

Butterwick Limited

# Butterwick House

## Inspection report

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## Ratings

Overall rating for this service

Good ●

Is the service safe?

Good ●

Is the service effective?

Good ●

Is the service caring?

Good ●

Is the service responsive?

Good ●

Is the service well-led?

Good ●

# Summary of findings

## Overall summary

We inspected Butterwick House on 24 February and 9 and 15 March 2016. The first day of the inspection was unannounced which meant that the staff and registered provider did not know we would be visiting. We informed the registered provider of the dates of our other visits.

Butterwick House provides care and support for babies, children and young people with life limiting and complex healthcare conditions. The services include specialist care, short breaks and respite care, end of life care, and family support before or after death. There are six beds within the hospice, four of which are for children and there is also a transitional unit, with two single bedrooms, to provide care and support to young adults between the ages of 13 to 25 years. The service is purpose built and situated in the grounds of the University Hospital of North Tees. Within the hospice there is a day room, sensory room and a hydrotherapy pool. There is accommodation for parents / carers on the first floor. At the time of our inspection there were three children who used the service.

Butterwick House had a registered manager in place. 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.

There were systems and processes in place to protect children from the risk of harm. Staff told us about different types of abuse and the action they would take if abuse was suspected. Staff were able to describe how they ensured the welfare of children was protected through the organisation's whistle blowing and safeguarding procedures.

There were enough qualified and experienced staff to meet the needs of the children and young people who used the service. Staff received regular training in areas relevant to their practice. Safe recruitment practices were followed when recruiting new staff and new staff had a structured programme of induction training.

Staff awareness and understanding of risk was good. Staff shared with us how they had dealt with children's needs changing or dealt with a medical emergency. Risks to children's safety were appropriately assessed, managed and reviewed. Care records contained a number of risk assessments specific to the needs of each child. The risk assessments had been reviewed and updated regularly.

Parents and carers told us they had been fully involved in drawing up the plan of care and making decisions. Children had been assessed and personalised care plans had been developed which were specific to the individual needs of each child. Evidence of likes and dislikes and what was important to the child was recorded within the plan of care.

The service had medicine management policies and procedures. Appropriate systems were in place for the management of medicines so that children received their medicines safely. The Hospice had developed an

excellent pain tool that was personalised to each child. Pain charts provided specific details of any changes the child may demonstrate to indicate their level of pain and a variety of pain relief was available for different types and levels of pain. This helped to ensure that children and young people's pain was managed effectively

Checks of the building and equipment were completed to make sure it was safe. However, fire drills were not taking place as often as needed. After the inspection the management team contacted the fire authority for advice. They told us they had updated the fire policy in line with the recommendations and fire drills were to be arranged making sure that all staff took part in two fire drills a year.

The hospice employed two doctors who worked during the day Monday to Friday. They were able to review children if they became unwell or deteriorated during their stay. In the event of an emergency children were taken by staff to North Tees hospital and each child was registered with a paediatrician so if any problems or concerns arose during their stay then their paediatrician was contacted for advice or to inform them if the child has been taken to North Tees. Out of hours (after 5pm and on a weekend) staff at the hospice spoke to specialist teams or if there were any concerns about the child's wellbeing then they went straight to North Tees hospital.

We checked whether the service was working within the principles of the MCA. At the time of our visit, there had been no applications to place a restriction on a person's liberty. We discussed the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards with staff and the management team. They told us that the impact of the Mental Capacity Act and Deprivation of Liberty Safeguards with regard to hospice care were still being addressed.

Children and young people's nutritional and hydration needs were assessed and recorded in care plans. Where needed the advice of the speech and language therapy service was sought so staff had guidance on supporting children and young people with eating and drinking.

The kitchen operated seven days a week and all meals were freshly prepared by the catering team. For children and young people who were able to eat orally, there was flexibility of food choices and if a child or young person wanted something special to eat, staff made every effort to provide this. Mealtimes were family orientated with hospice staff, children and young people [and their families if they wanted] all eating together. Most children and young people who were artificially fed brought in their own nutritional feeds and their usual regime was followed by the care team.

Butterwick House provided child and family centred care. Families were able to stay with their child throughout the duration of their stay. On the first floor of the service there was a comfortable flat with a lounge, two bedrooms and a bathroom. There was also a smaller lounge area with tea and coffee making facilities which overlooked the playroom downstairs in the main area of the hospice. Parents and carers told us this resource was invaluable.

Staff were extremely affectionate and caring in their approach to all children. They regularly provided reassuring touches, gave lots of smiles and spoke to the children in a kind and caring way. Parents and carers told us their children were excited when coming to stay at the service.

Staff respected children's privacy and dignity. Staff demonstrated a good understanding of the meaning of dignity and how this encompassed all of the care for a child. Children were taken into the bathroom or bedroom area when they required nappy changes or clothing changes.

The design and layout of the service provided young people (13 to 25 years) with privacy in the form of their own space to be together. There was a modern, bright lounge /dining area with comfortable seating, dining table and kitchen area for young people to use.

End of life care took priority when planning resources for the service. A child or young person approaching the end of life, and their family, could stay at Butterwick House for as long as needed. The care team liaised proactively with consultant paediatricians and the palliative care team.

