

Cynulliad Cenedlaethol Cymru  
Y Pwyllgor Iechyd, Gofal Cymdeithasol  
a Chwaraeon  
Ymchwiliad I wasanaethau Nyrsio  
Cymunedol a Nyrsio Adal  
HSCS(5) CDN01  
Ymateb gan Hospice UK

National Assembly for Wales  
Health, Social Care and Sport  
Committee  
Inquiry into Community and District  
Nursing services

Evidence from Hospice UK

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## 1. About Hospice UK

1.1 Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice and palliative care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families. Our vision is hospice care for every person in need and our mission is to enable hospice care to transform the way society cares for the dying and those around them.

## 2. About Hospices Cymru

2.2 Hospices Cymru is the collective voice of Hospice UK members in Wales. This includes the 13 adult hospices and the two children's hospices in Wales. The group seeks to advance hospice care and enable better palliative and end of life care for more people in Wales.

## 3. About this response

3.1 We welcome the opportunity to respond to this consultation on district and community nursing services in Wales. Hospice UK provides secretariat to the CPG Hospices and Palliative Care, which drew attention to the need for an inquiry into community and district nursing as the cornerstone of hospice and palliative care delivered to adults and children in their own homes and care homes, in evidence to the Health, Social Care and Sport Committee on 13 December 2018.

3.2 This response draws on the experience of hospices in Wales working in partnership with community nursing services to support people with terminal or life-limiting conditions and those at the end of life. We have therefore limited our comments to the role of community nursing in the delivery of hospice and palliative care.

## 4. Context: the involvement of community nursing in hospice and palliative care

4.3 District and community nurses organise and coordinate home health care for people with palliative and end of life care needs. For people with specialist palliative care needs, the community nurse is advised and supported by a palliative care clinical nurse specialist (CNS) and/or consultant in palliative medicine. The delivery of hands-on care around the clock may be provided by the community nursing team, including by health care support workers (HCSW) or assistants, or by a hospice at home service. The HCSW or hospice at home service

may be funded and organised by the health board, by a charitable hospice, or a combination of both, dependent on which area of Wales the person resides in.

4.4 Children and young people with palliative care needs are cared for by the health board community children's nursing (CCN) services, who are advised by a specialist paediatric palliative care nurse located in each health board. Each health board organises and funds its own CCNS. Across Wales there is variation in the funding of the paediatric palliative care nurses who advises the CCNS teams delivering hands on care, with some funded entirely by their hosting health board, others funded entirely by all-Wales monies through the End of Life Care Implementation Board, and others part funded by both sources.

## 5. Policy context

5.5 In line with the Welsh Government's vision in 'A healthier Wales'<sup>i</sup>, the End of Life Care Board has prioritised improving access to hospice at home services each year from the End of Life Care Delivery Plan's inception in 2017.<sup>ii</sup> Reporting on progress implementing this priority area in 2018 is expected in the forthcoming End of Life Care Delivery Plan Annual Report (March/April 2019).

5.6 Despite the crucial role that community nursing plays in enabling a person with palliative care needs to remain at home for as long as possible and the reliance of specialist palliative care providers in the community on the community nursing services, very few direct references are made to community and district nursing within the Welsh Government and NHS Wales Palliative and End of Life Care Delivery Plan 2017-20, indicating that strategic planning in these areas are happening in isolation.

5.7 In September 2018, the then Cabinet Secretary for Health and Social Services accepted in full the recommendation made by the Cross Party Group on Hospices and Palliative Care Inquiry, 'Inequalities in access to hospice and palliative care' regarding the provision of community nursing:

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 needs.

a) The equitable delivery of palliative care in the community for adults at the end of life is dependent on the local availability of an appropriately qualified community workforce. The End of Life Care Implementation Board, in partnership with health boards, adult hospices and third sector providers of specialist nurses, must address the gaps in this workforce, including succession planning. This should consider the District Nursing service as a priority, as well as the appropriate resourcing of Community Resource Teams and the distribution of staff with palliative care skills.

