Claire House Children's Hospice

Quality Report

Clatterbridge Road
Bebington
Wirral
Merseyside
CH63 4JD
Tel: 0151 3344626
Website: www.claire-house.org.uk

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This report describes our judgement of the quality of care at this location. It is based on a combination of what we found when we inspected and a review of all information available to CQC including information given to us from patients, the public and other organisations

Ratings

Overall rating for this location	**Outstanding** ☆
Are services safe?	**Good** ●
Are services effective?	**Good** ●
Are services caring?	**Outstanding** ☆
Are services responsive?	**Outstanding** ☆
Are services well-led?	**Outstanding** ☆

Overall summary

Claire House Children's Hospice is operated by Claire House. Claire House has a range of services to support children and families, both at the hospice or at home.

Claire House provides planned and emergency respite for babies, children and young people. There are 10 beds split into two distinct areas for younger children and older children.

Summary of findings

The hospice accepts referrals for symptom management and step-down care (help to leave hospital) after a long hospital admission or complex surgery.

The service provides family support and one-to-one counselling, and many of the services can be accessed as a planned day case. Other services include hydrotherapy, complementary therapy, music and play therapy.

Claire House provide end of life care at the hospice or home for both symptom management and emotional and practical support. The service is underpinned by a 24 hour rapid response team of nurse specialists. Families can stay with their child throughout.

Claire House have two 'butterfly bedrooms' where a family and their child can stay after they have died, and the team assist families with emotional and practical support.

We inspected this service using our comprehensive inspection methodology and the inspection was unannounced. The inspection was 8 and 9 October 2019.

To get to the heart of patients' experiences of care and treatment, we ask the same five questions of all services: are they safe, effective, caring, responsive to people's needs, and well-led? Where we have a legal duty to do so we rate services' performance against each key question as outstanding, good, requires improvement or inadequate.

Throughout the inspection, we took account of what people told us and how the provider understood and complied with the Mental Capacity Act 2005.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	**Outstanding** ☆	We rated this service as outstanding overall. The domains of caring, responsive and well led were rated as outstanding, and the domains of safe and effective were rated as good.

Summary of findings

Contents

Outstanding ☆

Claire House Children's Hospice

Services we looked at:
Hospice services for children.

Summary of this inspection

Background to Claire House Children's Hospice

Claire House Children's Hospice is operated by Claire House and opened in 1998. It is a private hospice in Bebington, Wirral. The service primarily serves the communities of Cheshire and Merseyside. It also accepts patient referrals from outside this area.

Claire House has a range of services to support children and families, both at the hospice or at home. Claire House provides planned and emergency respite for babies, children and young people. There are 10 beds split into two distinct areas for younger children and older children.

The hospice accepts referrals for symptom management and step-down care (help to leave hospital) after a long hospital admission or complex surgery.

The service provides family support and one-to-one counselling, and many of the services can be accessed as a planned day case. Other services include hydrotherapy, complementary therapy, music and play therapy.

Claire House provide end of life care at the hospice or home for both symptom management and emotional and practical support. Families can stay with their child throughout.

Claire House have two 'butterfly bedrooms' where a family and their child can stay after they have died, and the team assist families with emotional and practical support.

The hospital has had a registered manager in post since 2013.

In 2018-19 the service accepted 148 new referrals, and the hospice had 90% occupancy. The largest proportion of referrals were for perinatal referrals and respite care. The hospice currently has an active caseload of 288 children. The hospice have noted the complexity of children's needs has increased over time.

We inspected this service using our comprehensive inspection methodology and the inspection was unannounced. The inspection was 8 and 9 October 2019.

We spoke to three families and viewed feedback forms from families. We looked at 10 records and observed care interactions and a pharmacy meeting.

We spoke to 15 members of staff of different levels.

Our inspection team

The team that inspected the service comprised a CQC lead inspector and a specialist advisor with expertise in children's hospice care. The inspection team was overseen by Judith Connor, Head of Hospital Inspection.

Information about Claire House Children's Hospice

The hospice had two distinct areas. The first area was designed to fit the needs of older children and young adults, with the other area designed for younger children and babies.

The hospice had a hydrotherapy pool and therapy areas including alternative therapy, music therapy, and play therapy.

There were two butterfly rooms where families could stay with their child after they died.

The highest proportion of referrals were for perinatal referrals and respite care. The service also accepted referrals for therapy, symptom management, counselling and use of the hydrotherapy pool. Staff could provide services in families own home, and there was a rapid response team for the community.

Summary of this inspection

There were distinct teams to provide each service, although there could be crossover at times, for example counsellors could support families during activities or in the butterfly rooms.

Services provided at the hospital under service level agreement:

- Pharmacy
- Palliative care consultant

Summary of this inspection

The five questions we ask about services and what we found

We always ask the following five questions of services.

Are services safe?

Good

Our rating of safe went down. However, this was because the Care Quality Commission's inspection's methodology changed following the previous inspection in 2015. It was not a reflection that the care deteriorated.

We rated it as **Good** because:

- The service provided mandatory training in key skills to all staff and made sure everyone completed it.
- Staff understood how to protect patients from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.
- The service controlled infection risk well. Staff used equipment and control measures to protect patients, themselves and others from infection. They kept equipment and the premises visibly clean.
- There was a proactive approach to anticipating and managing risk and this was embedded across all staff levels. Staff identified and quickly acted upon patients at risk of deterioration.
- The service had enough staff with the right qualifications, skills, training and experience to keep patients safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix, and gave bank staff a full induction.
- The service used systems and processes to safely prescribe, administer, record and store medicines.

Are services effective?

Good

Our rating of effective stayed the same.We rated it as **Good** because:

- The service provided care and treatment based on national guidance and evidence-based practice. Staff protected the rights of patients in their care.
- Staff gave patients enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for patients' religious, cultural and other needs.
- Staff assessed and monitored patients regularly to see if they were in pain and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.

