

FOI Ref: 2021164  
Date: 5<sup>th</sup> March 2021  
Due date: 15<sup>th</sup> March 2021

Dan Steer  
[Dan.steer@togetherforshortlives.org.uk](mailto:Dan.steer@togetherforshortlives.org.uk)

Dear Dan,

### **Freedom of Information Act 2000 – Request for Information**

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.

NHS Calderdale CCG's answers the questions you ask are all no in terms of specifications; however, it would be worth contacting children's hospices in our area to get a greater understanding of their actual models of provision.

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)

Please refer to our answer to question 1.

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)

Please refer to our answer to question 1.

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)

Please refer to our answer to question 1.

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)

Please refer to our answer to 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)**

Please refer to our answer to question 1.

- 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)**

Please refer to our answer to question 1.

- 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)**

Please refer to our answer to question 1.

I trust that this information answers your request. However if you are not happy with our response or the service you have received in relation to your request and wish to make a complaint or request an internal review of our decision you should write to the Chief Officer, NHS Calderdale CCG, 5<sup>th</sup> Floor, F Mill, Dean Clough, Halifax, HX3 5AX, quoting the reference number above.

If you are not content with the outcome of the complaint or internal review with regards to this Freedom of Information request, you have the right to appeal to the Information Commissioner under Section 50 of the Freedom of Information Act. The Information Commissioner will not investigate your case unless you have exhausted our complaints procedure. The Information Commissioner can be contacted at: The Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

## **Re-Use of Public Sector Information**

If you wish to re-use the information you have requested, in whole or in part, please write to myself at NHS Calderdale CCG, 5<sup>th</sup> Floor, F Mill, Dean Clough, Halifax, HX3 5AX, quoting the reference number above stating the purpose(s) you wish to re-use the information for. You will receive a response within 20 working days of receiving your request with any conditions and charges that relate to the re-use of the information. These will be determined in line with the 'Re-use of Public Sector Information Regulations 2015 (SI 2015 No. 1415).

Yours sincerely

Neil Smurthwaite  
Chief Operating Officer