

The Donna Louise Trust

Donna Louise Trust

Inspection report

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Ratings

Overall rating for this service

Good ●

Is the service safe?

Good ●

Is the service effective?

Good ●

Is the service caring?

Good ●

Is the service responsive?

Good ●

Is the service well-led?

Good ●

Summary of findings

Overall summary

This inspection took place on 26, 27 and 28 July 2016 and was unannounced.

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, and distinctive areas of landscaped gardens, areas of interests and relaxation.

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 staffs' ability to keep them safe. The provider had established direct working relationships with external agencies to share information to promote the welfare and safety of children and young people. Internal meetings were held that provided a forum for potential concerns and risks to be identified. Enabling the provider to provide timely support to families.

We found improvements were needed in the assessment of risk and the plans to mitigate risk, in some areas, which included medicine management and within the care plans that detailed areas of individuals care. The provider assured us they would take action and we received information following our inspection advising that improvements had been made.

Young people who used the service and a parent we spoke with said medicine was managed safely and staff provided support where needed. Medicine was stored securely within the service and staff responsible for the administration of medicine had their competency regularly assessed.

The provider employed sufficient qualified and experienced staff, from a range of disciplines to meet the needs of children and young people. This had a positive impact on the experience of children, young people and their families. For children and young people it presented opportunities for them to take part in

activities including play. Whilst for the families of children and young people, the provider recognised the impact of a child's health on the wider family. They had recruited a strong contingent of volunteers to support the wider family, through befriending services and the support provided to siblings, through activities and social events. Staff received regular training in areas relevant to their practice. Safe recruitment practices were followed when recruiting new staff.

The provider worked in partnership with children, young people and their families by providing opportunities for all to comment and influence the care and treatment provided. This enabled staff to deliver person centred care, with staff and volunteers supporting children and young people, both within the hospice and at home. Parents valued their relationships with staff who felt the support they received had a positive impact on their life and that of their child's. Staff focused on the wellbeing of children and young people, and their families and worked together, with health and social care professionals in the sharing of information for the benefit of the child or young person and their family.

People we spoke with were positive about the meals and the quality of the food and told us that choices were always available, which included special requests. Mealtimes were family oriented with hospice staff, children and their families eating together. Any special dietary requirements were noted in the care plan, which included where children and young people were artificially fed. The facilities provided within the dining room and family rooms that enabled families to have independent access to food and drink which were complementary.

There were excellent recreational facilities, for which children and young people could access, and a range of holistic therapists were available to them and their parents. There was a commitment shown by all staff with regards to the quality of life of children and young people. Staff and volunteers provided support so that they could take part in activities and play. Children and young people were observed playing, with other children, with many families attending the activities organised for families throughout the summer holidays.

Parents spoke with great enthusiasm and passion as to the relationships they had developed with key staff involved in the care of their child. They told us how these positive and caring relationships, nurtured by the staff; had given them confidence as parents to contact staff when they needed additional support. Parents spoke of the impact the counselling services had on their family and the tailored and personalised approach by counsellors in the support they provided.

Parents spoke with passion as to the positive impact of staff from the hospice had on the family. They made specific reference to how staff liaised with health and social care professionals, in helping them to access and understand the services they were entitled to. Parents acknowledged the support provided by staff in liaising with staff in schools to assist them in understanding the impact on the wider family of having a member of the family with a life limiting condition.

A child or young person approaching the end of life, and their family, could stay at the hospice. Anticipatory symptom management plans and medicines were in place in order to respond rapidly to escalating symptoms at the end of life to keep the child or young person as comfortable and as pain free as possible.

Children and young people who died at the hospice and some who died elsewhere could access the 'The Garden Room'. The facility could be personalised for each child or young person by their family. Following the death of a child or young person bereavement support was provided to the family, for as long as they wished.

Bereaved families were invited to an annual memory day where all children and young people were

remembered following the death of a child or young person. Memory features were around the hospice and grounds, which included memory sticks made by siblings in a specific garden area, to painted pebbles placed in a family's favourite area.

A complaints policy and procedure was in place. Where parents had raised a concern we found their concerns had been robustly investigated with the parent being kept informed at all stages of the investigation.

Parents spoke of the inclusive and person centred environment of the hospice and how their views were continually sought in order that the provider and staff continued to further develop and improve the service. Parents were actively involved in fund raising and had strong links with the local community, raising the awareness of the hospice and its work.

Parents and young people's voice had been recognised by the provider as a key aspect in the provision and understanding of the needs of young people as they transferred to adult services. A focus group had been established and had actively sought young people's views and that of their parents. The chief executive as part of their Master's degree in hospice leadership had focused on the transition of young people to adult services, with a view to improving the experience and care of younger people with life limited and life threatening conditions as they became adults. The provider had received permission with building plans for the further development of the service in its provision of respite and day care for those 19 years and above. To be provided within a purpose built building adjacent to the existing hospice building.

The five questions we ask about services and what we found

We always ask the following five questions of services.

Is the service safe?

Good ●

The service was not consistently safe.

Risk assessments were in place; however identified risks in some key areas of care intervention were not sufficiently personalised or robust to ensure safe and consistent care.

The provider and staff demonstrated robust systems for the protection of children and adults. These were underpinned by staff knowledge and training to protect children and young people.

Children and young people were supported and cared for by sufficient numbers of staff. Staff were qualified and experienced and had a range of skills, ensuring individuals were safe and had their needs met.

We found improvements were needed in some aspects of management of medicine, we received assurance from the provider that improvements had been implemented.

Is the service effective?

Good ●

The service was effective.

Staff received regular training and had their skills regularly assessed to ensure they were competent to carry out their role. Staff knowledge and experience was shared with the wider health care community to improve palliative and end of life care.

Children and young people's records contained up to date consent forms relating to care, treatment and activities. These reflected the power of the courts where the legal system was involved. Parents were supported to understand the implications of legislation and young people's rights as they transferred into adulthood.

Mealtimes were family orientated, and all meals were freshly cooked on the premises. Children and young people whose dietary needs were met artificially had care plans specific to their individual needs.

Staff supported children and young people to maintain their health and liaised with parents and external health care services and education departments where appropriate.

The design, adaptation and decoration of the hospice met the needs of children and young people in the promotion of their independence and facilitated their care, whilst providing a stimulating and interactive environment for play and activity.

Is the service caring?

Good ●

The service was caring.

Children, young people and their family members received a range of support from the different elements of the service. Parents spoke of the positive relationships developed with staff and volunteers and the positive impact they had in the support provided to the family.

