Emergency Care Impact Assessment (ECIA) Project
Claire House Children’s Hospice

EXECUTIVE SUMMARY

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Foreword

This executive summary presents the main findings of the emergency care impact assessment study undertaken from September 2013 to August 2014. The study was conducted by researchers from the Evidence-based Practice Research Centre (EPRC) at Edge Hill University, in collaboration with Claire House Children’s Hospice. All data collection and analysis was led independently by the Edge Hill team. The full report was submitted to Claire House in September 2014.

Background

Children with Life-Limiting Conditions (LLCs)

The term ‘life-limiting conditions’ is used for those where “there is no reasonable hope of cure and from which children are expected to die” (Together for Short Lives (TfSL), 2013). There are over 300 diagnoses for which children and young people require specialist palliative care. It is important to note that not all children with LLCs have an official diagnosis due to the rarity of their condition or the complexity of their symptoms (TfSL, 2013).

There are approximately 49,000 children and young people under 19 years in the United Kingdom who may require palliative care services due to living with a LLC (TfSL, 2013). Annually, children with LLCs account for approximately half of all infant mortality in the UK; approximately 3000 deaths per year (Hill & Coyne, 2012; Hain et al., 2011). During 2011, in the North West of England (i.e. Cumbria, Lancashire, Greater Manchester, Merseyside, Cheshire and the Isle of Man) approximately 2,637 children aged from birth to nineteen years had life-threatening and life-limiting conditions requiring palliative care (Northwest Children’s Palliative Care Network (NCPCN), 2011).

Children’s Palliative Care Services

Children’s palliative care includes taking an active and total approach to enhance the quality of life of children and young people with LLCs, ensuring that their symptoms are controlled and that both the child and their family are supported from the point of diagnosis or recognition of their condition throughout their ‘life, death and beyond’; but it also comprises the provision of respite and short breaks (TfSL, 2013; Crozier & Hancock, 2012: 198; Grinyer et al., 2010; Craft et al., 2007).

Children’s palliative care in the UK is provided by a range of services including specialist and core palliative care providers, children’s services, health agencies, local authorities and children’s hospices. It is funded by local authorities, direct payments, personal budgets or charities (Robertson et al., 2011). Care can be provided in primary, secondary or tertiary settings, at home, in hospices, specialist residential settings or the home of contracted short break carers (Hill & Coyne, 2012; Robertson et al., 2011; Naidoo & Wills, 2009).

There is wide variation in the illness trajectory for children with LLCs, with some children living for a short time and others living for decades (Hain et al., 2011). Children’s palliative care is often prolonged because, unlike adult palliative care which often requires one episode of end of life care, children’s palliative care may involve many episodes of critical illness management (Hill & Coyne, 2012; Ling, 2012; Thomas & Price, 2012; Rogers et al., 2011; Knapp et al., 2012). Children’s unique palliative care and multiple complex healthcare needs can only be met by a limited number of care providers, whose resources are stretched, thus affecting the availability of, and access to, care (Noyes et al., 2013; Hill & Coyne, 2012; Ling, 2012; Thomas & Price, 2012; Knapp et al., 2012; Robertson et al., 2011; Rogers et al., 2011).
Transition into Adult Services

As a consequence of medical science and technological advances increasing numbers of young people with LLCs are living into adulthood and require transition into adult services (TfSL, 2013; Hill & Coyne, 2012; Ling, 2012). Current providers are facing decisions on how to ensure availability of, and access to, quality care for all who need it, within this growing and aging population. Factors such as the length of time the child and their family require palliative care and family support, in addition to changing demographics and the expectations of the children and families to have choice and control, places strain on current services (Noyes et al., 2013; TfSL, 2013; Hill & Coyne, 2012; Thomas & Price, 2012; Robertson et al., 2011; Rogers et al., 2011; Craft et al., 2007). The gap in services for young adults upon reaching the cut-off age of provision from children’s hospices is a growing UK-wide issue.

