Claire House

Claire House Children's Hospice

Inspection report

Clatterbridge Road,
Bebington,
Wirral, Merseyside
CH63 4JD
Tel: 0151 334 4626
Website: www.claire-house.org.uk

Date of inspection visit: 9 July 2015
Date of publication: 08/09/2015

Ratings

Overall rating for this service	Outstanding	☆
Is the service safe?	**Outstanding**	☆
Is the service effective?	**Good**	●
Is the service caring?	**Outstanding**	☆
Is the service responsive?	**Outstanding**	☆
Is the service well-led?	**Outstanding**	☆

Overall summary

The inspection took place on 9 July 2015 and was unannounced. Claire House Children's Hospice provides care for babies, children, and young people up to the age of 23, with life-threatening or life-limiting conditions. Services include specialist respite, palliative, end of life and bereavement care. The hospice supports families from across Merseyside, Cheshire, North Wales, West Lancashire and the Isle of Man. It is mainly funded by charitable donations.

The hospice describes its purpose as 'To reach out to every child with a life-limiting or life-threatening condition and their families, making sure they can get the very best support when and where they need it.' At the time we visited, 191 families were receiving support from the hospice, either by the in-house care team or the 'Hospice to Home' team, a specialist group of nurses who take the care of the hospice out into the community and into the family home. The service also supported 179 bereaved families.The service had a 'Mums and Tots' group that met fortnightly.

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

We found that every effort was made to ensure that children and young people were kept safe when receiving services from Claire House. Safeguarding policies and procedures were in place and the staff we spoke with had received training and were aware of their responsibilities. Any safeguarding issues were clearly identified in children's care plans. Robust risk assessments were in place for all clinical areas, equipment, activities, and outings, with risk assessors and reviewers in every department. Each child and young person had a personalised care plan which assessed and balanced the risks associated with activities against the individual's quality of life.

Security of the building had been enhanced as part of a recent refurbishment. Records showed that arrangements were in place to ensure that premises and equipment were well-maintained. Infection prevention and control policies and procedures were in place and staff received training on induction and annually.

There were enough highly qualified and experienced staff to meet the needs of the children and young people who used the service. Staff received regular training in areas relevant to their practice. Safe recruitment practices were followed when recruiting new staff and new staff had a structured programme of induction training.

People told us that mealtimes, the quality of food, and the choice offered were exceptional. Their individual needs were met and staff went out of their way to meet their preferences. Mealtimes were family orientated with hospice staff, children and young people and their families all eating together if they chose. Any special dietary requirements were noted in the care plan and the kitchen plan so that staff could cater accordingly. A nutritional assessment was undertaken on each admission and reviewed according to the length of stay and the child's care needs. The hospice team liaised closely with specialist hospital and community dieticians for specific children's nutritional requirements.

In the records we looked at there were up to date consent to care and treatment forms and consent for activities. During our visit we observed that staff sought consent for all care interventions. The care plans we looked at included personal care preferences, specialised care needs, and any cultural or spiritual needs and choices. Care plans and risk assessments were reviewed on every visit, and daily for those approaching the end of life. Each child had a full annual review of their care needs.

The service employed four play specialists who developed and planned individual and group activities both inside and outside Claire House. There were excellent recreational facilities. A range of holistic therapies were available for children and young people and for family members.

Each child was allocated to a specific team of staff who built up a relationship with the child and their family and identified their specific needs, likes, and dislikes, and acknowledged birthdays and anniversaries. The team made regular contact with the family and the other services involved in their care in between planned stays. All of the care interactions we observed were caring, respectful and age appropriate and met the needs of the individual, for example use of communication boards and Makaton signs. There were multiple communal recreational areas that catered for different age groups and abilities.

End of life care could be provided at the child's home by the hospice to home team or at Claire House. A child or young person approaching the end of life, and their family, could stay at Claire House for as long as needed. Anticipatory symptom management plans and prescribing were in place in order to respond to rapidly escalating symptoms at the end of life and keep the child or young person as comfortable and pain-free as possible.

Children and young people who died at Claire House, and some who died suddenly elsewhere, could use a 'Butterfly Suite' at Claire House. These were special bedrooms that operated on a cooling system allowing the child or young person to lie at rest often until the time of their funeral. The Butterfly Suite could be personalised for each child by their family, the care team or both. Families and others with consent could spend as much time as they wished with the child and the child could go directly to their funeral from Claire House. During this time the family were offered one to one support by an appropriately skilled member of the care team. Following the death of a child or young person, the family support team continued to support the family for as long as needed, or for as long as they wished.

At every stage, parents could self-refer and a service could be provided. A fortnightly multi-disciplinary referral panel ensured a prompt response to all referrals. The referral process also included rapid response to referrals for end of life care at home or hospice. The hospice to home service provided end of life care, symptom assessment and management, emotional and psychological support, bereavement support, and specialist respite care for crisis management, which may be a family crisis rather than one connected with the child's health. There was a weekly meeting each Monday morning involving the hospice team, the hospice to home service, physiotherapy and family support, to discuss care scheduled and identify children requiring additional support.

A complaints policy and procedure was in place and this was included in the information pack for families. The records we looked at showed how complaints were dealt with, whether the complainant was satisfied, any other agency that had been involved, and any action taken.

Service development took account of feedback from children, young people and their families, and from staff, commissioners and healthcare professionals. We saw evidence of regular clinical audits, for example of care plans, infection prevention and control, medicines management and the care environment. These resulted in action plans for improvement where appropriate.

The registered manager had relevant and up to date experience and expertise to lead the service. During our visit we found that the seniors and managers were visible within the day to day service.

The Board of Trustees had a parent representative and there were two consultant paediatrician trustees. The service worked in partnership with other organisations to make sure they were following current practice and provided a high-quality service. They strove for excellence through consultation, research and reflective practice.

Following our visit to the service, the specialist professional advisor commented "People receive outstanding care from exceptional staff who are compassionate, understanding, enabling and who have distinctive skills in this aspect of care. Staff also care for and support the people that matter to the person who is dying with empathy and understanding."

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?

Outstanding ☆

The service was safe.

Appropriate safeguarding policies and procedures were in place. Staff had received training and were fully aware of their responsibility to protect children and vulnerable young people.

Risk assessments were in place for all clinical areas, equipment, activities, and outings. Risk assessments for each child and young person balanced the risks associated with activities against the individual's quality of life.

Security of access to the building had been enhanced as part of a recent refurbishment and arrangements were in place to ensure that premises and equipment were well-maintained at all times.

Infection prevention and control were given high priority. Robust policies and procedures were in place and staff received training on induction and annually.