Summary of this inspection

- The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.
- Staff supported patients to make informed decisions about their care and treatment. They followed national guidance to gain patients' consent. They knew how to support patients who lacked capacity to make their own decisions or were experiencing mental ill health. They used agreed personalised measures that limit patients' liberty.

Are services caring?

Outstanding 

Our rating of caring stayed the same. We rated it as **Outstanding** because:

- Children, young people and their families were valued as individuals, and empowered as partners in their care. There was a culture of inclusivity and staff made sure all care was tailored to the individual.
- Feedback about the service was continually positive. Staff went the extra mile and the care and support exceeded expectation.
- Staff were committed to working in partnership with people. Staff empowered people who used the service to have a voice. Children, young people and their families' individual preferences and needs were always reflected in how care was delivered.
- For example, we saw a child friendly 'contract' which described the child's preferences for treatment, which everyone signed. The contract had pictures and clear descriptions with a treat listed at the end.
- There were two butterfly suites available for families to use. Families could stay with their child after they had died for up to a week; staff provided extensive emotional and practical support during this time.
- Staff made sure rooms had items that were important to the child and family. For example, the service purchased bedding in the same theme children liked.
- Play therapists noticed the needs of siblings and could arrange activities in a timely manner.
- The counselling team could support the child and all different members of the family including grandparents.
- Staff tried hard to help families make memories with their child. For example, they took photographs and put together booklets and cards.

Summary of this inspection

- Staff went the extra mile for families of children who were near the end of their life. For example, staff would change their shifts and co-ordination of activities responsively.

Are services responsive?

Outstanding 

Our rating of responsive stayed the same. We rated it as Outstanding because:

- Meeting the needs of local people was central to the delivery of tailored services. The service provided person-centred pathways of care for children and young people with multiple and complex needs and involved other service providers.
- There was a proactive approach to understanding the needs of the children, young people and families that used the service. Provision was made to meet the spiritual and cultural needs of children, young people and their families.
- The service had a commitment to equality and diversity and adapted to meet cultural, religious and dietary needs.
- There was an active outreach service to reach as many families as possible and identify those in need at an early stage.
- Children, young people and their families could access the service in a way and time that suited them.
- Staff forged innovative approaches to provide person centre pathways of care, involving other service providers.

Are services well-led?

Outstanding 

Our rating of well-led stayed the same. We rated it as **Outstanding** because:

- There was compassionate, inclusive and effective leadership at all levels. Leaders had high levels of experience, capacity and capability needed to deliver excellent and sustainable care.
- The strategy and objectives were challenging and innovative, while remaining achievable. Strategies and plans were aligned with the wider health economy and leaders demonstrated commitment to system-wide collaboration and leadership. Plans were consistently implemented and had a positive impact on quality and sustainability of services.
- Leaders had an inspiring shared purpose and motivated staff to succeed. There were high levels of satisfaction across all staff.
- Leaders operated effective governance processes throughout the service. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.
- Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and

Summary of this inspection

issues and identified actions to reduce their impact. They had plans to cope with unexpected events. Staff contributed to decision-making to help avoid financial pressures compromising the quality of care.

- The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements. The information systems were integrated and secure. Data or notifications were consistently submitted to external organisations as required.
- There was consistently high levels of engagement with staff and the people that used the service. Managers sought feedback from families to help hold the service to account and improve.
- All staff were committed to continually learning and improving services. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation.

Detailed findings from this inspection

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Hospice services for children	Good	Good	Outstanding	Outstanding	Outstanding	Outstanding
Overall	Good	Good	Outstanding	Outstanding	Outstanding	Outstanding

Outstanding

Hospice services for children

Safe	Good
Effective	Good
Caring	Outstanding
Responsive	Outstanding
Well-led	Outstanding

Are hospice services for children safe?

Good

Our rating of safe went down. However, this was because the Care Quality Commission's inspection's methodology changed following the previous inspection in 2015. It was not a reflection that the care deteriorated. We rated it as **good.**

Mandatory training

The service provided mandatory training in key skills to all staff and made sure everyone completed it.

The administrative team monitored mandatory training rates and reminded staff when their training was due for renewal.

Staff received training required for their role; the service aimed for between 85 and 90% compliance, dependent upon module. For 2018/2019 completion rates were 94% for moving and handling, 98% for basic life support and anaphylaxis and 98% for infection prevention and control.

Mandatory training included infection control, resuscitation, data security and equality and diversity. Staff also received training in spotting the sick child. All compliance rates met the service target.

The service arranged new training for 2018-19 in psychological support for the rapid response team.

The service arranged one day per month for staff to keep up to date, for example with electronic learning.

Safeguarding

Staff understood how to protect patients from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse, and they knew how to apply it.

There were comprehensive systems to keep people safe. All staff were trained in safeguarding children level two or three dependent upon role, and senior staff were trained up to level four. The registered manager was the safeguarding lead. Training included the recognition of female genital mutilation and Prevent (training about safeguarding and supporting those vulnerable to radicalisation).

The safeguarding systems were externally audited every year and we saw the report for 2018-2019. The report stated Claire House had strong safeguarding arrangements and showed a commitment to staff training and responsibilities. The audit did not highlight any areas for improvement.

Managers attended external safeguarding conferences arranged by the clinical commissioning group to discuss safeguarding incidents and share best practice. Learning was shared, and staff received safeguarding supervision.

The service had a clear safeguarding policy and process which staff were aware of and knew how to access.

Staff knew when to raise safeguarding alerts with local authorities and described having good working relationships with social workers and other agencies.

Compliance rates for safeguarding training:

Safeguarding children level one: 94%

Safeguarding children level two: 93%

Hospice services for children

Safeguarding children level three: 100%

Safeguarding adults' level one: 97%

Safeguarding adults' level two: 100%.

We checked staff personnel records and saw the recruitment process included Disclosure and Barring Service (DBS) checks.

