

## Helen & Douglas House

# Helen and Douglas House

### Inspection report

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## Ratings

### Overall rating for this service

Good 

Is the service safe?

Good 

Is the service effective?

Good 

Is the service caring?

Good 

Is the service responsive?

Good 

Is the service well-led?

Good 

## Overall summary

Helen and Douglas House Hospice for Children and young adults is a hospice charity based in Oxford providing palliative, respite, end of life and bereavement care to life limited children and young adults, and their families. Helen House was the first children's hospice opening in November 1982. It is registered to accommodate children from birth up to 18 years of age. Douglas House is adjacent to Helen House where young adults from 16 years of age up to 35 who have life shortening conditions can stay for either respite care or symptom management.

Helen House can accommodate up to eight children and Douglas House seven young adults.

Two or three of the rooms cater for emergency admissions, with the remaining five or six rooms available for symptom management, step discharge from hospital or residential short breaks. At Helen House provision can be made for parents/carers to sleep in the same room as their child and four of the bedrooms have interconnecting doors, making a double room for use of a family with more than one child who has a progressive life-shortening condition. Families may stay in one of Helen Houses' four family flats.

# Summary of findings

Douglas House has seven single rooms, two of which are normally available for emergency admissions. The remaining five rooms are available for residential short breaks. Family members and /or carers accompanying a young adult may stay in one of three family suites.

The Care Teams are responsible for all the care of the children, young adults and families. The members of the team have varied skills and professional backgrounds including Registered Nurses, in different areas of expertise. Consultants, Care Team Members, Nursery Nurses, Play specialists, and Activities Co-ordinator, Chaplain, Music Therapist, Aromatherapists, Physiotherapists, Occupational Therapist and Social Workers. They work as a team, sharing their skills and carrying out all procedures normally achieved at home by the parents/carers.

The inspection was carried out on 3 and 4 December 2015 by two inspectors and one palliative nurse specialist. It was an unannounced inspection.

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 supported by a team which included a Board of Trustees who ensure that Helen and Douglas House was run in accordance with its legal, moral and ethical obligations.

Staff were trained in how to protect children and young adults from abuse and harm. They knew how to recognise signs of abuse and how to raise an alert if they had any concerns. Risk assessments were centred on the needs of the individual. Each risk assessment included clear measures to reduce identified risks and guidance for staff to follow or make sure children and young adults were protected from harm. Accidents and incidents were recorded and monitored to identify how the risks of recurrence could be reduced.

There was sufficient staff on duty to meet children and young adults needs. Staffing levels were calculated according to people's changing needs. Robust recruitment checks were carried out prior to staff working in the houses. Staff had received essential training and

attended refresher courses when necessary. All members of staff received regular one to one supervision sessions and had received yearly appraisals to promote a culture of learning and to encourage staff to discuss their learning needs and how to address these

Medicines were administered in line with current policy and procedure and a pharmacist visited the service on a regular basis to ensure correct stock control was maintained and medicine charts were appropriately completed.

Before young adults received any care or treatment they were asked for their consent and the provider acted in accordance with their wishes. In the case of children consent was given by a parent. We saw staff interacting with children and young adults in an appropriate manner and respecting their privacy by waiting after knocking on room doors before entering.

The service was aware of their responsibilities in regard to the Deprivation of Liberty Safeguards (DoLS). These safeguards aim to offer protection for anyone using services from being inappropriately deprived of their liberty. These safeguards are used when there is no other alternative way of supporting someone safely. If young adults had been assessed as not having capacity any decisions made would follow the Mental Capacity Act 2005 (MCA).

The staff provided meals that were sufficient in quantity and met everyone's needs and choices. Staff were aware of dietary restrictions and preferences.

One family member we spoke with commented, "The staff are amazing, you walk in and it's a happy place." The family member went on to say that now that her child had a syringe driver in place this was where they wanted to be. They also commented that every time they came in, their relative's care plan had been updated and that a specific care plan had been introduced that addressed how end of life care was to be managed.

Bereaved relatives were able to stay for as long as possible after their child's death, often up to five days and if possible up to their funeral. A bereavement support group contacted relatives and encouraged them to come back and visit the hospice to have a chat/tea. There is whole family support including support for siblings.

