

Demelza House Childrens Hospice

Demelza, Hospice Care for Children - SE London

Inspection report

5 Wensley Close
Eltham
London
SE9 5AB

Tel: 02088599800
Website: www.demelza.org.uk

Date of inspection visit:
19 September 2016
21 September 2016

Date of publication:
11 January 2017

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?

Outstanding ☆

Is the service well-led?

Good ●

Summary of findings

Overall summary

Demelza, Hospice Care for Children - SE London (known as Demelza SEL) provides services for children and young people from birth to 18 years old with life limiting conditions and their families. They provide residential short breaks for children for respite care and end of life care. They provide additional support services for the family. There were six residential places for children and young people. When we visited four children were receiving care and a total of 193 children and young people were using the service.

The service was last inspected on 28 October 2013 when we found all of the regulations inspected were met.

The service has a registered manager. A registered manager is a person who has registered with the Care Quality Commission to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 and associated Regulations about how the service is run. The provider also runs a children's hospice in Kent (Demelza Kent) and the registered manager is registered for both services. She had an office at each of the provider's sites and spent time at both.

Children and young people who used Demelza SEL, and their families received care that was compassionate and kind. People felt the practical and emotional help they were given had an impact on their lives, both during their child's illness and afterwards. Care was provided with regards for children's privacy and dignity and parents' roles were valued.

The staff were responsive to children and families' individual needs and they were assessed and catered for. Care planning was on going so changes in children's conditions were addressed. There were therapeutic activities which children enjoyed and were suitable for their needs. The staff took into account the needs of the whole family and support was available for siblings and grandparents as well as parents. Groups were arranged for siblings to meet others in the same position.

The care provided was safe. Staff were knowledgeable about abuse and the action to take if they suspected children were at risk of harm. Medicines were managed well and children received them as prescribed. Staff recruitment made sure staff were suitable to care for children. The building was kept safe and well maintained.

Staff were trained and supported to do their jobs well. Children and young people were supported with their nutritional needs. Demelza SEL had effective relationships with hospitals and health professionals to ensure that children and young people's needs were met without delay. This helped to minimise children and young people's pain, discomfort and distress.

Staff were trained in the principles of the Mental Capacity Act 2005 (MCA). People's rights were respected and when necessary decisions were made in children and young people's best interests.

There were good management arrangements to check and ensure the on-going quality of the service. The provider kept in touch with developments in the field of paediatric palliative 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. Children were looked after by staff who were knowledgeable about how to recognise abuse and the action to take if they suspected children were at risk of harm.

There were enough staff to care for children. The recruitment procedures were thorough and made sure staff were suitable to provide care. Medicines were handled safely and children received their medicines as prescribed.

The building was clean and hygienic. Staff were knowledgeable about the prevention and control of infection.

Is the service effective?

Good 

The service was effective. Staff were well trained and supported for their work.

There were good working relationships between Demelza SEL and other health care professionals. They shared information to make sure all the professionals understood the children and young people's needs.

Children and young people were provided with enough to eat and drink to meet their needs. Meals were designed, where possible, to give children choice and meet their nutritional, cultural and religious needs.

The facilities in the building met children and young people's individual needs.

Staff were aware of and implemented the policies and procedures in place to comply with the Mental Capacity Act 2005 (MCA).

Is the service caring?

Good 

The service was caring. The staff team showed empathy and compassion in their work. Children and young people were shown gentleness and kindness. Staff understood how to communicate with children and knew what made them happy.

Staff were committed to helping the whole family. They respected parents' wishes and opinions. The service supported the family emotionally and practically and provided facilities where they could spend time with their children.

Family members told us they valued the care and support they and their children received. They described the care as "a lifeline" and felt the staff team was caring and kind. Children and family's privacy and dignity were respected.

Is the service responsive?

Outstanding ☆

The service was outstanding in its responsiveness to the needs of the child, young person and their family. Assessments took into account their health, social and spiritual needs and were on going so changes in their conditions and preferences were recognised and planned for.

