NHS
St Helens
Clinical Commissioning Group

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Our Ref: FOI 8231

Date: 2nd March 2021

Dear Sir/ Madam

Re: Freedom of Information Request

Further to your recent Freedom of Information request regarding Children and Young People Palliative care, please see below our response to your request.

Request:

The questions below which we would like you to answer are designed to help me understand how you commission children's palliative care for children and young people with life-limiting and life-threatening conditions in your local area. In order to help you meet my request, I provide definitions to the terms I use in my questions below:

Children's palliative care

"An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement."

Life-limiting and life-threatening conditions

"Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer."

End of life care

"Care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement."

Please note that NHS England and NHS Improvement has created a draft Children's and Young People's Palliative and End of Life Care Service Specification. This is available for CCGs to access from the FutureNHS Collaboration Platform

The following national standards apply to palliative and end of life care for children and young people in England:

NICE Guidance NG 61: End of life care for infants, children and young people with life-limiting conditions: planning and management
https://www.nice.org.uk/guidance/ng61

NICE Quality Standard QS 160: 2017. End of life care for infants, children and young people – NICE quality standard [QS160].
https://www.nice.org.uk/guidance/qs160

Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'.
http://bit.ly/2oOUsfj

NICE guideline NG43: 2016. Transition from children to adults' services for young people using health or social care services
https://www.nice.org.uk/guidance/ng43

NICE Quality standard QS140: 2016. Transition from children to adults' services
https://www.nice.org.uk/guidance/qs140

My questions

1. Do you have a children's palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.

2. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan? (Yes/No)

3. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care? (Yes/No)

4. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it? (Yes/No)

5. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No)

6. Do you have a children's palliative care service specification which states that parents or carers of infants, children and young people approaching the end of life should be

offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No)

7. Do you have a children’s palliative care service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care? (Yes/No)

8. Do you have a children’s palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite? (Yes/No)

Response:

Please see the attached service specification which will answer the above questions.

Should you require any further information or clarification regarding this response or do not feel that your request has been answered as you would expect, please contact us to discuss.

We also wish to take this opportunity to inform you that a formal complaints and internal review process is available, which will be managed by a FOI Appeals Officer.

This can be formally requested and must be done within a reasonable period of time (3 calendar months) from the date this response was issued.

Where you are not satisfied with the response to a request for information that falls within the Environmental Information Regulations, you should make a representation for a review to FOI Appeals Officer, sthelensccg.foi@nhs.net within 40 days of receipt of the response.

If you are not satisfied with our review under the Freedom of Information Act or the Environmental Information Regulations, you may apply directly to the Information Commissioners Office (ICO) for a review of your appeal decision. Generally, the ICO cannot make a decision unless you have exhausted our complaints procedure.

The ICO can be contacted at;

ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF
www.ico.gov.uk

Should you need any further clarification or assistance, please do not hesitate to contact me quoting the above reference.

Yours sincerely,

Angela Delea

Angela Delea
Associate Director – Corporate Governance
NHS St Helens Clinical Commissioning Group

SCHEDULE 2 – THE SERVICES

A. Service Specification

Service Specification No.	
Service	**Palliative Care Services for Children and Young People- Claire House: To include Community Support and Emergency Respite Provision**
Commissioner Lead	**Suzanne Rimmer Assistant Director Children's Health (Integrated Commissioning)**
Provider Lead	**Claire House Hospice**
Period	**1st April 2020-31st March 2024**
Date of Review	**Annually as part of contract monitoring**

1. Population Needs

1.1 National/local context and evidence base:

The government paper Better Care Better Lives (Department of Health, 2008) recognises the specialist skills and expertise of the voluntary sector, particularly children's hospices, in palliative care and end-of-life care. This paper is further supported by the NHS Long Term Plan which supports local partners working with hospices to identify the most appropriate ways to provide and deliver this support for children and their families. The NHS Long Term Plan (v1.2 August 2019) states that:

"*With patients, families, local authorities and our voluntary sector partners at both a national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care. By rolling out training to help staff identify and support relevant patients, we will introduce proactive and personalised care planning for everyone identified as being in their last year of life. A consequence of better quality care will be a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen*"

It also commits to an enhanced funding programme for palliative hospice care for Children and Young People (CYP) with CCGs identified to lead on a local partnership approach to the planning and delivery of services:

"Children's palliative and end of life care is an important priority for the NHS. But local NHS funding has not kept pace with growth in clinical care costs or inflation, and NHS England's children's hospice grant programme currently provides an annual contribution of £11m. Over the next five years NHS England will increase its contribution by match-funding clinical commissioning groups (CCGs) who commit to increase their investment in local children's palliative and end of life care services including children's hospices"

A Guide to Children's Palliative Care: Supporting babies, children and young people with life-limiting and life-threatening conditions and their families (Fourth Edition 2018) also provides a framework and quality standards for the planning and delivery of palliative care for CYP.

