Children’s palliative care in Wales

A briefing from Tŷ Hafan, Tŷ Gobaith and Together for Short Lives

Summary

1. The growing number of seriously ill babies, children and young people in Wales – and their families – rely on palliative care provided in hospital, children’s hospices and in the community, by the NHS and voluntary sector. Children’s palliative care providers offer a range of services which support 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.

2. The Welsh Government’s ‘Palliative and End of Life Care Delivery Plan – March 2017’[1] and guidance from the National Institute of Health and Care Excellence (NICE) [2] states that children and famlies should have opportunities to discuss and record how and where they would like to receive the palliaitve care they need. They should expect to be able to receive palliative care in the community 24 hours a day, seven days a week, wherever in Wales they live, if this is what they choose. This is particularly the case at the end of a child’s life.

3. However, there are signficiant barriers which are preventing this from happening.

   - the postcode lottery in the way in which local health boards (LHBs) plan and fund palliative care for children and their families

   - a dearth in the number of professionals with the skills, knowledge and experience needed to provide palliative care to seriously ill children and their families in Wales

   - a lack of knowledge about the number of children in Wales who need active palliative care at any one time – and the extent to which they are receiving this care from hospitals, children’s hospices and community services.

4. Tŷ Hafan, Tŷ Gobaith and Together for Short Lives ask Assembly Members to use this debate to ask what steps are being taken by the Welsh Government to address these vital issues. In particular, **we need to see action on the recommendations made by the Cross Party Group for Hospice and Palliative Care following its inquiry into inequalities in access to hospice and palliative care.**

5. **We have also asked that Welsh Government commission and fund a study which examines the demand for children’s palliative care in Wales – and the extent to which this is being met.** We believe that ministers should follow the example of the Scottish Government, which funded research to identify the number of babies, children and young people with life shortening conditions in Scotland. This research, ‘Children in

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[1] Welsh Government. 2017. Palliative and end of life care delivery plan - March 2017. Available to download from: http://bit.ly/2pW2Kjs

[2] The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

Scotland with Palliative Care Needs' (ChiSP)[3] was published in 2015 and has been shared with Welsh Governmetn officials.It showed that the number of babies, children and young people in Scotland who needed palliative care was much higher than previously thought. The study also showed that two thirds of babies, children and young people who die each year in Scotland did so without access to specialist palliative support. Welsh Government officials have been in discussion with the End of Life Care Board, and representatives of Tŷ Hafan and Tŷ Gobaith about taking this work forward, but we would like to see swift progress now, as this has been a recommended course of action over a number of years – and previous Wales and UK studies have all concluded that there is a high level of unmet need for paediatric palliative care.

About children's hospices in Wales

6. Together, Tŷ Hafan and Tŷ Gobaith care for life-limited children and their families right across Wales. They are two separate charities, but with the same single mission: to provide support, care and dignity to families at a time when they need it most. Tŷ Hafan, Tŷ Gobaith and Together for Short Lives are proud to work together to ensure that our voices are heard where crucial decisions are made.

7. Every Assembly constituency and region in Wales has families they are supporting through the toughest of times. Either through respite care in the hospices, bereavement care for parents and siblings, or through special nursing support in hospitals and out in the community. We have an open door to all Assembly Members who want to learn more about the care we provide – and we are happy to provide constituency level data on request.

8. Health Inspectorate Wales (2019 report into Children's services)[4] had this to say about Tŷ Hafan and Tŷ Gobaith: "We found staff were kind and caring and there was good support available to families. Young people received care that was tailored to their specific needs and were supported with an extensive range of facilities and programmes to enhance their well-being." The same report also concluded that Welsh Government needed to do more to assess unmet need for these vital services.

About Together for Short Lives

9. 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.

Life-limiting conditions in children – and the palliative care they need

10. 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.

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[3] Fraser L, Jarvis S, Moran N, Aldridge J, Parslow R, Beresford B. 2015. Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study). Available to download from: http://bit.ly/2ArO3i9

4 Health Inspectorate Wales. 2019. How are healthcare services meeting the needs of young people? http://hiw.org.uk/docs/hiw/reports/290319thematicyouthen.pdf

11. 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.

12. 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.

13. 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.

14. 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.

15. There are 1,000 babies, children and young people in Wales with life-limiting and life-threatening conditions[5], a number which is growing as a result of advances in medical technology and better care. In 2011, there were 222 registered child deaths in Wales[6]. A significant proportion were seriously ill children who needed end of life care.

