

15 March 2021

**FREEDOM OF INFORMATION – DECISION NOTICE**

Dear Requester

**FOI Reference Number: 002468**

I refer to your email of 15 February requesting information in relation to children’s palliative care. A full copy of the request is attached.

I can confirm on behalf of Norfolk and Waveney CCG and in accordance with S.1 (1) of the Freedom of Information Act 2000 (FOIA) that we do hold the information that you have requested.

Established on 1 April 2020, the CCG is still a newly formed public sector organisation, though we may hold information pertaining to NHS Great Yarmouth & Waveney, NHS North Norfolk, NHS South Norfolk, NHS Norwich and NHS West Norfolk CCGs which date back to April 2013. Where appropriate for the request we have indicated below which of the above previous organisations the information relates too.

**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.**

      The CCG has a draft service specification for its local specialist service provider, see attached.  We have a functioning Children and Young People’s Palliative Care Network for Norfolk and Waveney.  The CCG plan to co-produce a Children and Young People’s Palliative and End of Life care strategy with the Network.  This work will take place during 2021/2022 and will include working towards implementing the new national 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)**

      This is included within the current provider service specification.  This will also be included within the strategy and system-wide service specification.

**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)**

     This will be included within the strategy and system-wide service specification.

**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)**

      This is included within the current provider service specification.  This will also be included within the strategy and system-wide service specification.

**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)**

 This will be included within the strategy and system-wide service specification.

**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)**

      This is included within the current provider service specification.  This will also be included within the strategy and system-wide service specification.

**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)**

      This is included within the current provider service specification with regard to nursing advice.  This will also be included within the strategy and system-wide service specification.

**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)**

      This is included within the current provider service specification.  This will also be included within the strategy and system-wide service specification.

I hope that this answers your queries with the information we currently hold, but if I can be of any further assistance please do not hesitate to contact me.

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to

Arden & GEM CSU

FOI Team, Room 18

Scarsdale

Newbold Road

Chesterfield

S41 7PF

Email agcsu.foi.norfolkwaveneyccgs@nhs.net

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided the CCG.

The Information Commissioner can be contacted at: telephone 0303 123 1113, email casework@ico.org.uk and <https://ico.org.uk/global/contact-us/>

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Yours faithfully

Philip Humphreys

***Corporate Senior Manager, Arden & GEM CSU*On behalf of Norfolk and Waveney CCG**