Children, young people and their parents were encouraged to express their views and were involved in decisions about their care, treatment and support. This included the future development of the service for those entering adulthood.

Privacy and dignity were respected and promoted in all aspects of staff interaction with children and young people. Following the death of a child or young person, staff continued to provide care and supported the family.

Is the service responsive?

Good ●

The service was responsive.

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.

The provider had a positive approach to listening to parents and individual's using the service, seeking their views and responded to concerns and complaints.

Is the service well-led?

Good ●

The service was well-led.

The provider had developed the service to promote a positive and open culture. Opportunities for parents and young people

were able to comment on the services provided, through questionnaires, support groups, organised events for public speaking and fund raising.

The Board of Trustees and managerial teams provided strong, effective leadership. They provided a clear strategy for the long term development of the service that had included collaboration with young people and their parents.

The provider had systems to monitor the quality of care provided. Staff within the service worked collaboratively with external organisations to influence the care of young children with life limiting and life threatening conditions, both within the hospice and at home.

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Detailed findings

Background to this inspection

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

This inspection took place on the 26, 27 and 28 July 2016 and was unannounced.

The inspection was carried out by an inspector, a pharmacy inspector and a specialist advisor. The specialist advisor had experience working within children's hospices.

Before the inspection, we asked the provider to complete a Provider Information Return (PIR). This is a form that asks the provider to give some key information about the service, what the service does well and improvements they plan to make. The PIR was completed and returned to the Care Quality Commission. We found the information in the PIR was an accurate assessment of how the service operated.

Prior to the inspection we sent out one survey to someone who used the service, 25 to children and young people's parents or guardians, seven to nursing and medical staff and nine to staff. In response we received one from someone who used the service, one from a parent or guardian, five from nursing and medical staff and five from staff.

We also reviewed the information that the provider had sent to us which included notifications of significant events that affect the health and safety of people who used the service.

We spoke with a child, four young people, and the parents/guardians of twelve individuals, either in person or by telephone, who use the services of Donna Louise Trust. We spent time with children and young people observing their participation in play and group discussions.

We attended three meetings, which included the staff 'handover', the staff involvement group and the weekly resource panel. Our attendance at the meetings was to find out how information was shared and communicated and the impact it had on those using the service.

We spoke with the director of care (registered manager), the chief executive, human resource manager, volunteer services lead, education and development lead, a counsellor, a care co-ordination team leader, the head of integrated care, communications manager and the director of operations, two nurses, care support worker and the chef.

We reviewed the care plans and records of two children and young people to see how their support was planned and delivered. We also looked at the records of a child who has died to ascertain how the child's end of life care had been managed. We checked the medicines prescribed on six prescription charts of children and young people who were accessing respite care.

We also looked at a range of policies and procedures, quality assurance and clinical audits and the minutes of meetings.

Is the service safe?

Our findings

We asked young people who used the service whether they were safe at Donna Louise Trust. One young person told us, "I do feel safe no one can get in or out, without the staff knowing. There are no problems with bullying here. ..., the staff here are always there to talk with."

Parents we spoke with had confidence in the staff team to keep their child safe. They felt staff were trained and motivated to provide good quality care and demonstrated a good understanding of their child's individual needs. Parents told us, "I can support my son in taking part in activities within the hospice as I know that he's safe here with the staff nearby, things that I wouldn't be able to do outside, such as hydrotherapy." "I know [child's name] is safe, all the staff know him so well."

Information gathered through questionnaires sent out by us found, people who used the service, their relatives, health care professional's staff employed by the provider were confident that children and young people were safe. Leaflets containing information about safeguarding were made available to all those who used the service, children and young people's parents along with staff and volunteers.

The provider had safeguarding policies and procedures for children and adults and had an open and inclusive approach to ensure information about safeguarding was openly discussed and shared. The provider had commissioned an external review, which was carried out by Children England of their safeguarding policies and procedures. This evidenced the commitment of the provider to promoting the welfare and safety of children.

We spoke with staff about safeguarding and found all staff understood the principles of safeguarding. Staff had receiving training in child protection. Representatives of the provider were members of the voluntary sector safeguarding group, having a direct relationship; reporting to the local safeguarding children's board. This enabled the provider to share information and promote the welfare and safety of children and young people. All staff knew how to raise a concern and how to escalate safeguarding issues both internally and externally. This confirmed the information provided within the PIR.

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 and agreed response to support families and mitigate potential risk. Staff involved within care coordination were actively involved in the referral of children and young people to the local authority. An overview of all safeguarding concerns was reported to the clinical governance committee. This enabled the provider to have an oversight in the promotion in child welfare.

Environmental equipment helped to promote safety. For example ceiling hoist tracking was installed in bedrooms and bathrooms so children could be safely transported between these rooms. 'Safe-space' cots and beds had been provided so that children who were at risk of harm when sleeping in a regular bed or cot

were protected.

There was a clear process for clinical and non-clinical incident reporting including near misses and safeguarding concerns. The provider had taken appropriate action by liaising with an organisation that regulates professional conduct and standards, where concerns about staff practice had been identified. This showed that the welfare of children and young people was promoted. Reports were generated which identified any actions that had been taken to mitigate future risk and monitored by the provider, by committees of people with specific responsibilities and knowledge. A report detailed corner protectors had been fitted to a dining table, following an incident where a child had bumped the table corner.

Equipment and the premises were well maintained. A business risk and continuity policy was 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.

With regards to another individual, a nurse we spoke with was aware of the fragility of the individual's skin and the care required, however a risk assessment had not been completed and the care plan did not reflect the care required, which had a potential to impact on the consistency of care provided. A nurse we spoke with told us they were involved in the development of a tissue viability assessment tool, which evidenced that staff had acknowledged improvements were required. The minutes of meetings of the senior management team recognised and acknowledged the work being undertaken to bring about an improvement in relation to skin care.

The approach to the identification and mitigation of risk, through assessment was not consistently applied by staff in all areas of care for children and young people. This meant individuals, may not receive consistent care to promote their welfare. Risk assessments for a young person requiring non-invasive ventilation (support with breathing by use of a mask) at night or when sleeping were not tailored to the needs of the individual and the generic risk assessments were electronic and not readily available to staff. We spoke with staff providing the care and they were able to talk to us in depth about their care needs, which included potential risks and their role in mitigating these. We spoke with the head of care and respiratory lead nurse, who appreciated the value of personalising the risk assessments and making them accessible to all staff that provided care.

