

Demelza House Childrens Hospice

# Demelza, Hospice Care for Children - Kent

## Inspection report

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Date of inspection visit:

15 August 2016

16 August 2016

Date of publication:

31 October 2016

## Ratings

Overall rating for this service

Outstanding 

Is the service safe?

Good 

Is the service effective?

Good 

Is the service caring?

Outstanding 

Is the service responsive?

Outstanding 

Is the service well-led?

Good 

# Summary of findings

## Overall summary

Demelza, Hospice Care for Children – Kent, is a local registered charity that provides specialist palliative care to children and young people aged 0-19 with advanced progressive life-limiting illnesses, both within the hospice and in the comfort of their homes. It aims to meet children and young people's physical, emotional, social and spiritual needs. Its catchment area is Kent & Medway, East Sussex and specific boroughs in South London.

The service includes a nine bed In-Patient Unit (IPU), a Day Care, a Community Team, a Family Support Team and a Therapy Team. The Community Team supports children, their parents and siblings with symptom management and end of life care in their own homes. Over the course of our inspection, six children were staying in the hospice, seven to ten children and young people used the day care and 24 children were supported in the community. Services are free to families and the hospice is largely dependent on donations and fund-raising by approximately 1200 volunteers in the community.

This inspection was carried out on 15 and 16 August 2016 by three inspectors and one pharmacist specialist. It was an unannounced inspection.

The provider included a Chief Executive Officer and a board of Trustees. There was a manager in post who was registered with the Care Quality Commission (CQC). A registered manager is a person who has registered with the CQC 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. The registered manager was also the Director of Care and oversaw the running of the service. They were part of a senior leadership team that included a director of people and resources, a director on income generation and a director of finance.

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

There were sufficient care and nursing staff on duty, to support and care for children and young people in the In-Patient Unit, the Day Care and in the community. Staffing levels were calculated and adjusted according to children's changing needs. Staff had appropriate training and experience to support children and young people with their individual needs. There were thorough recruitment procedures in place which included the checking of references.

Risk assessments and symptom management were centred on the needs of the individual. Each risk assessment included clear measures to reduce identified risks and guidance for staff to follow to make sure children and young people were protected from harm. Medicines were ordered, stored, administered and disposed of appropriately as per legal requirements.

There was an effective system in place to ensure people remained as safe as possible from the risk of

acquiring an infection. The premises were cleaned to a high standard. Throughout the service, fittings and equipment were regularly checked and serviced.

People said they were extremely satisfied about the way staff gave them the care they needed. They told us, "The staff work with us the family, we work together" and, "The staff understand they have to be flexible and they adapt to us, not us to them."

Staff knew how to communicate with each person and understood their individual needs. Consent was sought, obtained and recorded before any aspect of children and young people's care and treatment was carried out. Staff formed close and positive relationships with children, young people and their families, and often went beyond the scope of their duties to show they cared.

The CQC is required by law to monitor the operation of Deprivation of Liberty Safeguards (DoLS) which applies to hospices. Staff were trained in the principles of the MCA and the DoLS and were knowledgeable in the main principles of the MCA that they applied in practice. They assessed young people's mental capacity when necessary and when applicable they held meetings to make decisions on their behalf and in their best interest.

Staff protected children and young people effectively from the risks of poor nutrition, dehydration, swallowing problems and other medical conditions that affected their health. A relative told us, "The food is always lovely."

People were referred to specialists and healthcare professionals when necessary and their advice was sought and acted on.

The premises had been adapted to specifically meet children and young people's needs. They were well designed, welcoming and well maintained. Relatives described the suitability and adaptations of the building and décor as, "extraordinary" and, "amazing."

Staff were skilled at giving relatives face to face information and explanations they needed and the time to make decisions. Relatives valued their relationships with the staff team and told us that they often went 'the extra mile' for them, when providing care and support.

The service took account of people's cultural, religious and linguistic needs. The service valued practice that acknowledged diversity and promoted equality. Clear and comprehensive information about the service and its facilities was provided to people, relatives and visitors through a wide range of methods.

Family support was recognised by staff as vital to people's wellbeing and staff strived to meet the emotional and practical needs of people and their families. The service provided emotional support for children's families including their siblings, that was continual and beyond the provision of care for children and young people.

All the relatives and healthcare professionals we spoke with told us how they positively appreciated the service that was provided and the manner in which it was delivered. All their comments were overwhelmingly positive in regard to staff in the IPU, the community team and family support team. Children and young people were referred and signposted to appropriate services without delay in order to respond quickly to their needs.

Children, young people and their families were at the heart of the service and were fully involved in the

planning and review of care, treatment and support. Individual needs were met and responded to in a way that may exceed people's expectations. Staff anticipated how children, young people and their relatives felt when planning care and support so people felt valued and understood. Staff delivered support to people according to their unique support plan and responded to their specific needs.

Staff understood how to respond to children and their siblings' artistic and emotional needs at times that mattered. Innovative activities were provided to stimulate people's interests and creativity. The lead art therapist had won an award in March 2016, which recognised and paid tribute to those who go above and beyond to deliver the best quality care on a daily basis.

Families and young people took part in discussions with staff to express their views, preferences and wishes in regard to their child's care, support and treatment, and were invited to take part in 'advance care plans'. Their views, wishes and plans were respected.

People were actively encouraged to give their views and raise concerns or complaints. Complaints were addressed promptly and followed up with an action plan in order to drive improvement and lessons were learned as a result.

There was an open and positive culture which focussed on children and how to enhance the quality of their life. The service actively sought feedback from children, siblings, parents, grandparents, and healthcare professionals. The feedback obtained was extremely positive. A comment included, "You have been a life line, a shining light in the darkness."

The service took a key role in the community and was actively involved in building further links. It had the support of approximately 1200 volunteers.

People's feedback about the way the service was led described it as, "extremely caring" and, "well organised." The service and the registered manager worked in partnership with other organisations to raise standards of care.

There was a robust system in place to maintain and monitor the quality of the service across all departments that was effective in driving continuous improvement. Comprehensive audits were carried out about every aspect of the service to identify how it could improve. When needs for improvement were identified, remedial action was taken to improve the quality of the service and care.

## The five questions we ask about services and what we found

We always ask the following five questions of services.

### Is the service safe?

Good 

The service was safe.

Staff were trained to protect people from abuse and harm and knew how to proceed if they had any concerns.

Risk assessments were centred on individual needs and there were sufficient staff on duty to meet people's needs safely.

Practices regarding the storage and administration of medicines were in line with current legislation.

There was an effective system in place to ensure children and young people remained as safe as possible from the risk of acquiring an infection.

Robust and safe recruitment procedures were followed in practice.

The environment was secure and well maintained.

### Is the service effective?

Good 

The service was effective.

Staff were trained appropriately and were fully supported to carry out their role effectively.

Staff were effectively trained in the principles of the Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLS) and were knowledgeable about the requirements of the legislation. They assessed young people's mental capacity and held meetings in their best interest appropriately.

