



"our lifeline"

Children's hospices in Wales
The voices of our families



hope house tŷ gobaith
children's hospices



contents

Foreword	4
1 Introduction	5
2 The bigger picture	6
2.1 Prevalence and demand	7
3 The survey and interviews	8
3.1 Our approach	8
3.2 Online survey	8
3.3 Interviews	8
3.4 Ethics	8
4 Presentation of findings	9
5 Key messages from the families	10
5.1 Hospice services provide essential support to families	10
5.2 The hospices are often the main or only source of support	12
5.3 Access to respite / short break care is essential to family coping and wellbeing	14
5.4 The impact on family life of providing complex care	15
5.5 The whole family need support	16
5.6 The importance of end-of-life care in a preferred setting	17
5.7 Young people leaving hospice services need support	18
5.8 Bereavement support and counselling make a difference	19
5.9 Why services are not always easy to access	20
5.9.1 Availability of service	21
5.9.2 Distance from services	22
5.9.3 Financial constraints	22
5.10 What families want more of: The magic lamp	23
6 Final observations	24
7 Bibliography	26
8 Acknowledgements	26

foreword

This is a critical moment in the development of children's hospice care in Wales. Providing more services than ever before, we are seeing demand grow. It is time to make important investments so that we can meet the needs of life-limited children and their families, not only today but in the future too. This report, based on a survey of views from families using hospice services, represents the most vital voice in charting that journey: that of the children, young people and their families who rely on our services to enhance the quality of their short lives.

Thanks to advances in care and medical science, children with life-limiting conditions today are more likely to live longer, with ever more complex needs. The families who receive hospice support say they see it as their "lifeline" – somewhere to turn to when they need help. These people are in desperate need of more care and more support. Yet we know that only a fraction of the families that need our help are getting it. The nature of this growing deficit, between family need and available support, goes some way to explaining why we have received nearly twice the number of responses to our survey than we anticipated. We are incredibly grateful for all the time the families invested to provide us with these insights into their daily lives. Lives that are characterised by hardship, too little sleep, and huge stress; lives which are almost completely hidden to the rest of the world. These are families who do not just want their voices heard, they **need** their voices heard.

Any debate about the future of hospice care is one that must begin with a clear idea of what children with life-limiting conditions and their families value the most, and their anticipated need in the future. It is crucial their voices frame, and are central to, what we do and how we plan for the future.

The two questions at the heart of this survey were:

- What do families with children and young people 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.

The evidence speaks for itself - many families are on the brink, with little time or money to spare. Yet they took time to respond to our request for information in an unprecedented way. It is a cry for help. They told us repeatedly that we are their lifeline and we are now sounding the alarm on their behalf.

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 respite is, and must remain, an absolutely critical part of provision for every single family. Too often these stays are crisis driven, and families need more. Families also told us that the holistic "wrap around" care they get from our hospices is crucial - the emotional support and advocacy; and of course bereavement care. Such services are all vital to family wellbeing. To ensure that hospice services can respond to the ongoing wellbeing needs of families as well as providing a crisis response when required, it is clear that we need to continually evolve our offer and how our services are delivered across Wales.

As charities we stand ready to play our part. We continuously adapt to the changing needs of our families, and Covid-19 has challenged us to be even more agile, but families are telling us they need so much more. We now look to our partners and supporters to consider this report, to take the families experiences on board and work with us to create a brighter, better and more sustainable future for children's hospice care in Wales.

Maria Timon Samra
Chief Executive Officer
Tŷ Hafan

Andy Goldsmith
Chief Executive Officer
Tŷ Gobaith

1 Introduction

Tŷ Gobaith and Tŷ Hafan the only children's hospices in Wales providing care for children and young people with a range of life-limiting conditions across Wales. The hospices broadly cover different areas, with Tŷ Hafan covering the south, east and west of Wales and Tŷ Gobaith primarily north Wales; and through its sister hospice Hope House, extending support to children and families in north Powys. Based on current health board population data it is estimated that together Tŷ Gobaith and Hope House support around 25% of the Welsh population of children with life-limiting conditions, whilst Tŷ Hafan serves the remaining 75% of this population.

Both hospices provide a balance of end-of-life care and continuing care to children and young people with complex health care needs arising from life-limiting conditions, often over many years.

Palliative care is provided from the point at which a child is diagnosed with a life-limiting condition through to the end of the child's life and includes respite care, crisis care and end-of-life care. Family care continues in the form of bereavement support. Where a young person survives into adulthood, support pivots towards facilitating a smooth onward transition to adult services.

Children's palliative care also supports families with help

and advice to manage their child's pain and distressing symptoms, and provides families with short breaks, end-of-life care, and emotional support up to and beyond the child's death.

This level of support requires effective joint working with multi-disciplinary teams from across health care, social care, and education. Children's hospices provide a unique role within this, journeying with children and young people and families over many years, enhancing quality to short lives through the sharing of expert skills and providing access to personalised services that enhance and complement those provided through statutory service models. The care hospices provide is often care that would be seen as statutory health and social care provision, symptom management, end-of-life care and respite.

The hospices actively seek to ensure that a short life is a full life, and work with the child's entire family to create meaningful memories that last a lifetime.

In late 2019, Tŷ Gobaith and Tŷ Hafan came together to give the families of children and young people with a life-limiting illness a unique opportunity to tell their stories – the result is 'Family Voices'.

Key findings

- Hospice services provide essential support to families
- The hospices are often the main or only source of support
- Access to respite / short break care is essential to family coping and wellbeing
- The impact on family life of providing complex care
- The whole family need support
- The importance of end-of-life care in a preferred setting
- Young people leaving hospice services need support
- Bereavement support and counselling make a difference
- Why services are not always easy to access
- What families want more of ... the magic lamp

2 The bigger picture

The wider context of the survey includes a prediction of increasing demand. While there is no recent Wales specific incidence and prevalence data, cross application of refreshed projections in England confirms this trend. A key driver for this is the number of children and young people living longer with life-limiting conditions and complex health and care needs due to advances in medical treatment. Longer life expectancy has serious implications for children's hospices. The most important is the age at which young people can no longer use these services and what services are available for them in young adulthood.

The increased complexity of care, including greater technological dependence has implications for recruiting and retaining care staff with the expert skills and experience required.

Tŷ Gobaith and Tŷ Hafan are two separate hospice charities, who between them have the capacity to provide up to 18 in-patient hospice beds for Wales: eight in Tŷ Gobaith / Hope House and ten in Tŷ Hafan.

Resourcing these beds has not always been straightforward, especially for Tŷ Hafan, where the depleted pipeline for qualified children's nurses has led to recruitment challenges.

The recruitment challenge reflects the nursing shortage across the UK. In 2019 the nursing vacancy rate in Wales was estimated to be as high as 25% in some areas¹. Sustainable funding is critical in order to secure the provision of these essential services in line with current demand.