Cleanliness, infection control and hygiene

The service controlled infection risk well. Staff used equipment and control measures to protect patients, themselves and others from infection. They kept equipment and the premises visibly clean.

The hospice was visibly clean and clutter free. There were clear systems to make sure each bedroom and communal area were cleaned regularly. Housekeeping staff used a checklist to monitor wear and tear of items such as mattresses and cushions and systems were in place to replace when needed. We looked at checklists for the previous four weeks and saw that all had been completed.

The service had an infection control lead who delivered training to staff and completed audits, such as hand hygiene and environmental. The service audited hand hygiene and in June 2019 achieved 98% compliance.

All rooms and items were cleaned after the respite period. Maintenance staff followed a schedule to complete a deep clean of rooms, using a decontamination system.

The service had 'clean' and 'dirty' areas to manage soiled items and laundry. There were designated bins for waste and we saw sharps bins were locked away and not over full. Cleaning products were stored in line with regulations.

All bedrooms and areas had personal protective equipment available for staff to use, and there was a sink in all bedrooms for staff to wash their hands. Water used to clean any spillages was disposed of in the sluice area.

Before children and young people visited the unit, staff contacted families and GPs to check whether the child or young person currently or previously had an infection such as Methicillin-resistant Staphylococcus aureus (MRSA) or Clostridium difficile.

The infection prevention and control annual report reflected no outbreaks of infection between April 2018 and March 2019.

New staff received infection control training as part of their induction.

Environment and equipment

The design, maintenance and use of facilities, premises and equipment kept people safe. Staff were trained to use them.

The service completed environment audits and we looked at the June 2019 audit. This showed that all areas were inspected, and actions taken to address any issues, for example to replace a bin which had a failed closing mechanism.

We checked electrical items and found the services were in date and had received electrical safety testing.

Resuscitation equipment was in date and staff completed weekly checklists to ensure items were available and in date.

Oxygen tanks were secured.

Areas for children and young people had ample room for equipment such as wheelchairs and breathing equipment. Bedrooms were spacious, and all bedrooms had ceiling track hoists.

Assessing and responding to patient risk

There was a proactive approach to anticipating and managing risk and this was embedded across all staff levels. Staff identified and quickly acted upon patients at risk of deterioration.

Staff took a detailed medical and social history for children and young people before they came to the hospice. This included speaking to families and carers, and other health professionals involved in care. Comprehensive risk assessments and care plans were completed, including breathing, moving and handling, feeding regime and medicines. These were reviewed for every respite episode or following a change.

Families stayed at the service with their child during the first admission to provide a thorough handover to staff. This meant there was a clear crossover of information about their child including health, medicines, routine and preferences.

Learning disability nurses undertook behaviour support plans and disability distress assessments. Staff spent time getting to know children and young people and their preferences, and anything that caused anxiety. Staff could minimise any issues and used least restrictive techniques to help reduce distress or anxiety.

Staff undertook handovers at the bedside. Key information was discussed alongside information about the past 24 hours.

Staff received training about how to spot an ill child. Staff were aware that some of the common signs of illness did not always apply to the children and young people they cared for. Staff had good knowledge about what was 'normal' for an individual child or young person so could easily recognise any change or deterioration.

The service had good links with the local GP service and all children were registered when they visited for respite. Staff knew to dial 999 for any medical emergency.

All risk assessments were completed alongside the child, their family and relevant health professionals.

Staffing

The service had enough staff with the right qualifications, skills, training and experience to keep patients safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix, and gave bank, agency and locum staff a full induction.

The service was nurse-led and there were qualified nurses on each shift, supported by team co-coordinators. There was a nurse on-call over a 24-hour period.

The service organised respite in six months blocks which meant managers could allocate staffing levels with the right skill mix.

The service did not use agency staff and used their own bank which consisted of staff that previously worked at Claire House and student nurses.

There was a service level agreement for a palliative care consultant, provided by the local NHS foundation trust.

There was an agreement in place with the local GP practice and a named GP from the practice provided daily cover. The service had an agreement with the GP out of hours service to provide cover for nights, weekends and bank holidays.

Records

Staff kept detailed records of patients' care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.

The service recently began using an electronic system for patient records. The first page had a photograph of the child or young person. There was a section to clearly flag needs of a child. For example, the box turned red if there were safeguarding concerns.

The system had sections to record all the needs and care plans for children and young people which staff downloaded onto their handheld electronic devices. All staff had personal log in details with different levels of access to the electronic system dependent upon role.

We checked 10 patient records and the electronic system clearly showed the lead professionals involved in care, and daily communication logs. The logs reflected multidisciplinary team involvement; occupational therapists and physiotherapists could save therapy goals and plans directly into the log which we saw.

The care plans included a wide range of information including past medical history and social needs. Staff recorded information about the needs of the wider family including siblings.

The service kept a log of communication with families and carers and we saw evidence of communication with the child or young person's GP and other medical professionals.

We saw evidence of transition planning and staff recorded behaviour support plans and health passports. The passports included information about the child or young person's preferences and how they would like staff to care for them.

Medicines

The service used systems and processes to safely prescribe, administer, record and store medicines.

There was a medicine management policy in place and a service level agreement (SLA) with the local pharmacy. The SLA included direct support from two pharmacists. The pharmacists were specialists in paediatric/neonatal medicine and palliative care. The pharmacists attended the pharmacy meetings to review medicine incidents, provide pharmacy supervision and attended the clinical governance meetings.

The pharmacists reviewed individual symptom management plans for palliative and end of life care.

The SLA also covered:

- supply of medicines
- stock top up
- drug procurement, receipt, storage and recall
- supply of controlled drugs
- supply of emergency boxes
- service management information
- out of hours or on-call service
- education and training.

The service had seven non-medical prescribers and two student non-medical prescribers. Staff received in-house prescribing supervision every six weeks from the palliative care consultant.