b) 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 paediatric 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 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 paediatric nurses with appropriate qualifications in paediatric palliative care. This should involve creating specialist posts to support the development of the existing workforce, where necessary.<sup>iii</sup>

## 6. Acuity and level of need for district nursing for people with palliative and end of life care need, now and into the future

6.1 The Welsh Government estimates that around 23,000 people die in Wales each year with a palliative care need,<sup>iv</sup> though more recent academic estimates have placed this figure higher at around 28,000.<sup>v</sup> These are people whose deaths could reasonably be predicted because of conditions such as cancer, COPD, organ failure, dementia and frailty.

6.2 In its 'Future Trends Report' the Welsh Government highlights that the number of people aged over 65 is set to be 40 per cent higher by 2039 than in 2014.<sup>vi</sup> With people over 65 accounting for 85 per cent of all deaths,<sup>vii</sup> palliative care providers are likely to see a greater volume of people with end of life care needs by the end of this period.

6.3 Despite these estimates of need, data is not currently available to assess the total number of people in Wales who have received the right hospice or palliative care, delivered by the right services, at the right time. This includes an absence of data on the number of people with palliative and end of life care needs who have been cared for by community nursing services. This is because data at a national level is held on the total number of people who receive specialist palliative care (11,000 people in 2016-17),<sup>viii</sup> and separate data on the total number of people who are known to their GP as needing palliative care (as recorded on the GP palliative care register – 10,000 people in 2016-17),<sup>ix</sup> but it is not possible to cross reference these at an individual level to understand the patient journey. Without greater clarity on who is being cared for, where, and by whom, it is impossible to accurately determine the level of unmet need for palliative care more widely in Wales or to quantify the real, and the potential need for input, from community nursing services to meet every person's need for community palliative care.

6.4 Of the total number of deaths each year in Wales, 24 per cent of people died in their own homes and 16 per cent in a care home.<sup>x</sup> These people would likely have received care from their community nursing service, as well as from a host of other agencies, such as social care, their GP, and hospice and specialist palliative care nurses and consultants.

6.5 The Welsh Government has recognised the value and importance of Advance and Future Care Planning to improve people's experience of end of life care.<sup>xi</sup> Evaluations demonstrate that, where an ACP is in place, the home death rate for people receiving hospice care rises to 40 per cent in comparison with the national average of 24 per cent.<sup>xii</sup>

6.6 While community nursing services support people with palliative care needs in their own home throughout their illness, their input is likely to significantly increase as the person requires end of life care during their final weeks of life. Access to the community nursing service, as well as appropriate social care, around the clock is essential if a person is to remain at home for as long as possible and to avoid unnecessary hospital admissions or a call out to the emergency services, if that is their preference.

### *Children's numbers*

6.7 At any given time, an estimated 1,050 children and young people in Wales will have a palliative care need;<sup>xiii</sup> of these, around 10 per cent, or 105 will die each year.

6.8 Children with palliative care needs may receive routine care from their CCNS throughout their lives but are particularly reliant on the service as they approach end of life, if their family preference is to be cared for at home.

## **7. Challenges and ways forward: workforce and resource**

7.1 General feedback from hospice teams working alongside community and district nursing services report that the service is over-stretched and under-resourced, meaning that district nurses can find it difficult to attend multi-disciplinary team meetings to discuss palliative care patient caseloads.

7.2 Hospice services likewise noted that resource management in the organisation of district nursing teams has seen the service move from a culture of 'calling in' on patients on the caseload to a more task-based approach. This means that if there is no specific task to be undertaken, e.g. administering medication through a syringe driver, then a person may have no contact with their district nurse or healthcare staff and could go a significant period without hands on care.

7.3 With limited resource, greater proportions of community nursing teams are comprised of HCSWs as opposed to registered nurses. While this is an appropriate way to reach greater numbers of people within budget, this can have implications for the provision of hands on palliative care. For example, across Cardiff and Vale University Health Board the hospice at home service is primarily comprised of HCSWs, who are able to provide personal care for people at the end of life but are not able to administer medications, such as for pain relief and symptom control.

