

Donna Louise Trust

Quality Report

1 Grace Road Trentham Stoke n Trent Staffordshire ST4 8FN Tel: Website:

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This report describes our judgement of the quality of care at this location. It is based on a combination of what we found when we inspected and a review of all information available to CQC including information given to us from patients, the public and other organisations

Ratings

Overall rating for this location	Good	
Are services safe?	Good	
Are services effective?	Good	
Are services caring?	Good	
Are services responsive?	Good	
Are services well-led?	Good	

Overall summary

The Donna Louise Trust is operated by The Donna Louise Trust

Donna Louise Trust provides care for children and young people as they become adults with life threatening or life limiting conditions. Services include specialist respite, palliative, end of life and bereavement care.

The service provides support to families of children and young people both within the hospice, through the

provision of respite and day care, along with support in individual's own homes and the wider community. The hospice supports families across Staffordshire and Cheshire.

Donna Louise Trust provides a residential respite facility for up to eight children and young people at any one time, within individual bedrooms. At the time of our inspection there were four children and young people accessing respite care. The facilities provided by the

hospice include, a multi-sensory room, computer room, soft play area, Jacuzzi, music room, separate lounges for children and young people, an art and crafts area and day care facility. Accommodation is also provided for parents and their families should they wish to stay. The grounds of the hospice incorporated a range of facilities for children to play, distinctive areas of landscaped gardens, areas of interests and relaxation. There was also a purpose-built play area, designed specifically to enable families to play together and create memories.

The service had a registered manager. A registered manager is a person who has registered with the Care Quality Commission to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 and associated Regulations about how the service is run.

Parents and young people we spoke with highly commended the service and staff and had confidence in the care and treatment that was provided.

The registered manager had been in post at The Donna Louise Trust since 2011

The service was registered to provide the one regulated activity of Treatment of disease, disorder or injury (TDDI) to people under the age of 25 years

We inspected this service using our comprehensive inspection methodology. We carried out the inspection on the 09 October 2019

To get to the heart of patients' experiences of care and treatment, we ask the same five questions of all services: are they safe, effective, caring, responsive to people's needs, and well-led? Where we have a legal duty to do so we rate services' performance against each key question as outstanding, good, requires improvement or inadequate.

Throughout the inspection, we took account of what people told us and how the service understood and complied with the Mental Capacity Act 2005.

Services we rate

Our rating of this hospice stayed the same. We rated it as Good overall because:

We found **Good** practice in relation to the hospice:

- The service provided mandatory training in key skills to all staff and made sure everyone completed it.
- Staff understood how to protect children and young people from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.
- The service-controlled infection risk well. Staff kept equipment and the premises clean and used control measures to prevent the spread of infection.
- The service had suitable premises and equipment and looked after them well.
- Staff completed and updated risk assessments for each child or young person. The records were clear and updated regularly.
- The service had enough staff with the right qualifications, skills, training and experience to keep people safe from avoidable harm and to provide the right care and treatment.
- Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date and easily available to all staff providing care.
- The service followed best practice when prescribing and giving medications and children and young people received the right medication at the right dose at the right time.
- The service managed children and young people's safety incidents well. Staff recognised incidents and reported them appropriately. Managers investigated incidents and shared lessons learned with the whole team and the wider service.
- The service provided care and treatment based on national guidance and evidence of its effectiveness. Managers checked to make sure staff followed guidance.
- Staff gave children and young people enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service adjusted this for children and young people's religious, cultural and other preferences.

- Staff assessed and monitored children and young people regularly to see if they were in pain. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.
- Managers monitored the effectiveness of care and treatment and used the findings to improve them. They compared local results with those of other services to learn from them.
- The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and monitor the effectiveness of the service.
- Staff of different kinds worked together as a team to benefit patients. Doctors, nurses and other healthcare professionals supported each other to provide good care.
- The service delivered a full inpatient service for children and young people receiving palliative, respite or end of lie care seven days a week.
- Staff understood their roles and responsibilities under the Mental Capacity Act 2005. They knew how to support patients who lacked capacity to make decisions about their care.
- The service planned and provided services in a way that met the needs of local people.
- The service took account of children, young people and the families individual needs.
- People could access the service when they needed it. Waiting times from referral to treatment and arrangements to admit, treat and discharge patients were in line with good practice.
- The service treated concerns and complaints seriously, investigated them and learned lessons from the results, and shared these with all staff.
- Managers at all levels in the trust had the right skills and abilities to run a service providing high-quality sustainable care.

- The service had a vision for what it wanted to achieve and workable plans to turn it into action developed with involvement from staff, children and young people, and key groups representing the local community.
- Managers across the service promoted a positive culture that supported and valued staff, creating a sense of common purpose based on shared values.
- The service had effective systems for identifying risks, planning to eliminate or reduce them, and coping with both the expected and unexpected.
- The service collected, analysed, managed and used information well to support all its activities, using secure electronic systems with security safeguards.
- The service engaged well with children, young people, staff, the public and local organisations to plan and manage appropriate services and collaborated with partner organisations effectively.
- Staff cared for children, young people and their families with compassion. Feedback confirmed that staff treated them well and with kindness and sensitivity
- Staff provided emotional support to children, young people and their families to minimise their distress.
- Staff ensured that children, young people and their families were partners in decisions about their care and treatment.

Services we rate

Our rating of this service stayed the same. We rated it as good overall

• The service had enough staff to care for children and young people and keep them safe. Staff had training in key skills, understood how to protect children and young people from abuse, and managed safety well. The service-controlled infection risk well. Staff assessed risks to children and young people, acted on them and kept good care records. They managed medicines well. The service managed safety incidents well and learned lessons from them. Staff collected safety information and used it to improve the service.

- Staff cared for children and young people with compassion, empathy and respect. Feedback from parents confirmed that staff treated them and their children well and with kindness. People were truly respected and valued as individuals and empowered as partners in their care, practically, spiritually and emotionally.
- The service responded to children's and young people's individual needs and preferences which were central to the delivery of tailored services. There were innovative approaches to providing integrated person-centred pathways of care that involved other service providers, particularly for children and young people with multiple and complex needs. The services were flexible, provided informed choice and ensured continuity of care.
- There was an embedded team of volunteers who helped support the service There was a separate volunteer induction and training programme. Volunteers were valued members of the service who were provided with support and who felt part of the care team.
- Staff provided good care and treatment, gave children and young people enough to eat and drink. Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked well together for the benefit of children, young

- people and their families, advised them on how to lead healthier lives, supported them to make decisions about their care, and ensured they had access to good information.
- Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, took account of their individual needs, and helped them understand their conditions. They provided good emotional support to children young people, families and care givers.
- The service planned care to meet the needs of local people, took account of individual needs, and made it easy for people to give feedback. People could access the service when they needed it and did not have to wait too long for treatment.
- Leaders ran services well using reliable information systems and supported staff to develop their skills. Staff understood the service's vision and values, and how to apply them in their work. Staff felt respected, supported and valued. They were focused on the needs of the children and young people receiving care. Staff were clear about their roles and accountabilities. The service engaged well with children and young people and the community to plan and manage services and all staff were committed to improving services continually.

Heidi Smoult

Deputy Chief Inspector of Hospitals (Central Region)

Our judgements about each of the main services

Service

Hospice services for children

Summary of each main service Rating

The Donna Louise Trust provides an eight-bed inpatient unit providing short term care for complex symptom management, respite and end of life care for children and young people up to the age of 25 years The service provides support to families of children and young people both within the hospice, in individual's own homes and in the wider community. The hospice supports families across Staffordshire and Cheshire

We rated this service as good overall. Because we rated safe, effective, caring, responsive and well led as good.



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Location name here

Services we looked at Hospice services for children

Background to Donna Louise Trust

The Donna Louise Trust (Stoke-on-Trent) is operated by The Donna Louise Trust. The service was registered with the Care Quality Commission in 2011.

The Donna Louise Trust is a local independent charity offering respite, palliative and end of life care to children and young people with life limiting conditions living within Staffordshire and Cheshire

The Donna Louise Trust has had the same registered manager in post since 2011. 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.

We inspected the service at short notice on Wednesday 9th October 2019.

The team that inspected the service comprised of a CQC lead inspector and a specialist advisor with expertise in palliative care.

Our inspection team

The team that inspected the service comprised of a COC lead inspector and a specialist advisor with expertise in hospice care.

Information about Donna Louise Trust

The Donna Louise Trust is operated by The Donna Louise Trust (Stoke-on-Trent)

The Donna Louise Trust is a hospice which provides a wide range of services for children and young people who have advanced, progressive illnesses and where the focus is on respite care, palliative and end of life care. The service provides a residential respite facility for up to eight children and young people at any one time, within individual bedrooms. At the time of our inspection there were four children accessing respite care. The facilities provided by the hospice include, a multi-sensory room, computer room, soft play area, Jacuzzi, music room, separate lounges for children and young people, an art and crafts area and day care facility. Accommodation is also provided for parents and their families should they wish to stay. The grounds of the hospice incorporated a range of facilities for children to play, and distinctive areas of landscaped gardens, areas of interests and

The Donna Louise Trust is registered to provide the following regulated activities:

The service was registered to provide the one regulated activity of Treatment of disease, disorder or injury (TDDI)

Before we inspected The Donna Louis Trust, we reviewed the information we held

about the service. For example, the statement of purpose for the service and notifications we had received from the service. A notification is information concerning significant events which the service is required to notify us of.

