



North East Lincolnshire
Clinical Commissioning Group

Your Ref: NEL 2039

10 March 2021

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Dear Mr Cooper

Your Request for Information

I am writing in response to your recent request that we received on 15 February 2021, in which you requested the following information under the Freedom of Information Act 2000.

Information Requested

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."

Clinical Chief Officer: Dr Peter Melton

Lay Chair: Mark Webb

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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

NHS North East Lincolnshire Clinical Commissioning Group (CCG) can confirm that the CCG does not hold the information requested.

The CCG does not have a service specification for palliative care; palliative care services are commissioned as part of the wider Children's Community Nursing Service; however, this is not formerly outlined within the service specification.

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If you have any concerns about the way your request has been handled; the operation of the Publication Schemes; the response received, or the 'exemption' decision, you should, in the first instance contact me to try to resolve them. If you are not happy with the outcome, you can write to our Chief Clinical Officer at the address above to make a request for an internal review.

If you are not satisfied with the outcome of the internal review, you can then write to the Information Commissioner:

FOI/EIR Complaints Resolution
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline telephone: 0303 123 1113

Please do not hesitate to contact me should you need any further assistance. You can find out more information about our Clinical Commissioning Group by visiting our website <http://www.northeastlincolnshireccg.nhs.uk/>

Yours sincerely

Freedom of Information Officer
NHS North East Lincolnshire Clinical Commissioning Group