Children and young people who died at the hospice and some, who died elsewhere, could use the 'Sunflower Suite' at Butterwick House. This was a special bedroom that operated on a cooling system allowing the child or young person to lie at rest often until the time of their funeral. The Sunflower Suite could be personalised for each child by their family, the care team or both, for example with favourite toys, pictures, music, and soft furnishings. The hospice went the extra mile and loaned out equipment to bereaved parents / carers to enable their children who had died to remain at home until the funeral.

The family support team were committed to providing excellent support to children, young people and their family. The sibling support group provided a fantastic opportunity for brothers and sisters of sick children or young people to meet up make friends and enjoy wonderful trips out and breaks away. The family support team were available to support families and the care team during end of life care. Following the death of a child or young person, the family support team continued to support the family for as long as needed. Bereaved families were able to access group or individual counselling.

Staff at the service supported people to create beautiful memories. There was a memory book in which there were photographs of children and young people and messages and remembrance. Each year in January there was a service held in memory of the children and young people who have died. A representative from the family support unit sent out invites to the family and carers of the deceased child or young adult. Staff at the hospice attended and took the memory book to put on the alter. Staff told us this was a thanks giving and celebration event.

The service had a beautiful chapel which could be used by children, young people, parents and carers. A chaplaincy service was available two hours each day from Monday to Friday. There were also services held in the chapel three times a week. This chapel could be used by people of all faiths.

The registered provider had a system in place for responding to people's concerns and complaints. Parents and carers did not report any concerns to us.

There were effective systems in place to monitor and improve the quality of the service provided. Staff told us that the service had an open, inclusive and positive culture.

## 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.

Checks of the building and equipment were completed to make sure it was safe. However, fire drills were not taking place as often as needed. Action was taken by the registered manager following the inspection to address this.

Staff could explain indicators of abuse and the action they would take to ensure children's safety was maintained. This meant there were systems in place to protect children and young people from the risk of harm and abuse.

Staffing numbers and skills mix were sufficient to provide a good level of care to keep children and young people safe. Robust recruitment procedures were in place to make sure staff were suitable to work with children.

### Is the service effective?

Good ●

The service was effective.

Children's healthcare needs were carefully monitored. Information on children and young people was shared with relevant health professionals.

Staff told us they felt supported by the management team, however formal supervision sessions had not taken place. The management team had recognised this and supervision was to be introduced in April 2016

Staff received regular training to ensure they had the knowledge and skills to deliver high quality care. Staff had a structured programme of induction training.

Mealtimes were family orientated and all meals were freshly cooked on the premises.

### Is the service caring?

Good ●

The service was extremely caring.

Parents and carers told us that staff at Butterwick House were extremely caring. They told us the hospice cared for the whole family not just the child or young adult receiving care. Ongoing care and support provided was invaluable to families. Staff had developed excellent relationships with children, young people and their family which was based on trust.

The views and preferences of children, young adults and parents were central to the care provided. Parents and carers made decisions about the care and support their children received.

There was a beautiful chapel and spiritual support was available to the whole family. The chapel was used by people of all faiths. The hospice often went the extra mile by loaning out equipment to a families in the community and allowing children and young people who died elsewhere to use the Sunflower Suite.

### **Is the service responsive?**

The service was responsive.

Butterwick House provided a flexible service to children, young adults and parents and carers. There was a wide range of activities and outings for everyone to enjoy where memories were created.

Parents and carers told us they felt confident expressing any concerns or complaints about the service they received.

Excellent support was available from the family support team. There were numerous groups available to support everyone whilst children and young adults received care and after death.

Parents and carers were fully involved in developing care plans which were person centred and clearly described the care and support needed. The hospice had developed an excellent pain tool which was individual to each child or young adult.

**Good** ●

### **Is the service well-led?**

The service was well led.

The management team gave strong and effective leadership and provided a clear strategy for the long term development of the service.

There were clear management structures and lines of accountability. Staff told us the service was well managed, that they were treated with respect and were actively involved in

**Good** ●

decision-making.

Systems were in place to monitor the quality of the service provided to ensure the service was run in the best interest of people.

All staff shared the commitment to excellence in every aspect of their work.

# Butterwick House

## Detailed findings

### Background to this inspection

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

We inspected Butterwick Hospice on 24 February and 9 and 15 March 2016. The first day of the inspection was unannounced which meant that the staff and registered provider did not know we would be visiting. We informed the registered provider of the dates of our other visits. On the first day of the inspection there was a pharmacist inspector. On the second day of the inspection there was one adult social care inspector and a specialist advisor in end of life and palliative care. On the third inspection day there was one adult social care inspector.

Before the inspection we reviewed all the information we held about the service, this included notifications of significant changes or events. The registered provider was not asked to complete a provider information return (PIR) prior to the inspection. This is a form that asks the registered provider to give some key information about the service, what the service does well and improvements they plan to make.

We spent time with all three children who were using the service and we spoke with four relatives / carers.

