spiritual needs including before, during and after death. Staff told us and records confirmed that they had received training and information to enable them to do this. There was a service level agreement with a local health trust for chaplaincy services. The chaplain visited each week. The arrangement was flexible to allow them to attend on different days to meet families and young people. The chaplain told us that they could call on religious workers of different faiths for support when needed. The chaplain also arranged for someone from a different faith to attend staff training sessions each month and worked with staff on how to have difficult conversations about spiritual needs.

Families, and as far as possible the young person, were fully involved in the planning of the care and support they received. Staff, in particular the transition team, worked with relatives to support them to accept changes as their child grew up and the fact that some had the capacity to make decisions themselves. Relatives told us that they were asked how their child needed to be cared for and many spent time at the service showing staff what and how things needed to be done.

At the time of our inspection no children or young people were receiving end of life care at the hospice but they were using the service for short breaks, activities and therapy. The family support team helped family's to put a memory box, music or book of memories together. The hospice ran a number of different support groups to offer people the opportunity to meet with others in similar circumstances and to talk about their thoughts and feelings in a supportive environment. For example, there was a Mums4mums group and a siblings group. One relative told us that the mum's group helped just by being able to speak with other mum's in similar situations. They also ran activities for the family. On one of the days of the inspection there was a rainforest activity day with food, activities and a music session, all with a rainforest theme. Staff were seen to come down to the level of the child when speaking with them and talking in a way they understood. There was lots of chatter and laughter during the whole day from children which made it clear they were enjoying the event. Children were relaxed and smiling.

There was a special room, the Rainbow Suite, which had a cooling system and allowed a child or young person who had passed away to lie at rest often until the time of their funeral. This suite could be used for children who died at the hospice or elsewhere and could be personalised with favourite things. Families could spend time there with their child after they had died and before the funeral. Counselling and bereavement support was offered to children and young adults (5-19 years) who had a life-limiting or life-threatening illness and their relatives, friends, and carers. Following the death of a child or young person, the family support team continued to provide counselling and support for the family for up to two years. However, this could continue indefinitely if needed. A bereaved relative told us, "They have helped at a very

dark time." Staff also advised on funeral arrangements if needed and the chaplaincy service offered spiritual support for all faiths. There was also a quiet area set aside for families to visit to commemorate the passing of their child. This area could be candle-lit and had a frame on a plinth in which a photograph of their child could be placed.

The hospice family support services worked holistically to provide advice, guidance, emotional support and counselling to children and young people who used the services, their relatives and carers. This was provided individually or as part of a family group and took place pre and post bereavement. In addition people could phone the hospice 24/7 for advice and guidance. Calls were taken by the nurse in charge of the residential unit at the time. There was a service level agreement with a local health trust for the provision of translation services. This was face to face for prearranged meetings and also available by telephone when needed. Therefore appropriate support and guidance could be provided for those with little or no English.

Any records or confidential information relating to the care and treatment of children and young people were securely kept and staff were clear about issues of confidentiality.



## Is the service responsive?

## Our findings

Children and young people received an individualised person-centred centred service based on their specific needs, choices and preferences. Support for families was also based on need and preference. The service responded as flexibly as possible to ongoing and changing needs. For example, some people used the service for residential stays, others for day care, music therapy or perhaps just a weekly bath. A nurse told us, "Personalised care is care given to an individual based on individual needs. It's about the person being in the centre of the care and about it being holistic."

Systems were in place to ensure that children and young people's needs were fully assessed prior to them using the service and that the hospice was able to provide the service that they needed. Referrals to the service were made by families, carers or health and social care professionals. When a referral was received the family or carer were asked to consent for Richard House staff to contact other involved parties to obtain up to date clinical information. Once the information was received the referral was considered at a multidisciplinary team meeting. If cases were very complex the information was reviewed by the consultant paediatrician. When children and young people met the eligibility criteria for the service they were then invited to Richard House for an assessment, to tour the facility and to make a booking to use the service. Whenever it was identified Richard House was not the most appropriate service families were signposted or supported to obtain services from other agencies. The multidisciplinary meetings were held each week and this meant that there was not a delay in cases being discussed and people being offered a service.