There were enough highly qualified and experienced staff to meet the diverse needs of the children and young people who used the service. Safe recruitment practices were followed when recruiting new staff.

Is the service effective?

Good ●

The service was effective.

Staff received regular training to ensure they had the knowledge and skills to deliver high quality care. New staff had a structured programme of induction training.

The records we looked at contained up to date consent forms relating to care, treatment, and activities. During our visit we observed that staff sought consent for all care interventions

Mealtimes were family orientated and all meals were freshly cooked on the premises. A nutritional assessment was undertaken on each admission and the hospice had close working links with dieticians.

Is the service caring?

Outstanding ☆

The service was caring.

Each child was allocated to a specific team of staff who built up a relationship with the child and their family and identified their specific needs, likes and dislikes, and acknowledged birthdays and anniversaries. The team made regular contact with the family in between planned stays.

All of the care interactions we observed were caring, respectful and age appropriate and met the needs of the individual.

Summary of findings

End of life care was at the child's home by the hospice to home team or at Claire House. A child or young person approaching the end of life, and their family, could stay at Claire House for as long as needed and receive one to one support from an appropriately skilled member of staff. Anticipatory symptom management plans and prescribing were in place to respond to escalating symptoms at the end of life.

Following the death of a child or young person, the family support team continued to support the family for as long as needed, or for as long as they wished.

Is the service responsive?

Outstanding ☆

The service was responsive.

The care records we looked at evidenced that children and young people, and their families, were always involved in care planning. Care plans and risk assessments were reviewed on every visit, and daily for those approaching the end of their life

A fortnightly multi-disciplinary referral panel ensured a prompt response to all referrals.

The service employed four play specialists who developed and planned individual and group activities both inside and outside Claire House.

A complaints policy and procedure was in place and this was included in the information pack for families. Records we looked at showed that complaints had been addressed and learned from.

Is the service well-led?

Outstanding ☆

The service was well led.

Service development took account of feedback from children, young people and their families, and from staff, commissioners and healthcare professionals.

We saw evidence of regular clinical audits, for example of care plans, infection prevention and control, medicines management and the care environment. These resulted in action plans to improve where appropriate.

The registered manager had relevant and up to date experience and expertise to lead the service. During our visit we found that the seniors and managers were visible within the day to day service.

The service worked in partnership with other organisations to make sure they were following current practice and provided a high-quality service. They strove for excellence through consultation, research and reflective practice.

Claire House Children's Hospice

Detailed findings

Background to this inspection

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

This inspection took place on 9 July 2015 and was unannounced. The inspection team consisted of an Adult Social Care inspector, and a specialist professional advisor (SPA) who was a registered nurse with considerable experience of managing a children’s hospice.

Before the visit we checked the information we held about the service and the provider. This included the notifications that the provider had sent to us about incidents at the service and information we had received from the public.

The provider had completed a ‘provider information return’ (PIR) prior to the inspection. 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.

During our visit we spoke with three parents, one sibling, and one young person who used the service. We looked at the care records for four children who used the service. We spoke with the Chief Executive Officer, the Director of Clinical Services who was the registered manager, the care manager, the hospice to home manager, the practice development manager, the estates manager, a physiotherapist, three nurses, three health care support workers, a play specialist, and two catering staff. After our visit we received feedback from two family members who used the service and two commissioners. We read the research report relating to Claire House that had been written by a team from Edge Hill University in 2014.

Outstanding ☆

Is the service safe?

Our findings

We asked a parent how their child was kept safe at Claire House. They told us "During every visit to Claire House with our daughter we had a member of staff with us at all times. Even though we never left her, a member of staff remained with us. When using the pool, two members of staff are present at all times. Each child in for respite has a member of staff with them during the day and the staff member participates in activities with the child. During the night CCTV is used at the nurse station to monitor every child."

We spoke with two families during our visit. They told us that they knew their child was safe at Claire House because they trusted the care team and acknowledged how much time the care team took to understand and document their child's care needs and review this regularly.

The service had safeguarding policies and procedures for children and vulnerable adults and there were nominated safeguarding leads for children and young adults. There was also a whistle- blowing policy. We spoke with four members of staff about safeguarding. They all knew the principles of safeguarding and in particular for the vulnerable groups of children and young people they supported. They demonstrated an understanding that this group may be at particular risk. All knew how to raise a concern and how to escalate safeguarding issues both internally and externally. All were aware of procedures to follow when a child died.

Body maps were completed for each child on every admission. Any safeguarding plans or concerns relating to a child were clearly documented in their records using a pink sheet for ease of identification by the care team. During our visit we saw evidence of special precautions put in place when care was provided for a child where there were safeguarding concerns. We saw that there were separate sleeping and living areas for younger children up to 14 years of age, and for those over 14 years. The manager told us that all senior clinical managers were booked to attend 'managing allegations' training during 2015.

As part of a recent refurbishment, a reception area had been built with secure, swipe-code access to all external doors of the hospice. A parent told us "The changes to the reception and entrance area of the hospice has seen increased safety for the children. I have attended meetings in the evening and have been required to sign in with details of my car. A member of staff must come to the door to let me in and swipe me past the doors to the conference/office area. The hospice area is separate now helping to protect the children." Visitors were required to sign in and wear visitor badges. All staff were identified by name badges and with photo identification. There was a specific night time lock up procedure and a flow chart of actions to be taken in the event of unauthorised people in the grounds. CCTV was used to monitor external security.

Risk assessments were in place for all clinical areas, equipment, activities, and outings, with risk assessors and reviewers in every department. Risk assessments were monitored and reviewed annually. Individual risk assessments were completed for families who received home-based care including assessment of the home environment and any family risks. We saw care risk assessments in four sets of records that we looked at, detailing personalised assessments for each child or young person on each stay at the hospice. These had been updated as care needs indicated, for example daily skin mapping for very poorly children.

We saw that a very high sided cot bed was in use for a child who was very vulnerable when out of their wheelchair. This cot bed provided a safe night time environment that could otherwise only be achieved by sleeping on a floor mattress. The manager told us that this cot bed was only used if the child had a similar bed at home. Adaptations had been made to the cot bed to enable the child to see out from the high sides and the care staff to be able to observe them. The use of the cot bed was documented on a risk assessment. Fabric bed rails were used to keep some children and young people safe in bed and assessment for this was documented in their care plan. Risk assessments were also in place for the use of wheelchair safety straps for daily living wheelchairs, and bath/ shower hoists, and hoists used in the swimming pool.

