

# CLAIRE HOUSE QUALITY ACCOUNT 2024-25





# WHO WE ARE

Claire House Children's Hospice helps seriously and terminally ill babies, children and young adults from before birth to the age of 25. With a team of trained professionals, Claire House offers a 24 hour, seven days a week service. We provide specialist nursing and end of life care, as well as emotional support.

# **CLAIRE HOUSE VALUES**

- TOGETHER WE ARE STRONGER We respect and trust each other to get the job done, remembering that we're all different; with different skills, personalities and experiences. We're not perfect but we work at our relationships. Amazing things happen when we pull together
- FUN We have a sense of fun even though we often do difficult work
- **KINDNESS** We care for each other we give each other time and we listen. We are there with a hug or a cuppa if that's what's needed. We are honest, but when we give and receive feedback we do so with a balance of courage and kindness
- PASSION, PRIDE AND POSITIVITY We believe passionately in the cause. We love our work. We look
  after ourselves in and outside of Claire House which means we are able to work with energy and
  positivity.



# **OUR MISSION FOR CARE**

To make a difference to the lives of children with life-limiting or life-threatening conditions, and their families, by:

- Striving to be a centre of excellence for children who need specialist respite and end of life care, and their families, enabling them to feel safe and supported in the place of their choice: at Claire House, in their own home, and through our family support work.
- Developing needs-led services. Giving the best care that our resources will allow, while also planning for the future.
- Striving for lasting partnerships, for example with our supporters, and with healthcare partners such as other charities and the NHS. Inspiring and developing our people.
- Being a local organisation people are proud to work and volunteer for.
- · Living the values of Claire House.

# **OUR STRATEGY AND 5 YEAR PLAN**

At Claire House we have always passionately pursued our vision that one day, every baby, child and young adult who is seriously or terminally ill, will receive the very best care and support, together with their family, wherever and whenever they need it.

We have an ambitious strategy covering 2024-29.



# STATEMENT ON THE QUALITY OF OUR CARE FROM THE CHIEF EXECUTIVE



I'm delighted to introduce the Claire House Children's Hospice Quality Account for 2024-25. Our annual Quality Account sets out how we deliver our vision of being there for every child with a life-limiting or lifethreatening condition and supporting their families.

This year, we have made significant strides in improving the quality of care and expanding our services.

Our quality improvement priorities for 2024-25 have shown substantial progress. The introduction of our new Quality and Governance team has strengthened our commitment to maintaining high standards and ensuring the best outcomes for our children and families. This team has worked tirelessly to implement new protocols and standards, which have already resulted in measurable improvements in the quality of care we provide. Our regular audits and feedback mechanisms have been instrumental in identifying areas for improvement and ensuring that we continuously evolve to meet the needs of those we serve.

We have successfully launched our Advanced Communication Skills courses for healthcare professionals, which have received excellent feedback and are undoubtedly enhancing the delivery of paediatric palliative care across our region. These courses have been designed to equip our staff and partners with the skills and confidence needed to handle sensitive conversations with both children and their families. The positive impact of these courses

has been reflected in the increased satisfaction rates reported by families who have benefited from our care. Our Perinatal Service continues to provide invaluable support to families navigating complex pregnancies, offering tailored antenatal classes, emotional support, and comprehensive care plans to ensure that every family receives the individualised support they need during this critical time.

The Rapid Response Team has been instrumental in bringing hospice services into the family home, ensuring that children can receive end-of-life care in their preferred setting. This 24/7 service, staffed by highly skilled palliative care specialists, has been a cornerstone of our care delivery. The team's ability to respond quickly to emergencies and provide continuous support has been a lifeline for many families, allowing them to create meaningful and memorable moments together in the comfort of their own home.

Our commitment to education and training remains strong, with over 250 hours of training delivered to in-house staff and community teams. This year, we have focused on embedding the Patient Safety Incident Response Framework (PSIRF) and continuing our robust audit cycle to monitor and improve quality performance. The PSIRF has been pivotal in helping us to understand and learn from incidents, ensuring that we take proactive measures to prevent them in the future. Our training programmes have been expanded to include not only clinical skills but also holistic approaches to care, ensuring that our staff are well-equipped to meet the diverse needs of the babies, children, young people and families we support.



We have also made significant progress in our sustainability efforts, aiming for a net zero carbon new build in Liverpool and implementing initiatives to reduce energy consumption and waste. Our commitment to sustainability is reflected in every aspect of our operations, from the materials we use in our buildings to the recycling programmes we have put in place. We are leading the way in creating a sustainable future for our hospice and the wider community.

Claire House is committed to continuous improvement, and we are proud of the dedication and resilience of our staff and volunteers. Their hard work and compassion ensures that we can provide the highest quality of care to those who need us. Our volunteers in particular play a crucial role in enhancing quality of life, whether it's through organising activities, providing companionship, or offering practical support to families. Their unwavering commitment and generosity are truly the backbone of our hospice.

Thank you for your ongoing support. Together, we are making a profound difference in the lives of children and families facing the most challenging of circumstances. We look forward to continuing this journey with you, ensuring that every child in our care has the opportunity to live life to the fullest, surrounded by love, care, and dignity.

David Pastor, CEO Claire House Children's Hospice

# WHAT OUR SERVICE USERS HAVE SAID ABOUT US

Claire House is such a valuable place for families at such a difficult time. Everything happened so fast, it was difficult and is still so hard to take in, but Claire House somehow takes a lot of that stress away and this is why we as a family will be forever grateful to everyone for their support.

Everyone has been amazing and we couldn't fault a single thing. This place is just gorgeous and we just feel so calm being here.

Thank you for being such a special group of selected individuals who offer impeccable standards of care. You couldn't work at such a beautiful place and not love the children you serve.

I could not have had better care and attention for my son. The staff involved with not just my son but also my family, went above and beyond to help us.

The support, love and care at Claire House has been amazing. The work that Claire House do is priceless for families and we will be forever grateful.

A massive thank you for all of the love and support you showed us whilst we stayed at the hospice. A very difficult time was made more bearable with your care, hugs and words of support.

# ASSURANCE FROM BOARD OF TRUSTEES



The Board of Trustees of Claire House Children's Hospice is pleased to present this Quality Account for 2024–25. We are proud to confirm that, to the best of our knowledge, the information contained within this report is accurate and a fair reflection of the quality of services provided.

This Quality Account demonstrates our continued commitment to delivering outstanding care to children, young people and their families. It reflects the dedication of our staff and volunteers, who consistently go above and beyond to ensure that every child receives compassionate, safe, and personalised support — whether at the hospice, in their home, or in hospital.

Throughout the year, we have seen significant developments across our services. The introduction of a dedicated Quality and Governance team has strengthened our clinical oversight and embedded a culture of continuous improvement. The implementation of the Patient Safety Incident Response Framework (PSIRF) and the expansion of our audit programme are key examples of how we are enhancing safety and learning across the organisation.

We are particularly proud of the growth in our Rapid Response and Perinatal services, which have enabled more families to access care in their preferred setting and receive tailored support during the most critical moments. Our commitment to education and training has also remained strong, with over 250 hours of training delivered and new initiatives such as the Advanced Communication Skills Training (ACST) and Gentle Birthing antenatal classes making a tangible impact.

The Board is also encouraged by the progress made in equality, diversity and inclusion, sustainability, and staff wellbeing. Initiatives such as the Bronze BAME accreditation journey, ESG Plan, and the introduction of Long Service Recognition Awards reflect our holistic approach to quality — one that values people, place, and purpose.

We would like to thank our staff, volunteers, partners, and supporters for their unwavering dedication. Their collective efforts ensure that Claire House remains a place of hope, dignity, and excellence for every family we serve.