# Summary of findings

Helen House had a cold bedroom used if parents wish to say goodbye to their deceased child in a peaceful setting. This room could also be used by families who had lost a child in a hospital setting.

Young adults were involved in activities. Douglas House had outings and activities that were suitable for the age range of young adults whilst Helen House had play specialists who provided activities for young children.

The registered manager was open and transparent in their approach. They held a vision for the service that included, to be the regional centre of expertise and lead provider of age-appropriate core and specialist palliative care, complex symptom management, supportive care and enablement for children and young adults with

palliative care needs across the Thames Valley, working in partnership with patients, families/carers and the professional services around them, and with supporters, funders and commissioners.

The service's priority was to 'keep the focus' and any challenges that had been identified were dealt with as soon as possible. Keeping the Focus is a document that the organisation had introduced to reinforce the services aims and priorities. Helen and Douglas House acknowledged the importance of quality governance to support the effective delivery of care and improvements to services. Actions during 2014-15 included items identified in the previous year's quality audits and in turn, informed priorities for the forthcoming year. One area identified was the implementation of a new patient notes system. This has been fully implemented and was running well.

# Summary of findings

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

We always ask the following five questions of services.

### Is the service safe?

The service was safe.

Staff were trained to protect children and young adults from abuse and harm and knew how to refer to the local authority if they had any concerns

Medicines were managed in accordance with current best practice and where specific advice was received from professionals this had been reviewed with a pharmacist.

Risks had been appropriately assessed as part of the care planning process and staff had been provided with clear guidance on the management of identified risks.

Good



### Is the service effective?

The service was effective.

Staff were highly motivated, in their role, well trained and effectively supported. Induction procedures for new members of staff were robust and appropriate.

Young adults and children's choices were respected and staff understood the requirements of the Mental Capacity Act.

The staff provided meals that were sufficient in quantity and met needs and choices. Staff were aware of any dietary restrictions and preferences

Good



### Is the service caring?

The service was caring.

The established staff team knew young adults and children well and provided support with compassion.

Privacy and dignity were respected by staff.

Families and young adults were fully involved in their care and treatment.

Good



### Is the service responsive?

The service was responsive.

The young adults and their families were involved in all aspects of their care and were fully supported with how their symptom management was carried out.

A range of activities that were age specific were provided. Families were encouraged to remain involved with the service following the end of their child's life.

Views and comments were listened to and acted upon to improve the service.

Good



# Summary of findings

## Is the service well-led?

The service was well led.

There was an effective leadership and management team that oversaw the running of the service. Senior staff and managers were described by staff as being visible and approachable.

There was an open and positive culture which valued and responded to the joys, hopes and fears of each individual.

Strong emphasis was placed on continuously improving the quality of the service and maintaining high standards of care through a range of activities, thus creating an environment in which clinical excellence will flourish.

Good



# Helen and Douglas House

## Detailed findings

### Background to this inspection

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

This inspection was carried out on 3 and 4 December 2015 and was unannounced. The inspection team consisted of two inspectors and one specialist nurse advisor. A specialist nurse advisor is someone who has specific knowledge in an area of nursing; in this instance the nurse had experience in palliative care.

Before the 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. The registered manager had submitted a Provider Information Return (PIR) in May 2015. 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. During our inspection the provider supplied us with

information in relation to changes within the service and areas that are in progress, for example, Helen House had undergone major refurbishment to enhance the environment and improve facilities to look after more complex children. During this period children's hospices services were relocated to the adjacent Douglas House building, ensuring continuity of provision.

We looked at the premises and looked at six care records that related to people's care. We examined five medicine charts. We consulted documentation that related to recruitment files and to the monitoring of the safety and quality of the service. We looked at the activity programme and sampled policies and procedures. We observed staff interaction with children and their families.

We spoke with the registered manager, the doctor, managers in both houses, and seven members of staff, a family member and volunteers. We also spoke with three people who received support from the service. We also attended a multi-disciplinary team meeting that we were invited to.

At our last inspection on 23/07/2013 no concerns were found.

