

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 30

Ymateb gan: | Response from: [Tŷ Hafan](#) and [Tŷ Gobaith](#) | [Tŷ Hafan](#) a [Tŷ Gobaith](#)

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor **Initial priorities identified by the Committee**

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrsgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?

Q1. Which of the issues listed above do you think should be a priority, and why?

Tŷ Hafan and Tŷ Gobaith welcome the opportunity to comment on the committee's priorities for the sixth Senedd.

Our views on the priorities of the Committee are outlined throughout this response – although we believe that particular attention should be given to the issue of funding for Wales' children's hospices. Our views on this issue can be found in response to Question 3 – and we urge the committee to consider this area as a potential priority for the Sixth Senedd, following recognition from the Welsh Government that they need to do better on this issue, and longstanding commitments to review funding for third sector providers of paediatric palliative care in Wales.

Support and services for unpaid carers



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, care for more than 450 families across Wales, and provide over 2500 nights of respite care each year. Accordingly, we are reaching just over half of the families that need our support. The [Family Voices report](#), jointly published by Tŷ Hafan and Tŷ Gobaith in 2020, made clear that the families of children with life-limiting conditions want both more and longer respite – allowing them to have essential breaks from their caring responsibilities. The full findings of the family voices report can be found in [Appendix 2](#) at the end of this response.

We know that the families of a child with a life-limiting condition undertake unpaid caring roles. Caring for children with such complex conditions is a full-time job, and one that in many instances results in family members stopping their paid employment to meet the needs of their child.

While the recently published Welsh Government strategy for unpaid carers – which highlights the need for greater access to respite and short breaks provision – was welcomed, Tŷ Hafan and Tŷ Gobaith fear that many will continue being unable to access the services that meet the specialist care needs of children with life-limiting conditions in Wales. Tŷ Hafan and Tŷ Gobaith – the only two children's hospices in Wales – are able to provide respite that provides a real break, as the families know that we have both the resources and skills to meet their children's needs. For respite breaks to be real respite, such specialist provisions are an absolute necessity and general short break services will not provide the reassurance or comfort that the families of children with life-limiting conditions need in order for them to truly have a break.

Accordingly, Tŷ Hafan and Tŷ Gobaith urge the Committee to pay consideration to the role of unpaid carers in Wales, particularly carers for children with life-limiting conditions and complex needs, how they can be better supported to access respite provision – that provides a real break and that meets the specialist needs of those children, whether that is at a children's hospice, in the community or other short-break setting. The most important element of any respite for the carers of a child with a life-limiting condition is ensuring that their specialist needs can be met.

The Committee could address this by surveying Wales' local authorities to formally understand what support is available to unpaid carers – particularly in relation to carers of children and young people with complex conditions – across different areas in Wales. The hospices would also welcome any work to develop the relationships between local authorities and third sector hospice providers to ensure that partnership working is not a barrier to unpaid carers receiving the care and support they both need and are entitled to as a result of the Social Services and Wellbeing Act 2014.

We feel that this work should be a priority for the Committee and begin as soon as is realistically possible – to ensure the effectiveness of the new Strategy for Unpaid Carers in Wales. Tŷ Hafan and Tŷ Gobaith would welcome any opportunities to support this work, and would encourage our service users – many of which are unpaid carers – to participate to ensure key stakeholders views are considered throughout.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd

Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;**
 - b) social care and carers;**
 - c) COVID recovery?**
-

Gwasanaethau iechyd

Health services

Health and Social Care Workforce

Tŷ Hafan and Tŷ Gobaith, ultimately, seek to provide the best possible support and care to the greatest number of children with life-limiting conditions, and their families, in Wales. While the hospices long have, and continue, to be a lifeline to many within the current funding and policy frameworks, there are two issues that potentially prevent them from going further:

1. A lack of statutory funding for children's hospices in Wales, with less than 10 percent of our funding coming from statutory sources, that is the Welsh Government, Local Health Boards and Local Authorities; and
2. A lack of community nurses, specialising in paediatric palliative care.

