



Staffordshire and
Stoke-on-Trent
Integrated Care Board

Our Ref: VP/TLR/FOI/1024/1027

31st October 2024

Stafford Education & Enterprise Park
Weston Road
Stafford
ST18 0BF

Telephone: 0300 123 1461

Sent by email

Dear

FOI-1024-1027

Your request for information under the Freedom of Information Act 2000

Thank you for your request for information received on Friday 11th October 2024. We can confirm that the Staffordshire and Stoke-on-Trent Integrated Care Board can provide the following information.

An anonymised copy of this response will be made publicly available on the ICB website.

The questions below which we would like you to answer are designed to help me understand how NHS Staffordshire and Stoke-on-Trent ICB commissions children's palliative care for children and young people with life-limiting and life-threatening conditions in its ICB footprint. 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."

Chair: David Pearson MBE

Chief Executive Officer: Peter Axon

Please note that NHS England has created a draft Children's and Young People's Palliative and End of Life Care Service Specification. [This is available for ICBs to access here from the NHS England website.](#)

We have also launched a new resource to help ICBs commission children's palliative care. This resource can be accessed [here](#).

The following national standards and guidance apply to palliative and end of life care for children and young people in England:

Ambitions for Palliative and End of Life Care. Available to download from: <https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/>

Palliative and end of life care: statutory guidance for integrated care boards (ICBs): <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

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>

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.**

Yes, but we are unable to attach a copy of the service specification at this point in time as we are in the final stages of the approvals process with our service provider(s).

- 2. Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment? (Yes/No). If yes, please attach your completed self-assessment to your response to this FOI request.**

Yes, see below for the ambitions assessment scoring as at 10.10.24.

Name of Organisation(s):	Staffordshire Stoke on Trent ICB					
Name of Person or Group completing the self-assessment:	CYP-palliative care network CIG					
Version Control:12	12					
Date of Completion:	10/10/2024					
Sign off by locality Clinical Lead for Palliative/ End of Life Care:	Yes by system partners					
Mar-24	Level 0	Level 1	Level 2	Level 3	Level 4	Level 5
Ambition 1: Each Person Seen as an Individual	0.0%	0.0%	0.0%	5.3%	63.2%	15.8%
Ambition 2: Each person gets fair access to care	0.0%	0.0%	0.0%	100.0%	0.0%	0.0%
Ambition 3: Maximising comfort and wellbeing	0.0%	0.0%	6.3%	25.0%	18.8%	50.0%
Ambition 4: Care is coordinated	73.9%	4.3%	13.0%	8.7%	0.0%	0.0%
Ambition 5: All staff are prepared to care	0.0%	0.0%	14.3%	42.9%	28.6%	14.3%
Ambition 6: Each community is prepared to help	0.0%	100.0%	0.0%	0.0%	0.0%	0.0%

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 have opportunities to be involved in developing an advance care plan? (Yes/No)

Yes

4. 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

5. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition, their parents or carers and their siblings should be given information about emotional and psychological support, including how to access it? (Yes/No)

Yes

6. 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

7. Do you have a children's palliative care service specification which states that siblings and 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

8. 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

- a. **Note: We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly or providing advice to other nurses providing direct care.**
 - b. **Note: NHS England state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they:**
 - i. **Have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum.**
 - ii. **The ability to manage the full range of symptoms experienced as disease and illness progresses.**
 - iii. **Lead and develop services within their region.**
 - iv. **Enable, support, teach and train other health care professionals.**
9. **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

To request an internal review

You can request an internal review by contacting the Staffordshire and Stoke-on-Trent ICB FOI team by emailing; staffsstokeFOI@staffsstoke.icb.nhs.uk or by post to the address at the top of this letter.

If you are not content with the outcome of your internal review, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the Staffordshire and Stoke-on-Trent Integrated Care Board's FOI complaints procedure.

The ICO can be contacted at:

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

www.ico.gov.uk

Yours sincerely

Lia Pitarokoili
Head of Governance