Children were unable to talk with us because of their conditions; however, we observed how the staff interacted with the children and their families. We looked at how children were supported throughout the day which included at meal time, during individual play and therapeutic activities. We looked at five children's care records, one recruitment file (this was the number of staff who had been recruited in the last 12 months), the training chart and staff training records, as well as records relating to the management of the service and a variety of policies and procedures developed and implemented by the registered provider.

During the visits we spoke with 14 staff, this included the registered manager, the doctor, the clinical lead of children's services, the chaplain, the health and safety advisor, a family support counsellor, nurses, nursery nurses, two student nurses on placement and health care assistants. Prior to the inspection we contacted external health care professionals by email to seek their views on the care and service received. This

included consultants in palliative care medicine and professionals from the continuing care team. Their views can be read in the main body of the report.

## Is the service safe?

### Our findings

Parents and carers told us they had every confidence their child was safe whilst in the care of the staff and the hospice environment. One parent / carer said, "They are absolutely fantastic. They keep [child] safe by closing all the doors as they know [child] likes to explore." Another relative / carer said, "These are the only people who can look after [child] like we can. We feel comfortable with them [staff]."

The registered manager had an open culture to help people to feel safe and supported and to share any concerns in relation to their protection and safety. We spoke with the staff about safeguarding children and the action they would take if they witnessed or suspected abuse. Everyone we spoke with said they would have no hesitation in reporting safeguarding concerns.

Staff were able to describe local safeguarding procedures and demonstrate an awareness of the types and signs of abuse. This included who to contact to make referrals to or to obtain advice from at their local safeguarding authority. Staff told us that they had received child protection training. The service had safeguarding and whistleblowing policies and staff told us that they felt confident in whistleblowing (telling someone) if they had any worries. One of the nurses who worked at the service was the safeguarding lead.

Staff and management awareness and understanding of risk was good. Staff shared with us how they had dealt with children's needs changing and / or a medical emergency. We saw this during the inspection when one child became unwell. Clear protocols were in place detailing action that staff should take to support the child. The protocol was followed and the child was transferred by a paramedic ambulance to North Tees hospital, where they were reviewed by a specialist paediatric consultant. Staff told us they had good communication methods to share information in relation to risk through staff handovers. Risks to children's safety were appropriately assessed, managed and reviewed. Care records we looked at during the inspection contained a number of risk assessments specific to the needs of each child. The risk assessments and care plans we looked at had been reviewed and updated regularly.

We looked at the arrangements in place to ensure safe recruitment procedures were followed and children were protected from unsuitable staff. The service did not have a high turnover over of staff. We looked at the file of the last staff member to be recruited in July 2015. We saw that they had completed an application form, which included information about their qualifications, experience and employment history. There were two written references and one of which was from the last employer, copies of personal identification and evidence of a Disclosure and Barring Service check. The Disclosure and Barring Service carry out a criminal record and barring check on individuals who intend to work with children and vulnerable adults. This helps employers make safer recruiting decisions and also to minimise the risk of unsuitable people from working with children and vulnerable adults. The recruitment records showed that safe recruitment procedures had been followed.

We saw that checks with the Nursing and Midwifery Council (NMC) were completed before nurses started work and on an annual basis to make sure they were eligible to practice.

Staff told us that there was good team work and that everyone worked well together. We reviewed duty rotas and spoke with the care team about staffing levels and shift patterns. All the staff we spoke with during the inspection told us they thought there were sufficient staff on duty to meet the children's needs. The clinical lead of children's services told us that during the day there were one to two nurses and a health care assistant and a nursery nurse on duty and overnight there was one nurse and a healthcare assistant. The hospice employed two doctors who worked during the day Monday to Friday. They were able to review children if they became unwell or deteriorated during their stay. Each child was registered with a paediatrician who could be contacted if there were any problems or concerns during their stay.

Relatives / carers told us they thought there were sufficient staff on duty to meet children's needs and provide stimulation and outings for children.

The management team told us that the water temperature of baths, showers and hand wash basins were taken and recorded on a monthly basis to make sure they were within safe limits. We saw records that showed water temperatures were taken regularly and were within safe limits.

Records which confirmed that checks of the building and equipment were carried out to ensure health and safety. There was documentation and certificates showing that relevant checks had been carried out on the fire alarm, fire extinguishers, emergency lighting and gas safety.

Tests of the fire alarm were completed on a regular basis to make sure it was in safe working order. All fire zones within the hospice were tested over a four week period. Records showed that the most recent fire drill had been undertaken in July 2015. We could not be sure that this covered all staff and in particular night staff. We asked the registered manager to contact the fire authority after the inspection to seek advice regarding fire safety.

Following the inspection the fire authority visited the service. The registered manager told us the fire authority had advised that staff must take part in two fire drills a year which included a simulation of practice involving evacuation. They told us they had updated the fire policy in line with the recommendations and fire drills were to be arranged.

We saw that hoists had been serviced in December 2015; however we noted that this did not include a check of the hoist slings. This was pointed out to the management team. After the inspection the registered manager told us a responsible individual had been identified to complete the sling checks in line with guidance from the Lifting Operations and Lifting Equipment Regulations (LOLER).

