Bluebell Wood Children's Hospice

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**Inspection report**

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| Date of inspection visit: | 30 August 2016  
01 September 2016  
| Date of publication: | 21 November 2016 |

**Ratings**

| Overall rating for this service | Good
| Is the service safe? | Good
| Is the service effective? | Requires Improvement
| Is the service caring? | Outstanding
| Is the service responsive? | Good
| Is the service well-led? | Good

1 Bluebell Wood Children’s Hospice Inspection report 21 November 2016
Summary of findings

Overall summary

Bluebell Wood Children’s Hospice offers care and support to children and young people with life-shortening, life-threatening conditions. Children and their families receive support through regular care in their own homes, planned periods of respite care at the hospice, end of life care and counselling and bereavement support.

The hospice has an eight bed unit. All bedrooms are equipped with medical equipment, including hoists and piped oxygen; all have their own en-suite. Bedrooms also have a sofa bed or an extra bed can be accommodated, so parents have the option to sleep in their child’s room. Alternately family members who stay with their child at Bluebell Wood can have their own double bedroom, as well as use of a family lounge and kitchen.

Bluebell Wood covers a large geographical area, supporting children, young people and families across South Yorkshire, North Nottinghamshire, North Derbyshire and North West Lincolnshire.

Bluebell Wood support children and young people up to the age of 25 and provide a wide range of support services for all family members.

The hospice have a transitions team which work closely with all who are approaching young adulthood to ensure the right support is in place in a variety of ways.

Bluebell Wood are currently supporting around 250 families, both in their own homes and at the hospice.

Bluebell Wood has two end of life suites where children who have died can stay until their funeral. Both have family accommodation to enable families to stay if they wish.

The hospice sits in extensive grounds with a variety of garden areas with accessible playground and specialist play equipment. There is also the 'Dragonfly Garden' which is a reflective and memorial space for bereaved families.

Bluebell Wood has 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 2008 and associated Regulations about how the service is run.

Day-to-day operation of the hospice is delegated by the Board of Trustees to the Chief Executive Officer (CEO). The CEO discharges responsibilities through the Hospice Leadership Team.

Our last inspection at Bluebell Wood took place in August 2014. The hospice was found to be meeting the requirements of the regulations we inspected at that time.
This inspection took place on 30 August 2016 and 1 September 2016. The inspection on 30 August 2015 was unannounced. This meant staff at Bluebell Wood did not know we were coming. On 30 August 2016 five beds in the hospice were occupied and one child was being supported in day care.

We saw the children and young people we met were happy and very relaxed in the company of staff. Parents told us they were very happy that staff kept their child safe.

Staff were trained in how to protect children and young people from the risk of abuse and harm. They knew how to recognise signs of abuse and how to raise an alert if they had any concerns.

Staff were recruited safely to ensure that children and young people were cared for by suitable staff. There were enough staff on duty that had the specialist skills needed to make sure children and young people’s needs could be met safely. Staffing levels were increased to respond to children and young people’s rapidly changing needs.

The service had appropriate arrangements in place to manage medicines so children and young people were protected from the risks associated with medicines. Staff had received training and support to manage children and young people’s medicines. We identified some shortfalls in the record keeping, storage of medicines and staff training although there was no indication children or young people had been placed at risk.

Staff were well informed about the risks to children and young people and we saw staff were trained in managing risks specific to each child’s care, safety and medical condition.

Systems were in place to maintain the safety of the hospice. The environment was well designed, welcoming, well maintained, clean and suited children and young people’s needs. We identified some potential shortfalls surrounding fire evacuation procedures (Personal Emergency Evacuation Plan) and fire practices. There was no indication children or young people had been placed at risk but we advised further guidance be sought from the local fire and rescue service.

Staff said the training and support they received was good. However, poor record keeping did not evidence that staff received the support and training they required to ensure they had the knowledge and skills to carry out their roles and provide high quality care to meet children’s and young people’s needs.

Children and young people were supported to maintain a nutritious diet. Young people and families told us about the high quality and choice of the food.

Staff were trained in the principles of the Mental Capacity Act (MCA) and the Deprivation of Liberty Safeguards and were knowledgeable about the requirements of the legislation. Staff worked within the principles of the Mental Capacity Act (MCA) where appropriate.

Young people had been involved in decisions about their care and treatment by staff. Parents’ decisions regarding their child’s treatment and end of life care had been sought.

Care and support was offered and provided with exceptional dignity, respect and compassion.

Families’ feedback about the caring approach of the service and staff was overwhelmingly positive and described it as "amazing, exceptional and wonderful."
Families' feedback surrounding the end of life care and bereavement support they received was described as "Outstanding."

The care plans we looked at reflected the children’s or young person’s needs and gave information about their treatment regimes.

There were good links with regional NHS antenatal and children’s services to ensure families had early involvement with the hospice. The hospice staff worked closely with community-based professionals to provide an integrated service.

Children and young people had access to a wide range of activities, outings and events suited to their needs and age.

There was a positive approach to receiving and managing concerns or complaints which were used to improve the quality of the service.

Quality assurance and clinical governance systems were in place and were used to improve the service.

Management had a clear vision and strategy to improve the services on offer to children, young people and their families. They had developed a 'service improvement plan' to be implemented over the next three years. The registered manager and chief executive shared this plan with us.

There were strong links with specialist palliative care professionals and other providers to share best practice and expertise so that children and young people had high quality palliative care.

We received very positive comments regarding the overall management of Bluebell Wood Children’s Hospice from staff, other care professionals, relatives and people who used 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?

**Good**

The service was safe.

Children and young people were protected from potential harm or abuse by staff that had been trained in recognising and reporting abuse.

There were enough suitably trained staff to support children and young people and keep them safe.

There were arrangements in place to safely manage children’s and young people’s medicines.

Systems were in place to maintain the safety of the hospice. The environment was well designed, welcoming, well maintained, clean and suited children’s and young people’s needs.

### Is the service effective?

**Requires Improvement**

Some areas of the service were not always effective.