2.1 Prevalence and demand

Between 2010 and 2014, it was estimated that the absolute numbers of children with a life-limiting condition rose by 28%; by 2016, the estimated number had risen to 3,200. In 2020, the estimated population of life-limited children and young people was somewhere around 3,580 to 3,720. ⁱⁱ

In 2019, around 500 children and young people, and their families, were supported by children’s hospices in Wales. This suggests that the number of families currently accessing hospice support is outnumbered by those who are not being referred to hospice support. Whilst it is possible that many of these families do not wish to access hospice support, these numbers could indicate a shortfall between potential demand and availability of services.

Research shows the number of children and young people with life-limiting conditions has grown, and modelling suggests the numbers will continue to increase slightly year on year over the next decade. The estimated 3,600 children and young people with a life-limiting condition is far in excess of the number currently being supported by the hospices.

The same research identifies that the highest prevalence and number of deaths is in babies under one year of age ⁱⁱⁱ. This reflects the experiences of the hospices who have seen an increase in demand for support to babies.

One of the reasons the number of children and young people with life-limiting conditions is increasing is because their life expectancy is increasing. They are living longer due to advances in medical treatments and technologies, and as a result, more young people are moving from children to adult services.

Longer life expectancy has implications for hospice services and how they deliver support to this growing number of young people needing to make the transition to adult services.

Hospices across the UK have taken different approaches to the age at which they discharge young people to adult services but **a common theme for all, regardless of age, is the ‘cliff edge’** that young people face when moving on to adult services.

There are clearly identifiable gaps between increasing demand on services, service availability and sustainable funding. The Cross Party Group ^{iv} on Hospices and Palliative Care in the Welsh Parliament has identified that there are ‘too few palliative care services which meet the needs and wishes of young people in ways which are appropriate to their age and developmental stage’. A global analysis of prevalence of children and young people with a life-limiting illness concluded better understanding need ‘is a critical step in meeting their needs ^v.

There has also been a recommendation to ensure that funding for charitable hospices is regularly reviewed in line with growing need and demand for services.

Funding has been static for a number of years and is currently the lowest statutory contribution of the four UK home nations with **6% of Tŷ Hafan Funds** and **11% of Tŷ Gobaith/Hope House funds** coming from the Welsh Government and Local Health Boards.

In comparison, the contributions from the Scottish Government are **over 50%**; in Northern Ireland around **30%** and an average of **21%** in England.

3 The survey and interviews

The survey sought to understand what families living with a child with a life-limiting condition need to live the best life they can and whether the children's hospices in Wales provide this support. Where families identified a shortfall in support, the survey looked to understand potential barriers to the support they needed to better improve their health and well-being and quality of life.

The findings suggest distance to the hospice matters, the two local authorities (LA) returning the highest number of surveys are the two LA where the two hospices are based.

The survey responses reflect the population size of local health boards (LHBs) in Wales, the most responses received came from the most populous LHB, Betsi Cadwaladr, the least from the smallest LHB, Powys.

3.1 Our approach

Our approach was centred around two key questions:

- What do families with children and young people 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?

To encourage the widest possible participation and to truly hear the family voice, the approach centred on an online survey and ten face-to-face / telephone interviews.

3.2 Online survey

An online survey was developed to evaluate the services offered. Three bespoke versions were created – one for families who were currently using the service; one for families who have been bereaved; and one for young people accessing support.

To maximise involvement, the online survey was sent to families by email from the hospices, by text invitation to mobile phones, advertised on hospice social media and shared with families, children and young people when in the hospice, receiving support or attending events. The survey was conducted between November 2019 and 31 January 2020.

3.3 Interviews

The survey responses were supplemented with ten in-depth interviews in January and February 2020. A skilled

and experienced independent interviewer conducted the interviews to gain a deeper understanding of the support provided and its impact on the interviewee's lives.

Interviews lasted between 25 minutes and one hour. The interviews were semi-structured, allowing interviewees the time and space to share and reflect on their own and their family's experience, and the impact of the support provided. The questions were developed in agreement with the hospices.

All ten interviewees consented to their interview being recorded. They also agreed that their comments could be used in this report. Verbal consent was gathered in interviews and participants were reminded that their participation was voluntary. The purpose of the survey was explained to each interviewee at the beginning and a recap was provided at the end.

Interviews were analysed to identify common meanings and themes using an interpretive approach. No qualitative software was used. Initial thematic analysis identified multiple basic themes.

3.4 Ethics

The Medical Research Council online web tool was used to determine whether the study could be classified as a formal 'research' project. Given the study was not randomised, did not involve changing treatment or care, and the findings would not be generalisable, the tool concluded the study would not be considered 'research' by the NHS. The project was determined to be a 'Service Evaluation', and as such, did not require NHS ethics approval.

Although the survey and interviews did not require formal ethics approval, best practice was used throughout. Tŷ Hafan and Tŷ Gobaith / Hope House developed a data management plan, including protocols around data storage to ensure compliance with data governance and the General Data Protection Regulations (GDPR). This provided safeguards to protect interviewees' confidentiality.

The findings from the interviews and the open-ended questions in the online survey were anonymised to remove any identification of children and young people or their families.

4 Presentation of findings

The online survey received 133 responses to the three bespoke questionnaires. This included 77 families currently using the service; 44 bereaved families and 12 young people accessing services. The young persons’ questionnaire focused on overall wellbeing and hospice support generally but did not identify demographic data, specific services or the hospice accessed; for this reason, the presented data does not represent their responses and is based on the 121 responses from the current and bereaved families. 84 survey responses were received from families being supported by Tŷ Hafan, and 34 from Tŷ Gobaith or Hope House. Three families received support from both hospices. In terms of the different sized potential hospice populations this indicated an equitable response rate from both hospices.

Three-quarters (74%) of respondents were women (n=90/ 121). 97% identified as White Welsh or White British (n=117/ 121), slightly above the White population in Wales (96%), and representative of the current hospice users demographic.

The survey responses from family members were monitored throughout the collection period to ensure there was representation from across Wales. Table 1 and 2 shows the distribution of families completing the survey across local authority’s (LA) and local health board’s (LHB).

Local authority	Responses received	Local authority	Responses received
Vale of Glamorgan	17	Bridgend	5
Conwy	11	Ceredigion	4
Caerphilly	10	Gwynedd	4
Cardiff	10	Torfaen	4
Newport	8	Wrexham	4
Flintshire	7	Pembrokeshire	2
Anglesey	6	Powys	2
Neath Port Talbot	6	Carmarthenshire	1
Rhondda Cynon Taf	6	Denbighshire	1
Swansea	6	Merthyr Tydfil	1
Blaenau Gwent	5	Monmouthshire	1

Table 1. Survey responses by local authority

¹ 74 of the 77 families who completed the form are using the service and three are in transition or are discharged

The survey responses reflect the population size of Local Health Boards in Wales. The greatest number of responses came from the most populous (Betsi Cadwaladr; Cardiff; and Aneurin Bevan), and the least from the smallest (Powys). The highest survey responses were from the areas closest to the hospices, Vale of Glamorgan and Conwy which suggests families in closer proximity may feel more connected to the hospices.