Signed on behalf of the Board of Trustees,

Leila Williams

**Chair of the Board of Trustees Claire House Children's Hospice** 

Veila Williams

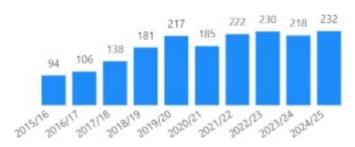
# OVERVIEW OF CLINICAL SERVICE CLAIRE HOUSE PROVIDES

The new referrals we receive are at the highest we have ever seen. On average we accept 85% of all new referrals.

#### **New Referrals**



#### **New Referrals over 10 Years**



We are proud to provide the following services.

## **RESPITE CARE**

Care breaks are an opportunity for parents and guardians to take a holiday or simply spend some time looking after their own needs, or those of other siblings, safe in the knowledge that their loved one is receiving the very best care.

## **PLANNED RESPITE**

Allocated every 6 months and all families receive the same planned offer. Families are welcome to request any special dates, but all dates and allocation are looked at fairly. The current allocation is 5 nights every 6 months.

## **EMERGENCY RESPITE**

Emergency respite is available to all children and families in the event of a family crisis, family illness or bereavement, parent or carer exhaustion, breakdown in care package, step-down or urgent symptom management.

## **PLANNED CARE**

Planned care services offer daycare as an alternative respite choice, daycare is allocated fairly every 6 months. This is offered either morning or afternoon and families can choose either Claire House Liverpool, Wirral or within the family home. Emergency daycare is available based on priority and availability. We also offer monthly stay and play group sessions for those families who are not ready to leave their child with anyone. These are informal sessions offering play, sensory and story time, enabling peer support, relationship building and an introduction to Claire House. The Planned Care Team offers sessions of respite care at home to respond to crises or emergencies that may arise. Such crises could be step down care from hospital following surgery or a period of illness; acute illness at home i.e. chest infection; social crisis; end of life care and other unplanned situations. During the respite session, activities will be planned around what we know the child or young person likes, such as sensory play, massage, storytelling or a trip out with our wheelchair accessible vehicle.

## SYMPTOM MANAGEMENT

Many of the children and young people accessing Claire House services may experience some difficult symptoms throughout their lives, whether that be pain, nausea, respiratory difficulties, seizures, or spasms, and will require assessment and management. The Rapid Response team is able to work in partnership with the child's consultant and other professionals involved to assess symptoms, implement any symptom management plans and review how effective they are.

## **STEP DOWN CARE**

Step down care (help leaving hospital) following prolonged hospital admission or major surgery can be arranged to support parents prior to going home. In addition to conventional medical and pharmacological approaches, with agreement from the child/young person's consultant, we can offer complementary therapies such as reflexology, aromatherapy, or reiki, to aid symptom management.

## **END OF LIFE CARE**

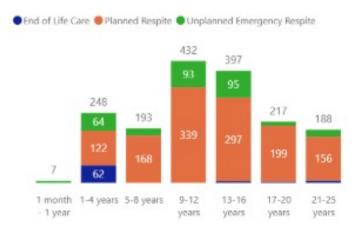
End of life care is always a priority for Claire House, and we will endeavour to respond to all referrals or requests for end of life care in the family's preferred care setting, whether that be at the hospice, home or hospital. Rapid Response Team will contact the child/young person's parents/guardians to establish where the family wish for the child's end of life care to be; hospice, home or hospital. If end of life care is to be provided in the hospice or home, the Rapid Response Team will assess, plan, coordinate and evaluate holistic and individualised end of life care. The team provide a 24-hour, 7 day a week on call service which is staffed by palliative care nurse specialists, and they offer around the clock complex symptom

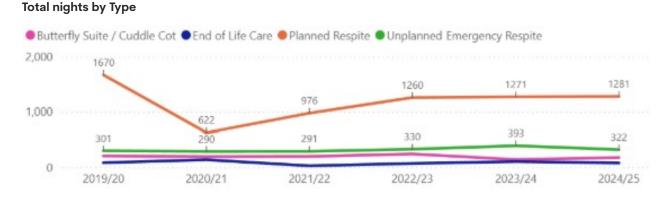
assessment and management, as well as emotional and practical support which can be via telephone or face to face. The specialist nurses are highly trained and have undertaken palliative care, advanced clinical skills, non-medical prescribing, and verification of death courses, which enhances the timely assessment and management of end-of-life care symptoms. We can arrange wishes and dreams on behalf of families and gather mementoes such as hand and footprints, perfect charms and professional photographs.

## **BUTTERFLY TEAM**

When a child or young person has died, the Butterfly Team is a dedicated bereavement team able to offer emotional and practical support to help families in the early days of bereavement. Families are given the choice of whether they wish their child to be transferred to the Butterfly Suites in the hospice, to remain at home with specialised cooling equipment, or transferred to funeral directors. The Butterfly Team will guide families through the time between death and the funeral, helping and supporting with registration, funeral planning and signposting to services that can help with other practical issues.

#### Total nights by Age and Type

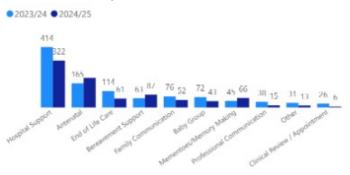




## PERINATAL CARE

The perinatal service provides support through pregnancy, birth, baby's life, and death, as well as post-bereavement support. The key aim of the service is to ensure parents at any stage are aware of the choices available to them and can access the full range of services provided by the perinatal team and wider Claire House teams, such as emotional support, birth planning, counselling, complementary therapies and tailored antenatal classes for their specific circumstances. The perinatal team will also support parallel planning for families facing the possible death of their child and enable earlier rapid transfer/discharge to the hospice or home for end-of-life care as needed.

**Perinatal Activity** 



## **BABY GROUP**

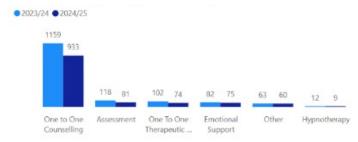
Once a fortnight we run a baby group, alternating between Claire House Wirral and Claire House Liverpool, for babies and their parents either known to the hospice via the perinatal team or referred for early support. The group provides a supportive environment for new parents of a baby with complex health needs, and offers peer support over a coffee and cake alongside play, sensory, music and complementary therapy activities. The group is led by trained healthcare professionals to help with any clinical care and therapeutic needs, as well as a source of information and advice with links to other hospice services if required.

## **GROUPS AND COUNSELLING**

Family support and 1:1 counselling is available from the point of referral and can continue through bereavement and beyond. Dedicated counsellors can offer support

and counselling to the whole family. Person-centred bereavement support is offered to all families who have experienced the death of their child. This can be on a 1:1 basis and/or as part of a group with other bereaved parents. Claire House now has a Clinical Psychologist who is able to support when more complex needs arise.

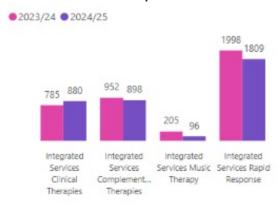
### Counselling Activity (F2F and phone)



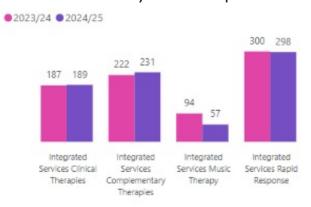
## **THERAPIES**

Children and young people have access to a range of therapies that include play, music, arts and craft as well as dedicated holistic therapies. We have a dedicated play team and a music therapist. A range of holistic therapies are provided for parents.