Staff said the training and support they received was good. However, records did not evidence that staff received the support and training they required to ensure they had the knowledge and skills to carry out their roles and provide high quality care to meet children’s and young people’s needs.

Young people and families told us about the high quality and choice of the food.

Staff worked within the principles of the Mental Capacity Act (MCA) where appropriate.

Young people had been involved in decisions about their care and treatment by staff. Parents’ decisions regarding their child’s treatment and end of life care had been incorporated into their planned care.

### Is the service caring?

**Outstanding**

The service was caring.
Care and support was offered and provided with dignity, respect and compassion. Young people and families spiritual needs were supported and respected.

Families' feedback about the caring approach of the service and staff was overwhelmingly positive and described it as amazing, exceptional and wonderful.

Families' feedback surrounding the end of life care and bereavement support they received was described as "Outstanding."

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Bluebell Wood 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 was carried out 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 was carried out on 30 August 2016 and 1 September 2016. The inspection on 30 August 2016 was unannounced. We gave short notice to the registered provider of our visit on 1 September 2016 because we needed to be sure that key people would be available during our inspection visit. The inspection team consisted of two inspectors and a specialist advisor in palliative care.

Prior to our inspection, we spoke with stakeholders, including local NHS Clinical Commissioning Groups. This information was reviewed and used to assist with our inspection and the findings are included throughout the report. Stakeholders we spoke with told us they had no concerns about Bluebell Wood Children’s Hospice and provided positive feedback about the service.

Before our inspection, we reviewed the information we held about the hospice. This included correspondence we had received about the service and notifications submitted by the service.

Before the inspection, the provider completed a Provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make.

During the inspection we spent time observing the care and support being offered to children, young people and families. We spoke with two young people and ten family members or visitors who had previously used the services of the hospice.
Over the two days of inspection we spoke with 27 hospice staff. Staff we spoke with included the registered manager/director of care, head of care, head of family support and well-being, medical director, physiotherapist, community nurse, clinical educator, counsellor, activity coordinator, sibling coordinator, nursing and medical staff, nurses on placement at the hospice and support workers. We also spoke with the chief executive officer, chairman of the board of trustees, administration staff, volunteer coordinator, facilities, catering and housekeeping staff and people who worked as volunteers at the hospice.

During our inspection we looked at the systems in place for managing medicines; spoke with five members of medical and nursing staff involved with prescribing and giving people their medicines, looked at four children's and/or young people's medicines charts and spoke with a young person and three family members in relation to their children's medicines management.

We spent time looking at records, which included four children or young person's care records, six staff records and other records relating to the management of the hospice such as training records and quality assurance audits and reports.
Is the service safe?

Our findings

Parents and families were positive in their comments about the safety of their child. Parents and families said, "When we were at our most vulnerable staff made us feel safe in their hands," "We always knew she [child] was in safe hands, and they always contacted us if there was a problem." "I can leave [name of child] with staff both in the hospice and in my own home; I have 100% confidence in them doing everything necessary to keep them safe" and "My child is in safe hands and I can relax and read my book." One young person using the service said, "I like it here, if I am concerned about anything I can speak to the staff."

Procedures relating to child protection and adult safeguarding were available. We saw information leaflets were available for children and their families in the entrance hall and information packs. These provided clear child friendly information using words and pictures to inform children and young people about their right to be protected.

We spoke with staff about safeguarding people from abuse and they knew what to look for and how to report abuse if they had concerns. They told us that they had completed training in this area and this was repeated on an annual basis to ensure they were kept updated. We spoke with a member of staff who was a safeguarding champion. They told us there was a group of champions who met regularly and were trained by the local council. The purpose of the group was to support other staff in this area and offer support and guidance where needed. Staff also told us they received a safeguarding supervision session with their line manager. This was a one to one meeting with the focus on safeguarding people from abuse.

The head of family support and well-being was the designated safeguarding lead. A new safeguarding clinical lead model had been implemented within the care team and links had been developed for ongoing support and advice with both local authority and clinical commissioning teams.

Staff said, "Everyone who works here, volunteers included undergo safeguarding training. We all have regular updates and opportunities to discuss the procedures and our manager checks our understanding."

We saw documentary evidence that all safeguarding concerns involving a child or young person were monitored and reviewed.

Children and young people were protected and their freedom supported and respected because the risk of possible harm was identified and managed. Risk assessments had been carried out to identify and manage people's individual risks. The care records included some risk assessments including mobility, use of slide sheet, hoist and wheelchair and the risks in use of medical and other equipment within the hospice. Some risk assessments were incorporated into the children’s care/support plans.

We found it somewhat difficult to navigate through the children’s risk assessments and care plans but in the main we found the information was there and documents were up to date. We spoke with the registered manager and two nurses about the children’s care plans and risk assessments. They told us a staff working party had reviewed the current care plans and risk assessments. A plan had been formulated and new
format of care plan was being rolled out for all children and young people commencing late September 2016. The aim of the new care plans were to ensure the plans are more 'person centred' and the key information and risk assessments easier to navigate to.

Systems were in place to ensure medical equipment in use at the hospice was regularly checked and tested for safety. This was carried out on a daily basis to ensure equipment such as oxygen was available to respond to emergency situations. The systems for the reporting of accidents and incidents were viewed and found to be robust.

Parents were very happy with the staffing arrangements at the hospice, parents told us, “There is always an allocated staff member when we arrive, they meet us at every visit; they always have time to talk to us,” “Staff are always on hand, they are very supportive and have time for us,” and "The children are never unsupervised; enough staff to care, nurse and play with them."

The registered manager had systems in place to calculate how many staff were required to provide appropriate levels of care and support for people. The registered manager said they had sufficient staff to increase staffing levels at short notice should people's increasing needs require this.

The registered manager told us staffing levels were calculated based on the needs of the child. The registered manager told us they were working with another children's hospice to develop a 'specific dependency tool' to help calculate staffing numbers based on the children's and young person's needs.

Staff we spoke with told us there was always enough staff on duty and they felt they worked well together as a supportive team. Staff were confident the safety of children and young people could be managed effectively by the staffing levels.