Each child and young person had a personalised care plan which assessed and balanced the risks associated with activities against the individual's quality of life. For example, children and young people living on permanent invasive ventilation were able to access the swimming pool but only with two members of staff and being in the care of the senior physiotherapist with a respiratory specialty. Portable oxygen supply was available for children and young people who needed continuous or intermittent oxygen therapy so that they could go into the garden.

Outstanding ☆

Is the service safe?

Young people over the age of 18 were able to drink alcohol sensibly and we saw the risk assessment documentation to manage this which highlighted specific risks such as medicine incompatibility. This meant children and young people were enabled to enjoy their lives while remaining safe.

We spoke with the estates manager and he showed us records which confirmed that services and equipment were tested and serviced on a regular basis as required. Excellent records were maintained. A service level agreement was in place with the adjoining Clatterbridge Hospital for the maintenance of most of the equipment provided at Claire House. A generator for emergency power supply was maintained by the hospital team and a clinical waste contract was in place with the hospital. A pest control company was contracted for the control of 'cluster flies'.

The electrical installation certificate for the premises had been renewed in 2014 when the major refurbishment was completed. An external company tested the emergency lighting system monthly and a contract was in place for maintenance of the automatic entrance doors. The intruder alarm system was checked monthly. Portable appliance testing was carried out annually for all electrical equipment. All of the water outlets were flushed out twice a week and the housekeeping staff had received training about this. Specialist baths and hoists were serviced twice a year, and specialist beds had an annual service. The outdoor play equipment also had an annual safety check.

A new fire alarm system was installed as part of the refurbishment and this identified each room. The fire procedure was clearly displayed on walls around the building and the manager told us that new fire training procedures were being implemented. Training in progress included the new pager system and a safe haven for wheelchair users on the first floor. Fire extinguishers were checked monthly, and the fire alarm system quarterly.

We found that the environment was clean, with a housekeeping team working throughout the week and supported by volunteers. There were additional housekeeping staff on Mondays as this was usually a busy day when children were admitted and discharged for respite care. Housekeeping cleaning schedules were in place for clinical areas. Alcohol hand gel was available before entering the main hospice and we saw supplies of personal protective equipment, such as disposable gloves and aprons, in the bedrooms.

Infection prevention and control policies and procedures were in place and staff received training on induction and updated annually. Volunteers working within the service had the same training as care staff. There was a lead nurse for infection control and an annual infection control report was written. We saw records of comprehensive infection control audits. We were told that infection prevention and control was always an agenda item for team, senior staff and clinical governance meetings. During our visit we observed a high level of good practice in relation to hand hygiene and care interventions, for example when providing tracheostomy care.

Policies were in place for infection prevention and control when using the hydrotherapy pool. A chemical dosing system was used to disinfect the water and this was serviced quarterly. The pool water was tested every day and a weekly sample sent to Clatterbridge hospital laboratory for testing. We saw records of the water testing and risk assessments and practices for children and young people who wanted to use the pool who had active or colonised infections such as MRSA or pseudomonas. Waterproof continence aids were available and toys and other equipment were taken out of the pool and cleaned after each use.

There was a clear process for clinical and non-clinical incident reporting including near miss events. We were told that all incidents were logged and discussed at clinical governance meetings. The manager told us that the service maintained robust incident reporting within a no blame culture, with outcomes and actions used as learning tool to improve or change practice if required. Nursing representatives attended health and safety, and clinical governance committees.

At the time the provider information return was written, the service employed 44 nurses and 42 healthcare support workers. Within the hospice building, daily staffing was based on one to one support for ten children or young people. There was a minimum of three registered nurses on daytime shifts and two at night, with seven healthcare support workers. Children were supported by one or two staff according to their care needs. Children who required assisted ventilation always had two staff. Following a death, a member of the care team provided care for a bereaved family as an extra to the team caring for the other children and young people. Staffing was flexible to meet the needs and dependency of the children and young people who were cared for each day and was planned to match the key staff and skills required for each child or young person, for example the rota showed that there were seven nurses on duty on a Sunday afternoon, which was a popular time for children to come into the hospice.

Three senior nurses were supernumerary to the staff rota. An on-call manager was always available to ensure any staff shortages were covered and for advice. Prescribing on-call cover was available every day between 8am and 8pm.

There were key working teams for each child and young person. The staff team had a skill mix with varying nursing and therapy specialist qualifications including bereavement counselling, caring for teenagers, caring for babies, disease specific, high dependency nursing and therapy skills for example invasive ventilation, tracheostomy care, and care for those with neuro-muscular disorders. The team of nurses included registered children's nurses, general nurses, and learning disability nurses. All of the healthcare support workers had a national vocational qualification (NVQ) level 3 and had additional training for specialities such as ventilation, tracheostomy, and catheterisation.

Four registered nurses and one healthcare support worker worked in the hospice to home service. They did not provide a regular planned service, but responded to crises and end of life care. Two physiotherapists were employed and covered seven days a week. A bank physiotherapist was available to provide cover. The Claire House staff team also included three whole time equivalent counsellors who supported families directly and supported the care team in developing their communication skills. There were two volunteer counsellors who were directly managed by the counsellors. Four specialist play staff and a music therapist were also part of this team. Volunteers supported the catering staff, the housekeeping team, the administration staff and the maintenance team.

A weekly multi-disciplinary team meeting was held every Monday to discuss the care scheduled for the forthcoming week and identify children who may require additional support. This promoted effective use of resources and responsiveness to child and family needs and managed staffing and skill mix. The manager told us that a respite stay may be offered to a family if there was spare capacity. Staffing levels were also planned to support response to emergency respite and end of life care. We were informed that a working hours review was being carried out with the remit of developing a more flexible workforce that also took account of the flexible working requirements of staff. The review was being led by the 'clinical leadership team' and was aiming for autumn implementation of any new proposed shift patterns.

We looked at personnel records for four members of staff who started working at Claire House during recent months. The records were comprehensive and confirmed that robust recruitment and interview processes were followed. Prior to being employed, all new staff had an enhanced Disclosure and Barring Service check, at least two valid references and health screening. For nurses, a check of their Nursing and Midwifery Council registration was carried out. We were informed that senior clinical managers had done 'safer recruitment' training and other senior managers in the organisation were going to do this before the end of 2015.

The manager told us that recruitment of senior nurses was a current challenge and an action plan had been put in place to address this. The action plan included a development programme for current junior nurses to progress to a senior nurse role.