Local Health Board	Responses received
Betsi Cadwaladr	31
Aneurin Bevan	29
Cardiff & the Vale	27
Cwm Taf	14
Abertawe Bro Morgannwg	10
Hywel Dda	7
Powys Teaching	3

Table 2. Survey responses by local health board

5 Key messages from the families

The family responses identified several key themes which have been categorised as follows:

- Hospice services provide essential support to families
- The main places that families access the support they need
- Access to respite/ short break care is essential to family coping and wellbeing
- Complexity of care and impact on family life
- Importance of support to wider family
- Access to end-of-life care in a preferred setting
- Support for young people leaving hospice services
- The need for bereavement support and counselling
- Barriers that restrict access to services
- What families want more of

5.1 Hospice services provide essential support to families

Families reported that hospice services were essential to the wellbeing of their child and their whole family. They viewed it as both a core service (respite, clinical support) and a service that offers support not available elsewhere (emotional support, sibling support, peer group support, counselling).

They told us:

- "...people think a hospice is there to mop up where it shouldn't be there to mop up, it's there to support, **essential support for parents**, not mopping up."
- "Honestly, if (hospice) wasn't there then I **honestly don't know what so many families would do**, especially mine. It would just be so hard, be a **strain on other services** because we wouldn't have the hospice to rely on."
- "I could pick up the phone and ring the hospice, 'I'm a bit concerned, she's doing this' and they would explain, not to worry. Having that **reassurance at the end of the line, they would always be able to guide me, I could always get an answer.**"

Families identified that hospice services had made a positive impact on their lives with an average score of 4.26 (from 5). Families identified that hospices provided them with a range of services that improved their family life and kept them functioning well.

- "It is **more than just respite** – medical advice you could trust too, access to GP etc."
- "They are the only ones who have helped consistently over the years, **they have always been there**. If there was no hospice I would probably have been in a mental hospital by now to be honest".

The survey responses clearly indicated that generally families felt that the hospices were an essential part of their wider support services. The survey also asked families to identify what services they accessed from all providers, health, social care, education, third sector etc. and how essential they believed these services were.

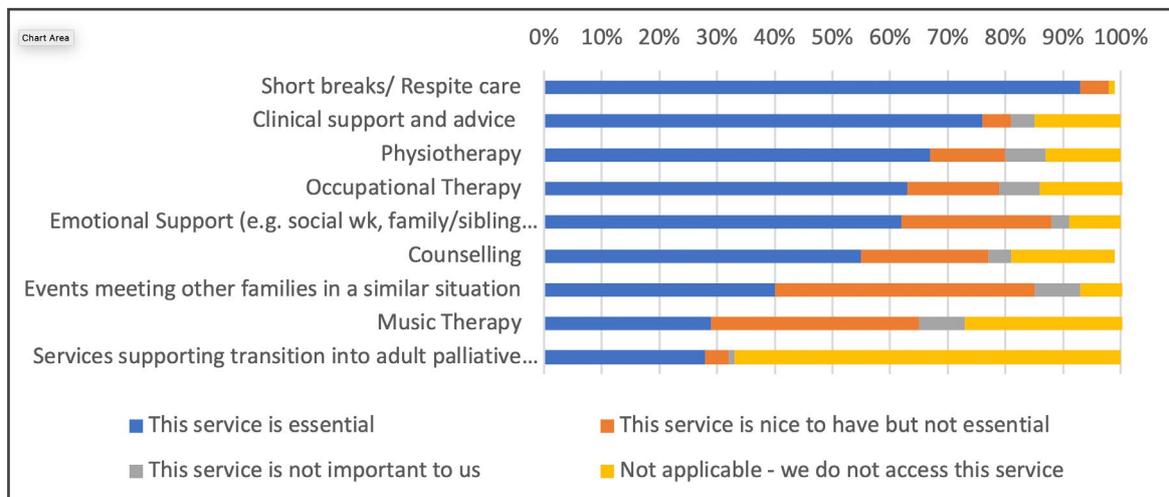


Figure 1. Essential services (any provider)

Service	% accessing/ accessed	% identified as essential
Respite care	100	94
Clinical advice / support	38	76
Physiotherapy	54	67
Occupational therapy	50	63
Emotional / family support	85	62
Counselling	40	55
Family events	64	40
Music therapy	38	29

Table 3. Services accessed and importance to families

* 1% identified above as not accessing respite had previously accessed this service

Respite care and clinical advice were clearly identified as the two most essential services; when we asked about where families mainly accessed their essential services hospices were identified as the main source of respite whereas most families accessed their clinical support from the NHS. Although some families identified the hospice as a source of clinical advice (38%) it would appear that the majority of families were unaware of, or chose not to use the hospice for clinical advice.

Although the majority of families identified the importance of knowing they could access end-of-life care support from the hospices, families also highlighted that pre-conceived misconceptions that hospices only provided care at the very end of life had resulted in them being anxious about engaging with hospice support earlier.

Once a referral had been made, families quickly recognised the support provided by hospices to be so much more than places to offer compassionate end-of-life care. They quickly understood the ethos of wrap around holistic care for families to ensure that the child gets to live the best life possible.

- "I remember being struck with horror thinking what do we need that for? Because I did know about hospice...but I didn't know what hospices do, especially children's hospices...I thought it would all be end of life, whereas **there's a lot more to hospice than that**"

Families overwhelmingly stated that the hospices provided them with a 'lifeline'. They said

- "It is our lifeline ... it is like our 999 call."
- "I don't know what would have happened to us if we didn't have the support ... it was only possible for me to have cared for 'our child' for as long with the support from the hospice."
- "These places are essential to families like ours, to the children and the families, the whole family not just the child. **They are the ones that keep us from breaking.**"

5.2 The hospices are often the main or only source of support

Respite care was overwhelmingly provided by the hospices with 85% of families stating this was their only or primary source of respite.

One family told us:

“(Hospice) is essential because we simply cannot ask anybody to look after (our child) in the way they do, the professionals involved, the activities they provide, the equipment they have – there is **nobody else that can provide that level of care**”