We found there was a good staffing skill mix on duty on the day of the visit. We observed there was sufficient staff to provide children and young people with a high level of interaction. We saw children engaged in arts and crafts sessions and playing games with staff. These services were further complemented by activity coordinators, counsellors, music therapists and volunteers. In addition we saw that administrative, housekeeping, catering and maintenance staff all complimented this structure.

The medical provision at Bluebell Wood is provided through one part-time consultant in paediatric palliative care (Medical Director) and 3 training posts under the direct supervision of the medical director. The medical staff employed were all at registrar level. The training post included a paediatric specialist registrar in palliative care medicine.

There was also out of hours support 24 hours a day, seven days a week, from the consultant and registrar for children and young people on their case load. The other children's own paediatricians and GP's, local GP surgery and out of hours GP medical services were used to access medical advice and support for end of life care, for the other 150 plus children/young people receiving support from the hospice as and when required.

Senior nurses on-call services were available to support and advise the in house care team 'out of hours.' A staff member told us, "I never feel isolated, I feel well supported even at night. We have senior staff on duty and there is on call support from managers and from either the medical director, paediatric doctors at the local hospitals or GP’s."

Volunteers, managed by a volunteer coordinator, were observed working in the hospice in a variety of areas
including helping in housekeeping, gardening, fundraising, activities, administration and managing reception.

We reviewed staff recruitment records for four staff members. The records contained a range of information including the following: application, references including one from the applicant’s most recent employer, employment contract and Disclosure and Barring Service (DBS) check. The Disclosure and Barring Service (DBS) provides criminal records checking and barring functions to help employers make safer recruitment decisions. We also saw evidence where applicable, that the nurse’s Nursing and Midwifery Council (NMC) registration had been checked. This told us that people were cared for by suitably qualified staff who were of good character.

We looked at the systems in place for medicines management. We assessed four prescription records and spoke with five members of medical and nursing staff involved with prescribing and giving children and young people their medicines.

A majority of the medicines used were brought in by the children’s families. The family get a courtesy call by the care team ahead of their visit to remind them to bring in medicines that are correctly labelled with dose, name and expiry date and there are enough medicines to cover their stay.

Pre-emptive/ anticipatory medications for end of life are ordered if required via a local pharmacy. These are written up by one of the two nurse prescribers (head of care/ head of community services) or medical team. Staff told us medical staff will check the nurses’ prescriptions or offer advice if requested.

There were medicine policies available in folders observed in the pharmacy/ treatment room to cover medication management.

Staff told us nurses generally transcribe the medications brought in by families onto a Medication Administration Record (MAR) on arrival. The families sign the chart once medicine has been written up. Medicines must be in date and correctly labelled with name of child/ young person and dose/ frequency. A supporting medication list or accompanying letter confirming medications is sometimes sent in with the family by the GP or Paediatrician. The nurses’ check there is enough medication for the child’s visit. The doctors will check the charts if necessary and may write some charts up, but this is not usual practice for all children and young people.

Four MAR sheets were observed. All the MAR’s were transcribed and signed by nurses. The MAR’s were legible and written in black. We saw that allergies were clearly stated on the front page of MAR. Prescriptions and administration records were completed accurately, and children were given their medicines as they had been prescribed. No gaps were observed in the charts observed. We found two MAR sheets hadn’t got a parent’s signature to countersign medications to be given on the back page of the MAR. The hospice policy is that all MAR’s should be countersigned by the parent if the child’s medicines have been brought in by them.

The registered manager gave assurances that they would address and rectify the issue of staff not ensuring parents sign the MAR as a priority and remind staff about their responsibilities when checking (reconciling) medicines brought into the hospice.

Children’s medications were kept in individual locked cupboards in each child’s room. They have coded locks on the doors. Parents are not given the access combination although they were involved in giving medicines to their children. The nurse in charge carried the keys for the pharmacy and CD cupboard.
Room temperatures were not monitored for medicines stored in the cupboards in individual bedrooms. The nurse said on one hot day she had called pharmacy for advice and they moved all the medicines into the air-conditioned pharmacy room. It was a very warm day on the day of the visit and no way of knowing at what temperature the medicines were being stored. We discussed this issue with the registered manager. The registered manager had sought further advice and the decision had been made to purchase thermometers for all children’s rooms, to monitor temperatures daily and to move medicines to the cooler treatment room during warmer conditions.

Medicines requiring refrigeration were stored appropriately in the treatment room and records were maintained in accordance with national guidance.

There were appropriate arrangements in place for the management of controlled drugs (medicines that require extra checks and special storage arrangements because of their potential for misuse) and we saw evidence of routine stock checks.

In the event of an anaphylactic reaction there was provision for the availability of emergency treatment packs.

We observed the administration of medicines by a nurse on the lunchtime medication round. All medicines were labelled with the child’s name and dosage corresponding to the MAR.

We saw medicines administered to a child at lunchtime via Jejunostomy tube (a soft, plastic tube placed through the skin of the abdomen to provide nutrition or administer medicines). We saw the nurse followed safe practices and sought consent. The nurse spoke to the child letting her know what she was doing and made good eye contact.

Syringes used were washed in the pharmacy after medicines administered and put back in child’s room for re-use. This practice may provide an increased risk of cross infection. The registered manager said they would look again at this practice with a view to introducing single use syringes when staff administer medicines.

All new staff, including support workers, had to complete a medications training course during induction before they can administer medicines in the hospice. Carers and nurses will administer for children in their care. We saw evidence of this training having taken place.

Staff interviewed said the medical team and nurse prescribers were very pro-active and pre-emptive/anticipatory medicines.

Syringe drivers were regularly used at the hospice. The nurses we spoke with said they had received syringe driver training. We saw records of this training having taken place.

The nurses interviewed could describe the hospice incident/accident procedure, which would be used in the event of a medication error. All incidents, including drug errors, were regularly reviewed by head of care and head of community services in order to look for patterns and learning. Actions such as training required or changes in practice were shared with the team, agreed and actioned through team meetings or relevant committees.

