

## SCHEDULE 2 – THE SERVICES

### A. Service Specifications

Service Specification No.	1
Service	Children's Emergency Respite Service
Commissioner Lead	NHS Wirral Clinical Commissioning Group
Provider Lead	Claire House Children's Hospice
Period	3 years (1 <sup>st</sup> April 2016 – 31 <sup>st</sup> March 2019)
Date of Review	1 <sup>st</sup> November 2016

### 1. Population Needs

#### 1.1 National/local context and evidence base

Better Care: Better Lives (DH 2008) sets the future direction for children's palliative care services, to tackle inequalities and improve the experiences of children and young people and their families. It is based on the recommendations of the Independent Review of Children's Palliative Care Services (May 2007). The review identified the lack of short breaks as a key issue for families, and significantly increasing the range and availability of short breaks was a priority in the NHS Operating Framework.

The future changes and impact of the Children and Families Act 2014 and The Care Act 2014 legislation and the implementation of the SEN:D reforms in 2014 will have clear recommendations around the provision of services and care for this group of children.

Children/ young people with life limiting/life threatening illness and their families require high quality, accessible, responsive service matched to individual need, focused on improving their life experience. Claire House will provide emergency respite including end of life care for children and young people who have a life threatening or life limiting condition and who have palliative care needs.

Emergency respite/unplanned care includes end of life care, symptom management, respite following prolonged or complex hospital admission, significant family illness or events affecting the provision of care for a child (e.g. where the existing care package is not able to respond rapidly). Having this element of care provision commissioned enables Claire House to be able to prioritise this and respond rapidly and flexibly to requests for emergency respite and unplanned care. This element of care is provided above any other planned respite and support care at the Hospice or at home, which is resourced by the Hospice as a charity.

This service is provided for families to meet the needs of families as the main carers.

### 2. Outcomes

#### 2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	1.6
Domain 2	Enhancing quality of life for people with long-term conditions	2.1, 2.4
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care -Improving the experience of care for people at the end of their lives.	4.6

Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm	
----------	--	--

## 2.2 Local defined outcomes

- Improved quality of life for children and their families.
- Lessen the likelihood of family breakdown and the child/ young person needing to be accommodated by the Local Authority.
- Proved specialist respite care for crisis management.
- Improve support networks for children and young people with a life-limiting and life threatening conditions
- Reduced hospital spells or episodes for children.

## 3. Scope

### 3.1 Aims and objectives of service

- To provide emergency respite for children, young people with a life – limiting and life threatening conditions
- To improve outcomes and experiences for children, young people and their families living with a life – limiting and life threatening conditions; for families with children who have life limiting or life threatening conditions to have the support they need to live ordinary family lives as a matter of course.
- To work in partnership with the child, young person and family to provide the highest standards of care in a home from home environment and to support all family members
- To ensure an effective integrated model of care is developed that is safe, provides a quality and cost effective service that supports the end of life needs of children, young people and their families.
- To support the development of effective partnership arrangements between health providers that enables advanced planning and co-ordination of integrated care.
- To provide advice, review and feedback for health professionals and families.
- To utilise the project in conjunction with existing services to support the development of comprehensive children's community nursing; which meet the varied needs of children and young people and move care closer to home where clinically safe and appropriate to do so.

### 3.2 Service description/care pathway

The service will:

- Deliver an emergency respite service for 110 nights (ceiling).
- Be person centred with the ability to respond rapidly but safely to facilitate choice in place of care.
- Be provided by practitioners with appropriate qualifications, skills set and expertise.
- Work collaboratively with statutory services, maximising the services the child and family receives. Work duplication will be reduced and therefore resource waste will be eliminated.
- Take into account safety issues in order to reduce any potential harm for the child, family or the staff providing the service.
- Implement and monitor policies in order to reduce risks associated with all aspects of clinical governance.
- Establish and agree an individualised care plan with each family.
- **Claire House is responsible for all of the governance and monitoring with regards to Non-Medical Prescribers**

### 3.3 Population covered

All children and young people within Wirral aged 0-18 years inclusive with an identified need registered with a Wirral GP or who reside in Wirral.

### 3.4 Any acceptance and exclusion criteria and thresholds

Referrals for emergency respite can be made by both families and health or social care professionals.

The reasons for the referral for emergency respite may include:

- Close family bereavement
- Parent/carer exhaustion
- Parent/carer illness/hospital admission
- Step down from hospital after a prolonged stay or major surgery
- Breakdown of care package (short term only)
- Significant building work at home.

