

Cyflwynwyd yr ymateb hwn i ymgynghoriad y [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Children, Young People and Education Committee](#) consultation on [Sixth Senedd Priorities](#)

CYPE SP 24

Ymateb gan: Lewis Clark, Hosbis Plant Tŷ Hafan a Hosbis Plant Tŷ Gobaith

Response from: Lewis Clark, Tŷ Hafan Children's Hospice and Tŷ Gobaith Children's Hospice

Beth yn eich barn chi yw'r prif flaenoriaethau neu'r materion y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd? Os oes modd, nodwch eich barn o ran sut y gallai'r Pwyllgor fynd i'r afael â hyn.

What do you consider to be the main priorities or issues that the Committee should consider during the Sixth Senedd? Where possible, please set out your view about how the Committee could address them.

Thema 1: Addysg oedran ysgol | Theme 1: School-age education

N/A

Thema 2: Addysg bellach ac addysg uwch | Theme 2: Further and higher education

N/A

Thema 3: Iechyd a lles, gan gynnwys gofal cymdeithasol (i'r graddau y maent yn ymwneud â phlant a phobl ifanc) | Theme 3: Health and well-being, including social care (as they relate to children and young people)

Tŷ Hafan and Tŷ Gobaith children's hospices welcome the opportunity to comment on the priorities of the Children, Young People and Education Committee for the Sixth Senedd.

Our key ask is that the Committee gives consideration to paediatric palliative care in Wales, particularly children's hospice care, and how it is funded, following recognition from the Government that they should be doing better on this matter.



In the last few months, Tŷ Hafan and Tŷ Gobaith have come together to create an all-Wales voice for children with life-limiting conditions and have called on the Welsh Government to increase statutory funding for children's hospices above the existing 10 percent, which is the lowest of all the nations across the UK. We want to work constructively with all key stakeholders, including this Committee, Welsh Government, Local Health Boards and Local Authorities to create a truly sustainable funding solution for paediatric palliative care and third sector children's hospices. Our aim is to ensure that every child facing an unfairly short life has the best quality of life, be that through support in a hospital, hospice, in the community, or at home.

We welcome recent commitments from the Welsh Government to review the funding issue, but we believe that true progress for these children and their families requires a whole-Senedd approach, with this Committee at the vanguard. We would welcome any opportunities to work with the Committee to develop recommendations for the Government in this area.

We do not believe that the work of children's hospices is well understood – for instance how much work we do in the community and with families at home, in addition to respite care. It is also the case that politicians, media and the public are always astounded to learn how little funding we receive from Government, given the complex medical conditions we deal with every day. Perhaps most alarmingly, there is also very little public understanding of what life is really like for these most vulnerable children and their families, who constantly live their lives on the brink of crisis. As charities we have worked hard to address this, but we believe the Committee has a vital role to play in supporting our children and young people to get the hearing that their situations deserve.

Background

It is estimated that there are around 3,600 children in Wales living with a life-limiting condition. Approximately 800 of these children have ongoing palliative care needs which require contact with hospital services, only about half of whom access respite at children's hospices.

Tŷ Hafan and Tŷ Gobaith - together - provide paediatric palliative care for more than 450 children with life-limiting conditions and their families across Wales and offer around 2,500 nights of respite care each year. We are calling for a more sustainable funding solution to allow us to futureproof our services and extend our reach, particularly into more rural communities across Wales, as we expect the need for our services to continue to grow following the Welsh Government commissioned prevalence study. A breakdown of the families we support across Wales can be found in [Appendix 1](#).



Children's hospices in Scotland receive 50% of their funding from the statutory sources; in Northern Ireland it is 25% - while the Republic of Ireland recently announced it would fund 30% of running costs for their children's hospices³.

What we have seen in England, notably in 2020/21, is an increase in state funding for children's hospices from circa 21% to 34% of charitable expenditure⁴. This is largely a result of both additional government funding support through the Children's Hospice Grant and also a drop in the levels of charitable expenditure across the sector. While this figure of 34% may well be an anomaly due to the pandemic's impact on the third sector's expenditure, what it does suggest is that funding for children's hospices in England is moving in the right direction, while Wales is getting left further behind.