We also asked the service to complete a Provider Information Return (PIR) before the inspection. This is a form which asks the service to supply certain key information concerning the service, what the service does well and improvements they plan to make. We used this information to inform our planning.

During the inspection we spent time observing how staff provided care for people so that we gained a better understanding of their how they experienced care. We

spoke with two family members and 11 staff members We reviewed four children's care records which included medication administration charts and three advanced care plans.

We spoke with the chief executive officer for the service, the registered manager, a member of the counselling team, the education and development lead, two social workers, a team co-ordinator, nursing staff, administrative staff, one chef and two parents,

Track record on safety 4 April 2018 to 31 March 2019

- No Never events
- One serious incident (moderate harm)
- No incidence of a healthcare acquired infection
- The service followed best practice when prescribing and giving medications. Children and young people received the right medication at the right dose at the right time.
- The service managed children and young people's safety incidents well. Staff recognised incidents and reported them appropriately. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave honest information and suitable support.
- The service provided care and treatment based on national guidance and evidence of its effectiveness. Managers checked to make sure staff followed guidance.
- Staff gave children and young people enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary.
- Staff assessed and monitored children and young people regularly to see if they were in pain. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.
- Managers monitored the effectiveness of care and treatment and used the findings to improve them. They compared local results with those of other services to learn from them.

- The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and monitor the effectiveness of the service.
- Staff of different kinds worked together as a team to benefit patients. Doctors, nurses and other healthcare professionals supported each other to provide good care.
- The service delivered a full inpatient service for children and young people receiving respite, palliative and end of life care seven days a week.
- Staff understood their roles and responsibilities under the Mental Health Act 1983 and the Mental Capacity Act 2005. They knew how to support young people experiencing mental ill health and those who lacked capacity to make decisions about their care.
- The service planned and provided services in a way that met the needs of local people.
- The service took account of children and young people's individual needs.
- People could access the service when they needed it. Waiting times from referral to treatment and arrangements to admit, treat and discharge patients were in line with good practice.
- The service treated concerns and complaints seriously, investigated them and learned lessons from the results, and shared these with all staff.
- Managers at all levels in the trust had the right skills and abilities to run a service providing high-quality sustainable care.
- The service had a vision for what it wanted to achieve and workable plans to turn it into action developed with involvement from staff, patients, and key groups representing the local community.
- Managers across the service promoted a positive culture that supported and valued staff, creating a sense of common purpose based on shared values.
- The service had effective systems for identifying risks, planning to eliminate or reduce them, and coping with both the expected and unexpected.

- The service collected, analysed, managed and used information well to support all its activities, using secure electronic systems with security safeguards.
- The service engaged well with children, young people, staff, the public and local organisations to plan and manage appropriate services and collaborated with partner organisations effectively.
- The service was committed to improving services by learning from when things went well and when they went wrong, promoting training, research and innovation.
- Staff cared for children, young people and families with compassion. Feedback confirmed that staff treated them well and with kindness, respect and dignity.
- Staff provided emotional support to children, young people and families to minimise their distress.
- Staff ensured that children, young people and those close to them were partners in decisions about their care and treatment.

The five questions we ask about services and what we found

We always ask the following five questions of services.

Are services safe?

Our rating of safe stayed the same. We rated it as **Good** because:

- The service provided mandatory training in key skills to all staff and made sure everyone completed it.
- Staff understood how to protect patients from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.
- The service-controlled infection risk well. Staff kept themselves, equipment and the premises clean. They used control measures to prevent the spread of infection.
- The service had suitable premises and equipment and looked after them well.
- Staff completed and updated risk assessments for each child and young person. They kept clear records and asked for support when necessary.
- The service had enough staff with the right qualifications, skills, training and experience to keep people safe from avoidable harm and to provide the right care and treatment.
- Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date and easily available to all staff providing care.
- The service managed safety incidents well. Staff recognised incidents and reported them appropriately. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave honest information and suitable support. The service followed best practice when prescribing and giving medications and patients received the right medication at the right dose at the right time.

Are services effective?

Our rating of effective stayed the same. We rated it as **Good** because:

- The service provided care and treatment based on national guidance and evidence-based practice.
- Staff gave children and young people enough food and drink to meet their needs and improve their health.
- Staff assessed and monitored children and young people regularly to see if they were in pain, and supported pain relief in a timely way.
- Staff monitored the effectiveness of care and treatment.

Good



Good



- The service made sure staff were competent for their roles.
- All those responsible for delivering care worked together as a team to benefit children, young people and their families.
- Staff gave children, young people and their families practical support and advice to lead healthier lives.
- Staff supported children, young people and their families to make informed decisions about their care and treatment.

Are services caring?

Our rating of caring stayed the same. We rated it as **Good** because:

- Staff cared for children young people and their families with compassion. Feedback from children young people families, loved ones and care givers, without exception confirmed that staff treated them very well and with kindness and dignity There was a strong, patient-centred culture from all staff.
- Staff were motivated and inspired to offer care for children and young people with kindness, compassion, dignity and respect through supportive relationships.
- Staff provided emotional support to children, young people and their families to minimise their distress. Staff understood that emotional needs were as important as physical needs.
- Staff ensured that patients and those close to them were partners in decisions about their care and treatment. All the relatives and care givers spoke highly of the care their loved one had received and reported that had felt fully involved in all aspects of care and had also had their opinions considered.

Are services responsive?

Our rating of responsive improved. We rated it as **Good** because:

- Services were tailored to meet the needs of individual people and delivered in a way to ensure flexibility, choice and continuity of care and they coordinated care with other services and providers.
- The service planned and provided care in a way that met the needs of local people and the communities served. It also worked with others in the wider system and local organisations to plan care.
- There were innovative approaches to providing integrated person-centred pathways of care that involved other service providers, particularly for children and young people with multiple and complex needs.
- It was easy for people to give feedback and raise concerns about care received

Good



Good



 The service treated concerns and complaints seriously, investigated them and learned lessons from the results and shared these with all staff

Are services well-led?

Our rating of well-led improved. We rated it as **Good** because:

- Managers had the right skills and abilities to run a service providing high-quality sustainable care.
- The service had a vision for what it wanted to achieve and workable plans to turn it into action developed with involvement from staff, patients, and key groups representing the local community.
- Managers promoted a positive culture that supported and valued staff, creating a sense of common purpose based on shared values.
- There was a systematic approach to continually improving the quality of its services and safeguarding high standards of care.
- The service was committed to improving services by learning from when things went well and when they went wrong.
- The service had effective systems for identifying risks, planning to eliminate or reduce them, and coping with both the expected and unexpected.
- The collected, analysed, managed and used information well to support all its activities.
- The service engaged with patients, the public and local organisations to plan and manage appropriate services and collaborated with partner organisations effectively.

Good



Detailed findings from this inspection

Overview of ratings

Our ratings for this location are:

Hospice services for	
children	

Overall

Safe	Effective	Caring	Responsive	Well-led
Good	Good	Good	Good	Good
Good	Good	Good	Good	Good



Safe	Good	
Effective	Good	
Caring	Good	
Responsive	Good	
Well-led	Good	

Are hospice services for children safe?

Good



Our rating of safe stayed the same. We rated it as **good.**

Mandatory training

The service provided mandatory training in key skills to all staff and made sure everyone completed it

The service had a mandatory training and competency framework, compliance was monitored through the training database. All competencies were reviewed on a regular basis to ensure that they met current guidelines and procedures and each competency document had a review date. In key areas such as moving and handling, infection control and confidentiality.

Staff undertook annual mandatory training to ensure they remained suitably skilled to undertake their job role. Staff told us that both the mandatory training and induction were comprehensive.

Whilst not part of the mandatory package, training to support patients with mental health needs, dementia, autism and learning disabilities was provided. Records demonstrated that all staff were up to date with this training.

The service set a target of 100% for mandatory training compliance. Data showed for the period April 2018 to April 2019 a mandatory compliance rate of 88%.

All new members of staff and volunteers underwent a structured and comprehensive induction training programme appropriate to their role. This induction was also undertaken by all bank staff that the service used.

All bank staff had access to all of the trusts training programme, but were paid to attend mandatory training only.

As part of their induction, all bank staff were required to complete two shifts where they were extra to the shift staffing requirements.

Safeguarding

Staff understood how to protect children, young people and adults from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.

The service had an up to date adults and children policy which clearly identified different types of abuse including female safeguarding genital mutilation and child sexual exploitation and how to recognise these. The policy contained a clear flow chart to direct staff to appropriate actions to take if abuse was suspected, with the contact numbers and addresses for the relevant agencies, including the local authority.

The director of care was the safeguarding lead for the service, they had completed level four safeguarding training, as had other relevant key members of staff. All level three trained staff were on a safeguarding rota and available 24/7 for advice and assistance.