#### **Face to Face contacts by Service**



#### Face to Face contacts by Service - unique children



## HYDROTHERAPY AND PHYSIOTHERAPY

We have a dedicated physiotherapy team who support the provision of inpatient and outpatient hydrotherapy, as well as a range of physio support services, including respiratory support.

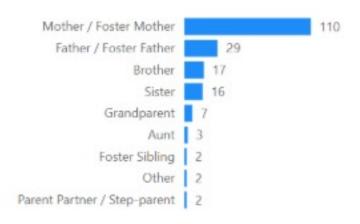
## DAY CARE

We offer daycare as another form of respite care, and monthly stay and play groups for children/families. We cater sessions to ensure person-centred care is provided, and tailor each session around the child/young person's needs. Many of our services and activities can be accessed as a planned day case. This includes hydrotherapy, complementary therapies, music and play therapies. Some of our young adults access the hospice for an immersive bath when not available to them at home.

## **SIBLINGS**

We give time and attention to siblings, and support for grandparents and the wider family through group and one-to-one counselling and dedicated activities and groups. Brothers and sisters are invited to join any of our planned activities, trips and residential breaks throughout the year, including a summer activity camp with other siblings, a night at the museum in Chester, a trip to the capital to see the dinosaurs at the London Museum, go-karting, Easter Egg Hunt and an overnight, outdoor Bushcraft event.

### Family member types supported



### TRANSITION

The move from children to adult services can be a complicated one. We have a dedicated Young Adult Coordinator, Andy, who works closely with young people and their families to provide additional advocacy and support during transition. They support and advise the Care Team on aspects of policy and practice for young adults including the Mental Capacity Act.

# RAPID RESPONSE TEAM (FORMERLY HOSPICE TO HOME)

The Rapid Response team brings all the services offered at the hospice into the family home in order to offer choice to children/young people and their families. The team particularly supports choice in place for end of life care, and this 24/7 service has now been commissioned by Cheshire and Merseyside ICB. The team is led by a Nurse Consultant, along with a team of highly skilled palliative care nurse specialists and health care support workers (HCSW) who are dedicated to supporting families in their own homes. The team has access to the play specialists, physiotherapists, music and complementary therapists to provide holistic care.

## ADVANCE CARE PLANNING

Sometimes families worry about what might happen if their child suddenly or unexpectedly becomes unwell. Talking through what might happen can help reduce some of these worries and concerns, and having such discussions documented in an advance care plan, can reduce how often these difficult conversations are needed.

# **END OF LIFE CARE**

This chart shows families' preferences on where their baby, child or young adult died.

Preferred place of death	Home	Hospice	Hospital	Other Country	Grand Total
Home	17		3		20
Home/Hospice		1			1
Hospice		5	1		6
Hospital			22		22
Other Country				2	2
Grand Total	17	6	26	2	51

47 In preferred location

51 Death where preferred location known

92.2%

In 2024-25, of those CYP that expressed their preferred place of death, we were able to achieve this in 92% of cases. Of the 8% where this could not be achieved this related to a sudden deterioration in condition where transfer was not an option.

# SUCCESSES FROM 2024-25

## TRANSITION AND SOCIAL GROUP

In 2024, a residential trip was organised for five young adults to participate in specialist sports and activities such as abseiling, rock climbing, and canoeing—experiences they wouldn't typically have access to elsewhere. It was a truly unique and memorable adventure for everyone involved.

Art Attack Project – The social group took part in a creative and delightfully messy wheelchair art project, showcasing their imagination and teamwork.

We supported one of our young adults in planning and carrying out his own fundraiser, benefiting both Claire House and the wheelchair hockey league. He impressively stayed active for a full 24 hours, playing wheelchair hockey and football throughout.



## **THERAPIES**

We employed a new music therapist, Elen, at the start of 2025. Claire House has seen the benefits of music therapy, such as enhancing emotional well-being, reducing stress, anxiety, and depression through therapeutic musical experiences, improving cognitive function – particularly in individuals with neurological disorders – and increasing motivation and self-esteem. These outcomes contribute to boosting quality of life and encouraging self-expression. Music therapy is a versatile approach that can significantly improve mental and emotional health.



## **QUALITY AND GOVERNANCE**

Our new Quality and Governance Lead, Viv, and administrator, Jane, started in post in late 2024. Some positive changes have already been made including a monthly clinical governance newsletter to share learning from incidents, audit and complaints and also shared positive feedback.

Weekly incident review meetings commenced every Monday morning to review and discuss incidents and implement actions to help reduce the risk of recurrence of incidents, therefore improving safety and experience for our CYP and their families/carers.

We have transitioned over to PSIRF (Patient Safety Incident Response Framework) in line with NHS requirements and training has been rolled out to all care staff. We now look at the themes and trends of incidents and use a systems thinking way of learning, looking at the complex systems and processes we use rather than proportioning individual blame. This has helped reduce recurrence of incidents where themes and trends were observed.

Quarterly audit meetings have been set up to review the current audit schedule and ensure quality improvement through the audit cycle.

# ADVANCED COMMUNICATIONS COURSE TRAINING

The ACST has also been a great success with excellent reviews and feedback. It appears to be having a positive influence on the delivery of paediatric palliative care across our network. The courses are multi-disciplinary and revolutionary in improving communication within paediatric palliative care for managers, doctors and specialist nurses. On the back of this we have developed an intermediate communication course for administration, nursing and support staff. We have received positive feedback from the first session.

## PERINATAL SERVICE

Gentle Birthing: Antenatal Support for Complex Pregnancies

Our *Gentle Birthing* Antenatal Course is specially designed for parents navigating a complex pregnancy. Held monthly and led by our compassionate midwife, Hannah, this class offers a safe and supportive space to connect with others in similar situations.

The course provides practical guidance on pregnancy and birth, alongside calming hypnobirthing techniques such as breathing and relaxation. Topics covered include:

- Preparing for birth
- Understanding signs of labour
- Birthing your baby
- Breathing and hypnobirthing techniques
- Pain relief options
- The role of the birthing partner
- Bonding with your baby

This course was created after reflecting on how many families with complex pregnancies missed out on traditional antenatal classes, often arriving at birth feeling unprepared and unaware of their choices. *Gentle Birthing* aims to change that—offering both knowledge and the chance to build peer support, just like in regular classes.

Families who have attended have shared how much the course helped them feel more confident and informed, making a meaningful difference in both their birth planning and experience.

"The class was really brilliant. We took away so much and I feel like I have so many tools now for what will be a hard/sad/joyful time"

"The class was great thank you. Hannah did an absolutely fantastic job and was so lovely. It really gave me that further reassurance that not everything is out of my control"

## YOUNG ADULT SERVICE

New relationships have been built with St Rocco's and Halton Haven adult hospices this year. Our reputation is strong within adult Palliative care, and others are keen to work with us. Honorary contact with CCC (Clatterbridge Cancer Centre) continues to be beneficial. We have strengthened relationships with the Teenage and Young Adult team and building new relationships with CCC palliative care team.

We continue to be an active part of the Cheshire and Mersey Palliative Care Network.

We have led on the development of the Gold standard regional framework for transition – '10 steps to transition', facilitated by NHS England.

## PHYSIOTHERAPY AND HYDROTHERAPY

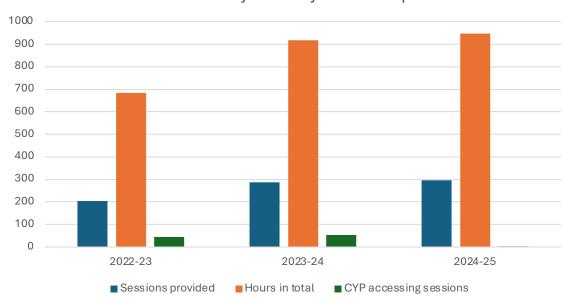
From a care perspective, with the aim being maintaining our CQC outstanding award, as a team we have delivered a huge amount of training to in-house staff throughout the year. This equates to over 250 hours of training delivered. We have also delivered training to outside community teams.