We saw that staff followed policy for medicine reconciliation. Staff contacted the child or young person's own GP for up to date information. Nursing staff contacted family prior to respite to check the medicines chart and identify any 'stops, starts or changes'. Staff encouraged families to bring new, unopened medicine bottles where possible. Once medicines were reconciled the non-medical prescriber could review charts.

The service completed medicine audits including prescribing, controlled drugs check, and fridge temperature audits.

The director of clinical services was the controlled drugs accountable officer and completed the quarterly controlled drugs audits. Controlled drugs were prescribed by the non-medical prescriber using their own prescription pad and were dispensed by the local community pharmacy.

We checked 10 medicines records. Each record had a photograph of the child or young person, and all were signed and dated. All records showed whether the child or young person had any allergies and whether antibiotics were prescribed as per guidelines.

The age and weight was recorded, and prescriptions were appropriate to weight where required in all 10 records checked.

We saw that 'as required' medicines were written on the other side of the same prescription chart, clearly marked for as required. We observed the pharmacy staff meeting and found the pharmacist noted this and recommended changes.

Medicines were stored in a locked room which was accessible via a key card for specific staff. Medicines were stored in a locked cupboard or fridge in this room.

Incidents

The service managed patient safety incidents well. Staff recognised and reported incidents and near misses. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave patients honest information and suitable support.

We reviewed the service serious incident reporting policy with was in date and contained the necessary information and references.

The service recently started using online 'care improvement forms' to record incidents and staff told us the system worked well.

The service monitored clinical incidents and rated the level of harm accordingly. These incidents were recorded in the clinical governance report with recommendations and changes described.

Staff involved families and provided feedback about any changes or improvements made following an incident.

The service reported three serious incidents in the past year and identified changes as a result. These included increasing training opportunities for non-invasive ventilation, and provision of two respiratory training days.

Hospice services for children

Staff knew how to report incidents and were informed of any changes made. Staff noted changes made to handovers as an example, and felt handovers were more efficient and child focussed.

Safety Thermometer (or equivalent)

The service used monitoring results well to improve safety.

The service monitored information via their incident reporting system. For example, falls were recorded as incidents and managers analysed themes regarding any clinical incidents.

The service did not monitor infection rates as children and young people only stayed at the hospice for a few days.

Are hospice services for children effective?

(for example, treatment is effective)

Good

Our rating of effective stayed the same. We rated it as **good.**

Evidence-based care and treatment

The service provided care and treatment based on national guidance and evidence-based practice. Staff protected the rights of patients in their care.

The service followed National Institute for Clinical Excellence (NICE) guidelines. For example, 'end of life care for infants, children and young people with life-limiting conditions: planning and management' (NICE clinical guideline NG61). The service looked at whether they were compliant with all aspects of the guidance. This included being alert for signs or situations that the child, young person or carers needed more information.

The service used tools to look at whether they needed to make improvements in line with guidance.

Staff arranged different groups for children and young people, for example 'wind down Wednesday' and 'fizzy Thursday' which provided physiotherapy and occupational therapy. Therapy was incorporated into play therapy, for example using soft play to increase a child's range of movement.

The service noted an increase in referrals for children experiencing cardiac conditions and the therapists worked as a team to improve children's fine motor skills during play therapy.

The service had a hydrotherapy pool. Staff used this to provide physiotherapy and splash sessions.

Nutrition and hydration

Staff gave patients enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for patients' religious, cultural and other needs.

Staff took detailed information about the nutrition and hydration needs of children and young people before the respite stay. This was always reviewed before every respite stay and following a change in health.

The needs of children or young people that had feeding regimes were clearly recorded and staff had good knowledge. The care plans included information about specialist equipment, likes and dislikes and whether the child used the dining room.

The chef took account of the child or young person's preferences and prepared meals accordingly.

Pain relief

Staff assessed and monitored patients regularly to see if they were in pain and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.

Staff assessed pain levels and used recognised pain scales for children that did not communicate verbally. Staff involved the parents and all care plans to treat pain were individualised in line with National Institute for Clinical Excellence guidance.

The process for admissions, and involvement with families and carers meant that staff had excellent

baseline knowledge of children and young people. Staff could easily recognise a change in the child's non-verbal behaviour which may indicate they were experiencing pain.

Staff could describe non-verbal cues they used, for example facial expressions or movements.

Staff used the same pain scales that were used at home or at school to maintain continuity and help the child feel comfortable.

We saw evidence that staff took account of pain in all of the 10 records checked.

Patient outcomes

Staff monitored the effectiveness of care and treatment. They used the findings to make improvements and achieved good outcomes for patients.

The service participated in several external audits including safeguarding and education environmental audit. The education environmental audit looked at measures such as whether the service had comprehensive induction programmes and multidisciplinary opportunities for staff.

The service established a comprehensive internal audit programme through their 'audit planning memorandum' and focussed on their agreed main risk such as income generation.

The service collected information about the types of referrals made and what services were offered to children and young people. The service monitored this information to adapt to the changing needs of the local community and continually improve their offer.

The service was included in the NHS England controlled drugs accountable officer report which highlighted Claire House had systems in place to effectively identify concerns related to controlled drugs, mitigate concerns, and communicate intelligence and learning.

Managers were part of the child death overview panel and the panel noted that involvement in this had been hugely beneficial.

Therapy staff set goals for example around eating and drinking and improving trunk control to support. Therapists recorded goals in the electronic record which we saw evidence of.

Competent staff

The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.

New staff completed a comprehensive induction and were enrolled onto the training programme. New staff were required to complete competency booklets which included modules relevant for the role, for example management of tracheostomies.

New staff were supernumerary for the first two or three weeks which could be flexible.

Staff received supervision every six to eight weeks and an annual appraisal which we saw were up to date.

Senior staff arranged regular training sessions for staff to refresh knowledge and skills. For example, there was a rolling bi monthly programme of training in infection prevention control awareness including a hand hygiene practical.