We asked the management team about personal emergency evacuation plans (PEEPs) for children who used the service. PEEPs provide staff with information about how they can ensure an individual's safe evacuation from the premises in the event of an emergency. PEEP's were completed for each individual child. These were reviewed on an individual basis with PEEPs added and removed as children were admitted and discharged from the hospice.

We looked at the arrangements in place for managing accidents and incidents and preventing the risk of reoccurrence. The registered manager said that accidents and incidents were not common occurrences; however they had appropriate documentation in which to record them should they occur.

We looked at the systems in place for medicines management. We assessed four medication administration records (MARs).

Medicines were stored securely and the keys were held by the nurse on duty. 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 balance checks.

Medicines requiring refrigeration were stored appropriately and records were maintained daily. However, maximum and minimum temperatures had not been recorded in accordance with national guidance. This was addressed during our visit.

Medicines were reconciled (checked) on admission by a nurse to ensure the most up to date medicines were transcribed onto the MAR. Children's own medicines were assessed by the nurse on admission and there was a policy in place to ensure this was carried out safely.

Comprehensive care plans represented the individual child's routines, likes, and dislikes and ensured medicines were prescribed and given in a person-centred way.

End of life prescribing was performed by the doctor or nurse prescriber and medication was tailored to the individual needs of each child. There was a symptom assessment chart which indicated when and how an end of life medicine was to be used, and this provided clear instructions to the nursing staff.

The hospice used a pain assessment chart to record the characteristics of each child's pain in liaison with the parents / carers and nursing staff. This allowed nursing and caring staff to understand how the child displayed pain and how different levels of pain should be treated.

The policies and procedures for medicines were regularly reviewed and up to date. In addition a risk assessment toolkit had been developed and was incorporated into the care plans. For example, if crushing tablets was required then a risk assessment proforma was used to identify the risks associated with the medicines that were to be crushed.

We were told about medicines reconciliation training and calculation assessments completed by staff on an annual basis. The hospice had close links with the local NHS trust for training with regards to specific medical needs for example training had been given for a specific type of feeding tube prior to a child's admission.

Audits were completed annually using a nationally recognised tool. Actions from audits were documented and fed into the governance meetings. We looked at the Incident reporting system for medicines and found that lessons learnt from incidents were discussed in the integrated governance meeting and disseminated to staff through care team meetings for shared learning.

## Is the service effective?

### Our findings

Relatives and carers told us that they felt their children were cared for by skilled and knowledgeable staff. One parent / carer said, "The staff are absolutely fabulous and they know everything about [child]. We have total confidence in them." Another person said, "They [staff] are fantastic and quick to pick up if anything is wrong. Communication is very good they always let you know what's going on."

Staff we spoke with during the inspection told us they felt well supported; however, staff had not received formal supervision sessions with their managers. Supervision is a process, usually a meeting, by which an organisation provides guidance and support to staff. The management team had recognised this and showed us records to confirm that a group supervision session had been arranged for the last Thursday in April 2016. They told us that further dates had been set for the rest of 2016 and staff were aware they needed to attend at least three supervision sessions a year. Although formal supervision hadn't taken place staff told us they had recently been through a difficult month and to support staff with this, group sessions with a psychologist had been arranged. The clinical lead of children's services told us that they knew the staff well and would offer counselling on a one to one basis if requested.

Staff on duty sat around a large table for their meals, [we were included in this meal time experience] where they discussed various topics, offering support to each other. Staff told us they regularly spent time with other staff and management during handovers, at the beginning and end of a shift and whenever else they needed to talk and provide support to each other. We saw records to confirm staff received an annual appraisal which included a review of performance and progress within a 12 month period. This process also identified any strengths or weaknesses and areas for growth.

Induction was structured and included an introduction to hospice working, syringe driver use and communication and family involvement. All new staff completed training which included, moving and handling, infections control, safeguarding adults and children, COSHH, health and safety, fire, management of oxygen and resuscitation. This training was completed again at regular intervals.

Mandatory training for clinical staff which included all nurses, health care assistants and flexi and bank staff was reported to Hartlepool & Stockton on Tees Clinical Commissioning Group. Butterwick Hospice contract and quality performance report for quarter three, 2015/16 showed that 73% of staff were up to date with their training.

The Hospice had the Care Certificate embedded into its ethos. The Care Certificate sets out learning outcomes, competences and standards of care that are expected. Excellent records were available in a well organised manner to show every health care assistants progress with the program. Staff were given study time and one to one support to achieve this.

Two members of staff have attended a two day transition workshop run by 'Together for Short Lives:' aimed at caring for young adults. Together for Short Lives is the UK charity that speaks out for children and young people who are expected to have short lives. They have the vision that children and young people with life-

shortening conditions should have as fulfilling lives as possible, and the best care at the end of life.

The management team at the hospice had accessed systems to support nurses in their revalidation. Revalidation is the process where registered nurses and midwives are required every three years to demonstrate to the Nursing and Midwifery Council (NMC) they remain fit to practice. The clinical lead of adult services told us they had signed up for an online appraisal toolkit for nurses which would enhance the quality of care through learning and development and reflection. Training material and records used for revalidation had been set up on a display within the hospice for nurses to use.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people (aged 16 and over) 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 and hospitals are called the Deprivation of Liberty Safeguards (DoLS).