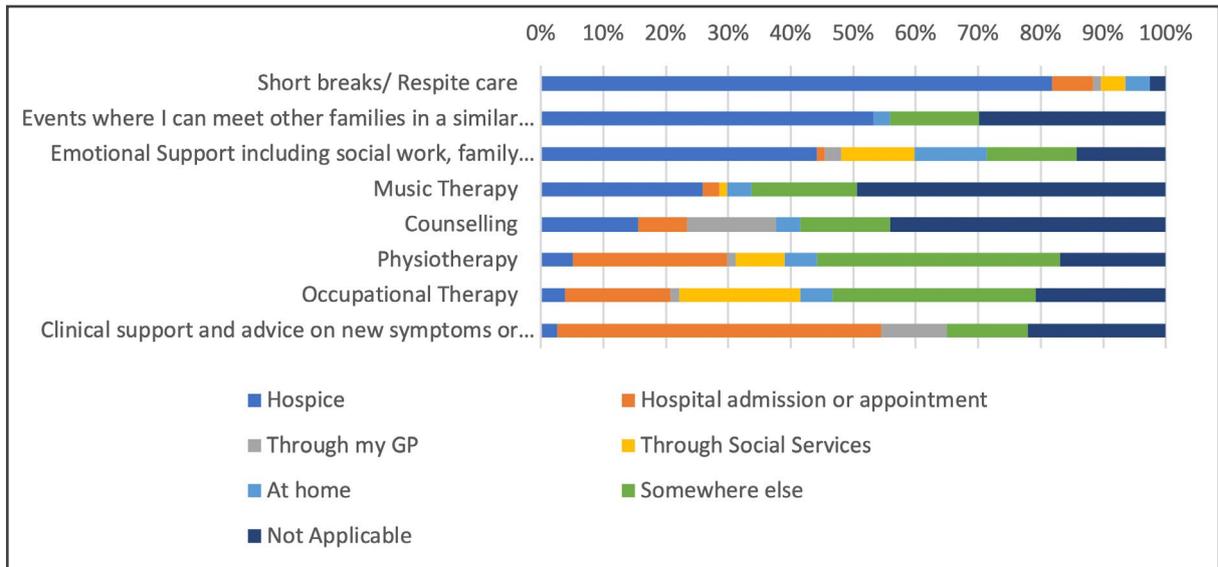


Figure 2. Main places families access key support services

33 families (43%) received continuing care support from the NHS, but 57% of these families reported that the package was either not fully delivered or did not meet their needs. They shared that securing this support was difficult:

- “We now get three hours a week of direct payments...but it took over a year to get it.”

Families identified that even if they felt the care package did not meet their needs, they were still grateful that they did at least get something. They recognised that there was a growing pressure on health services to provide home based care which impacted on timely delivery of care; this resulted in care not always being as flexible or responsive as wished. A few families highlighted the benefits of the hospice teams and the community nurses working together to provide care and support when it was needed.

Most families (96%) who needed to access clinical support

and advice did this via their medical team or school. This is unsurprising given the regular contact with schools and clinical teams that most families have. Not all families realised that this type of support was also available from the hospices, but those who did value it being available around the clock. Having access to 24/7 support was identified as essential by many families. One family said:

- “The NHS support was not available out of hours – only place you can call for advice/ support was the hospice”

Therapies, such as physiotherapy and occupational therapy were mainly provided by the statutory services (87%) but families who had accessed this support from the hospices were grateful for the additional support as they often felt they didn’t get enough or the right sort of support elsewhere.

Music therapy was most often accessed via the hospices (51%) and schools (38%). Counselling was primarily accessed via statutory agencies (64%) with 29% accessing support from the hospices. 45% of those responding reported that their main source of family support came from the hospices. Family support covers a range of activity designed to provide emotional, social and practical support to families and includes sibling support, groups and one to one support

during and in between hospice stays. Other sources of family support services were identified as primarily social services and schools but it would appear that the families really value having ready access to this care from the hospices, particular mention was made about family events and sibling support.

Most families said they do not receive adequate support, only around a third of families felt that the support they needed was always available and for some services as many as 20% identified these as just not being available. Parents reported struggling to access services they are entitled to outside of the hospice.

This is what parents told us:

- "There are pockets of support out there, but you need to know... **lack of services is quite frightening**, I used to work in social services. To be on this side is really scary."
- "Had to **reach crisis point to receive any care** which was not forthcoming and a long wait for any support."

Families identified that their health and wellbeing needs would have greater impact on other services if the hospices were not

available. They would feel as if they were on the edge, and without vital support from the hospices, would be forced to find alternative sources of support from other agencies (e.g. hospitals, GPs, local mental health services).

Families told us this is what it meant to them:

- "I sat there and just cried for half an hour and they were just fantastic. They said this is so normal, how you are feeling is normal, I said I just feel guilty for feeling sad, I am angry at the condition, angry at the situation and feel really cross... **it's the grieving process of losing that child that you were meant to have, that you don't have anymore.**"
- "It's about time people realise hospices and all the services they provide **save all the statutory services a lot of money**, a hell of a lot of money because the hospice **helps us as a family, refer us to the appropriate services, medical services, so we don't reach a crisis point.**"

On average families identified that they were always able to access services when they needed only around 30% of time.

The family responses indicate that families are not always aware of the full range of services on offer from the hospices or not aware how to access them if needed. There is a need to be clearer with families what services are available, to whom and how they can be accessed.

Service	% accessing / accessed	% not offered the service	% identified as essential
Respite care	100	nil	94
Emotional / family support	85	6	62
Family events	64	9	40
Physiotherapy	54	26	67
Occupational therapy	50	33	63
Counselling	40	34	55
Music therapy	38	36	29
Clinical advice / support	38	37	76

Table 4. Availability of support offered by the hospices

5.3 Access to respite / short break care is essential to family coping and wellbeing

Access to excellent quality child centred respite is seen as essential by families not just in terms of the expertise needed to care for the child but because of the positive impact on wider family health and well-being. 94% of families stated respite care was an essential service and that although a range of services were important, respite was the most valued service offered by the hospices.

- “Because we came (to the hospice), we were able to carry on with our life. If we didn’t have that support, maybe things would’ve been different, because we couldn’t do anything as a family if we didn’t have the hospice here, **our normal life would’ve stopped.**”

For many families, the daily routine involved providing care 24 hours a day, every day of the week. It isn’t unusual for a parent to sleep in the same room as their child with many worried that their child might not survive the night. This level of anxiety, day in day out, over months and years takes its toll; it is unsurprising that this unending lack of sleep and meaningful rest results in high levels of physical and emotional exhaustion for parents.

Sleep, or lack of it, was identified by most families as primary reason why respite was so important. 92% of families reported that ‘a good nights’ sleep’ makes a big difference. However, 74% of respondents identified that they struggled to achieve a good nights’ sleep. Some families noted that a break at the hospice was the only time they managed this and that they had gone many months without access to proper rest.

- “I can **catch up on my sleep – it is a lifeline.** Routinely do 3+ nights a week as no carers and only break from that is stays at hospice. Even only if twice a year it is a lifeline – it makes a difference.”
- “Getting a nights’ sleep / rest made a big difference – those few days allow you to have a **normal life.**”

A high importance was placed on respite care for families when it came to parent relationships. Families told us how essential access to respite was to maintain positive family functioning:

- “(Without the hospice) it would be very hard. It would cause a lot more strain on the family situation, possibly even Mum and Dad’s relationship, the mental health of everyone in the family, me, my siblings, my parents, we

wouldn’t know what to do without that respite and care because **we rely on it so much.**”

- “**Respite is so, so, so important,** for not only our children but for us as parents, our marriage, for siblings.”

The family centred nature of the respite provision was also identified as crucial and for some families the opportunity to have a break away as a family was especially important to them. 79% of families reported that to ‘stay and enjoy a break away together as family’ added real value to their lives, and 77% families reported that being able to play/socialise as a family ‘makes a big difference to our lives’.

This type of family respite offer is unique to the hospices which offer comfortable, separate accommodation for families to stay with their child if they wish.

- “Lack of sleep was the main issue and we were desperate for respite, but it was the **family focused respite that was key.** We couldn’t have just left our ‘child’ somewhere, being able to stay as a family made it possible to get the break we needed.”

Most families felt they were able to access some respite when they needed it. 34% reported respite care was ‘always available’, and 62% that it was ‘sometimes available’. However, over 75% families identified that they would like or benefit from more respite provision at the hospices because of the beneficial impact on wider family life.