Medicine audits were carried out by the pharmacy from a local NHS hospital. The last audit, July 2016, did not highlight any issues or concerns. Staff said telephone support was available and accessible from the
pharmacy at Sheffield Children’s Hospital or local community pharmacist.

Staff understood how they should respond to a range of different emergencies including fire, and fire training was part of their induction and on-going training. Staff took part in fire drills which helped them to remember the procedures and there was appropriate signage about exits and fire equipment throughout the home. However, records we checked showed the last fire practice/drill took place over six months ago. The records held did not identify which staff took part or if any corrective action was required following the drill although staff we spoke with confirmed they had been trained in fire and evacuation including drills.

We found there were no individual personal emergency evacuation plans (PEEPs) in place for children or young people. This information assists the emergency services in the event of an emergency arising, helping to keep people safe. We discussed with the registered manager the need for PEEP's whilst taking into account the equipment, such as portable ventilators or oxygen, which may need to accompany a child if evacuation was ever required. We did, however, observe there were sufficient staff who knew all the individual children very well. Staff we spoke with said with this knowledge of children and the layout of the building (each bedroom led directly onto a ground floor patio area) they would be able to evacuate children quickly and safely.

The registered manager and facilities manager agreed to contact the local fire service as a priority to discuss the requirements of PEEP's and said they would also increase the frequency of fire drill practices.

Records we checked showed fire safety equipment had been serviced and was regularly checked. Throughout the service, fittings and equipment were regularly checked and serviced. There was a system in place to identify any repairs needed and action was taken to complete these in a reasonable timescale. Maintenance issues were dealt with in a timely manner.

The clinical areas and premises were very clean, organised and uncluttered. Staff wore appropriate personal protective equipment (PPE) which was in ample supply. These measures protected children and young people from the risks of acquiring an infection while in the service as much as possible to keep them safe.
Is the service effective?

Our findings

We spoke with children and relatives and were told that they had confidence in the abilities of the staff. Every parent we spoke with commented that their child received excellent care from skilled staff. Family members said, "The staff are amazing, they are excellent at what they do," "Staff know what they are doing and are well trained" and, "From the moment we arrived I knew [name] was safe. Staff just took all the pressure off us. I have every faith in them."

We looked at how staff were supported to develop their knowledge and skills. We looked at the induction programme that newly appointed staff had to undertake on commencement of their employment. Induction programmes help staff to understand what is expected of them and what needs to be done to ensure the safety of the staff and the people using the service.

The induction training programme included topics such as; health and safety, and understanding the philosophy and values of the hospice. One staff member told us about their induction programme and how they were supported and supervised through this period. They said, "I received a very good induction, I feel very supported here."

We spoke with staff about the training they received and they told us this was worthwhile and covered subjects appropriate to their role which included, safeguarding, tracheostomy care, basic life support, health and safety and food hygiene. Staff said there was a new clinical educator in post to coordinate and deliver training to the team.

We spoke with the clinical educator who showed us a plan of the initial training that was planned for staff. This included what they had identified as mandatory training (attended by all staff annually on one of two annual training days) - face to face, including, fire safety, safeguarding adults and children, medicines management, infection control (to be led by hospice link nurse), basic life support, moving and handling and mental capacity.

Staff said all of the team could access specialist courses to support their practice and internal training in palliative care, based on end of life scenarios. Staff said some palliative care training was carried out in a simulation suite at a local hospital using mannequins.

Staff told us the medical director delivered specialist training which included the support of nursing staff who were undertaking degree and masters courses in palliative care and/or to become advanced nurse practitioners.

The in house medical team, who cover some of the caseload of more acutely ill children/ young people, all have joint roles with local children's hospital and one with a local children's hospice, improving communication and team working with these services. The consultant and two registrars in training work part time for the hospice on service agreements. They received all their management support and appraisals/ supervision from their team in the local children’s hospital. The two registrars were training in...
palliative care, one was training to become a paediatric palliative care consultant, the other was working for six months in palliative care as a specialist interest to support their practice when they become a consultant paediatrician. The registrars told us they received supervision and appraisal/development support from the consultant/hospice medical director. They had both been in post a few weeks and said they had both completed an induction programme. They both said they were enjoying work at the hospice and the opportunity to specialise and have time to help children and young people with symptom management, palliative care and end of life care. The consultant had led much of the palliative/end of life care training and introduced use of the local simulation suite which has been well received by the hospice team.

Staff told us there were clinical lead roles which included moving and handling, infection control, safeguarding and transition.

Although staff told us they received regular training we found some training, including some which the service identified as mandatory was not up to date, could not be evidenced by records kept at the hospice and therefore did not cover the right areas to meet children’s needs, such as medicines training and basic life support training. Records identified the last training updates for any staff receiving basic life support training and medicines management training were September 2011 and July 2011 respectively. The training log identified staff should receive this training annually.

We spoke with the volunteer coordinator about the training volunteers received. They explained that all volunteers received induction training when they started volunteering at the hospice. This covered some mandatory training such as children's safeguarding and health and safety. The coordinator could not evidence what training volunteers had received since their induction. They said they did not keep records of this training and in theory some volunteers may not have received any updated mandatory training since they started volunteering at the hospice, possibly eight years ago.

We found the service had policies on supervision and appraisal. Supervision is an accountable, two-way process, which supports, motivates and enables the development of good practice for individual staff members. Appraisal is a process involving the review of a staff member’s performance and improvement over a period of time, usually annually.

Staff said they felt supported. Staff said that clinical supervision happened regularly and team debriefs were taking place after the death of a child/young person.

Staff appraisals were in place and the process included a 360 degree feedback format from up to nine, or more depending on the role, of the member of staff’s colleagues. Forms to record feedback were observed. Staff completing them said these were very time consuming, but helpful. We saw staff appraisal records were stored in staff files which were held in the human resources department.

Records seen showed staff were provided with some supervision for development and support. However, records showed inconsistencies in the frequency of supervisions provided. The supervision policy stated that staff should be provided with supervision every eight weeks.

We asked to view a sample of staff supervision files to check the frequency supervision occurred. Some staff files we requested were not available because staff were not on duty or the files were with a manager who wasn’t available. We did not check the personal content of any supervision recorded. We found inconsistencies in the frequency of supervision for each staff member.