All staff had attended recent training on the MCA. We saw records to confirm this. Staff we spoke with understood their obligations with respect to choice and consent.

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. When young people aged over 16 were first admitted to the hospice they were asked if they were happy to be cared for at the hospice. If people were not happy or unable to consent then staff at the service considered the persons capacity and whether a DoLS was necessary. At the time of our visit, there had been no applications to place a restriction on a person's liberty. We discussed the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards with staff and the management team. They told us that the impact of the Mental Capacity Act and Deprivation of Liberty Safeguards with regard to hospice care was still being addressed.

At the time of the inspection all children who used the service were under the age of 16. A multidisciplinary team had responsibility for making best interest decisions in relation to the care and support the children received. Parents and carers confirmed they were involved in making day to day decisions about the care, support, health and welfare decisions and activities amongst others for their children. Care and treatment decisions were recorded with the care plans we looked at during the inspection. Individual care records indicated that attention was paid to making sure that consent from parents was obtained for areas such as activities and outings, taking photographs and using the computer.

Many of the children and young adults who used the service were unable to communicate verbally, however each child / young adult had a communication passport / assessment within their care records. This provided information on their first language, hearing, vision and how they communicated their needs such as by using facial expressions, body movements or eye gaze. This helped staff to understand how to communicate effectively with the child / young adult.

We looked at pain charts which were individual to each child and detailed the characteristics and the level of each child's pain. This enabled each child to communicate their level of pain for example from being uncomfortable to severe pain.

Within the lounge area there were communication boards which showed the main Makaton symbols. Makaton is a language programme using signs and symbols to help people communicate.

Children and young people's nutritional needs were assessed and care plans were recorded regarding food and fluids. Where needed the advice of the speech and language therapy service was sought so staff had guidance on supporting children and young people with foods and fluids.

The kitchen operated seven days a week and all meals were freshly prepared by the catering team. For children and young people who were able to eat orally, there was flexibility of food choices and if a child or young person wanted something special to eat, staff made every effort to provide this. Healthy snacks and drinks were always available as well as treats such as biscuits and cakes. Mealtimes were family orientated with hospice staff, children and young people [and their families if they wanted] all eating together. There was a separate dining area for younger adults should they wish to eat away from the younger children to have more privacy. Most children and young people who were artificially fed brought in their own nutritional feeds and their usual regime was followed by the care team.

Within the hospice there was also a canteen which was accessible to children and young adults who used the service, relatives and staff. The canteen provided an opportunity for family time.

The hospice employed a range of staff. This included nurses, healthcare assistants, nursery nurses, a team of people who provided family support and counselling and complimentary therapists to help to ensure children's needs were met. The hospice employed two doctors who worked during the day Monday to Friday. They were able to review children if they became unwell or deteriorated during their stay. In the event of an emergency children were taken by staff to North Tees hospital. Each child was registered with a paediatrician so if there were any problems or concerns during their stay then their paediatrician was contacted for advice. Out of hours (after 5pm and on a weekend) staff at the hospice spoke to specialist teams or if there were any concerns about the child's wellbeing then they went straight to North Tees hospital. The registered manager told us there was a 24 hour advice line available to staff for advice with paediatric palliative care. A physiotherapist visited the hospice one day a week. Staff told us the physiotherapist was responsible for developing the moving and handling plans for each child or young person and they spent time with children in the hydrotherapy pool doing exercises.

Each child or young person that came into the hospice had their original Emergency Health Care Plan (EHCP) with them which was laminated and attached to their wheelchair. This detailed the agreed level of intervention that should be taken if the child or young person was to deteriorate, what level of resuscitation should be applied and where they should be taken. This meant that relevant and up to date information was available in the event of an emergency. The hospice was copied into all medical, and other professional letters regarding the child's health and treatment plan. All current letters were kept at the front of the notes and documented on the relevant care plan. This meant that hospice staff were kept up to date with the care and treatment needs of each child and young person.

Before the inspection we contacted numerous external professionals to seek their views on the care and service provided. A health professional we contacted told us, "My experience so far of working with the Butterwick team (Children's' services) has been very positive. The service they provide is excellent and is truly multidisciplinary. There have been several occasions when they went out of their way to accommodate our request for additional help and support for children and families. The team certainly offer a very effective and efficient service."

Another healthcare professional told us, "The service provides a valued source of care and respite for our client group and as such there are no concerns apparent that I am aware regarding their service delivery. The Integrated Team receive written relevant information From Butterwick House following each child's stay. For new referrals and enquiries from ourselves there is always a timely and clear response from the Team Lead and other staff members as required. Parents often commenting on their positive experience of their first visit to Butterwick House. Upon accessing the Butterwick for planned stays the families and children are extremely appreciative. It is a much valued resource."

Parent and carers spoke highly of the nursing staff and doctors who worked at the hospice, one person said, "I have absolute confidence with all of the staff who work at Butterwick."

