

Ref: CF1919

12 March 2021

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Dear All

## **FREEDOM OF INFORMATION REQUEST**

I am writing regarding your request for information, which was received on 15 February 2021, about Children's Palliative Care.

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. However, children's palliative care needs are included in a range of other specifications; e.g. children's community nursing, Occupational therapy, specialist psychological support.**

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)*

**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)*

**Not as such, however we have specifications for paediatric services that require medical leadership for all Children and Young People with serious health conditions.**

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)*

**We don't have a specification, but we do have a system by which Children and Young People can access specialist psychological support, CCNs support families to access it. This service is currently under review with the intention to improve access.**

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)*

**No. There is no local specialist palliative team, however the CCNs take this on and liaise with regional specialist team and other local services to ensure a multi-disciplinary service is provided.**

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)*

**The CCNs provide this or enable access to it for families and 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. The small dispersed population means that we cannot maintain such a team 24/7 however the CCNs work flexibly to provide 24/7 support families at EoL.**

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, we support the local children's hospice through grant funding to provide short breaks for Children and Young People with life limiting or palliative needs.**

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on NHS North Cumbria CCG's website.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision you should write to:

Head of Communications and Engagement  
NHS North Cumbria Clinical Commissioning Group  
Parkhouse Building  
Barron Way  
Kingmoor Park  
Carlisle  
Cumbria  
CA6 4SJ  
Email: [FOI@northcumbriaccg.nhs.uk](mailto:FOI@northcumbriaccg.nhs.uk)

If you are not content with the outcome of the internal review, you have a right under section 50 of the Freedom of Information Act 2000 to apply for a decision by the Information Commissioner as to whether we have properly dealt with your request. Please note that an application to the Information Commissioner may be refused if you have not exhausted any organisational review (complaint) procedure we provide, if there has been undue delay in making it, if the Information Commissioner considers your application is frivolous or vexatious or if your application has been withdrawn or abandoned.

The Information Commissioner can be contacted at:

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

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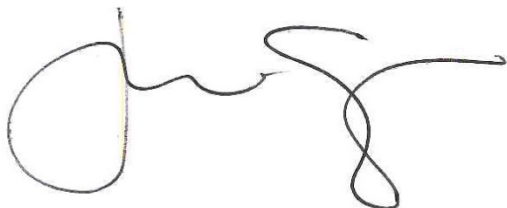
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We will provide this response in another format if requested.

Yours sincerely

A handwritten signature in black ink, consisting of a large, rounded initial 'D' followed by a series of connected, flowing lines that end in a small loop.

Head of Communications and Engagement  
NHS North Cumbria Clinical Commissioning Group