As the only Manual Handling Trainers for Claire House, the Clinical Therapies Team have continued to provide 3 times the legal requirement for Manual Handling training due to the complexity of our children and young people We have compiled our own training record matrix to ensure that we can be proactive and not reactive in ensuring that Claire House staff maintain their competencies in Manual Handling (MH). We have continued to update Clinical Therapy competencies and hospice guidance in line with current research and have ensured that we meet MHRA bed cot side safety alert recommendations.

Hydrotherapy continues to be one of the most popular activities for our children and young people to undertake. Last year's audit of swims (2024) showed that we deliver on average, 232 swims over 12 weeks which equates to 19 swims a week. At the end of 2024 into 2025, we had issues with the pool which meant the pool closed for a number of weeks and this has prevented another audit, however we hope to be soon back to achieving these numbers into 2025 and beyond into 2026.



## Community and Day care Groups



# PLANNED CARE (COMMUNITY DAY-CARE & GROUPS)

The service has grown significantly, and the team has developed too. A new service offer has been implemented, reviewed and monitored to ensure an effective and equitable service offer, the allocation has developed to ensure we can reach out further and support more CYP and families.

We have supported more CYP and families and provided more day-care sessions throughout the year with a consistently growing caseload. We continually receive positive feedback.

Positive relationships have been built with CYP and families, therapeutic support has increased significantly. Two of our Assistant Practitioners within the team are currently undertaking a counselling course to support this.

Families receive much needed respite in the day to spend quality time with siblings as well as to build a vital relationship with our staff.

#### Benefits include:

 The team support within the navigation and transition to Claire House and other offers of care.

- Anxious families have been able to leave their child with our team for day-care and some now access respite.
- Daytime respite whilst knowing the care is safe and effective is vital.
- Very low number of incidents.
- Responsive to need; increased unplanned support such as emergencies, relationship building, memory making.
- Ward rounds/hospital support has been very successful for increased support and remaining in contact – positive relationships built.
- Team and service growth with a stable offer of care sustained.
- Consistency within the team is key for families.
- Effective use of resource from a small team
  of Assistant Practitioners (APs) and Healthcare
  Support Workers (HCSWs) with a growing service
  for respite, therapeutic support, family support,
  relationship building, memory making and support
  for other teams.

We are hoping to sustain this level of care and support, grow teams' skills/knowledge, work with others collaboratively and introduce further groups aimed at older children/young adults.

CARE COORDINATION (CASELOAD TEAM)

The service has developed effectively and meaningfully, providing consistent and clear messaging to all families. Effective point of contact for all families and professionals; gaining updates, responsive to need and offering holistic support. The service links in with many other Claire House HUB & spoke services to support the navigation of Claire House for families with clear and effective processes in place.

The team have built very positive relationships with CYP and families, supporting with any concerns and providing reassurance.

Caseload review has shown an increase of contact, equitable service offers and well-rounded support equally to all families having a positive impact on family lives with a further streamlined and consistent team offering, clear messaging and support.

A Research SEN volunteer has likewise been implemented for family support.

## **REFERRALS**

An increase in referrals to Claire House for a variety of service offers. A new referral form and welcome email has been produced to provide families with all the offers of care we provide. A holistic needs assessment has been implemented for a further holistic approach. We have been involved within the Together for Short Lives national project work to streamline referral criteria with children's palliative care.

We have collected data and built positive relationships with professional teams to reach out further and increase the number of CYP we are able to help.

We are planning to develop roles and responsibilities with the team, review panel and assessments in collaboration with Together for Short Lives.



# **SAFEGUARDING**

Claire House Children's Hospice maintains policies that are in line with current legislation. We have two designated safeguarding leads, one leading on safeguarding adults and the other leading on safeguarding children. We also have a safeguarding link nurse who is a champion within the clinical setting.

Safeguarding supervision takes place in a number of settings such as group sessions, individual sessions and ad hoc 'tea and chatter' sessions.

Mandatory training compliance is closely monitored, and we have recognised that training compliance in

2024-25 has decreased from 85% to 70% for safeguarding adults and from 85% to 56% for children. We have addressed this in a training week that was undertaken at the start of the year in April 2025 and this will be reflected within next year's report, however we expect compliance to be above 90% by the end of the year.

We maintain a good relationship with LADO (Local Authority Designated Officer) and continue to work in partnership when required.

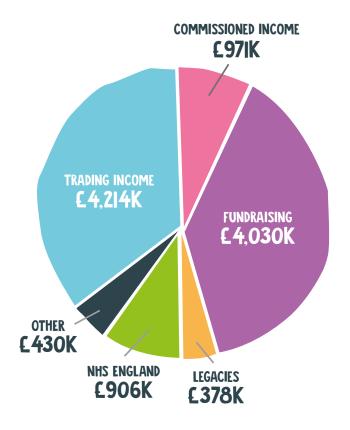
# FINANCE AND FUNDING

Claire House has continued to receive fantastic support, enabling the charity to provide vital care and support to the children and families who need us. Despite an uncertain external environment, we maintained a strong financial position.

Due to the continued support and generosity of our supporters, and the dedication of our staff and volunteers, the charity has spent £8.5m (2023-24: £7.5m) on care for dying children and other service-related activities.

Income has increased to £10.9m (2023-24: £10.6m). This is a result of growth in our trading income, from both our shops and through our lottery. During the financial year, Claire House has also received £175,126 from Hospice UK under the Department of Health and Social Care Capital Grant Programme. This has been invested in a variety of assets across the organisation that will help the organisation to continue to deliver care to the children and families who need us today and in the future.

## **HOW WE RAISED OUR MONEY**



## **HOW WE SPENT OUR MONEY EVENTS & CHALLENGES** £I37K **FUNDRAISING TRADING** £2.503K **COST OF GENERATING VOLUNTARY INCOME RESPITE IN HOUSE CI444K** £ 4.979K HOLISTIC & **PHYSIOTHERAPY THERAPY** £335K **MUSIC** COUNSELLING & **FAMILY SUPPORT** t13K £698K **RAPID RESPONSE PLAY SERVICES** £287K

£2.230K

Claire House continues to receive funding from the Integrated Care Boards of £953,050 (2023-24: £861,316). In addition to this, Claire House received a continuation of its NHS England grant of £906,213 (2023-24: £880,990), designed to provide an element of interim public sector funding until a more reliable funding structure is implemented. This grant has been extended into 2025-26. NHS England also provided a grant of £173,661 (2023-24: £135,549) towards the NHS pension contribution incurred by the organisation.

Claire House maintained its strong relationships with public healthcare commissioners, who invested in services, which provided both a cost saving to the NHS and better outcomes for the child and the family.

The Fundraising Team generated a total net income during this period of £4.2m (2023-24: £4.7m), income from the public and corporate bodies has remained strong whilst legacy income has dropped after several strong years.

As mentioned above, income from trading continues to grow, reaching £4.1m (2023-24: £3.7m), this includes Retail income which has grown to £2.4m (2023-24: £2.2m), this trend is expected to continue as consumers increasingly choose to shop in charity shops due to cost of living pressures and an increased focus on sustainability.

Investments during the year contributed £426,858 (2023-24: £293,341).