# Is the service safe?

## Our findings

Children and young adults said they felt safe staying in the house, they said staff spent time with them and nothing was too much trouble

Medicines were administered by trained staff that had been assessed as competent by senior staff. Two staff checked medicines in syringe drivers every four hours. There was a syringe driver guide book in the treatment room; this was referred to for guidance on compatibility of different medicines. A syringe driver is a small battery powered infusion device that is used to administer a continuous infusion of drugs from a syringe. Protocols were in place to address any potential errors in the administration of medicines. A pharmacist visited the service on a weekly basis to ensure correct stock control. We observed staff administering medicines safely. The administration of medicines was observed by a specialist advisor who was part of the inspection team and they confirmed the procedure was correct and in line with the service's policy and procedure of safe administration of medications.

The medicines management team included a consultant, non-medical prescribers, clinical governance lead and nurse representation from both houses. They specifically looked at any incidents that had occurred and put any action plans in place to address this. We saw documents to support this. They had created training materials and there was a work book for all staff to work through.

There was a Datix system for reporting incidents and accidents. Datix is a web based patient safety software for healthcare risk management. This system allows accidents and incidents to be reported in a more structured way, for example it identifies trends, location type and severity. This in turn identifies how the service can support people safely.

Staff knew how to identify abuse and how to respond to and report internally and externally. Staff knew how to access policies related to safeguarding and whistleblowing. Training records confirmed that staff had completed training in these areas and that these were included in the induction process. A member of staff told us "if I had any concerns, I would report it immediately".

Staff wore name badges and there were boards with the name of the co-ordinator and the number of registered nurses on duty. There was sufficient staff on duty, to ensure the changing needs of young adults and children using the

service could be met. Most children and young adults had one to one care. This was observed throughout our visit. This meant that a single point of contact was available for the child, young adult and their family. There was emotional and practical support as needed for families with a child with complex needs such as a complex neurological disorder.

Staff rotas were completed early in advance of admissions. Because people were booked in for respite visits over the year the number of staff required could be planned in advance to ensure there were enough staff to meet their needs. The service does not use agency staff but have their own bank staff. The service use their own bank staff when needed, to ensure the member of staff know the children and young adults and their needs. This is also beneficial for the children and young adults as they build trust with staff who they are familiar with.

The service had robust recruitment procedures in place to ensure that staff employed to deliver care were suitable for the role. All potential employees had to undergo a health screening procedure. The recruitment process included identity checks, right to work checks, employment history and references, professional registration and qualification checks. Staff were subject to criminal checks made through the disclosure and barring service (DBS). These checks are to assist employers in making safer recruitment decisions thereby uncovering potential warning signs about candidates.

Risk assessments were centred on the needs of the individual and kept in the care plans. These were reviewed at every admission which were documented and dated; comments were made even if there were no changes to the plan of care. If a specific area required extra support for example behavioural problems, more detailed guidance was provided for staff to follow to ensure the safe management of this risk. For example, many of the children and young adults attended outings in the community. This was risk assessed prior to the trips. Staff who took the children and young adults out attended the Minibus and Driver Awareness Scheme (MIDAS) training. The course content included the legal obligations of carrying a wheelchair user.

Both houses were cleaned to a high standard. This was evident during our visit when we were given a tour of the premises; we also looked at the cleaning schedule that confirmed the areas that had been cleaned. There was an

## Is the service safe?

infection control lead at the service who was the focal point for the service. The infection control lead identified risks to care and took responsibility for implementing and monitoring actions to manage risks. These measures protected children and young adults from the risks of acquiring an infection whilst using the service.

The provider managed risk to a high standard. A positive safety culture was clearly engrained within all day to day activities. This included an emergency fire evacuation plan for both houses, access control for visitors, unauthorised

access to kitchen area, Legionella testing, inspection of medical gases. Environmental Health visited both houses and both were awarded a 5 star rating. The Health and Safety Committee met monthly to review risk assessments.

All Health and Safety Leads had been trained in Health and Safety to the Institute of Occupational Safety and Health (IOSH) standards. The Health and Safety Leads were available on a day to day basis to provide immediate health and safety advice. For example, play tables and chairs were left by the fire escape door into the garden compromising egress, this was moved and a briefing note to staff to always keep egress routes clear was advised.