There was an efficient system of communication with families and with external healthcare professionals to ensure continuity of care. Clear and comprehensive information was provided to children, young people and their relatives when appropriate.

Children and young people were supported to eat and drink sufficient amounts to meet their needs and were provided with a choice of suitable food and drink.

People were referred to healthcare professionals promptly when needed.

### Is the service caring?

Outstanding 

The service was outstandingly caring.

Relatives valued their relationship with staff and gave very positive feedback about the caring approach of the service and staff. They described the delivery of care as, "Superb, it cannot be faulted" and "exceptional."

Staff were skilled at giving relatives face to face information and the explanations they needed. The staff approach towards children and young people was kind, patient and respectful. Staff often went beyond the scope of their duties to enhance children's wellbeing.

Children, young people and their family's cultural, religious and linguistic needs were taken into account when care was planned and delivered. The service valued practice that acknowledged diversity and promoted equality. Children and young people's dignity and privacy were respected.

The service provided emotional and practical support to children, young people, their parents, grandparents and siblings that was continual.

### Is the service responsive?

Outstanding 

The service was outstandingly responsive to children, young people and their family's individual needs. People's feedback about the responsive approach of the service described it in positive emphatic terms.

Children, young people and their relatives were fully involved in the planning of their care, treatment and support. Care plans were personalised to reflect children's wishes and what was important to them; they included siblings' needs and these were met with a specialised service.

Staff delivered support to children and young people in accordance with their unique care plan and responded rapidly to their specific and changing needs.

Staff understood how to respond to children, young people and their family's emotional needs at times that mattered. Innovative activities were provided that stimulated children's interests, developed their artistic ability and promoted their creativity.

## Is the service well-led?

Good 

The service was well-led by a provider, a leadership team and a management team who placed children, young people, their family and staff at the heart of the service.

Relative's feedback about how the service was run included, "well organised." Staff felt valued and supported by the service.

The service took a key role in the community and was actively involved in building further links. The service worked in partnership with other organisations to ensure good standards of care were maintained.

There was a robust system to monitor, maintain and improve the quality of the service and care across all departments.

# Demelza, Hospice Care for Children - Kent

## **Detailed findings**

### Background to this inspection

We carried out this inspection under Section 60 of the Health and Social Care Act 2008 as part of our regulatory functions. This inspection was carried out to check whether the provider is meeting the legal requirements and regulations associated with the Health and Social Care Act 2008, to look at the overall quality of the service, and to provide a rating for the service under the Care Act 2014. The inspection team included three inspectors and one pharmacist specialist. It was an unannounced inspection.

Before our inspection we looked at records that were sent to us by the registered manager and the local authority to inform us of significant changes and events. This included a Provider Information Return (PIR) which the registered manager had completed prior to our visit. The PIR is a form that asks the provider to give some key information about the service, what the service does well and what improvements they plan to make. This helped us identify areas to focus on during the inspection.

We looked at the premises and equipment. We looked at 12 sets of records that related to children and young people's care in the hospice and in the community. We looked at children and young people's assessments of needs and care plans and observed to check that their care and treatment was delivered consistently with these records. We consulted documentation that related to staff recruitment, training and management, and records relevant to the storage, ordering and administration of medicines. We observed the administration of medicines and examined three medicines charts. We looked at checks that were carried out by the provider concerning the monitoring of the safety and quality of the service. We sampled the services' policies and procedures.

We spoke with five relatives of children who stayed in the Inpatients Unit, a young person who stayed in the hospice for respite care and four of their relatives. We also spoke with relatives of three children who received support from the community team in their own home.

We spoke with the registered manager, the Director of People and Resources, the Lead Nurse, the

Community Services Manager, the Family Support Services Manager, the Head of Fundraising, the Clinical Nurse Specialist Governance, the health and safety lead, three nurses, seven care workers, two art therapists, one member of the housekeeping team and a catering assistant. We also spoke with three healthcare professionals who had experience of the service who oversaw children's care in the community. We obtained their feedback about their experience of the service.

At our last inspection on 31 October 2013 no concerns were found.

# Is the service safe?

## Our findings

Parents told us they felt their children were safe when using the service. They said, "This is not a place that makes you feel afraid, quite the contrary, this is a place where you feel your child is absolutely safe and in the best hands possible" and, "The staff are so watchful I feel totally confident leaving my child here."

The registered manager was the safeguarding lead. The Lead Nurse and the Family Support Services Manager had undertaken advanced training in safeguarding children. The training in the safeguarding of children was part of the induction for all members of staff. This was complemented by annual training and refresher courses which were up to date. Safeguarding was discussed at a caseload management meeting on a monthly basis and at child protection meetings held in partnership with the local authority when necessary. The safeguarding policy reflected the guidance provided by the local authority and had been updated in April 2015 to reflect the Care Act 2014 and changes in legislation. There was an effective system in place to evaluate risks, and staff knew how to identify abuse and how to respond and report their concerns internally and externally.

There were sufficient care staff on duty, to support and care for children and young people in the In-Patient Unit (IPU), the community and care services, and the Day Care centre. Two nurses were on-site in the hospice at any time and a third one was on call. Staff told us there were enough staff to care for children and young people in the way they needed and at the times they preferred. They told us, "The main thing that's good about this service is that we can spend time with the children and spend time with the families." The registered manager had taken into account the support needs of children and young people when determining the required staffing levels. This allowed staff to spend one to one time with children without being rushed. Staff we spoke with confirmed that additional support was provided when needed. For example we were told that sometimes children who stayed in the service had different sleep patterns and where necessary the staff shift pattern would be altered to match children's individual needs. A child had been awake all night and extra staff had been deployed to ensure the child had one to one support throughout the night. One staff member commented "We are lucky because we are able to flex up and look ahead and plan for support needs". The community team included five specialist nurses, 13 care workers, a family support worker, a care rota coordinator and an administrator.

Risk assessments for individual children were comprehensive and included clear guidance for staff concerning the steps they needed to take in order to keep the children safe. Risks associated with children and young people's skin integrity, levels of mobility and risks of falling were assessed before they came into the hospice to stay. These were reviewed daily and were updated appropriately. Staff were aware of the risks that related to each individual. Control measures to minimise risks to children and young people included the provision of specialist equipment and instructions to staff to work in pair when necessary. For example, there was a risk assessment in place that would allow children to access the hydro pool and surrounding area safely and this included the level of support and supervision they required in the water and at the pool side. A risk assessment was in place for a child in relation to skin viability. This included clear instructions for staff concerning how to prevent skin concerns from developing. For example, the risk assessment noted that the child should sleep on an airflow mattress and should be repositioned every two to three hours. Staff

followed this in practice.

The service held a clear policy on the use of restraint and this was used only as the least restrictive option when all other alternatives had been fully explored. Four nurses were trained in caring for children with learning disabilities and all the care team was trained in behaviour management and de-escalation of behaviours that challenged.