We looked at six staff files and found little evidence that consistent supervision had taken place. For
example, one staff member had been employed at the service for seven years and there were only four supervision records, one in 2014, one in 2015 and two in 2016. Another file showed the member of staff had received two supervisions with a manager in the last two months but no other supervision over the previous year. Two files identified staff had received supervision on an eight weekly basis.

This showed supervision was not being provided for some staff as outlined in the hospices policy and procedure.

Some training was recorded on a matrix system updated by the human resources department; other training records were held with individual specialist trainers, managers and mentors of staff. Some staff held some of their own training and supervision records. This meant the provider could not track and fully evidence that all staff received the support and training they required to ensure they had the knowledge and skills to carry out their roles and provide high quality care to meet people's needs.

We spoke with the chief executive and registered manager and the concerns surrounding staff training and supervision. They said they had recognised the approach to training and supervision had been "disjointed." The registered manager said their plan was to hold all staff training and development and supervision and appraisal records in individual staff files within human resources. This would enable closer monitoring of staff's training and support needs.

Parents and families said they were involved in any decisions affecting their children. Young people we spoke with said they could make choices and were always asked by staff for their consent before any care was provided. We saw consent to treatment and other areas of consent agreed in a young person's care plan we checked which covered areas such as use of photography and access to the Jacuzzi, outings, music therapy and art activities.

A parent said, "Families lead the care, we are always asked, whatever we want staff do their best to make sure it happens and is done the way we want it, every area of care is covered including counselling support, having the right food and ensuring we get rest and sleep at times we want."

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. For children under 16 years of age the MCA does not apply. There are certain parts of the MCA that do not apply to young people aged 16-17 years.

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). Any deprivation of liberty for a young person of 16 to 17 would generally need to be sanctioned by the Court of Protection pursuant to the provisions of the MCA.

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. At the time of our visit, there had been no applications to place a restriction on a person's liberty.

Staff had received training in MCA and the DoLS. We saw records of this training. We found from speaking with staff they had a good understanding and application of the MCA and DoLS.
We saw some children and young people had a 'Do not attempt cardio-pulmonary resuscitation' (DNACPR) or Limitation of Treatment Agreement (LOTA) documents in place which had been discussed and agreed by the child’s parents and palliative care consultant. Some children with a DNACPR in place had a comprehensive advanced care plan (ACP). Two parents told us, “Staff discussed this with us in a sensitive way. We were grateful staff were open, honest and understanding.”

Young people’s and children’s nutritional needs were identified on admission to the hospice and discussed with them and their family.

The dining area was the hub of the hospice where children, relatives and staff could meet to share a meal. Meals were nutritious and healthy. We spoke with the catering staff and were told that fresh fruit and vegetables were always available. The menus were based on a healthy diet and included a wide variety of foods to suit different tastes. The chef was knowledgeable about people’s likes and dislikes and was able to cater for specific dietary requirements.

The mealtimes we observed were a lively yet relaxed affair with plenty of shared laughter heard. Some young people chose not to eat in this area and preferred to eat in their room and their wishes were accommodated by staff.

Children and young people were offered a range of food choices. One young person said, “I like cheese sandwiches and that’s what I get.” Families said, “The food is lovely, too nice in fact” and “There are great choices available and there is always a healthy option” and “Food here is brilliant. You can help yourself to drinks and snacks and we can eat our meals with the children.”

Bluebell Wood also had children/young people who required parenteral nutrition and support. Staff said advice for this was received from the specialist at the children’s hospital in Sheffield. This advice was recorded in one child’s records we observed.

A new ‘milk room’ had recently been refurbished within the hospice. This room was specifically used so milk formulas for infants could be prepared in a hygienic environment.

The care team have received training from the local speech and language department at the hospital to advise on specific feeding techniques and to assist them in meeting children’s individual needs.

External health professionals spoke highly of the care and support at the hospice. Comments we received included, “We do get verbal feedback from families which is that this is a very good service and I have never received one negative comment about Bluebell Wood.”

The nurses and medical staff we spoke with said they linked closely with a number of other external organisations and services including other local and national children’s hospices. The medical director, director of care and other medical and nursing staff also functioned in a number of children specialist palliative care forums/networks both regionally and nationally.

In 2014/15 the hospice commissioned a research project titled, ‘An Investigation regarding the Available Transition Options for Young Adults at Bluebell Wood.’ The project worked in partnership and engaged young adults, families and staff to explore the different models of transition. Case studies were obtained from children’s hospices for the group to explore the options available. The key themes that emerged were based on a community and partnership model. Further funding was gained to support the development, implementation and evaluation of the model which was due to be completed late 2016.
All the feedback we had from young people and their families about the hospice environment and facilities was very positive.

The hospice was furnished and equipped to meet the needs of the different age groups served and also to sensitively support the delivery of palliative/end of life care. There were specially designed and equipped bed rooms with family facilities where children could lie in rest until their funeral.

Children and young person’s bedrooms were large with mechanically adjustable beds, ceiling tracked hoists and specialist pressure reliving mattresses for those who need them. There were pea pod beanbags, on wheels and trolleys to ensure children and young people could lie down and be moved round to enable their position changed.

Other facilities included a large activity room, a music room, messy play room, cinema, soft play area, sensory room and Jacuzzi.
Is the service caring?

Our findings

Throughout the inspection we observed staff supporting children who used the service with consideration, dignity and upmost respect. We spoke with children and relatives and they were highly satisfied with the care and support provided. One child said, "The staff are nice with me and I really like it here, it's great." One relative said, "Staff listen to me and advise me if I need it. They put my mind at ease. I have also found the chaplain very comforting." Another relative said, "When we are caring for [child] at home and I'm worried about anything, I can contact staff here. There is always someone on the end of the phone." Another relative said, "This is a happy place where we can spend time together. Staff make sure we are all happy and comfortable and we are treated like royalty." Another relative said, "The service is amazing, exceptional and wonderful. We had been through thinking we were losing [child], planning a funeral, to then turning a corner, we have been allowed to clear our minds, to make memories that we will never lose."