Benefits of Hospice Care for Families

Caring for children with LLCs is physically, emotionally and socially challenging & isolating. It often impacts negatively on lifelong health, education, social wellbeing and quality of life of the wider family, such as siblings or grandparents, whose needs may be overlooked and who ‘may miss out on a ‘normal’ life’ (Eaton, 2008: 3197; Thomas & Price, 2012). The provision of positive palliative care & family support increases the child’s ability to meet their developmental and social potential and can improve the whole family’s well-being & quality of life (Thomas & Price, 2012; Grinyer et al., 2010; Eaton, 2008).

No literature addressing the balance, or value, of planned versus emergency care was identified. Children’s hospices face increasing demand on their services from a growing population. Decisions on how best to balance the provision of hospice planned short breaks and emergency care in a sustainable way are needed. CH is currently conducting a review of its service and it is timely that the views of all user and stakeholder groups are explored, to inform future planning of services.

Claire House Children’s Hospice

Claire House (CH) based in Bebington, on the Wirral, opened in December 1998 & was the first children’s hospice in the area. It is a ten-bedded hospice, providing free of charge respite and end of life care to families whose children have life-limiting conditions (LLCs) or life-threatening conditions (LTCs) from birth to 23 years of age.

“[The purpose of CH is] to reach out to every child with a life-limiting or life-threatening condition and their families, making sure they can get the very best support when and where they need it” (CH, 2013a).

CH serves a large catchment area which includes Merseyside, Cheshire, North Wales, West Lancashire and the Isle of Man (CH, 2013b). Currently, there are approximate 170 families receiving care from CH.

Services Provided by CH

CH provides a range of services including: respite short breaks; end of life care; after death care in the Butterfly Suite; bereavement support and counselling and a wide range of therapies including physiotherapy, hydrotherapy, music, alternative and complementary therapies. CH also runs a parent and tots group. The core teams providing these services comprise the in-house Care Team, Hospice to Home team, Family Support team which includes bereavement support and counselling, and the therapies team. Additionally, CH includes a fundraising team and volunteer workers as well as a management team including administrative support services.
The CH services can be grouped as planned care and emergency care:

*Planned care*: CH provides planned home-from-home respite short breaks within the hospice for children or the entire family for a maximum of 17 nights a year. Additional nights are sometimes made available to families as bonus nights. Telephone support is available 24 hours a day for all families. Families can also access day therapy services including counselling and bereavement support.

*Emergency care*: Unplanned hospice nights (outside the standard allocation of planned nights) can be available when family emergencies arise or carers are unable to fulfil their role. End of life care can be provided in the hospice or the home, working in partnership with a variety of specialist teams across the local area, including the Specialist Paediatric Care Team based at Alder Hey Children’s Hospital in Liverpool. The Hospice to Home service provides specialist respite, palliative and end of life care, and support to children, young people and their families within the family home or other settings such as hospital delivered by a specialist nursing team (CH, 2013c).

**Referral Process**

Referrals can be received from family members or any professionals involved with the care of the child or young person with LLCs, who would typically be under 18 years of age, although all referrals are considered on an individual basis.

**Aim of the study**

To explore the impact and benefits of the planned and emergency care provision for CH service users (children/YP, families including siblings and professionals) in all areas of the service provided so that clear recommendations could be made to support the future development of CH services.

**Project Methodology and Design**

The study consisted of two phases:

**Phase one: Qualitative Data Collection**

Interviews and focus groups with young people, families (inc. siblings), health and social care professionals and CH staff to explore their views and experiences of the planned and emergency care provision from CH.

**Participants**

53 participants took part in Phase 1:
- 1 young person’s forum with 6 participants;
- 5 family interviews involving 8 participants (individual & joint interviews with 4 current family users & 1 bereaved family);
- 7 interviews with professionals from primary, secondary, tertiary, community and specialist care;
- 7 interviews with CH staff;
- 3 professional group meetings across the North West involving 25 participants from primary, secondary, tertiary, community and specialist care.

**Phase two: Survey of service users and stakeholders**

An online survey was created inviting a larger sample of participants to share their views, preferences and experiences of CH. The survey contained open and closed questions on the core services of CH. Paper versions were made available where required.