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We spoke with staff about safeguarding and found all staff were knowledgeable about safeguarding children and adults. All staff knew how to raise a concern and how to escalate safeguarding issues both internally and externally.

Potential safeguarding concerns and problems, which included changes to a child or young person's health or change in family circumstances; were identified and discussed as part of a weekly meeting involving representatives from all areas of the service. This enabled staff at the meeting to highlight any potential problems and take a pro-active approach in providing a co-ordinated an agreed response to support families and mitigate potential risk.

Staff told us they felt confident to speak to the social work team or their manager if they had any safeguarding concerns.

All staff and volunteers underwent a Disclosure and Barring Service (DBS) check at the correct level for their role as part of the recruitment process.

Cleanliness, infection control and hygiene

The service-controlled infection risk well. Staff used equipment and control measures to protect patients, themselves and others from infection. They kept equipment and the premises visibly clean.

The service-controlled infection risk well. Staff used equipment and control measures to protect children, young people, themselves and others from infection. They kept equipment and the premises visibly clean. All areas of the building were observed to be clean and tidy as were the grounds and the gardens.

Patient areas we inspected were visibly clean, including the reception and waiting area. Staff did not wear uniforms, but all staff were observed following the 'bare below the elbows' protocol. Hand gels were readily available in all areas of the hospice. There were plenty of handwashing sinks to use and lots of dispensers for aprons and various sized gloves, which were all fully stocked.

We saw staff washing their hands before providing care and treatment to patients. They had access to personal protective equipment such as gloves and aprons and were seen to be using these appropriately.

Hand hygiene audits were undertaken quarterly between April 2018 to March 2019. Data showed that for each audit there was a 100% compliance rate trust target of 100%.

All the toilets in the unit were well stocked with soap and paper towels and again were visibly clean and tidy.

Clinical waste disposal systems were used which included sharps bins for the safe disposal of used needles and other equipment.

Good standards of hygiene were maintained. Housekeeping staff were clear in their responsibilities and there were procedures to reduce the risk of cross-infection.

The flooring used enabled staff to carry out appropriate cleaning to maintain a suitable level of hygiene and reduce the risk of cross infection. We saw completed cleaning rotas and we observed housekeeping staff working throughout the day.

Clinical waste and domestic waste bins were emptied by the cleaning staff on the ward area and disposed of through the trusts waste disposal procedures. Staff adhered to correct principle for managing and disposing of sharps. Sharps bins were correctly assembled and were not overfilled (all bins were observed to be below three quarters filled).

There were two cool rooms referred to as 'garden rooms'. These provided facilities for relatives such as comfortable seating and privacy. There were various 'cooling' items such as blankets, cots and a bed to keep the deceased cool. The air conditioning was also reduced to 12 decrees Celsius.

Environment and equipment

The design, maintenance and use of facilities, premises and equipment kept people safe. Staff were trained to use them. Staff managed clinical waste well

The service was based at a purpose-built accommodation. The building was on two levels with stairs and a lift for staff access. All patient care was based on the ground floor.

There was a reception desk and a waiting area, with comfortable seating. People entered through a set of automatic doors into the reception area. Behind the receptionist was another set of automatic doors into the



hospice. These were accessible only by staff who wore secure electronic access cards. All visitors to the hospice, were seen by the receptionist who would then ring through to a member of staff who would attend reception and accompany people into the hospice. Nobody was allowed to enter without a member of staff to accompany them.

At the reception desk, there was no emergency call bell to notify other staff if a visitor was being aggressive or other help was needed. The receptionist told us, they would use the phone to ring staff in the normal manner and advise if there was a problem, however, this type of situation had never occurred.

We observed staff in the use of specialist equipment which included beds and seating equipment, feeding equipment, non-invasive ventilator support and adapted play equipment.

Hoists were available for the safe moving and handling of patients. We saw that when not in use they were cleaned and stored safely.

Medical equipment was checked and serviced in line with manufacturers' guidance. Syringe pumps were serviced annually and when needed. The service used the T34 McKinley syringe pumps for patients who required continuous infusion of medication to control their symptoms and these met the current requirements of the Medicines and Healthcare Regulatory Agency (MHRA) for end of life care patients who required continuous symptom management. This meant that patients were protected from harm when a syringe pump was used to administer a continuous infusion of medication because the syringe pumps used were tamperproof and had the recommended alarm features.

Rooms were accessible to staff by a secure key pad entry. For example, the rooms which held medicines and cleaning equipment were secured to prevent patient harm.

There were arrangements in place for the testing of electrical equipment. We saw during our inspection that equipment had been tested for safety and had stickers on with the date they had been serviced.

Assessing and responding to patient risk

Staff completed and updated risk assessments for each patient and removed or minimised risks. Risk assessments considered patients who were deteriorating and in the last days or hours of their life.

Staff completed regular risk assessments for all children and young people at the hospice. We reviewed four sets of notes, all included up to date care plans and risk assessments. Risk assessments included information concerning mobility, the risks of seizures and the management of skin integrity, choking risks and risks relating to patient's health conditions. Staff also demonstrated they knew what action to take to keep children and young people safe.

There were emergency plans in place for children and young people who experienced epileptic seizures. Staff had received training in administering emergency epilepsy medicine and were clear about the actions they needed to take when children and young people experienced seizures.

Individualised epilepsy protocols were in place which gave staff clear direction on how to identify seizure activity and how staff should use medicines to respond. Staff we spoke with were aware of the possible side effects of the emergency medicines and described how they would observe children and young people for signs that might require further medical intervention.

Some children and young people required long term ventilation (LTV); this is the ongoing use of mechanical ventilation to help them breathe. Staff understood the risks when children and young people required the use of mechanical ventilators. For example, they could describe how they would identify possible mucus build up and had been trained to perform the required suction to prevent children and young people from choking.

Records showed checks had been completed routinely to ensure the ventilation equipment was in working order and remained safe to use.

At the time of our inspection, the hydrotherapy pool was out of action as it was being refurbished, however, staff told us of regular swimming sessions with the children and young people.

Staff understood each child and young person's vulnerability to infection and took action to protect them



from the spread of infection. We saw staff washed their hands prior to undertaking any procedures and when delivering care and they had easy access to hand washing facilities in the hospice.

The hospice undertook body maps of all children and young people admitted to the hospice. A body map is a schematic diagram of the front and back of the child or young person which is anatomically correct. The document is used clinically to document the location of lesions, lacerations, bruises or rashes and is for future reference.

Data showed that in January 2019 84% of children and young people had a body map undertaken, against the trust target of 100%. Data also showed that 70% of the of the body maps had been undertaken correctly, however 16% of the children or young people had not had a body map undertaken on admission to the hospice.

Social and complimentary therapy activities were risk assessed for each child or young person and this was noted in their care plans.

Staffing

The service had enough staff with the right qualifications, skills, training and experience to keep patients safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix.

There were sufficient numbers of staff employed in appropriate roles to provide care for the children and young people in the hospice and to keep them safe. However, the hospice was operating at a five-bed capacity during the time of our inspection due to lack of funding and challenge in recruiting registered children's nurses. The roles included nursing, medical, care support staff, counsellors, allied health and social workers.

During our inspection, we saw that staff were deployed effectively. Staffing levels were determined following the assessments of each individual child or young person. Each child or young person was supported on a one to one basis by a nurse and or a care worker depending on their needs. Following risk assessments some children or young people were supported by two staff or nurses when required.

An out of hours G.P. on call system ensured emergency medical cover was available if needed.

The minimum safe staffing levels were two registered nurses per shift, with the requirement for one nurse per shift to be a qualified children's nurse. All care provision was supported by care support workers who provided one to one care for the children and young people.

Where there was an unplanned admission the staff competencies and experience were taken in account and adjusted to ensure the correct skill mix to provide safe care where possible, if this was not achievable, the admission was refused.

Staff working within all areas of the service told us staffing levels were appropriate for people's holistic care needs and told us they had enough time to give compassionate and responsive care.

The registered manager told us that recruiting qualified children nurse was very difficult and that at the time of our inspection, only five of the eight beds were being utilised as there were not enough nursing staff to ensure safe staffing levels for eight children or young people.

Data showed the service was one point six whole time equivalent nursing posts and one nursing care coordinator under compliment.

Medical cover was provided by a combination of consultant paediatric sessions and on-call GP's, which provided 24/7 access to medical support. This was reviewed regularly, with all professional registrations checked monthly.

The hospice had access to four sessions per week of consultant paediatrician advice and support from the local NHS trust. Additionally, the hospice was able to call the children's medical assessment unit at the local NHS trust for advice if needed outside of the four paediatric consultant sessions, advice would also be sought from the child's lead consultant.

Consultant paediatric advice could occasionally and on a pre-arranged basis, be available out of hours for end of life care.

The out of hours local GP service provided an on-call service. This service was provided via a service level agreement.

Records



Staff kept detailed records of patients' care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.

The service used an electronic patient record system to store patient records and produce letters to GPs and referring clinicians. Letters were sent to GPs by encrypted email and also to the referring clinician.

All paper records were scanned and stored against the electronic patient record then destroyed.

There had been no instances when a patient record was not available.

Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date and easily available to all staff providing care. Personalised care plans documented individual's care, which included social stimulation, activities and play. Care plans for those receiving end of life care were regularly reviewed. This enabled staff to respond to changing needs and included information for their on-going care following death.

We looked at four patient records on the system and saw that the system was secure. All the records we viewed included detailed information about the management of symptoms,

discussions and interventions, there was a full past medical history and family history.

The care coordination team for the hospice service liaised with relevant professionals to ensure all information held on children and young people was up to date and any changes to care was documented in the care records.

Changes made to a child's medical care or symptom management plans were communicated to the child's lead consultant or relevant professional, by secure email.

The system had a 'flagging' system to advise if a child or young person was on a child protection plan or classed as a child in need. We looked at the electronic case notes of one child who was on a child protection plan and saw the entries were detailed including who was allowed to have contact with the child.

Medicines

The service used systems and processes to safely administer, record and store medicines.

The service followed best practice and local policy when prescribing, dispensing, delivering, storing and monitoring medicines. Children and young people received the right medication, at the right dose at the right time.

Medicines were stored correctly. Controlled drugs were appropriately stored in line with current legislation. We saw the temperature of areas used to store medicines was recorded daily and was within safe limits. An audit of the controlled drug management for July 2019 showed 100% compliance.

There were procedures in place for stock control, administration and storage of non-controlled drugs and a controlled drugs policy and procedures.

The service kept a medicines stock control record and a spreadsheet showed those medicines that were within a month of their expiry date.

Medicines were stored in lockable and dedicated cupboards that were secured in place. Stock was rotated in accordance with expiry dates.

Medicines that required storage at temperatures below eight degrees centigrade were appropriately stored in pharmaceutical grade lockable fridges with temperature monitoring equipment.

Some children and young people due to their illness, required continuous medication administration through a syringe pump to control their symptoms. Staff were knowledgeable about syringe pumps and the medicines which were usually placed in them. Staff told us some patients required more than one due to incompatibilities between some medicines. All staff were required to undergo specific competency training for managing a syringe pump, with a duration of supervised practice prior to being able to lead on this.

Bank nurses were required to have their medicines administration with a permanent registered nurse whilst on a bank shift but if they wanted to single check medicines they were required to complete the trusts medicines management competency, including a practical assessment.



Bank nurses will be not allowed to care for patients who were invasively ventilated or who had a tracheostomy without providing evidence of competency or completing the hospice own tracheostomy and competency training.

The hospice had a service level agreement with the local NHS pharmacy for the supply of medicines.

We saw records of fridge temperature monitoring and no instances where the temperature had been out of range.

Incidents

The service managed patient safety incidents well. Staff recognised and reported incidents and near misses. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave patients honest information and suitable support. Managers ensured that actions from patient safety alerts were implemented and monitored.

The service knew how to manage patient safety incidents. Systems were in place to monitor and manage accidents and incidents to maintain children's and young people's safety. Staff knew how to recognise and report incidents and had received appropriate training.

The service had an incident management policy which was in date. The policy gave clear guidelines about the process for reporting and categorising incidents and encouraged an open culture of incident reporting.

There was a clear process for clinical and non-clinical incident reporting including near misses. The director of care told us they had ensured robust reporting of incidents through the adoption of a no blame culture, with outcomes and actions used as learning to improve or change practice if required.

Staff reported incidents through the services electronic reporting system. All staff understood their responsibilities to raise concerns and report incidents and near misses. Staff told us that learning from incidents was shared during study days, meetings and supervision.

There was a risk management plan is in place to ensure safe care when both children and adults are in the same environment.

Managers investigated incidents and shared lessons learned with the whole team and the wider service at regular team meetings, electronic communications and training sessions. When things went wrong, staff apologised and gave honest information and suitable support to the patients and their families. The registered manager audited incidents and accidents to analyse any trends or to identify where improvements could be made to minimise their reoccurrence. Lessons were learnt, and improvement.

Data showed that from the period May 2018 to May 2019 the service reported no never events.

A never event is a serious, wholly preventable patient safety incident that has the potential to cause serious patient harm or death, has occurred in the past and is easily recognisable and clearly defined.

During the same period, the service reported one serious incident which had been fully investigated with lessons learnt and information disseminated to staff.

The service had a comprehensive whistleblowing policy and procedure in place that included duty of candour responsibilities and requirements.

Staff had a clear understanding of the duty of candour. The duty of candour is a regulatory duty that relates to openness and transparency and requires providers of health and social care services to notify patients (or other relevant persons) of certain 'notifiable safety incidents' and provide reasonable support to that person. The hospice had not had reason to apply duty of candour for the reporting period of May 2018 to May 2019.

Are hospice services for children effective? (for example, treatment is effective)

Our rating of effective stayed the same. We rated it as **good.**

Evidence-based care and treatment. The service provided services based on national guidance



The service offered in-patient, palliative and respite care to children up to the age of 25 who had life limiting or life-threatening conditions. There was also the provision of day care services, alternative therapy treatments and sibling support groups.

The service completed a range of audits, including audits of medicines management, patient safety, infection prevention controls. All the on-going work and updates were fed back to the clinical governance committee. Audit results were shared with staff by email and at team meetings. Recommendations from the audits were incorporated into any action plans and monitored by the clinical governance quarterly meeting.

Policies and procedures were readily available for all staff. Policies appropriately referenced current good practice and national guidelines from organisations such as the National Institute for Health and Care Excellence (NICE) and Royal Colleges. The documents contained flow charts and contact details of relevant agencies, as well as clear guidance for staff.

The director of care was responsible for ensuring that policies and procedures were kept up to date and in line with national guidance. The hospice was signed up to the notification service for the National Institute for Health and Care Excellence and updated any policies and procedures in accordance with updated national guidelines.

We saw that clinical policies and procedures and care pathways reflected national guidance and were available for staff to review. For recording the outcome of planning discussions, an ACP is designed to communicate the health care wishes of children who have chronic and life limiting conditions.

The service was using the Child and Young Persons Advanced Care plan document (CYPACP) and life-limiting conditions. The document was designed to communicate the health-care wishes of children and young people who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates. It provides a framework for both discussing and documenting the agreed wishes of a child or young person and their parents, when the child or young person develops potentially

life-threatening complications of their condition. The CYPACP incorporated the Recommended summery Plan for Emergency Care and Treatment (ReSPECT), which included decisions concerning resuscitation.

The CYPACP was designed so that it can be used in all environments that the child or young person encounters. For example, home, hospital, school, hospice and respite care. It is also appropriate for use by the ambulance service.

Where a child or young person is considered to have capacity, their views are considered in the decision-making process Capacity is related to specific decisions so a child or young person may have capacity for one decision and not another.

The CYPACP has a section on a resuscitation plan and or as an end-of-life care plan. The plan is a legal document and remains valid when parent(s) or next of kin cannot be contacted.

We saw during our inspection that Advance Care Plans were completed and reviewed regularly with the children and young people and their families to identify wishes in life and at the point of death. These were conducted in a sensitive time responsive manner.

Symptom management plans and health passports were utilised to achieve the best possible health status for children and young people. These included pain assessments, seizure management plans, behaviour support plans, communication plans and the management of other signs and symptoms. We saw during our inspection they were reviewed regularly in response to the changing symptoms and condition of the child or young person.

Health passports for children and young people were designed for the parents or care givers to have the opportunity to advise the health professionals about their child or young person so that their care experience is a positive one as far as is possible. The health passport aims to give staff extra information about the child or young person without the parents and or care givers having to regularly repeat everything about the child or young person in different care settings.

The service had guidelines policies and procedures that were up to date and accessible to staff on the trusts



electronic intranet based on current guidance relating to end of life care. Equality and diversity training which part of the mandatory training programme is was also easily accessible.

Nutrition and hydration

Staff gave children and young people enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for patients' religious, cultural and other needs.

The hospice had a fully equipped kitchen with catering overseen by appropriately trained staff who provided a wide range of food to suit individual needs and specialised diets.

The hospice delivered a catering service that met all the areas of nutritional needs. There were a number of different aspects to the food served by the kitchen. For example, culturally appropriate, vegetarian, vegan and specific diets concerned with food allergies. The likes and dislikes of the children and young people were also recorded.

There was provision for children and young people who did not want regular meals or who did not want to eat at set times. Staff told us they always kept a selection of sandwiches, soups and cereals for children and young people and they would always try to ensure whatever the child or young person wanted for their meals, was provided.

Parents told us the nurses were regularly asking them if they would like a drink or a snack and that the food was very good and that there were plenty of drinks available.

Each child had a detailed care plan with specific details on dietary, feeding and hydration regimes which was updated at every admission to the hospice A food and drink plan was attached to nutritional part of the care plan on the database.

The service used their own saw the malnutrition screening tool to identify children and young people who were malnourished, at risk of malnutrition or obese. It also included management guidelines, which can be used to develop a care plan.

