

Tŷ Hafan & Tŷ Gobaith Briefing: A Lifeline Fund for Wales

Summary

Tŷ Hafan and Tŷ Gobaith - Wales' two children's hospices – are delighted to be working with the Welsh Government, Members of the Senedd, and the End-of-Life Care Board to establish a new Lifeline Fund to support more children with life-limiting conditions, and their families, in Wales. A sustainable funding solution will ensure that both hospices can reach more children and their families and tackle increasingly complex conditions – whether that is at home, in the community or in the hospice.

Both hospices are hopeful that these ongoing, constructive discussions will result in greater funding for children's hospices in Wales, more closely aligned with that of other UK nations, enabling both Tŷ Hafan and Tŷ Gobaith to evolve and develop their services to provide the best possible outcomes for children and young people who face unfairly short lives.

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

- 1. 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.
- 2. 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.
- 3. 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.

Specifically, we need to address our nation's lack of provision of respite care for children with life-limiting conditions and the disparity in funding for Welsh children relative to their peers in other UK nations.

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 significantly¹.

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. Despite this, we receive less than 10 percent of our funding from statutory sources – that is the Welsh Government, Local Health Boards and Local Authorities². 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](#).

Now, more than ever, additional support for the families of children with life-limiting conditions is needed. The families have told us that Tŷ Hafan and Tŷ Gobaith are best suited to provide that support, both in the hospice, at home and in the community. However, in order to achieve this, we need a sustainable funding solution from the Welsh Government. This will further the ambition to create a more compassionate Wales, one that values the importance of caring for a child towards the end of their unfairly short life and supports their family through the most difficult of times.

Background

Children's hospices in Wales are asking Welsh Government to respond to the increasing demand for our services, to address the growing complexity involved in providing care for children with life-limiting conditions, and to help us reach every child and family across Wales that would benefit from our service.

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. In Wales, the comparable figure is less than 10%.

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 as 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 as a result of 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. A summary of the comparison between the UK nations statutory funding for children's hospices based on pre-pandemic 2019 figures, can be found in [Table 1](#).

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.

² 2021 saw an increase in statutory funding, as a result of the one-off emergency covid-19 fund. For the year ending March 2021, Tŷ Hafan received £1.585m in emergency covid funding, while Tŷ Gobaith received £566,628.

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.

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.

The vast majority of families surveyed for the Family Voices report, said that hospices were their only, or primary, source of respite. Relying almost entirely on charitable funding we are only able to meet those needs about a quarter of the time. The message is very clear – families urgently need more support⁵.

A summary of the findings of the Family Voices report can be found in [Appendix 2](#).

Tŷ Hafan and Tŷ Gobaith have welcomed recent commitments from the Welsh Government, particularly from the Minister for Health and Social Care who, on 7 July 2021, during Minister's Questions, recognised the need to “do better” in terms of statutory funding for Wales' children's hospices. We now look forward to the End-of-Life Care Board's workshops which began on 21 July and mark the beginning of the review into hospice funding, as first outlined by the previous Minister for Health and Social Services on 5 March 2021⁶. This review is expected to be completed in early Autumn 2021, with an announcement on hospice funding expected in the Welsh Government's Budget for 2022-23.

How Children's Hospices in Wales are Currently Funded

Together, Tŷ Hafan and Tŷ Gobaith receive less than ten percent of their funding from statutory sources, including Welsh Government, Local Health Boards, Local Authorities and Regional Partnership Boards. The hospices respective Income Generation teams are left to fundraise for over 90 percent of our care costs, relying on the generosity of the Welsh public to ensure provision of these vital palliative care services

While the hospices have received some support from statutory sources – for example Tŷ Gobaith receive £220,000 from Betsi Cadwaladr Health Board as part of the National Hospice Grant – such funding does not equate to the services provided, nor the need for them across Wales. Tŷ Gobaith receives only £6,700 each year from Powys Teaching Health Board, despite providing end of life care and respite to more than 20 families in that area and has no service level agreement or contract with either Health Board, highlighting the fragility of the existing arrangements.

Similarly, Tŷ Hafan, which supports families from across Wales' Health Boards, received £511,937 from public funding and the Health Boards in 2019/20. This equates to around 5% of their income and does not reflect the services offered or the support provided to hundreds of children and families across Wales.

This means that the majority of the income generated by both hospices must come through different activities, all of which involve a cost to the hospices:

- Monthly regular donations from individuals
- Charity shops across Wales

⁵ The Family Voices report was a jointly commissioned study by both Tŷ Hafan and Tŷ Gobaith, examining in detail what the families we support want more of in Wales.

⁶ [Written Statement: Update on Palliative and End of Life Care \(5 March 2021\) | GOV.WALES](#)

- Organised events
- Lottery
- Businesses fundraising for or providing services free of charge
- Legacy gifts, i.e., supporters leaving gifts in their wills
- One-off donations from supporters at events or through our website
- Fundraising activities by individuals, schools, churches and community groups
- Non-recurring funding, for example Tŷ Hafan has a commissioned bed, which is available to local authorities at a cost. This is essentially spot-purchasing and is not a sustainable funding solution.

A Lifeline Fund: Summarised

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:

- 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'.
- 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.
- Reduce unplanned and crisis hospital admissions for children with life-limiting conditions, in turn reducing the burden on, and financial costs to, the NHS.
- 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.
- 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.
- Support local government to meet its statutory requirements in relation to respite care, which cannot be met without a sustainable children's hospice sector.
- Ultimately, help to ensure that Wales makes a vital step in its national mission to become a compassionate country.

Further to this, the table below outlines the impact of additional statutory funding in terms of additional nights of respite care for the families we support across Wales, relative to the other UK nations⁷.

⁷ Ranking of funding by nation and impact if applied to Children's Hospices in Wales

Table 1: Comparison of children's hospice funding across the UK.

Country	Current statutory funding level	How this translates: equivalent funding level for Wales' children's hospices	Additional funding required to attain parity	Extra nights of specialist respite support this would fund in Wales
Scotland	50%	£3.75m	£3,050,000	An additional 7 nights of respite per year, per family.
Republic of Ireland	30%	£2.25m	£1,550,000	An additional 4 nights of respite per year, per family.
Northern Ireland	25%	£1.9m	£1,200,000	An additional 3 nights of respite per year, per family.
England	21%	£1.6m	£900,000	An additional 2 nights of respite per year, per family.
Wales	<10%	£0.7m		Current statutory support funds around 2 nights of respite per year, per family.

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.

Appendices

Appendix 1 – Breakdown of Tŷ Hafan and Tŷ Gobaith Service Users in Wales

Tŷ Hafan & Tŷ Gobaith Service Users by Health Board:

Health Board	Aneurin Bevan	Betsi Cadwaladr	Cardiff & Vale	Cwm Taf	Hywel Dda	Powys Teaching	Swansea Bay	Total
Service Users	66	123	97	54	47	26	51	464

Tŷ Hafan & Tŷ Gobaith Service Users 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 - Family Voices report: What families want more of

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'. The report, based on a survey of views from families using or who have used hospice services, provides an important voice in understanding what these families need.

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. Respite care is for coping and wellbeing, but they spoke of needing more. We know that our support is more important than ever, and this report is essential in helping us plan for the future.

The full report can be found online here: [English](#) / [Cymraeg](#)

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%