There were systems in place to reduce risks to children and young people with regards to their mobility, which reflected the information provided within the PIR. Assessments were comprehensive and identified specialist equipment to be used with input from the physiotherapist. The physiotherapist told us that equipment they had been identified to support children and young people had been provided, which we saw being used. Risk assessments reflected how support and equipment was to be used to enable individuals to take part in activities with consideration to both safety and the promotion of their independence. For example one person's assessment identified that they were to sit in an especially designed chair when engaged in activities. Our observations saw the person being transferred to the appropriate chair when accessing activities.

We spoke with staff about the care of two people who used respite care. Staff were able to tell us about the child or young person and the risks in providing their care and how these were managed. Risks they told us about were with regards to mobility, the risks of seizures and the management of their airway. Information about these risks were discussed as part of the staff 'handover', which included any medicines prescribed, known as 'rescue' medicines and the need for suction to be readily available.

Risk assessments had been completed where staff provided support and care to children and young people at home and reflected the safety of the individual and staff. Assessments had also been carried out on the environment where the family lived, to identify any potential hazards and mitigate potential risk to the child, young person or staff.

Our observations showed there were sufficient staff on duty to provide care and meaningful activities and engagement for all children and young people who were accessing respite care and day care. All those using the service had their individual needs assessed which were used to determine staffing numbers, which included looking at the skills and training of staff. Where children required the support of two staff, this was provided. For example, when a person required the support of two staff when being hoisted, due to their physical and health needs.

Nurses we spoke with told us they felt safe when on duty and knew the procedure for increasing the number of staff on duty, and had access to a team leader who was always on call, should staff have concerns regarding staff numbers. Staff told us staffing numbers would be increased when required, for example should a child or young person require end of life care. Staff recruitment was currently in progress at Donna Louise Trust and until such a time that the service is fully staffed the number of beds made available to children and young people were being regularly reviewed. This was to ensure that children and young people's needs could be met safely.

Staff recruited by the provider underwent a robust recruitment and interview process to minimise risks to people's safety and welfare. Prior to being employed, all new staff had an enhanced Disclosure and Barring Service (DBS) check, at least two valid references and health screening. (A DBS is carried out on an individual to find out if they have a criminal record which may affect their working with children or young people, which may impact on the safety of those using the service.) For nurses, a check of their Nursing and Midwifery Council registration was carried out. This confirmed information as detailing within the PIR.

Parents we spoke with had confidence in the staff team to administer their child's medicine. They told us, "They're good at managing their seizures and medicines. They always check the medicines when we come into the hospice; if medicines have changed we bring a note from the doctor to confirm this." "With medicines I don't have to worry, the staff give them, this means I can don't have to be practical thinking about care, but can just play with him."

Medicines that were brought in to the service by children and young people were used in addition to medicines prescribed by a local GP or a palliative care consultant. Medicines were obtained from the local trust including those required out of hours. When an individual was admitted to the service, medicines were checked by a nurse to ensure medicines were suitable to use. Nurses gave individuals their medicine when they needed it and not at set administration times. This was a child centred approach, enabling the child, young person or parent to influence the care provided.

We checked the medicines prescribed on prescription charts and found there to be clear recording of the prescribed medicines including additional instructions for their safe administration. These included any known allergies the child had to help safeguard them from receiving medicines which would put them at risk. We however had concerns that one child who had been prescribed an antibiotic, which needed to be administered on an empty stomach was receiving it with or just after their meals, which meant the antibiotic would not work properly. The medicine records detailed for the medicine to be administered at mealtimes, which had been completed based on the information provided by the child's parent as to its administration. A nurse told us that she was not aware that the medicine should not be given with food and told us that they usually give the medicine as the parent would give it at home.

Medicines requiring cold storage were stored appropriately and records showed that they were kept at the correct temperature to ensure that they remained effective. The temperature of the medicine room was not monitored which meant that staff could not be sure the medicines were being kept at the correct temperatures for effective use. We discussed this with the head of care who understood the need to monitor the temperature that medicine was kept but told us that it had previously not been considered. They told us the monitoring of the room temperature would be actioned. Medicines that require additional controls because of their potential for abuse (controlled drugs) were stored securely and monitored according to safe practice. The PIR detailed that a representative of the provider was a member of the local intelligence network for controlled drugs management and that an annual audit was undertaken to promote safe working practices.

In the event of an anaphylactic (severe allergic) reaction, there were no medicines for emergency treatment available. Staff told us children usually brought in their own emergency medicine if needed. There were no risk assessments available to show the risk of not having immediate treatment available but the hospice has now assured us that the emergency medicine is kept in stock.

Nurses had to give medicine to some children through a tube in their stomach. There was not always enough information available on the prescription chart or in the care plan to let staff know exactly how to give this medicine. We discussed this with the provider who told us that this is something they would improve following our observations and comments.

Incidents involving medicines were reported and investigated, which produced an action plan detailing how the likelihood of similar incidents could be reduced from being repeated. Where incidents involving medicine errors involved the same member of staff the staff member's competency in medicine management was re-assessed and used as reflective practice regarding lessons learnt.

The provider had a competency checking system for all staff involved in medicines administration, as detailed within the PIR. This meant that they were able to see if staff were competent to give medicines safely and if there were any training requirements. The PIR stated the provider was in discussions to establish an agreement for pharmacy support with regards to medicine management to support with the provider's commitment to continuous improvement and the further development of internal medicine management.

Is the service effective?

Our findings

The effective use of staff experience, knowledge and roles meant children and young people had access to a range of services and support. These included support from counsellors, a psychologist, physiotherapist and a play specialist.

Parents spoke with much enthusiasm and positivity about the counselling services provided for the whole family, telling us of the positive impact it had on them. "We've accessed the father's group and mother's group. Our daughter) has received support; the counsellor has sat with her and through drawing has encouraged her to explore and understand her feelings."

Information gathered through questionnaires sent out by us found all who experienced the service to be supported by staff with the appropriate experience and skills who had knowledge of their needs and who knew them well. Information from questionnaires completed by all staff recorded staff were confident in the training they received. This in their view enabled them to provide good quality care by meeting the needs of individuals in a person centred way and by following information as detailed within care plans.

The physiotherapist through their involvement with children and young people's care had been able to create opportunities to make physiotherapy part of play, both within the hospice and the child's home. The physiotherapist spoke of their approach, "Anything is possible, nothing is a barrier. If a child wants to do something, then let it happen." They told us how they had utilised the outside play area to incorporate physiotherapy into play and relaxation. This included using the opportunity for children to listen to stories whilst receiving physiotherapy. Physiotherapy had been used as an opportunity to engage the wider family and encourage play and interaction. For example, by supporting a sibling to blow bubbles whilst their brother received physiotherapy.