The action that the Welsh Government has taken

16. The Welsh Government's 'Palliative and End of Life Care Delivery Plan – March 2017'[7] states that, after their child had died, families would be able to say:

    - Conversations about their child's serious illnesses were appropriate and empowered them and their child to take informed decision
    - Their child's illness and the fact that they needed palliative care – were identified early
    - They and their child experienced care that met their needs and preferences
    - They and their child felt supported at all stages and by all staff
    - They and their child had the information they needed to make decisions
    - Professionals caring for them and their child were equipped in all health care settings to support them.

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[5] Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P. 2012. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: http://bit.ly/1z24ZQw

[6] Royal College of Paediatrics and Child Health. 2014. Why children die: death in infants, children and young people in the UK.

[7] Welsh Government. 2017. Palliative and end of life care delivery plan - March 2017. Available to download from: http://bit.ly/2pW2Kjs

17. In the 'Palliative and End of Life Care Delivery Plan – March 2017'[7], the Welsh Government states that to plan effectively for their populations, local health boards must build and lead coalitions with NHS Trusts, locality networks, GPs, nursing homes, pharmacists, dentists, opticians, social services, prison services and the third sector voluntary bodies. An all-Wales Paediatric Palliative Care Network and Implementation Group, chaired by Dr Richard Hain, enables a one Wales approach, providing peer support and acting as an effective information sharing platform.

In the context of today's debate, it is important to understand if the Welsh Government is confident that the Palliative and End of Life Care Delivery Plan and the NICE guideline on end of life care for infants, children and young people are implemented in full across Wales.

The extent to which the End of Life Care Delivery Plan is being met for children and families

18. Freedom of information (FOI) requests made of each local health board (LHB) by Together for Short Lives in June 2017 found variances in the ways in which children's palliative care is planned, funded and monitored across Wales. For example, when we asked whether LHBs are implementing the NICE clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'[8], one LHB (Cwm Taf) confirmed that they are doing so, two stated that they are not (Aneurin Bevan and Powys), and three stated that this is delivered at an all-Wales level. Six of the seven (all except Cardiff & Vale) LHBs responded to our FOI requests.

19. Similarly, when we asked whether the LHBs ensure that community paediatricians can provide care out of hours and at weekends, just one LHB (Cwm Taf) stated that this was the case, while four (Abertawe Bro Morgannwg, Aneurin Bevan, Betsi Cadwaladr, and Powys) said they do not. One (Hywel Dda) said that this is delivered at an all-Wales level.

Suggested question: **Will the Minister clarify with LHBs that they are responsible for planning, funding and providing children's pallative care?**

The barriers preventing seriously ill children and their families from accessing the palliative care they need

20. In 2018, a Cross Party Group for Hospices and Palliative Care[9] inquiry found a number of challenges facing children and families in Wales:

Too few professionals with the skills, knowledge and experience to care for seriously ill children

21. Workforce pressures – specifically shortages of GPs, district nurses and community paediatric nurses who coordinate and deliver the day-to-day care of people with palliative care needs in the community – presents a real barrier to achieving this shift. The Group heard how this shortage has a particular impact in rural areas.

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[9] Cross Party Group for Hospices and Palliative Care. 2018. CPG Hospices and Palliative Care: Inquiry - Inequalities in access to hospice and palliative care - July 2018. Available to download from: http://bit.ly/2LKQ12f

The End of Life Care Implementation Board

22. While paediatric representation on the End of Life Care Implementation Board is welcomed, paediatric palliative care is not always prioritised and is poorly resourced in comparison with representation from the adult sector.

Access to children and families in West Wales and in rural areas

23. The location of children's hospices – in North, South East and cross-border – make the reality of an open offer of support to all children across Wales challenging. Access is particularly limited for families in West Wales and in rural areas.

Access to specialised medical support

24. In 2018, Together for Short Lives highlighted that only one consultant session is funded in North Wales, and none in Powys. While an increase in the cover provided by children's palliative care consultants was secured in July 2018, with a proposed interim arrangement funded until 2020, a sustainable arrangement beyond this has not yet been secured.

Suggested question: **What is Welsh Government doing to ensure there is access to specialised children's palliative care medical support out of hours and at weekends in all parts of Wales?**

Access to nursing support (see also Annex re Health Committee report)

25. Local arrangements for, and the viability of, enabling children, young people and their families to achieve their preferred place of care and, where appropriate, preferred place of death, were cited as significant challenges.