Some of these standards that are to be included within the provision of this service are:

- Palliative care can be seen as a thread that runs through the lives of children, often alongside other treatments and this is why the concept of parallel planning is important
- Palliative care needs to be dynamic and responsive to the changing needs of children and their families
- The need for a palliative care approach should always be assessed on an individual basis
- Pain and symptom management is a quality priority
- All families should be provided with accurate and relevant information
- Where possible, children should be cared for in the place of the family's choice, including at home
- Emotional, psychological and spiritual support should be offered to the child and those close to him or her
- Children and young people should be given the opportunity to access education (or employment) that is right for them
- The child and family's wishes concerning end of life care should be discussed and planned for well in advance and should be supported by a co-ordinated team

This service specification is based on a four year funding/ Grant Agreement that has been reached between this Clinical Commissioning Group (CCG) and this Provider (as identified within this contract) who will have available a menu of services for children with palliative care needs who are eligible, based on the threshold criteria.

The Provider is expected to provide:

1. Emergency respite care, (which includes end of life care (EOLC) for children and young people who have a life threatening or life limiting condition and who have palliative care needs) of 30 bed nights per year, with an option for the CCG to purchase additional nights as required
   And
2. A 24 hour rapid response service for EOLC (Hospice at Home), working in partnership with existing local children's community nursing service and Alder Hey(regional) specialist palliative care teams

(NB: The allocation of funding between the 2 elements will be reviewed on an annual basis as the demand for respite beds is expected to fluctuate)

The Provider is expected to provide holistic, family centred care in either a residential establishment or within a child's own home.

It is anticipated that the model of delivery will be as non-medicalised as possible within the parameters of the child's medical and nursing needs.

The Provider will also make available specialist expertise and advice to local children's community nursing teams and paediatric teams as part of local integrated pathways of care, and the wider local workforce as required, within the child's local area. The CCG would wish to work in partnership with the Provider and local service providers to further shape this aspect of the service specification and Grant Agreement as our local integrated care system evolves

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).

2. Key Outcomes

2.1 National outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-term conditions	✓
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.	✓
Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm	✓

2.2 Locally defined outcomes

- Children and young people with palliative care needs and their families will have their emotional and physical challenges mitigated by the care and support they receive by the services delivered by the hospice

- Families and children report that their social, cultural, spiritual, physical and emotional needs of the child/young person and their family are met.

- It can be demonstrated that child/young person is pain free or pain is minimised as far as possible

- Child and family can demonstrate that they are supported to improve the quality of their lives through access to specialist clinical (and psychological) expertise, either for regular interventions, in an emergency or for respite care

- Parents and children report they are well informed about their conditions and the support/services available both within the hospice and within their own local area

- Parents and siblings experience choice and a positive experience in the last days/hours of their child's (sister or brother's) life through the provision of timely interventions and support

- The child and family will expect clear links and regular information exchange to be made with the named professional (key worker) in child's local community

- Choice of place of death

2.3 Quality statements

The Provider will adhere to and demonstrate compliance with the following quality statements (End of life care for infants, children and young people Quality standard [QS160] September 2017):

Statement 1: Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Statement 2: Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.

Statement 3: Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

Statement 4: Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

Statement 5: Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Statement 6: Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care

3. Scope

3.1 Aims and Objectives of the Service

The Provider will aim to offer high quality care and support to children and young people with life limited or life - threatening illnesses, who are registered with a GP within the catchment area for St Helens Clinical Commissioning Group (CCG).

The Provider will work in the context of the wider network of services and support that are commissioned and provided by the CCG and other partners for these children and families.

The Provider will work:

- To support the development of effective partnership arrangements between health providers that enables advanced planning and co-ordination of integrated care.
- To provide critical review and feedback for health professionals and families.
- To work closely with neighbouring areas with consideration of geographical boundaries and other services involvement e.g. other Merseyside CCG’s, West Lancashire, Cheshire.
- To ensure that continuous and clinically led reviews of the service are undertaken to review benefits of proposed model of care in conjunction with full cost evaluation of service development.
- To work with the CCG and provider services locally to support the transformation of integrated paediatric services including the development of comprehensive children’s community nursing services/ pathways; 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/Pathway

The service will:

- Deliver an emergency respite service with the option to fund additional nights if required and approved by the CCG.
- Deliver an equitable, rapid response EOLC service to be available 24/7 365 days per year
- Be person centred with the ability to respond rapidly but safely to facilitate access to respite provision.
- 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 including help and support for siblings.