# Is the service effective?

## Our findings

Children and young adults we spoke with commented positively about the service. One family member said “It’s brilliant; it’s lovely; they have everything that’s important.” They went on to say that the staff also ensured siblings were included and were very much part of the ongoing support system

We saw staff having positive in depth conversations with children and young adults staying in Helen and Douglas House, who were laughing and chatting to staff in an informal comfortable way. We observed positive communications in both houses. In Helen House, staff and play specialists had various creative crafts in progress. The children were absorbed in what they were doing only to look up and smile at us when we visited the house. In Douglas house, we saw the young adults planning their day with staff.

We observed staff handover, where staff discussed the contents of a communications book which included future appointments and considered any actions that were outstanding. The coordinator gave handover to staff in Douglas House on the late shift. This included discharge preparation and updates on young adults using the service. This system ensured effective up to date communication about individual care and treatment. In Helen House the handover informed staff of any changes to care and treatment including updates on the families who may be staying.

New staff had a thorough induction before they started working at the service. This comprised of a one day corporate day followed by several weeks of being supernumerary and shadowing an experienced member of staff before they were able to work unsupervised. The number of week’s supernumerary was individual to each member of staff according to previous relevant experiences and qualifications.

The induction included a work book to complete which was signed off by the team leader on completion. This usually took up to six months to complete. Registered nursing staff had the opportunity to develop their professional skills, to share knowledge and expertise and to create opportunities to enhance professional understanding and develop the field of children’s and young adult’s palliative care services. Staff had the

opportunity to receive further training specific to the needs of the children and young adults they supported. One member of staff was currently completing a degree course at Oxford Brookes University which was fully supported by the service. This ensured that staff were supported in their professional development, thereby promoting a service where staff were knowledgeable in their chosen field and that have a commitment to deliver high quality nursing care to all those they supported. There was also an internal working party looking at revalidation. Revalidation is the process where registered nurses and midwives are required every three years to demonstrate to the Nursing and Midwifery Council (NMC) that they remain fit to practice.

Debriefings were available for all staff. This was an opportunity to discuss any emotional difficulties they may have experienced during the shift and have some ‘time out’ to reflect and explore their feelings with the rest of the team. The service were aware of the emotional part of the job and had a specific ‘Work related Counsellor’ available for staff should they need it.

De briefing was also available on a one to one basis between senior staff and junior staff. This ensured that staff had effective emotional support when dealing with difficult and challenging situations. There was also a psychologist available to support staff should they require this. One to one and group supervision sessions for staff were regularly carried out in accordance with the supervision policy. Annual appraisals were scheduled to ensure staff were appropriately supported in their role and achieved delivery of excellence in care.

The Mental Capacity Act 2005 (MCA) provides a legal framework for making particular decisions on behalf of people who may lack the mental capacity to do so for themselves. The Act requires that as far as possible people make their own decisions and are helped to do so when needed. When they lack mental capacity to take particular decisions, any made on their behalf must be in their best interest 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 interest and legally authorised under the MCA. The application procedures for this in care homes, hospitals and hospices are called the Deprivation of Liberty Safeguards (DoLS.)

The Care Quality Commission (CQC) is required by law to monitor the operation of Deprivation of Liberty Safeguards (DoLS). We discussed the requirements of the Mental

## Is the service effective?

Capacity Act (MCA) 2005 and DoLS with the registered manager and they demonstrated a good understanding of the process to follow. Staff had been trained in the principles of the MCA and DoLS and the five main principles were applied in practice. The organisation had a process in place to ensure the requirements of the MCA are met and had a steering group to look at any DoLS requirements.

Staff sought consent from young adults in Douglas House before they supported them. In Helen House consent was sought from parents. This was evident in the care plans we looked at.

Staff told us “It is sometimes the wish of the young adults to be left alone, this is always respected. However, we will always discreetly check on them to see if they change their mind”. The service had an open and transparent policy when a conflict of opinion occurred. For example, in relation to food and fluid intake the hospice had arranged a meeting to discuss the ethical issues around conflict. The meeting outlined who would be involved in the discussions.