Children and young people's own medicines and stock medicines were kept securely. Appropriate arrangements were in place for ensuring medicines were not used past their expiry date. Children had any emergency medicines they required prescribed by their regular GP or consultant, and these were brought into the service with them. On the day of the inspection there was no anaphylaxis (severe allergy) kit available for use. The registered manager immediately undertook a risk assessment and obtained a medicine which could be used to treat severe allergies in an emergency. Waste medicines were stored securely and disposed of appropriately. Records for the medicines fridge stated only current temperatures, and not the recommended scale of temperature. This meant it was not possible to tell if medicines had been stored at the correct temperature. On the day of the inspection, the hospice created a new record form to include maximum and minimum temperatures at each reading and we have since been provided with evidence that this is now being undertaken. It should be noted that when fridge temperatures fall outside the recommended range, a reason for this or record of action taken should also be recorded.

Controlled drugs (CDs) (medicines which are at higher risk of misuse and therefore need closer monitoring) were stored securely. Destruction of controlled drugs was undertaken and recorded appropriately. Staff conducted balance checks of controlled drugs. Blank prescription forms (FP10s) were stored securely. This is important in preventing misuse of prescriptions. Staff had good access to up to date resources which they may need for medicines administration, including guidance on the use of syringe drivers (portable pumps that are used to provide a continuous dose of medicine through a syringe). Staff were able to clearly explain information to children or their carers about unlicensed medicines or medicines which are used off-label (licensed medicines which are used outside their normal terms).

Processes were in place to ensure that medicines for management of pain were administered in a safe and timely manner. The service had effective processes in place to allow children to take out medicines when on day leave. Child-friendly pain scales were used to monitor children's pain levels, so staff knew when children required pain relief. Several audits of medicines had been carried out throughout 2015-2016. This included an audit on safe medicines transcribing practices. Staff had good knowledge of how to report errors and were able to demonstrate learning from previous events.

Safe recruitment procedures were followed in practice. Staff who were employed by the service had passed appropriate pre-employment checks to ensure that they were suitable to work within the service and had provided two references including one from their most recent employer. Verification was obtained to ensure that references were genuine. A full employment history was documented for all of the staff who worked in the service in accordance with legal requirements. Staff had completed Disclosure and Barring Service (DBS) checks prior to beginning to work at the service. The service checked and monitored the registration of all of the nurses who worked in the service to ensure that their professional registration was appropriate and up to date. Disciplinary procedures were in place to ensure staff respected their code of conduct. .

Accidents and incidents were reported by staff electronically and this system included prompts to provide staff with feedback following accidents and incidents so that they were aware of the outcome. Staff were positive about the introduction of the system as it meant they were informed about what had happened with any concerns they had raised. The system prompted department managers to ensure that any lessons

that could be learned from adverse events were captured, and shared to improve practice where possible.

The premises were cleaned to a high standard and records were kept to evidence frequent cleaning throughout the day. There was ample provision of personal protective equipment which the staff used throughout the day. Staff washed their hands appropriately, and guidance about hand washing was on display throughout the service. Hand gel dispensers were placed at the entrances to the IPU and we observed staff using this in practice throughout our inspection and reminding visitors to share this practice. The temperatures of served food, fridges and freezers were monitored and documented. These measures protected children and young people from the risks of acquiring an infection while in the service as much as possible to keep them safe.

There were cleaning schedules in place that included regular deep cleaning of areas on a rotational basis. Additional support from the housekeeping team could also be requested as and when required. Other staff members spoken with during the inspection were very positive about the contribution of the housekeeping team to the service. One staff member told us "We have a phenomenal housekeeping team". Another staff member told us that "Nothing is too much bother for the housekeeping team". The kitchen area was very clean and cleaning schedules that broke down cleaning tasks into daily, weekly, fortnightly, monthly and bi-annual tasks were appropriately completed.

An effective system was in place to ensure children and young people remained as safe as possible from the risk of acquiring an infection during their stay. There was an infection control lead for the service who had received specialist training and who provided additional support and guidance to staff. Infection control audits were completed to ensure that systems in place to prevent the spread of infection were effective. For example, audits had been carried out to monitor the hand hygiene of visitors and staff entering and leaving the inpatient unit. Systems in place for the segregation of laundry and the management of waste were implemented appropriately to minimise risks of contamination.

The premises were secure for children and young people due to a robust security system in place. The building had an electronic access control system which activated selected doors and gates, enabling restricted access to individual staff and volunteers. Reception staff and staff within the building were vigilant and only allowed access after thorough checks of visitors' identity.

Systems were in place to ensure that the premises were well maintained and repairs carried out in a timely manner. There was a dedicated maintenance team with the service who addressed issues such as repairs and the on-going maintenance of the service. All equipment in use at the service was regularly maintained by specialist contractors. Systems were in place to monitor when equipment needed to be checked and serviced.

Clear and detailed environmental risk assessments were carried out to maintain the safety of the premises. A Health and Safety and Therapy Pool Committee met every eight weeks and provided effective management of all areas of the service in relation to health and safety.

Staff understood how to respond to a range of different emergencies including fire, and fire training was part of their induction. Fire drills were regularly held. Staff rehearsed evacuating smoke filled areas in order to ensure that they would be able to do this in a real emergency. Information about children's individual levels of mobility was ready to be used in the event of an emergency such as the evacuation of the premises. Fire safety equipment that included smoke and heat detection, fire alarm, fire blankets, and fire extinguishers was routinely checked and serviced. A comprehensive business continuity plan was in place that provided staff with clear guidance concerning how to run the service in case of the loss of essential services such as

electricity.

## Is the service effective?

### Our findings

Parents and grandparents told us they were extremely satisfied about the way staff provided the care their children and grand children needed. They told us, "The staff who come into our home got to know our daughter very well and as they are the same faces it gives her a consistent and familiar routine which is so important", "The staff work with us the family, we work together" and, "The staff understand they have to be flexible and they adapt to us, not us to them." Relatives described the suitability and adaptations of the building as, "extraordinary."

Staff told us they felt well supported in their role. They told us, "'I've never felt I couldn't ask if I needed help", "Support is always there, and we look after each other", "We can take time out if we need to if it's getting too much; it's ok to say 'I can't do it'." The service had carried out an employee engagement survey in April and May 2016 which indicated 67% of staff that took part felt well supported by their line manager. The registered manager told us, "We are taking on board staff suggestions for improvements."

All nurses and care workers received a thorough induction before they started working at the service. The induction included the shadowing of more experienced staff for at least six weeks until they could demonstrate they had attained the level of competency required for their role. Specific competency checks were carried out to ensure that staff were competent to manage and administer medicines. Each new member of staff was allocated a mentor who was a nurse or an experienced care worker, and these mentors monitored and signed off their competency checks. A practice development nurse role had been implemented in 2000 to provide mentorship support to all new staff and an additional post created in 2012.

There was a bespoke leadership development training programme in place that had been operating for four years, for all line managers and registered nurses. It included face to face training on positive performance management, problem solving decision making and facilitation skills, assertive communication skills, and training and developing staff. As line managers and nurses were trained in these aspects of leadership, children and young people could be confident that the staff delivering their care were competently led and managed.