We saw that all aspects associated with dietary requirements were covered. For example, how, the child and young person was fed and how often. The care plan also included enteral feeding routines. Enteral tube feeding (ETF) is the intake of food via the gastrointestinal (GI) tract. This means nutrition normally taken through the mouth, is instead taken through a tube that goes directly to the stomach or small intestine. Enteral tube feeding is used to feed patients who cannot achieve an adequate oral intake from food and or oral nutritional supplements, or who cannot eat or drink safely. The aim is to improve nutritional intake and so improve or maintain the patient's nutritional status.

All nursing and care support staff (with exception of bank care support) were competent to give enteral feeds.

Records showed staff working in partnership with speech and language therapists, dietetics and paediatricians with regards to nutrition, and included input from the physiotherapist in terms of appropriate and safe positioning of individuals for eating and drinking.

Pain relief

Staff assessed and monitored children and young people regularly to see if they were in pain and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.

We saw that care followed the National Institute for Health and Care Excellence (NICE) Quality Standard NG61. This quality standard defines clinical best practice for end of life care which includes the prescribing of strong opioids for pain in palliative care for infants, children and young people with life-limiting conditions up to and including the age of 17 years.

The service also followed the National Institute for Health and Care Excellence (NICE) Quality Standard CG140. This quality standard defines clinical best practice in the safe and effective prescribing of strong opioids for pain in palliative care of adults for those young people over the age of 17.

We saw children and young people had been prescribed pain relief medication as and when required (PRN) so that breakthrough pain could be managed. Breakthrough pain



can occur in between regular, planned pain relief. Staff confirmed syringe pumps were accessible if a patient was receiving end of life care and required subcutaneous medication for pain relief.

Staff assessed and monitored children and young regularly to see if they were in pain. They supported those unable to communicate using a 'Faces pain scale' rating pictorial assessment tool and gave additional pain relief to ease pain as required.

We reviewed the records four children and found the care had been provided and managed appropriately. We found care plans and assessment tools for pain to be in place and where the pain had been assessed as high the records showed how this was managed effectively. Records showed the parents had been actively involved in the assessment of pain and its

Parents told us staff had discussed pain relief with them and they understood what they were taking and the effect the medicine would have.

A pain assessments audit undertaken in August 2019 found that 100% of the children and young people treated by the hospice had a pain assessment completed.

Patient outcomes

Staff monitored the effectiveness of care and treatment. They used the findings to make improvements and achieved good outcomes for patients.

The service had a strategic approach to monitoring outcomes, which included future development to improve outcome monitoring and had processes aimed at identifying how well it met children and young people's needs, and the scope of the services provided. This was undertaken and monitored through team dashboards and had an audit schedule for clinical services which was reviewed at the quarterly clinical governance and care development committee.

The audit schedule covered a number of subjects, for example controlled drugs, transition, mandatory training and privacy.

The service audited itself against national standards of best practice. They had delegated leads for the main areas who have responsibility for maintaining up to date best practice. For example, service user feedback.

Staff attended regular professional peer group meetings, where people could use their shared experiences to give and receive advice support from each other.

Patients and families were given the opportunity to complete an electronic feedback survey using iPads. This was analysed quarterly, and a report produced for the clinical governance meeting.

The service records preferred place of death on the child's Advanced Care Plan, However not all children will have an ACP. Children and families were given the opportunity to complete an ACP on a regular basis.

Competent staff

The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.

The service had a mandatory training programme and in addition to this there was a clinical training and competency framework for all clinical staff.

Staff told us that they could access a variety of training relevant to their role. Volunteers recruited to the hospice undertook the mandatory training and induction programme within the hospice.

The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and monitor the effectiveness of the service.

Annual appraisals give an opportunity for staff and managers to meet, review performance and development opportunities which promotes competence, well-being and capability. All qualified nursing, medical and health care support workers we spoke with confirmed they had received a meaningful appraisal within the past year.

All staff told us they felt very well supported and competent to fulfil their role.

Data showed that in the past 12 months, 100% of nurses had received their appraisal, against a trust target of 100%. With 100% of allied health receiving their appraisal during the same period.

Qualified nurses working at the hospice undertook continuous professional development to maintain their registration with the Nursing Midwifery Council (NMC).

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Staff received regular supervision and opportunities to attend meetings. A nurse told us they had a clinical supervision planned and available as a group. Clinical supervision was available on a one to one basis monthly with one session per year being mandatory. A range of other regular supervision was available to all staff, including safeguarding, peer and line management supervision. Staff said following significant events a team de-brief took place, which enabled staff to discuss how a particular situation was managed and how staff experience could be used for any future situations.

Multidisciplinary working

All those responsible for delivering care worked together as a team to benefit patients.

Staff of different kinds worked together as a team to benefit patients. Doctors, nurse and other healthcare professionals supported each other to provide good person-centred care.

There were effective systems to facilitate communication amongst, staff, children young people children, parents and external health and social care professionals. We attended a nursing handover at shift change time. We found the handover to be concise and included all the relevant information about each child and young person. The information shared during handover ensured that care delivered was safe and timely.

All members of the multidisciplinary team worked and interacted well with each other to enable a coordinated approach to the way in which care was delivered. We saw evidence of regular input from counsellors' occupational therapists, physiotherapists and social workers involved in the care and treatment of children and young people. Staff and volunteers worked closely and effectively together with a culture of respect for each other's roles.

Staff also worked in partnership with external providers of palliative and end of life care in assessing, planning and delivering care and treatment. This included GP's, primary care nursing teams, allied health professionals, social care providers, secondary care and other voluntary sector workers. All relevant teams, services and organisations were informed in writing, over the telephone or by email if children and young people were discharged from the service. Discharges were undertaken

at an appropriate time of day and only done when any necessary ongoing care is in place. We saw these recorded in-patient records, in discussions with staff and those who used the service.

The service had its own transition policy, which followed NICE Guidance NG43 which is concerned with the transition of young people from children services to adult's health and social care provision.

The hospice worked in close partnership with adult care services to support all young people through transition to adult care. The hospice employed a social worker with experience in transition support and a young adult support worker to assist with this.

All young people under the care of the hospice were prepared for and supported through the transition process by their care coordinator, the adult support worker and the adult social worker. Each young person has a plan in place for continuing health and medical support which is part of their health passport to assist in the transition from child to adult health care services. The hospice works closely with the learning disability health facilitators, adult hospice teams and other relevant staff.

Health promotion

Staff gave patients practical support to help them live well until they died.

The hospice promoted a healthy diet and wellbeing sessions were part of the provision including various forms of and relaxation and alternative therapies.

As well as supporting patients the hospice worked to identify the needs of families and care givers and part of this was to ensure they were supported to remain healthy.

One parent we spoke to said the staff always asked how they were and if they wanted a cup of tea and a chat.

Consent and Mental Capacity Act

Staff supported young people to make informed decisions about their care and treatment. They knew how to support patients who lacked capacity to make their own decisions or were experiencing mental ill health.



Parents, we spoke with told us staff did not provide any care without first asking their permission. All the patient records we looked at, we saw copies of signed consent forms and that consent to treatment was obtained appropriately.

The Mental Capacity Act (2005) allows a certain level of restraint and restriction to be used if they are in a person's best interest. Deprivation of Liberty Safeguards (DoLS), are needed if the restriction and restraint used will deprive a person of their liberty. Staff we spoke with could describe the process of assessing capacity and the requirements for obtaining consent if the patient was assessed as lacking capacity.

DoLS assessment were initiated with the local authority when a young person who is an in-patient turns 18 years old.

Staff demonstrated a good understanding and application of the Gillick competence. This is when children under 16 can consent if they have sufficient understanding and intelligence to fully understand what is involved in a proposed treatment, including its purpose, nature, likely effects and risks, chances of success and the availability of other options.

All mental capacity and DoLs assessments are identified by the adult's social worker who then will then make a referral to the local authority for completion.

Are hospice services for children caring?

Good



Our rating of caring improved. We rated it as **good**

Compassionate care

Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and took account of their individual needs.

The majority of care was provided on a one to one basis. We saw that time was taken to deliver care that was personalised to the individual needs of each child or young person. For example, selection of clothes, what time they would like to get up in the morning and go to bed at night and what music do they like.

Throughout our inspection and without any exception we observed that children and young people were at the heart of everything staff members did. Staff responded compassionately when children, young people needed help. Support was always given by caring staff, to meet the needs of the children and young people and their families and feedback from people who used the service was continually positive about the way staff treated people. Staff identified children and young people who needed extra support and discussed changes care and treatment with the families and or their care givers.

Patients were treated with dignity, compassion and empathy. We observed staff introducing themselves and providing care in a respectful manner.

The service provided support to families and care givers to maintain their own health and wellbeing.

There was a strong, patient-centred culture from all staff. Staff were motivated and inspired to offer care for children and young people with kindness, compassion, dignity and respect through supportive relationships with children, young people and their families, care givers and loved ones.

We observed all staff members speaking to children and young people and their relatives with compassion and we observed sensitivity being shown during those conversations.

One of the parent told us, "The staff are all fantastic"

All the staff at the hospice were dedicated about delivering compassionate care, with the child or young person at the centre of everything they did.

The hospice had a dedicated well-being team which provided spiritual care and counselling support for families which extended after death.

Emotional support

Staff provided emotional support to patients, families and carers to minimise their distress. They understood patients' personal, cultural and religious needs.