Volunteers undertook a comprehensive screening and induction process. Volunteers contributed significantly to the experience of families, by providing support to the siblings of children with life limiting and life threatening conditions, enabling them to play and enjoy the time they spent at the hospice and at home. A volunteer told us, "There's a wonderful atmosphere here, really enjoy coming. It's nice to see children with smiles on their faces despite the circumstances." Parents told us that by having volunteers to support the children, it meant they could relax knowing all of their children were taken care of. Parents comments included, "The volunteers play with our daughter, making her feel special." And. "The volunteers here are priceless, ensuring everyone is happy and has a good time."

Parents we spoke with who received a service within the family home, told us the staff had the necessary skills and knowledge required to support their child, which meant that they as parents could confidently leave them in their care. A parent said, "We have specific staff allocated to [child's name], who understands autism and learning disabilities." They went onto tell us how leaving their child in someone else's care was difficult and that this was possible with the staff from Donna Louise Trust, as they trusted them and knew their child would be cared for. "To leave your child is terrifying and staff know how precious children are and how difficult for parents it is to leave them." A second parent said, "We have two staff that are competent in

'trachi' (tracheostomy – an opening in the neck, created in order to place a tube into the person's windpipe) care so I know he is in good hands and is safe, they play with him and take him out."

A parent told us what it meant to them, having confidence in the skills and knowledge of staff, enabling them to leave their child in the care of staff. They told us, "Only place I don't worry. Highly skilled carers and nurses who are effective, professional and compassionate."

We observed staff in the use of specialist equipment which included beds and seating equipment, feeding equipment and non-invasive ventilator support and adapted play equipment. Records reflected the specialist equipment and support individual's required and all interventions of care and support provided by staff were documented.

A support worker who had worked at the hospice for two years was able to reflect on their induction, which they described as comprehensive and supportive, being allocated a mentor. They spoke of the core clinical skills they had undertaken, which had included theory and practical assessment as to their competence. A nurse we spoke with told us they felt very much supported in their professional development.

The education and development lead spoke to us about the schedule of training all staff undertook, which included training specific to people's roles and reflective of the needs of children and young people. Staff had their competence to perform these tasks, reviewed and assessed through the providers competence framework and included specific training to meet individual needs of children and young people by support workers. Staff had an annual education and development plan that was monitored and reviewed as part of staff supervision. The provider was committed to the introduction of practice development days, which would focus on topics to support staff in the delivery of the services visions and values.

Staff received regular supervision and opportunities to attend meetings. Nursing staff as part of their reflective practice considered training they received and the impact this would have on the care of children and young people and on their own nursing practices. Reflective practice through action learning sets and team de-briefs were attended by staff to enable them to reflect on events within the hospice in relation to care. This provided an opportunity for staff to discuss the scenario and situation and review what had worked well and what if any improvements could be made should a similar situation occur, in order to improve the service to children and young people.

The provider though its staff liaised with external organisation as part of their commitment to staff training and development 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 Families Bereavement Alliance. The provider had established links with local universities, which offered placements at the hospice for nursing and medical students. The provider viewed this as an opportunity for shared learning.

We found there to be effective systems to facilitate communication amongst, staff, young people and children, parents and external health and social care professionals. We attended a group 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.

Styles of communication had been considered. There was evidence that an interpreter was used regularly for a family whose first language was not English. The team were also developing the wider use of Makaton

(use of signs and symbols) as a communication tool with a small group working on this, some Makaton signage around the hospice was in place, providing information to children and young people.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf must be in their best interests and as least restrictive as possible.

People can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in hospices are called the Deprivation of Liberty Safeguards (DoLS).

We checked whether the service was working within the principles of the MCA, and whether any conditions on authorisations to deprive a person of their liberty were being met. There were no DoLS authorisations in place when we inspected the hospice and the PIR completed by the provider confirmed this.

We found where concerns about children or young people had been identified, and where legally binding decisions had been made in the best interest of the individual, copies of the authorised decisions were held within their records. We found evidence of facilitation of improving relationships between all parties involved in the best interests of the young person and family.

The PIR recorded that children and young people had in place advance care plans, which recorded their views and those of their parents. Some individuals had a do not attempt cardio pulmonary resuscitation order (DNACPR) in place. We found clear and comprehensive information of best interests decisions being made, with regards to end of life care, which included the gradual withdrawal of food as a child's health deteriorated and the increase of medicine to control symptoms. All had been signed and dated by the parent or guardian and others involved in the discussions.

We found mealtimes were family orientated with hospice staff, children and young people and their families all eating together if they chose. Parents we spoke with told us they valued having their meals provided as it enabled them to spend time with their child or children, without having to prepare and cook meals. The menu was displayed each day and people served themselves. The dining room contained a fridge for children, young people and their families to serve themselves with snacks and drinks. Facilities were available for staff to provide meals when required when the catering staff were not on site.

We spoke with the chef about the nutritional needs of children and young people, which included those who could not eat or drink orally and those requiring specialist food production such as a pureed, specialist or cultural diet. The chef was aware of how to prepare such diets as ketogenic diets (balancing of carbohydrate, protein and fat, tailored to the person) and had received training in this and had an accessible resource to refer to when preparing ketogenic diets. The chef was aware of cultural diets with halal diets being quoted as the most common cultural diet required. However, they were not able to provide halal meat as an appropriate source had yet to be identified and therefore provided a vegetarian meal for Muslim families.

The chef evidenced menus were carefully considered for variety and nutritional value and they and other catering staff had recently attended a course on enhancing nutrition. This had provided them with ideas on how to increase the nutritional value of meals.

Individual's needs were recorded on a nutritional care plan, which had been completed by a nurse and were comprehensive in their detail. All care plans were reviewed upon each admission to the hospice with a care plan review sheet signed being by the parent and member of staff. However individual care plans were not dated and signed and we found the care plan for nutrition was separated from the other care plans and kept by the chef. Therefore there was a potential risk of an updated or revised care plan not being shared with the chef and the ability to check whether it was current being compromised. This was discussed with the registered manager and head of care, who advised the practice of signing care plans, would be reviewed.

Each child and young person had a clear care plan in place with regards to nutrition, which included personalised feeding routines for those artificially fed. The times of feeds were documented in the care plan. We observed individuals being supported with their nutrition and hydration, consistent with their care plan. A support worker told us that they had their competence to provide enteral feeds (food supplement administered via a tube direct into the stomach) assessed annually. We found a child was being introduced to taking food orally; staff supported the child with 'oral tasters' in a safe and skilled manner, to promote their safety and provide a positive experience of food.

We found evidence in records of 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.