26. Progress has been made through the appointment of specialist paediatric palliative care nurses who are now in post in all health board areas. Despite the impact these posts have had at a regional level, particularly in acute settings, the Group heard that they are not yet achieving the desired impact at an all-Wales level. There was an expectation that these posts would be made available to contribute to the all-Wales out-of-hours nursing advice line, supporting the delivery of care for children and young people in their own homes. This has not yet happened. Complexity and variation in the funding arrangements for these posts – with varying degrees of funding from hosting health boards and all-Wales monies contributing towards each post – is a significant barrier in achieving consensus on the specialist paediatric palliative care nurses' remit.

27. Delivering care on a day-to-day basis to children in their own homes, overseen by the specialist nurse, is the responsibility of the community paediatric nurse. The scarcity of these roles across Wales, and difficulties in filling these posts with suitably qualified people when posts become available, was cited as a significant and ongoing barrier.

28. Services, such as Hywel Dda University Health Board's Palliative Care Children's Outreach In reach Nursing Service (COINS), are able to support children and young people to die in their own homes where this care is needed only for a short time (typically seven to 10 days). Shortages of community paediatric nursing staff, and limitations on the ability to release paediatric palliative care nurses from hospices for long periods, mean that longer term care for children in their own homes is not always possible.

29. While community paediatric nurses have a wider role in delivering care to children and young people with a variety of conditions – not limited to palliative and end of life care – they are instrumental to a sustainable approach to enabling children with palliative care needs and their families to achieve their care preferences, where this preference is to be cared for at home. Without the availability of community paediatric nurses across all areas of Wales, delivering on the local specialist paediatric palliative care nurse's advice and guidance, choice about preferred place of care and/or death for children and young people remains unequal across Wales.

Suggested question: What action is the Minister taking to make sure that all LHBs plan and fund community children's nursing, including out of hours and at weekends, for all children who need palliative care, provided by the NHS and/or the children's hospices?

Identifying children and families who need palliative care

30. There is no central register or database recording children with life-limiting conditions that could support case-finding by providers. Work to gain up-to-date data on the number of children with life-limiting conditions has not been undertaken by Public Health Wales and is not expected to be undertaken in the near future.

31. We are asking the Welsh Government to commission and fund a study which examines the demand for children's palliative care in Wales – and the extent to which this is being met. We believe this should follow the example set by the Scottish Government, which funded research to identify the number of babies, children and young people with life shortening conditions in Scotland. This research, 'Children in Scotland with Palliative Care Needs' (ChiSP)[10] was published in 2015. It showed that the number of babies, children and young people in Scotland who needed palliative care was much higher than previously thought. The study also showed that two thirds of babies, children and young people who die each year in Scotland did so without access to specialist palliative support.

Suggested question: Will the Minister commit to commissioning and funding a study which examines the demand for children's palliative care in Wales – and the extent to which this is being met? Will the Minister ensure this information is collated and monitored on an annual basis to ensure services are keeping up to date with changes in need?

Professionals and services being unaware of the children's palliative care services that are available

32. With just two children's hospices located in Wales, some children and young people living in Wales will therefore access specialist support from hospices and children's hospitals in England. Despite hearing that children's hospices and hospitals on both sides of the border work constructively together for the benefit of the child, the cross-border dimension is an additional complexity in ensuring that all children who have a palliative care need are able to access this service. Referral is dependent on whether the child has been referred to statutory tertiary care and the knowledge and awareness of

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[10] Fraser L, Jarvis S, Moran N, Aldridge J, Parslow R, Beresford B. 2015. Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study). Available to download from: http://bit.ly/2ArO3i9

clinicians in this setting about children’s hospice care. Poor awareness of the service leads to delays in access to care. The Group heard that late or missed referrals are most common in paediatric neuromuscular, cardiac and renal services.

Suggested question: Will the Minister take steps to ensure that professionals and services are aware of the children’s palliative care services they can refer seriously ill children and their families to?

Age and developmentally-appropriate palliative care for young people – and transition to adult palliative care services

33. Clinicians and carers alike referred to transition between children’s and adult services as a period where adolescents and young people were missing out on appropriate care. An all-Wales Paediatric Palliative Care for Transition post was established in 2016 to address some of the concerns regarding care at this juncture. Despite this, carers and families giving evidence to the committee said that they feared the process of transition because of a perceived withdrawal of support, which is often felt most acutely in moving between children’s and adult social care services, with changes to respite and short breaks a particular feature of change.

Suggested question: What action is the Minister taking to make sure that young people with life-limiting conditions are assessed by local authorities for the social care they are likely to need as adults before they reach adulthood?

34. A shortage of age-appropriate residential placements for young people – both for respite or short breaks and acute end of life care – is a considerable issue in meeting the palliative care needs of this group. Young people with complex needs are often placed in older people’s care homes, which may struggle to accommodate their specific needs or to provide a suitable environment.