7.4 Limited numbers of registered nurses within the community nursing team can have particular implications during out of hours periods. Anecdotally, we hear that district nurses have to manage patient and family expectations about the level of contact and care they can expect during out of hours periods. This, in turn, can make people and their families nervous about the prospect of remaining at home for their care and more likely to seek an emergency admission to hospital. In some areas of Wales the charitable hospice and district nursing service work together to supplement out of hours nursing care. For example, Paul Sartori Hospice at Home retains one registered nurse to work on an evening, seven nights a week. This nurse is not allocated to a patient until late in the afternoon or

evening, leaving them available to deliver urgent, same-day referrals for overnight respite care from the district nursing teams in the area. Similar models rolled out elsewhere could support the delivery of end of life care at home – where registered nursing skills are required – during out of hours periods.

7.5 The Cross Party Group on Hospices and Palliative Care 2018 inquiry into inequalities in access to hospice and palliative care heard that children are less likely to be able to be cared for at home at the end of life than adults because of the significant shortage of CCNs with appropriate palliative care skills.

7.6 While it is recognised that there is an ageing workforce and there is a lack of trained children’s nurses throughout Wales, the number of places allocated for training is not considered adequate by those working in community paediatric nursing to address the current and future shortage. Places are limited to 135 each year with upwards of 1,000 applicants.

7.7 End of life care services for children and young people are often time-limited as CCNs cannot be released for longer periods to offer tailored, personalised support to dying children and their families. For example, while the COINS service (Palliative Care Children’s Outreach In reach Nursing Service) operating across Hywel Dda University Health Board is to be welcomed as a step forward in widening access to 24 hour end of life care for children and young people in the area, wherever the child resides, it is not sustainable beyond a period of seven to ten days care.

7.8 Working together to address the current workforce shortages in areas most in need, Tŷ Hafan has recently jointly funded CCN posts with Powys Teaching Health Board and Abertawe Bro Morgannwg University Health Board, specifically to support children and young people with life-limiting conditions in the community setting. It is envisaged that the post holders will increase capacity in the community setting to deliver hands-on care as well as benefiting from developing specialist palliative caring skills that can be disseminated to others within the team. The hospice is exploring the potential to partner with other health boards in its catchment to increase capacity in the community nursing workforce where this is feasible.

## 8. For further information

8.1 Please contact xxxx, Policy and Advocacy Manager (Wales), Hospice UK or xxxx, Head of Policy and Advocacy

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<sup>i</sup> Welsh Government (2018). ‘A Healthier Wales’.

<sup>ii</sup> Welsh Government (2017). ‘Palliative and end of life care delivery plan: March 2017’.

<sup>iii</sup> CPG Hospices and Palliative Care (2018). ‘Inequalities in access to hospice and palliative care: challenges and opportunities’.

<sup>iv</sup> Welsh Government (2017). ‘Palliative and end of life care delivery plan: March 2017’.

<sup>v</sup> Hospice UK (2018). ‘Hospice care in Wales 2018’.

<sup>vi</sup> Welsh Government (2017). ‘Future Trends Report’.

<sup>vii</sup> Welsh Government (2017). ‘Future Trends Report’.

<sup>viii</sup> Welsh Government (2017). ‘End of life care: annual statement of progress: December 2017’.

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<sup>ix</sup> Welsh Government (2017). 'End of life care: annual statement of progress: December 2017'.

<sup>x</sup> 2016 ONS commissioned report by Paul Sartori Hospice at Home.

<sup>xi</sup> <https://beta.gov.wales/written-statement-advance-care-planning>

<sup>xii</sup> Age UK (2018). 'Later life in the United Kingdom'.

<sup>xiii</sup> Welsh Government (2017). 'End of life care: annual statement of progress: December 2017'.