

Freedom of Information Response

Request: FOI 096

Date received: 15 February 2021

20 day response deadline: 15 March 2021

Question:

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:

- 1) Do you have a children's palliative care service specification? If so, please attach a copy to your response to this request.
No. NHS Bury CCG do not have a sperate specification for this provision. However, children's palliative care in Bury is provided by the Children's Community Nursing Team (CCNT). This service is provided by the Northern Care Alliance.
- 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?
No, however, the CCNT deliver nursing care closer to home for children and young people who are acutely ill, including those with long term conditions, complex health or palliative care needs. The service principles are :
 - **Safeguarding;**
 - **No decision about me without me;**
 - **Shared Decision making;**

- **Safety & Effectiveness;**
- **Using an evidence-based nursing model and process;**
- **Partnership and involvement of children/young people and families in all aspects of care;**
- **Partnership with other health care professionals and agencies;**
- **Promotion of health and well-being;**
- **Accessibility and provision closer to home;**
- **Improvement of health outcomes;**
- **Deliver a service based on the You're Welcome Quality Criteria.**

- 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?

No, however, our CCNT specification states that for those with palliative care needs that they are actively case managed by appropriately skilled staff in partnership with primary care, specialists and children's services Community Paediatrician (Dr Bose-Haider) and families supports this delivery.

- 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?

No, the CCNT follow Government guidance 'When a child dies guide for parents and carer' information is included in there.

- 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?

No, however, the aim of the service is to provide a united and coordinated service between primary, secondary, community and care in the home setting and to facilitate early discharge and prevent attendance or admissions to hospital. This is achieved by providing the child, young person, parent and carer with advice, education, counselling and nursing care within the community environment. The team also liaises regularly with GP's, consultants, health visitors, school nurses and hospital staff.

- 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?

No, however, support is given and parents and carers are signposted to Winston's Wish, SANDS, Child Bereavement Network, Lullaby Trust, Child Bereavement UK and counselling at Derian House. Palliative care counselling - Rainbow Trust Children's Charity provides a range of support to parents from diagnosis through treatment and beyond. They support the whole family both emotionally and practically including siblings and grandparents.

<https://www.rainbowtrust.org.uk/support-for-families/for-parents>

- 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?

No. This is not detailed in the CCNT specification

- 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?

No, in practice referrals made to Derian House for inpatient care for families as well. (Families not able at present due to COVID).

Queries:

It is hoped you will find these details helpful to your enquiries. However, if you are unhappy with this response please let us know, giving your reasons for believing we have not satisfied the requirements of the

Freedom of Information Act.

The matter will then be considered by the Freedom of Information officer who will respond in writing. This correspondence will include details of the Information Commissioner who you can contact if you remain dissatisfied with our response.

If you have any further queries, please contact

NHS Bury Clinical Commissioning Group (CCG)
Townside Primary Care Centre
1 Knowsley Place, Knowsley Street, Bury, BL9 0SN

www.buryccg.nhs.uk

Email buccg.burypatientservices@nhs.net

Telephone number – 0161 253 7854