## Is the service caring?

### Our findings

Relatives and carers told us they were very happy and that the staff were extremely caring. One parent / carer said, "It's important knowing [child] belongs." Another said, "The staff are lovely and always greet you with a smile. They make you feel welcome and there's always a cup of tea and biscuit." One parent / carer told us how they had relied on another relative to take their child to Butterwick House for their most recent respite stay as they had been unwell. They said, "My niece had to take [child] as I was poorly. They took the time to make [niece] welcome. They showed [niece] around the hospice and [child's] bedroom and then they made tea and biscuits."

We saw that Butterwick House provided child and family centred care. Families were able to stay with their child throughout the duration of their stay. On the first floor of the service there was a comfortable flat with a lounge, two bedrooms and a bathroom. There was also a smaller lounge area with tea and coffee making facilities which overlooked the playroom downstairs in the main area of the hospice. Grandparents and other family members and friends were encouraged to visit and there were no restrictions on visiting times or use of facilities within Butterwick House by visitors. We spoke with two relatives who told us they had used the flat when their child first started using the service. They told us they had found this facility invaluable and it had provided them with peace of mind. They also told us staff at the service had filled them with such confidence in caring for their child that they had slept right through the night which they hadn't done for quite some time.

Parents / carers we spoke with during the inspection confirmed that they were involved in making decisions about the care and support that their child received. They told us that staff at the service communicated well with them. One parent said, "I'm kept fully updated about everything that [child] has or how they have been during their stay." Staff told us they supported and encouraged children and young people to make decisions. Due to their condition this may be simple choices about the clothes they wore or the activity they would like to do. However, for others this was complex decisions about their care and treatment.

One parent / carer told us their child was excited when they realised they were going to the hospice, they said, "As we pull round the barrier [child] sits and claps and gets all excited." Another said, "You can just tell in here that all of the staff love their job. They are so loving and caring."

One child arrived for respite on the afternoon of one of our inspection visits. When this child arrived staff were quick to greet and make the child feel welcome. Staff approached the child to give them a hug. We spoke with the relative of this child who said, "[Child] is always smiling when they come in here. [Child] is constantly getting hugged."

Throughout our visits staff were extremely affectionate and caring in their approach to all children. They provided reassuring touches, gave lots of smiles and spoke to the children in a kind and caring way. One staff member tickled the back of the neck of one child who responded with a smile and a giggle. On another occasion a child approached staff for a cuddle to which they responded.

One parent / carer we spoke with during the inspection told us they had moved out of the area and had been offered respite at a hospice nearer to where they had moved, but chose to continue using the services at Butterwick House as they didn't feel anywhere would match up to the care and support they received from the service.

We saw that staff respected children's privacy and dignity. Staff demonstrated a good understanding of the meaning of dignity and how this encompassed all of the care for a child. We saw how staff ensured privacy when supporting children with personal hygiene. Children were taken into the bathroom or bedroom area when they needed nappy changes or clothing changes.

The design and layout of the service provided younger people (13 to 25) with privacy in the form of their own space to be together. There was a modern, bright lounge /dining area with comfortable seating, dining table and kitchen area for young people to use. Staff recognised the importance of privacy and space. They told us this was an area where young people could go and close the door and be on their own to think or to spend quality time with other young people of a similar age.

The registered manager and staff told us that end of life care took priority when planning resources for the service. A child or young person approaching the end of life, and their family, could stay at Butterwick House for as long as needed. The care team liaised proactively with consultant paediatricians and the palliative care team.

Children and young people who died at the hospice and some, who died elsewhere, could use the 'Sunflower Suite' at Butterwick House. This was a special bedroom that operated on a cooling system allowing the child or young person to lie at rest often until the time of their funeral. The Sunflower Suite could be personalised for each child by their family, the care team or both, for example with favourite toys, pictures, music, and soft furnishings. Staff gave us examples of how the 'Sunflower Suite' could be adapted to suit the multi faith needs of the families of deceased children and young people. Staff told us how they recognised and respected individual cultures and beliefs. The Quran, bible and other reading material was available to people. Attached to this suite was a seating area. There was a bowl full of painted stones [each with a child or young person's name on it] which had been made in memory of the children and young people. A stone was also painted and given to the family. There was also a memory book in which there were photographs of children and young people and messages and remembrance thoughts from parents, relatives and carers. The family support team were available to support families and the care team during end of life care. Following the death of a child or young person, the family support team continued to support the family for as long as needed, or for as long as they wished. Bereaved families were able to access group or individual counselling.

Each year in January at different churches in the Stockton area there was a service held in memory of the children and young people who have died. A representative from the family support unit sends out invitations to the families and carers of the deceased child or young adult. Staff at the hospice attended and took the memory book to put on the altar. Staff told us this was a thanks-giving and celebration event. This event was attended by many families of children and young people who had recently died or who had been deceased for many years. This event provided on going bereavement support and enabled families to come together to show a public display of support in which to give meaning to the life of the child or young person.

A health professional told us, "The palliative care, post bereavement and other support offered by Butterwick for family and siblings is invaluable." Another health professional told us, "Butterwick were recently kind enough to loan out a cold 'cuddle blanket' for a 'palliative' baby girl who died at home, when

her mum wanted to keep her body at the house prior to the funeral. Butterwick had not had previous involvement with the child, but supported our community nurses during this time." We were also told about a young person who had used the service for many years and how their relatives / carers were extremely satisfied with the management and symptom control at end of life, and the aftercare offered.