Parents we spoke with told us about the invaluable support provided by their identified care co-ordinator in co-ordinating all the professionals involved in their child's care. Parents told us how they supported them to attend meetings involving a range of health, social and educational professionals. Parent's comments included, "You sit at a meeting with professionals and you can be overwhelmed, sometimes the people in the room have never met your child, and the care co-ordinator acts as your voice, supporting you." And, "[staff name], we couldn't do without her, she's our champion, always there to support us when we need to make decisions about [child's name] health care."

Effective care was supported by the collaborative working, connecting all services involved in a child's and families lives. The records demonstrated communication with external health professionals, social care and education and the involvement of staff in CHIN (children in need) meetings. Upon every admission for respite or day care, the care plans were reviewed and updated in full, involving a discussion with the parent, child and young person as appropriate. This included general health as well as specific needs.

For those receiving a service within their own home, staff involved in the delivery of care liaised with community health care professionals. The records we looked at evidenced cross party working and the sharing of information and its benefit on families. The physiotherapist told us how part of their role was to work in conjunction with community physiotherapists to promote continuity of care and for the purpose of shared learning.

Throughout our visit we saw staff engaging individuals in a range of activities, providing therapy and treatment, which had a positive impact on those involved. We saw children and young people engaged in play, taking part in interactive computer games and the use of sensory stimulation, which took place in the sensory room. We spoke with other staff that held key roles within Donna Louise Trust, which included a counsellor, the volunteer services lead, a physiotherapist and care co-ordination team leader. Our discussions identified how they contributed to the holistic approach to children and young people's care and support and the maintenance of their health.

Children and young people's health care is supported through the local acute trust, through identified times

of support by two paediatric consultants. Along with six general practitioners from a range of practices who have a special interest in children and young people's palliative care, who attend the hospice when requested.

We looked at the records of a child who had used the service to find out how the individual's care had been provided and managed. We found a care plan and assessment tool for pain to be in place and where the pain had been assessed as high the records showed how this was managed effectively to manage the child's pain. Records showed the parents had been actively involved in the assessment of pain and its management.

Is the service caring?

Our findings

We asked young people attending the youth club in the evening, what the respite service meant to them. They told us, "Respite is cool, get to get up when I want." Whilst a second person said, "Staff are very caring and most are funny. It makes it easy to speak with them."

Parents of children and young people valued the services provided by Donna Louise Trust and how the relationships, understanding and knowledge of staff meant they had confidence and trust in the services provided. We spoke with the parents of two children, who chose to stay within the family quarters of the hospice whilst their child was in respite; they told us what it meant to them. "We can stay here with [child's name] knowing she is cared for, and our other daughter gets to play and enjoy herself, playing with all children, including those with disabilities, showing her its normal to get involved." "I explain to my friends, that coming here as a family is like going on holiday. You unpack your suitcase and settle in, and then you have time to spend, how you want to. Knowing [child's name] is being cared for. We get to spend time as a family, playing and relaxing."

Parents spoke very positively of all the services provided by the hospice. They told us how they were supported as a family through the sibling support groups and activities organised, especially during the summer holidays. They told us, "The hospice is more than the four walls, it's a community." "The hospice is my life line." "They're not just there for the child but for the whole family." "We think they're brilliant, only ones that came to provide help when we needed it." One parent speaking about their family said, "We were broken and they've helped put us back together." And, "It has saved us as a family. The counselling services and hospital support service is all so important, it's very holistic, it's about the whole family."

When we spoke to parents, they told us how getting together with other parents in groups facilitated by staff helped them. "I go to the craft night, where we have coffee and cake; we're also creative with crafts. We get to talk about issues and share information, information that only those accessing services will know about." "I access the dad's group, we go on days out, off road driving and clay pigeon shooting, you name it. It's an opportunity to talk and not be judged, being able to express your emotions within a safe environment."

Parents were enthusiastic in their praise of the counselling services and its impact on the family. They made particular reference to the adaptability of the counsellors to provide counselling sessions away from the hospice and the benefit this had. One parent told us how they met their counsellor in a local park and how walking around the park, seeing how plants changed through each visit helped them to recognise that life continued outside of the hospice. A second parent told us how their counsellor had visited them at work and that it was good to meet outside of the hospice, to help gain a sense of normality.

Parents were very positive, when speaking of art and how it was used by counsellors to support siblings and parents of children to explore their emotions and understand their feelings. Parents told us, "Our daughter has received counselling, although she doesn't recognise it as such. She's encouraged to draw and through her drawing is encouraged to express her thoughts and emotions." Parents told us how the counselling service had supported them as a family, when their other children had experienced bullying at school.

"[Counsellors name] visited the school's head teacher and class teacher to talk about the issues we were experiencing as a family."

Information gathered through questionnaires sent out by us found people who used the service were introduced to staff when they commenced with the service. Questionnaires reflected positive and caring relationships were developed, with consideration to respect and dignity being met. They also identified the involvement of children, young people and their parents in decisions about care. This was reflected in the questionnaire completed by all staff who confirmed they delivered high quality care and their approach being that of respect and the promotion of dignity.

Volunteers played a key part in the delivery of support to families. This included practical support and well-being sessions, which included 'pamper days' for parents. Volunteers provided a be-friending service, which helped support parents who felt isolated and included bereaved parents who having received training were able to provide individualised support. The volunteer service lead told us how they had links with volunteers, who provided one off support, which had included working with the ministry of defence on a local level, where they had provided personnel to help clear a families' garden.

Volunteers provided support by spending time with the siblings of children and young people, engaging them in play and activities, within the hospice and external clubs and outings. Parents were complimentary about the services their children accessed telling us the positive influence it had on them. One parent said when speaking of their child's sleepover as part of sibling support, "They came back all grown up." Parents spoke of the day trips and parties their children took part in, supported by volunteers and staff from the hospice, saying, "[child's name] loves it, the stays combined with the Saturday morning club group, are really enjoyed by him."

The relaxed, homely and calm environment created within the hospice enabled parents to relax and enjoy their time at the hospice; this was evident in how parents interacted with staff. We saw parents relaxing in many areas; one parent played the guitar in the music room whilst we saw another parent crocheting in the lounge whilst their children played. Parents saw the hospice as their second home, making themselves snacks and drinks, spending time with their children playing and spending time to themselves doing things they enjoyed.

