



Policy priorities for the next Welsh Government



**Ensuring every seriously ill child in Wales can
access the palliative care they need**



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April 2021

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About Together for Short Lives

1. Together for Short Lives is the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector. We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers.
2. We work closely with the organisations that provide hospice care to children and young people in Wales – Tŷ Hafan and Tŷ Gobaith – and the professionals and services across the statutory and voluntary sectors that comprise the All-Wales Paediatric Palliative Care Network. We also work closely with Hospice UK and fully support the policies it has set out in its [Senedd Election 2021 paper](#)¹

Summary

3. For families caring for seriously ill children, feelings of isolation and loneliness are already very common, but the coronavirus pandemic has intensified this. Many parents, exhausted after months of providing 24/7 care for their child at home, may choose to carry on shielding their child and family long after social distancing ends because they are extremely nervous about the impact that contracting COVID-19 could have on their household.
4. The next Welsh Government needs to commit to ensuring that all children with life-limiting conditions and their families can receive the support they desperately need. Working with professionals and children's palliative care services in Wales, we have identified actions which the parties contesting the 2021 Senedd elections should commit to addressing if they form the next Welsh Government. These are of equal importance and should be implemented together:

¹ Hospice UK. 2021. Senedd Election 2021. Available at: [https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/huk-manifesto-calls-2021-\(full\).pdf?sfvrsn=0](https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/briefings-and-consultations-documents-and-files/huk-manifesto-calls-2021-(full).pdf?sfvrsn=0)

1. The Welsh Government should fund the new palliative and end of life care programme to enable it to sustainably resource the All-Wales Paediatric Palliative Care Network for the lifespan of the sixth Senedd.

- This should include money to secure sustainably funded on-call community nursing services which make sure that all children in Wales with life-limiting and life-threatening conditions can access end of life care and symptom management at home, 24 hours a day, seven days a week if they or their families choose it.
- This would be supported by supported by a national team of specialist paediatric palliative care nurses across Wales offering 24-hour telephone advice.

2. The Welsh Government should create a Lifeline Fund for Tŷ Hafan and Tŷ Gobaith, the children's hospices in Wales, to equitably and sustainably provide the specialist short break (respite) care needed by children with life-limiting or life-threatening conditions and their families.

- The fund should bring statutory funding for children's hospices in Wales into line with other UK nations, all of whom make a greater percentage contribution to children's hospices.
- The promised review into funding arrangements for all hospices in Wales must properly reflect the very specific and lifelong palliative and end of life care needs of children and young people.

Children's palliative care: what it is and the children and families in Wales who need it

5. Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It is an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week.
6. Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, many families still have difficulties accessing the care and support they need.
7. The impact on families is profound. New research shows that mothers of children with life-limiting conditions are much more likely to develop serious physical and mental health problems, compared to mothers caring for children with no long-term health condition². The risk of premature death for mothers of a child with a life-limiting condition is more than 50% higher compared to mothers with children with no long-term health condition. And mothers caring for a seriously ill child have a significantly higher incidence

² Fraser LK, Murtagh FE, Aldridge J, et al Health of mothers of children with a life-limiting condition: a comparative cohort study Archives of Disease in Childhood Published Online First: 02 March 2021. doi: 10.1136/archdischild-2020-320655. Available to download at <https://bit.ly/2Py6RnW>

of depression, anxiety and serious mental illness, and physical conditions such as cardiovascular disease, type 2 diabetes, hypertension and obesity.

8. Children with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including bereavement care after they have died. Palliative care for children includes, but is not limited to, end of life care, and the two terms should not be used interchangeably.
9. These children and their families rely on palliative care provided in hospital, children's hospices and in the community, by the statutory and voluntary sectors. Children's palliative care providers offer a range of services, including supporting families to manage their children's pain and distressing symptoms, providing children and their families with life-line short breaks and offering bereavement support both before and after the child has died.
10. Families want to be able to choose where they receive the lifeline children's palliative care services that they rely on, when they need and want them. They also want to choose who cares for their child and which treatments they receive.
11. It is clear that the number of children who need palliative care is growing. Whilst there is no recent data set for the numbers of children who need palliative care in Wales, numbers can be estimated from data available in England. 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 in Wales was somewhere around 3,580 to 3,720³.](#)