Staff had appropriate training and experience to support children and young people with their individual needs. Essential training included moving and handling, infection control, fire, safeguarding and mental capacity. A varied range of additional training was available and delivered to staff through 'competency theory training' days. These differed for nurses and care workers although all were trained in bereavement and communication and positive behaviour support. Nurses were trained in updates regarding intravenous care, medicines, symptoms management, tracheostomy (a procedure undertaken when a person is unable to breathe normally), ventilation and syringe drivers. Care workers were trained in enteral feeding, respiratory care, seizure care, post-death and non-invasive ventilation. An effective system tracked the training programme and ensured each member of staff had received their training within a set time frame. Staff we spoke with felt that they had been given the specialist training they needed in order to be effective in their roles. Two members of staff told us, "I've never worked anywhere that offered this much training"

and, "We're proud we've got the skills to do complex care."

There were systems in place to ensure good standards of practice were maintained. The service liaised with Health Education England to check the appropriateness of their training programme. They took on student nurses from four local universities in 'placement' who were supported by two 'student placement links nurses', who measured their progress. The Clinical Nurse Specialist Governance met with these two nurses regularly.

All staff received regular one to one supervision and were able to request additional sessions when needed. Monthly managerial and clinical supervision sessions were recorded, and addressed any concerns that were raised. Post-death debrief support sessions were also provided to staff to help them cope with any associated feelings of bereavement. A member of staff said, "There's always a debrief if a child passes, you get that much needed support." Senior staff had an external as well as an internal supervisor. One department manager we spoke with told us how their external supervisor had come from a different work background and this had helped them to reflect on their practice using another perspective. Staff were positive about the support they received as part of the supervision process. One nurse told us, "It's really useful and a chance to reflect on practice." Staff received regularly appraisals to monitor their performance. A member of staff said, "We have an appraisal every year and it keeps you on track, it gets us achieving what we should be achieving." All members of the senior management team staff received fortnightly one-to-one supervision from the CEO.

An effective system ensured that staff were knowledgeable about children and young people's individual care, treatment and history when they came in the IPU. The service engaged with tertiary centres, such as two London children hospitals, community children nursing teams, special needs schools and other relevant health or social care professionals for up-to-date information about the child or young person's life-limiting condition. Nurses could therefore carry out 'pre-planning' of care before any child or young person stayed in the IPU, to be as prepared as possible. The community team supported children whose needs were predominantly for 'nine to five respite'. However when that team helped parents care for their children who approached the end of their life in their own homes, they liaised with a local community children nursing team to provide 24 hour support.

There were daily multi-disciplinary meetings in the service where individual needs in the community were discussed and a more formal monthly meeting. The multi-disciplinary team included the lead nurse, the head of care, a care co-ordinator, the family support team and a care team that included two nurses. Each child or young person in the IPU had a named keyworker and a named nurse. A key worker is a named member of staff with special responsibilities for making sure that a child has what they need. Staff with the right skills were selected as much as possible to ensure specific needs were met. For example, when a child came in who needed antibiotic medicines to be administered intravenously, staff with these specific skills were allocated to provide their care.

Staff shared information about children and young people's care every twelve hours at handovers to ensure continuity of care. They discussed their findings with doctors when necessary and ascertained the best way forward to manage children and young people's symptoms. Three doctors were on call for consultation at any time.

Ways for staff to communicate with each other including 'posting' their comments on an internal website called 'Dotty'. A member of staff told us, "We post whatever we choose about the work and we get feedback from our peers that way." Each directorate held an annual away day where staff got together and got to know each other.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of young people aged 16 and over who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf must be in their best interests and as least restrictive as possible. People can only be deprived of their liberty to receive care and treatment when this is in their best interests and legally authorised under the MCA. The application procedures for this in 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.

The service complied with the MCA requirements. Consent was sought, obtained and recorded before any aspect of children and young persons' care and treatment was carried out. Parents and staff discussed and recorded the decisions that were taken in children's best interest, and young people were actively involved in every decision when they were able to do so. An assessment of a young person's mental capacity had been carried out when they had declined to wear their ventilation mask during their treatment. As a result, the right to make their own decision had been respected. The Lead Nurse told us, "We are very clear on what we can and cannot do."

Staff protected children and young people effectively from the risks of poor nutrition, dehydration, and swallowing problems that may affect their health. Menus gave several options of a balanced meal. A relative told us, "The food is always lovely." A catering assistant who had been trained in food and hygiene at Level two told us, "If a child doesn't want any item on the menu we cook what they want." The children also had a cooked evening meal that gave two choices of a main course. There was an effective system to communicate children' food preferences, dislikes, allergies and dietary requirements such as required food consistency. Food and fluid intake was recorded when necessary and these records were checked daily by nurses. Good practice guidelines were being followed in the storage and preparation of food.

Children and young people were referred to healthcare professionals when necessary and their advice was sought and acted on, such as to Speech and Language Therapists (SALT), occupational therapists, physiotherapists and wheelchair services. To ensure that decision-making and symptom management were well co-ordinated and supported by best practice guidelines, the service had a service level agreement with a local GP practice and a London children hospital. This support included scheduled visits by GPs, consultants and clinical nurse specialists.

The premises had been designed and adapted to provide an exceptional environment for children, young people and their families. They were spacious, decorated in bright colours, lit by large windows, welcoming and promoting cheerfulness. All areas were furnished to a high standard and provided comfortable sitting and sleeping. The sensory room had a waterbed, a ball pool and a wide range of lights and equipment. An Information Technology suite was available for children to access several computers and specialist communication equipment. All areas were fitted with tracking hoists. Children and their siblings used a spacious hydrotherapy pool with floats and a lighting and music system. A large soft play area included a trampoline and a ball pool where lights could be controlled by the children. There were adapted swings to allow wheelchair access.. There was a dedicated music therapy room and a space for art therapy that was away from other areas allowing for individual work with children or their siblings. Staff told us, "The space has been created so 'Day Care' is everywhere." A 'tweens corner' within the communal area was dedicated for children aged nine to 13 years of age. The 'Tiz' zone for teenagers included a kitchen, an IT suite, a wide screen television and vibrating easy chairs. A home cinema could be used by families that had surround sound and there was family accommodation which was directly above the IPU allowing easy access to the unit. There was a large outdoor covered area with soft artificial grass and several play houses.

As the environment was specifically designed for children, young people and their siblings, they could enjoy spending time in the service and their parents could have some respite from their caring duties. A relative told us, "As soon as I came here and saw this place I thought everything will be OK, this can be home from home, and even better than home, for my child, and also for me." Another relative told us, "The buildings are simply marvellous, they thought of everything to make the kids feel happy here, it is extraordinary in every way."

There was a quiet space for reflection that was used for celebrations and ceremonies. Two cold rooms were furnished and decorated as bedrooms and were used by families who wished to spend time with their child after they had passed away. A large conservatory was available for families to use at the time of bereavement and this was an adaptable space that could be made smaller or larger by using sliding doors depending on the needs of the families.