Parents spoke passionately about their involvement and the opportunity to influence the support their child and that of the family received, once they had been notified they were eligible for a service. Parents told us of the flexibility of care co-ordinators who contacted them to discuss their needs in meeting with them at a location convenient to themselves, which included at home and in hospital. "The care co-ordinator met us at the hospital, met our daughter and spoke to us about what we wanted from the service. They have taken everything on board and incorporated our views and information into her care plan. Small things which are so important, such as the importance of shampooing and conditioning her hair, having the physiotherapist sing to her like her dad does and requesting they read books to her as we do when she goes to bed. Even down to the 100% cotton sheets to help with the monitoring of her body temperature."

The commitment to person centred and individualised care was obvious in how bedrooms were prepared prior to each child or young person's arrival, to provide a welcoming and homely environment. This included making the beds with the child's chosen bed linen, adorning the walls with pictures and art, placing toys individual to the child into the room and putting their name and picture on the bedroom door.

Children and young people's care plans were person centred and included information as to how the person communicated. Care plans were written in partnership with the child or young person and their family. The

purpose of care plans was to ensure that staff had clear guidance to follow which was as reflective of the child's home routine as possible.

The provider used an outcome based assessment and care planning approach, identifying goals specific to the individual and family, based on physical health, home life, emotional and spiritual needs and support network. Individual's care plans, which were tailored to each person reflected how care should be provided, with consideration to communication styles and their meaning, likes and dislikes and parental views. For example a goal for a parent was for their child to be able to play like ordinary children do. When we spoke with the parent they told us, "Coming to Donna Louise enables my poorly child to play alongside his well sibling something that is almost impossible to do outside, the play days make this possible".

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. Parents of a child told us they were impressed by the space provided as it was a self-contained unit, which had separate access from the family rooms, which meant they 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.

The care team liaised proactively with health care professionals to ensure information as to the care being provided was shared to support a continuation of care. In some circumstances a child or young person was transferred from another setting, such as a hospital. The involvement of families continued following the death of a child, with on-going communication and bereavement support provided to the family by a named member of staff.

We spent time with children, staff, volunteers and parents and saw how children, young people their siblings and parents were supported to engage in a range of activities. On one day of our inspection visit, there was a themed open day, creating a seaside environment. A donkey visited the hospice and a range of activities took place, which all enjoyed. Parents told us how the organised holiday themed days, held each week provided an opportunity for all of their children to take part in activities that were fun. A parent told us, "Here, it's like a fun house, we all get to spend time together and laugh."

We spent time in a number of different areas of the hospice. Staff and volunteers engaged children and their siblings in activities, which included painting, accessing the sensory room, playing with toys and games as well as using the outside play area and equipment. We observed staff supporting a child in their bedroom whilst they played an interactive football game through their television. The young person shared with us their pictorial care plan, which included pictures and photographs of the things that were important to him. Earlier in the day they had visited the local football ground with a member of staff, they told us how much they enjoyed playing football.

The views, privacy and dignity of children, young people and their families was a key element in the approach of staff and volunteers, with a focus on person centred care for the individual and the family. The visions and values of the provider, as detailed on their website, underpinned all aspects of the service, influencing staff supervision and appraisal, the involvement of parents in the care of their child and their role in the services continued development.

Is the service responsive?

Our findings

The pro-active approach of care co-ordinators and the relationships they had developed provided families with the confidence and surety that the service would be able to provide support when it was needed. All parents we spoke with who used the services said that they were fully involved in all aspects of their child's care. Parents said staff were able to adjust the services and the care they provided to meet any changing needs, such as the expansion of their family or when their child was unwell. Examples of how support was provided, responsive to unplanned situations, included when respite care had been made available to a family when they experienced a failure of utility services at home.

Parents spoke positively about the referral process, in some instances parents had made a referral themselves, whilst others had had a referral made on their behalf. Parents said the referral process was timely and within a few days of being accepted, they were contacted and a visit organised to discuss their needs. This visit was also used by staff to provide information about the services offered by Donna Louise Trust. Once a family referral has been accepted parents were encouraged to visit the hospice. Staff recognised that being accepted to receive a service, meant for some parents, having to acknowledge and recognise the needs of their child and family, which was difficult. Therefore the introduction of families to the hospice was tailored for each family. A parent told us when they visited the hospice for the first time, "We were petrified of going; you have a perception of what it will be like. When we arrived and taken past the reception area into the hospice, we realised it was full of life."

Representatives from all aspects of the service met weekly to discuss new referrals, significant issues affecting families with a view to an agreed way forward to provide support. This enabled the provider to respond to the changing needs of families, providing a personalised response to their situation. We attended the meeting as part of the inspection and saw first-hand how information was shared and used to support families. The actions agreed included the social worker providing support to a family to ensure the benefits they were claiming were reflective of their circumstances, to help with a parents return to work. We also heard recognition that additional counselling should be offered to a family experiencing a range of complex issues within the home. And of the assistance to be provided to a family whose child was in hospital, which included practical support along with support for siblings through counselling.

Parents emphasised the support they received from staff when accessing hospital services and its impact on them. Parents of a child told us how staff had visited them in hospital, whilst their child was an in-patient, getting to know them and their child. Whilst a second parent told us, "When [child's name] has been in hospital, the staff have provided support by staying with them in hospital, so that we can go home for a while, have a shower and spend time with our other children. It's something we very much appreciate and the support to the family is something we could not manage without."

A number of focus groups had been established to gather feedback to be used by the provider to develop its future strategy, feedback provided a strong sense of concern from young people as they approached 19 years of age and their parents as to their future care needs and how these would be accessed and met, away from the hospice service. The provider as a result of the focus groups had established a group specifically to

look at how the hospice and other agencies could support young people and their families as they entered adulthood. The outcome of the group had been the provider's commitment to continue to provide services to young people once they had reached 19 years of age, which in part was to be met a new purpose built building, providing respite care.

A group of young people, attending the youth club spoke about their involvement in the planning of the expansion of the service. Young people shared with us their expectations of the planned service and their hope that it would support them in achieving greater independence and autonomy with regards to independent living, along with learning and work opportunities.

The facilities and equipment provided at the hospice, enabled children and young people to access all the resources of the hospice and supported their independence. There were computer packages enabling children to communicate by moving their eyes, indicating their choices and wishes. This had been achieved by collaborative work with an external company, to facilitate communication. We saw children, supported by staff, visiting other children in their bedroom to watch television and play computer games together. Height adjustable equipment enabled the space to be effectively used by children and young people of different ages and needs. This included adjustable height sinks in bedrooms, we saw a member of staff encourage a young person to brush their teeth independently, and adjustable height baths and shower facilities were also in place. Specialist chairs referred to as 'P pods' enabled children to sit comfortably and move around the hospice.