Cost pressures have been felt across the organisation. Claire House has sought to maintain competitive remuneration for staff to ensure the finest team is in place to provide our services on both our Liverpool and Wirral sites. Investment has also been made in systems and IT to ensure we are in the best place to support our children and families now and in the future. Our strong financial position has also allowed to invest in our future strategy and in particular our plans for the development of our Liverpool site.

Overall, as of 31 March 2025, Claire House had a deficit of unrestricted funds before movements on investments of £1,710,009 (2023-24: £304,981).

Whilst a deficit in the current year was expected due to continuing investment across the organisation, Claire House is confident that it has the resources to meet the deficit and the investment made will benefit the children and families who will need us in the future.

The Trustees have established the level of reserves that the charity ought to have as £4.2m after a detailed analysis of the financial risks to which it is exposed. This reflects the financial security it would require should one of its significant funding streams dip, and the time it would take to replace any such diminished funding while still maintaining services. An example of this would be a change in the NHS England grant or a drop in gifts in wills, a vital yet unpredictable source of support.

# CARE QUALITY STANDARDS/CQC

In 2019, we were proud to be rated as 'Outstanding' by the Care Quality Commission (CQC). According to the report, parents of children who used Claire House services said: "It's a fantastic place. My daughter loves it there. The staff are excellent," and "The aftercare has been superb".

We have had three virtual CQC reviews focussing on infection prevention control and service provision and development as we emerged from the pandemic period, with positive feedback and no concerns raised and our CQC 'Outstanding' remains in place.



# **QUALITY IMPROVEMENT PRIORITIES FROM 2024–2025**

From May 2024 the organisation has focused on the 5 strategic priorities. The Care and Family Services prioritised creating a Quality & Governance structure, with a designated Lead (Band 7) for Quality & Governance and a designated Administrator (Band 4) to support this area of work. We successfully recruited into both roles which enabled the team to be set up during Q3.

Having a designated team in place has provided the skills and knowledge to focus on ensuring we are working at an 'Outstanding' level. We implemented the CQC module on the Vantage system, built a dashboard for incident reporting enabling clearer monitoring and oversight of incidents and actions. We also started to benchmark ourselves against external guidance and standards.

Focus was also on achieving sign-off from the Integrated Care Board for our PSIRF policy and plan. This was achieved in Q4 2024-25.

# OUR QUALITY IMPROVEMENT PRIORITIES FOR 2025–26

Our five-year strategy continues, with a proactive, continuous approach across all 5 strategic priorities. Our main areas for improvement will be:

### 1. Audit

In 2025-26 we aim to set up an Audit and Quality Improvement (QI) Committee with the first meeting scheduled for July 2025. The aim of this committee is to meet quarterly to drive improvement across the Hospice with a consistent approach to audit with common understanding across the Hospice. The monitoring and effectiveness of audits will be reviewed with the aim to drive quality improvement through the audit cycle.

## 2. Patient experience

Our aim is to increase our co-production work with families. We want to improve our response to recurrent themes by moving feedback onto the Vantage system. We also aim to improve families' welcome experience at Claire House using the 15 Steps Challenge. NHS England 15 Steps Challenge will highlight areas for improvement across the Hospice from the perspective of a family's first impressions. The 15 Steps team will carry out regular walk-arounds looking at four key areas, to ensure our services are welcoming, safe, caring and involving, well organised and calm. Feedback will highlight positives and recommendations. An action plan following the feedback will be developed as part of our approach to continuous improvement across the Hospice.

## 3. Service User Safety

Claire House Children's Hospice is now live with PSIRF (Patient Safety Incident Response Framework). Our aim for 2025-26 is to embed PSIRF and train staff in this new way of learning from incidents. Our focus will be to review themes in trends of incidents using systems thinking and focus on our priorities within patient safety incident response plan.

# **ACCREDITATIONS**

We have started work on achieving the Bronze Black, Asian and Minority Ethnic (BAME) accreditation. A working group has been set up to help achieve this and we expect to have achieved accreditation by 2026.



# TRAINING AND COMPLIANCE INCLUDING AUTISM TRAINING

Our Practice Development Team is made of two nurses (1 child nurse and 1 learning disabilities nurse) and one Assistant Practitioner. The Team deliver training in both planned and ad hoc sessions. We follow the Core Standards Framework and our goal for 2025-26 is to have clear evidence of all completed training, with compliance being monitored on a monthly basis. Our expected minimum annual compliance for all training is 95% (excluding maternity leave and long-term sickness).



In 2024-25 we worked with Autism Together who have provided face-to-face Tier 2 Oliver McGowan autism training to 43% of our staff and over the next 12 months we expect all of our care team to have been on the tier 2 training course.

The Hospice supports the next generation of Nurses. Formal

learning agreements are subject to an annual audit by one of the local Higher Education Institutions (HEIs) and need to adhere to Nursing & Midwifery Council standards. The hospice partners with Edge Hill University, Liverpool John Moores University and University of Chester, and offers places for 1st, 2nd or 3rd year pre-registered Child, Adult and Learning Disability Nursing students. Post-registration Nursing placements are offered for Specialist Community Practitioner course. The hospice must have appropriate nursing staff to support student learning in practice. This is monitored internally by the Practice Education Team and externally by the HEI's as part of their audit. Students are requested by the HEI to complete an online evaluation of the placement; the hospice has access to these results.

We have supported 20 students from across the three local universities in 2024-25 and we have also developed two Nursing Associates who completed their training in September 2024.

# PATIENT SAFETY INCIDENT RESPONSE FRAMEWORK

The NHS has implemented PSIRF (Patient Safety Incident Framework) which has replaced the Serious Incident Framework. As we have services commissioned by the NHS, we are expected to implement PSIRF too. We are now live with PSIRF and our policy and letter of endorsement from the Integrated Care Board (ICB) can found on the website.

There will be a preference for thematic review and quality improvement planning for incident types that have been seen to reoccur.

The following local focus has been identified within thematic reviews and incident review meetings. Incidents

requiring further individual incident investigation will have a decision agreed through the Multi Disciplinary Team (MDT). The decision will be based on a number of factors including;

- Incident Complexity.
- · Potential for new learning.
- Level of risk to future care.
- Views of those affected by the Patient Safety Incident.

The following table provides a guide for some of the types of incidents observed during review of previous years.

Patient safety incident type or issue	Planned response	Anticipated improvement route
Non-Controlled Drug (CD) related incidents – Documentation error resulting in the medication reaching the service user.  CD related incidents – resulting from the storage or documentation of CD's.	Care Improvement Form completed within 24 hours.  After Action Review (AAR) – as soon as possible after incident identified.	Led by Quality and Governance Lead Nurse.  Completed within 5 days from start date.  Reviewed by Clinical Governance.  All Controlled Drug incidents submitted to LIN.  Review of reoccurring areas for improvement against improvement plan.
Care related issues resulting in patient safety incident.	Care Improvement Form completed within 24 hours. Continuation of thematic review work currently being undertaken. PSII if severe harm.	Led by Quality and Governance Lead Nurse. Completed within 5 days from start date. Reviewed by Clinical Governance. PSII if applicable.
Incident as a result of incomplete or missing documentation within the care plan.	Care Improvement Form completed within 24 hours. Continuation of current thematic review work.	Review of reoccurring areas for improvement.  Led by Quality and Governance Lead Nurse.  Reviewed by Clinical Governance.