Each child and young person had a personal file which included a medical and nursing notes folder and a care folder. These were clearly laid out and covered every aspect of the care and support they needed, wanted and liked. Care plans were reviewed with relatives and carers before each residential stay at Richard House and any updates obtained from other professionals involved in the child or young person's care. Relatives also provided any specific information that might be needed if a child or young person was taken to hospital in an emergency. One relative told us, "They scrutinise everything in the care plan. Everything gets updated and medicines are checked. This is what makes me feel good about [my child] going." Another said, "I go in to speak to them about care plans and any changes." This ensured that staff had current information and were responsive to people's complex and changing needs.

Although care plans were detailed we found that in some cases parts of the information were not always specific and could be contradictory. For example, for one child it said that something should be done intermittently throughout a 24 hr. period but there was no detail as to how often this should actually be. For another the information on how frequently they needed to be turned was different in different sections of the file. We discussed this with the registered manager and head of residential care and they immediately put an action plan in place to address this.

In some cases relatives remained with their child during their stay at Richard House and provided care and support with staff. This was because it was their wish to do this or in some cases to demonstrate and guide staff about their child's needs. Some children and young people received 'step down' care. This was when their condition was stable enough for them to be discharged from an acute hospital to a homelike setting

such as the hospice. It supported the family care for their child, if needed to train carers to support the child at home or whilst equipment and adaptations were being arranged at the family home.

There was a wide range of activities on offer which relatives, children and young people enjoyed and benefitted from. The activities coordinator told us, "There is a family activity day every school holidays and a summer festival open to the community. We try to put a range of different activities on including around different festivities. For example, Christmas, Easter, Eid and, Diwali." One relative told us that there were enough activities to keep their child occupied. They added, "So good here. Good fun. Had a treasure hunt in the garden." Another relative said, "They manage them quite well, sensory activities, activities on the floor, have a quiet room if it gets too much for any child." A young person told us, "The best thing is everything is a lot of fun, they have a lot of activities" and then told us about a trip to the Harry Potter Studios. Activities were age appropriate and another relative told us that their child attended a young adults group and that taking part in activities and being at Richard House had given them more confidence.

Richard House also had a transition team for young people aged 14 and above to assist with their journey into adulthood and with accessing adult services. The team ran forums for discussions and information and also fun and educational activities. These included a Saturday club for youths aged 14 to 17 and a young adults group for ages 18 to 25. In the Richard House information pack we saw that one relative had said, "The move into adulthood is a time of high uncertainty but the transition programme has made things easy for [my child] and our family." Richard House staff worked closely with a local adult hospice to help provide expertise, advice and referral to the right services to help young people prepare for the new and sometimes different services provided to adults.

The provider had a positive approach to using complaints and concerns to improve the quality of the service. There was written evidence of complaints and responses to them. The complaints records showed that any concerns had been taken seriously, investigated, action taken and lessons learnt. Complaints were monitored and discussed at corporate governance meetings to ensure that they had been appropriately dealt with and that the necessary action had been taken to improve people's experience. Relatives were aware of how to make a complaint and felt that any complaint would be resolved. They appreciated being able to raise concerns or phone anytime they were not happy about anything. One relative told us that they had never needed to complain but if they had to they would go to the nurse on duty or the chief executive as they "passed his office on the way in." Another said they would complain to the chief executive, registered manager or activities coordinator if needed.



## Is the service well-led?

## Our findings

There was a registered manager in post and they had relevant and up to date experience and expertise to lead the service. Relatives were positive about the care provided and the management of the hospice. When asked about the registered manager one relative told us, "She's lovely. She's dedicated, very open and honest." Can phone up any time; don't need an appointment if you want to speak to her." Another said, "The registered manager is good. She is good at approaching families." Staff also felt that the service was well managed. One member of staff told us, "There was something I brought to her attention and it was resolved." Another told us that the manager was a good leader and added, "She comes down every morning and every evening. Everybody knows they can give her a call."

There was a clear management structure with senior staff allocated lead roles. The management team demonstrated a strong commitment to provide a safe, high quality and caring service and to continually improve, extend and develop the service to reach as many people as possible. The service had adopted a different model of care, the 'hospice as a hub.' This placed the hospice as a community hub where families accessed specialist children's palliative care, support, advice and guidance, and signposting to other services. As part of the change an 'outreach' service had been piloted which took hospice care out of the building and into people's homes giving them greater choice and more flexibility. This provided the opportunity to have end of life care and/or respite at home or in their place of choice, which could also be within a school, hospital or social care setting. The pilot project had been reviewed and two outreach nurses were being recruited to further develop that service. People used a service that was continuously developing and improving to ensure that they received the best possible care where and how they wanted this.