3.3 Population covered

All children and young people within St Helens aged 0-23 years with an identified need registered with a St Helens GP

Description of Life-limiting or life-threatening conditions:

Category 1	Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation
Category 2	Conditions where premature death is inevitable, these may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health. Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1.
Category 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses and other severe metabolic conditions.
Category 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Palliative care may be required at any stage and there may be unpredictable and periodic episodes of care Examples: severe cerebral palsy, complex disabilities such as following brain or spinal cord injury

A guide to Children's Palliative Care TfSL 2018

3.4 Any acceptance and exclusion criteria and thresholds

All referrals will be accepted for children and young people where there is an agreement between professionals and the family that end of life is the now the focus of care and home is the preferred option for EOL.

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

3.5 Interdependence with other services/providers

- Alder Hey specialist palliative care teams
- Children and Young People Continuing Care – lead nurse as point of contact and links with Complex Needs Panel
- Local health services to include Primary Care, Children's Community Nursing, Paediatrics
- Local Social Care services
- Local Education services

4. Applicable Service Standards

4.1 Applicable national standards

End of life care for infants, children and young people with life-limiting conditions: planning and management
NICE guideline [NG61] Published date: 07 December 2016   Last updated: 25 July 2019

A Guide to Children's Palliative Care Supporting babies, children and young people with life-limiting and life-threatening conditions and their families Fourth edition 2018

End of life care for infants, children and young people Quality standard [QS160] Published date: 12 September 2017

4.2 Applicable local standards

Children and Young People Complex Needs and Continuing Care Provision

4.3 Safeguarding

The Provider will comply with safeguarding policies for St Helens CCG and the St Helens Safeguarding Children Partnership Board. These documents are available via the St Helens Safeguarding Children Partnership Board website. The Provider will contribute to the delivery of the Early Help offer as specified by the Local Authority and St Helens Safeguarding Children Partnership Board.

4.4 Equalities

- The organisation is working towards full cultural competence in that: access should be available to all families regardless of their age, gender, race, religion, ability, class, culture, ethnicity or sexuality'.
- Translation costs are accessible when required. Exceptional cases involving additional funding will be requested by the service and reviewed by the commissioner on a case by case basis

- Leaflets and information about the service is fully accessible to children and young people and their families where English is not a first language
- Ensure the service is accessible to families, specifically those who have difficulty communicating or have a disability. Exceptional cases involving additional funding will be requested by the service and reviewed by the commissioner on a case by case basis
- Ensure mechanisms are in place for families who do not speak English or have difficulty communicating to participate and access the complaints system. Exceptional cases involving additional funding will be requested by the service and reviewed by the commissioner on a case by case basis
- Compliant with the Equalities Act 2010
- Continue to ensure the service captures the Equality strands information as set by the commissioners, collecting statistical data and this information is further used in the development of accessibility for young people

5. Location of Provider Premises and Accessibility

This service will be provided by Claire House Children’s Hospice

This service will operate out of:

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

Activities or sessions that take place outside of official premises will ensure appropriate safeguarding measures are in place.

6. Key Performance Indicators

The service will collect activity and performance information as specified below and a report will be sent to the commissioner in line with the agreed/ scheduled quarterly contract monitoring meetings.

Activity and quality information to be submitted for each quarter will include:

For each individual:
New referral or re-referral (known to service)
Gender Age and Ethnicity
GP
Referral Source
Reason for referral: - For emergency respite night - For EOLC support Category of Need
Duration of support: - Number of respite nights used - Length and type of EOLC support
Outcome of provision Include place of death, impact for parent/ carer and YP, referral to other services, home provision, MDT contributors
Confirmation of Personalised care plan/ Advanced care plan in place
Parent/ Carer/ Young Person feedback- evaluation of support

Service Overview:
Per Quarter- total number of respite bed nights used Running Annual total of respite bed nights used Costs to date
Per Quarter – total number of CYP EOLC support provided Running annual total Costs to date
Case Study- against service and quality standards
Compliments and complaints and action taken
Friends and Family Test
Infection Control rates: MRSA C Diff Pressure Ulcers
Service Improvement Opportunities/ Initiatives