Training was delivered during team days with different themes. For example, the last session focussed on sepsis group discussion and the NHS educational video was shown. Staff could practice the capillary refill technique.

Staff could access higher education at local universities. Training included advanced paediatric clinical assessment skills degree module, and palliative and end of life care for children and young people degree module.

Managers ensured staff could access relevant external training including Makaton, counselling and 'transforming loss'.

Multidisciplinary working

The staff and wider team were committed to working collaboratively, providing efficient ways to deliver joined up care.

Hospice services for children

Prior to planned respite staff communicated with external health professionals to gain knowledge about complex care needs to ensure safety and continuity. Every child was allocated their own key worker.

We saw there was a holistic approach to all aspects of a child or young person's care, whether this was on-going, transition or discharge.

The service benefitted from a range of specialist teams and roles including a counselling team, complementary therapy team, transitions team, learning disability nurses, occupational therapists, physiotherapists and play therapy. We saw excellent working between all levels to reach a common goal for the child. The service had regular team meetings to discuss the needs of the children and young people.

Staff worked with other professionals involved in the child or young person's life. For example, schools, community therapy teams and social workers.

The physiotherapy team spent time developing links with the community to highlight the work done at the hospice and also provide continuity and consistency.

Staff worked with adult hospices to effectively plan a young person's transition and to share broader good practice.

Health promotion

Staff consistently supported children, young people and their families to live healthier lives, including identifying those who need extra support.

Staff ensured that all aspects of health and wellbeing of children was managed during their respite, for example helping children keep up to date with vaccination programmes.

The service had several ways to identify and meet the emotional needs of wider family members, for example counselling. The service arranged different activities for users of the service and we saw that staff could use informal settings to get to know family members better and identify any extra needs around wellbeing.

There was a 'dad's footy' support group every month which promoted both physical and mental wellbeing.

Staff could access different resources and could make referrals to child and adolescent mental health services if required.

We found several leaflets about other support groups and clubs available in the local community.

Consent and Mental Capacity Act and Deprivation of Liberty Safeguards

Staff supported patients to make informed decisions about their care and treatment. They followed national guidance to gain patients' consent. They knew how to support patients who lacked capacity to make their own decisions or were experiencing mental ill health. They used agreed personalised measures that limit patients' liberty.

Staff received training around the Mental Capacity Act and Deprivation of Liberty Safeguards, and compliance was above the service target of 90%.

Staff could describe the principles of the Mental Capacity Act and felt confident in completing assessments. Staff knew this applied to children over the age of 16.

There was a process in place for identifying children that may lack capacity and were deprived of their liberty during respite. The transitions co-ordinator completed mental capacity assessments and best interests' decisions. These were submitted to the local authority for the deprivation of liberty to be authorised. We looked at three records during the inspection and saw that paperwork was comprehensive and took account of all the restrictions including a rationale. There was evidence this was done in conjunction with the young person, their family and relevant professionals.

We found risk assessments for the use of bed rails and this was included in the deprivation of liberty safeguards paperwork.

Staff sought consent of children and young people for all caring interactions and therapy.

We saw evidence of resuscitation status of children in records. Staff told us this was usually completed by health professionals external to the hospice.

Staff could manage situations where families disagreed about how to care for a child or young person. Staff consulted family members individually and put together

plans to compromise. Staff had been involved in situations previously and could work with all parties to reach a compromise. Staff felt it was important that all family members were involved and that their wishes and views were respected.

Staff established who had parental responsibility for a child at the point of referral. The service had effective relationships with the local authority. Staff described providing the same level of support to foster carers as they would for any family, and all decisions were made with the involvement of the local authority for any child that was a 'looked after child'.

Are hospice services for children caring?

Outstanding ☆

Our rating of caring stayed the same. We rated it as **outstanding.**

Compassionate care

Children, young people and their families were valued as individuals, and empowered as partners in their care. There was a culture of inclusivity and staff made sure all care was tailored to the individual.

Staff gave examples which demonstrated they had consistently gone the extra mile to understand and meet the needs of children and young people, and their family.

Staff in the butterfly rooms made sure rooms had items that were important to the child and family. For example, the service purchased bedding in the same theme children liked and arranged for items such as specific flowers the child preferred.

Staff found innovative ways to meet the needs of children. For example, a child wanted to visit the local aquarium however their needs restricted this. Staff were able to use technology to provide an interactive light show which mirrored an aquarium.

We saw an example of a child who was very scared about a regular procedure. Staff found ways to learn about and find the best way to complete. The service was able to provide reassurance and child continued to have the procedure completed at the hospice. The time taken reduced from four hours to 20 minutes and the child felt confident.

Staff could provide counselling for children who were at the end of their life and provided support to the whole family both emotionally and practically. For example, we saw that staff went out of their way to make sure a child could stay at home at the end of their life. Staff worked extra hours and liaised with different agencies to make sure the correct equipment such as a bed and hoist were in place within a day, as staff realised how important this was to the child and their family.

Play therapists noticed the needs of siblings and could arrange activities in a timely manner. For example, a birthday party was arranged within a day for a sibling, and we saw that interactions with children and their families was very caring and child friendly. We found that this helped parents cope with very difficult situations.

The service had distinct areas for different age groups of children. Young people could access dedicated areas which had a substantial amount of age appropriate items and technology available. Young children could also access rooms which had a wealth of toys, games and crafts available.

Parents we spoke with consistently spoke highly of the service and that the needs of the whole family were considered as part of the overall care.

The service could take account of cultural and religious needs for example access to chaplaincy services.

Emotional support

Feedback about the service was continually positive. Staff went the extra mile and the care and support exceeded expectation. There was a clear person-centred culture. We found that staff were highly motivated to offer care. Relationships between staff and those that used the service were respectful and supportive, and highly valued.

Staff understood that emotional needs of children and their families were as important as physical needs.