The additional challenges facing seriously ill children and their families in Wales as a result of the pandemic

12. The COVID-19 pandemic and lockdown has had a dramatic impact on children with life-limiting conditions and their families. [Together for Short Lives, in collaboration with Martin House Research Centre and the University of Southampton⁴](#), found that most families caring for a child with a life-limiting condition have felt even more isolated and alone than normal during the Coronavirus pandemic, with some parents describing that they feel like a "forgotten group":
 - 93% of families felt isolated during the pandemic
 - 57% said isolation has brought up negative memories
 - 95% are fearful that their child will catch the virus from their parent
 - 93% fear their child's treatment will be cancelled or delayed.
13. For families caring for seriously ill children, feelings of isolation and loneliness are already very common, but the coronavirus pandemic has intensified this. Many parents,

³ Lorna K Fraser et al. 2020. Make Every Child Count. Available at: https://www.togetherforshortlives.org.uk/wp-content/uploads/2020/04/Prevalence-reportFinal_28_04_2020.pdf

⁴ Together for Short Lives, Martin House Research Center, University of Southampton. 2020. Forgotten Families. Available at: <https://www.togetherforshortlives.org.uk/forgotten-families-families-feel-more-isolated-than-ever-under-lockdown/>

exhausted after months of providing 24/7 care for their child at home, may choose to carry on shielding their child and family long after social distancing ends because they are extremely nervous about the impact that contracting COVID-19 could have on their household.

Achieving 24/7 access to palliative care for seriously ill children and young people in Wales

14. [Standard 6 of the National Institute for Health and Care Excellence \(NICE\) quality standard 161 'End of life care for infants, children and young people'](#)⁵ states that infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.
15. The extent to which seriously ill children and young people can choose to receive palliative care at home, including at the end of their lives, depends in large part on whether they can access community children's nursing 24 hours a day, seven days a week. Community children's nursing can be provided by the NHS, children's hospice at home teams or a combination of both.
16. Worryingly, there are too few community children's nurses (CCNs) in Wales with the skills and experience needed to provide palliative care to children and young people. This means that too many children and families are missing out on the care and support they need, when and where they need it. It also means that too many seriously ill children need unplanned, prolonged emergency hospital admissions, when their needs could potentially have been met at home. As a result, the NHS is failing to achieve non-cash savings in the resources it spends on these children and their families.
17. In 2018 the [Cross-Party Group for Hospices and Palliative Care](#)⁶ published a report following its inquiry into the inequalities in access to hospice and palliative care in Wales. [The report highlighted the shortage of CCNs in Wales and the variation in the number and skills of CCNs across local areas](#)⁷. It recommended that the End of Life Care Implementation Board should develop a robust action plan to address shortages in community nursing for both children and young people, and adults with palliative care need. The report found that children and young people with life-limiting conditions should have the same choices about preferred place of care and/or death as adults at the end of life. For this to happen, the variation in numbers and skills of CCNs would need to be addressed to enable the delivery of end of life care for children in their own homes.
18. **Together for Short Lives has recently estimated that 240 additional community children's nurses (CCNs) are needed to provide a holistic community children's nursing service in Wales.** This has been calculated using the current number of CCNs (43) and the number estimated to be needed using recommendations from the Royal College of Nursing. In an area with a child population of 50,000, a minimum of 20 Whole Time Equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service (283 CCNs needed in total across Wales).