## Is the service caring?

### Our findings

All the relatives we spoke with told us how they positively appreciated the service that was provided, the manner in which it was delivered and of their trust in the staff. Their comments were overwhelmingly positive in regard to staff in the IPU, the community team and family support team and indicated that children and young people were placed at the heart of the service. They told us, "It's an amazing place to be and a phenomenal thing to be part of; if my child is in intensive care I don't leave her side, but if she is in Demelza I'm happy to go on holiday and I don't have any worries at all", "The staff here are so caring and it's not just the care staff, even the fund raisers have photos [promotional posters] of Demelza children on their desks [in their office]; it would be difficult to find an example of when they are not caring." They described the delivery of care as, "Superb, it cannot be faulted" and "exceptional." They said, "The people who work here make this place special."

All the staff we spoke with stated feeling "proud" or "privileged" of working for Demelza, and some of them told us, "We are giving something special to the family and the child that they couldn't get anywhere else", "We can make a difference and that's what's important" and, "We give holistic care – we sign up to the same values and we sign up to support children and their whole family." A member of staff said, "It's hard for mums to hand over their children and we know we have to earn their trust and we do."

Children had one to one support and were actively supported by staff who understood them and who pre-empted their needs with empathy and kindness. Staff demonstrated genuine affection towards children, by connecting with them, smiling, laughing, using body language and cuddling them when appropriate. Staff and children played while baking a cake and some of the children enjoyed throwing flour around. Staff were laughing with the children and prioritised children's joy over the fact that mess was created. At the end of the activity, the children were covered in flour and chocolate. Staff told us, "If the children are happy, that's the most important thing; no one cares about the walls or the floors or getting covered; this gets washed afterwards; they need to have fun" and, "It can be loud and messy in here – it's normal life."

At mealtimes, staff and children interacted as equals. They sat and ate together on a large table and staff remained vigilant of the children's needs. One child was having difficulties with eating so a member of staff got up and offered him a plate guard so he could maintain dignity in front of his peers. A care worker ensured a child knew exactly what was in each spoonful by prompting him with comments such as, "This is pork chop" and letting him see and smell the food before tasting it. The child was so relaxed being supported to eat that he put his foot in the care worker's lap. An infant was being fed through a tube that had been surgically inserted in her stomach. Staff ensured that she was part of the mealtime, utilised the bell that was hanging from her push chair as well as using eye contact and gentle speech to interact with her. They held her hand and gave her tactile objects to hold. Staff were smiling continuously and conversed with children with genuine interest at a level of communication they could understand and mirror. Staff involved the children whenever possible by asking them questions such as, "Is that nice, [X]?", "You don't like mushrooms do you, [X]?", and paying attention to their replies or body language. A child had been sneaking his mushrooms on to his care worker's plate and when the staff realised this, they celebrated the joke and laughed together. The staff involved shared the joke every time someone walked by, which clearly pleased

the child. Two members of staff told us, "It's all about life – this service is about creating wonderful memories" and, "We can spend quality time with the children."

Staff talked with children ensuring they were positioned at their eye level to facilitate effective communication. We observe a child who sat in the play area with a care worker, pressing buttons on a toy car. The child enjoyed pressing the buttons and then hearing her care worker repeat the noises of phrases the car made. Another child was playing with a range of sensory toys, and staff asked, "Shall I turn that off now?" and the child clapped to say 'yes'. They used a gentle tone when they spoke to settle them, a cheerful tone to engage them in play, and appropriate touch to support different levels of communication. Staff were aware of the need to gain consent from children where possible and we observed that one child was asked if he was happy to have his photograph taken. He used a communication device to indicate his refusal and staff respected his wishes.

Staff used a specific assistive technology to communicate with several children. This included 'The Eye gaze', an innovative eye-operated communication and control system that empowers people with disabilities to interact with others. By looking at control keys or cells displayed on a device screen, children and young people could generate speech either by typing a message or selecting pre-programmed phrases. A relative told us, "My child loves the Eye gaze and enjoys making 'farting' noises with it", and a member of staff said, "Any communication is good, we encourage children to express themselves in any way that feels best for them." A communication care plan for a child who was supported at home clearly included explanations for staff to understand when the child was frustrated, angry or felt unsafe, and how to respond. Another indicated how a child was signalling yes or no by looking in certain directions.

Staff formed close and positive relationships with children and their families and often went the 'extra mile' to show they cared. Staff had supported a child's transition to a foster home by taking photographs of the child in their familiar surroundings and of their new home. They had compiled a photo album that they presented to the child and also his birth mother and grandparents so they could picture him in his next environment. They had learned Makaton so they could teach key words to a child and help them communicate. A child who stayed for respite did not want to be parted with her puppy. Staff had assessed all associated risks, written a care plan for the animal and had managed its inclusion in the service close to the child. A child's life support relied on the use of a ventilator and the child wanted to join a nursery class, a horse-riding class and a swimming class. Staff had looked at how this could be enabled, discussed all associated risks with the family, and had supported the child through this integration. Such measures ensured that children could retain and find comfort in activities and routines of their choosing, as well as reduce isolation. Even though Demelza Hospice cared for children up to the age of 19, the Family Support services provided outreach support to young people aged from 19 to 25 to help them with any issues they may have, such as accessing education. Young people were able to bring a friend to stay with them overnight in the hospice. A member of staff told us, "Sleepovers is what you do at home and while they are here, this is their home."

Families were supported in a meaningful way before and after their child has passed away. "A member of staff said, "It's humbling when the families accept you into their circle; they appreciate the little things, the favourite flower, hand prints, phoning the photographer; little things can be so meaningful." Another staff member told us how she placed children who had died in their coffin herself instead of the undertaker, when this was what families preferred. She said, "They trust me, this is something I can do for the families, I have cared for them in life and they know I'll do it right" and, "They have to look right for the final journey." Outside the cold rooms where a child body may lay at rest, there were warm fleeces for relatives to wear when they stayed with their child. A relative told us, "Little touches mean so much."

The relationship between staff and children and young people receiving support consistently demonstrated a respect of their dignity. There was a close circuit camera placed in every room that had 'live feed' to the care team office only and no recorded images. These cameras provided an effective way to monitor children's safety. Demelza's Data Protection Officer had liaised with the Information Commissioner's Office to confirm that this system was compliant. The cameras were turned off every time staff provided help with personal care to preserve children's dignity. Private changing facilities were available for those accessing day care.

Staff promoted children and young people's independence as much as possible. They encouraged children to actively participate during play-time and at mealtimes and do as much as possible themselves so they could retain elements of control. A care plan for a young person in the community who needed topical cream applied daily included, "Encourage him to do this and take the lead, as preparation for involving him in the process in the future." Children and young people staying in the service chose when to get up, what to do and when to go to bed. Staff told us, "We take our 'cues' from them, we present options and they choose, we follow."