We observed staff interacting and supporting children and their relatives. We saw staff were knowledgeable about how children/young people liked to be supported and knew what the children's likes and dislikes were. For example, one care worker asked a child what they were having for lunch and they told the staff member what they wanted and said they would like to eat their meal on their knee in the lounge area. When the staff member fetched the plate they realised it was cold and so placed a towel on the child's knees so they would not feel the cold plate. This showed consideration for the child's comfort.

We were sat with one child who we could not communicate with. However we saw a broad smile appear across their face when we asked what they thought of the staff and when staff came into the room to see if they were alright.

Families and staff said there were times of great sadness in the hospice. However, throughout our two day inspection we observed lots smiling faces of shared laughter between staff children/young people and their families. It was positive to see staff, children and families following the Bluebell Wood Children's Hospice motto of, 'living with love and laughter.'

One support worker we spoke with told us about a child who was frightened to use the hoist but had been assessed to use it for all transfers. The support worker told us how they worked with the physiotherapist to break down the task to make it more bearable for the child. The support worker said, "We had to build up a relationship of trust and confidence."

Staff saw communication was a vital part of caring for children. We saw a Makaton sign display chart on each dining table which included symbols around eating and drinking. This was used to support spoken language and helped children with no speech to communicate.

Staff knew how best to interact with the parents which was an important part of the child’s support network. Relatives we spoke with spoke highly of the support they had received. One parent said, "Staff are fabulous, they were outstanding, made all the funeral arrangements, this took the pressure off me. A member of staff came with me to register my child's death." This support had been invaluable to the parent at a really
difficult time.

Relatives we spoke with valued the relationships they had developed with the staff and felt they went the "extra mile" to support and include them. Parents were involved in every aspect of their child’s care and support. The service asked each parent to stay at the hospice on the child’s first night to ensure they have all the information they needed to be able to support the child and their families to the best of their abilities. One support worker said that they tell parents, "We are led by you."

Staff told us how one of the values and the vision of Bluebell Wood was to keep the family and family life at the centre of everything they did. An example of this was that families and children were welcome to bring their own pet into the hospice to visit the children/young people. Pets could access the child’s room though the patio doors which led into each room. The hospice had its own very popular member of staff called George. George is a cocker spaniel dog who was known to families and children/young people. A family member told us how much they and their family enjoyed taking George a walk in the gardens.

We saw a welcome pack was available to parents which gave information about the service and the surrounding area. This also gave details about how to complain, activities and groups within the hospice and restaurants in the local area.

A handover sheet was given to staff at the start of each shift with a summary of each person’s support. Staff also read care plan evaluations and checked specific care needs and any requests such as making a birthday card for a relative. Staff were designated to support one child each shift to take responsibility for every aspect of the child's care and support needs.

Staff enabled parents to remain the main carer and had an in-depth appreciation of people's individual needs around privacy and dignity. Relatives told us how staff intervened at appropriate times but also gave time and space for them to grieve. One support worker said, "It's all about what the family and child want and we will support whatever they want."

The hospice had two end of life suite’s named 'forget me not' and 'primrose.' These suites comprised of a self-contained flat and a cold bedroom where parents and a deceased child could stay until the funeral if needed. This gave parents and family members time to say goodbye to their loved one with the hospice staff around to comfort and support as needed.

It was notable to see that a number of parents, since the loss of their child, had volunteered to work in various roles at Bluebell Wood. These parents had specifically asked to speak with us so they could tell us about the end of life care their child had received and the support they had received from staff. Parents told us they were so grateful for the care their child had received that they wanted to give 'something back'. One relative said, "I couldn't have got through it without this. The staff were brilliant and on hand whenever we wanted them." Another relative said, "Even when my child had passed away, staff continued to treat [child's name] with dignity and as though they were still alive." Another relative said, "After [child's name] had passed, the staff made tea and fetched it to us, knowing we hadn't eaten. These little things you remember."

In addition to the suites the hospice had several bedrooms which families were able to use if they chose to stay overnight at the hospice. The rooms were all en-suite and had access to the garden area. Parents were also accommodated in their child’s room if they preferred to stay with their relative or children could be accommodated in the parent’s room. It was clearly evident that staff were keen to support parents and family members in whatever way suited them, and they were very accommodating.
One relative told us how the staff did hand and foot casts and saved some of their child’s hair. The relative said, “They placed them in a presentation gift box.” This meant a lot to the parents and showed that staff were supportive.

There was also a support group called ‘shooting stars’ which was set up to support siblings. Groups were held at the hospice and out and about to various places of interest. We observed one of the groups taking place and spoke with siblings who attended. They were excited about forthcoming adventure breaks which the hospice had organised. These were to take place in October 2016. Siblings who were attending the group at the time of our inspection spoke very highly of the group and felt supported by each other. They told us they were able to talk things through with each other and did not feel alone.

The hospice provided spiritual care and support to families. At the hospice there was a room called the ‘Butterfly’ room designed for families to sit and reflect, light a candle, listen to music and add a prayer, thought or memory onto the memory tree. The room was open 24 hours a day for families to use.

Whether or not families held religious beliefs, the hospice had a chaplain who was available to support children, families and care staff, both in the community and at the hospice.

The hospice had a counsellor who was available to support children, relatives and staff when needed. This is extended to a support group for relatives which commences about six months after they have been bereaved. This consisted of six structured sessions going through the grieving process. Some parents are part of a group called ‘the forget me not group’ where parents can meet and support each other.

When a child passed away parents were given a pebble with the child’s name on. Families were able to do what they wanted to do with the pebble. Some chose to keep it at home and other chose to place it at the hospice in the ‘dragonfly garden.’ This was a remembrance garden in the grounds of the hospice where parents could visit whenever they wanted to. The hospice held a remembrance day every year for relatives to attend to remember their loved one. Relatives we spoke with found this to be a helpful part of their grieving process.
Our findings

Children we spoke with and their relative's told us that they felt their needs and their relative's needs were fully met by staff. People told us they had been involved in initial care planning and were asked about any changes every time they used the service. Relatives told us that they felt confident that staff knew their children well and that if they were concerned about their health they would quickly take action. Parent's said, "The staff talk to us about our child’s needs," "We are at the centre of every decision and discussion," "Staff listen and are with us every step of the way" and "Someone from the hospice contacts us even before [name] comes here, to check that everything is Ok with the admission and whether anything has changed. The doctors and all the staff really do ask your opinion and involve us."