Staff spoke fondly and were knowledgeable about the children and young people they cared for. They showed a good understanding of the individual choices, wishes and support needs of children within their care. All staff were respectful of children's needs and described a sensitive and compassionate approach to their role. We saw casts of feet and hands that staff had produced for families of their children, which they could keep. Parents and carers told us how they valued the keep sakes.

The service had a beautiful chapel which could be used by children, young adults, parents and carers. A chaplaincy service was available two hours each day from Monday to Friday. There were also services held in the chapel three times a week. People of all faiths were able to use the chapel. We spoke with the chaplain who told us they spent time with children and their families. They told us how sometimes they would pray with people, help with planning a funeral or just sit and chat with people.

## Is the service responsive?

### Our findings

Parents and carers said they felt the service was responsive to the children's and their needs and wishes. One parent / carer told us they had been able to extend the respite care at the hospice as they had been unwell. They said, "Last week they were very accommodating. I was poorly so [child] had a few nights extra. It was an absolute god send."

Children and young people were assessed by a health professional before they could use the hospice facility. The amount of respite received was dependent on child and family circumstances. The registered manager told us bookings for respite were done a year in advance and every effort was made to accommodate the dates that parents and carers wanted. Staff told us the average length of stay for respite care was two to three days, however parents and carers could request up to seven nights or maybe more depending on the circumstances. Staff told us they had always been able to accommodate children and young adults when they were at end of life, on a very rare occasion this has meant a change to the date of planned respite for another child. Parents and carers told us they were accepting and understanding of any changes to respite particularly in the event of an emergency or another child needing end of life care.

We reviewed the assessment and care planning documentation for five children who were or had used the hospice. Parents and carers told us they had been fully involved in drawing up the plan of care and making decisions. Children had been assessed and personalised care plans had been developed which were specific to the individual needs of each child. Evidence of likes and dislikes and what was important to the child was recorded within the plan of care. For example, one child had a detailed night time routine, which included a bed time, the type of bed covers used as well as the fact they would kick off covers during the night and that staff were to check their skin and if cold to replace the covers. The plan also detailed they had specific aromatherapy oils to be used with a plan of which techniques they enjoyed. The care plan clearly outlined the child's understanding and communication, and told us they enjoyed cuddles, touch and stroke. This meant that care records provided the information that staff needed to make sure bedtime was a calm and relaxing experience for the child in a way that was personal to them. We asked to see the care notes both medical and nursing of a child that had recently died at the hospice to follow the plan of care. Evidence of advanced care planning with the multidisciplinary team and parent's involvement was very clear. Care plans were reviewed and updated on each admission to the hospice.

The Hospice had developed an excellent pain tool that was personalised to each child. The chart had a pre-printed scale of one to 10. Against each of the numbers there was a description of the non-verbal communication a child would show if they were in pain. One pain chart had been completed by the parent of a child and gave clear descriptions of fine detail of changes in facial expressions to indicate the level of pain. Pain scores had been updated to ensure the suggested pain relief was adequate to meet level of pain or agitation. We saw how one child was to have paracetamol before their nappy was changed as they would flinch suggesting they could be in pain. This pain tool helped to ensure pain was managed effectively and the children and young people were comfortable.

During the inspection we spoke with a representative of the family support team. They told us how they

provided support to children and young adults and the opportunity for them to talk about any worries they may have with representatives from the family support team. They also told us about one of the groups held in the hospice on one evening a month. The aim of the group was to support bereaved children; this may be children who had lost a sibling. There were three staff (listeners) present together with volunteers of all age ranges. The children had buffet type food and played games. During this time any child could have a one to one chat or speak as a family. This staff member told us how age specific activities such as dance, acting and drawing helped children to express their feelings and anxieties. Children were able to attend these meetings for as long as they need. Adults who brought the children sat in a separate area where they too could talk with other adults or staff members.

There was also a sibling support group which has been set up to provide brothers and sisters of sick children or young adults the opportunity to meet and make friends with other children in a similar situation. The group met every six weeks and had provided siblings with fantastic opportunities and activities. Siblings had been on a tour of Middlesbrough football club, been bowling and been to see The Lion King. Last year siblings enjoyed a weekend break in Kielder in Northumberland.

Children and young adults who used the service were also provided with amazing experiences. The Cash for Kids children's charity had donated twenty seats on a dream flight which had enabled children and young adults who used the service, their family and some staff to enjoy an hour's flight in an aeroplane and meet Santa. Children dressed up in Disney costumes and received presents from Santa.

The representative from the family support team told us about other services available to carers and the family of children and young adults who used the service. This included a bereavement support group that provided support to families after death. There was also a drop in service that was available on a Saturday morning in which relatives could call in for a cup of tea and a chat with a volunteer listener. They told us they would visit people and their families at home to open up discussion. They told us they were skilled with working in children and how through activities they could address emotions such as sadness and fear. Counselling was available to people who used the service and relatives.