- “Respite gives a bit of normality. Have night care in house so respite allows a break, **nice not to have anyone (professionals) in the house.**”
- “If I had the option, I’d come here **all the time.**”
- “Longer or more frequent breaks because (our child) is the **happiest we have ever seen them at the hospice** and it give us, as parents, much needed rest.”
- “The **respite is essential,** it saves you from breaking, saves your mental health, gives time to recuperate.”

5.4 The impact on family life of providing complex care

The complexity of care required for a child with a life-limiting condition means many parents are not able to leave their children with friends or relatives. As such, the strain on parents is immense with significant impact on family wellbeing.

Respondents identified the support provided by the hospices as essential for the wellbeing of the family and they told us that hospice support had a positive impact on their family life. The average impact score for family wellbeing was 3 (out of 5):

- "Time for us. **Time to be together** and not on high alert all the time."
- "We couldn't do anything as a family if we didn't have the hospice here **our normal life would have stopped.**"

Some children with extremely complex medical needs required 24-hour support and supervision, often akin to nursing care but almost always delivered by parents. This is exhausting and isolating for families:

- "I'm not a nurse, but **I had to be a nurse**, I had to be a mum, I had to be a carer."
- "I think it is really hard to convey to someone how different life has become when you say child needs **24 hour care** I don't think people understand that."

Families described feeling isolated (20%) and lonely (16%) because of these complex care needs. They reported life was difficult (38%) and stressful (45%). They described lack of ability to engage in 'normal day to day activities' because of the equipment their child needed to stay well and in some cases to stay alive. The complex medical needs of their child meant there was nowhere other than the hospice that they trusted to look after their child.

- "There wasn't anywhere else that could've facilitated 'looking after' (my child), there **wasn't anywhere else**, it would have been a hospital ward."
- "Without 'hospice' we would have no support – they are amazing **I trust them with my life, with my child.**"
- "What they like is to care for her **exactly the way we would care for her**, no matter how tiny the detail, it is really important to them that they get it right, makes us feel confident and okay to 'let go'."

Some families highlighted the impact of caring on their ability to work and the isolating effects that this had on them. This impact was especially felt by mums, who gave up work to fulfil caring duties. Some dads also identified this, and talked about not taking promotions, and experiencing cuts in income to balance out being at home when needed.

- "The reality is **you can't work**. In the past two months, our child has spent 27 days in hospital. I can't see any employer being reasonable about taking this time off."
- "Not being able to go out to work, see people is isolating, **it's a weird life.**"
- "It's emotionally tiring, it's physically tiring, financially tiring - **I have had to give up work**. That's been hard - I am not having that break. It was tough, giving up work. I enjoyed work it was my escape."

5.5 The whole family need support

Access to the wide range of services provided by the hospices helped families to feel better supported. Having somebody to talk to, access to practical and emotional support, access to counselling when needed, and opportunities to meet other families and attend family focused events were all seen as beneficial.

The fact that all this support, alongside access to short break care, symptom advice and therapies was available from one place was a positive for families as it reduced the impact of liaising with several different services.

- “The support especially provided by the family support officer... great source of support. Child's care so intense, sometimes it took the two of us 24/7 care, hard to put into words what they did for us, they basically saved our family.”

Mental health care and emotional support services, such as skilled family support and counselling are highly valued services which help families to deal with their situation. Some families described the skilful emotional support they received from the hospices as counselling and felt that this support met their needs, however some families did identify that easier access to formal counselling would have been beneficial.

Generally, families wanted more of these services, and for them to be offered rather than having to request them.

Counselling and emotional support was in the top three services families reported they wanted but do not always receive at the level they wanted.

- “(Counselling) helps, a lot... helped me express the way I'm feeling, to my parents. I've had a lot of **anxiety and fears** about being in the house on my own because I'm not as mobile anymore and **(counsellor) has helped.**”
- “We are accessing family support, my husband and I are both accessing counselling now through the hospice, we've never had it before. They approached us and my husband kind of shuts down a lot of the time, but they've got this magic knack, they just get it, **they get everything.**”

The children's hospices are key providers of emotional support to families, bringing about a positive impact on mental health and well-being, and family functioning. 45% of families identified that their main source of family support services came from the hospices:

- “(Hospice) made it possible to live **as much of a normal life** as we could in the five years we had with (our child).”
- “At home it gets quite stressful and when you come to the hospice it all goes away and you can **relax and forget your troubles** for a couple of days.”
- “Meeting other families is beneficial, it gives you opportunities to share and not feel so alone”
- “Family support was really supportive, and my child loved the play and music –we always wait for them at the window.”

Wider family support services were also identified as being important by families including social work, advocacy, providing navigation across services and a link between services, as well as opportunities to meet with other families to share information, guidance, and support.

For families with other children at home, the availability of dedicated services and support for siblings was important. These opportunities for their other children to have their own focused support improved overall family wellbeing and were viewed as being extremely important. Parents spoke about the guilt they felt about the impact on their other children when 'normal' activities were curtailed or just not possible.

- “Caring for a child who has a life-limited condition - the effects it has on a family are massive. We have come to accept the impact on us as parents, but the **guilt about how siblings' lives are affected** is massive.”

Families saw how the holistic support offered by hospices fosters a sense of togetherness that helps with coping and builds resilience:

- “The family support and sibling support really helps – gives us family time and couple time. Someone to talk to **who understands**, can explain things and can understand the fear.”
- “So, so important for, not only our **children**, but for us as **parents, our marriage, for siblings.**”

Another key role played by the hospices was advocacy, especially when it came to facilitating access to other services when a need was identified:

- “Whereas before, I genuinely thought that this was going to be it then, we are just fighting it by ourselves and there is nobody out there. So now that we have been given this lifeline we are **not fighting this battle alone.**”

5.6 The importance of end-of-life care in a preferred setting

The high quality, family focussed end-of-life care provided by hospices gives families essential choice about the place, and ethos, of care for their child. Around half of the bereaved families responding to the survey had experienced end-of-life care at one of the hospices and many had also benefited from outreach hospice support at home or in the hospital.

74% of families reported that knowing they can access symptom management and/or end-of-life care really matters to their family and makes a big difference to their lives:

- "Staff understood how difficult it was, how exhausting, the conflicting emotions. I had to resuscitate my child a few times, questioned whether I should, **was I doing the right thing**. Staff understood my fears."

Families who had experienced the death of their child spoke bravely about the impact of the support from the hospices at the time of their child's death. Some children died in hospital (39%) and families expressed gratitude in being able to transfer their child to the hospice after death to allow extended family time in a supported environment.