Hospice services for children

Parents commented they had complete confidence in the service and without this they would feel unable to leave their child in their care. Parents told us they valued relationships they built with staff, and many stayed in contact after their child passed away.

The service had a number of ways to support children, young people and their families' emotional needs.

The counselling team could support the child and all different members of the family including grandparents. The team organised different support groups, for example for bereaved parents. They completed both one-to-one counselling and group work. Staff adapted to fit in around parents' schedules. For example, staff visited a parent at 7am who worked long shifts. Staff could see children at school or at home.

Children and families who were facing bereavement or who had been bereaved were supported by the counsellors and other staff at the hospice. Families could use the butterfly suite and were supported by counsellors and staff during this time.

Staff arranged memory days for families for which the service received positive feedback. This meant families could contact other families and provide support to each other.

Staff tried hard to help families make memories with their child. For example, they took photographs and put together booklets and cards.

Staff went the extra mile for families of children who were near the end of their life. For example, staff would change their shifts and co-ordination of activities to make sure that children and young people could access activities such as using the splash pool with their families.

Users of the service could access complementary therapy.

Staff organised sibling events, including trips to the zoo.

Staff recognised their own limitations to providing emotional support and could make referrals to external agencies for example community mental health teams.

Understanding and involvement of patients and those close to them

Staff were committed to working in partnership with people. Staff empowered people who used the service to have a voice. Children, young people and their families' individual preferences and needs were always reflected in how care was delivered.

Staff had different ways to involve children of different age groups in planning their care. For example, we saw a child friendly 'contract' that had been put together with the child, their family and staff to describe their preferences for treatment, which everyone signed. The contract had pictures and clear descriptions with a treat listed at the end.

Staff used 'passports' to record children's wishes in a child friendly way. This was a holistic booklet which recorded the child's preferences in all aspects of their life. There were clear and age appropriate descriptions about what to expect, to help children understand complicated and worrying procedures. Staff used the booklets during care.

Staff established a 'counselling agreement' completed with both children and family members. This clearly described what would happen during counselling to help people understand what to expect and how they would be kept safe.

There was also a 'parental agreement' which clearly explained what was being provided for the child or young person and what to expect from counselling or therapy.

We spoke to parents of the service who were very positive. Parents said using the service was the best decision they ever made. Parents valued the support offered to siblings and said staff met the needs of siblings of different ages and requirements.

Parents told us staff worked hard to build up trust and described Claire House as being the only place they would allow complex procedures to be undertaken.

One parent described that staff were very supportive and 'in touch' with the needs of the whole family.

Another parent told us that communication was excellent and that 'nothing gets missed'.

Are hospice services for children responsive to people's needs?

Hospice services for children

(for example, to feedback?)

Outstanding ☆

Our rating of responsive stayed the same. We rated it as **outstanding.**

Service delivery to meet the needs of local people

Meeting the needs of local people was central to the delivery of tailored services. The service provided person-centred pathways of care for children and young people with multiple and complex needs and involved other service providers.

Staff forged innovative approaches to provide person centre pathways of care, involving other service providers.

For example, the service experienced an increase in referrals for perinatal support. In response they developed an integrated perinatal and bereavement pathway and based the palliative care team at the local women's hospital.

Staff were involved in the development of the local neonatal and foetal medicines unit to aid referrals and reach more children and families.

The service identified gaps in adult palliative care provision and in response the transitions lead developed pathways between Claire House and the local adult hospice, improving the experience of young people and ensuring continuity of care.

There was partnership working with the local children's hospital. Staff from the rapid response team were present at the high dependency unit and paediatric intensive care unit every week. This aided the successful transfer of six patients to Claire House for compassionate withdrawal of ventilation, with plans to continue.

Claire House was a partner in the Merseyside and Cheshire Children's Palliative Care network, with the ambition eventually to be the hub for the Managed Clinical Network for Children's Palliative Care for Merseyside and Cheshire.

The service effectively planned for and managed their residential respite capacity. The service recognised the need for emergency respite and put plans in place to meet this.

The service widened the type of services they offered, including family support and counselling, rapid response and complementary therapies.

The service had a range of facilities for families. This included a large playground area outside for children and their siblings. The service had different types of accommodation available and families could use the amenities within Claire House to help feel at ease.

Staff could use the translation service when needed, especially for handover with parents.

Staff involved families in the design and running of the service, for example regarding staff uniform.

Meeting people's individual needs

There was a proactive approach to understanding the needs of the children, young people and families that used the service. The service recognised the different and complex needs of users of their services and strove to meet in different ways.

Through engaging with young people, staff realised the respite offer did not always suit the needs of older children and teenagers. They worked with this group to design a better service. This included providing an 'adolescent weekend' so young people could access the hospice at the same time and use the online gaming facilities together. Children that did not want to stay overnight could access during the day only.

The service continued to offer emergency respite where needed.

The building was designed with different age groups in mind. All bedrooms had access to the garden, and children and young people could use the multi-sensory room, art room and jacuzzi. There was a separate area with a bar, sound system and gaming consoles for teenagers and young adults.

Staff could easily adapt the service to be as flexible as possible during difficult times. Staff had different ways to meet needs for children at the end of their lives. This included providing hydrotherapy and practical support.

Hospice services for children

Staff provided a holistic service to families of children who were near the end of their life and after their death. Families could stay in the butterfly rooms which had facilities for all members of the family. Staff provided high quality emotional support during these times.

Staff organised different types of support groups for family members including parent groups, friendship groups and grandparents' groups.

Staff produced a calendar of events for the forthcoming year including social groups and parties so that children and families could plan around these.

Staff organised a wide range of events and activities to meet the needs of different groups and ages. For example, the service organised memory events and sibling events. We saw an event plan which included visits to an ice disco, mad science and the party bus.

The service made links with local organisations to jointly arrange events and activities for siblings, for example woodland camps and Halloween parties.

There was an integrated therapies team consisting of physiotherapists, occupational therapists, and play therapists.