Fittings throughout the premises had been installed with children's need for independence in mind. Sinks were height adjustable and had easy turn taps fitted. This enabled children to wash themselves whenever possible, and wash their paint brushes in the art room after they had used them. The lift between the ground floor and the Tiz (Teenage zone) had been adapted so it could be operated by teenagers who may have low muscle tone. Baths, toilets facilities and bidets were height-adjustable and had warm air and water vents. Two bedrooms were fully equipped to enable young people to have autonomous control of their environment, such as system to open and close doors, make telephone calls and adjust room temperature and lighting. The hydro pool had a lighting, music and sounds system which could be controlled by children using a system of pedals. The Director of People and Resources told us, "We want children to feel empowered and in control as much as possible."

Staff focused on what children could do and worked hard to ensure that special wishes were granted wherever possible, taking a positive approach to risks. They worked with families to make sure situations involving potential risk were safely managed. A member of staff told us, "Some parents struggle to give the children normality when they're not sure how long they've got – we give them that normality." They told us about how one family wanted to take their child for a visit to a local zoo. The staff team had worked with the family to plan this visit, talked through what would happen if there was an emergency and liaised directly with staff from the zoo. A staff member was provided who was on hand should additional support be needed and who remained discreetly available, so as not to intrude on 'family-time' while giving the parents peace of mind.

Clear and comprehensive information about the service and its facilities was provided to children and young people or their relatives and visitors. This included a seasonal newsletter booklet produced jointly by the service and their sister service. This included personal accounts and stories from families, dates of events, and explanations of what particular teams could offer in and out of the service. A separate newsletter was dedicated to the work of volunteers.

A wealth of informative leaflets was available on specific medical conditions. Large notice boards were dedicated to information concerning clinical education and displayed staff names and photographs, and dates for the scheduled parent / carer forums. Signage was used throughout the service to indicate rooms' functions and where to go. The service's website was comprehensive, regularly updated and easy to navigate.

Staff took account of children, young people and their families' cultural and religious needs. A member of the nursing team was working on developing a guide to pastoral care which could be shared with colleagues. A local pastor had been brought in to give a presentation on spiritual care. Religious services could be held at families' request in a large quiet room that had a stained glass window. The registered manager told us this room was not called a chapel as this may have associated it specifically with one particular belief system rather than being a multi-faith space. There was a book of remembrance on display that included messages from families, poems and prayers. This helped families express some of their grief.

The service valued practice that acknowledged diversity and promoted equality. For example, staff were aware that for families from certain cultures it would not be appropriate to have mixed gender access to the hydro pool and therefore different times were arranged when single gender access to the pool was provided. A Kurdish family was supported in the community and the registered manager told us that they had planned to enlist an interpreter's help at the beginning of the child's stay in the hospice. A Sikh family had been enabled to remain three days close to their child who had died, as per their custom. The conservatory had been used by members of a travelling family who had needed to congregate in a large group. A community nurse accompanied parents who had learning disabilities or hearing impairment to appointments and helped them understand relevant information about their child. Staff had challenged hospital staff when parents had been misunderstood, and had advocated on their behalf to represent their views.

Family support was recognised by staff as vital to families' wellbeing and staff strived to meet the emotional and practical needs of children, young people and their families. A Family Support Team carried out 'generalised anxiety disorder' assessments and made timely referrals to GPs or statutory mental health providers when appropriate. They offered practical assistance with applying for benefits and grants applications. They focused their support on those who have suffered a bereavement, younger and older siblings, parents and community partnerships. The Therapy Team offered a range of therapies, including art and music, to children and families. Their services also included the use of bereavement suites, memory-making, end of life planning including funeral arrangements, group support sessions for parents, grandparents and in schools. They organised events such as 'snowdrops planting', candlelight services and signposted to external support when appropriate. Support was provided 'as long as necessary'; therefore the service provided emotional support for families that was continual, beyond the provision of care for children and young people.

## Is the service responsive?

### Our findings

All the young people, relatives, visitors and healthcare professionals we spoke with described in emphatic terms the way staff responded to children's needs, such as, "Fabulous, beyond what I expected", "excellent, "brilliant"" and, "marvellous". A young person told us, "I come here for respite and all the staff know me well and I know them well, they know what to do for me, this is a wonderful place." Relatives told us, "They provide a life line, literally", "It's friendly, lively, bubbly – there's so much for the children" and, "We could not have coped without them, they totally understand us." A relative had written to the service saying, "You have been a life line, a shining light in the darkness." A member of staff told us, "Death is a tiny part of it – most of what we do is about life." A NHS Speech and Language therapist who provided guidance to the staff told us, "Staff working in the community are guided directly by parents; the management team at Demelza took the initiative to ask our clinical team for expert advice to address specific questions [about individual needs]."

The service responded to children and young people's needs in regard to symptoms and end of life management in the community. There was no definitive list of conditions or illnesses which may or may not meet the eligibility criteria for access to services. Young people could refer themselves once they had written consent for a referral from a person with parental responsibility.

The service ensured there was a rapid response to children and young people's changing care needs and that advice on care and support was available round the clock. The Community Team visited children or young people and their parents to fully assess their needs and wishes, and wrote a care plan the same day. The multi-disciplinary team was available and an out of hours registered nurse 24/7 on call system was in place to offer urgent guidance or signposting if needed. Three doctors assured 24 hours cover on a rota system and prescribed medicines when GPs prescriptions were not available.

Comprehensive assessments were also carried out before children were admitted into the IPU to ensure that their needs were understood and could be met appropriately. This included a seizure plan if required, any specific medical needs, current social issues, issues at school, medicines and emergency contact details for families. Care plans were clear, comprehensive and included information relevant to medical, social and emotional needs that staff needed to provide effective care and support. For example, if children needed suction, ventilation, or particular moving and handling procedures, there were instructions concerning how this should be managed and how staff were to pay attention to the way children may feel during each task. The care plans were 'working documents' and were continuously updated by staff to reflect children and young people's changing needs, wishes and preferences. One child's care plan highlighted that they liked pasta but disliked potatoes; another disliked bright lights or loud toys; another liked stories, dancing, singing and dominos although they enjoyed these particular games only for a certain period of time. Photographs were used to guide staff concerning physiotherapy exercises or when it was necessary to position children in a particular way due to their physical health conditions.

Each care plan was written in partnership with children when they were able to participate, their parents and the multi-disciplinary team. Care plans were centred on individual needs so that staff who referred to them could be well informed and respond fully to these needs. Triggers which could lead to behaviour

difficulties were noted and clear guidance for staff was in place concerning how to de-escalate behaviours which may be challenging. For example, there was guidance concerning the need to prepare a child with a countdown to any changes of activity. A NHS speech and language therapist who provided clinical support to pupils in a school told us, "Staff at Demelza approached our clinical team in order to receive guidance about how to best help at mealtimes to ensure the safety and dignity of children; they wanted to make sure risks of aspiration or adverse events were being considered by parents who directed staff, that mealtimes were not unduly long, and that they were considering the needs of children who may be unable to use speech." As a result of the staff request for guidance, they had received bespoke eating and drinking training and had worked in collaboration with the therapist, the children and their parents to agree mealtime's needs.