# **QUALITY PERFORMANCE**

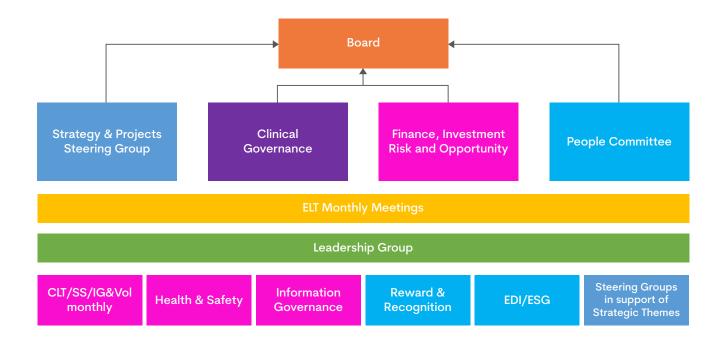
Key Performance Quality Issues	2022-23	2023-24	2024-25
Formal Clinical Complaints	0	2	2
Clinical Incidents	44	39	40
Notifiable Patient Safety Incidents (Duty of Candour)	0	0	1
Medication related Incidents	58	35	60
Patient Falls	0	0	0
Pressure Ulcers acquired in Hospice	0	0	0
Hospice Acquired Infections (inc Covid, C-Diff, MRSA)	0	0	0

There has been a noted increase in clinical and medicine incidents in 2024-25. We believe this is due to a positive reporting culture in which staff and volunteers are aware of potential risks and in which, in an atmosphere of openness, staff are actively engaged in safely reporting incidents. We feel through training and effective communication, we have created an environment in which unsafe situations in processes are easily addressed and improved.

A patient Safety Incident investigation (PSII) was undertaken for the notifiable patient safety incident. The hospice was able to learn from the investigation and put measures in place to prevent recurrence. One of the actions that arose from the investigation has been very effective in supporting junior staff. This was achieved by increasing senior support to the care team from the Practice Education Team and physiotherapy team.



# LEADERSHIP AND GOVERNANCE



Claire House is led by a Board of Trustees that meets quarterly as a Board and also has a lead for different key areas of the organisation. The four main Governance committee meetings are chaired by a member of the Board, with a member of the Executive Leadership Team (ELT) sitting on each group.

ELT consists of the leads from across the organisation (Chief Executive, Director of Care & Family Services,

Director of Income Generation & Volunteering, Director of Strategy & Operations, Head of Finance, Head of HR, & Head of Communications).

The Leadership Group report into ELT and lead their departments from both a strategic and operational level. Leadership Group lead and/or participate in the meetings that feed up to the Governance committee meetings as shown in the meeting structure plan.

# SAFE STAFFING

Staffing levels are good and remain stable with minimal vacancies across all Care & Family Services with the exception of the Inpatient Care Team. The Inpatient Care Team has the highest amount of staff turnover with a common reason for leaving being related to working a 24/7 shift pattern.

Vacancies within the Inpatient Care Team are closely monitored by a dedicated Inpatient Manager, who also ensures a safe skill mix, staffing numbers of shift, and excellent bed management and bookings. Staffing is always 1:1 with a supernumerary shift coordinator at the very least during day shifts, and all shifts have a minimum of 2 Registered Nurses.

The WTE for Care & Family Services has increased year on year which is evidence of the growth of services:

	2021	2022	2023	2024
TOTAL CARE WTE	77	90	90	96

During 2024-25 we are very proud to have recruited into a new Quality & Governance Lead role, and to also have expanded our administration team. We committed to recruiting newly qualified nurses and supporting them on a 12-month preceptorship programme, and three internal staff successfully completed their apprenticeship to become Registered Nurse Associates.

We have a core group of highly experienced bank staff who provide planned and responsive shift cover.

# **AUDIT**

This year our focus has been on structuring and giving depth to our internal clinical audits to measure, monitor and improve our quality performance. We had a new Quality and Governance Lead start in November 2024 who has created an action plan and schedule of audits and will maintain oversight of the programme. Results, learning and areas for improvement are discussed at audit meetings and presented to the clinical governance committee and shared with staff.

Our focus for the next 12 months will be to embed the audit process and effectively monitor areas for improvement. We are currently working on our audit schedule for 2025-26 but the following audits have been undertaken in 2024-25

- Hand Hygiene Audit (monthly)
- IPC Cleaning Inspection Audit (weekly)
- Body Maps Audit (monthly)
- Mattress Audit (6 monthly)
- Audits of various checklists (quarterly)
- MCA 1&2 Audit (quarterly)
- Care Plan Audit
- Audit of Controlled Drug Daily Stock checks (annually)
- Audit of Medicine Fridge Temperatures (annually)
- Controlled Drug Accountable Officers (CDAO) (quarterly)

Some audits have been undertaken following complaints and incidents.



# FEEDBACK FROM COMPLAINTS, COMPLIMENTS AND SUGGESTIONS

Claire House Children's Hospice recognises that all feedback, both negative and positive, plays a crucial role in improving the care and services we provide by guiding continuous quality improvement and ensuring that our service-users and families/carers receive compassionate, effective support. Positive feedback reinforces best practices, boosting staff morale and encouraging the continuation of high-quality care. Conversely, negative feedback highlights areas needing attention, such as communication gaps or inefficiencies in service delivery. Claire House Children's Hospice actively listens to and acts on the feedback we receive, and we can tailor care plans more effectively, enhance staff training, and build trust with families.

Anyone raising a complaint or concerns is treated fairly, and we aim to respond promptly and sensitively. We will always endeavour to meet with anyone raising a

complaint or concern to understand their issues as soon as possible. Whilst we receive very few complaints each year, we do take all concerns and complaints very seriously. All complaints and concerns are fully investigated with any learning from investigations shared with the complainant. We also apply Duty of Candour where necessary. All actions arising from complaints are monitored by the Clinical Governance Team with oversight at the quarterly Clinical Governance meetings.

During 2024–25 there were two formal complaints received and because of these complaints the hospice implemented some changes to improve service-user experience. These changes included a review of our Care database system including care plans, further senior support from Practice Education Team and Physiotherapy Team and further ad hoc training sessions including vent updates and equipment updates.

# INFECTION, PREVENTION AND CONTROL

Effective Infection Prevention Control (IPC) has always been a high priority. In 2024–25 we implemented the National Standards for Quality Health Care Cleaning and invested in standardized external training for our housekeeping team to support the maintenance of these standards.

In 2025-26, we aim to utilise the Hospice UK IPC template to audit all clinical areas for infection prevention control compliance.

We work in partnership with St John's Hospice to ensure our IPC audits, policies, SOP's and processes are effective and in line with current guidance.

# EQUALITY, DIVERSITY AND INCLUSION

In 2024 Claire House launched its Environmental, Social and Governance (ESG) Plan focusing on: environmental sustainability, equality, diversity and inclusion, and governance to enhance our role within the community. We use research to influence our services. Whilst our data is limited, it shows we receive a slightly higher proportion of referrals from ethnic minority groups in comparison with the demographic makeup of our catchment area.

Our play team has actively encouraged the celebration of a wide range of cultural holidays including Eid and Chinese New Year. The children have been involved in celebrating these holidays, making decorations and listening to traditional music.

Our priorities for 2025-26 are as follows:

- We will focus on creating an inclusive environment that celebrates diversity and promotes equity.
- Implement inclusive recruitment practices to attract a diverse pool of candidates and providing regular staff training on EDI topics, including neurodiversity and faith at end-of-life.

- Engaging with the community, including partnerships with Jewish and Muslim organisations.
- Providing a translation service for families who need it.

## Governance overseen by our Executive Leadership Team

- We will ensure we have a well-run and transparent organisation.
- Recruiting a diverse and skilled board of trustees, who take part in an external evaluation every 5 years.
- Creating transparent reporting, including regular publication of Annual Reports and Quality Accounts.
- Establishing ethical standards through a robust code of conduct and whistleblower policies. Freedom to Speak up Guardians (with representatives from around the organisation) were established in 2023.



