

NEL CSU
1 Lower Marsh
London
SE1 7NT

Email: nelcsu.foi@nhs.net

Dan Steer

Dan.Steer@togetherforshortlives.org.uk

Dear Mr Steer,

Re: Freedom of Information request

Reference FOI.20.NHE181

12 March 2021

Thank you for your request under the *Freedom of Information Act 2000* (the Act). This response is provided on behalf of NHS Northamptonshire Clinical Commissioning Group (CCG). Your request, along with the CCG's response, is detailed below.

- 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 we do have a palliative grant agreement, please find attached documents.

- 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

- 2. 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

3. 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)

Yes

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)

Yes

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)

Yes

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, but for the nursing component only. Please find attached local end of life pathway for children's community nursing.

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)

Yes

Please note: The grant agreement is reflective of hospice care arrangements between Northamptonshire CCG and its paediatric hospice providers. Northamptonshire does not currently have a single specification covering all of children's palliative and end of life care, however provision for these children is covered through the service specifications and delivery of a number of our community teams, continuing care services and regional hospices. CCG also have an end of life care pathway in county for children's community nursing. CCG are in

the process of setting up a palliative care pilot in the county which will give us the information required to inform future development in this area, including a potential specification.

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If you remain dissatisfied, you can ask us to review our decision by making a written request for an internal review. In order to assist with the review, you should include your address, a description of the original request and the reasons why you are dissatisfied. Please send this to:

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The review will be handled by more senior staff who were not involved in the original decision. Although this will not apply to Section 36 claimed exemptions in accordance with Department of Health Directive, your request will still be reviewed. We aim to complete all internal reviews within 20 working days. If you then wish to appeal you should contact the Information Commissioner for an independent review at the following address:

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|--------------|--|--|
| 01625 545745 | The Information Commissioner, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF | www.ico.gov.uk |

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Your feedback is welcome to help us improve the service we provide. Please send comments or suggestions to our address.

Yours sincerely,

Freedom of Information Team

NEL