Families felt their children benefitted from the range of therapies which were available for children including music, art and play. The therapies facilitated communication and children enjoyed the sessions, so they helped their sense of well being.

The service promoted care of the whole family and plans were targeted towards this aim. Sibling support groups had been arranged so they could gain support with others in a similar position.

Demelza SEL worked in partnership with neonatal intensive care units to support families whose unborn babies had life limiting conditions.

People were aware of the complaints procedure and felt confident to use it

Is the service well-led?

Good ●

The service was well led. The trustees visited the service and they were informed about the performance of the service so they could ensure progress towards the agreed goals.

Management arrangements were open and staff's views were sought so they could be taken into account when planning. A range of quality audits were conducted to ensure the ongoing quality of care provided.

Demelza, Hospice Care for Children - SE London

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.

The inspection took place on 19 and 21 September 2016 and was unannounced. An inspector, a pharmacy inspector and a specialist advisor carried out the inspection. The specialist advisor is a nurse with experience of working with children with life limiting conditions.

Before the inspection we reviewed the information we held about the service. This included the Provider Information Return (PIR) which the provider had completed and sent to us. 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. We also reviewed notifications sent to us by the service. A notification is information about important events, which the service is required to send us by law.

We observed staff interaction with four children and spoke with five family members. We spoke with the registered manager and the chief executive officer. We spoke with 12 other staff, including cleaners, health care assistants, nurses, the social worker and a volunteer.

We looked at personal care, planning and support records for eight children. We looked at other records relating to the management of the service, including medicines records, recruitment records, health and safety checks and audits of the service.

We received feedback about the service from four health and social care professionals.

Is the service safe?

Our findings

Children were protected from abuse because the provider had suitable arrangements in place to keep them safe. Family members told us they felt their relatives were "in good hands" and "well cared for and safe".

Staff were knowledgeable about the signs of physical and emotional abuse and clear about the action to take if they felt children were at risk of harm. The staff had information available to guide them through the process to follow if concerns arose about a child's safety. In addition senior staff were available to consult about concerns, including out of office hours and at weekends.

Staff at the service worked in partnership with professionals to protect children. Safeguarding was discussed at a caseload management meeting each month. They used a system to assess risks to children and to target appropriate interventions in response. Staff made referrals to safeguarding teams when necessary and worked with local safeguarding boards and contributed to safeguarding investigations. One health and social care professional who had contact with the Demelza SEL told us, "Demelza staff will always attend [safeguarding] meetings, where they have enough notice" and commented "If they are not able to attend, the quality of their reports is good."

Staff, at all levels had been trained in safeguarding awareness. This was also covered as part of the staff induction training. Staff showed awareness of maintaining children's safety, for example reception staff were diligent in ensuring only authorised people were allowed on the premises. However we were concerned that a path that went round the building could have allowed access to unauthorised people. Although a closed circuit television (CCTV) system was in place outside the building this may not have prevented people entering the area and this could have presented a risk to children and staff. We raised this concern and managers arranged that a risk assessment of the area would be conducted with a view to making improvements to minimise risks to children.

All of the bedrooms had a camera over the bed so children could be observed when sleeping. They were used as an addition to the child being physically observed by staff. Demelza's Data Protection Officer had liaised with the Information Commissioner's Office to confirm that this system was compliant. During the inspection work had begun to install a new system. Staff reported that the cameras were useful as part of their supervision of children. None of the recordings were stored and children's privacy and dignity were maintained by switching off the cameras during personal care

Children were protected from foreseeable risks because they were assessed and planned for. Staff assessed risks that children were subject to as a result of their health conditions and put in place plans to manage them. For example moving and handling assessments were conducted to plan for children's needs in this area. Plans took children's specialist needs into account and ensured, when necessary, equipment was available, and there were no risks to them or staff. Children's risk of pressure ulcers was assessed using a paediatric tool and specialist equipment was provided to promote good pressure area care.