- "My child passed away in hospital but came back to the hospice...to **have that time** - the peace, the quiet, we stayed here as a family, it was amazing. My Mum and close friends came, lucky able to do that here, we're just one family, I just imagine loads of families don't have that. We were looked after, they are gentle people, understanding, **they know what to say to make you feel good at a bad time.**"

Place of death	No. (%) of children dying in setting	No. (%) where this was chosen place of death
Hospice	21 / 48%	20 / 21 (95%)
Hospital	17 / 39%	5 / 17 (29%)
Home / other	6 / 13%	3 / 6 (50%)

Table 5. Where children died / preferred place of death

Whilst this reflects the experiences of a relatively small number of bereaved families (n=44) it appears that the majority of families (95%) who experienced their end-of-life care at the hospice had identified this as their preferred setting. 70% of families whose child had died in hospital would have preferred this to be another setting, so did not achieve their preferred place of death. It is widely accepted that the preferred place of death for most families is home. However, it appears that for many families the hospice is their chosen environment. Further investigation of family preference would ensure that resources are targeted in the most appropriate way to ensure families receive the best support possible at this most critical and distressing of times.

The hospices were often involved in supporting families to record their wishes in an end-of-life care plan for their child. Across Wales, this is a Paediatric Advanced Care (PAC) Plan which is co-ordinated by the child's medical team. Making plans in advance can support families to consider how and where they would like their child to be cared for, including whether a transfer to the hospice or community-based hospice support is preferred (where available).

Skilled support at the right time to explore wishes was identified as vital. 60% families identified that they had an end-of-life care plan, and just under 10% said that they didn't want one. This means that 30% of families either declined (but this was not recorded), weren't offered the opportunity, or perhaps didn't understand the scope and purpose of making a plan.

Families overwhelmingly indicated through this study that they both trust the hospices and feel supported by them. This suggests hospices are well placed to support families with the advanced care planning process.

5.7 Young people leaving hospice services need support

The transition between child and adult care services is often described as difficult with services not always being developmentally appropriate for young people with life-limiting conditions; this is a cause of anxiety for young people and their families. Parents and young people have described this transition like 'falling off a cliff' and often refer to the safety net that they feel the children's hospice provides them.

Young people and families consistently said that they wish hospice services didn't have to stop for them and that they could keep coming for stays.

Young people at Tŷ Hafan, where stays stop at 18 and those at Tŷ Gobaith / Hope House where stays stop at 25 years old, reflected that they would like hospice support to continue and that they felt anxious about where their support was going to come from in the future:

- "I told my Mum I don't want to go to any adult respite because **it's not the same... we have visited (adult respite centres). There aren't a lot, the age range is very big, not a small group of people, it's a large scale, I feel uncomfortable with that.**"

Children's hospices have played an increasingly key role in working with adult service providers and adult hospices to ensure services are developed to meet the needs of this population. They also play a pivotal role in ensuring that young people and families get the preparation and support they need to make the transition to adult care successfully. Of the families responding to the survey only a small number (12%) had accessed the transition support provided by the hospices. This support is usually provided by one or two key staff, often dedicated transition nurses, who act as 'keyworkers' for young people to support the move to adult services.

Even though only a small number of families had accessed this support, over 25% of total respondents saw it as an essential or important service provided by the hospices.

When asked what impact hospice services had had on the lives of the young people, they reported this as positive with over 50% identifying that the hospice support had had a significant beneficial impact. They were asked about the

'services that make the biggest difference to their lives' and identified the following themes:

- Access to hospice services for respite, emotional support and events/ activities were all seen as making a difference to over 65% of respondents
- Access to counselling support and complementary therapy also made a difference to over 40% of the young people.

Over 75% of young people identified that access to a break away was the most valued service provided by the hospices.

One young person told us:

- "It's nice respite for mum, I rely on her a lot, it's nice for me to have a break and for her to have a break as well"

75% of young people especially valued the emotional support offered by the hospices, with 66% identifying the importance of emotional support being available for the wider family. 16% of the young people identified that access to formal counselling support had been beneficial. 66% of young people felt that opportunities to attend events and meet other young people were important, and 41% valued the access to complementary therapy.

For young people with life-limiting conditions to feel safe and well, they identified that they needed their families, friends, school, and importantly, to have fun.

25% told us the hospice made them feel happy, safe and well. Hospice was the place where they felt seen as a young person in their own right. Having people understand their condition and treat them as a whole person was highlighted as important to achieving this.

Young people valued the opportunity to make new friends and have new social experiences with other young people. They also said that access to transition information, advice, and support around growing up and independence, from the specialist transition nurses was helpful.

Responses from the young people indicated that they worried about their families, they were concerned about the increased caring role occupied by their parents and in particular their mums.

The young people were also asked what they would change about the support they get from the hospices or what they would want more of, if they had a magic lamp:

- 50% identified that there was nothing they would change

- 50% said that they would like more or longer stays at the hospice
- 33% would like more events / activities designed for young people and where they could meet others in similar situations
- 25% would like more post discharge support to mitigate the feelings of loss they felt on leaving the security of the children's hospice setting
- 17% identified that more access to therapies (physiotherapy / hydrotherapy and complementary therapy) would be beneficial

We asked young people to choose words to describe their family life and, whilst 75% described their family life as happy and 66% as full of love, around half of them said

family life was difficult and a third said that it was lonely. They identified the positive impact hospice support had on their family life. Several young people highlighted how grateful they were for the hospice support and for one young person it had 'changed their life'.

- "If it wasn't there then I honestly don't know what families would do ... it would cause a lot more **strain on the family situation**, ... Mum and dad's relationship, the mental health of everyone in the family".

5.8 Bereavement support and counselling make a difference

The provision of excellent end-of-life care and bereavement support is a clearly articulated aim of NHS Wales for 'families with palliative care conditions, the need for well managed end-of-life care and bereavement support is vital to the long-term wellbeing of parents and families'.^{vi}

Our survey responses indicated that over half of the bereaved families (28/44) had only accessed bereavement support via the hospices with the remainder of the families who had accessed support doing so via a GP, hospital, their workplace or another charity. A few identified that they had not accessed bereavement support either through choice or availability.

Bereavement support provided by the hospices was highly valued and seen as essential, but the survey identified that access to this is not always consistent and family experience has been varied.

75% of the bereaved families accessed memorial events at the hospice and many identified that these remembrance opportunities were comforting:

- "The memorial events are integral to our support and well-being and just **remaining part of the**

hospice family means so much to us."

- "The knowledge that twice a year we can **celebrate my child's life** amongst those who 'get it' is invaluable."

Families identified the importance of ongoing contact, memorial services and the support at key times like birthdays and anniversaries but not all families reported getting this level of support.

Over 80% of bereaved families felt that the support they had received did meet their needs, but this leaves around 20% left feeling that they needed more.

- "The one thing that went awry a little bit, we **didn't get any bereavement counselling.**"

Service	Total % (No.) accessing
Memorials	75% (33)
Family events (bereaved)	45% (20)
Family events (open)	38% (17)
Family support / emotional support	34% (15)
Sibling support	34% (15)
Counselling	18% (8)

Table 6. Services accessed by bereaved families

Whilst some families only accessed a single service, such as a memorial event, other families accessed multiple bereavement services. There was a correlation between length of bereavement and access to emotional support and counselling, but no significant correlation in relation to access to sibling support services (including groups) and attendance at family events. Over a third of the families responding had been bereaved for over five years and nearly a quarter for over ten years.

In relation to what families felt they needed more of, or suggestions as to how support could be improved, there were some common themes.