We observed lunch in the open dining area of Douglas House. The staff had their meals with the children/young adults and their families. This was beneficial in that it allowed young adults and their families to share any concerns they may have had around aspects of their care in an informal setting. Staff confirmed that often families and young adults will discuss any worries or concerns in a more relaxed atmosphere such as during lunch time.

The atmosphere was happy, relaxed and a very positive experience. The chefs provided meals at Helen House and Douglas House for everyone and took care of the kitchen and food store. All special dietary needs for the children, young adults and families were catered for. The food was healthy and nutritious all children and young adults at the service were supported to have sufficient to eat and drink.

The medical team provided medical cover in house as well as 24/7 on call. They offered symptom management, emergency medical care, end of life care, stepped discharge from hospital, and medical management of any current illness. They also provided medical oversight (clerking, problem-solving, advising on symptom management) for children and young adults staying for planned respite care who often needed significant medical

input during their stays. One comment from a mother whose child stays at Helen House said, “the doctors and nurses at Helen and Douglas House work to manage pain and distressing symptoms to help families like ours to have fun together”.

The premises had been designed and decorated taking young adults physical and psychological needs into consideration. For example, when the building was being designed in Douglas House the young adults had requested that the corridors be made wide enough so they could have wheelchair races. This was granted and the wheelchair races were part of the activities in the house. There was a sensory room which featured a wide range of sensory stimulation including a water bed, lights and projections. There was a music room with accessible musical instruments which was also used for music therapy and just for fun. The music room could be individualised and age specific, for example, the younger children liked to ‘make a noise’ by banging the instruments together. Whereas the older children and young adults had a more structured music session. Helen House had a spa which the family could relax in together in the warm waters. There was a play area for individual or group play, and a specific area for art work and creative activities. We observed play specialists during our visit who supported parents and implemented appropriate play strategies as part of the child’s holistic care.

The attractive gardens that surround both of the houses were maintained to high standards and had been designed to promote an atmosphere of peace and tranquillity. It included seating areas for people and families to relax in.

Each bedroom in Douglas House featured a fully accessible bathroom, laptops with internet access, and patio doors leading into the garden. Helen House had ‘The Little Room’ which is a where a family could be with their child after they had passed away. It gave families the opportunity to say goodbye in their own time and in their own way. In Douglas House they had ‘The Starfish Room’. Feedback from families was positive. One family commented, “although we knew [name of child] was dying Helen and Douglas House gave us the time and space which meant we could somehow stay together as a family whilst facing the heartbreak of losing [name of child] so soon after he had come into this world.”

# Is the service caring?

## Our findings

All the people we spoke with, their families, and healthcare professionals were overwhelmingly positive about the service. One family member told us “You walk in and it’s a happy place, in terms of end of life care they couldn’t do any more, the nurses have always included us as a family. [Child’s name] came in two weeks ago for pain management and is clear that this is where they want to be, they feel safe. [Child’s name] says they are ready to pass away being cared for by staff that knows them.” The family member went on to say, “As the regulations have become tighter the place has kept its charm”.

Staff showed kindness and knew how to convey their empathy when people faced challenging situations. They were aware of the pace that they needed to follow; there were frequent humorous interactions between the young adults and staff. Bereavement counselling was available to families and siblings

Staff responded quickly to children and young adults changing needs. For example, one young adult decided they wanted to remain in their room and not join in with the activity that was planned. However, they changed their mind and wanted to join in after all. The staff responded immediately and assisted them to the activity room.

Families were able to bring children and young adults pets in to visit their owners to lift their spirits and bring them comfort. We observed one young adults dog was accompanying her on an outing. Families could visit the service at any time. Staff told us that if a child came in for respite care then this gave the families some much needed ‘breathing space’ and the break from constantly worrying about their child could be handed over to skilled experienced staff who knew the child from previous visits. One family who regularly visited the hospital with their child said “it’s like a mini holiday with everything you need. [Young adults name] likes to visit the wonderful gardens and use the tree house. They also like to use the spa and the computer.”

A relative told us it was reassuring to know that they had the long term support of Helen and Douglas House. As their child matured into adulthood and their emotional and support needs changed they would have Douglas House to go to for specialist respite and to gain some independence.