Children were protected because the provider followed their recruitment procedure. The procedure was

comprehensive and aimed at ensuring the safety and well-being of children. The provider did checks of the person's suitability for the work by requesting at least two references, including one from the person's previous employer and checks of people's eligibility to work in the UK. Human resources staff scrutinised applicants' work histories and explored any gaps in employment. They also arranged a check of Disclosure and Barring Service (DBS) records which included verifying whether the person had a criminal record. Appointments were not made unless the provider was satisfied with the outcome of the references and checks. The provider did not confirm staff in post until they had successfully completed a probation period of at least six months. The on-going suitability of staff was monitored by the provider's management systems. This included monitoring that staff continued their registration with professional bodies, including the Nursing and Midwifery Council and worked in accordance with their codes of practice.

Adequate numbers of appropriately skilled staff were available to meet children's needs. On the first day we visited there were three nurses and three healthcare assistants providing care for four children. At night time two nurses and a healthcare assistant provided care and an additional nurse was on call for advice. In addition nurses had access to 24 hour specialist advice from Great Ormond Street Hospital. Family members told us they were confident there were sufficient staff available to provide good care to children.

Children were protected against the risks associated with medicines because the provider had safe arrangements in place. A parent told us they "felt confident [staff] give [my child] their medicines when they need them." We looked at the medicine administration records (MAR) for three of the four children who were using the service during our visit. The records showed children received their medicines when they needed them. There were no gaps on the administration records and any reasons for not giving children their medicines were recorded. Any allergies were recorded on the MAR charts.

The provider stocked a limited range of medicines and medicines administered to children were normally brought into the hospice by their carers. All medicines brought into the hospice or returned for disposal were logged, with the quantity recorded.

The provider had a policy in place to verify the correct medicines and doses were being administered. Medicine instructions were transcribed by a nurse on to the MAR chart and then checked by a second nurse. A doctor from a local GP practice visited the service each weekday to review children's care and confirm the medicines had been transcribed correctly. We saw sometimes MAR charts were reused each time a child was readmitted for care which could potentially lead to incorrect doses of medicines being administered if there had been any changes since the previous admission. We discussed this with the registered manager and she said the advice was helpful and would change the procedure in response.

Demelza SEL had access to pharmacist advice via a service level agreement with the local retail pharmacy.

Medicines were stored securely. Medicines requiring cool storage were stored appropriately and records showed that they were kept at the correct temperature, and so would be fit for use. Controlled drugs were managed appropriately.

We saw medicine incidents were recorded on the computer system. These were reviewed at the monthly clinical management team meeting and any learning shared across the Demelza group.

Children were protected from the risk of infection by the practices within the service. A member of the nursing team was responsible for infection prevention and control at the site. They had a link advisor at Public Health England which provided advice and guidance on infection control procedures. All staff were trained in infection control issues. Items of personal protective clothing were available and used when

necessary. We observed staff cleaning their hands before giving care. There were anti-bacterial cleansing gels throughout the building. The location of anti-bacterial gels allowed staff and visitors to clean their hands frequently, including when entering and leaving areas where children spent time.

Children were protected from risks associated with an unclean environment. The building was well maintained and visually clean to a high standard. We observed staff cleaning the building throughout our visits to the service. They followed cleaning schedules which were compliant with nationally agreed good practice.

There was a range of fire prevention and fire safety arrangements in the building which contributed to keeping children safe. A fire risk assessment had been confirmed as appropriate by the fire brigade. Regular checks of the fire safety systems ensured they were in good order. Staff received training and took part in fire drills. They demonstrated awareness of fire safety issues and ensured visitors knew the action to take in an emergency.

Food hygiene was managed well to reduce the risk of infection associated with food. Environmental health officers assessed the food preparation facilities in Demelza SEL in March 2015. They awarded a rating of five which showed the food preparation facilities in the service were well managed and had high standards of hygiene.

Is the service effective?

Our findings

A relative of a child who used the service said staff were, "very well trained," and this gave them, "confidence" in the ability of staff to care for their child. A health and social care professional told us, the quality of the staff and their skills meant, "Parents trust Demelza and the care that they provide."

