

Tŷ Hafan & Tŷ Gobaith Briefing: Accessing Appropriate Short Break Services in Wales

Executive Summary

Tŷ Hafan and Tŷ Gobaith support more than 450 children with life-limiting conditions, and their families, across Wales. We provide end of life care, symptom management, play and therapeutic services, advice and advocacy, as well as short break services.

Our 2020 [Family Voices Report](#), a survey of what the families supported by the hospices need most, made clear that short breaks were a “lifeline”. The survey found that around half of all the families we support in Wales wanted access to more and longer short breaks, highlighting just how crucial they are to families often on the brink of crisis. The full findings of the survey can be found in [Table 1](#).

The pandemic has compounded the challenges faced by unpaid parent carers, with many taking on greater responsibility due to services being restricted, unavailable and not properly funded. The Association of Directors of Social Services told the Senedd’s Health and Social Care Committee in February 2022 that “they are having to focus on covering individuals who are at very high risk”, and are “relying very heavily on family and friends.”¹

While recent years have seen a move to more integration between health and social care in Wales there remains a serious level of confusion over which statutory agency is responsible for providing and funding access to short break services for children with complex medical needs.

To respond to the need for a ‘lifeline’, and to support families through the most challenging of times, Tŷ Hafan and Tŷ Gobaith believe that the families of children with life-limiting conditions in Wales must have access to appropriate short breaks, at a place of choice (in the community, in their homes or in a hospice). Short breaks must properly meet the needs of children in a timely way, and should be free at the point of service. No family should have to endure long waits for short breaks; nor should they be party to agencies fighting over their heads to determine who is responsible for funding this support.

We are calling on statutory providers of health and social care in Wales to:

1. Commit to meeting formally with Tŷ Hafan and Tŷ Gobaith to discuss how we can support them in meeting their statutory duties with respect to providing short breaks to children with life-limiting conditions.
2. Commit to properly funding the hospices for the short break services we provide to children with life-limiting conditions within their locality or region.
3. Recognise the need for short breaks in appropriate settings, where the family of a child with life-limiting conditions can be assured that they will have their complex clinical health and social care needs met.

¹ [No respite for unpaid carers as pressures continue to increase \(senedd.wales\)](#)

Family Voices Survey: The Importance of Short Breaks

In 2020 Ty Hafan and Ty Gobaith came together to survey the families of children supported by the hospices. The two questions at the heart of this survey were:

- What do families with children with life-limiting conditions need to live the best life they can?
- What role do the children's hospices in Wales play in providing this support?

The responses we received paint a very clear picture of how vital our services are, but also how desperate families and young people are for more of what we do. With over half of our families surviving on an annual income of less than £25,000, they have little or no room to fund such extra support themselves.

We know that one of our primary purposes is to be there at the end of life. However, the responses we have received to our questions show short breaks are, and must remain, an absolutely critical part of provision for every single family. Too often these stays are crisis driven, and families need more. 100% of respondents stated that they access the hospices' short break services, and 94% identified these services as essential to them² with many noting that Ty Hafan and Ty Gobaith are the only source of short break services they can access. The full findings of the report can be found below.

Table 1: Findings of the Family Voices Survey

Service	Total
More / Longer Short Breaks	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%

² [Family-Voices-Project-English.pdf \(tyhafan.org\)](#)

Challenges Around Continuing Care Needs

Under the Social Services and Wellbeing (Wales) Act 2014, all of Wales' twenty-two local authorities have a statutory duty to support unpaid carers to access short break services. It also stresses that carers should only take on caring responsibilities if they are willing and able to do so.³ It appears that these principles of the law are being undermined by confusion and disagreement over which statutory authority (Local Authority, or Local Health Board) is responsible for the funding of access to short break services for children with life-limiting conditions and complex needs. This ultimately results in many families taking on greater responsibility, often to the detriment of their own physical and mental health.