Staff told us two children who have been visiting Helen House since they were very young had now ‘graduated’ from the children’s hospice to the hospice for young adults, Douglas House. Over the years they (the two young adults) had become firm friends as have their families.

There were a number of social events to promote social interactions enabling peer support. One example was a bake off competition where staff had arranged for professional ovens to be installed in the dining area. Staff had arranged for one young adult to visit their sibling who was studying at a local university.

Privacy and dignity was maintained at all times. Staff knocked on children and young adults doors and waited before entering. Children and young adults were assisted with their personal care that respected their dignity. Members of the team were aware when personal care was being carried out by the use of a ‘do not disturb’ sign on doors.

Helen and Douglas House successfully bid for Department of Health funding to enhance children’s palliative care services. The bid proposed a number of initiatives including the provision of specialist clinical support, family support and bereavement services. The service acknowledged that children’s palliative care was concerned with the need to maintain the quality of life, not just end of life care, but also in the weeks, months and years before death. We observed that the service was successful in its end of life aims for children and their families, by way of individualised care plans, involvement of the wider range of support for families and their children and the acknowledgement from bereaved families that although their child’s death was inevitable the process was made manageable by all involved in the care.

A chaplain was employed by Helen and Douglas House as part of the Family Support Team and was available for those who wished to talk with them. The chaplain provided information on places of worship in the local area. Occasionally simple religious services were arranged within the Houses to which all children, young adults and families were welcome. There was a book of remembrance in ‘the quiet room’ situated in Douglas House. The Chaplain also developed links with a range of faith communities to increase awareness of these within the organisation.

# Is the service responsive?

## Our findings

People and families told us staff were approachable and open and were exceptional in what they did. The clinical office had an extensive collection of testimonies thanking the staff for their care and kindness

There were unique personalised care plans across the age range. Every child and family had a multi-agency care plan agreed with them for the delivery of coordinated care and support to meet the individual needs. A keyworker to assist with this was identified and agreed with the family. Care plans were comprehensive and specific to each individual. For example, a young adults care plan informed staff that if the person vomited they could become unwell very quickly. There was a specific procedure to follow if this occurred.

There was a focus on the need for a coordinated approach and effective communications between the two houses throughout the transition process Transition planning runs in parallel with a period of life when the young adult may increasingly wish to express autonomy over decisions they make about care. For example, life events and changes of staff that the young adult is used to can all affect the details of care and treatment.

Plans had been continually reviewed to meet the young adults ongoing care and support needs as well as their end of life plan of care. A young adult who uses the service explains why good transition into adult care is essential. 'The transition from children's services can be scary and confusing. Young adults must leave the people and teams and services they have built trust in. My own transition was fantastic, preparing me well in advance supporting me and taking everything at a pace that I was happy with and able to cope with'. Helen and Douglas House aim to ensure that the young adults and their families have a positive transition to adult services.

A doctor who provided care at the service told us, "the team is very close and communicates very well with medical colleagues from different medical backgrounds". We observed how communication was shared with staff from different backgrounds. For example, present in the Multi-disciplinary team meeting we attended during our visit was, a secretary, a psychologist, the House Manager, a social worker and a doctor. Having expert knowledge from staff from different clinical backgrounds would ensure

young adults and children were offered services that were not specifically 'medical'. For example, a psychologist offered a different aspect on care that was tailored to meet emotional needs.

The referrals team allocated a young adult and their family to a contact worker who developed a supportive relationship with them by contacting them regularly. How often and whether by phone or email was negotiated with the young adult or family. This enhanced the quality of the young adults stays, when for example they may wish to do something special, the service worked to achieve this. For example, one young person wanted to see McBusted [a pop group] in concert, the staff arranged this.

The service anticipated a child's/young adults palliative care journey by way of advanced care planning. Advanced care planning sets out an agreed plan of care when a child's condition deteriorates. The child and family were helped to decide on an end of life plan and were provided with support to achieve this as closely as possible. The service had a specific end of life care plan as a guide to overall care needs. In addition there was a bereavement plan that included preparation of the starfish room, and the wishes of the family such as having a footprint, lock of hair, or hand prints of their child/young person.

Family Support and Bereavement workers worked directly with families offering emotional support around the many issues of living child, brother or sister with a life limiting condition, and dealing with grief and loss. This included support for parents, brothers and sisters of the child or young person.