Children and young people were cared for by staff who were trained and supported to carry out their roles. We spoke with a staff member who had recently begun work at the service. They said they were enjoying their induction to their role. The induction was designed to last for four weeks and they felt they were gaining knowledge and confidence from it. They had been allocated a mentor who was an experienced member of staff in the same role and this had provided valuable support.

Staff said there was a positive attitude to training at the service and they could access courses provided by external organisations. They completed relevant courses including bereavement training, advanced care planning, positive behaviour support, and specialist training in pain and symptom management in palliative and end of life care, including syringe drive training. Staff had also completed essential health and safety courses including fire safety, food hygiene, safe moving and handling and infection control, and all staff were trained in data protection issues.

The provider recognised the importance of supporting staff with their work. Each member of staff received formal supervision. This gave staff regular opportunities to meet formally with senior staff to discuss work and training issues. All senior staff had an external supervisor which ensured they had the opportunity keep up to date with professional development issues. Their supervisor from within Demelza SEL provided line management supervision. Each member of staff had an annual appraisal so future goals and development could be discussed and their achievements recognised. A staff well-being survey was conducted annually to ensure the trustees and managers addressed any areas that needed improvement.

Informal support was available to staff whenever it was required. Staff said they felt supported and there was a sense of team work at the service. The provider and senior managers recognised the staff and volunteers needed to reflect on their work and gain mutual support. After a child had died staff were provided with sessions to reflect with colleagues in 'post-death debriefs'. This helped them to share their feelings in a supportive environment.

The service had policies and procedures in place to comply with the Mental Capacity Act 2005 (MCA). 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. The service was working within the principles of the MCA.

Parents had signed forms that consented to their children's care and they were reviewed on each occasion they stayed at the service. Young people over 16 were asked for their consent when care was provided. Staff

held meetings with parents and a range of health and social care professionals to discuss children's care. They focussed on whether they were acting in children's best interests and that Demelza SEL was the most appropriate place for care to take place.

Children benefitted from effective working relationships Demelza SEL had established with a range of health and social care providers. They had regular contact with hospitals, including Great Ormond Street Hospital (GOSH), Evelina Children's Hospital and the Royal Marsden Hospital. A Clinical Nurse Specialist from Demelza SEL was based at Evelina Children's Hospital. Children's care records included symptom management plans which had been drawn up with specialists and they would provide on-going support during end of life care. Demelza SEL had contact with the London Ambulance Service to share 'patient specific protocols' for children who had advanced care plans in place, so there was clarity about the care they should receive.

Professionals told us the approach of Demelza SEL staff was positive and the service was committed to partnership working. One health and social care professional stated, "I have found Demelza to be involved in working in partnership with health professionals and parents" and "Demelza have been a welcome addition to a multi-agency team approach... attending and hosting meetings."

Children's distress, pain and discomfort were relieved by effective working relationships with other health care professionals and hospitals. Demelza SEL had an arrangement with GOSH which provided 24 hour advice on symptom control management and this assisted them to manage symptoms and pain quickly. A professional involved with a child who stayed at Demelza SEL confirmed they had used the service and this had benefitted children, "Demelza seek regular symptom control management input from GOSH and have been able to manage symptoms and pain in a timely way."

Children were supported with their needs in relation to eating and drinking. Care records included an assessment of their needs in this area and a plan for how they would be met. Nutritional and fluid intake was recorded and monitored as part of the overall monitoring of children's conditions.

Care plans included guidance and advice from speech and language therapists (SALTs) for children who received their food and drink orally. The SALT advice included instructions about the texture and consistency of foods and drinks the children needed and associated risk assessments. Members of staff attended training with the SALTs about particular children so they were alert to particular risks they may be subject to. The care plans included detailed guidance, including photographs, to illustrate how the child should be seated to ensure they were safe.

Staff helped children and young people to enjoy the mealtime experience. A range of dietary needs could be catered for at the service, including religious needs. For example halal food was available, as was a vegetarian diet and the service was developing meals which reflected children's cultural backgrounds. Choice was available at meals and a pictorial menu assisted children to select their meal independently.