One young person told us that staff go through their care plan with them and their parent to see if anything has changed and, "To get my view on things."

Staff told us how Bluebell Wood was developing their community team to enable families to have choice around where they receive short breaks, including offering day care support. Once a week a multidisciplinary meeting takes place to discuss current children and families, this meeting also involved external health care professionals including oncology and specialist nursing teams.

Families we spoke with told us their child had a planned respite stay at Bluebell Wood every few months. In between visits, they said they felt very well supported and could contact the care team at Bluebell Wood who would respond to any concerns or queries they had over their child’s care.

Before an admission, a member of the care team called the parents to ask if there were any changes in the child’s care needs or any worries or concerns. After each admission, a member of the care team called the family to ask how the child and family felt about their stay and whether there had been any problems. This meant Bluebell Wood had all the up to date information before the child was admitted again to the hospice.

Young people and families told us that the way staff responded to their needs was, "Brilliant" and "Really good."

On the days of inspection we observed staff being very attentive to children’s and family’s needs and responding to their requests for assistance in a timely manner. Staff were very visible around all areas of the hospice and were heard to frequently ask parent’s if they were alright or wanted any help or support.

Staff said care planning at our hospice was done on an individual basis and the involvement of the child/young person and family, wherever possible, was pivotal in this process.

We looked at the care records belonging to four children/young people. We found care plans gave basic information about the children’s needs and support requirements. From speaking with people we found that some plans did not include individual preferences to the extent they could have. For example, likes and dislikes around specific hobbies and interests and food preferences were not always included.
The care plans were quite difficult to navigate through and did not give a clear picture of the child as an individual. The care plans were updated when the child/young person came into the hospice and then on a daily basis and were discontinued where they were no longer required (as the child/young person’s condition changed).

There was regular monitoring of people’s condition. We found one of the children had an emergency care plan in place for active resuscitation. One of the children was on overnight ventilation and staff were monitoring overnight observations whilst the ventilator was in place including respiratory rate, pulse, oxygen saturations. The charts were completed and up to date. This enabled staff to respond to any changes in the child’s physical treatment.

Staff interviewed said the medical team and nurse prescribers were very pro-active and responsive with preemptive / anticipatory medicines. We saw there were advance care plans available for some children/young people who were at end of life. These plans are so children/young people’s care can be managed in a place of their choice and their wishes around end of life care are documented.

We did discuss the format of the care plans with several nurses, head of care and the registered manager. Although the care plans contained all the key and required information to care and support the child/young person they appeared very standardised and did not provide the detail to give a clear picture of the child/young person’s personality and their likes/dislikes.

Staff and managers said our observations had already been recognised and a specific ‘working party’ had completed a review of the documentation. the hospice were now ready to ‘roll out’ a new format of care plans. We were told these care/support plans were less clinical, although key clinical information and risk assessments were accessible and easier to navigate too, and the plans more focused on the child/young person as the individual they were.

The registered manager and staff told us how it was important to recognise some of the young people who attend the hospice were now approaching adulthood and how this will affect their future care and support. Staff said they were responding to this in several ways.

Young people who have used the services of Bluebell Wood from a younger age could if they chose to continue to use services up until they were 25 years. The young adult co-ordinator supports young adults and their families through the transition from children’s services to adult services. Children who come to Bluebell Wood start to attend our ‘young adults group’ from the age of 14, so they are surrounded by similar aged people where they can become friends and enjoy activities together. Bluebell Wood supports young adults through transitioning periods. They support young adults into services within their own community across education, housing and health and social care organisations.

The hospice understood the need for social contact and provided activities which were based on the children’s needs and preferences. There was stimulation for both younger and older children. For example, the garden and outside space was vast and contained sections of garden, sensory areas and play areas. In the main these had been designed by children who used the service and their relatives from pictures they drew. The garden also had access to a nature reserve.

Within the hospice there were well-equipped activities room with arts and crafts. Children had access to computer games, a cinema, messy play room, which enabled them to play independently whilst under supervision. Staff told us they planned activities around the child’s known interests and we saw on the day children were supported in age appropriate play; there were toys on the floor and a table football game.
There were activity coordinators, day-care, young adult, befriending and sibling coordinators, who with other staff, all supported children and young adults with play, leisure, education and social interaction.

The hospice had a music room and a music therapist who worked 20 hours a week. On the day of our inspection we spoke with a parent who told us that their child really enjoyed the music room. The relative said, "[Child’s name] likes to make a noise and really benefits from the use of the music room."

We saw from the activities board that events for special occasions during the year had been planned. For example, celebrations for Valentine’s day, Chinese New Year, and Spring and Easter activities. We saw a weekly activity plan which included arts, crafts, water play, and story and sign time. Children also made activity books which included photos of what they had done.

We saw a child play happily with a member of the care team. The child enjoyed brushing the member of staff’s hair and the staff member willingly participated in imaginary scenarios.

The sensory room provided a range of sound, light and touch objects to stimulate children and we saw some children enjoying this. Spontaneous and planned visits to the onsite Jacuzzi pool enabled children to both relax and enjoy fun in the water.

We saw staff had been trained in music therapy so that they could engage children in this. A range of planned activities and events had taken place; these included trips out and events held at the hospice for parents and children to enjoy.

The hospice provided sibling support for brothers and sisters who may have needed emotional support, or simply some time to have some fun. The sibling coordinator provided one-to-one support when a child needed it, which included visits to home and school. Siblings took part in the activities they wanted to and these included, going on trips or activities which helped them to be themselves and have fun and meet other children who understood their situation.

The hospice also had a sibling group called ‘Shooting stars’. The group met monthly, or more frequently particularly in school holidays, and gave children the chance to enjoy a wide range of activities and experiences.