The service had medicines management policies and procedures which included a medicines reconciliation process. All medicines were prescribed either by the child's specialist consultant or their GP. Any additional medication required during a stay at Claire House was discussed with the child, the medical team and the parents. The service had five non-medical prescribers and we were told that they could, for example, start antibiotic therapy for chest or other infection. There were additional procedures in place for the hospice to home service where anticipatory drugs may be kept in the child or young person's home if death was expected. This meant children and young people using the service received pain relief, or medication to relieve their symptoms, quickly and therefore make them more comfortable.

Routine medicines were brought into the hospice by the child or young person and stored in a locked cupboard in their bedroom, unless specialist storage such as refrigeration was required. Medicine cupboard keys were held by one of the nurses on duty. All medication administration was individually timed and given in the child's bedroom. All medicine administration was checked by two nurses..

Outstanding ☆

Is the service safe?

During our visit we observed excellent practice of the administration of three medicines. We saw that, where medication was given via a gastrostomy or jejunostomy tube, each medicine was drawn up into a syringe. The syringe was immediately labelled with a pre-printed label that stated if the drug was to be given via a gastrostomy or jejunostomy tube. Liquid medicine bottles were clearly labelled with the date of opening and where they were stored, for example ‘requires refrigeration’.

All clinical staff had an annual medicines competency assessment and this included syringe driver competency. One of the team leaders was the designated medicines management lead. The nurses we spoke with were aware of and followed national medicines safety guidance. Specialist pharmacist support was available for all aspects of medicines management. All medicines incidents were reviewed at clinical governance meetings.

Good ●

Is the service effective?

Our findings

We spoke with two families during our visit. Both families told us they had received phone calls on occasions when their child had been staying at Claire House to discuss changes in health status and discuss care plans and treatments. Both families welcomed this as they knew their child was fragile and changing health and care needs were swiftly and actively managed.

We saw that the induction programme for new staff covered two full weeks and included fire procedures, staff handbook, safer working practice, safeguarding, infection prevention and control, moving and handling, equality and diversity, practical skills, medicines and record keeping. Several senior members of staff were involved in delivering the induction. The induction process included a training needs analysis to identify essential training needs for each new member of staff. In addition, there was a preceptorship programme lasting four to six months for new nurses which covered a number of competency areas. We saw an example of this being completed for a nurse who started working at the hospice in 2014. There was a further detailed induction for new hospice to home staff that covered specific areas such as lone working.

The manager provided details of mandatory training that had been completed by the nurses and other staff during the last 12 months. The subjects covered were: bereavement; dignity, respect and person-centred care; equality, diversity and human rights; fire safety; health and safety; malnutrition care and assistance with eating, including specialist feeding; medication, safe handling and awareness; moving and handling; palliative and end of life care; prevention and control of infection; safeguarding; emergency aid awareness.

A smaller number of staff had done training for first aid (12), food hygiene (12), Mental Capacity Act and Deprivation of Liberty Safeguards (26). Other training courses provided in the last two years were: intermediate level communication skills; safer working practices; documentation and record keeping; advanced care planning; peritoneal dialysis; invasive ventilation; lone working; tracheostomy; verification of an expected death. Some of these were additional skills and competencies expected to be achieved by all senior nursing staff and optional for junior nurses and healthcare support workers. Core clinical competencies were completed and reviewed annually for all of the care team and qualified mentors signed off competencies. Where needed, training for new skills was developed, for example training to care for a child who required dialysis.

We were told that training was delivered in different formats which may be one to one, group sessions, e-learning, workbooks, and external courses. A training budget was available for identified external qualifications, courses and study days. For example, a secondment was in progress for one of the physiotherapists to develop respiratory skills and the family support and counselling manager had successfully completed a doctorate researching assessment tools for bereaved parents.

The service had a ‘head of practice education and quality' manager who was responsible for ensuring that appropriate training was completed by all staff to ensure the capability of the workforce to deliver high quality, safe and effective care. There was a clinical skills room within the care area. This was equipped with a computer and mannequins that allowed for safe practise of skills such as tracheostomy care, care of enteral feeding tubes, catheterisation and resuscitation. The clinical skills room also held literature resources, details of training opportunities and the action plan from the last year’s accidents and incidents report and complaints analysis.

Each member of staff was allocated to a team and each team had a bi-annual ‘team day’ for clinical updates, mandatory training and caseload review. A system of clinical supervision for all clinical staff was in place. A healthcare support worker told us they had not had formal supervision for some months as their supervisor had left and they were awaiting a new supervisor to be allocated. However, the member of staff felt they could access supervision and support as needed through staff meetings, debriefs following a death, and from colleagues on a daily basis. We were told that all staff had an annual appraisal that included personal and professional development needs. In the care team office there was a ‘Care Team TV’ screen which had rolling messages reminding staff about meetings, debriefs following a death, training events etc.

We discussed the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards with the registered manager. She told us that the impact of the Mental Capacity Act and Deprivation of Liberty Safeguards with regard to hospice care were still being addressed. The service was awaiting further guidance from the 'Help the Hospices' organisation and from CQC regarding the implications of this legislation.

The manager told us that the organisation was actively seeking to develop the skills and knowledge required for the application of the Mental Capacity Act and was considering employing an additional member of staff to deal with issues of consent with young people over the age of 18 and had plans in place to deliver specialist training from an outside agency. There were currently 39 young people over the age of 18 years who used the service.

Staff we spoke with had a good understanding and application of the Children Act (1989) and the 'Gillick Test' which helped clinicians to identify children aged under 16 who had the legal capacity to consent to medical examination and treatment. They must be able to demonstrate sufficient maturity and intelligence to understand the nature and implications of the proposed treatment, including the risks and alternative courses of actions.

In the four sets of records we looked at there were up to date consent to care and treatment forms and consent for activities. Consent forms for parents included consent for medication administration, first aid, photographs, use of the pool, and use of CCTV in bedrooms. During our visit we observed that staff sought consent for all care interventions. Physical restraint was not used in the service. Restraint in terms of specialist beds and bed rails were supported by risk assessments and care plans and in the main parental consent form.

Two of the care records we looked at contained 'do not attempt cardio-pulmonary resuscitation' (DNACPR) completed documents. These were both completed fully and supported by comprehensive advanced care plans, both of which had been initiated by a children and young people's palliative care consultant. The document was easily identifiable and accompanied the child whenever they went within Claire House. It was also documented on the 'front page' of the electronic database. We observed that during care handovers, the resuscitation status was identified for each child.

