



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board



Freedom of Information Request: Our Reference CTMUHB_555_24

You asked:

- 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.**

Where appropriate, children are actively involved in the development of advance care plans, considering their current health condition and mental capacity. For children unable to fully participate, advocacy ensures their voice and rights are represented. Advance care plans are developed using a multidisciplinary team (MDT) approach. Delivery occurs through home visits by palliative clinical nurse specialists, local clinicians, and hospice services. The planning process is deliberately paced to ensure all perspectives are considered and the child's best interests are upheld.

- 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.**

Children requiring palliative care are supported by a local paediatrician specialising in palliative care, a consultant general paediatrician who coordinates overall care, and hospice consultants who provide expertise in symptom management when needed. Children who have life limiting conditions, but not currently under the palliative team, will be supported by a local paediatrician and specialist nurse/community children's nurse.

- 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.**

Families are provided with information through discussions with healthcare teams, signposting to appropriate services, and active liaison with support providers. Hospices also play a key role in offering advice and delivering emotional and psychological support.

- 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.**

The multidisciplinary team includes local consultants with a special interest in palliative care, consultants from the All-Wales Palliative Care Network, clinical nurse specialists in palliative care, and the children's community nursing team. This team collectively supports palliative care patients across the Local Health Board. For children who are not under the care of palliative services, local consultants liaise with palliative team for advice and refer as appropriate.

- 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.**

Bereavement support is coordinated by the bereavement officer within the Local Health Board, working alongside the clinical nurse specialist for palliative care. Hospices also provide specialised support to families, addressing their grief and loss needs.

- 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.**

- 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.**

A 24-hour on-call consultant is available for children nearing the end of life. Hospices provide a 24-hour service to address family concerns for those choosing home-based care. Paediatric wards within the Local Health Board provide additional support, and a clinical nurse specialist for palliative care is available Monday to Friday, 09:00–17:00, for guidance and advice.

- 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.**

Currently, there is no hospice service available for short-term respite due to staff shortages and increased patient demand. However, symptom management beds are available for short-term stays, and crisis support is provided to families as needed.

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

There are 59 children within the Local Health Board with palliative care needs who would be seen by local consultants. Of these, 16 children are receiving specialist palliative care and would be reviewed by both local and palliative

care consultants, with 15 of these children having advance care plans in place. However, there are a higher number of children with life limiting conditions across paediatrics in general. It would be difficult to give an exact number, without a clear definition of life limiting.