# INFORMATION GOVERNANCE

Claire House takes its information and data governance very seriously and has undertaken the following steps in the past 12 months to ensure our policies continue to be maintained and enacted in accordance with UK GDPR regulations.

# Audits/developments carried out during Q1/2 2025 in the following areas:

- Annual DSP Toolkit submitted again for June 2025.
   The previous year's was submitted with a clean bill of health.
- Annual PEN test completed and passed for external and internal protection with all advisories corrected.
- Regular data destruction of IT kit carried out, including physical paper-based material.
- Data retention policy expanded, and schedule enacted.
- Vantage development has been ongoing, and a number of modules have gone live.
- Summary review of Data Protection Act (DPAs)/ Data Protection Impact Assessment (DPIAs) completed and any high risks identified.
- Suite of Data Protection (DP) policies reviewed and updated where necessary.
- Updates made to maintain the Information Asset Register and keep it up to date.

- Audits with data privacy implications completed e.g. Gambling commission (passed), Sophos (passed).
- Business continuity/disaster recovery plans expanded and played out in desktop exercises.

## Audits/developments planned for 2025-26:

- Data risk assessment audit planned to highlight any specific areas of risk where data may be exposed.
- Access control and regular systems permissions audits to be introduced for movers (access updated), leavers (access removal), long term off (maternity, sick leave-access suspended or restricted).

# CH has also submitted the following statutory/external commitments:

- Care activity and HR workforce reporting in conjunction with Hospice UK.
- Quarterly ICB care activity reports.
- · Individual grant project impact reporting.

# PARTNERSHIP WORKING / ADVANCED COMMUNICATIONS COURSE

The Rapid Response service works in partnership with many different teams including the Alder Hey Specialist Palliative Care Team, a variety of community nursing teams and other professionals from the MDT, from primary, secondary, and tertiary services to ensure high quality care is sustainable for as long as it is needed. The team strives to make a real difference to the child and family during this extremely difficult time by helping families create lasting memories.

The perinatal service works closely with The Fetal Medicine Department at The Liverpool Women's Hospital. Midwives and fetal medicine doctors have become more holistic to families and are using grounding techniques with ladies following a teaching session provided by our Perinatal Palliative Nurse Consultant. This has helped families by having a positive influence on the midwifery team which reflects a more compassionate and positive experience for families.

Claire House Children's Hospice has a close relationship with Together for Short Lives and our Perinatal Palliative Nurse Consultant recently presented sessions at the Together for Short Lives Conference in Manchester. The conference was attended by a number of Claire House staff and the whole event received excellent feedback.

"The event was incredibly well-presented and provided a fantastic opportunity for professionals to engage with valuable discussions, real-world case studies, and expert insights. Inclusion of hospice and charity stands, allowing for further networking and awareness, was also a great addition.

It's clear that this study day made a meaningful impact on participants, reinforcing best practices and improving knowledge across the field"



Claire House proudly facilitates and hosts a 2-day Advanced Communication Course. This course is offered to Health and Social Care Professionals who are regularly involved in complex, difficult or challenging conversations with patients, families or colleagues. The course has been well represented with a multi-disciplinary approach, hosting professionals from a variety of areas including palliative medicine, intensive therapy, oncology, ward managers and complaints managers. The course is hosted at our Liverpool site and is presented by Lesley Fellows, Director of Care and Family Services and Kat Williams, Perinatal Palliative Care Nurse Consultant and has received excellent feedback. The course has been so well received that they now facilitate a one-day intermediate communications skills training day aimed at nursing and administration staff.

# **WORKFORCE SURVEY**

In February 2024 we conducted the Best Companies staff survey, for the first time, which we have committed to doing for the next 5 years. The results were positive and Claire House overall was awarded 2 stars which represents outstanding levels of employee engagement. High scoring areas included effective leadership and management, working together as team and people feeling committed to the cause and the contribution they could make to the children and families we look after. The survey was repeated in February 2025 and the results improved from a score of 698.3 in 2024 to 721.8 in 2025. This means that Claire House remains an outstanding employer and is working towards its goal of becoming World Class.



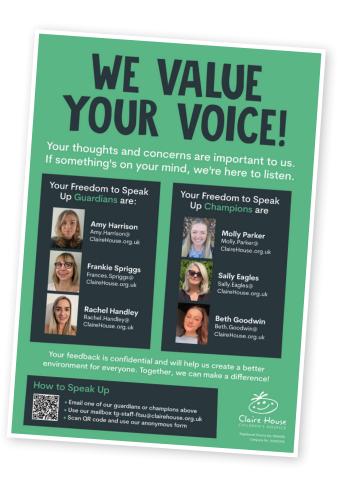
# FREEDOM TO SPEAK UP

Claire House promotes an open and transparent culture where we recognise that sharing issues and concerns openly is crucial in both patient safety and the quality-of-care patients and carers receive.

We have three Freedom to Speak up Guardians and three Freedom to Speak Up Champions.

All guardians and champions have completed the appropriate training, and the guardians have established mentors in place. They meet monthly as an opportunity to check in, raise any queries or concerns, and discuss promoting the service to help minimise the barriers to speaking up. We also have a nominated Freedom to Speak Up Trustee who provides independent support for the FTSU guardians and provide guidance with investigations and escalate issues to the Board as required.

We have a Freedom To Speak Up policy, which was updated in 2024-25 and this demonstrates the hospice's commitment to speaking up safely without fear of reprisal.



# LONG RECOGNITION AWARD

Long Service Recognition Awards for staff were introduced in January 2025, with 113 staff eligible for an award which we backdated to their last milestone (5, 10, 15, 20 or 25 years of service). The awards consisted of a letter of recognition from their Line Manager, CEO or Trustees, depending on length of service, a voucher, pin badge which staff wear with pride, and a small celebration within teams. The awards were well received by staff, in a follow up survey staff gave them 4.64 out of 5 stars.



Elaine Gillespie (Health Care Support Worker) has achieved 17 years' service:

"Thank you, this was a nice surprise. It is an honour to work in our great hospice."



Rachael Hogg (Counsellor) has been at Claire House for 10 years:

"It was lovely to receive a personalised letter which really made me feel appreciated and valued in my role and the organisation. Thank you."



Matt McGeagh (Manager at Neston and Heswall shops) has achieved 5 years' service:

"It was really nice to be recognised for length of service and receive a personalised letter. Made me feel really valued and a little bit emotional."



# **OUR GREEN PLAN**

As an organisation that is supported by our community as well as serving it, we are keen to play a positive role in improving the world we live in. Not only will this help us reach more families, but also to protect the environment, play an active role in improving our society and be a transparent, well-run organisation that makes the most of all its resources.

## AIMS:

1. Resource Efficiency: All departments will be encouraged to know what our energy use is and optimise the use of resources, including water and energy, through efficient practices. This will include applying for grants to help fund these improvements.

- 2. Waste Reduction: Minimise waste generation and promote recycling and reuse across all operations this will be inherently designed into the new Liverpool site and, and where possible, adopted at the Wirral site. We will also seek to reduce waste and encourage recycling in our Retail department, as well as ensure our fundraising events are as sustainably run as possible.
- **3. Sustainable Procurement:** Wherever possible and affordable, we'll use local companies and source materials and services that are environmentally friendly

and ethically produced. We'll encourage our suppliers to do the same and endeavour to include this in our procurement policy.

**4. Community and Education:** We'll help to raise awareness about sustainability and involve staff, children, and families in our environmental initiatives.