People told us that mealtimes, the quality of food, and the choice offered were exceptional. Their individual needs were met and staff went out of their way to meet their preferences. The kitchen operated seven days a week and all meals were freshly prepared by the catering team. We saw that, for children and young people who were able to eat orally, there was flexibility of food choices and if a child or young person wanted something special to eat, Claire House made all efforts to provide this. Healthy snacks and drinks were always available, including treats such as ice lollies. Although there were set mealtimes, individual mealtimes were facilitated, for example for babies or young children needing more frequent meals, for medical needs, or for emotional care.

Mealtimes were family orientated with hospice staff, children and young people and their families all eating together if they chose. We saw an alternative dining room that could be easily accessed by any child or family wishing to have more privacy. There was also a dining room in the upstairs family accommodation. Meals could be provided there or families could make their own meals.

We spoke with members of the catering team, which included volunteers. They told us they had all completed level 3 food hygiene training. They said they did not have many special dietary needs to cater for, but a record of each child's likes and dislikes were produced by the care teams and given to the kitchen staff. Any special dietary requirements were noted in the care plan and the kitchen plan so that staff could cater accordingly. Dietary requirements for health or culture were provided for and the catering team were trained to provide these. Specialist diets were prepared under the supervision of the nurses.

Most children and young people who were artificially fed brought in their own nutritional feeds and feed pumps and their usual regime was followed by the care team. Claire House was actively participating in a recent national development of using pureed 'real' food via a child's artificial feeding tube. A new policy, protocol and training had been developed for the small number of families that had transferred from using artificial feed preparations to using blended 'real' food, with a parental disclaimer in place. This was a relatively new introduction and the manager had checked with specialist dieticians to ensure this was safe practice, and care plans had been adapted accordingly. The manager had also ensured that insurers were happy with the waiver produced by the regional children's hospital.

Specialist feeding equipment was usually brought in by the family and the child's care plan documented how to use

Good ●

Is the service effective?

the equipment. Care staff were trained in safe supported eating, in caring for those with tracheostomies whist eating, and in using eating aids such as ‘neater eaters’. These eating aids were designed to enable people to use their own movements to feed themselves which increased independence, encouraged social interaction and helped maintain dignity. The support required with meals was assessed each time a child or young person had a stay at the hospice. Members of the care team received food safety awareness training in order to prepare a meal safely in the absence of the kitchen team out of hours. There was a separate milk kitchen where feeds for babies could be prepared by care staff.

A nutritional assessment was undertaken on each admission and reviewed according to the length of stay and the child’s care needs. The hospice had close working links with the dietician team based in the community and at Alder Hey hospital. Details of the child’s dietician were kept on file.

Weights were checked six monthly, or more frequently if there were concerns. Staff had received training about the ‘ketogenic diet’, a high-fat, adequate-protein, low-carbohydrate diet that was sometimes used to treat difficult-to-control epilepsy in children and other conditions and may be recommended for some children who used the hospice. There was also close collaboration with the diabetes team and dietician for children who had specific dietary needs to manage their diabetes. The manager told us that the care or catering team often liaised with families or young people with special needs in advance of admission to discuss and plan menus.

We saw that although all of the children and young people supported by Claire House had a life limiting condition, every opportunity was taken to support a healthy life-style and enhance abilities and independence and balance risk with quality of life. The service was supported by a team of local GPs who attended daily for planned visits and were also available on-call 24 hours a day, seven days a week. The manager told us they liaised with midwives or health visitors for neonates and babies to ensure that general health checks, progress checks, weight- monitoring, and immunisations were continued as appropriate. There was a weekly teleconference with the specialist hospital palliative care team to discuss children whose care was shared. We saw many examples of collaboration with other health professionals such as dieticians and occupational therapists. The records we looked at contained ‘care escalation plans’ for if a child’s health deteriorated.

The care manager showed us around the premises. The hospice was purpose-built in 1998 and an adolescent wing was added in 2006. A major refurbishment was completed in 2014. This involved a new main entrance, other extensions, landscaping, and remodeling of the interior including upgrading bedrooms, the milk kitchen, adding a new teenage den, a reception area and a counselling and holistic therapies suite. The new main entrance extension had provided the additional entry space required for the arrival of families with large equipment.

We were told that young people who used the service, families and staff had contributed to the design and refurbishment. The specialist professional advisor considered ‘Claire House goes way beyond the requirements of the Disability Discrimination Act in providing multiple options of different beds and equipment to meet age, size and care/ health needs for all children and young people.” New ceiling track hoists had been added in all areas. There were well-equipped bathrooms and shower rooms with various equipment to cater for different needs.

The development took account of new play and therapy technology, and in particular the needs of young people with chronic conditions who now survive for longer, and the needs of neonates who are surviving longer after birth. There was a young people’s den that was for over 16s only. We were told that it had been designed by young people who used the service. The hydrotherapy pool had been enhanced for those with sensory impairment.

Other facilities included separate parents’ accommodation on the first floor, however parents could also be accommodated in the child’s bedroom if requested. There was adapted outside play equipment including a swing and roundabout for wheelchair users. There were well-tended grounds and gardens with paths for wheelchairs. A large, accessible ‘Wendy House’ in the garden had heating and lighting.

Is the service caring?

Our findings

During our visit we were able to speak with a child who used the service. She told us that she loved coming to Claire House, that she knew all the care team and knew many of them very well as they cared for her on her visits. She said that she loved the activities and the music therapy and liked being able to choose what activities she did while at Claire House.

A parent told us “Without Claire House we would not have been able to do half the things we have been able to do with [child’s name].” Another parent said “Claire House has been a lifesaver for us as a family. This is a fantastic service. We looked at alternatives and walked straight out as we felt they would not get to know [child’s name] as an individual and the facilities were basic. At Claire House we know they know [child’s name] personally and meet her individual needs. The facilities are excellent and [child’s name] loves coming here.”

Following our visit we spoke with a parent who used the ‘Mum and Tots’ group. She told us “Claire House has helped us massively. I can’t speak highly enough of them. They have been a fantastic safety net.” She described how Claire House staff had supported the family when dealing with medical professionals in difficult situations, attending appointments with them, also helping to accessing specialist equipment for use in their home. The hospice to home team was always available by phone and the counselling service was “amazing”.

A parent told us about how end of life care was provided for their child: ‘Our feelings with regard to the inevitable were never questioned. We were never pushed into having to admit what was coming. Claire House knew what was coming next, through a close relationship with the hospital so had everything in place for us without us knowing. Once the clinical treatment was ended, palliative end of life care just flowed into our lives. We had 24 hour telephone contact with the team. When our daughter died, she was taken to Claire House and they continued to look after her as they did when she was alive. They organised her funeral with us and the return of all medical equipment. Bereavement care has now taken over for ourselves and our younger daughter. Again never pushed into anything but a definite presence anytime we need them. A card on an anniversary, a yearly memory day, parent groups and an invite for our younger child to spend time with other siblings.’

