

Cyflwynwyd yr ymateb hwn i ymgynghoriad y [Pwyllgor Plant, Pobl Ifanc ac Addysg](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Children, Young People and Education Committee](#) consultation on [Sixth Senedd Priorities](#)

CYPE SP 66

Ymateb gan: Dan Steer, Swyddog Materion Cyhoeddus a Pholisi, Together for Short Lives
Response from: Dan Steer, Public Affairs and Policy Officer, Together for Short Lives

Beth yn eich barn chi yw'r prif flaenoriaethau neu'r materion y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd? Os oes modd, nodwch eich barn o ran sut y gallai'r Pwyllgor fynd i'r afael â hyn.

What do you consider to be the main priorities or issues that the Committee should consider during the Sixth Senedd? Where possible, please set out your view about how the Committee could address them.

Thema 1: Addysg oedran ysgol | Theme 1: School-age education

n/a

Thema 2: Addysg bellach ac addysg uwch | Theme 2: Further and higher education

n/a

Thema 3: Iechyd a lles, gan gynnwys gofal cymdeithasol (i'r graddau y maent yn ymwneud â phlant a phobl ifanc) | Theme 3: Health and well-being, including social care (as they relate to children and young people)

Background

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.



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 support the consultation submission made by Tŷ Hafan and Tŷ Gobaith.

Together for Short Lives is requesting that the Committee commit to addressing the challenges facing children with life-limiting and life-threatening conditions in Wales. This includes ensuring that they have access to children's palliative care 24 hours a day, seven days a week. This also means ensuring that there is sustainable funding for Wales' children's hospices who provide lifeline care for seriously ill children across the country.

Ensuring 24 hours access to children's palliative care

National standards are clear children should have access to 24-hour care. [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'](#)¹ 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.

We know that 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.

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 noncash savings in the resources it spends on these children and their families.

In 2018 the [Cross-Party Group for Hospices and Palliative Care](#)² published a report following its inquiry into the inequalities in access to hospice and palliative care in

¹ 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/Qualitystatement-6-Care-at-home>

² Cross Party Group for Hospices and Palliative Care. 2021. Available at:

<https://business.senedd.wales/mgOutsideBodyDetails.aspx?ID=502>



Wales. [The report highlighted the shortage of CCNs in Wales and the variation in the number and skills of CCNs across local areas](#)³. 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.

Together for Short Lives has 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).

The 2017 Palliative and End of Life Care Delivery Plan⁴ 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 home
- 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.

³ 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/cpgreport_english_web.pdf?sfvrsn=4

⁴ Welsh Government. 2017. Palliative and End of Life Care Delivery Plan



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.

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.

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.

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 2021⁵](#). The Framework stated that the programme serves as a vital national requirement for investigating challenges, supporting transformation, and developing solutions.

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 Children, Young People and Education Committee to 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

⁵ 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-alearning-health-and-care-system.pdf>



- 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 Wales' children's hospices

Together for Short Lives supports Tŷ Hafan and Tŷ Gobaith's call to create a sustainable funding solution for children who need palliative care in Wales. The hospice's aim is to ensure that every child facing an unfairly short life has the best quality of life, be that through support in a hospital, hospice, in the community, or at home.

Tŷ Hafan and Tŷ Gobaith - together - provide paediatric palliative care for more than 450 children with life-limiting conditions and their families across Wales and offer around 2,500 nights of respite care each year. The hospices are calling for a more sustainable funding solution to allow them to futureproof their services and extend their reach, particularly into more rural communities across Wales, as they expect the need for their services to continue to grow following the Welsh Government commissioned prevalence study.

Currently, across the UK, children's hospices in Scotland receive 50% of their funding from the statutory sources; in Northern Ireland it is 25% - while the Republic of Ireland recently announced it would fund 30% of running costs for their children's hospices⁶.

Recently in England, notably in 2020/21, there has been an increase in state funding for children's hospices from 21% to 34% of charitable expenditure⁷. This is largely a result of both additional government funding support through the Children's Hospice Grant and also a drop in the levels of charitable expenditure across the sector. While this figure of 34% may well be an anomaly due to the pandemic's impact on the third sector's expenditure, what it does suggest is that funding for children's hospices in England is moving in the right direction, while Wales is getting left further behind.

Tŷ Hafan and Tŷ Gobaith have continued, and will continue, to do everything they can to attract funding through charitable donations. Around 90% of their funding comes from the generosity of the Welsh public through their donations. However,

⁶ Tŷ Hafan and Tŷ Gobaith Children's Hospices. 2021. A Lifeline Fund for Wales. Available at: <https://www.tyhafan.org/uploads/lifeline-fund/Ty-Hafan-and-Ty-Gobaith-Briefing-Document-A-Lifeline-Fund-for-Wales-2021.pdf>

⁷ Together for Short Lives. 2021. Pushed to the limits – The impact of COVID-19 on children's hospice funding 2019/20-2021/22. Available at: <https://www.togetherforshortlives.org.uk/wp-content/uploads/2021/06/210622-Pushed-to-the-Limits-the-impact-of-COVID-19-on-childrens-hospice-funding-a-report-from-Together-for-Short-Lives-FINAL.pdf>



the recent [Family Voices report](#)⁸ made clear that we cannot meet future challenges alone. The hospices want to move Wales up from its current position at the bottom of the league table of home nations in funding this vital lifeline of support for the families of children with life-limiting conditions.

Together for Short Lives supports the hospices in this aim. We are calling on the Children, Young People and Education Committee to work with Tŷ Hafan and Tŷ Gobaith, and with Welsh Government, to achieve sustainable funding for Wales' children's hospices.

Thema 4: Plant a phobl Ifanc | Theme 4: Children and young people

⁸ Tŷ Hafan and Tŷ Gobaith Children's Hospices. 2020. Children's hospices in Wales. The voices of our families. Available at: <https://www.tyhafan.org/uploads/Documents/Family-Voices-Project-English.pdf>

