

Ref: ER 1988

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."

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

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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.

Yes, NHS East Riding of Yorkshire Clinical Commissioning Group (CCG) jointly commissions the Children's Community Nursing Service, and this service includes palliative and end of life care. As requested, please find attached a copy of the service specification: (ER 1988 – Attachment 1).

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The service specification referred to is for the local Community Children's Nursing Service. The CCG also has access to other specialist services, however as they are not necessarily directly commissioned by CCG's there are no service specifications. There is a regional Specialist Palliative Care Consultant employed by Leeds Teaching Hospitals NHS Trust who works across the region and at Martin House Hospice which also provides palliative care services to the region. The specialist consultant works in partnership with local paediatricians. Our population also accesses palliative care nursing services at Andy's Children's Hospice in Grimsby.

The Yorkshire and Humber Children's Palliative Care Network (YHPCPN), Regional Network Coordinator can be contacted via Martin House Hospice at the following link: <https://www.martinhouse.org.uk/>

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)
Yes. The service specification includes a requirement for joint care planning. This includes children with advanced care needs.
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)
No. The service specification is Children's Community Nursing. All children requiring medical support and intervention have a named Paediatric Medical Consultant. For those requiring specialist care, this will include a named medic from the Specialist Provider (this is an Out of Area Specialist Commissioned Service).
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)
No, this is not included in the service specification for Children's Community Nursing.
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)
The service specification makes requirements of those working within the service to ensure care coordination and input to the multi-disciplinary team supporting that child and family. We do not commission a specialist palliative care team in the East Riding. Specialist palliative care is provided out of area with an understanding of shared care arrangements in local areas.
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

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

Yes. The service specification includes a multi-disciplinary approach in the care and support required to meet the personalised needs of children and their families at end of life and beyond.

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)

Yes – in part. The Children's Community Nursing Service provides end of life care at the choice of place of death which includes the child's home or in the local nurse-led respite facility that has specialist End of Life provision. Consultant advice and care is provided through shared-care agreements.

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)

The Children's Community Nursing team provide care within the local short-breaks respite care facility. The criteria for access include all children and young people with health needs. This includes palliative and end of life care.

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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 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:

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Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline telephone: 0303 123 1113

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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.eastridingofyorkshireccg.nhs.uk.

Yours sincerely

Nicky Lowe

Corporate Services Manager

NHS East Riding of Yorkshire Clinical Commissioning Group

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