The research study conducted by Edge Hill University in 2014 found ‘Key factors of the service include the long-term, trusting relationship and good communication between Claire House staff and families.’ Families who completed a survey told the researchers ‘The care provided is excellent.’ and ‘Trust is hard to find but found at Claire House, which enables us to relax.’

A member of the young people’s forum commented ‘It’s good to just mix with everybody else and chill out with everybody else that understand your needs and not just the staff but the other young people who come here.’

A healthcare professional commented: ‘An excellent service. I link parents after their children have died expectedly or unexpectedly I link families for palliative care. I have nothing but praise for the services. The Butterfly Suite is a fantastic resource for grieving families.’

A commissioner told us ‘I visited Claire House following its refurbishment earlier this year and was amazed at the work they do and the facilities they provide for children and families. I had no idea it operated at that level, and left there feeling very inspired and pleased that we, as a CCG, were supporting them financially. The staff are extremely committed to their roles and genuinely care about the children they look after. It was wonderful to see.‘

We saw that Claire House provided child and family centred care. Families were able to stay with their child throughout the duration of their stay. Grandparents and other family members and friends were encouraged to visit and there were no restrictions on visiting times or use of facilities within Claire House by visitors.

The manager told us about services they provided including accompanying parents to hospital appointments to support them, visiting a child in hospital so that parents could have a rest, and providing emergency respite care either at home or in the hospice if the family was experiencing a crisis or needed additional support for any reason. They helped to assess the equipment that would help in caring for the child at home, for example specialist beds and wheelchairs, and offered advice or liaison with

Is the service caring?

external professionals. Transport could be provided for respite visits if needed. Individual counselling sessions were provided for children and young people and for family members. Holistic therapies were available for families.

The manager told us they built relationships with families at their pace and in a setting of their choice, hospice or home. There was an option for under 5s to attend a parents and tots group to gently introduce the hospice to families in a very informal way. This met fortnightly and enabled parents to meet as well as having therapeutic interventions and gaining an insight into the hospice services.

Each child was allocated to a specific team of staff who built up a relationship with the child and their family and identified their specific needs, likes, and dislikes, and acknowledged birthdays and anniversaries. The team made regular contact with the family and the others services involved in their care in between planned stays in order to follow up how stays went and identify any concerns or other feedback which may be positive or identify areas for improvement. Each child had an 'All About Me' document that recorded what activities they enjoyed and didn't enjoy, what made them smile or made them unhappy, even how they like their clothes washed. We observed that the diverse needs of the children and young people were understood by the staff team and communicated by means of the 'All about Me' document. During our visit we saw a healthcare support worker, who was working with a child for the first time, referring to the 'All About Me' document to understand how to make the best of the child's day and deliver appropriate care.

Staff recognised the different needs of adolescents and arranged planned admissions for young people who wished to attend together or on dedicated adolescent weekends. There were also special interest groups for neonates, siblings, children with special communication needs and transition for young adults.

All of the care interactions we observed were caring, respectful and age appropriate and met the needs of the individual, for example use of communication boards and Makaton signs. The signage around the home was designed to meet age and sensory needs and to offer a non-institutional environment. Most signs were bespoke and purpose made. One example we saw was a sign to warn that oxygen was in use in a child's bedroom. This had been specially made by the team to lessen the feel of a hospital or institution, but was clear and accurate.

Each child and young person had a personalised care plan that was reviewed on every admission, and every 24 hours, or as needs changed, while they were being cared for in the hospice. The care plans showed evidence that the preferred sex of carers was established and chosen either by the child, their parents, or both. Each child was cared for in an individual bedroom and more spacious rooms were provided for the older children and young adults. We saw signs on bedroom doors requesting do not enter personal care in progress that were removed when personal care was completed. There were multiple communal recreational areas that catered for different age groups and abilities, for example a small dining room was preferred by some young people so they could eat more privately using eating aids which could cause them embarrassment. We observed three medication administrations that were given in the child's bedroom and not in a communal area.

The manager told us that end of life care took priority when planning resources for the service. A child or young person approaching the end of life, and their family, could stay at Claire House for as long as needed. The care team liaised proactively with consultants and the palliative care team at Alder Hey and expert advice could be obtained 24 hours a day. Anticipatory symptom management plans and prescribing were in place in order to respond to rapidly escalating symptoms at the end of life. Anticipatory prescribing was supported by the team of GPs who had undergone extra training, and the five nurses who were qualified non-medical prescribers. Advance care plans could be instigated or reviewed as the child's condition changed or at parents' request. We found evidence of anticipatory care planning for end of life care in two sets of records that we looked at. This ensured that their wishes and wants were documented with reference to preferred place of care, clinical care, psycho-social support, spiritual wishes and care around end of life care and through to bereavement. The child or young person's wishes were documented in their 'All About Me' document and the care team tried to fulfil any special wishes, for example meeting a celebrity.

End of life care could be provided at the child's home by the hospice to home team or at Claire House. Claire House provided services such as 'compassionate extubation' for a child being cared for in hospital when all hope of recovery was exhausted. This involved the removal of mechanical help with breathing and could lead to immediate death, or in some cases a longer period of palliative care and

Is the service caring?

symptom management. The Claire House team participated with medical consultants in explaining to families the outcomes and choices and facilitated compassionate extubation either at the child's home or at Claire House. A funeral plan could be put in place before the compassionate extubation took place.

Children and young people who died at Claire House, and some who died suddenly elsewhere, could use a 'Butterfly Suite' at Claire House. These were special bedrooms that operated on a cooling system allowing the child or young person to lie at rest often until the time of their funeral. The Butterfly Suite could be personalised for each child by their family, the care team or both, for example with favourite toys, pictures, music, and soft furnishings. The Butterfly Suites also had a lovely private garden and lounge. Families and others with consent could spend as much time as they wished with the child and the child could go directly to their funeral from Claire House. The family were offered one to one support by an appropriately skilled member of the care team. Memory mementoes such as finger print jewellery, hand and foot print pictures, and locks of hair could be made for the family by the care team. The family support team were available to support families and the care team during end of life care.

Following the death of a child or young person, the family support team continued to support the family for as long as needed, or for as long as they wished. Bereaved families were able to access group or individual counselling. There were therapeutic and social groups provided for bereaved parents, grandparents, and siblings. Bereaved families planned and contributed to an annual memory day that was facilitated by the counselling and therapy team. A peer support group for bereaved parents was being developed by the bereavement counselling team. Social, age appropriate events were held throughout the year for the siblings of children and young people who used the service including bereaved siblings.