- Increased access to counselling and/ or emotional/ family support was identified as needed by nine respondents (20%)
- Offer of more structured group support for newly bereaved families
- More opportunities for siblings, particularly in relation to therapeutic activities
- Groups and events to be more locally / area based – closer to home
- Regular contact and contact at key anniversaries

5.9 Why services are not always easy to access

Whilst 21% of families told us they had not experienced barriers to accessing services many of the families highlighted multiple barriers.

Barrier	Total families (%)
Availability of service	73
Distance from services	55
Schooling (access to hospice breaks in term time)	30
Cost	28
Transport	11

Table 7. Barriers to access identified by families

Other barriers identified by families, particularly in relation to accessing wider support services and social activities were sleep deprivation; parental ill health; child frailty or the use of invasive equipment; child's behaviour; costs of and access to appropriate equipment/ changing spaces.

A few families identified that they had felt bereft when the regular contact they were having from known and trusted hospice staff had decreased over time. They understood that the support needed to change but the loss of this contact, compounded their feelings of loss and grief.

Over 50% of bereaved families could not identify anything additional they would want in terms of the support they got from the hospices. And over 20% of respondents identified that hospice support had had a significant positive impact on their health and wellbeing, with several families saying that they do not feel they would have coped, or even survived, without the support:

- "I honestly don't know how we would have coped, coped without the hospice support. They basically **kept me going**, gave me the strength to keep going ... I don't know where I would be, whether I would be here ... really I think **they saved me.**"

5.9.1 Availability of service

Many families responding to the survey identified that they would like increased availability of services. This was particularly in relation to respite with almost 60% of respondents reporting that respite is only sometimes available when needed. 85% of families reported that

physiotherapy was needed but this service was only always available for 35% of families. 70% of families wanted formal counselling and almost 25% of respondents reported that it is not available.

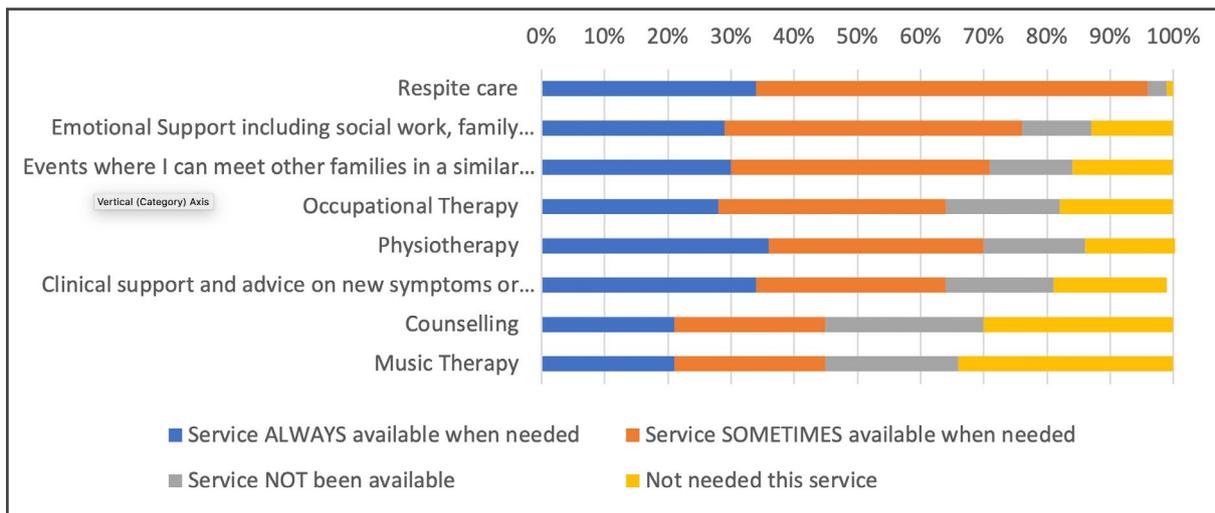


Figure 3. Availability of services from all providers (hospices/ statutory services etc)

Families stated that accessing services they were entitled to or they identified as necessary was often 'a struggle' particularly in relation to services accessed away from the hospices.

- "The (nursing team) are unable to meet my child's needs alone so we rely heavily on support from the hospice. The hospice provides our family with the **support we need to care for (the child).**"
- "I have had to **fight and plead**, on my own, a lot over the years to get equipment that (child) needs, still needs."
- "We had to reach crisis point to receive any care, ... **A long wait for any support.**"

5.9.2 Distance from services

72% families travel more than 30 minutes to access respite services, and over one quarter travel more than 1 hour. 28% of families have to travel more than 30 minutes to access a range of therapies (including physiotherapy, occupational therapy and music therapy).

Almost 10% of families identified that services closer to

home would be beneficial to them.

- “We would have accessed sibling support if it was closer – 2.5 hrs drive away and **nothing locally**, so didn’t really work for us. Would be better if services were closer to home.”

5.9.3 Financial constraints

For many families, having a child or young person with a life-limiting condition means that one parent has to give up work.

It is estimated that nearly two thirds of mothers of life-limited children have had to give up work to care for their child, and around one quarter of dads ^{vii}.

This reality, along with added costs of raising a seriously ill child, results in financial difficulties being experienced by many families.

It is estimated to cost an extra £581 per month for a family with a disabled child to have the same standard of living as a family without a disabled child, leaving families living with a life limited child at increased risk of experiencing poverty.

Financial constraints were identified by some families as barriers to accessing the support from hospices and wider services with 25% of families citing cost as a barrier and 11% citing transport issues.

51% of families have an annual income of less than £25,000 with 21% of families relying on less than £12,000; 66 respondents (87%) identified that they had experienced financial hardship and 54% of families incurred debt to cover expenses within the last two years:

- 59% of families identified they were unable to afford holidays and 44% days out
- 38% of families experienced financial hardship regarding petrol/ transport costs
- 29% of families have difficulty affording specialist equipment
- Over 25% identified issues with household bills including rent/ mortgage
- 25% of families identified difficulties affording birthday/ Christmas gifts
- Over 20% families reported difficulties affording school uniforms and school trips