**Participants**

82 participants took part in Phase 2:
- 33 families (40%); current family users (n=28), bereaved families (n=5);
- 24 NHS professionals (29%); Health Visitors, Community & Hospital-Based Nurses (n=25), Consultants (n=3), NHS Commissioners & Managers (n=5), GP & GP Commissioners (n=2);
25 CH staff (31%); Care team (n=6), Hospice to Home team (n=4), Family Support team (n=3), Therapy team (n=3), Fundraising team (n=3), Voluntary Services (n=1) & non-nursing & administrative staff (n=5).

Results

The findings for Phase 1 and 2 are presented together in 10 key themes:

Theme 1: The complexity of needs of children and young people who use CH

- Children and young people who meet the CH eligibility criteria have profound complex care needs, often due to the number of co-morbidities or severity of diagnosis. The challenge of providing care increases as the child matures, growing physically larger and heavier.
- Children and young people with LLCs often require a high level of technology, bulky equipment or frequent medication. These requirements can limit the families’ ability to be spontaneous and to socialise, even with members of their extended family, leading to feelings of isolation.
- It is emotionally, physically and socially challenging to care for a child with LLCs. Parents can struggle to meet their own physical and health needs, including sleep, which can lead to exhaustion and ultimately result in a crisis point being reached. Additionally, parents can find it challenging to have quality time together as a couple and find it challenging to prioritise the needs of other family members.
- The complexity of some children’s needs can result in limited choice of alternative care provision and make it difficult for families to trust other providers. It takes time for families and service providers to develop a trusting relationship with good communication.

Theme 2: Planned care provision

- CH planned care delivers holistic and individualised care to the whole family via a range of services.

“The care provided is excellent & me & my family would be lost without Claire House” (Family survey).

- Key factors of the service include the long-term, trusting relationship and good communication between CH staff and families; the flexibility to use planned short breaks as a family or for the child with LLCs to give the family a break from caring; access to opportunities and activities not available elsewhere; peer and counselling support, tailored support for siblings and socialising opportunities.

“Trust is hard to find but found at CH, which enables us to relax” (Family survey).

- Benefits for the families include: access to different opportunities and independence for the children and young people with LLCs; a total break from caring; quality time together as a couple or family with other family members; something to look forward to; improved well-being, reduction in isolation and promoting resilience to cope with challenges.

“Parents can recharge their batteries safe in the knowledge their child is in a safe environment, with professional carers, with the familiarity of surroundings & staff” (Professional survey).

“It's good to just, you know mix with everybody else & chill out with everybody else & you know that understands your needs &, not just the staff but the other people who come here as well” (Young person forum).

Theme 3: Emergency care provision

- There is a lack of appropriate emergency care options for many children and young people with LLCs due to their level of complex needs; leading to high levels of anxiety in families.

“We have no other options which will be VERY scary from this year when CH facilities won't be an option for us anymore” (Family survey).
• CH emergency care delivers a high quality, responsive, needs-led service to the whole family.
• Key factors of the service include: the existing relationship with CH staff; responsive care in a choice of location; professional, competent staff.

“CH Hospice to Home is such an excellent service & provides such flexibility that the parents really value” (Professional survey).

• Benefits for the families include: reassurance that the child is being well cared for by staff who know them; being able to concentrate on the emergency; prevention of hospital admissions or reduced length of stay for the child; increasing empowerment of parents to provide care for the child themselves with CH support.

“The support makes you feel that you are not alone & that your children are not left in a vulnerable position at a difficult family time” (Family survey).

Theme 4: End of life care

• CH end of life care provides tailored support for the whole family, including members of the extended family.

“Parents have focused on the memories they have been able to create & grandparents have felt comfort in knowing their children have been supported through such difficult times” (CH staff survey).

• Key factors of the service include: the trusting relationship with CH staff; responsive care provided in a choice of location to suit the wishes of the family; pre-bereavement support and planning; CH can provide a neutral meeting place and act as gatekeepers when required; CH staff working with external professionals to provide the best care possible.