Systems were in place to monitor the quality of the service and evaluate the care and treatment children and young people received. Families were asked for feedback on specific aspects of the service throughout the year by means of questionnaires and also at meetings with staff and at family days. One relative said, "I have been asked for feedback and we do fill them in." Another told us that they were asked for feedback at the end of most sessions. There was also an annual family consultation and survey. To ensure that feedback was received from as wide a range of people as possible this was completed by telephone, in person or in writing. A bilingual health advocacy and interpreting service had been commissioned to interview some families with limited English. At the time of the inspection feedback was still being received but the response was already higher than in 2015. We saw that responses to surveys were analysed and information used to help plan future developments and improvements. For example, looking at whether halal food could be provided at events, revising timing of events and acting as a hub to provide advice, guidance and signposting.

There was an audit program in place which was carried out over the course of the year. In the last year the audit schedule had been changed and increased to strengthen clinical governance. External audits included a pharmacy audit by Guys and St Thomas' NHS Foundation Trust and Great Ormond Street Hospital reviews of treatment plans for all of the children on their shared caseload. The hospice also chose to undergo a two yearly quality accreditation audit by Caspe Healthcare Knowledge Systems. The last audit was in November 2015 and the hospice had been accredited for a further two years. When areas for improvement were

identified in audits we found that changes were made.

Internal audits included daily checks and also monthly audits in the residential unit. We saw that on occasions some of the checklists had not been completed and had gaps. However, the head of care had already allocated a named nurse to be responsible for monitoring the checklists and audits and to put an action plan in place to address any issues.

There were three main governance committees covering all of the operational areas of the service. Each governance committee was chaired by a trustee and reported to the board of trustees. The senior management team linked to key roles reported to the relevant governance committee. Each committee had its own work plan and information regarding this was cascaded out to the board so they could oversee any high-level issues and risks. Board members were from a variety of different backgrounds and areas of expertise to enable them to effectively oversee and support the service both from a clinical and non clinical aspect. Two family members of children and young people who used or had used the service were trustees. The chair of the trustees told us that their presence was invaluable and helped to give true diversity of experience to the board.

People used a service that recognised the importance of good governance and was developing and changing its governance systems to ensure that a safe and good quality service was provided.

The provider was aware of the importance of forward planning to ensure the quality of service they provided continued to develop. There was a three year strategic plan for 2016-2019 in place to enable Richard House to achieve its overall aim which was to, "Enhance the lives of children and young people with life limiting conditions, and the lives of their families, through life, death and beyond." People used a service that was committed to work collaboratively with partners to provide a high quality service and to become a leading provider for children's palliative care.

People used a service where staff felt valued and listened to and staff were involved in shaping improvements to the service. A staff consultation and well-being group was in place. We saw that in a recent meeting internal communication had been discussed and ideas put forward on how to improve this.

The hospice team had good links to the local community and approximately 150 volunteers supported the work they did. This was both in fund raising and in the hospice itself. For example volunteers worked in shops, in the garden, on reception and helping run activities.

The service worked in partnership with other organisations to make sure they followed current practice and provided a quality service. Richard House had strong links with the UK children's hospice organisation 'Together for Short Lives' (the UK umbrella charity for children's palliative care). The chair of the board of trustees was the first chair of Together for Short Lives and together with the chief executive was instrumental in the formation of Childrens Hospices across London (ChaL). This is a group of six children's hospices working together to reach out to more families in London and to improve the quality and consistency of care and services. There was a clinical and community engagement committee and we saw that at one meeting the palliative care consultant had commented that the Family Matters clinic had been very successful and that they had been able to take immediate and important action following meeting with families at these. The consultant felt that this was an excellent example of joined up working between organisations.

## This section is primarily information for the provider

# Action we have told the provider to take

The table below shows where regulations were not being met and we have asked the provider to send us a report that says what action they are going to take. We will check that this action is taken by the provider.

Regulated activity	Regulation
Treatment of disease, disorder or injury	Regulation 12 HSCA RA Regulations 2014 Safe care and treatment
	Systems were not in place to adequately minimise risk and to ensure that people were supported as safely as possible. Regulation 12 (1) (2) (a) & (b)