

<b>Reference:</b>	FOI.15889.24
<b>Subject:</b>	Paediatric palliative care
<b>Date of Request:</b>	5 November 2024

**Requested:**

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.
  - 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.
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?

**Response:**

1. Hywel Dda University Health Board (UHB) can confirm that parents and carers are always involved in the development of advance care plans. Children and young people (CYP) are also involved in discussions and development provided they are age appropriate and/or cognitively able.
2. All CYP with a life limiting condition have a named medical specialist. This is either their named Paediatrician or if active on the Palliative Care caseload, they will also have the named Paediatrician with a specialist interest in Palliative Care/Palliative Care Specialist Consultant who will support with symptom control.
3. All CYP with a life limiting condition and their families will be signposted to both NHS/third sector support for both emotional and psychological support. The UHB also offers a Palliative Care Play Specialist service to both CYP and their siblings.
4. Yes, the UHB's Paediatric Palliative Care (PPC) team who support CYP with life limiting conditions consists of:
  - Consultant Paediatrician with special interest in PPC
  - Band 7 PPC Nurse Specialist
  - Band 6 PPC nurse
  - Band 5 PPC Play specialist
  - Pharmacist with PPC special interest
5. Anticipatory grief support is delivered by the PPC team, and the service is currently evaluating a Family Counsellor vacancy, to ensure this is the best use of resource. The UHB's wider bereavement service currently cannot offer a service for CYP and their families for anticipatory grief. All PPC and oncology staff attend training regarding difficult conversations and bereavement.
6. Yes, the All-Wales network provides a 24-hour PPC support advice line for staff only. Within the UHB, we have developed a 'Children's Outreach Inreach Nursing Service' (COINS) delivered by both substantive PPC/Oncology and Community Children's Nursing and bank staff, which is mobilised to deliver end of life care at home if this is the preferred setting for families. This is delivered by our PPC nursing team in collaboration with our Paediatric Oncology Nursing team being first on call. Both Nurse specialists within the PPC team have successfully completed their MSc in Palliative Medicine recently. All nursing staff working within our COINS attend training delivered by our PPC/Oncology team in collaboration with the All-Wales Network.
7. Due to an increase in demand for end-of-life care and symptom control support, our local hospice no longer provides short breaks that families had depended upon for respite previously. As a result, regular short breaks for respite via the Local Authority are extremely limited within our UHB. However, there is opportunity via the grant fund, Amser, for short breaks, but these are for the whole family rather than respite.
8. The UHB's current active PPC caseload has 32 CYP who will be in receipt of specialist PPC input. There will also be CYP who are known to the UHB with a life limiting condition who access Ty Hafan and Children's Community Nursing, but are not on the UHB's PPC active caseload.