The arrangements for social activities were innovative and met children's individual needs. The art therapy that was provided was 'non-directive' (when art and play followed the children's lead) and included a wide range of creative play. The lead Art Therapist had won a Creative Counselling Initiative award in March 2016, part of annual care awards which recognise and pay tribute to those who go above and beyond to deliver the best quality care on a daily basis. The Art Therapist had adapted her role to include children with learning disabilities to those who had life limiting conditions. They worked with children, young people and their siblings, using original ways to provide opportunities for expression. This included sculptures, a home-made 'spin machine' where children and their families could work with colours that related to particular memories; and therapy dolls where children could place a message inside the dolls and any worries they may have inside the doll's satchel. A social worker in the Family Support Team had been shortlisted for the Well Child National Award a few days before our inspection; an affiliate complimentary therapist was one of four finalists for the Volunteer of the Year 2016 Kent Charity Awards. This meant that children and young people were supported by staff who strived to think imaginatively using new ideas, instead of traditional or expected ideas. As a result, their imagination was stimulated and their modes of expression were particularly encouraged.

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 and young people 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 to the Family Support Team for psychological, emotional and practical support. Three specialised family support workers and trained volunteers supported families in the service or in their home. They helped with applications for special equipment, letters of support or advocacy to access other services, assisted with applications for benefits or special holidays and referred to professionals, support groups and therapists. The range of therapies available included art and music; complementary therapies such as aromatherapy, Indian head massage and reflexology were offered to adults who were supporting a child. Infant massage and relaxation were provided to children. Sibling and peer support was provided in one to one sessions, groups, or in conjunction with schools. Children's rights to education were promoted by the service. A child in the IPU who was due to remain for a prolonged period was on-roll at a local special education needs school and staff had committed to taking him weekly to the school, to ensure his education was continued.

Links were made to antenatal services to support families where unborn babies had life-limiting conditions. The service had formed strong professional link with the Pan London Lead Nurse for Neonatal Palliative Care and a hospital Neonatal Consultant, to support expectant mothers who wished to continue their pregnancy to term when their baby had a very short life expectancy. Following such a referral, the Care Service Lead had established contact with a baby's mother and family who had visited the service, viewed

the facilities including the Hop Garden suite (cold bedroom) and had discussed in detail what they felt would be helpful to them. Although the baby died peacefully at home, the mother had expressed a wish to return to the hospice and use the Hop Garden suite. The family had then been supported by the Care Team and Therapy teams with memory making activities such as hand and footprint montages, while the Family Support Team had assisted with organising the funeral, securing financial support via the benefit claiming processes. The mother, grandmother and sibling all remained residents within this time, which ensured that they were able to spend time processing their grief. The family continued to be offered bereavement support as staff especially considered possible risks of post-natal depression.

Creative ways had been sought in order to engage with bereaved families. A group of parents had been invited three years after the death of their child, to attend an accredited training course in active listening and take the lead in setting the agenda for three yearly commemorative events. This group of parents acted as ambassadors of the service and welcomed other parents who may be apprehensive about engaging with a hospice service. They explained to them how the service had helped them and their children, and played a part in taking the stigma out of hospice care. A parent told us, "It is good to talk with other parents who have gone through similar challenges because we can see they are coping so it gives us hope." As a result, more families engaged with the service as some of their fears may become reduced or dissipated.

A support group for siblings, 'SIBS', engaged in direct work with siblings of all ages and organised activities and outings for them, such as canoeing, ice skating, archery, bowling and paint-balling. A 'care volunteer' with the Family Support Team described to us how a group of siblings aged five to ten had been taken to a local farm for day of activities, how they had been encouraged to make friends and express the way they may feel about their sick or dead siblings. They told us, "We listen and we understand; sometimes you can see the relief on a child's face when they realise they are not alone feeling the way they do." A relative told us, "Demelza are very responsive; we stayed here for a month when our house was being adapted and during that time three families were bereaved. Siblings were encouraged to play together, and my son's mind was put at rest that when the time would come, him as a brother will be looked after too."

Support was given to families before and after the death of a child or a young person. A wide range of informative leaflets explained how bereavement support could be accessed. This support took several forms as it was adapted to families' individual needs. For example, children and families may participate in end of life care planning, funeral plans and 'memory making' projects, such as creating memory boxes, taking photographs, recording voices and sounds, and talking about how much the child was loved. Care workers who knew the child participated in these projects. After the death of a child or young person, families were helped with managing practicalities and their own emotions. They were assisted with contacting funeral directors, choosing the clothes to lay the child to rest in, and supported with telling younger siblings what had happened to their brother or sister. Families were told, 'Our role is to assist you without interrupting your grief, so you remain in control'. The Family Support Services Manager told us, "We provide very targeted family support model based on families individual needs, and we endeavour to think outside the box."

Approximately five weeks after the funeral, the service offered support to families by care staff who had known the child or young person whilst they were under the care of the service. This was in response to some bereaved parents having suggested this would be helpful towards the grieving process. If longer support was needed, the Family Support Team made contact with families three months after the funeral. When families had consented to this, the team telephoned them four times a year to create an opportunity for families to let them know whether support was needed.

The service placed children and young people at the heart of the service, using individual ways of involving

them so that they felt consulted and empowered. Two children had attended the interview panel when the CEO was recruited and their views had been taken into account. The Board of Trustees had invited a teenager to their meeting to relate his experience of services. As a result, children and young people could be confident that their views mattered and that they played an active part in decisions about the service.

Staff understood aged-related needs and adjusted to accommodate these. For example some of the older teenagers who used the service had wanted to stay up late after a music festival. Staff had stayed on shift longer to allow this. One member of staff told us, "They need to enjoy life; it's all about life." Staff had escorted a group of teenagers out to a nightclub after having organised a stretch limo and a minibus which staff had decorated with red carpet. A member of staff told us how teenagers had conversations with staff about coming to terms with death and told us, "'I've had some amazing conversations, conversations they may not have with their parents as they are mindful of not upsetting them – it's a really deep need that we're meeting."

The environment had been adapted paying great attention to children and young people's needs. There were wheelchair-level activities on the walls such as puzzles and convex mirrors. Bedrooms were spacious and included a divan area that friends could use to spend a night if they wished. Each bedroom was connected to a spacious bathroom with a ceiling hoist; they opened onto the gardens to a patio area with an awning that shielded children from the sun. Some toilet facilities included warm air as well as water to facilitate personal care. Doors were wide enough to allow for children who needed to remain in their beds access facilities such as the sensory room. A 'Twins corner' dedicated to children aged between nine and 13 included access to computer games consoles and CD players. A bathroom had been added to the facilities within the 'Teen zone' following teenagers' suggestions. A well-furnished family room and space for siblings to stay with their loved one included kitchen and laundry facilities. The hydro pool included a viewing area for families who wished to watch their child. A relative told us, "The pool has been improved; it was already better than the school pool we used." In the grounds, paths had been paved to accommodate wheelchairs and allow children to see the raised flower beds, which had been selected to produce as much fragrance and visual stimulation as possible. A covered play area was used by children who may have sensitive skin. A large pirate ship was equipped with ramps for wheelchair access; footsteps had been installed on the grass for children to follow. The Art Therapist told us, "There is so much space here; it's important as it gives children freedom, especially the young boys in their electric wheelchairs, as they may not have the space at home."