## **OUR 5 YEAR TARGETS:**

- Energy Reduction: Achieve a 15% reduction in energy consumption at main Wirral and Liverpool sites through improved insulation by replacing wooden doors and windows, energy-efficient lighting, and HVAC systems. We'll monitor this through our energy bills until we have technology in place to provide live data.
- Work with our Waste Management Providers: Establish a robust waste management system to reduce landfill waste by 10%.
- Green Spaces: Capitalise on the space we have at Liverpool to incorporate green spaces in the new building design to enhance biodiversity and provide amazing and calm environments for children and families in Liverpool.
- Carbon capture: Investigate tree planting and other carbon capture initiatives on both our sites.

- Net Zero Carbon: Aim for the new build of the Liverpool building to be net zero carbon, utilising renewable energy sources such as solar panels and ground source heat pumps.
- Water Efficiency: Reduce water consumption in Liverpool by 25% through the installation of low-flow fixtures and rainwater harvesting systems.
   We'll also investigate creating our own bore hole for water to reduce the distance travelled for this resource (we use quite a lot as our hydrotherapy pool is an essential part of our offering).
- Carbon Footprint Reporting: Calculate the carbon footprint of our technology usage and set reduction targets.

# **SUPPORTING STATEMENTS**

### **Feedback from Child Death Review Panel**

Panel would like to express their thanks to you all for the important role that you played in helping a little boy spend as much time as possible at home with his family and also in supporting his Mum who had her own vulnerabilities. Often the work you do to support families goes unnoticed and panel want to ensure that in this case, your care and excellent team working was acknowledged.

Panel recently reviewed the deaths of twins and would like to formally acknowledge the level of support which the family were offered from Claire House. Panel recognised that at times, cultural differences can make it harder to engage with families and wanted to thank you all of the keyworkers involved for their tenacity in engaging with this family to allow them to access what was much needed support. Panel would like to thank all of the key workers for supporting a family facing such significant bereavements.

As the lead for CDR I would like to thank everyone for their dedication and care. This young man has been a presence in Claire House for some time and gained a great deal from accessing the Hospice, in recent years being a well known member of the Social group. It never ceases to amaze me in times of stress and upset how everyone in Claire House comes together to provide the best possible care for our patients. This young man and his family certainly got A\* care from different teams in Claire House.

# Feedback from Palliative Care Consultant at Marie Curie

I just wanted to say it's a pleasure to read these updates demonstrating how dedicated and holistic you and your colleagues are, to try and help a young man in any way possible. I think this has been an excellent example of collaborative working and you guys really do go above and beyond. I personally think it's reminded me of why we do what we do.

## SUPPORTING STATEMENTS CONTINUED

### **Feedback from Rainbow Trust**

What a huge benefit that organisations such as ourselves collaborating to offer a rounded approach can have. At Rainbow Trust, we are completely family-led with the support that we offer, and the referrals that we make into other services. We will continue to share your wonderful service with our families and to make referrals when the families agree and ask us to.

# Feedback from Dr Sarah Mahoney, Paediatric Intensive Care Consultant at Alder Hey.

"The exciting ambitions that Claire House is committed to achieving will have a huge impact on patients under the care of Alder Hey. Families will have greater choice in their child's place of death when there are 24/7 children's hospice facilities just a stone's throw away."

## Feedback from Dr Umber Agarwal, Fetal Medicine Consultant at Liverpool Women's Hospital

Claire house team help other professionals by respecting the baby and parents' journey and their decisions, and supporting them in a meaningful way to help them develop memorable experience for the family, regardless of pregnancy outcome.

# **Supporting Statement form St Johns Hospice, Wirral**

"Wirral Hospice St John's enjoys a close working relationship with Claire House Hospice that has developed over many years.

The partnership has seen the development of a robust service for young adults known to Claire House transitioning into adult services, with staff from both organisations working closely with the young person and their families to ensure a smooth transition. Due to the needs of each young person this is a bespoke experience, and we know we have the full support of Claire House team's knowledge and expertise throughout this transition. We also have mutually accessible education programmes, increasing the range and depth of education available to our teams.

Through working collaboratively across all of Wirral specialist palliative care providers we have been able to add Claire House's Young Persons End of Life Team as a caller option to the Wirral Wide Palliative Care Advice Line, ensuring the single advice line number can support access to the right services.

There is a mutually beneficial relationship between our two organisations, not only stemming from our geographical closeness both being located on the Clatterbridge site but also from two organisations who share the same values of palliative care and end of life and are focused on providing the highest standards of patient care enabling our patients to enjoy the best quality of life possible.

We have the greatest respect for the care provided by the Claire House team and feel privileged to have them as such close colleagues."

## Supporting Statement from Clatterbridge Cancer Centre – Teenage and Young Adult Service

We have been collaborating with the Young Adult team at Claire House for many years, strengthening our partnership with an increasing number of referrals each year. Early acceptance of referrals for young people with life-limiting conditions is invaluable, as it fosters strong and meaningful relationships from the outset. This early connection ensures that when their journey becomes more complex, Claire House is already a trusted presence, equipped with deep knowledge and involvement to guide conversations with sensitivity and expertise.

Claire House demonstrates exceptional responsiveness to our patient cohort, proactively adapting their age criteria to align with ours, 16-24 years. This ensures that no young person or family is left without the support they need. Our professional relationship continues to thrive, setting a national standard for collaborative best practice and delivering compassionate, holistic care to those who need it most.

# Supporting Statement from Fetal Medicine Unit at Liverpool Women's Hospital (LWH)

The Claire House team work collaboratively with the Fetal Medicine Team to provide outstanding support and care to women and families where there is a significant fetal concern. This includes participating in weekly regional Multi Disciplinary Team (MDTs), receiving referrals for women and families, attending appointments to support during investigations, procedures and counselling. The Claire House team have a daily presence in LWH and work closely with colleagues in Neonatology to provide individualised birth planning, seamlessly integrating women's preferences with complex management for the women, fetus and baby after birth. They also offer invaluable holistic therapies during challenging pregnancies, memory-making and ongoing support for women and families, including siblings after birth.

We are extremely fortunate to work this way with Claire House. Together we are providing perinatal palliative care and from feedback from clinicians in other regions and charities supporting women after losses, this stands out nationally.

Supporting Statement from Dr Fauzia Paize, Consultant Neonatologist at Liverpool Women's Hospital

We have been working with the Claire House team for over 10 years on the Liverpool Women's neonatal unit. They are an invaluable support to both staff and families as they support not only babies or families prior to their birth but also babies who have been born who are particularly sick on the neonatal unit. This includes our extremely preterm babies who are at high risk of death.

The Claire House team help facilitate transport to hospices for babies for end of life care. They also help support staff on the unit with end of life care if this is needed.

They are amazing at coming in to help families with anticipatory memory making. They support families at the cotside with regular discussions with them and often help the medical teams with difficult conversations

They have an invaluable input into the fetal medicine unit where they help families with uncertain pregnancies with things like complementary therapies and heartbeat recordings and regular discussions and support via phone calls and text messages. They help them with difficult decision making and can be there to support them with difficult invasive procedures.

Without the Claire House team we would be able to conduct our end of life care but they enhance the care of these families to a great extent. They help us with symptom management plans for babies. They help us with transport outside of the neonatal unit for end of life care. They help with bereavement care for families following the death of their babies by running events at Claire House such as support groups.

They can help support future pregnancies where there has been pregnancy loss in a prior pregnancy and also run baby groups for babies who have been at high risk of death but have survived their neonatal journey.

We are very fortunate to have Claire House on the neonatal unit in Liverpool due to the extensive enhancement that they provide to the care of the babies.





## Claire House Children's Hospice

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