Other activities and outings had also been enjoyed. There had been trips to Beamish Museum, meals out at restaurants, trips to the Jaguar garage where children and young adults had been able to sit in the cars. One child who liked water enjoyed going through a car wash. These events were evaluated by the children with smiley faces and thumbs up.

There was a beautiful enclosed garden area for children and young people to enjoy being in the fresh air. There was a trampoline at ground level and swings for enjoyment. The service had a hydrotherapy pool which was well used and during the inspection we spent time observing a child and staff member in the water. The staff member was playing games with the child and swirling them around in the water. The child smiled and giggled with enjoyment. Maximum use was made of the hydrotherapy pool. A relative told us that they could use the hydrotherapy pool at other times when the child was not in respite. They told us they had recently used the pool as a family to celebrate the child's birthday. They had appreciated this as they had spent quality time as a family.

Children took part in a wide range of activities during our visits. Staff helped people to make Easter cards and take parts in arts and crafts associated with Easter. Children enjoyed the experience of having their feet and hands painted. Staff helped children to touch and feel what they were playing with such as cotton wool.

Staff told us they had all received aromatherapy training. During the inspection we spent some time with

children and staff in the sensory room. There was sensory lighting and music playing. It was evident from the time we spent in this room that children enjoyed this form of relaxation and touch.

Staff described to us how meaningful activities which took place had desired outcomes. For example the desired outcome for children and young adults using the hydro pool was making sure they got the most out of the experience, for communication and interaction to take place whilst helping children and young adults to learn and enjoy the water. Staff evaluated if children and young people had enjoyed an activity. Photographs captured smiles and enjoyment that one child had experienced whilst in the hydrotherapy pool. The staff member recorded that the child liked to put their face in the water and scoop the water up in their mouth and how they got excited when they kicked and splashed. A focus on outcomes helped with planning future activities and achieving success.

Relatives and carers we spoke with told us there were plentiful activities and outings. One relative / carer said, "[Child] is always kept busy. They [staff] make things with [child] and always put them on the walls around the hospice." Another relative said, "They have a lot to offer [child] they let [child] explore and play and last time [child] was there they went out to feed the ducks."

Parents and carers told us they could express their views and that staff and the management team were extremely approachable. They told us they felt listened to and they were aware of how to make a complaint should they need to. One parent / carer said, "I don't have any worries, but if I did I could speak to any of the staff and I know they would listen to me."

We were shown a copy of the complaints procedure. The procedure gave people timescales for action and who to contact. Discussion with the registered manager confirmed that any concerns or complaints were taken seriously.

## Is the service well-led?

### Our findings

At the time of our inspection visit, the service had a registered manager in place. A registered manager is a person who has registered with CQC to manage the service.

The registered manager told us about their values which were communicated to staff. The registered manager told us of the importance of honesty, being open and transparent and treating everyone who used the service, their families and staff as individuals.

There was a clear management structure at the hospice. The staff we spoke with were aware of the roles of the management team and told us they were approachable and had a regular presence within the hospice. All staff we spoke with told us they had a commitment to providing a good quality service for people who they supported.

During the inspection the management team were very visible in the hospice and we saw they related well to staff. Staff we spoke with said the management team were approachable and they felt comfortable and confident to question practice or to raise any matters with them. Senior management was available out of hours and at weekends to support staff and come in if necessary.

Our observations over three days of inspection clearly indicated the staff were highly motivated, enthusiastic, kind, supportive and involved. Team work and communication between staff was good, as was communication with people and their visitors. One staff member said, "Staff have worked here for many years and they are very passionate about their work. Staff are fairly outspoken at care team meetings and any concerns are addressed."

Care team meetings were held every month and were well attended. Staff told us this was an opportunity to share information and put their views forward. Staff told us they felt listened to.

We saw the results of the most recent staff survey and actions that had been presented to the board of trustees. One action was to form a staff forum with the view to improve communication across the units. We saw that this had been taken forward and discussed at staff meetings.

Records reviewed showed the service had a range of quality assurance and clinical governance systems in place. Health and safety audits had been conducted and staff at the hospice had started a monthly environmental walkthrough audit, however the template prompts for this audit were vague so in some cases it was difficult to determine the actual checks taking place. Where actions had been identified these were quickly rectified. Infection control audits were performed unannounced by the infection control matron from North Tees Hospital. The audit was a comprehensive assessment of the service. The adult inpatients scored 93% which was the same as the previous year. The audit identified that the sharps bin had not been fitted correctly. Action had been taken to rectify this. Audits were evaluated and where required, action plans were in place to drive improvements. This meant there were systems in place to regularly review and improve the service.

The hospice had an annual business plan which clearly summarised the organisation's aims and objectives, with well-defined forward planning strategies being implemented. This helped the registered provider to focus on continuous improvement by regular assessment and monitoring of the quality of service provided.

The hospice used the Friends and Family Test to help them seek the views of the care and service provided. We looked at the results of surveys received from October 2015 to March 2016 which were extremely positive. Total satisfaction was expressed with the care and service received and people were extremely likely to recommend the service.

Butterwick Hospice has accreditation with Investors in People. The service was reassessed in March 2015 and was seen to continue to meet the requirements of the Investors in People standards.