

Our ref: IG/FOI/FOI.089.24

19 December 2024

Sent via email to: [REDACTED]

Dear [REDACTED]

## Request under the Freedom of Information Act 2000

I write further to your request for information which was received on 5 November 2024, and subsequent clarification received on 21 November 2024, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) does hold the information that you require. For ease of reference your request is set out below and my response follows.

### Your Freedom of Information (FOI) Request:

The questions below which we would like you to answer are designed to help me understand how Powys Teaching Health Board provides children's palliative care for children and young people with life-limiting and life-threatening conditions in its Health Board 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."

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

**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>

## **Questions**

1. In your Local Health Board area, are infants, children and young people with life-limiting conditions, along with their parents or carers involved in the development of advance care plans? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

2. In your Local Health Board area, do infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

3. In your Local Health Board area, are infants, children and young people with a life-limiting condition, their parents or carers and their siblings given information about emotional and psychological support, including how to access it? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

4. In your Local Health Board area, are infants, children and young people with a life-limiting condition cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

5. In your Local Health Board area, are siblings and parents or carers of infants, children and young people approaching the end of life offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

6. In your Local Health Board area, do infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

6a. 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.

7. In your Local Health Board area, do infants, children and young people with a life-limiting condition and their families have access regular short breaks for respite? (Yes/No). If yes, please specify how this is being delivered. If no, please specify why this is not occurring.

8. In your Local Health Board area, how many infants, children and young people are there with life-limiting and life-threatening conditions?

Clarification Requested:

Please can you confirm the age range you require the information on for young people.

Clarification Received:

To clarify, when referring to young people, we mean those aged 14-25.

Powys Response:

Please Note: For information on young people, Powys Teaching Health Boards (PTHB) response relates to the specialist palliative care team providing adult services only (generally 18+). Patients aged Under 18 would be cared for in the children team.

Q1. Yes, all children and their families are involved in any Advance Care Plans in conjunction with the All Wales Palliative Care Network.

Within adult services in Powys we use the My Life, My Wishes advance care planning document which was developed by the Specialist Palliative Care Team, this provides a person held tool / record for advance care planning.

Q2. Yes, all children and their families have a named medical lead and supported in conjunction with the All Wales Palliative Care Network.

Within adult services this would depend on the person's diagnosis and which teams are providing care, in some circumstances this would be provided via commissioned services e.g. the key worker for a person with cancer may be their Cancer Clinical Nurse Specialist (in a commissioned service) at appropriate times in their pathway.

Q3. Yes, All Children and their families with a life limiting condition would be referred for support from a Childrens Hospice where additional support would be offered for the whole family.

For adults with specialist palliative care needs this could be provided via our hospice partners, carers are also signposted to other support agencies as appropriate.

Q4. Yes, whilst PTHB does not have a dedicated Palliative Care Nurse within PTHB, we have a direct link to the All-Wales Paediatric Palliative Care Network where we can access medical support and supervision for case and symptom management.

For those meeting the referral criteria for the adult Specialist Palliative Care, Multidisciplinary Teams (MDT) care is provided but this would not necessarily include the paediatric team - this would be dependent on the individual e.g. where they have transitioned from paediatrics to adult services.

Q5. Yes, this would be offered in conjunction with the two children's hospices which serve the PTHB population.

Yes, adult services would signpost as appropriate for support, Cruse bereavement support is commissioned.

Q6. Children and young people being cared for at home would have 24-hour access to an on-call consultant within the Paediatric Palliative Care Network. Whilst we do not currently offer 24-hour access to children's nursing care through our Childrens Community Nursing team each case is considered on an individual basis, and the team are supported by the children's hospices.

Q7. Yes, children and their families can access respite care from the two children's hospices serving the PTHB population.

Q8. I can confirm that this is information not currently readily available.

Under the terms of the Health Board's Freedom of Information procedure, individuals seeking access to recorded information held by the Health Board are entitled to request an internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request, please contact us directly at the address below or register your complaint via [powysfoi.foi@wales.nhs.uk](mailto:powysfoi.foi@wales.nhs.uk)

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's

Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH.  
Telephone Number: 0330 414 6421.

Yours sincerely



**Claire Roche**  
**Executive Director of Nursing and Midwifery**

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi.

We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.