⁵ The National Institute for Health and Care Excellence (NICE). 2017. End of life care for infants, children and young people. Available at: <https://www.nice.org.uk/guidance/qs160/chapter/Quality-statement-6-Care-at-home>

⁶ Cross Party Group for Hospices and Palliative Care. 2021. Available at: <https://business.senedd.wales/mgOutsideBodyDetails.aspx?ID=502>

⁷ Cross Party Group for Hospices and Palliative Care. 2018. CPG Hospices and Palliative Care: Inquiry. Available at: https://www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/cpg-report_english_web.pdf?sfvrsn=4

19. The 2017 Palliative and End of Life Care Delivery Plan⁸ articulated the Welsh Government's vision and desired outcomes for palliative care services to achieve for both children and adults. This delivery plan aimed to ensure that:
- Children and young people will be appropriately supported closer to home by core service teams who have the appropriate support, skills and training
 - Children, young people, their families and the professionals that care for them will have access to specialist advice and support
 - Reduction in avoidable high intensity care or in-patient stays as children, young people and their families are supported to manage the child or young person's conditions safely in their own homes
 - Children, young people and their families are better supported by wider system organisations such as universal services, education and voluntary services as key links from core services are developed and maintained
 - Children, young people and their families will have choice, control and involvement in their care
 - Opportunities for self-management, for child or young person and family, are realised, offered and supported
 - Carers and family members feel supported and their needs are assessed and addressed.
20. The All-Wales Paediatric Palliative Care Network supports the work of the End of Life Care Board by leading and facilitating the ongoing implementation, maintenance and evaluation of a comprehensive, integrated and coordinated system of palliative/end-of-life care in so far as it relates to children.
21. The network comprises members of the all-Wales tertiary paediatric palliative care team, medical and nursing paediatric palliative care and transition leads from each Local Health Board, paediatric oncology outreach nurse specialists, representatives of third sector providers, including children's hospices, representatives from social care and education services, and also a representative from Together for Short Lives.
22. Progress has been made by the End of Life Care Board and network on these priorities for children and young people. However, the End of Life Care Board is unable to solve certain key challenges – such as the gap in community children's nursing or the provision of sufficient respite care to support carers and family members. This is due to a lack of resourcing.
23. We welcomed the Welsh Government's recent recognition of the End of Life Care programme's work in its new [National Clinical Framework published in March 2021⁹](#). The Framework stated that the programme serves as a vital national requirement for investigating challenges, supporting transformation, and developing solutions.

⁸ Welsh Government. 2017. Palliative and End of Life Care Delivery Plan.

⁹ Welsh Government. 2021. National Clinical Framework: A Learning Health and Care System. Available at: <https://gov.wales/sites/default/files/publications/2021-03/national-clinical-framework-a-learning-health-and-care-system.pdf>

24. However, part of this challenge is that infrastructure for community children's nursing is not being seen as part of palliative care itself, and so hasn't been considered part of what End of Life Care Board expects to fund – despite more recognition of this in recent years. This challenge is also due to a lack of resourcing for the Board making it unable to take action to provide a holistic community children's nursing service in Wales.

To achieve 24/7 access to palliative care at home for seriously ill children and young people in Wales, Together for Short Lives is asking the political parties contesting Senedd elections to commit that they will take steps to ensure:

- NHS children's community nursing teams, hospice at home teams, hospital outreach teams, or a combination, are sustainably planned and funded by the NHS in Wales, in collaboration with the children's hospices.
- There are enough children's nurses with the skills, knowledge and experience needed to provide palliative care to children in the community.
- The current and the next end of life care programme are given responsibility for community children's nursing infrastructure as a key part of children's palliative care needs and be given the necessary resources to take action to fill the 240 community children's nurses needed in Wales to provide a holistic community children's nursing service.

Achieving sustainable funding for children's hospices in Wales – and parity with the other UK nations

25. [Tŷ Hafan and Tŷ Gobaith children's hospices published report in November 2020¹⁰](#) which powerfully describes the needs of families of seriously ill children in Wales. Of the 133 families who access children's hospice services and who responded to Tŷ Hafan and Tŷ Gobaith's survey:

- 94% deem short breaks for respite provided by children's hospice as essential
- 85% said that Tŷ Hafan and Tŷ Gobaith were the only places they could get some much-needed rest, safe in the knowledge that their children were being looked after by care professionals
- 75% said they needed more frequent and longer respite stays.