If children became upset or anxious there was a counsellor and trained staff available at all times and appropriate support given.

On the day of our visit siblings and children/young people were enjoying a visit from the Sheffield Tigers speedway team. We saw the children and young people were enjoying meeting the riders and sitting on the bikes the team had brought with them. A family member said, "The team come regularly and the kids love it, the team also arrange for the children to go to the speedway meeting. The hospice is really good at supporting brothers and sisters."

We saw there was a clear and comprehensive system that enabled and encouraged children young adults and their families to bring a complaint should they feel it was needed.

Families' we spoke with said they knew the procedure to follow should they wish to raise a concern. Families' told us they had confidence their concerns would be acted upon immediately if they raised any. One person said, "There was an incident or misunderstanding once about something that happened. I wouldn’t say it was a complaint. We raised this with the head of care and they immediately acted on this, it
was handled sensitively, we thought very well. The situation was sorted to everyone's satisfaction. We still have nothing but praise for Bluebell Wood” and ”If I had a concern I would talk to staff and ask for a complaints form if needed. I have confidence that it would be resolved.”
Is the service well-led?

Our findings

Young people, families and other care professionals spoke very positively about their experiences with the hospice. Comments included, "Bluebell Wood is a wonderful place, I sometimes get talking to people around the region and even different parts of country and I am often told how lucky we are to have such a fantastic place on our doorstep," and "It is an unbelievable place, fantastic."

All of the staff we spoke with across the organisation demonstrated a very caring approach and were highly motivated to provide a high quality service to children, young people and their families.

All staff and volunteers we spoke with said they were proud to work at Bluebell Wood. Comments included, "When people ask me where I work I tell them at Bluebell Wood. People immediately say how they have heard good things about the place and say I must be so great to work there. I tell them it is me who is the privileged one privileged to be able to work here."

The service had a registered manager as well as other senior staff who were responsible for the various aspects of service delivered by the provider. The hospice was overseen by a board of trustees who, as well as attending board and management meetings, attended the hospice regularly.

We spoke with the chair of the board of trustees and were informed that some new trustees had recently been appointed. The board of trustees were in the process of developing a strategy to ensure the board was effective. All new trustees had been encouraged to do some shadowing of staff. We asked if there were any formal visits or audits carried out by the board, but were told that currently there were not. However this was something that was currently being discussed and would be developed in the near future.

We found there was a clear management structure with good organisation of the different teams whose staff understood their specific roles and responsibilities.

There was a very good understanding of the differing needs of children and their families and their unique circumstances. Transition arrangements were established to support young people moving into adult services.

Staff we spoke with felt supported by the management team and told us they gave them time out to access the counselling service if they needed to. A debrief session was held following a bereavement where staff met with the counsellor and had time to remember the child and reflect on what went well and how could they have done things differently.

The executive team of Bluebell Wood had recently developed and started implementing a service improvement plan. The team had a clear vision and strategy to improve the services on offer to children, young people and their families. They had developed the plan which was to be implemented over the next three years. The registered manager and chief executive shared this plan with us.
It was positive that the service had recognised that improvements were required in the approach to training and supervision and how records were stored. The service had started implementing plans to make improvements in this area.

A new clinical educator had been appointed to work in a newly revised role that incorporated both education and community palliative care delivery and a new skills matrix baseline questionnaire had been developed after a four month consultation with staff.

The registered manager said their plan was to hold all staff training and development and supervision and appraisal records in individual staff files within human resources. This would enable closer monitoring of staff's training and support needs.

We saw team meetings took place regularly and minutes were available. This gave staff a forum to discuss issues, raise any concerns and to be involved in any service developments. Staff we spoke with found the meetings supportive and worthwhile.

Staff we spoke with told us they felt involved in the development of the service. One support worker said, "I can suggest ideas and suggestions and I feel listened to. We are currently looking at care plans to make them clearer and a group of staff are involved in looking at this. This makes us feel valued."

The hospice’s management systems were supported by a formal structure of committees and governance groups. We checked the minutes of recent meetings to assess their effectiveness. The senior management team meeting looked at areas for improvement and development; monitored referrals and looked at plans to address increasing need for the hospice’s services within the community. This meant that senior managers within the service had oversight of developments and the needs of people who used the service.

We saw audits were in place to assist the management team in ensuring a quality service was being delivered. These included audits around medication, dignity and spiritual care, care planning, and slings and equipment. Audits concluded with a log of actions to complete to resolve any issue identified as part of the audit.

One parent said, "When [my child] accesses here you get a courtesy call asking how they could improve. We also get sent a questionnaire through the post about every six months asking for feedback."

Relatives told us that meetings took place every month and they could discuss issues with other parents and staff. Relatives also completed a questionnaire following each stay at the hospice to give feedback. Relatives were confident that feedback was used to develop the service.

The hospice policies were comprehensive, reflected every aspect of the delivery of care in the service and were updated continually. Staff were made aware of updates and knew where to locate the policies for guidance.

Bluebell Wood Children’s Hospice has a high profile and key role in the local South Yorkshire, North Derbyshire and North West Lincolnshire areas and was actively involved in building further links. There were many organised events such as the 8th birthday bash party, tea parties, parachute jumps, the colour dash run, charity runs/walks, links with local sports clubs, and the service had number of retail outlets. Volunteers and staff contributed to the planning of events. There was a fundraising team and communications team who ensured the hospice maintained a high profile in the community and was regularly prominent in the area press.
We met some of the active and enthusiastic fund raising team. Volunteers and families told of us of forthcoming events and how they are supported to fundraise after suggesting some fundraising ideas. The family said, "We come with an idea and the fundraising team are so enthusiastic to support you. They are honest if they think something is a nonstarter, but we are supported. We do it because we want to give something back to the Bluebell Wood."

Every year the hospice distributed three newsletters. These could be in an electronic version via Bluebell Woods own website. The provider had an active website in which they shared information about the services they offered.

The registered manager was aware of their responsibility to inform the CQC about notifiable incidents and circumstances in line with the Health and Social Care Act 2008.