Claire House worked in partnership with Edge Hill University to deliver a module for students in palliative and end of life care for children and young people. The registered manager and other senior staff were regularly involved in the teaching of palliative care at local universities for nursing, social care and pharmacy students.

An information pack provided details of the services offered at Claire House. This gave information about how to make a referral, the hospice to home service, the complaints procedure, and practical advice relating to respite visits.

Is the service responsive?

Our findings

We asked a parent who used the service how well the service responded to changing needs of families. They told us 'Our own experience of changing needs was dealt with seamlessly. Our initial introduction with a terminally ill child was as a community nurse through the hospice to home service. Our family was invited into the hospice to use the pool and art room to help our daughter with physio and keeping her from getting bored. The hospice organised days out and holidays to allow us to make every day count.'

Two families we spoke with said they were directly involved in planning their child's care at Claire House and appreciated the regular phone contact with Claire House even when their child was not staying at Claire House. One family told us that the care their child received at Claire House was as close to the care that they gave their daughter at home as they could get. The young person we spoke with said she was always offered choices and asked how she liked her care to be given. She was as actively involved in her own care as she was able to be. The care records we looked at evidenced that children and young people, and their families, were always involved in their care planning. Bedrooms were prepared with the child's preferences for planned stays.

The families we spoke with told us their child had a planned respite stay at Claire House about four times a year. In between visits, a member of the Claire House team called them every five to six weeks to find out how the child was. Before an admission, a member of the care team called the parents to ask if there were any changes in the child's care needs or any worries or concerns. After each admission, a member of the care team called the family to ask how the child and family felt about their stay and whether there had been any problems.

A Commissioner told us "This is an outstanding provider and we have an excellent working relationship with them. We receive very positive feedback from families. They are not focussed on finances and never refuse a child care even if it is beyond what is commissioned. They bend over backwards to accommodate families and mobilise incredibly quickly. Their philosophy is how can we do more and better. They are innovative and creative in what they want to achieve. They are a great partner to work with."

At every stage, from pre-natal to post-death, parents could self-refer and a service could be provided. A fortnightly multi-disciplinary referral panel ensured a prompt response to all referrals. All referrals were reviewed against eligibility criteria. A 'referral administrator' was responsible for ensuring that referrals were managed efficiently and provided a key point of contact for families and professionals. A flow chart showed how referrals were dealt with. The referral process also included rapid response to referrals for end of life care at home or in the hospice. The manager told us that referrals to counselling were always actioned within two weeks.

The hospice to home service provided end of life care, symptom assessment and management, emotional and psychological support, bereavement support, and specialist respite care for crisis management, which may be a family crisis rather than one connected with the child's health. A recent research study carried out by Edge Hill University found 'The ability of the hospice to home team to blend into the family home and be responsive to the needs of all members of the family whilst maintaining professional boundaries was perceived as a particular strength of the service.'

The hospice to home service operated a 24 hour, seven day a week call service for end of life care and could accept referrals at any time.

There was a weekly meeting each Monday morning involving the hospice team, the hospice to home service, physiotherapy and family support, to discuss care scheduled and identify children requiring additional support. The manager told us that this promoted the most effective use of resources and responsiveness to child and family needs and enabled staff to move from one service to another to meet needs. End of life care was always prioritised. A 'respite coordinator' managed both planned and emergency respite and worked closely with the senior team to ensure families received respite care when they needed it.

There was a designated key contact for each child and they completed the primary assessment of the child's needs and developed a child-centred care plan in partnership with the child, the family, and medical professionals. The care plans we looked at included personal care preferences, Outstanding ☆

Is the service responsive?

specialised care needs, and any cultural or spiritual needs and wants. Care plans and risk assessments were reviewed on every visit, and daily for those approaching end of life. Each child had a full annual review of their care needs.

Hospice staff, including physiotherapy staff, attended Alder Hey hospital regularly to review a child's progress and enable a co-ordinated rapid response to the child being discharged from hospital either for step-down care, end of life care, or increased home support. Emergency respite and end of life care were given priority and the team responded rapidly to such a request, utilising the rapid discharge plan to support children moving from one care setting to another.

The service employed four play specialists who developed and planned individual and group activities both inside and outside Claire House. The play specialists worked across seven days a week with flexible working hours to accommodate the children and young people using the service. They could also go out to people's homes. Activities were planned for each stay according to each child's needs, abilities and requests. Musical activities were provided by a music therapist for children and young people staying at Claire House. The play team and music therapist were developing programmes and assessments that could aid and improve communication with children and young people.

We saw that there were excellent recreational facilities including a new interactive room with accessible technology that could be used by children and young people including those with profound disabilities and sensory impairment. Six members of staff had been trained to use this highly- technology play equipment. An individual programme could be created for each child to reflect their interests and abilities. There was also an arts and crafts room and adapted outdoor play areas. A bar/ lounge area known as 'The Den' had been created for older children and young people.

Maximum use was made of the hydrotherapy pool, for example a Saturday morning swim session was available for children following oncology treatment. These children would not be able to use swimming pool facilities in the community due to the risk of infections. Holistic therapies were available for children and young people and for family members. The therapies available were aromatherapy massage, reflexology, Reiki, Indian head massage, crystal healing and acupressure.

Both families we spoke with said they knew how to raise a concern or complaint and would feel very able to do so and not feel judged or compromised if they did raise a concern. The staff we spoke with said they knew about reporting complaints, accidents or incidents and were included in the shared learning from such events. The Edge Hill University study found ' When things have not gone as well as expected at Claire House, the staff have maximised the opportunity to learn from the event and families have high confidence in the care provided.' A complaints policy and procedure was in place and this was included in the information pack for families who used the service. We saw record of four complaints that had been responded to during 2014. The records we looked at showed how the issues were dealt with, whether the complainant was satisfied, any other agency that had been involved, and any action taken.

Outstanding ☆

Is the service well-led?

Our findings

We asked a parent whether their views were listened to and they told us ‘Parents’ views are paramount in the care of children accessing the service. I have attended parents’ groups with the CEO present, board members and the care team. A bereaved parent was present as a board member also. Parents are asked to complete a survey annually. Parents were consulted over the building changes to the hospice.’

A healthcare professional commented ‘I recently spent a week's placement at this service and saw first-hand the excellent work carried out by the hospice team, hospice to home team as well as the bereavement support team and physios, play specialists and support staff within the service. There is a high priority given to professional development in order to improve outcomes for those accessing the service.’ Another professional reported ‘Whenever I have had to access the hospice the staff have always been very approachable, helpful and available to give advice and support.’