“I just think that they are so skilled in providing end of life care & they do it in a way that they can have children in for respite who never know that there is another child there having end of life care so it doesn’t impact on the rest of what the hospice is doing… it’s done in skilled way … it’s done with privacy & respect for the people whose child is at end of life. It speaks volumes that 15 years after a child has passed away, the family still want that link & they still have that link” (Professional interview).

• Benefits for the families include: the removal of general responsibilities so the family can concentrate solely on their child’s needs; high quality, personalised care at home or in the well-resourced environment at CH which empowers families to deliver care themselves; pre-bereavement care which facilitates access to bereavement support; support for siblings and wider family members; memory making opportunities.

“CH Hospice to Home team enabled the family to be together in the family home during [child’s] last days. This was invaluable...Thank you!”(Family survey).

Theme 5: Bereavement care

• CH bereavement care provides after-death care for the child and ongoing support to the family for an open-ended period.

“It gives the family ongoing support after community nursing team have stopped having input with the family” (Professional survey).

• Key factors of the service include: after-death care in the Butterfly Suite which provides a private space for the family to be with their child, while staff support them with the necessary activities such as registering the child’s death and funeral arrangements;

“We had the butterfly suite, & that ... was made as lovely as it could have been... & in fact the butterfly suite & all the arrangements there were perfect” (Family interview).

• Individual and group counselling for family members delivered in a choice of locations, including at school for siblings.
“Our daughter [sibling of child with LLCs] benefits from seeing her counsellor at CH, who visits her at school” (Family survey).

- Benefits for the families include: continuity of care into bereavement for the family due to the existing relationship with CH staff who knew the child; experienced staff providing guidance as needed e.g. when siblings should return to school; the open-ended nature of the bereavement support; linking with other families in a supportive network for peer support.

“CH played a huge part in our life for over 9 years… supporting us though troubled times, so… it’s still important to me to have some kind of link to CH” (Family survey).

Theme 6: Value for money of CH services

- Only a few participants spoke about the value for money of CH services due to participants reporting a lack of knowledge on the issue.
- CH was viewed as being good value for money compared to a child being admitted to hospital where additional resources would be required to meet the child’s complex needs above the average ward costs.
- CH was considered to provide an excellent quality of care with specialised staff and resources which are not available elsewhere.

Theme 7: Competence

- Throughout all phases of the evaluation the high level of competence of CH staff and services were viewed as a significant factor in the high quality of care provided across the service.
- Key factors include: the trusting relationship and good communication between CH staff and the families; staff maintain their high level of skill through regular use, especially for end of life care and symptom management; staff provide a personalised, attentive and respectful service which involves the whole family in decision making; CH provides a comprehensive service to families which is viewed as superior to other available services.

“The child being nursed by people who have the knowledge and skills to provide palliative and end of life care which can either be at CH or at home, helping the child and the family to be in the environment that is best for them” (Professional survey).

- Benefits for the families include: a high level of confidence in the care provided by CH staff to the child; families feel well supported by the holistic & professional service from CH staff from planned short breaks through to bereavement care.

“Caring for our daughter is 24/7 and exhausting and emotionally draining, we know her health needs are competently cared for whilst staying over at CH” (Family survey).

Theme 8: Prioritising planning and emergency care

- End of life care and emergency care was prioritised over planned care by participants.

“The priority of CH care should be end of life care… followed by emergency care, followed by respite care” (Family interview).

- The lack of other emergency care options for most families increases the priority of emergency care provided by CH.

“If it’s a real emergency, how can you do without that? What would you do? ... I think it’s more valuable, if you actually weighed it up, the planned stuff is lovely and it’s something to look forward to … but if I was given the choice … I think that actually emergency care is more valuable” (Family interview).

- Planned short breaks were reported to be very important to build the trusting relationship between CH staff and families; giving families’ confidence in CH emergency care and preventing families reaching crisis where they require emergency care.
“Planned care on a regular basis is vitally important so staff keep up to date with knowledge of your children so that they are able to jump in competently in an emergency situation” (Family survey).