Claire House will endeavour to meet the requests for emergency respite but will always prioritise referrals for end of life care

### 3.5 Interdependence with other services/providers

Claire House will work in partnership with Commissioners, existing children's community nursing, Continuing Care and Complex Care Teams, Alder Hey specialist palliative care team and tertiary and secondary care providers.

Emergency Respite is also commissioned at Claire House by 6 other Merseyside CCG's.

## 4. Applicable Service Standards

### 4.1 Applicable national standards (eg NICE)

- DH (2008) Better Care Better Lives. Improving Outcomes and experiences for CYP and their families living with life-limiting and life –threatening conditions. DH London
- NHS England (2013). E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications.
- Children and Young People's Health Outcomes Forum - Report of the Long-term Conditions, Disability and Palliative Care Subgroup (2012).
- Children and Families Act 2014 and The Care Act 2014: SEND Reforms

### 4.2 Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

- Together for Short Lives (TFSL) (2013) Commissioning children's palliative care: A guide for Clinical Commissioning Groups (CCGs)
- Together for Short Lives (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions
- Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives.
- Noyes J, Tudor Edwards R, Hastings RP, Hain R, Totsika V, Bennett V, Hobson L, Davies G, Humphreys C, Devins M, Haf Spencer L, Lewis M (2013). Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. BMC Palliative Care 2013, 12:18.

### 4.3 Applicable local standards

- NWCYP Palliative Care Network Strategy 2011-14

## 5. Applicable quality requirements and CQUIN goals

### 5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

### 5.2 Applicable CQUIN goals (See Schedule 4 Part E)

See separate CQUIN documentation.

## 6. Location of Provider Premises

**The Provider's Premises are located at:**

Claire House Children's Hospice  
 Clatterbridge Road  
 Bebington  
 Wirral  
 CH63 4JD

**7. Individual Service User Placement**

The service will collect activity and performance information as specified below and a report will be sent to the commissioner for each CCG by the 15<sup>th</sup> working day:

- |                                    |                                    |
|------------------------------------|------------------------------------|
| • Q1: Apr-Jun reported by 15/07/16 | • Q2: Jul-Sep reported by 15/10/16 |
| • Q3: Oct-Dec reported by 15/01/17 | • Q4: Jan-Mar reported by 15/04/17 |

Measure/Outcome	Additional information/Target	Reporting mechanism and frequency
<b>Activity</b>		
Total number of children on Claire House emergency respite service records		Quarterly report
No. of children with an individualised care plan	100% have a recognised individual care plan	Quarterly report
No. of new referrals		Quarterly report
No. of re-referrals		Quarterly report
Referrals by source	Alder Hey, GP, Children's Community Nursing Service etc and place of care at point of referral	Quarterly report
Gender and ages of all referrals	Breakdown by age bracket (0-3, 4-7, 8-10, 11-15, 16 plus)	Quarterly report
Length of time from referral to death (or discharge)	For each referral (time form referral to death is the time from referral for end of life care to death to demonstrate this time which may be hours, days or months)	Annual report
Reason for referral for emergency respite	Breakdown by close family bereavement, parent/ carer exhaustion, parent/carer illness/hospital admission, step down from hospital after a prolonged stay or major surgery, breakdown of care package (short term only), significant building work at home etc	Quarterly report
<b>Outcome</b>		
Nature of support required	Breakdown oncology, non-oncology etc	Quarterly report
No of children provided with emergency respite care		Quarterly report
Length of stay	For each referral	Quarterly report
No. of commissioned emergency respite nights used	For each referral	Quarterly report
Outcome	Breakdown deceased, step down etc	Quarterly report
No. of Significant Event Analysis completed	100% for every death	Quarterly report
Total onward referrals	No. and destination	Quarterly report
<b>Benefit analysis</b>		
No. of unplanned hospital	For each referral	Quarterly report

admissions avoided		
Cost savings per child	Breakdown HDU, oncology, no. nights on call etc.	Quarterly report
<b>Patient experience/satisfaction</b>		
Choice in preferred place of care	Evaluation of preferred and actual place of care	Quarterly report
Family survey – numbers of parent/carer feedback	Number and qualitative – comments	Annual Report
<b>Infection control</b>		
Rates of MRSA	Zero tolerance	Quarterly report
Rates of Clostridium difficile	Minimise rates	Quarterly report
No. of harm free incidents e.g. grade III pressure ulcer	Minimise rates	Quarterly report