Children who had sensory impairments were encouraged to smell and taste separate items in the meal so they could experience different tastes and textures. For those children who required enteral nutrition, (the delivery of nutritionally complete food through a tube into the stomach), details of their feeding regime were included in their care record. The children's feeding arrangements were transcribed at every stay they had at Demelza SEL to be sure the details were current and accurate.

Children and young people's individual needs could be met in the building because the facilities were adapted and designed with consideration of a range of needs. For example the service had a range of beds

and cots available so each child had one that was suitable for their needs and safe for their use. Fittings in bathrooms were adjustable to suit individual needs and, when possible, allow children and young people to use them independently. Hoists were available between bedrooms and bathrooms so children and young people could be assisted to move safely.

The building had several low level tactile art works to stimulate to a range of children, including those with sensory needs. There was a range of play spaces including a garden with equipment including a swing, roundabout, seesaw and climbing frame. Activity rooms indoors included a wet play room, music room and a multi-purpose room which had a range of sensory equipment. A family member told us the service had "very good equipment" that suited their child's needs.

Is the service caring?

Our findings

Family members told us they found the service caring and supportive. Parents said "yes, it is caring" and described Demelza SEL as, "an amazing place," and said their child "has an amazing time here." One parent said they valued highly the support given by the service, saying "I can't praise it enough. I feel blessed to have this service." They said the approach of staff was understanding and helpful, "They realise the importance of small things."

Health and social care professionals commented on the caring approach of Demelza SEL. One told us, "we found Demelza to be a compassionate, open and transparent organisation to work with, they put the child and family at the heart of their work."

Staff members had a gentle and kind approach with children. When staff were with them we noted they were not distracted by adults but fully engaged with the children. Children looked relaxed with staff, responding to them with smiles. Staff talked with children at their level, crouching if they were sitting or on the floor beside them. They maintained eye contact to aid communication. Staff knew children well and were familiar with their non-verbal communication which showed their likes, dislikes and if they were distressed or content. A family member said staff "know [our child] so well".

A parent described the strengths of the service as, "professionalism, care and empathy". Another parent described the help they received from Demelza SEL as "a life saver". They said they knew their child "gets really good care" and this meant they could feel confident while children received care there. The parent said they felt able to call their family support worker "when things are difficult because you really feel like they do care."

Care and support was available to all members of children's families. Groups were held for siblings of children who used the service. The groups gave siblings the chance to meet children and young people in similar circumstances and try new activities. The aims of the groups included providing a safe place to share their feelings about their siblings' conditions. An evaluation of a recent group found that all the members had been helped to make new friends, had enjoyed the experience and staff noted they used the opportunity to express their feelings.

Staff shared a commitment to supporting the families of children they cared for. A member of staff said they felt among the strengths of the service was "caring for the whole family." Another staff member described the service as, "Really caring, [with] lots of laughter, lots of fun and putting the family first." A third member of staff told us the staff team, "really want to make a difference" by helping children and their families. A health and social care professional praised the support the service gave to the whole family. They told us, as well as the care provided for a child they were involved with, "of equal priority is the practical and emotional support for the family, and ... the extended family."

Parents were respected and were central to decisions regarding their child's care. A parent told us that they particularly appreciated this aspect of the way the service worked, saying "no decisions are made without us

being involved." They felt this recognised and valued their position as parents and the professionals supported them so they could make informed decisions.

Children's and family members' privacy was protected. Personal care was carried out in the privacy of bedrooms and bathrooms. There were two large bedrooms with bathrooms and kitchenettes where families could stay. The rooms were large enough to have several beds so siblings could stay. The rooms gave the families privacy and time to be near their child.

Children and families' confidentiality was respected. Records were kept safely in places where only staff had access. The provider observed the requirements of data protection legislation. An e-mail system which encrypted information had been introduced. This ensured that essential information about children and young people's needs could be shared safely with organisations that 'needed to know'.