- Participants suggested that 10-15 nights of planned short breaks was the minimum required to maintain family confidence and a good relationship between CH and families.

**Theme 9: Raising awareness of the CH service**

Suggestions made to raise awareness of CH services include: keep families up to date regarding the services available; raise awareness with families from multicultural backgrounds; increase the use of social media; update the website regularly and add an interactive section for professionals and families; increase networking with all relevant professionals and services who work with children; advertise and hold meetings in settings such as GP practices, hospitals, special schools, children’s centres, community groups and charity shops; hold open days, joint training and study days for professionals; make the CH eligibility criteria more easily available to potential families and professionals; and have a dedicated member of staff with an awareness raising role.

**Theme 10: Future service provision**

- Recommendations made for the future service provision include: expand the Hospice to Home service, family support and counselling services to help more families, including siblings and parents; consider building a Liverpool based hospice or day care provision to reach more families outside of Wirral; build another unit to provide planned care for healthy children with LLCs, who do not yet meet the eligibility criteria but require specialist equipment, and/or assistive technology and competent staff.

- **Young adult transition**
  The lack of appropriate hospice and respite provision for young adults over 23 who are discharged from CH was a major concern for all participants, and a source of high anxiety for families.

“*We are about to leave the CH service and are very worried about our daughter’s future needs as we have nothing else to replace CH*” (Family survey).

- Recommendations made for *young adult transition* include: CH to become involved in strategic planning to address the gap of provision nationally; CH to have a dedicated member of staff to support families approaching transition; and for CH to work jointly with local adult hospices to support young adults prior to & following transition from CH.

- **Developing partnerships with other providers**
  CH have good partnerships with many services but recommendations to further develop partnerships include: explore options for other joint working; good communication and networking with other hospitals, palliative care providers, voluntary and community sectors and local schools; hold themed joint training and study days; develop secondments and placements for, and with, other providers; CH to take a lead role within the palliative care networks; create a link role at CH for the acute services; and develop partnerships with specialist on-call support.

**Recommendations**

Based on the findings presented in the full report the following recommendations are made.

**RECOMMENDATION 1:** Consider raising awareness about the range of services offered by CH to widen access by:

- Providing information in different formats to families and professionals about the services available, the referral criteria and how to access services.
- Improving and updating the website regularly to include information and developing interactive pages for families and professionals;
- Increasing links and networking regularly with hospitals and other providers.

**RECOMMENDATION 2:** Consider **dissemination of expertise** through existing and new partnerships by:

- Developing joint training days and attend meetings to give presentations and seminars;
- Developing secondments and placements at CH for other providers, such as hospitals and community nursing services;
- Developing a named link role with other key partners to raise awareness and share learning.

**RECOMMENDATION 3:** Consider introducing ways of **improving communication and information sharing about children’s care** with families & external professionals by:

- Introducing a Hospice to Home communication book to record details about the child’s stay including sleeping, eating, bowel movements and seizure patterns, illness and general health and well-being during their short break;
- Introducing the option for families to complete the care plan online, so it can be done in advance or kept up to date for emergency care;
- Ensuring all parties are aware of the importance of carefully reviewing the care plan, equipment and medication checks highlighting any changes since the last visit;
- Providing detailed feedback to professionals when children do not meet the eligibility criteria;
- Ensuring good communication and notification of death with all key professionals who have been involved in the children’s care;
- Taking a lead role in palliative care networks and attending multi-disciplinary meetings for children.