Information gathered through questionnaires sent out by the CQC found those using the service knew how to raise a concern or make a complaint and felt supported in making important decisions and knew how to contact the service. This was reflected in the questionnaires completed by all staff who indicated they knew who to contact in an emergency and felt any concerns they had would be listened to and acted upon.

The provider through its staff provided outreach specialist palliative care within local hospitals for staff and midwives, proactively supporting the local neonatal and paediatric intensive care unit (PICU) team. Thus enabling the staff to share its expertise and provide a service to parents and babies at this critical time.

Parents told us planning their child's care had included discussing their end of life care. A parent we spoke with told us, "We've visited the Garden Room, we want our daughter to be here at the end." And "We have discussed our wishes as a family and our views are recorded within the care plan." The hospice does not currently have any relationships with a chaplain; however a spiritual working group has been established to further develop support opportunities. In the records we reviewed there was evidence to support 'memory work' with a family before a child died, during their end of life phase. For example, a facility was made available for locks of hair and hand and foot prints to be secured for the family. Appropriate activities were created including a 'Make a Wish', a themed party for the dying child to create precious memories in the child's last days.

Staff provided support during the post bereavement period offering emotional support and practical help and signposting for the family to prepare for the funeral. Post bereavement care can continue informally or formally or both for as long as the family need this. Memory features were around the hospice environment and grounds, which included memory sticks made by siblings in a specific garden area, to painted pebbles placed in a family's favourite area. An annual 'Memory Day' takes place, where all families are invited, and is used as an opportunity to remember and celebrate lives through song, poems and quiet contemplation. This day also provides an opportunity for parents to meet.

Staff told us how they approached and supported children and young people with behaviour that challenged. We found relationships with staff at schools had been established and information shared so that behaviour management plans were followed at home, within the hospice and at school. These practices enabled a consistent approach to care provision. Staff resources were maximised, with regards to the number of staff on duty and their skills to ensure the needs of other children and young people were considered when planning respite care.

The responsiveness of staff in the planning of respite care ensured person centred care was experienced by the family. During our inspection a young child came to the hospice for respite care, it had been identified through the assessment process that both the child and parent experienced extreme separation anxiety and therefore a plan of support had been put into place. The agreed approach had been for staff to support the family prior to the respite stay, which had included day visits and a one night stay by way of introduction. A day prior to the planned respite stay the parent had visited the hospice to complete the admission documentation instead of on the day of their child's admission. This enabled the parent the following day to bring their child to the hospice and leave in a timely manner, so that staff could provide support for the parent and child to say goodbye and leave quickly to lessen the separation time and its impact. A member of staff who knew the child well was allocated to provide support upon their arrival to facilitate the admission. We saw how the child was engaged in an activity, which had included a personal item which the child sometimes used to communicate through already being in the child's bedroom. The parent also received support when leaving the hospice.

We spent time with the children and young people and saw how staff delivered responsive care that was personalised to each individual. Everyone 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.

We saw children and young people being supported to take part in social events and activities, which included a child being supported to use the jacuzzi, whilst several children were seen accessing the multi-sensory room, playing electronic games, watching films. We observed one child being supported by a member of staff who spent much time smiling as they interacted with the sensory lights. Many children were seen running around the soft play area, being supported to play by staff and volunteers.

Children were seen using the specialist play equipment, playing on swings, spinning on the roundabout and playing ball games. Children enjoyed using the quiet areas within the garden to listen to stories read by staff.

The PIR recorded how the provider had responded to comments made by parents and carers and had developed complementary therapy services for parents and carers; this was a volunteer led initiative providing free complementary therapy sessions. Parents told us how they appreciated these, saying they provided an opportunity to relax and focus on them for a short while and to feel special. Parents comments included, "My time, just to relax." And "My quality time, to focus on me."

The hospice staff were proactive in seeking the views of those who used the service by using different medias. The provider's website enabled comments to be made, whilst a number of opportunities were available for people to comment on the service they received following respite care and planned events, such as support groups and activities. Within the hospice boards entitled "You Said, We Did" provided feedback as to how comments received had been actioned. Parents we spoke with confirmed their views

were regularly sought saying, "They're always striving for perfection and asking for ideas." And "They regularly ask if there are any changes needed, we have a follow up phone call after each stay."

Young people and parents we spoke with were confident about raising concerns. They said, "I am aware of how to make a complaint, but have never had the need. Any small issues are discussed and dealt with immediately."

Information provided by the provider within the PIR identified that within a period of 12 months they had received one complaint and 35 compliments. The complaint received had been responded to consistent with the provider's policy and procedure; the complainant had been kept fully informed at all times. The complaint had identified improvements to practices within the hospice, underpinned by a change in policy and procedure.

Is the service well-led?

Our findings

We found that the provider created a range of ways in which children, young people, their families and staff working at the hospice, were involved in the services development. Parent's participation in fundraising and raising the profile of the hospice was something parents spoke about with commitment and passion. Parents told us, "We've organised a concert to raise money, it's been something positive for us to do." And, "I've taken part in the 10K walk, it's good to give something back, it makes you feel a part of something wonderful". Two parents told us how they used external events, which included the hospice's 'ball' and a ladies luncheon to speak about the hospice and its work and the impact of having a child with a life limiting illness on the family.

The success of counselling through art had resulted in the work being displayed throughout the hospice; in addition external exhibitions had been set up to display people's work. A parent told us how their pictures had been displayed and print copies made and sold. Monies raised from the sales had been invested into the hospice, which they told us was "a small way of saying thank you and giving something back."

People's views were sought annually by telephone, on-line and paper copy, volunteers were used to seek people's views via the telephone, and the results of the survey had been published and shared with parents and other stakeholders. The comments received reflected the impact of the service and what it meant to families. Additional comments collated included, 'The opportunity to sleep and re-charge batteries' 'Developed friendships and support networks, to talk to families who understand.' And 'The opportunity to discuss advance care planning and transition.'

We spoke with the chief executive about their involvement in the 'transition taskforce' and 'making connections'. The purpose of the taskforce was to engage with organisations supporting children and young people with life limiting conditions. They spoke of the 'Three Year People Plan', which sets out how the team plans to develop and improve aspects of the service, to meet future challenges. Our discussions with the chief executive officer and senior members of staff evidenced they understood the vision and values of the hospice.

The registered manager spoke with enthusiasm of being approached by 'Ted (technology, entertainment, design) Talks'. Ted Talks' is offered free with an online global audience used as an opportunity for identifying and sharing ideas within non-profit making organisations. The registered manager had been approached to present a piece of part of 'Facing the Future.' This was to be delivered by young people who used the hospice, to talk about their future and the need for parallel planning to assist young people's transition to adult services for those with life limiting conditions as they moved into adulthood.