Suggested question: What action is Welsh Government taking to ensure that young adults with life-limiting conditions and their families are able to access short breaks for respite that are appropriate for their age and developmental stage?

The action recommended by the Cross Party Group

35. To overcome these challenges, the Cross Party Group for Hospices and Palliative Care recommended the following action:

    - LHBs should demonstrate how they consider end of life care needs in determining their out-of-hours coverage and work cooperatively to resource children’s out-of hours services at an all-Wales level.

    - As part of wider reviews of out-of-hours care, end of life care needs should form a significant element in determining the level of coverage required within local health board areas, including contributing resource to provide all-Wales coverage. The group stated that this should include working cooperatively with the End of Life Care Implementation Board and children’s hospices to secure sustainable out-of-hours coverage for children’s palliative care by ensuring that appropriate consultant cover is available.

- The End of Life Care Implementation Board should develop a robust action plan to address shortages in community nursing for children and young people who need palliative care.

- 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 community children's nurses must be addressed to enable the delivery of end of life care for children in their own homes.

- The End of Life Care Implementation Board should work with local health boards and children's hospices to identify gaps in extant provision and work together to enhance the skills needed to support current community teams to develop community children's nurses with appropriate qualifications in children's palliative care. This should involve creating specialist posts to support the development of the existing workforce, where necessary.

Suggested question: Is the Minister confident that sufficient resources are being made available to fully respond to the recommendations made by the Cross Party Group for Hospices and Palliative Care for improving access to children's palliative care?

Statutory funding for children's hospices in Wales

36. The way in which the Welsh Government and LHBs fund the two children's hospices in Wales is outdated, inequitable and unsustainable. It also represents a much smaller relative contribution than that made by the NHS and local authorities in England or in Scotland.

37. In 2017/18, Tŷ Hafan incurred £4.4million in charitable expenditure providing care to seriously ill children in Wales. In 2017, Tŷ Gobaith incurred £2.9million in charitable expenditure providing care to seriously ill children in Wales[11]. Combined, both children's hospices provided care worth £7.3million to seriously ill children in Wales.

38. In 2017/18, Tŷ Hafan received £360,535 from LHBs, representing just 8.1% of its charitable expenditure. Tŷ Gobaith received £533,753 from the Welsh Government and LHBs, representing 18.2% of its charitable expenditure in Wales. Combined, both children's hospices received a total of £894,288, meaning that the state contributed just 12% to the amount children's hospices spend to provide care to seriously ill children in Wales. This is less than the 21% that children's hospice organisations in England received on average from the NHS and local authorities combined in 2018/19. It is much less than the 53% contribution that Children's Hospices Across Scotland (CHAS) received from the Scottish Government, the NHS and local authorities in 2017/18.

39. A large proportion of the care and support provided by the children's hospices is short breaks for respite, which includes both health and social care. It is therefore difficult to justify why neither Tŷ Hafan nor Tŷ Gobaith receive any funding at all from local authorities in Wales, which are responsible for planning and funding social care for disabled children.

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[11] This excludes the charitable costs that Tŷ Gobaith incurred in providing care to seriously ill children in England.

40. Earlier this year, NHS England committed to continue to provide a ringfenced grant to children’s hospices in England. This is currently worth £12million in 2019/20. NHS England has committed to increasing it incrementally to £25million in 2023/24[12].

41. In 2016, the Scottish Government committed £30million funding for CHAS over five years as part of increased investment in children’s palliative care[13]. The funding, which will began in 2017/18, is providing approximately half of the agreed running costs of running CHAS. This followed the publication of the CHiSP research findings in 2015[14].

For more information, please contact:

Andy Goldsmith
Chief Executive
Tŷ Gobaith
andy@tygobaith.org.uk

Rob Jones
Chief Executive
Tŷ Hafan
rob.jones@tyhafan.org

James Cooper
Head of Public Affairs and Policy
Together for Short Lives
james.cooper@togetherforshortlives.org.uk

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[12] NHS England. 2019. Children’s hospices to receive £25 million a year as part of NHS Long Term Plan. Available to download from: https://www.england.nhs.uk/2019/07/childrens-hospices-to-receive-25-million-a-year-as-part-of-nhs-long-term-plan/

[13] Scottish Government. 2016. Children's Palliative Care Boost. Available to download from: https://www.gov.scot/news/childrens-palliative-care-boost/

[14] Fraser L, Jarvis S, Moran N, Aldridge J, Parslow R, Beresford B. 2015. Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study). Available to download from: http://bit.ly/2ArO3i9