Children and young people who used service and those close to them were active partners in their care. Staff were fully committed to working in partnership with everyone relevant to the child or young person.



Ongoing support for parents, siblings was available from the care coordinator, social worker and emotional support team. Parent and care giver support groups, sibling support groups and activities. Complimentary therapies were available for parents and care givers.

All families had access to counselling and emotional support both prior to and post bereavement.

The service provided person centred care with people were placed at the heart of the service at all times. People were given every opportunity to express their views and be involved in making decisions about their care.

The service offered a range of emotional, practical and psychological support to parents, children and young people for example, the counselling team was based at the hospice and was available for children young people, parents, siblings and other members of the family who needed the service.

We saw all staff offering encouragement to parents in a reassuring manner, to alleviate anxiety. All discussions concerning aspects of patient care involved family members opinions being heard and valued

We observed staff supporting a children in the multi-sensory room, we could see the children was laughing and smiling was thoroughly enjoying the experience.

Understanding and involvement of children and young people and those close to them

Staff supported and involved patients, families and care givers to understand their condition and make decisions about their care and treatment.

Family support was seen as essential to children and young people's wellbeing and the needs of parents, grandparents and siblings were supported.

Children, young people and those close to them were partners in decisions about their care and treatment. Parents unanimously spoke highly of the care their child had received and reported that had felt fully involved in all aspects of care and had also had their opinions fully considered.

All the staff we spoke with showed a fundamental awareness of the importance of treating children, young people and their families in a sensitive manner.

Where appropriate, dependent on the age of the child, the nursing staff explained the treatment to the child and asked them if they were happy and had any questions.

We saw staff discuss care issues with parents, these were clearly documented in the child's notes.

We saw evidence in children's advance care plans that parents were involved in decisions about care and treatment and in developing the care plans. Parents told us that staff answered questions about care and treatment openly and in plain English.

Consideration of privacy and dignity was consistently embedded in everything the staff did and staff ensured that sensitive communication took place between staff and the child or young person in an atmosphere of dignity and respect.

Parents we spoke with told us their privacy and dignity was always maintained by staff. We observed, staff speaking in hushed tones near a sleeping child and using eye contact with children and open body language.

Parents told us that nothing was too much trouble for staff, they took time to listen and would go that 'extra mile' to ensure they were cared for and that whatever they needed was provided.

Because children with complex health needs are living longer, the hospice had employed a dedicated transition social worker who helped prepare families as their child begins to reach an age where they were too old for a children's hospice service. We heard how the transition social worker supported families to understand and access the support and respite services available to them in adult services. The transition social worker and staff were involved in meetings between health, education and social care professionals to ensure a co-ordinated approach for children and young people as it can be challenging for families to find services that can meet their children's needs.

The transition social worker described how they had supported a number of young people and their families to identify adult hospice services and how their transition is been planned on an individual basis. The hospice had worked proactively in partnership with these young



people, their families and adult services to plan their care and support with them and ensure their families would continue to receive the respite they required to enable them to continue to care for young adults at home.



Our rating of responsive improved. We rated it as **good.**

Planning and delivering services which meet people's needs

The service planned and provided care in a way that met the needs of local people and the communities served. It also worked with others in the wider system and local organisations to plan care.

The hospice is situated near the centre of Stoke - on -Trent and easily accessible by car with a major bus route nearby. There were two main car parks and an overspill small car park at the front and the side of the hospice, where all visitors to the hospice could park for free.

The entrance to the hospice was through automatic glass doors, making it accessible for those people with prams or wheelchairs. Behind the receptionist were another set of automatic glass doors that were only accessible by an electronic staff key fob, or by the receptionist pressing a door release button under their desk.

On entering the hospice, the receptionist would ask visitors to take a seat and ring through for staff to collect the visitors. Visitors were not allowed into the hospice without a member of staff to accompany them.

The services provided by the hospice reflected the needs of the population they served, and they ensured flexibility, choice and continuity of care. We found the facilities and premises were appropriate for the services that were delivered. For example, the leadership team demonstrated a passion for offering equal access to service for all children and young people who needed it . We found this ethos of providing high-quality care with equitability of access transcended through all levels of staff within the organisation.

The hospice provided a residential respite facility for up to eight children and young people at any one time, within individual bedrooms. At the time of our inspection there were four children accessing respite care. The facilities provided by the hospice included, a multi-sensory room, computer room, soft play area, jacuzzi, music room, separate lounges for children and young people, an art and crafts area and day care facility. Accommodation was also provided for parents and their families should they wish to stay. The grounds of the hospice incorporated a range of facilities for children to play, distinctive areas of landscaped gardens, areas of interests and relaxation. There was also a purpose-built play area, designed specifically to enable families to play together and create memories.

The counselling service led a dad's group once a month. This was a group which provided a safe environment for dads to talk and be heard. One of the counsellors told us they always started the group with 'chip butties' and would then have a range of activities they would undertake, for example days out undertaking various activities such as off-road driving and clay pigeon shooting.

Families were asked what they wanted to follow the death of a loved one as part of the advanced care planning. We also saw evidence that staff took account of patients' spiritual needs within end of life care plans. Staff supported bereaved families with practical arrangements such as liaising with funeral directors and registering deaths.

The hospice ran several events throughout the year from raffles, to themed events that everyone in the community could attend. Special days were well attended by local people, thereby strengthening the relationship between the hospice and the local community. For example, the hospice annual Christmas fayre.

The hospice was in the process of constructing a further building development of the service in its provision of respite and day care for young people 19 years and above. This was a purpose-built building adjacent to the hospice.

One of the social workers employed by the hospice showed us details of the campaign they were involved in to raise awareness for appropriate housing for the



children and young people and their families who were involved with the hospice. They had made a submission to a national conference to promote the work underway on the Housing project.

The hospice provided a play as therapy group monthly session that runs for two hours with refreshments provided, which is a parent and child group for children under four years old with complex or life limiting conditions. This was organised by a care support worker in the hospice with input from the play leader and the physiotherapist. The group provided themed therapeutic play activities including messy and sensory play, creative sessions that included music, stories, group activities and parent engaged activities.

The aim of the group was to provide an environment for children and parents to bond through fun and enjoyable activities and for everyone to socialise with others in a similar situation.

Between July 2017 and May 2019, 23 sessions have been held with 81 children and parents attending.

The hospice had policies to ensure the services offered did not discriminate against people on the basis of protected characteristics and were able to support people with various faith needs.

Meeting people's individual needs

The service was inclusive and took account of children, young people and their families' individual needs and preferences. Staff made reasonable adjustments to help patients access services. They coordinated care with other services and providers.

There were activities for children young people and their siblings, for example painting, activities in the sensory room, playing with toys and games as well as using the outside play area and equipment and art therapy.

We observed staff supporting children in the multi-sensory room. We could see the children were laughing and smiling and were thoroughly enjoying the experience.

There were two support groups for siblings. These groups engaged in direct work with siblings of all ages through organised activities. For example, the sibling groups were encouraged to make friends and express the way they may feel about their sick or deceased siblings.

There were facilities and equipment provided at the hospice which enabled children and young people to live as independently as possible. For example, there were computer packages which enabled children to communicate by moving their eyes, indicating their choices and wishes. Height adjustable equipment enabled the space to be effectively used by children and young people of different ages and needs. For example, height adjustable sinks in the bedrooms. There were specialist chairs referred to as 'P pods', these enabled children and young people to sit comfortably and move around the hospice.

Peoples individual needs and preferences were central to the delivery of tailored services.

There were innovative approaches to providing integrated person-centred pathways of care that involved other service providers, particularly for people with multiple and complex needs. For example the counselling service provided art therapy for anyone who wanted to partake in it. We saw this displayed throughout the hospice. Additionally, external exhibitions had been set up to display people's work, any money raised from the sales had been invested into the hospice.

Children and young people were taken out on day trips or for a short spell whilst at the hospice. There was a range of activities throughout the year on the activities calendar. For example, there were day outings to external clubs and the Saturday morning club group.

The service had an equality and diversity inclusion and human rights policy which included the privacy and dignity expectations of staff, for example encouraging practices that took into account the rights of individuals to be treated with dignity and respect.

The hospice had access to a translation service to meet the needs of those whose first language was not English. Information leaflets could be adapted to braille and other languages and formats as required.

Children, young people and their families could access a range of therapies, including complementary therapies. There was also day therapy which offered to a range of clinical, emotional and spiritual support services in a friendly and relaxed atmosphere. Day therapy was attended by nurses, physiotherapists and volunteers.

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Care after death was managed sensitively and, in a way which respected the wishes of families while following the appropriate process. For example, relatives wishing to view their loved one were allowed to stay with them for an extended amount of time. The hospice provided two 'cool rooms' referred to as the 'Garden Room' so that following a child or young person's death, families could spend time with them. The facility included a family lounge where families could spend time together. The 'cool rooms' were neutrally decorated and could be personalised by each parent. The service had two cool rooms as children and young people who had died at the local NHS trust were often transferred for viewing at the hospice by the family and loved ones.