The provider's commitment to encourage and promote an environment for staff to comment and influence the services provided had resulted in the establishment of the 'Staff Involvement Group' (SIG). Representatives from all areas of the service were represented at the meeting to promote inclusivity across the service. We attended the SIG meeting to hear first-hand the issues being discussed and the impact on the service. The provider having sought feedback on the proposed 'Charter' for the hospice provided an

update reflective of comments made by staff. The provider was now awaiting comments from the 'parent group' prior to a final version being approved by The Board of Trustees.

The provider had an open and transparent approach to sharing information. News and information for parents, staff and external professionals was available through the Donna Louise Trust 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. Reports, which included the 'Impact Report' and 'Annual Quality Account', were accessible through the website. The website incorporated social media and parents told us how their children had their own 'face book' page, which enabled them to communicate with other families, confidentially.

The vision and the values of the service were displayed throughout the hospice environment and were put into every day practice and were evident in the approach and attitude of staff in their interactions and approach with children, young people, their parents, other staff and visitors. This was particularly evident during the fun day, which was attended by many parents and their children, with staff and volunteers facilitating the event and through their interactions. The vision and values of the provider were incorporated into staff objectives which supported and evidenced how these were part of their everyday approach. When we spoke with a member of staff they told us how the value of 'excellence' for them had meant the sharing of their knowledge and learning to promote better outcomes for children and young people.

The director of care was the part of the West Midlands' Children and Young People's Palliative Care Network, working closely to identify local need and supporting colleagues in the development and audit of palliative care services. In addition they chaired the local children's palliative care network and children and families bereavement alliance. The minutes from meetings recorded how the director of care had agreed to contact a national funeral director, to discuss and identify good practice in the management of funeral's for children. This was in response to the support provided by staff to a family through its liaison with a funeral director following the death of their child. Other information recorded development and progress of support groups for parents following the death of a child. This included the planned implementation of a bereaved sibling's workshops at the hospice.

The provider in the recognition of good practice development had committed themselves to undertake the Investors in Volunteers Award, which they hoped to achieve in the near future. The volunteer service lead spoke about the positive impact it had on the service and the recognition of the importance of volunteers in the service provided. Examples of its positive impact had included the development of staff in the supervision of volunteers. Policies and procedures had been reviewed with recognition of the role of volunteers within the organisation along with identified areas for volunteer development to support those who may wish to develop their skills with a view to paid employment, through on-going learning and supervision.

The Donna Louise Trust in 2015 was awarded The Workplace Wellbeing Charter, which demonstrated the provider's commitment to the health and wellbeing of the staff team. The PIR detailed the provider's commitment to shared learning by supporting nursing students from universities and its initial contact with a university to provide a placement for those studying to become a social worker. Working with institutes for learning gives the provider another route to ensure its work practices reflect up to date guidance and thinking, as students share their knowledge with experienced staff employed at the hospice.

Information gathered through questionnaires sent out by the CQC found those who used the service had been provided with information about the services provided by the hospice in a manner that was clear and accessible. Questionnaires completed by health and social care professionals who worked alongside

children, young people and their families and the staff were overwhelmingly positive and reflected the commitment and dedication of staff in supporting those using the service and their families.

The provider had a manager who was registered with us and had relevant and up to date experience and expertise to lead the service. The registered manager (director of care) was a registered nurse in adult and children's health. During our visit we found the registered manager to be visible within the service, spending time with children, young people and the staff.

The board of trustees 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 assured 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.

There was a clear management structure with senior staff allocated lead roles. Throughout the organisation staff understood their lines of responsibility and accountability for decision making about the management, operation and direction of the hospice and its services. The management team demonstrated a strong commitment to providing children, young people and those closest to them with a safe, high quality and caring service and promoted high standards. All the staff we spoke with were enthusiastic about their work and shared the values and aims of the service.

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. Recent improvements that had been identified and actioned included, securing feedback from young people and the increasing of staffing resources. This had included an increase in hours for the physiotherapist along with the creation of identified roles within the service, such as the 'sibling lead role', these roles had a positive impact on those accessing the service.

The staff we spoke with described an open and supportive and enthusiastic leadership team, with a healthy no blame culture and desire to continue to learn and develop services

The provider within the PIR had identified planned improvements for the next year, evidencing their commitment to continuous improvement. A key component of the provider's vision was the expansion of the service to provide on-going care and support for young people as they moved into adulthood. An essential element that had been identified was the appointment of a social worker for adults. The planned expansion of the service acknowledged additional staff in a range of roles would need to be recruited, which would include a social worker for adults.

Planned improvements in some areas had already been implemented or were a work in progress. The provider had recognised the need to further develop spiritual and cultural support to children and their families. A nurse told us they had recently been appointed as the spiritual lead, and had recruited two nurses to work with them, forming the spiritual care working group. To support them in this role the lead had attended study days connected to spiritual care, part of this training required them to write an assessed case study as to the impact the service was anticipated to have on those receiving a service.

As part of the provider's commitment to the development of the service, the chief executive as part of their Master's degree in hospice leadership had focused on transition for their dissertation. This looked at how the UK hospice sector addresses the challenges of transition for young people into adult hood and makes reference as to the increasing number of young people surviving into adulthood. With recognition of the need to develop an appropriate response and approach to providing on-going support with the potential need for national legislative and regulatory changes. The provider was looking to use the findings of the dissertation to influence the further development of the hospice and other services within the wider community to improve the care and support children, young people and their families received.

Staff shared how they sought the views of children and young people in the development of their service. Their approach known as 'What's Tops/What's Pants' features in the publication 'Listen to My Voice', which forms part of a 'tool kit' designed to encourage positive engagement with children and young people with disabilities and specific needs.

The provider had dedicated resources to focus on data management and records, which included a 'task and focus group' having been established. The Director of Operations spoke of recognised practices and awards for data protection and how staff training had been a key factor in the management of data protection and training was made available to staff. They spoke of the Information Governance Toolkit, which had enabled the provider to undertake a self-assessment with regards to their management of information which had resulted in the production of improvement plan which focused on improvements.

Partnership working with other agencies involved in the care of children and young people was a key factor in ensuring person centred care was provided which was seamless whilst recognising the roles of all those involved. We were made aware of how staff liaison with external professionals benefited of those accessing the service. Parents expressed this in many ways, which included practical support in the completion of forms, attending meetings with health and social care professionals, financial advice and support as well as providing valuable links and support with schools. Locally this has included the Palliative CNS working with community specialist teams one day a week, attending joint visits and providing additional advice and support.