**RECOMMENDATION 4:** Consider possible solutions to **reduce barriers** for families wishing to access services, increasing support & reducing isolation for the child, siblings and family by:

- Introducing planned day care in settings across the catchment area to ease access and to provide short breaks through the Hospice to Home team to families who do not wish to use overnight short breaks;
- Increasing the frequency of social events across the catchment area and networking methods for young adults with LLCs using CH and siblings;
- Introducing internet forums for parents in an interactive section of the website;
- Facilitating regular sessions that the whole family can access (including evenings and weekends);
- Booking planned short breaks in shorter blocks throughout the year; prioritising the most vulnerable families to receive short breaks during peak times;
- Offering last minute planned short breaks to families who struggle to book ahead due to their child’s fluctuating needs;
- Developing a key worker system to build relationships with families new to the service and support them to access the different services provided;
- Training of extended family members and friends to increase the availability of emergency support;
- Considering a later pick up time on a Sunday to provide a full short break weekend or explaining to families the reasons for the current timings;
- Investigate the option for families to be able to buy CH services using the child’s personal budget to accommodate more children;
- Introducing a tiered service based on regular assessment of children’s needs to meet the varying levels of support required. This would enable children with LLCs who do not meet the high referral criteria, yet still require specialist equipment, assistive technology and appropriately skilled staff to access some support.
RECOMMENDATION 5: Consider how best to support young adults and their families who are leaving CH with their transition into adult services by:

- Developing links with adult palliative care services and the public sector to increase their understanding of the needs of young adults with LLCs;
- Exploring the possibility of providing a level of support to young adults with LLCs over 23 years of age and families in emergency situations;
- Involving the young people in discussions as to the type of support they require and communicate with their families, adult palliative care, public and private sector staff;
- Providing families with information about the adult services available and support them to access this;
- Having a dedicated member of staff or team whose role is specifically for supporting transition and support the young adult and family, working jointly with adult palliative care staff, for six months prior and six months following transition into adult services to ensure that adult palliative care staff gain the skills required to meet the young adults needs.

RECOMMENDATION 6: Consider how CH can contribute to national developments to support the transition of young adults by:

- Highlighting the gap in provision for young adults once they leave children’s hospices for respite and hospice stays;
- Highlighting the lack of appropriate emergency care for children and young people with LLCs due to their complex care needs;
- Evaluating and sharing learning from any transition support developed (recommendation 5)

RECOMMENDATION 7: Consider the following views from service users and stakeholders when proceeding with decisions about the balance of planned and emergency care:

- Balancing the provision of planned short breaks for current and potential families with emergency and end of life care is a challenging matter for all stakeholders and CH, which is unlikely to find a ‘fits all’ answer;
- The minimum number of nights required to maintain a good relationship which builds trust, confidence and shared knowledge between families and CH staff was 10, although most participants felt 10-15 nights would be optimal;
- The ranking of priorities for the different services was (1) end of life care, (2) emergency care and (3) planned short breaks;
- Clear policies and procedures need to be in place about the cancellation of planned care to meet emergency and end of life care demand to increase transparency and understanding between all service users and stakeholders;
- A comprehensive population and needs led assessment will be required if provision is to be mapped to the needs of current and future families.

Conclusions

The range and quality of services provided by CH was valued highly by all participants in the evaluation. When things have not gone as well as expected at CH the staff have maximised the opportunity to learn from the event and families have high confidence in the care provided. The lack of alternative emergency care for many of the families and the transition period are significant concerns for the children and their families. There is also a concern in some families that they may have a reduction in the number of planned short break nights as an outcome from the current CH services review.
The recommendations in the report address the key issues that have arisen from the data in the full report for CH to consider. CH is currently undergoing change and a review of services which this evaluation will feed into. It is anticipated that action on these recommendations will assist with the current changes and development of the CH service. However, it is acknowledged that change can be challenging and cause anxiety for staff and the families using the service. It is hoped that the views of all stakeholders expressed in this report will be useful and highlight any areas where CH may need to engage with them further. The funding of hospices is reliant on demonstrating improved outcomes or benefit to funders, so methods of gathering such evidence through activity data and feedback from service users is vital.

Many of the recommendations are internal matters for CH, but some relate to effective partnership working, and the potential to work with other services to explore opportunities to bridge the gap in current service provision. Like most hospices, CH has moved towards integrated working with other services rather than the traditional silo model. There are, however, still opportunities to develop the field of palliative care for young adults, particularly the transition period, through joint working with a range of organisations. CH is well placed to take an active role in this as experts in the field.

References


