

Our ref: SF/sb/FOI 192-20/21: Steer
Your ref:
Date: 12 March 2021

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Dear Mr Steer

Freedom of Information Act Request: Ref FOI 192-20/21: Response

I am writing further to your request made under the Freedom of Information Act 2000 received on 15 February 2021. NHS Cambridgeshire and Peterborough Clinical Commissioning Group's response is set out 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.***

Yes, we have a service specification as part of the CCG grant agreement with EACH for 2019/21. This accompanies this response letter as Appendix 1.

- 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 – this is standard practice.

- 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)***

Yes – this is standard practice.

- 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)***

Yes – this is standard practice.

- 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

The EACH Symptom Management Nursing Service (SMNS) has a nurse specialist team with specific training in Children's palliative care. This team works as part of the local and regional specialist managed clinical network for children's palliative care.

The Specialist Children's Community Nursing Team, work with EACH to provide palliative care in the community.

- 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.

This is described in the service specification (Appendix 1) with EACH on Page 15 at 3.7.4. This is also provided by CCNs, GPs and acute hospital bereavement teams.

- 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)**

The CCG does not have a specific service specification which covers this.

However, the CCG does support this (via the managed clinical network mentioned above) through the grant funding to EACH. There is a Paediatric Palliative Medicine Consultant hosted by CUH.

- 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, there is not an individual service specification, but this is referred to on page 24 of the attached service specification. Short breaks and respite care is joint responsibility between the Local Authorities and the CCG and is offered via the Local Authority Children with Disability Teams (LA) short breaks scheme. There is also the Children's Continuing Care framework and the grant agreement with EACH. Also, the EACH charity offers this and there is individual commissioning with the Milton Hub.

If you are dissatisfied with how your request has been handled or would like to formally appeal against our response please address your concerns, in writing, to the Freedom of Information Team at NHS Cambridgeshire and Peterborough Clinical Commissioning Group at Lockton House, Clarendon Road, Cambridge CB2 8FH: Telephone: 01223 725400
email: CAPCCG.freedomofinformation1@nhs.net

If, after we have addressed your concerns, you remain dissatisfied with how the CCG has responded, you are entitled to appeal to the Information Commissioner's Office at Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF. Further details can be found at <https://ico.org.uk/>.

Please do not hesitate to contact me if I can be of any further assistance.

Yours sincerely



Sharon Fox
Director of Governance