Tŷ Hafan and Tŷ Gobaith have continued, and will continue, to do everything we can to attract funding through charitable donations. Around 90% of our funding comes from the generosity of the Welsh public through their donations. However, the recent [Family Voices report](#) made clear that we cannot meet future challenges alone. We want to move Wales up from its current position at the bottom of the league table of home nations in funding this vital lifeline of support for the families of children with life-limiting conditions. A summary of the findings of the Family Voices report can be found in [Appendix 2](#).

The Lifeline Fund

Tŷ Hafan and Tŷ Gobaith are calling on the Welsh Government to establish a sustainable 'Lifeline Fund' to:

- **Support.** The vast majority of families surveyed for the Family Voices report, said that hospices were their only, or primary, source of respite and that the two hospices are a lifeline on which they depend. However, Tŷ Hafan and Tŷ Gobaith need additional funding to ensure we can continue to provide that level of support to families and children when and where they need it.
- **Sustain.** Tŷ Hafan and Tŷ Gobaith – together – receive less than **10 percent** of our funding from statutory sources in Wales, the lowest level of state funding across the UK nations. Without additional, sustainable funding, the hospices are unable to plan for the future, and provide care and support to the families across Wales that need our help – whether that is at home, in the community or in a hospice itself.
- **Extend.** Only around half of the children in Wales with a life-limiting condition currently access the services of either Tŷ Hafan or Tŷ Gobaith. We are calling for a sustainable funding solution to allow us to extend our reach across the whole of Wales, particularly into more rural communities, and ensure that every family of a child with a life-limiting condition can access respite, palliative and end of life care regardless of where they live.



A sustainable funding solution for Wales' children's hospices over and above the existing 10% would have a marked impact on the children and families that use our services. A Lifeline fund would:

1. Secure additional crucial nights of care at children's hospices, for children with life-limiting conditions in Wales. Family Voices was clear - extra nights of nurse-led respite for each child and family supported by the hospices are essential to the whole family's mental health and relationships. It saves them from 'breaking'.
2. Enable hospices to employ more nurses who can develop positive relationships with the family throughout a child's life, establishing trusted partnership working, and a deeper understanding of the child and families' needs. This in turn will lead to more effective end of life care and bereavement support, and better outcomes for the families at the time when they face the inevitable and heart-breaking loss of their child.
3. Reduce unplanned and crisis hospital admissions for children with life-limiting conditions, in turn reducing the burden on, and financial costs to, the NHS.
4. Ensure our hospices can sustain and expand our care in other areas such as: physiotherapy and other therapeutic support, clinical support and advice – and as part of the broader ecosystem of NHS providers, end-of-life care and bereavement support.
5. Give the hospices the financial confidence to plan to expand sustainable services to reach more children and families, knowing that we can meet their needs without depriving others of essential services.
6. Support local government to meet its statutory requirements in relation to respite care, which cannot be met without a sustainable children's hospice sector.
7. Ultimately, help to ensure that Wales makes a vital step in its national mission to become a compassionate country.

Our Ask

1. **Parity with other UK nations.** Tŷ Hafan and Tŷ Gobaith are calling on the Welsh Government to consider a move to, at a minimum, the English model of funding for children's hospices. By providing a grant at **21%** of our annual care costs, i.e., investing an additional **£900,000** per year, the Welsh Government would be supporting the children's hospices to provide two additional nights of respite care per year to each family of a child with life-limiting conditions. It would also support us in futureproofing our services and allow us to lever our charitable funding to extend our reach across Wales.