There was a complementary therapy team and a dedicated staff member providing music therapy both in groups and one to one.

Staff had access to different types of communication aids.

Access and flow

Children, young people and their families could access the service in a way and time that suited them.

The Claire House rapid response team could spend time in other acute services. This raised awareness for clinicians and helped reach families who required services at an early stage. Staff noticed an increase in referrals when this was implemented.

The service had a clear eligibility criterion although could adapt this at times for urgent or complicated situations.

Children and young people were classed as between 0 and 18, and the service accepted end of life care referrals up to age of 23. The service accepted referrals from any family member, and health and social care professionals.

Two staff completed the initial assessment and referrals were discussed at the referral panel. The panel included the GP, consultant, nursing and therapy staff. The service used a scoring system and discussed what options would be most beneficial to families, for example respite or day care.

The team monitored the referral to ensure the offer continued to be the right one and best suited the needs of the child or young person and their family.

The service had an administrator for the in-house and day care bookings, and families contacted the administrator directly. The administrator worked closely with the teams to ensure key staff were available. There was no waiting list for respite and day care.

The service also offered more specialised care such as rapid response, family therapy, counselling and play therapy. There was a small waiting list for counselling, however, the service could offer alternatives such as complementary therapy.

Referrals for these services could be made rapidly; updates were provided at the next referrals panel.

Staff worked hard to put things in place quickly to support children and young people who were discharged home; for example, assessing environments for hoists and assigning staff with the right skills.

Learning from complaints and concerns

It was easy for people to give feedback and raise concerns about care received. The service treated concerns and complaints seriously, investigated them and shared lessons learned with all staff. The service included patients in the investigation of their complaint.

The service had a child friendly complaints process. There were compliments and complaints forms with pictures and age appropriate questions. There were also child friendly feedback forms for both the respite stay and activities.

The service learned from complaints and made changes, for example improvements to care plans and establishing reflective practice sessions. Changes were captured via care improvement debriefs with staff and the clinical governance report.

Hospice services for children

Children and families we spoke with were aware of how to make a complaint.

We saw the complaints policy and looked at three complaints during the inspection. Staff responded to all three complaints in a timely way in line with the policy and apologised. The response showed that complaints were taken seriously, fully investigated with an explanation.

The service maintained a log of complaints, recommended actions and lessons learned.

Are hospice services for children well-led?

Outstanding ☆

Our rating of well-led stayed the same. We rated it as **outstanding.**

Leadership

There was compassionate, inclusive and effective leadership at all levels. Leaders had high levels of experience, capacity and capability needed to deliver excellent and sustainable care.

There was an embedded system of leadership development and succession planning. The service had a trustee succession policy where trustees would rotate on and off the board in a planned manner. The board completed a skills audit to assist recruitment of the next trustee. Succession planning was also in place for the senior leadership team and leaders were encouraged to develop and broaden skills.

Successful leadership strategies were in place to ensure and sustain delivery. Managers led by example and the positive culture was developed and maintained by the senior leadership team.

There were leadership programmes in place; staff received training to be a supervisor and facilitate group or individual sessions. New staff could access an external leadership and development programme through the Chartered Society of Physiotherapy.

Assistant practitioners and health care support workers were encouraged to commence the higher apprenticeship programme paid for by the service.

Trustees and the board met regularly, and staff knew lines of accountability. Relationships between different levels of staff were effective. Senior managers were based at the hospice and had an open-door policy which we saw during the inspection.

Senior managers were visible and approachable which staff commented on during the inspection; staff spoke highly of their managers.

Managers were aware of the challenges to sustainability and had clear sight on issues around finance and risk.

Vision and strategy

The strategy and objectives were challenging and innovative, while remaining achievable. Strategies and plan were aligned with the wider health economy and leaders demonstrated commitment to system-wide collaboration and leadership. Plans were consistently implemented and had a positive impact on quality and sustainability of services.

The service developed a clear vision and strategy, reflected in their 'Claire House Children's Hospice Care Services Strategic Priorities for 2019-20 – Staying Safe'. The service considered their current position and service priorities when planning how to deliver. They also considered what outcome measures would assess performance.

Managers described their vision as 'to reach out to every dying child, and their families, making sure they can get the very best support when and where they need it'.

The service set out how to achieve this via their 'Vison for Care'. The service recognised there were many children and families they did not reach due to increased demand and service capacity. Alongside structural changes already made within Claire House, the service planned to create a state-of-the-art hospice in their neighbouring city. They wanted care to be responsive and dynamic to meet the changing and complex needs of children and young people, as well increasing capacity to meet rising demand.

Claire House described their ambition to be the central hub for children's palliative care services for Merseyside and Cheshire, with a key role for service delivery and development, innovation, research, education and training.

Although space to build had been secured, managers decided to put building on hold until they were satisfied they could continue to provide an effective service in the meantime. Staff were fully embedded in the vision for Claire House with managers including all levels of staff in discussions and decision making.

Culture

Leaders had an inspiring shared purpose and motivated staff to succeed. There were high levels of satisfaction across all staff.

All staff we talked to spoke highly of the organisation and in particular the culture. Staff said they were proud to be part of the team and showed dedication to their work.

The service adopted a value and attitudes-based recruitment process, moving the focus away from purely clinical knowledge and skill. Managers and staff told us this hugely benefitted the culture of the team and therefore delivery of the service.

The caseload of staff included working in complex and emotionally challenging situations. Staff commented they received training and support to equip them with the necessary skills. Staff were positive in their role and spoke of high job satisfaction.

Many staff we spoke with had worked for the service for several years.

The service had a lone working policy. Risk assessments were completed for staff working in the community, and they had electronic devices to raise the alert if they felt at risk.

The company cars had satellite navigation systems in place and we saw that insurance, vehicle safety checks (MOT) and tax were up to date.