There was a self-contained domestic short term living area which had separate access from the family rooms, which meant people did not have to access other areas of the hospice if they chose not to. The rooms had dedicated cupboards containing end of life care boxes which held practical items to support a range of religious practices and beliefs such as prayer books

Whenever the garden rooms were occupied by a deceased child or young person, the service had a senstivie system for advising staff on entering and leaving the hospice of this fact.

There were a number of leaflets and practical help guides available for families. These included subjects such as what to say to someone who is dying and how to support relatives who have suffered a bereavement. Each leaflet contained details of useful contacts.

The hospice had signed up to Together for Short Lives which is the UK registered charity for children's palliative care. Together for Short Lives' vision is for children and young people in the UK with life-limiting and life-threatening conditions and their families to have as fulfilling lives as possible, and the best care at the end of life.

One of the nurses was a learning disability champion, who was in the process of developing staff knowledge and confidence in the use of relevant assessments and intervention tools.

The hospice had a number of memory boxes. All were made up individually after the death, for the families to remember their loved one. Each memory box contained items special to the deceased including letters, photographs and whatever else was a special memory.

Access to the right care at the right time

Children and young people could access the specialist palliative care service when they needed it. Waiting times from referral to achievement of preferred place of care and death were in line with good practice.

Staff delivered responsive care at the right time that was personalised to each individual. Every child or young person had a minimum of one member of nursing staff or member of the care team staff dedicated to their care each day, and in some instances two staff dependent upon their needs. The allocated staff were responsible for all aspects of the child or young person's care, which included their personal and health care needs along with their social needs, which included play and relaxation.

The hospice had an admissions policy. This was in line with other hospice care providers in the area and met the needs of local children and young people with life-limiting illness.

Children and young people were referred and signposted to appropriate services without delay in order to respond quickly to their needs. These referrals were discussed at multi-disciplinary meetings and took account of what children, young people and their families wanted to achieve.

There were specific staff with the skills to understand and meet the needs of children and their families in relation to their emotional support and the daily practical assistance they may need. Some children, young people, their parents, grandparents and siblings were referred for psychological, emotional and practical support.

Staff met daily to discuss new referrals, significant issues, and any aspects affecting families with a view to an agreed way forward to provide support. This enabled the service to respond to the changing needs of families and thereby providing a personalised response to their situation. For the period 2018-19, the service received 56 referrals, 43 of the referrals were accepted and 18 were declined.



The service always prioritised end of life care over planned respite care. Families of children in go home beds are made aware of the criteria

When the hospice had a deceased child in the garden room (post bereavement suite) services respond to the needs of the bereaved family. For example, the deceased child was included in the in-patient numbers of children and young people numbers, with care of the child and family delivered in a sensitive and professional way.

The hospice had a resource panel which met weekly to consider requests for care, support interventions and to allocate care.

People with a range of disabilities could access and use services on an equal basis to others. There was wheelchair access and access to those with disabilities, including those with sight and hearing loss.

The service was undertaking a full review of hospice premises with a view to a significant upgrade of the inpatient unit to reflect and be responsive to the needs of the service users.

Spiritual and person-centred care was integral to the care, including care after death. Staff worked closely with families and faith leaders to ensure individual beliefs and wishes were met.

The hospice had an urgent counselling referral pathway for children, young and families. The response time from the counselling team was 24 hours, however staff told us they had never known anyone who had been referred for urgent counselling wait for longer than 12 hours.

Discharge arrangements ensured that children, young people and their families understood prescribed medications, dates of follow-up appointments and follow-up telephone call and emergency telephone number.

Learning from complaints and concerns

It was easy for people to give feedback and raise concerns about care received. The service treated concerns and complaints seriously, investigated them and shared lessons learned with all staff. The service included patients in the investigation of their complaint.

We reviewed the complaints policy and saw it was relevant, up-to-date and clearly outlined the complaints process and steps people could take if unhappy with the outcome of a complaint.

Staff understood the complaints system and had access to policy and procedures on the staff intranet.

The service received no complaints between May 2018 and May 2019. For the same timeframe, the service received 520 compliments. The common theme from compliments was the acknowledgement that the services provided by the hospice were consistently compassionate, caring and effective.

All formal complaints were reported to and investigated by the clinical governance committee.

When new families were accepted onto the hospice case-load they are provided with a family information booklet, which includes a section about how to raise a concern.

All complaints and concerns were investigated and recorded. Complainants were advised of progress by telephone or in writing-whichever was their preference.



Our rating of well-led improved. We rated it as **good.**

Leadership

Managers had the right skills and abilities to run a service providing high-quality sustainable care.

There was compassionate, inclusive and effective leadership at all levels. Leaders at all levels demonstrated the high levels of experience, capacity and capability needed to deliver excellent and sustainable care.

All leaders had a clear understanding of the challenges to quality and sustainability of the service. They could identify actions to address these such as investing in staff pay, terms and conditions.



The executive team ensured there were comprehensive and successful leadership strategies in place to ensure and sustain delivery and to develop the desired culture. Leaders had an in-depth understanding of issues, challenges and priorities in their service, and beyond.

The hospice had implemented a leadership programme as part of the agenda for openness and candour to support the senior management team and emerging leaders to strengthen their understanding of themselves and others. The leadership programme was part of the care team's succession planning and complemented the established commitment to continual professional development and reflective practice.

Communication between the senior leadership team and staff was enabled regular through well-established manager and staff forums.

There was a clear commitment to the development of leadership at all levels, thereby recognising the importance of developing the rights skills, behaviours and values that are central in developing compassionate collaborate high performance.

The board of trustee's skills and competences were assessed at the time of their appointment and reviewed annually and were supported by a 'Fit and Proper Persons' Policy which ensures all required checks were undertaken when appointing trustees. The board of trustees had an equal balance of business and clinical skills and included a parent representative. The diversity of the make-up of the board of trustees meant that the services provided were reviewed and considered from differing perspectives. This enabled the provider to be confident that a range of opinions and voices were heard in order that the service was well led, having a positive impact on those who received a service.

Staff told us that leaders were visible and approachable. All staff told us leaders were accessible and responsive. Staff at all levels told us they felt valued and could openly discuss issues or concerns.

The leadership team were well-respected by staff for their collaborative working and influence to improve patient care outcomes within the geographical area the served. Staff and volunteer development were also highly valued.

The hospice had a vision for what it wanted to achieve and workable plans to turn it into action developed with involvement from staff, patients, and other stakeholders.

Organisational strategies were in place to guide each directorate in the delivery of innovation, evidence based best practice and research. In addition, the strategies supported sustainability and drive improvement.

The Donna Louise Trust mission statement was to ensure that every child, young person or member of their family from Staffordshire or South East Cheshire is able to access high quality palliative care services.

This was to be achieved by ensuring the service was fit for the future, always aiming for excellence, working with others to provide high quality services.

The strategy was fully aligned with plans in the wider health economy and the vision and strategy provided the foundation of the organisations strategic direction and guidance for delivering their goals. These goals were developed by staff, and the management team. This meant there was systematic and integrated approach to monitoring, reviewing and providing evidence of progress against the strategy and plans.

The strategy and mission statement were underpinned by the organisations values and behaviours the values were reviewed by all staff at the organisations staff day last year and as a result of the staff day a working group was set up to translate the values into clear behaviours that demonstrated the organisation were undertaking the values in all areas.

There was systematic and integrated approach to monitoring, reviewing and providing evidence of progress against the strategy and plans.

The service had organised a strategy away day in September with other providers to look at issues concerning the hospice movement and how to address theses, for example strategy, risk and assurance.

The hospice core values were. Openness, trust, togetherness, excellence and respect. (OTTER).

Vision and strategy



During our inspection we saw there were a number of pictures of otters at the hospice with the OTTER values clearly stated on them Staff were knowledgeable about the OTTER values and told us they lived them every day during their work.

The service recognised that a highly effective board is one of the fundamental drivers of organisational performance, and the leadership team were committed to that.

The hospice planned to undertake a review of Board development during 2019.

Culture

Managers promoted a positive culture that supported and valued staff, creating a sense of common purpose based on shared values.

The culture within the service was, completely focussed on the needs of the children, young people, their care givers, families and loved ones. This shared vision was demonstrated in the caring and compassionate way that care was delivered. Individual staff reported that they were respected and valued and there were no negative comments about their experiences working or volunteering for the service.

Staff felt supported, respected, valued positive and proud to work in the service. Staff told us that they felt pride in the work the carried out to ensure patients received good quality care.

Staff at all levels received regular meaningful appraisals, which provided them with development and career opportunities as well as their own wellbeing and safety was supported.

Staff told us they 'wouldn't work anywhere else' and were proud to support the people who used services.

Teams worked collaboratively, and we saw examples of positive cross-team working to provide joined up care for children, young people and their families.

Many of the staff had worked at the hospice for several years, they told us that the leaders were all enthusiastic and very passionate about the work the hospice did and how respite, palliative and end of life care was delivered to children, young people and their families.

Staff we spoke with told us that managers of all levels were visible, approachable, supportive and would always listen to staff if they wanted to discuss anything. Staff told us there were positive and effective working relationships. Staff told us that both the chief executive officer and the director of care came down on the unit frequently and interacted with staff well.