The service had two 'butterfly suites' where a child could lay at rest allowing their family to say good bye in a familiar and supportive environment. Close by the butterfly rooms was a private room which was available to family members for quiet reflection. The area was arranged so people did not have to go through other areas of the building if they preferred not to and this meant they could maintain their privacy. The cultural needs of the child and their family were observed during this period. Family members were offered the opportunity to stay at the Demelza SEL after their child had died. During this time families could be supported, if they wished, with memory making activities such as creating hand and footprint montages.

As well as emotional support families were offered assistance from the staff team with practical matters including making official notifications and arranging their child's funeral. We heard of times when family members returned to Demelza SEL, particularly around the anniversary of their child's death, in recognition of the importance of the service in their lives. On these occasions staff learned of the way their support had impacted on people's lives, with one person saying their support "had changed [their] life completely."

Family members were able to access support from Demelza SEL after the child had died. A statement about the philosophy of the provider said "We will continue to support each member of the family for as long as they would like us to." Staff had been trained in post-bereavement support and recognised this was an on-going need. In addition to the direct help, information leaflets were available which gave families sources of additional assistance, such as specialist counselling organisations. The service also provided information for parents to assist them to recognise if children needed additional help to come to terms with the death of a sibling.

Demelza SEL held memorial services for families and friends of children who had died so they could remember them with other bereaved families and gain mutual support.

Is the service responsive?

Our findings

Demelza SEL provided care and support that was centred on each child and family's needs so they provided an individualised service. Parents told us the staff at Demelza SEL understood and were responsive to their family's individual circumstances and needs. One parent said the service had "taken a lot of pressure off us [because] we are listened to." They told us the care that the service had provided meant they had been able to meet other family responsibilities. They also said the whole family had spent time at the service at events and that "everyone is comfortable here." A health and social care professional said Demelza SEL "has enabled parents ...to spend quality and enjoyable time with their child."

Joint working arrangements between Demelza SEL and hospitals facilitated support for neonates (babies less than one month old) who had a short life expectancy and their families. Where this had been identified before a child's birth Demelza SEL had worked with parents and health care professionals from the neonatal intensive care unit. They were part of the team supporting families to make informed decisions about their child's end of life care. Demelza SEL contributed to the emotional and practical support available to the families. We heard about one situation where the child's parent had little support available to them other than through the hospital where the condition was diagnosed until Demelza SEL became involved and provided end of life care for the baby. The effective joint working arrangements that Demelza SEL put in place, provided a supportive environment for the parent and the child which was not available elsewhere and which made a significant difference to their lives.

The service was responsive to individual needs. Children and families who wished to use the service for respite breaks were granted periods of time based on their needs. This was flexible to suit the children's changing needs and family circumstances, for example, families were able to use some of their respite allocation as day-care, rather than overnight stays, if this better suited the family's needs. A health and social care professional told us, "I have found Demelza to be pretty responsive to parents' requests to use [the service] for short breaks." There was a system to balance demand and as far as possible achieve equity. An allocation model was being piloted. Demelza SEL were working with other organisations to develop a response to increasing demand.

Children and young people received care which was tailored to their individual needs because they were assessed and planned for in a comprehensive way. When a referral for assistance from Demelza SEL was received a senior nurse and the social worker carried out an assessment of not only the child's needs but the whole family's needs at a visit to them within 48 hours. This ensured that the assessment took into account the child or young person's care needs and the overall family's social needs so they could be planned for. Information from other care providers, such as hospitals was also included in care planning to make children received seamless and coordinated care. For example we saw that a child's assessment from Great Ormond Street Hospital was shared with Demelza SEL so staff had the information they required to plan care that was centred on the child to meet their needs.

Children's needs assessments included information about their usual routines in a section called 'My day'. This gave details of the child's typical activities so staff from Demelza SEL could use this information to

understand the child's needs and preferences and to assist them to settle in. Wherever possible children were assisted to continue with their normal routine and to engage in daily activities they were used to, for example by attending school. Staff made arrangements for children and young people to travel between Demelza SEL and school so they could continue their education and friendships. Details of children's bedtime routines were recorded and where possible adhered to. Information about children's likes and dislikes were recorded so they could be taken into account. The care plans were based on the information gathered from the assessments.