Despite a move to greater integration of health and social care in Wales, including pooled funding, via the Regional Partnership Boards, disputes over responsibility are still preventing families from accessing services within an appropriate time-frame, and in some instances, not at all. Such assertions have been supported by the Children's Commissioner for Wales, who notes "there is Welsh Government guidance that says agencies must work together where continuing care is needed for children, but it only says that LHBs and LAs may jointly fund the care, which in practice is leading to regular disagreements, which leave children and their families in limbo and without the support that has been assessed to be required". The report adds: "Several Regional Partnership Boards reported that they feel stuck on this issue and would welcome Government intervention to come up with formulas for swifter, child-centred funding agreements"⁴.

This issue was also highlighted by a recent Freedom of Information Request submitted by the hospices to Wales' 22 local authorities. We asked, *can you please outline the costs paid to third sector children's hospices from the local authority to support respite care and short break services for children and their carers in 2020, 2019 and 2018 respectively?* What we found was that disagreements over responsibility for funding was, in most instances, resulting in no funding being made available to Wales' children's hospices for short break services for some of Wales' most vulnerable children – resulting in the hospices, and the public who support us, funding the 'lifeline' support these children and their families desperately need and are entitled to.

20 of the 22 authorities stated they did not offer any financial support to children's hospices to support short breaks in 2018, 2019 or 2020. While Wrexham County Borough Council declined to respond to the request, Rhondda Cynon Taf did provide a figure of £998,280 but this referred to all short break services and not those provided by the children's hospices.

A number of the local authorities claimed that the referral, and subsequent financial support, of disabled children for short breaks to third sector children's hospices is the responsibility of the relevant health board – not the local authority. This answer was based on an assumption that continuing care needs should be met by health providers, rather than social care. This artificial distinction between health and social care – and lack of responsibility on behalf of either – has long left third sector providers of short breaks footing **all** financial responsibility for some of Wales' most vulnerable children.

This issue has been further exacerbated by the fact that only around a quarter of all the children we support meet the eligibility for continuing health care, but are deemed to have too complex medical conditions to be supported by the local authorities' social care teams.

³ [No respite for unpaid carers as pressures continue to increase \(senedd.wales\)](https://www.senedd.wales)

⁴ [No-Wrong-Door-Report-February-2022.pdf \(childcomwales.org.uk\)](https://www.childcomwales.org.uk)

Our Ask

Tŷ Hafan and Tŷ Gobaith support a number of the recommendations found in the Children's Commissioner for Wales' most recent publication, *Making Wales a No Wrong Door Nation: How Are We Doing?* namely:

1. The Regional Partnership Boards must prioritise Continuing Care arrangements for children and young people as a matter of urgency. Board members and senior leads from LAs and LHBs should participate in a Welsh Government organised workshop to find a reliable and swift method to pool funding between their services to deliver suitable and truly joint multiagency arrangements for children with complex needs efficiently and effectively in the best interests of the child.
2. The Welsh Government should ensure the service leads in the health board and local authorities in each region produce a comprehensive written agreement in respect of Continuing Care arrangements.
3. The Welsh Government should strengthen the statutory guidance around the role of citizen, carer and third sector representatives to ensure they are active participants in every region.

Further to this, the hospices are calling on all statutory providers of health and social care in Wales to:

4. Commit to meeting formally with Tŷ Hafan and Tŷ Gobaith to discuss how we can support them in meeting their statutory duties with respect to short breaks and children with life-limiting conditions.
5. Commit to properly funding the hospices for the short break services we provide to children with life-limiting conditions, within their locality or region, allowing the hospices to extend their short break service offer to meet increased demand.
6. Recognise the need for short breaks in appropriate settings, where the family of a child with life-limiting conditions can be assured that they will have their complex clinical health and social care needs met.

What is clear is that more needs to be done to support children with life-limiting conditions and related complex medical needs, and their families, to access appropriate short break care services in Wales. The continued emphasis on a move to integrated services is failing to produce the intended results.

The hospices are proud of the role we play as part of the wider health and social care system in Wales, and we are keen to support statutory agencies to meet their duties under the Social Services and Wellbeing (Wales) Act 2014. We must ensure all children and their families have timely access to appropriate short break settings, and be confident that these services are properly funded by the agencies who have ultimate responsibility for their provision.