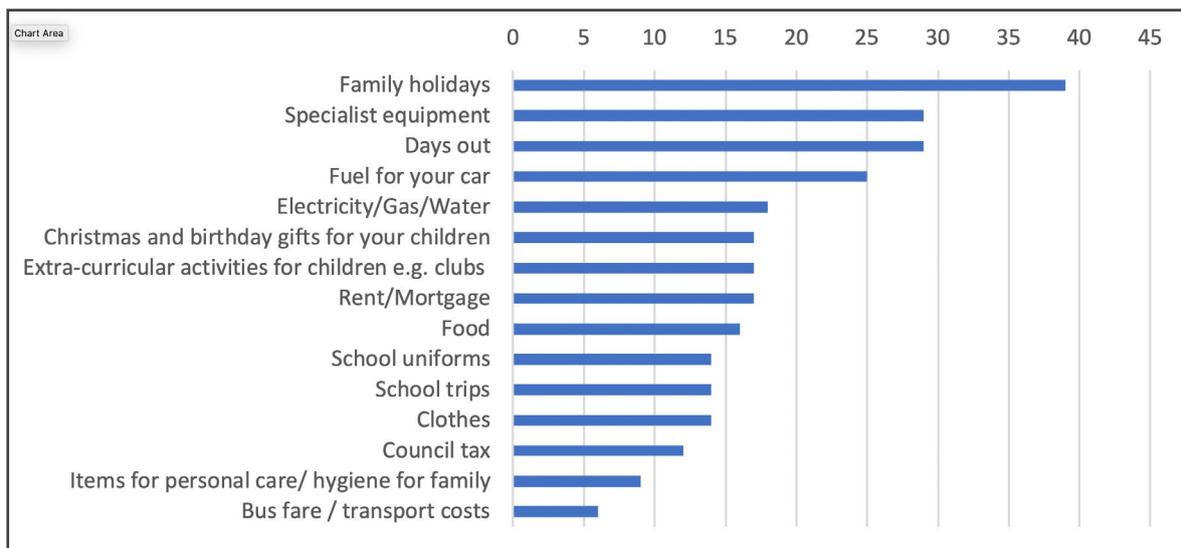


Figure 3. The items families have struggled to afford in the last two years (more than one answer available)

5.10 What families want more of ... the magic lamp

Our survey asked families to identify what they would like more of in the way of support. Specifically, they were asked if there was a 'magic lamp', what would make a difference to their lives.

Overwhelmingly the families identified that they wanted more respite and longer breaks, indicating just how crucial families feel respite support is for the wellbeing and resilience of the whole family.

Service	Total
More / longer respite	43% (33)
More availability of services	15% (12)
Advocacy / info / benefits / housing etc	13% (10)
Sitting / homebased care	10% (8)
More access to counselling / emotional support	10% (8)
Better communication between services (hospice and wider services)	10% (8)
Easier access / admission process	9% (7)
More local services	8% (6)
Increased age limit	8% (6)
More activities / events	6% (5)
More sibling support	5% (4)
More responsive to crisis	5% (4)
Better access to specialist PPC	4% (3)

Table 8. Services families identified wanting more of

It was clear from the responses to the survey, that families were grateful to the hospices for the support they provided. In many cases, hospices were viewed as the main or only provision of what families felt were essential services.

While it was the case for many that they would benefit from increased availability and a more responsive service, families said that without the existing support from the hospices their families would be struggling even more than they already were. Families also said that in some cases they felt 'lucky' to access hospice support knowing there were other families in Wales and in similar situations that did not have this.

- "It's when somebody else says but 'you are one of those families, your child is a poorly child, you do a lot of nursing care' it's only when you sit back and you say 'yeah, we do' but you don't look at it like that because they are your child, you have children you bring them up and **you look after them to the best of your abilities**'."

6 Final observations

The voices of the families known to the children's hospice services across Wales are a powerful reminder of the daily struggle that many of the families we serve face every day. Whilst the families describe their family lives as being full of love and joy, they also give us a window into understanding the exhaustion they face due to caring responsibilities and the emotional impact of living with the knowledge that their child is unlikely to live into adulthood.

This unfairly hard experience is further compounded by the very real fact that many of these families are also subject to financial hardship and instability. At a time when their lives already feel outside of their control and their physical and emotional resilience is at its lowest, they may live with the daily challenge of making scarce ends meet to provide a stable home and access to daily essentials.

They tell us that the things that many other families take for granted, like getting a good night's sleep, being able to enjoy social activities, go on holiday and afford a few little luxuries are not available to them. They describe a 'battle' to get the support they need, both for their complex-needs child, but also for the wider family to enable them to maintain their dual role as parents and full-time carers.

They call out the essential nature of respite care, vital to getting rest and building and maintaining the physical and emotional resilience required to sustain coping and their caring responsibilities. They highlight that gaining access to the level and quality of levels of respite required is fraught with difficulty as there are few providers other than the hospices equipped to deliver this support. They made it clear their primary source of any break from caring is

provided by the hospices.

95% of respondents identified respite as an essential service with 85% of families stating that they relied mostly or exclusively on the hospices for this. Access to appropriate respite and breaks from caring responsibilities is a key cornerstone of social care provision; initially in the Children Act (2004) and later replaced by similar duties under the Social Services and Wellbeing Act (2014). However, it appears that the complex needs of the majority of life-limited children make the provision of this essential support a challenge for statutory services. The hospices, with their unique skills and provision targeted towards this very population of children, are ideally placed to offer this much needed support but it comes at a significant cost.

The hospices currently provide millions of pounds' worth of respite support every year, of which over 90% is funded by the generosity of the Welsh public via charitable donations. Families told us in loud and resonating voices that they **see the hospices as their lifeline** - the source of support that stops them from falling apart. The provision of this essential support from the hospices mitigates the impact on statutory services and ensures families get access to the most appropriate support available. It is essential for these families that Tŷ Hafan and Tŷ Gobaith continue to play a key role in the delivery of this support, not least because by providing this support we strengthen family resilience, enabling families to establish trust, feel supported and to enjoy a level of security that continues to grow and develop for as long as they need this.

"A lot of children who go to the hospice have a really life-limiting condition, some of the parents do not know if their child is going to wake up in the morning. To have that fear We as a nation should be making sure those families live life to the full" (parent)



7 Bibliography

ⁱ RCN – Nursing Workforce in Wales report 2019

ⁱⁱ Fraser LK, Gibson- Smith D, Jarvis S et al. 'Make Every Child Count'. Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom'. Together for Short Lives 2020 Available from www.togetherforshortlives.org.uk/wp-content/uploads/2020/04/200415-Prevalance-report-Final.pdf.

ⁱⁱⁱ Cross Party Group Hospices and Palliative Care. Inequalities in access to hospice care. Cross Party Group on Hospices and Palliative Care 2018.

^{iv} Connor SR, Downing J, Marston J. Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis. Journal of Pain and Symptom Management. 2017 53 (2):171- 177

^v NHS Wales. Palliative and End-of-life care Delivery Plan. NHS Wales; 2017.

^{vi} Together for Short Lives. Preventing Family Breakdown through short breaks for respite. Available from www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/childrens-social-care

8 Acknowledgements

This report has only been made possible thanks to the many families known to Tŷ Hafan and Tŷ Gobaith / Hope House who took the time to respond to our survey and take part in interviews. We are very grateful to everyone who contributed to the finished report.

The report was authored by the project group:

Tracy Jones – Head of community services and partnerships, Tŷ Hafan
Jane Trevor – Head of community services, Tŷ Gobaith / Hope House
Deborah Ho – Director of Care, Tŷ Hafan
Karen Wright – Director of Care, Tŷ Gobaith / Hope House

Thanks also go to the following for shaping and supporting the initial project work:

Hannah Williams and Ceri Jackson – previously of Tŷ Hafan.
Dr Tammy Boyce – independent researcher.





Tŷ Hafan

Hayes Road,
Sully CF64 5XX

029 2053 2202 | www.tyhafan.org

Tŷ Gobaith

Tremorfa Lane,
Groesnydd LL32 8SS

01492 651 900 | www.tygobaith.org.uk