Staff closely observed and monitored children's conditions and were responsive to changes. Each child was assigned an individual nurse or carer for each day, who as far as possible attended to the same child when they were working, so they had consistency of care and this helped staff to recognise changes in a child's condition. Staff undertook on going assessments so they could monitor children's conditions and respond appropriately to them. For example pain assessment tools were used to monitor children's level of pain to determine the correct intervention. This helped to ensure that children's pain was relieved quickly. Records of the assessments were maintained so accurate comparisons could be made over time. A parent told us the staff were skilled at observing and reacting to their child. They said "[our child's] symptoms are so subtle and they know [them] so well."

Care planning was a continuous process and children and young people's needs were assessed throughout their stay. This ensured that any changes noted through the close observation of the children by staff was recorded and built into the care plans. This meant changes to children's needs and preferences were recognised and the information was shared amongst the staff team.

The Demelza SEL team ensured the unpredictability of some children's conditions was accounted for in care plans by 'parallel care planning'. One child's care planning included details of actions which could be taken if the child experienced a period of stability in their symptoms. However if this did not occur, and their needs increased, details of parents' wishes in these circumstances were included. In each of the arrangements the focus was on the need to care for the child according to the parents' wishes and to promote the best quality of care for their child.

Children and young people were able to join in a range of recreational activities to suit a variety of needs, that were arranged by staff. A parent told us, Demelza SEL "is a place that is always full of life, [our child] is always busy." The activities that were offered included music therapy, art therapy, play with sensory toys, wet play and trips to a hydrotherapy pool.

During a music therapy session we saw children were engaged and enjoying the time with the music therapist. A parent told us their child, "absolutely adores music therapy" and they valued the chance they had to take part in an activity that gave them so much pleasure. Music therapy had been shown to assist children including improving their breathing, reducing pain and promoting relaxation. Demelza SEL was keen to enable parents and family members to use music with their children and produced information to help them to do so. Staff told us that music therapy frequently included making recordings of a child's voice and laughter and these were valuable tools for 'memory-making' which were shared with the parents.

We were told how children had benefitted from individual music sessions. For example an evaluation of one child's progress after a six week course of music therapy noted that they had improved in several areas. These included how they related to other people, their emotional well-being and their play and creativity. Other children showed positive outcomes as the sessions led to improvements in their communication. For example a child used music and song writing to express their feelings and anxieties.

During children's stays at Demelza SEL, staff took the time to prepare a book called 'My Stay' as a record of their time there so the children could remember. The books gave details of the activities they had taken part in and often included photographs and pieces of art work completed by the child. This provided a tool for children and families to communicate about their time apart and could be used to talk about what to expect when they returned to Demelza SEL.

Children and families had the opportunity to use 'sensory music bags' which the Demelza SEL music therapist had designed and created for children who used the service. Each bag contained a story and various items including musical instruments and sensory objects. They were used to focus play and story sessions on themes, including a day at the beach and the circus big top. Parents could borrow the bags to engage with and allow children to be involved in experiences they would otherwise find difficult. The play kit assisted communication with children and stimulated their imagination. Children, young people and siblings who used Demelza SEL services were involved in the design of the bags.

Parents and children benefitted from the activities provided by Demelza SEL. For example some parents took part in a course learning infant massage techniques from an instructor. The evaluation of the course noted that during the course parents gave each other support. Some parents said although they had not been comfortable attending community groups they valued the Demelza SEL sessions and were able to use the techniques they learned at home and this helped them and their child to take part in a calming and relaxing activity.

Children and young people were encouraged to express themselves with the assistance of the art therapist. We saw an art work on display that children and young people had created by driving their wheelchairs through paint and onto canvas. It was a large canvas that was displayed in a stairwell. A member of staff recalled the children and young people enjoyed creating the work in the car park. Photographs of activities showed children and young people having fun.