2. **A centrally negotiated and distributed funding model.** We are calling on the Welsh Government to introduce a centrally negotiated and distributed “Lifeline fund” that covers all of Wales. Children’s hospices work across multiple Health Boards. If funding continues to be channeled through Health Boards this will require protracted multiple negotiations and result in different interpretations, funding models and levels of funding between Boards. This would perpetuate the funding discrepancies we experience today.
3. **Long-term.** A funding agreement for, at a minimum, the life of the Senedd, so as to give children’s hospices confidence to develop services and make longer term investments in staff and infrastructure. Such funding model could, for example, be based on 75% committed and 25% subject to annual review to give some flexibility and control to the government while enabling the hospices to plan services with confidence.
4. **Funding linked to need.** Any additional funding must be linked to need. This could be based on the calculated or estimated number of children with a life-limiting condition in Wales within the catchment area actively supported by the hospices. For example, In Cardiff and Vale all the funding for these children would go to Tŷ Hafan as they are the only children’s hospice supporting children in that area. The same for Tŷ Gobaith in Betsi. In Powys where both hospices provide support, the funding could be split proportionate to the number children supported by each hospice. By funding based on need children’s hospices can be held accountable for reaching more children and families and providing services that best meet their needs.
5. **Proportionate reporting.** All recipients of palliative care funding should provide outcome-based reporting. It is important that any additional funding does not generate onerous reporting requirements that cost either hospice considerable time or money to administer and provide. Reporting should be based on reach and meeting a certain need.
6. **Recognition of the cross-policy working of hospices.** Unlike other settings which separate health and social care, children’s hospices holistic child and family centered care that best meets the needs of children and families. It is important that funding does not make an artificial distinction between health and social care, where only certain services provided by the hospices are funded and others are not. Funding should be in the form of a single sum that hospices use to best effect to address the unique needs of children and families, taking account of their specific circumstances.
7. **Sustainable minimum commitment of annual funding.** To be forward looking, innovative and sustainable, any additional funding should be agreed and paid in one, or at most two, payments per annum. This will give the hospices the resources to invest in ensuring we can make the biggest difference to the children and families that require our services. Funding that is claimed each month become transactional rather than transformative and does not



enable us to address the relatively short but precious futures of life-limited children in Wales.

Tŷ Hafan and Tŷ Gobaith would welcome any opportunity to work with the Committee on the issue of funding for children’s hospices. We believe that the Committee has an important role to play in holding the Welsh Government to account on this issue, one that the Minister has noted the Welsh Government need to do better on.

Appendix 1: Family’s supported by Local Authority

| Local Authority | Service Users |
|--|----------------------|
| Blaenau Gwent County Borough Council | 2 |
| Bridgend Council Borough Council | 16 |
| Caerphilly County Borough Council | 19 |
| Cardiff City Council | 71 |
| Carmarthenshire County Council | 22 |
| Ceredigion County Council | 9 |
| Conwy County Borough Council | 13 |
| Denbighshire County Council | 29 |
| Flintshire County Council | 22 |
| Gwynedd Council | 17 |
| Isle of Anglesey County Council | 10 |
| Merthyr Tydfil County Borough Council | 9 |
| Monmouthshire County Council | 7 |
| Neath Port Talbot Council | 9 |
| Newport City Council | 22 |
| Pembrokeshire County Council | 19 |
| Powys County Council | 24 |
| Rhondda Cynon Taf County Borough Council | 29 |
| Swansea City Council | 41 |
| Vale of Glamorgan Council | 26 |
| Torfaen County Borough Council | 14 |
| Wrexham County Borough Council | 31 |
| Total | 461 |

Appendix 2: Findings of the Family Voices Report

In 2020, we completed a vital piece of work focused on understanding what families want and need from us. We called our report ‘Family Voices’.

We had over 133 responses – which told us just how vital our services are, but also how desperate families are for more of what the hospices provide:

| Service | Total |
|----------------|--------------|
|----------------|--------------|



| | |
|--|-----|
| More / Longer Respite | 43% |
| More Availability of Services | 15% |
| Advocacy / Information / Benefits / Housing Etc. | 13% |
| Sitting / Home-based Care | 10% |
| More Access to Counselling / Emotional Support | 10% |
| Better Communication between Services (Hospice and Wider Services) | 10% |
| Easier Access / Admission Process | 9% |
| More Local Services | 8% |
| Increased Age Limit | 8% |
| More Activities / Events | 6% |
| More Sibling Support | 5% |
| More Responsive to Crisis | 5% |
| Better Access to Specialist PPC | 4% |

Thema 4: Plant a phobl Ifanc | Theme 4: Children and young people

N/A