Complaints were addressed promptly according to the service's policy and to a satisfactory outcome. Four complaints had been received from foster carers about funding some elements of the care and as a result the service's Partnership Manager had liaised with the Local Authority to reach a satisfactory compromise.

## Is the service well-led?

### Our findings

There was an open and positive culture which focussed on children, young people and their families' needs. People's feedback about the way the service was led described it as "Extremely caring" and, "Well organised; everyone knows what they are doing and do it well."

All the staff we spoke with were positive about the management team and told us they appreciated the provider and registered manager's style of leadership; that they felt valued working in the service, and felt motivated to maintain high standards of care. They told us, "'There's an open door policy for any of us at any time; if I wanted I could knock on the CEO's door too", "I am so proud of working for Demelza, it is a privilege", "The kids, the families, all the staff and the management matter as equal partners" and, "When children and parents come here they know they will have quality of care." A member of the senior management team told us, "The registered manager is so supportive; she is always willing to help and understands the importance of our role; the CEO is very level-headed and also always ready to 'jump in' and help."

The registered manager had been in post for three years. They were the Director of Care and had a Master of Science (MSc) degree award in integrated governance and paediatric palliative care. They were part of a senior leadership team that included a Director of People and Resources, a Director of Income Generation and a Director of Finance. A Board of Trustees that included three clinicians and a Chief Executive Officer (CEO) oversaw the senior management team. The registered manager oversaw the running of five departments: care services (providing care in the IPU and the community), family support services, therapy services, governance team and statutory funding department. Each department was led by either a lead nurse, a manager or a clinical nurse specialist who reported directly to the registered manager.

There was a culture within the service that embraced opportunities for learning. One department manager told us 'We encourage people to tell us when we've got it wrong so we can work on getting it right.' The service's vision, mission and goals were displayed throughout the hospice. It also stated six strategic goals to achieve by 2021. The service's vision stated, 'For life to be better for children and young people who have life-threatening conditions; and for their parents, brothers and sisters, and those who love them, to receive support.' The service's values focused on innovation, quality, positivity, respect, and the environment. From what young people, their relatives and healthcare professionals told us, and from our observations, these principles and values were implemented by all staff throughout the service.

We spoke with the registered manager about their vision and values about the service and saw that they shared the service's philosophy of care. They told us, "We really want to make a difference and adapt our service to what children and families need so we can support them as best as possible. Many people still feel apprehension about hospices and this is why our provider is not called hospice but Demelza House; when children, young people and their families come through our doors, their apprehension is dispelled and we are as transparent as possible, not shying away from difficult conversations."

The registered manager was visible in the service and carried out unannounced visits out of hours to

monitor the quality of the service. Their findings were discussed with the Board of Trustees and action had been taken when necessary to drive improvement. At every board meeting, they presented a case or a topic relevant to the service, such as 'complexities in safeguarding' and 'how to help parents with no recourse to remain in the UK', to showcase a particular situation and share ideas. The Trustees were actively involved with the service and took part in the 'Work in their shoes' scheme where they worked or shadowed staff in the care team, or in the Demelza shops. Any member of staff was encouraged to take part in the scheme and staff swapped places with staff from other hospices to gain different perspectives of roles and work. This helped them gain different perspectives and become more knowledgeable about distinct ways of delivering care. This meant that children and young people were cared for by staff who were ready to embrace new ideas and different ways of providing care.

There were numerous scheduled meetings taking place, attended by the Board of Trustees and four committees including a clinical governance committee. Departmental meetings took place every six to eight weeks. All meetings were appropriately documented and indicated the service was monitoring the quality of service provided. As a result, new improved procedure regarding the production and updating the service's policies had been agreed and implemented.

The registered manager was open and transparent. They consistently notified the Care Quality Commission of any significant events that affected children, young people or the service, and exercised the 'Duty of Candour' when mistakes were made, to give frank and comprehensive accounts to relatives.

There were systems in place to gather feedback from families and action was taken as a result. At the last satisfaction survey, 89% of families stated the service had made 'a real difference'. As a result of their feedback, a new post of Referrals Coordinator had been created, to establish direct contact with families, explain what Demelza Hospice could offer and discuss time frames; also, staff were rostered to ensure the same nurse or care worker was available to children as much as possible for continuity of care. Grandparents held a quarterly forum; parents held a bi-monthly forum and met the Board of Trustees twice a year. A relative told us, "We are very involved with what is going on, consulted, listened to and our views are respected." Results of the last staff survey dated May 2016 were in the process of being analysed to identify how improvements could be made. Staff we spoke with expressed the opinion that they could share ideas and these would be acted on. For example, changes to the way admissions were managed had been made at the request of staff, to render the admission system more effective; they had been consulted in regard to proposed changes and expansion of the Community Team.

The service took a key role in the community and was actively involved in building further links. There were approximately 1200 volunteers in the community supporting the service. Current links were maintained through 24 Demelza charity shops across East Sussex, Kent and South East London and a wide range of fundraising events in the community. These included sporting challenges such as skydiving, cycled rides, Triathlons, Marathons, and events such as fun days, themed runs, walks, and concerts. Several people had provided barbeques and tea parties in their gardens to raise funds for the hospice. A volunteer told us, "It is an honour to contribute to this great service." The head of fundraising told us, "We are constantly looking for new ideas and we work with our business supporters to build long-term partnerships." As people in the community were active participants, links between the service and the community were maintained and strengthened.

There was a robust system in place to maintain and monitor the quality of the service. A wide range of audits were carried out, such as infection control, documentation, symptoms management, medicines, safeguarding, spirituality and MSc research projects. The audits were discussed at clinical management meetings and resulting action was discussed at clinical governance meetings.

The service worked in partnership with several other organisations to develop the service they provided. The service engaged with tertiary centres, including two London children hospitals, community children nursing teams, continence teams, and special needs schools to ensure continuity of care and of individual procedures when children came into the hospice. They also engaged with local authority and hosted 'child in need' meetings when there were safeguarding concerns.

The service had funded a post of a clinical nurse specialist based at a London children hospital, who was able to meet the multi-disciplinary team in the service and plan the care before the child transferred from the hospital to the service. They supported the family with the child's symptoms management and travelled with the child to the service. The registered manager told us, "This enables us to have an 'in reach' within a major hospital." The Lead Nurse chaired a quarterly Kent and Medway palliative care network, where medical staff from other children hospices, representatives from the community and local community nursing teams met to exchange ideas and work collaboratively on special projects, such as an advance care planning model for the region. The registered manager told us of a project in progress about joint planning with a British charity that cares for vulnerable children and young people, bereavement services, and the Parents Consortium for Kent.

All records relevant to the running of the service that we saw were well organised and reviewed regularly. All records were kept securely and confidentially and a system of encryption ensured emails were secure. The registered manager was a 'Caldecott Guardian' (a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing) and the CEO was the lead in data Protection. Archived records were kept for the appropriate period of time as per legal requirements and disposed of safely.