The location of our hospices, in North and South East Wales, makes the reality of reaching all those children with life-limiting conditions across Wales challenging – with access particularly limited for families in more rural areas. It is not uncommon for some families to have to travel upwards of two hours to access their nearest hospice, making short breaks or respite often simply not feasible.

Tŷ Hafan and Tŷ Gobaith want every child with a life-limiting condition in Wales to have access to the care and support they need, when and where they need it. This could be at home, at a hospital, at a hospice or in the community. But to achieve this, greater resources need to be developed right across Wales, covering every local authority and with enough depth to ensure no child goes without.

While some progress has been made through the appointment of specialist paediatric palliative care nurses, with posts in most health board areas, this is not translating to an all-Wales approach. Complexity and variation in funding arrangements for these posts – with varying degrees of funding from hosting health boards – is a significant barrier in achieving consensus on the specialist paediatric palliative care nurses' remit.

Tŷ Hafan and Tŷ Gobaith are ideally placed to support the establishment of a more robust community nursing service across Wales, working alongside statutory providers to ensure that no child or family goes without, and ensuring that palliative care is available in the most appropriate setting. Such an innovative approach to community paediatric nursing would be welcomed by both hospices, but requires the commitment of additional statutory funding in Wales, to allow us to support this work. More information about our calls for a sustainable funding settlement can be found in response to Question 3 below.

In 2021, Together for Short Lives calculated that the current shortfall in Children's Community Nurses in Wales stands at 240. This means that too many children and families are missing out on care and support they need, when and where they need it. It also means that too many seriously ill children need unplanned, prolonged and emergency hospital admissions, when their needs could have potentially been met at home, in the community or at a specialist hospice¹.

Further to this issue of resources, there is simply a lack of understanding of how many children and their families in Wales require the support of a hospice – partly as a result of a lack of a central register, or data set, of those children and young people living with a life-limiting condition or who require palliative care. This means that the responsibility of locating and reaching out to those in need of support is left to the hospices themselves, friends, relatives or statutory providers of health and social care to refer children and young people – with little in the way of a formalised approach. How can we develop evidence-based policy in relation to children and young people with complex, life-limiting conditions, when there is so little evidence regarding the population that make up this group?

Tŷ Hafan and Tŷ Gobaith urge the committee to give consideration to this issue, as part of a broader policy area of paediatric palliative care. The needs of children and young people are very different from those of adults, and children's palliative care is recognised as a specialist area of practice addressing both the physical issues of children's palliative care and the need to address the psychosocial and spiritual issues of the family as a whole.

Accordingly, attention needs to be given to the children's sector in its own right, including accurate and up to date data sets on the number of children with life-limiting conditions, addressing the shortfall in community services available right across Wales, ensuring the carers of children with life-limiting conditions can access respite or short breaks which meet the specialist needs of the child, and addressing the lack of sustainable funding for Wales' children's hospices which holds them back from reaching more children and their families, and therefore prevents those facing unfairly short lives from accessing the care and support they need.

¹ <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/9563-2/>

Unrhyw faterion eraill

Any other issues

C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?

Q3. Are there any other issues you wish to draw to the Committee's attention?

Our key ask is that the Committee considers 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. Politicians, the 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. A recently commissioned incidence and prevalence study will give us more up-to-date figures about the numbers of children with palliative care needs, and it is expected this figure will rise significantly².

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

² ¹ In August 2020, the All-Wales End of Life Board Core Group approved the research proposal: "Trends in the Prevalence and Complexity of Children with a Life-limiting or Life-threatening condition in Wales". We anticipate this will report later in 2021.

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

³ <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/9563-2/>

⁴ The latest data for 2020/21 showed that levels of statutory funding in England were at 34% of charitable expenditure. This is due to both additional government funding support through the Children's Hospice Grant and also a drop in the levels of charitable expenditure across the sector. This meant that more costs were met, as a percentage, by the state.

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 percent 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 Gobaiŷ 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 becomes 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.

Further information about the Lifeline Fund can be found online on either [Ty Hafan](#) or [Ty Gobaith's](#) websites.

Appendices

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%

Thank you for your consideration of the above response.