26. In the report families reported that hospice services were essential to the wellbeing of their child and the whole family and that hospices provided them with a 'lifeline'. In the report families 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."*

¹⁰ Tŷ Hafan and Tŷ Gobaith. 2020. Family Voices. Available at: <https://www.tyhafan.org/uploads/Documents/Family-Voices-Project-English.pdf>

27. Nerys Davies' family from Llanrwst also described Tŷ Gobaith as a lifeline for many families like hers and that more respite care is urgently needed to 'stop families from breaking'. Her child, Bedwyr, 5, was diagnosed with the genetic condition Coffin- Siris syndrome two years ago. The condition causes significant learning disability and is extremely rare with just 200 children diagnosed worldwide. Bedwyr is also tube fed, has respiratory problems and cannot speak.
- *"It's the little things you really look forward to that other people can take for granted, like being able to sleep at night, or sit down and eat a meal in peace even if it is just beans on toast, or just to have a cup of tea,"*
 - *"It's horrific going without sleep. Bedwyr has always co-slept with me, which means I don't get much sleep at all. If anything happens it is always in the middle of the night. Emergencies and rushing to hospital always happen at 2am in the morning, never in the afternoon.*
 - *"Respite is so important for us as parents physically and mentally because without it families end up in crisis. That will end up costing social services and health much more to deal with."*
28. The recent [Strategy for Unpaid Carers published by the Welsh Government in March 2021](#)¹¹ also highlighted respite care as essential to maintaining the health and wellbeing of those caring for others. Together for Short Lives welcomed the fact that the strategy prioritised equal access to different and innovative forms of short breaks and/or respite, and also committed to working towards a better understanding of how respite can be accessed, funded and delivered by a range of providers, including statutory bodies and the private and third sectors.
29. However, despite the essential services they provide seriously ill children and their families, [between them, Tŷ Hafan and Tŷ Gobaith, currently receive less than 10% of their annual funding from the Welsh Government.](#)¹² This funding means that children's hospices in Wales currently receive the poorest levels of statutory funding across the UK. Children's hospices in England receive 21% of their funding from the UK Government – more than double the amount of government funding received by children's hospices in Wales. In addition, Northern Ireland's children's hospices receive 25% of their funding from the government and in Scotland 50% of children's hospices income comes from the state.
30. [Tŷ Hafan and Tŷ Gobaith have joined together to call for a new sustainable 'Lifeline Fund'](#)¹³ and funding parity with the rest of the UK. Tŷ Hafan and Tŷ Gobaith's propose to move towards a sustainable model of funding that is more aligned with Children's Hospice charities in other UK nations. This funding would give the children's hospices in Wales confidence to sustain and expand our services to better meet the need of all

¹¹ Welsh Government. 2021. Strategy for Unpaid Carers. Available at:

<https://gov.wales/sites/default/files/pdf-versions/2021/3/2/1616489674/strategy-unpaid-carers.pdf>

¹² Tŷ Hafan and Tŷ Gobaith. 2021. Wales' children's hospices call for new sustainable 'lifeline fund' and funding parity with rest of UK. Available at: <https://www.tyhafan.org/latest-news/2021/03/19/wales-childrens-hospices-call-for-new-sustainable-lifeline-fund-and-funding-parity-with-rest-of-uk/>

¹³ Tŷ Hafan and Tŷ Gobaith. 2021. A Lifeline Fund for Wales. Available at:

<https://www.hopehouse.org.uk/news/call-for-welsh-childrens-hospices-parity-with-uk>

children with life limiting conditions and their families across the country, in turn addressing Wales' ambition to be a 'compassionate country'.

31. This Lifeline Fund would:

- Fund additional crucial nights of care at children's hospices, for children with life-limited conditions in Wales. Tŷ Hafan and Tŷ Gobaith's report 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 and saves them from 'breaking'.
- Allow hospices to 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.

To achieve sustainable NHS and local authority funding for children's hospices in Wales – and parity with the other UK nations – Together for Short Lives is asking the political parties contesting Senedd elections to commit to creating the Lifeline Fund proposed by Tŷ Hafan and Tŷ Gobaith. This would ensure that all children with life-limiting conditions and their families can receive the support they desperately need.

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