One parent commented after the death of their child "Helen House completely cocooned us it made us feel very safe it gave us the chance to do what we wanted to do for our child the way we wanted to do it. It made the most difficult moment in our life somehow very manageable. They are very cherished times."

Support groups such as a club called 'The Elephant Club' offered support to siblings both bereaved and non-bereaved who were aged between six and 17 years old. The club was an ongoing group that met every other month to provide young adults and their siblings the opportunity to socialise with others. Some children and young adults could be worried about discussing their fears and concerns with their parents because they did not want to add to their worries. Having a safe place to voice their

## Is the service responsive?

concerns could help these young adults to feel less anxious and less alone. Individual support was also offered to siblings and included bereavement support. This took place either at the hospice or the person's home.

The arrangements for social activities were age specific. Helen House had play specialists to encourage young children to be creative in crafts, art work and play therapy that was tailored to their age and abilities. Whilst Douglas House had planned outings to places such as theatres. In-house activities from craft workshops to play station tournaments were also provided. The young adults were kept busy during their stay at Douglas House with music sessions where they could explore their talent for playing a musical instrument or just to listen to music as they wished. The young adults who had respite care over many years had made firm friends with other young adults who had also stayed in the house. There was a bar area where they could catch up with others and socialise. Staff told us, without Douglas House many of the young adults would have little social interaction with people of their own age. The house offered the chance to have some independence and experience things they would not normally easily access, while still having the support and specialist care they need.

Feedback from one young adult was "I've decided that Helen and Douglas House would be the best place to go for respite...I've been going now for seven years... I've made new friends in the house...these people are there when I'm going as we book together. When I'm in Helen and Douglas House there are people there with the same condition... so we can chat to each other about day to day problems, ideas about the future and we have good fun." This would reduce social isolation and enhance psychological wellbeing.

A wide range of therapies were available in addition to medical and nursing care, such as aromatherapy, massage, music therapy, occupational therapy and physiotherapy. Staff told us, therapies helped children and young adults to relax and not feel the visit was focused on medication and 'essential' care.

The service played a key role in the local community and was actively involved with fund raising events. A fund raising event to 'conquer Kilimanjaro' in aid of Helen and Douglas House was planned for later in 2016. A Santa run was also planned to take place on 13/12/2016 to raise funds. A variety of additional events took place throughout the year, and people in the community were actively invited to support the service through local advertising. The overarching aim was to publicise and promote the charity to enhance public awareness and encourage on-going support which in turn benefited families and children who used the service.

Children and young adults were actively encouraged to give their views and raise concerns or comments. There was a comments, suggestions and complaints procedure in a booklet form. The key objective of the leaflet was to provide guidance on the most effective way suggestions, comments and complaints could be heard. If a complaint was made verbally the staff member who received the comment sought to resolve the problem immediately. An appropriate manager assisted with the complaint if it could not be resolved immediately by the staff member involved. If the complainant was not satisfied with the reply to the complaint they could escalate their concerns to a subcommittee of the organisation's Trustee body.

# Is the service well-led?

## Our findings

There was an open and positive culture that focussed on the children, young adults and their families.

A leading hospital consultant said after the death of a child “I would like to thank the different teams for the excellent care provided in an effective coordinated way” (Helen and Douglas House report). Staff had commented that the culture was open and fair and there were clear expectations. The leadership and management had been described by junior staff as leading by example, senior staff and managers were visible and approachable. Trustees were reported to often come and visit and talk to staff.

There was an effective leadership team that oversaw the running of the service. This included the Chief Executive Officer, who was the registered manager, a House Manager in both houses, and a board of trustees. The registered manager commented that one of the key drivers at Helen and Douglas House was the delivery of excellent safe care. They went on to say that safety was not just about identifying risks after an event had occurred but also about looking at areas they knew could cause harm to anyone using the service. The leadership team ensured a structure was in place to support improved practice and provide a basis for further organisational development. This identified opportunities to improve practice and challenges as they emerge. For example, a checklist for setting up feed pumps was introduced following reported incidents during an audit period.

The registered manager was open and transparent. They consistently notified the Care Quality Commission of any significant events that affected people or the service.

