



**North Lincolnshire**  
Clinical Commissioning Group

Your Ref: NL 1874

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/Response

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."*

Accountable Officer Emma Latimer

Chair Dr Faisal Baig

*The Freedom of Information service is provided to NHS North Lincolnshire Clinical Commissioning Group (CCG) by the Freedom of Information Team c/o Health House, Grange Park Lane, Willerby, East Yorkshire, HU10 6DT*

*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.

No. NHS North Lincolnshire Clinical Commissioning Group (CCG) can confirm that there is no specification for Children's Palliative Care, as it is under development. Currently, North Lincolnshire Children's Palliative provision is provided by the local Children's Community Nursing Service however, this is not outlined within the service specification.

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)

In relation to questions 2-5, the CCG can confirm No as the specification is under development as described in question 1.

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)

No, the specification is under development as described in question 1. However, as part of a local project, the CCG has commissioned the local children's hospice to support the delivery of grief and loss support in addition to the service the CCG commissions North Lincolnshire Council to provide which includes a grief and loss service to siblings.

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)

No, currently this is delivered informally and is not specified in the Children's Community Nursing Specification. North Lincolnshire CCG is working with Humber Coast and Vale partnership to plan how this can be delivered locally.

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)  
[No, however the CCG can confirm that short breaks are delivered by North Lincolnshire Council and forms part of the Local Core Offer.](#)

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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 [www.northlincolnshireccg.nhs.uk](http://www.northlincolnshireccg.nhs.uk).

Yours sincerely

**Freedom of Information Officer**  
NHS North Lincolnshire Clinical Commissioning Group