The service had a whistleblowing policy which was available to all staff and information on how to raise whistleblowing concerns formed part of mandatory training. Staff we spoke to knew how to raise concerns.

The caring ethos and philosophy of the hospice extended to staff well-being. Staff were supported where necessary to cope with difficult working situations. Regular de-briefs were held to enable staff to reflect and discuss what went well and what they would do differently. Counselling opportunities, and access to complementary therapies and employee assistance services were provided to support staff. All staff, without exception told us how much they enjoyed their work at the hospice.

All senior staff were knowledgeable about the duty of candour, there was a standard operating procedure that provided guidance to the requirements of duty of candour

Newsletters for parents and staff were produced, and available through the website. These newsletters provided information about planned events, including fundraising and photographs of children and young people engaged in activities both internal and external to the service. Photographs used were with the consent of the parent and or young person.

Governance, risk management and quality management

Leaders operated effective governance processes, throughout the service and with partner organisations. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.

There was a systematic approach to continually improving the quality of its services and safeguarding high standards.



Governance arrangements throughout the service had effective structures, processes and systems of accountability to support the delivery of the strategy and good quality, sustainable services, these were regularly reviewed and improved accordingly. There were clear lines of governance and accountability from the board of trustees through sub-committees to the chief executive, senior managers and to all staff. Staff were clear about their roles and responsibilities. Staff knew what they were accountable for and who they reported to

All levels of governance and management performed effectively and interacted with each other appropriately. The leadership team attended governance meetings and information was fed in to local teams at team meetings, in the form of minutes and emails.

The service had managers at all levels with the right skills and abilities to run a service which provided high quality sustainable care. The senior management team met regularly with the board of trustees.

The senior management team worked with a quality assurance dashboard based on five key questions is the service safe, effective, caring, responsive and well-led. An analysis of the information from the quality dashboard was used to develop action plans which were reviewed. A range of reports provided information to the board of trustees, outlining the clinical governance and care development committee information, all of which were supported by development and improvement plans, which were regularly reviewed. Improvements that had been identified and actioned included, securing feedback from young people and the increasing of staffing resources.

The quality agenda of the delivery of person and family centred care was central to the clinical governance and operational agenda. Key Performance Indicators across care services were monitored by clinical governance committee and the board.

Staff told us that the management structures supported their day to day work and personal development. They said they felt very well supported by all of the managers and found them to be open and approachable. Staff told us they were kept up to date with organisational issues and improvements.

There was a comprehensive portfolio of policies and procedures available to all staff. The polices were in appropriate detail for the services provided and they were regularly reviewed and updated to a schedule.

We saw that a comprehensive risk management system was in place with a schedule of when risk assessments needed to be repeated and this was adhered to.
Summaries of audits were reported in the service's annual report to the trustees.

Risks were monitored, mitigated and managed within the service using the board assurance framework, risk management policy, business continuity policy and incident management policy.

Risk assessments were used to identify risks and risk management systems were in place to mitigate identified risks. The service had two risk registers, one for care related issues and one for non-care issues.

Fundamental risks were considered when planning services, for example seasonal or other expected or unexpected fluctuations in demand, or disruption to staffing or facilities and these were discussed at trustee level.

Staff files showed criminal records checks had been undertaken with the Disclosure and Barring Service (DBS). Nursing and Midwifery Council (NMC) checks had been completed to ensure health professionals were fit to practice. There were copies of other relevant documentation including character references, interview notes, full employment history and proof of identification.

Equipment and the premises were well maintained. A business risk and continuity policy were in place providing comprehensive guidance as to the management of significant events, such as adverse weather. Agreements with local services and a hospice had been agreed to assist staff in the provision of continued care and support to children and young people should it be necessary.

A programme of audits was set out every year which covered areas such as infection control arrangements, accidents and incidents, medicines arrangements and the effectiveness of clinical supervision. The service held a regular clinical governance meeting where the outcomes of audits were reviewed. The audit programme



was also monitored through clinical governance committee and patient care committee to further assure any quality improvement measures had been effectively embedded in practice, and meaningful change has positively impacted on care and or service delivery. This meant they were able to monitor what improvements were needed and how they were implemented.

Regular analysis of incidents to identify themes that need addressing are routinely undertaken, with all risks overseen by the risk committee.

A full care needs analysis of all children and young people on the service caseload was undertaken every two years to inform the future workforce needs, skills and competencies to create a safer service. This included consideration of the need for input of: medical staff, therapists; catering; play staff; pharmacy; social workers, counsellors, family therapists and other specialist roles.

Information systems supported quality patient care and treatment. Information was kept securely and maintained the confidentiality of patients and information was only shared with relevant agencies after patient consent had been obtained.

Management records were well organised, and records were detailed and kept up to date.

Care records were easy to follow and kept securely as were personnel records.

There were several computer stations with intranet and internet access available throughout the service and there were sufficient numbers of computers for staff to access information. The computer systems were password protected and staff were aware of how to protect access to computer systems and patient identifiable information.

All staff received confidentiality training and where information was shared with other organisations there was guidance, for example we saw a policy for the sharing of infection control concerns with other providers.

The registered manager was the Caldicott Guardian for the service. A Caldicott Guardian is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly.

Public and staff engagement

Leaders and staff actively and openly engaged with patients, staff, equality groups, the public and local organisations to plan and manage services. They collaborated with partner organisations to help improve services for patients.

The service engaged well with patients and staff to plan and manage appropriate services. Staff reported they were involved in meetings about the running of the service and their input was

encouraged and valued.

The service worked with external organisations as part of their commitment to staff training, development of the service and the sharing of knowledge. Staff worked alongside recognised organisations providing sector specific guidance, including the west midlands children's palliative care network (WMPPCN), the stoke and Staffordshire children's palliative care network, together for short lives and the Staffordshire children and family's bereavement alliance and the dove service, which offers counselling and support to those struggling with the impact of bereavement, significant loss, or life changing or life limiting illness.

The service had established links with local universities, which offered placements at the hospice for nursing and medical students.

The service undertook an annual staff survey. The results of the 2019 staff survey showed that 58% of staff felt very satisfied and proud to work for the service whilst 39% were satisfied to work there the survey results meant there was good level of staff engagement. Staff told us they felt engaged within the hospice and that views and feedback were valued and taken seriously. Data showed that 62% of staff took part in the staff survey.

The hospice engaged well to meet the needs and requirements of their children, young people and families and they celebrated the good working relationships with the families they cared for. The hospice considered feedback from the local community and service users as invaluable in informing of the service of what was working well and areas to be enhanced. For example, following direct feedback and subsequent consultation with young people and families, in 2016 the board of trustees took the decision to support the development of a dedicated young adult service as children and young people had little or no service provision available to them



as they transitioned into young adulthood. A service user consultation was carried out to inform service development and planning. Funds were secured in 2017 to build a new stand along young adult facility, young people worked with the design team to develop the brief for the building. Young people then worked with interior designers to shape all aspects of the internal space with a focus on delivery facility that truly met their needs and young people with life limiting illness. As a result, a person-centred facility has been development that will house the new young adult service in the near future.

At the time of our inspection, the service was in on-going discussions with the local clinical commissioning groups to provide further support to the health economy in meeting the needs of children, commissioners to develop a local plan for children's step down, respite and end of life services.

The care support team were working with the local housing department as the provision of suitably adapted housing within the hospice catchment area is severely restricted. As part of the hospice in-put two specifically adapted houses have been built for families supported by the hospice with other housing associations now making a commitment to building further suitably adapted homes.

The service had an open and transparent approach to sharing information. News and information for parents,

staff and external professionals was available through the hospice website. Information included planned events, including fundraising and photographs of children and young people engaged in activities both internal and external to the service along with useful links to external resources.

The hospice produced a regular newsletter for both staff and service users and we saw evidence of where families had thanked and praised staff for their care. There was also the organisations own weekly lottery, where a prize of £25,000 could be won, with 73 pence of every pound donated going directly to the care of the children and young people.

There was a facility on the hospice website for children, young people and their families to undertake a feedback survey. The hospice also produced a family booklet which contained information about the organisation including the counselling service, from meal times to the different support groups.

Learning, continuous improvement and innovation

The service had established links with local universities, which offered placements at the hospice for nursing, allied health and medical students. At the time of our inspection the hospice had just won a student placement of the year award for the third year in succession.

Outstanding practice and areas for improvement

Outstanding practice

- The counselling service led a dad's group once a month. This was a group which provided a safe environment for dads to talk and be heard.
- The sensitive manner in which the provider made staff aware of a child or young person in the garden room

Areas for improvement

Action the provider SHOULD take to improve

- The provider should ensure that all staff involved in the treatment of children and young people should have level three training, in safeguarding children which is in line with the intercollegiate guidelines.
- The provider should ensure that all staff involved in the treatment of children and young people should have level two training, in safeguarding adults which is in line with the intercollegiate guidelines.
- The director of care who is the safeguarding lead for the service, should ensure their level four safeguarding training undertaken in 2014 is updated to the current level four requirements.
- The provider should ensure that all safeguarding training is updated within a three month period.