All the staff we spoke with praised the service and the way it was managed. One member of staff said “I would work here even if I won the lottery, it’s a privilege to work here, and we are one big family”. Staff said they felt valued and motivated to maintain high standards of care.

As well as direct delivery of care, Helen and Douglas House had an active profile in regional and national forums relevant to palliative and supportive care for children and young adults- seeking to improve practice, structural delivery and funding of services to this population. The pursuit of excellence in the delivery of care, and the support services underpinning them, was a strategic aim of Helen and Douglas House. Performance against this aim

was regularly reviewed by the Charity’s Trustees either at full meetings of the Board or via ‘assurance’ committees. Care was based on the unique needs of each individual child or young adult; it was holistic in nature and aimed to ensure that each child or young adult was enabled to live life to the full.

In January 2015 the organisation hosted and presented its first conference focused on “Making a Difference” for young adults with life limiting conditions, which attracted professionals from Europe and North America, as well as from the UK. Strong positive feedback indicated that the day was “Influential and inspiring”. There was a robust system to monitor the quality of the service. There were monthly staff meetings held in each house. These meetings were a forum for information sharing and presented an opportunity to share concerns and ask questions about all aspects of care and staff issues. All members of staff were encouraged to add items to the agenda and took turns to chair the meeting and had an equal voice. This demonstrated that staff played an important role in ensuring standards remained high. The benefit for the young adults who use the service was that front line staff were able to influence aspects of care that they felt would have a direct impact on service users.

In 2014-15 Helen and Douglas House consolidated its educational function across the organisation, under a new Learning and Development team, with research being the responsibility of the Research Co-ordinator and the senior speciality doctor. All members of staff were encouraged and supported to be involved in research at a level appropriate to their role and experience-through daily practice, in-house training and forums, specific projects and university based courses. Some staff were completing professional development at Masters’ level in palliative care.

The assessment of clinical quality was driven through a comprehensive audit programme including medication, care planning, infection control and risk assessments managed by the Clinical Governance Lead in support of legislative and regulatory requirements, and clinical best practice. High quality clinical practice was supported by a suite of organisational policies and guidelines which were reviewed regularly to reflect changing requirements. National and local quality requirements are also defined within NHS Standard Contracts, which provided a framework for external reporting.

## Is the service well-led?

Helen and Douglas House had an annual audit programme which ensured that the service was continually improving their clinical services. Audits discussed at management meetings had shown the organisation was continuously improving the quality of care delivered to all who used the service. Within Helen and Douglas House, quality of care was monitored throughout the year via a governance programme which includes, monthly Clinical Governance meetings, bi-monthly Clinical Assurance Committee meetings that feed in to the Trustee Board, and an annual schedule of clinical audits. This included a patient feedback survey, the continued focus on Information Governance, the development of systems and processes to ensure compliance with the Mental Capacity Act and Deprivation of Liberty Safeguards (DoLS), and continued monitoring of incidents to ensure the safety of people at all times.

Helen and Douglas House acknowledged the importance of quality governance to support the effective delivery of care and improvements to services. Actions during 2014-15

included items in the previous year's quality audits and in turn, informed priorities for the forthcoming year. One area identified was the implementation of a new patient notes system. This has been fully implemented and was running well.

Actions identified during 2014-15 included items identified in the 2013-14 Quality Account which, informed the priorities for the forthcoming year. One of the priorities was to introduce a new patient notes system which had now been fully implemented following a pilot and was running well. Young adults benefited from this new system as the information was more detailed and specific to their changing needs. For example, if young person preferred to stay up late on their visits and get up later in the morning this was clearly identified.

In 2014/15 the service led in the advancement of care and had nursing and medical representation on the National Institute of Health and Care Excellence (NICE) Board to inform paediatric palliative guidelines and policies.

This section is primarily information for the provider

## Action we have told the provider to take

The table below shows where legal requirements were not being met and we have asked the provider to send us a report that says what action they are going to take. We did not take formal enforcement action at this stage. We will check that this action is taken by the provider.



This section is primarily information for the provider

## Enforcement actions

The table below shows where legal requirements were not being met and we have taken enforcement action.