Commissioners told us ‘Patient/carer feedback I believe is very good. During the contract monitoring of this services, to my knowledge, there have never been any issues raised re this service about the care they provide.’ and ‘I am a commissioner and the CCG I work for commissions services from Claire House. I believe they provide an excellent service and we have a very close working relationship with the management team there.’ Another commissioner told us

‘I receive quarterly performance reports, always on time, that include all the appropriate information and data that we need to feel satisfied that the service is meeting its required standards. I am also welcome to attend, and have attended, their palliative care zonal network meetings to hear more about the work that they are doing and how they are working collaboratively with Alder Hey around their palliative care. They were keen to hear our views as commissioners and I will certainly attend more meetings in the future, to keep up to date on current plans for the service.’

Staff feedback included ‘Very supportive team all round.’ and ‘The service provided is exceptional with positive feedback from both service users and external professionals. It is a privilege to be part of the service.’ A member of staff we spoke with said they were very proud to work for such a “fantastic organisation”. Other feedback from staff were ‘As a staff member I feel I am valued and listened to. Any initiatives that I believe will provide a better service to the children young people and their families are welcomed and invested in. I feel the organisation is dedicated to personal development of staff and am encouraged to grow my knowledge and skills. I love my job at Claire House and feel we as an organisation offer a great service to the children and families.’ and ‘So far in my career this has been my most challenging yet most rewarding job. I work within a fantastic team of nurses and care staff that are dedicated and hardworking and who are guided and supported by an excellent manager.’ Staff we spoke with during our visit told us that the whole team, including senior nurses and managers, were very supportive and easily accessible when support or advice was needed.

There was a monthly whole care team meeting and monthly senior staff meetings to discuss clinical care and best practice. An annual staff survey was conducted by an external company and an action plan was coordinated by the head of human resources. People development policies were in place to ensure fairness and equality for staff. There were opportunities for healthcare support workers to develop, and three had enrolled to do a two year training course for qualification as ‘Assistant Practitioner’.

The manager told us that a family survey was usually carried out annually, but was not done in 2014 because a number of families were already involved in the large study being carried out by Edge Hill University. The manager told us that the family survey feedback was shared with the teams and action plans formulated. She said that service development took account of feedback from children, young people and their families. We saw the results of a questionnaire for parents using the ‘tots’ group which asked them what times, days, and activities they would like to have. There was a teenagers group that met monthly with minuted records, a parents action group, and a family support group. There was a suggestions box in the parents’ lounge. The manager told us that a review of user engagement was planned for mid-2015 with young people and families to identify a range of different ways to gain feedback and have consultation about service provision and development, ‘so we can ensure their views help us shape our future service provision’.

Outstanding ☆

Is the service well-led?

We saw evidence of regular clinical audits, for example of care plans, infection prevention and control, medicines management and the care environment. These resulted in action plans to improve where appropriate. Debriefs were held when significant events occur and action plans were formed. The manager told us that 'Specific organisational values have been developed and have been embedded across the whole organisation and incorporated into the new appraisal process and underpin the 'Open and Honest' and 'Learn, Develop, Grow' culture' across the organisation. Across the organisation, expected behaviours and values are constantly being reinforced in word and action by managers, trainers, leaders and peer groups. The whole organisation participated in externally facilitated training days to explore reconnection with our key purpose and vision and how we can all work together through great fund raising to achieve our vision for children and families. There was a whole organisation away day in April 2015 to launch the next five years strategy and build on the foundations of working together to achieve our vision of making more of a difference to more children and families.'

The service had a manager who was registered with CQC and had relevant and up to date experience and expertise to lead the service. Prior to taking up the post of Director of Clinical Services at Claire House, the manager had considerable previous experience at a senior level in palliative care for children and young people. During our visit we found that the seniors and managers were visible within the day to day service. The seniors and managers shared lunch with the staff and people using the service on a daily basis. Many of the senior team were education facilitators for the care team. We observed the care manager to be involved with care staff and communicating with children and families throughout our visit.

The Board of Trustees had a parent representative and there were two consultant paediatrician trustees. A review of the effectiveness of the Board of Trustees was being conducted by an external agency. Trustees attended all sub-groups including clinical governance, risk and health and safety, and induction and relevant training days. A report on clinical governance, clinical risks, and complaints was presented at the quarterly meeting of the Board of Trustees.

The service worked in partnership with other organisations to make sure they were following current practice and provided a high-quality service. They strove for excellence through consultation, research and reflective practice. They could also show how they sustained their outstanding practice and improvements over time. Claire House had strong links with the UK children's hospice organisation 'Together for Short Lives' and participated in the development of national guidance, supported national research and facilitated inter-hospice working groups. Claire House also had strong links and active multi-disciplinary team working with Alder Hey Hospital. Claire House worked as part of the local children and young people's palliative care forum and with the Clinical Commissioning Groups (CCGs) in developing and leading on services for children and young people with palliative care needs across the region. A commissioner from a CCG identified that ˜Our relationship with Claire House has sharpened our focus and understanding of the needs of children with the most complex needs.'

Claire House had established a research partnership with Edge Hill University. An 'Emergency Care Impact Assessment' had been carried out and a report completed in September 2014. This balanced the relative value and effectiveness of planned respite care and emergency provision with reference to future planning of services and best use of resources. A further research project had been commissioned for a qualitative study looking at the experiences of families during end of life care in different care settings. The registered manager was employed on a part-time basis to deliver palliative care training at the university.

We saw that the primary assessment pack included consent forms for sharing information with medical professionals and advice for the family about how information was used and shared in line with legislation such as the Data Protection Act (1998). An information and communications technology lead had been appointed for the organisation and Claire House was registered with the NHS Information Governance Toolkit. This is an online system which allows NHS organisations and partners to assess themselves against Department of Health Information Governance policies and standards. The registered manager was 'Caldicott Guardian' for the organisation and had responsibility for protecting the confidentiality of information and enabling appropriate information-sharing. An NHS email account had been obtained to facilitate the sharing of confidential, patient information.

Outstanding ☆

Is the service well-led?

The manager told us about plans for future development of the service. These included exploring the potential for delivering a range of day care options in the hospice and in people’s homes. Consideration was also being given to offering care in more settings of choice, for example a Liverpool base to increase access for current and new Merseyside families. There were plans to build on the small number of volunteers who worked within the care team. A ‘transition group’ had been established to look at how the hospice team could work in partnership with other agencies to support young people when they exceeded the upper age limit for Claire House.