Teenagers had the opportunity to attend activity days at the service that were targeted at their interests. The teenage activities were called 'Teenage Inclusion Zone' (TIZ). These days gave teenagers the opportunity to meet other young people in similar situations in a relaxed and supportive setting. There had recently been a music day, feedback sheets from young people who attended included positive comments. A Star Wars themed day was held and was well attended. A parent told us they had visited with their children and they had enjoyed the day, especially as they had the opportunity to meet an actor from the Star Wars film.

Staff at Demelza were aware of the needs of younger people moving into adulthood and who may continue to use hospice and end of life care services. Contact and links had been made between Demelza SEL and an adult hospice in South East London. This provided opportunities for older teenagers to have a smooth transition to adult hospice services when necessary.

Children and families' diverse needs were considered as part of the provision of care and treatment to children. Where the need had been identified translation services were available for people whose first language was not English. Posters in the reception area informed people that this service was available if they needed it. This helped to signpost to people that they were welcome at the service and that the hospice was supporting them to have a voice.

People who used the service had opportunities to raise complaints, and make comments about the service they received. The provider's complaints policy and procedure had clear time scales to acknowledge and to respond to complainants. All complaints were investigated and monitored with the aim to resolve these and to make any changes to improve the service where this has been identified. Leaflets about how to make

comments, compliments and complaints were available in the reception area at Demelza SEL and information was also displayed on the Demelza SEL's website. Parents felt able to raise complaints if they had the need. One parent said they had no complaints about the service, but commented, "My only complaint is that [my child] can't come here more often." Another echoed this view saying "I would like [the service] to be bigger so they could take more children."

The registered manager told us it was planned that a family forum would be set up to encourage consultation with family members and as an additional way to receive feedback from them.

Is the service well-led?

Our findings

A family member described the overall management of the service as "really good" and praised the way the service was led. Families, children and young people were familiar with the managers from their visits to Demelza SEL. The chief executive officer (CEO) relocated his office to the Demelza SEL from the provider's other service in Kent shortly before our inspection visit. This ensured he was accessible to staff and families who used Demelza SEL.

Children and their families benefitted from the commitment of the staff team to their work. The staff and managers of the service demonstrated they had shared values and a fundamental one was prioritising the wellbeing of children, young people and their families. Staff spoke of the importance of "putting yourself in the shoes of the families" and of their pride in "caring for the whole family."

The service had a registered manager in post as required by the provider's registration with the Care Quality Commission (CQC). She was suitably experienced and qualified for her role. A member of staff told us the management team was "visible and approachable." This helped to develop an open atmosphere between staff and managers.

Staff were involved and consulted about the future development of the service so their ideas and experience could be taken into account and used to drive improvements. The consultation methods included a staff forum, staff surveys and formal consultation about the annual business plan. The team members spent time together at 'team days' so they could discuss current issues and future developments.

Senior staff reported to the registered manager who in turn reported to the CEO. We heard they had frequent contact with each other throughout the week. A board of trustees that included three clinicians oversaw the senior management team and the overall governance of the organisation. Members of the senior management team attended the board meetings and discussed with them developments within the service.

The governance arrangements ensured that the trustees were involved with the overall management of the service. For example a nominated trustee had leadership responsibility for safeguarding arrangements within Demelza SEL. In addition there was a range of audit systems that were used to assess the quality of care provided. Reports were given to the trustees about a range of issues. For example information about the profile of the service user group (including age, ethnicity and diagnosis) so they could monitor the effectiveness of the organisation. Other information they studied included occupancy of the service, incidents and complaints.

The registered manager visited the service without notice during evenings and weekends to monitor the quality of care at all times. Trustees made visits to the service and spent time with staff so they understood the work undertaken.

The senior management team had a system to examine incidents which took place and establish if any

changes were needed to prevent recurrence. The process followed was thorough and the aim was to make improvements to ensure the safety and wellbeing of children and young people.

Demelza SEL was a member of bodies which promoted the interests and provided information about care for children and young people with life limiting conditions. These included Together for Short Lives and Children's Hospices Across London. This ensured the organisation was informed about national and regional developments in the field of children's palliative care.