Staff were aware of the whistleblowing policy and knew who their freedom to speak up guardian was. Staff were aware of their responsibilities to Duty of Candour. This is a duty placed on providers of healthcare to be open and honest about when things go wrong in their care.

The health and wellbeing of staff was promoted in various ways. Staff were offered free external counselling to help manage difficult and emotional times. Staff were also offered the flu vaccine free of charge.

Governance, Risk Management and Quality Management

Leaders operated effective governance processes throughout the service. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.

Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact. They had plans to cope with unexpected events. Staff contributed to decision-making to help avoid financial pressures compromising the quality of care.

Close working meant that managers were assured about the quality of information, and themes and issues were presented at governance meetings. Leads for issues such as infection prevention control and medicines were responsible for completing end of year reports and audits which fed into the governance meetings.

End of year reports looked at incidents and reviewed and rated risks. Senior managers were aware of their top risks, for example funding streams and staffing, which echoed staff concerns.

The service had a clinical risk register and a corporate risk register. Risks identified included reputational risk caused by high profile cases and increased demand to the service. Risks were rated, with measures to alleviate and actions taken documented. The risk register also took account of any financial impact.

One funding stream was via the clinical commissioning group (CCG). The CCG supported governance through regular contract monitoring and reviews.

The service participated in external audits, for example safeguarding to ensure they were meeting their responsibilities effectively.

The service had an emergency plan for adverse or unplanned events and major incidents, a copy of which was held off site.

Managers monitored performance of both staff and the service. Leads could describe how they would deal with poor performance effectively and worked alongside personnel staff to ensure policies and procedures were followed.

Managing information

The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements. The information systems were integrated and secure. Data or notifications were consistently submitted to external organisations as required.

The service had a senior information risk owner who had responsibility for data security. The information governance assessment showed there were clear data security and protection policies in place, which were fully understood by staff.

The service commenced their 'care database' in December 2018 to capture and review all service activity for the following six to nine months.

This included information about referrals, for example by age group and reason for referral, and the increase in demand for their service.

Data collected showed a 155% increase in referrals over the past five years, with the majority of referrals in age zero to four. Information was analysed and presented in the end of year report to assist planning for future capacity and demand.

The service used 'SharePoint' so that staff could access the correct and most recent information electronically, including policies and procedures.

All staff were provided with handheld electronic devices. Staff could access emails, documents, policies and care plans. Staff used these to input care notes in real time.

Managers submitted notifications to external organisations such as the local authority, clinical commissioning groups and Care Quality Commission as required.

Engagement

There was consistently high levels of engagement with staff and the people that used the service. Managers sought feedback from families to help hold the service to account and improve.

The service had established different ways to engage with children and their families. For example, we saw their parents' newsletter which contained clear and useful information including photographs of staff and their role.

The service had their own page on several social networking sites to update parents about changes and receive feedback. Parents used the pages to stay in touch with both the service and each other. Parents helped other parents know what to expect when their child used Claire House.

Families were encouraged to complete surveys, for example about staff uniform. We saw that changes were planned following feedback.

Families were encouraged to fill in evaluation forms following events. We saw positive feedback about the memory days and how much parents valued these.

The service had a webpage with all the information families needed to know, and there were leaflets and books available detailing what to expect.

There were booklets developed by families and staff which described individual stories, to help other families understand.

The service used a messaging application to communicate with families and carers.

The service had different ways to engage with their staff including surveys, questionnaires and regular one to ones.

Staff told us they felt listened to and valued and had regular team days; staff felt things improved all the time.

The service organised a staff conference every two to three years. These days helped staff to understand how their role contributed to the overall service.

Staff were recognised for good practice in various ways. Staff were nominated for 'healthcare professional' at the Butterfly Awards.

Hospice services for children

The service organised annual events for both staff and families at a local hotel for which they received positive feedback. Families commented on how they were able to make links with different services and other families who were facing similar situations.

Learning, continuous improvement and innovation

All staff were committed to continually learning and improving services. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation and participation in research.

The service was proactive in developing links with local trusts and other services to improve the quality of care and pathways between services. For example, the rapid response team were based at the local children's hospital and women's hospital to link in with children and families who may need the service.

Through research, the service identified gaps in knowledge in adult services for childhood diseases and also a gap in the provision of care. The service initiated work to improve the transition between children and adult palliative care services. They developed a five year overlap of services to jointly manage care needs. This was achieved in several ways including joint clinics and appointments, parallel plans and case conferences. Staff felt this helped adult services understand children's conditions better and provided continuity and consistency.

The service had recognised a significant increase in demand for the butterfly suites. In response the service created a team of butterfly co-ordinators to manage the suite and referrals, allowing the rest of the team to continue to provide high level care.

The service won the Queens Award in 2018 for their volunteer services provided to children and young people.

Outstanding practice and areas for improvement

Outstanding practice

We found areas of outstanding practice during the inspection:

- There were two butterfly suites available for families to use. Families could stay with their child after they had died for up to a week; staff provided extensive emotional and practical support during this time.
- Claire House rapid response teams spent time at acute services to reach children, young people and their families who may benefit from the service at an early stage.
- The service thought proactively about how to meet the needs of children and young people and communicate effectively. For example, we saw a child friendly 'contract' which described the child's preferences for treatment, which everyone signed. The contract had pictures and clear descriptions with a treat listed at the end.
- Staff forged innovative approaches to provide person centre pathways of care, involving other service providers. For example, the service identified gaps in adult palliative care provisions and developed pathways with the local adult hospice, improving the experience of young people and ensuring continuity of care.
- There was compassionate, inclusive and effective leadership at all levels. Leaders had high levels of experience, capacity and capability needed to deliver excellent and sustainable care.
- The strategy and objectives were challenging and innovative, while remaining achievable. Strategies and plans were aligned with the wider health economy and leaders demonstrated commitment to system-wide collaboration and leadership. Plans were consistently implemented and had a positive impact on quality and sustainability of services.