

Cross Party Group  
**Hospices and Palliative Care**

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# **CPG Hospices and Palliative Care: Inquiry**

Inequalities in access to hospice  
and palliative care

July 2018



# About the Cross Party Group on Hospices and Palliative Care

The purpose of the Cross Party Group on Hospices and Palliative Care is to maintain and develop understanding and interest by Assembly Members of issues affecting hospice and palliative care services, in the furtherance of improving end of life care in Wales.

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# Chair's foreword

The care of people at the end of life and with long term degenerative conditions in Wales has come a long way in the decade since the Sugar Report placed a spotlight on the strategic development of hospice and palliative care. Each year, the End of Life Care Implementation Board report that greater numbers of people are supported by our charitable hospices and NHS palliative care services, and more people – adults and children – are cared for in their own homes and communities by such services.

Nevertheless, as part of this Cross Party Group inquiry, we heard of both old and new issues affecting the equal provision of, and access to, hospice and palliative care in Wales. These ranged from issues common to the health and care sectors as a whole – such as workforce pressures, IT infrastructure, and care out-of-hours – to those specific to palliative care, including limited awareness of hospice and palliative care amongst the public and clinicians resulting in low or late referrals to appropriate care, and the specific impact of caring for people at the end of life. With many of the strategic challenges addressed in the last decade, now is the time to work for greater equality of access to hospice and palliative care for all in Wales who could benefit.

Our report also celebrates examples of the inspiring and pioneering work our hospice and NHS colleagues shared with us during this inquiry. We must take action to harness these pockets of innovation and mobilise our communities to ensure that all people across Wales have access to the same great care.

I would like to express my thanks and gratitude to all those who contributed to this inquiry and shared their professional and personal experiences with us. The breadth of experience that has informed this report comes from colleagues in the hospice sector, the NHS and the third sector working across health and social care. We heard time and again in our evidence gathering of the importance of partnership and integration; only by working together can we maximise the benefits and fill any gaps in provision to improve equality of access to hospice and palliative care for all across Wales

**Mark Isherwood AM, Chair  
Cross Party Group on Hospices and Palliative Care**

# Recommendations

**Recommendation 1. The Cabinet Secretary for Health and Social Services should monitor, and have oversight of, progress against shared priorities between the Palliative and End of Life Care Delivery Plan and other Health Delivery Plans.**

A strategic approach to joint working should be taken by the End of Life Care Implementation Board and the Implementation Groups of related Health Delivery Plans, including cancer, heart disease, respiratory health, neurological conditions and the Dementia Action Plan. This is needed to ensure access to expert hospice and palliative care for all people who could benefit from it. Progress towards short/medium term targets and priorities should be included in the End of Life Care Delivery Plan Annual Progress Report. Shared measures should be developed, where appropriate, to facilitate joint working. This should be monitored, overseen and reported on by the Welsh Government/Cabinet Secretary for Health and Social Services.

**Recommendation 2. The Welsh Government and End of Life Care Implementation Board should establish a target for increasing the number of people on General Practice Palliative Care Registers and introduce measures to monitor their effectiveness in supporting adults with all life-limiting conditions.**

For people with life-limiting conditions other than cancer, little is known of the effectiveness of Palliative Care Registers in enabling access to appropriate palliative care and delivering good outcomes. In line with reporting on specialist palliative care referrals, the Welsh Government and End of Life Care Implementation Board should require health boards to establish the proportion of people recorded on Palliative Care Registers who have diagnoses other than cancer. Following this benchmark, ambitious targets should be set to ensure all people who could benefit from expert end of life care, regardless of diagnosis, are recorded on GP Palliative Care Registers.



### **Recommendation 3. Charitable hospices and health boards should demonstrate how they promote improved awareness of the breadth of hospice and palliative care services.**

Early access to the full breadth of hospice and palliative care services is dependent both on referral from professionals and the person's readiness to receive this care. Hospices and NHS palliative care providers have a responsibility to educate colleagues across the health and care sector about the role of palliative care, the pathways to access this care, and how to conduct difficult conversations with people being referred. In partnership with the Welsh Government, End of Life Care Implementation Board and 'Byw Nawr', where appropriate, hospices and health boards should also undertake specific work to encourage people in their communities to talk about death, dying and bereavement and to better understand the wider role hospices play in supporting their communities. Important discussions leading to Advance Care Plans should play a part of this.

### **Recommendation 4. Health boards should demonstrate how they consider end of life care needs in determining their out-of-hours coverage and work cooperatively to resource paediatric 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 health board areas, including contributing resource to provide all-Wales coverage. This should include:

- a) Appropriately resourcing and promoting the 24/7 specialist advice line for adult palliative care and directing out-of-hours clinicians – whether GPs, nurses or pharmacists – to this service to support adults with palliative care needs, including (but not limited to) people on Palliative Care Registers.
- b) Working cooperatively with the End of Life Care Implementation Board and children's hospices to secure sustainable out-of-hours coverage for paediatric palliative care by ensuring that appropriate consultant cover is available and that paediatric palliative care nurses are released to contribute to the on-call nursing rota.

### **Recommendation 5. Regional Partnership Boards should make use of pooled budgets to support the delivery of palliative care in care homes.**

An integrated approach between health and social care is needed to meet the increasing demand for palliative care in care homes. Regional Partnership Boards are best placed to lead and facilitate a strategic approach to improving access to appropriate palliative care for the people in their areas. Pooled budgets to support palliative care provision within care homes should be utilised, including for capacity building in the care home workforce and in-reach services as appropriate. In reporting on the progress against delivering pooled budgets in improving integration for older people and other groups, Regional Partnership Boards should demonstrate how they have supported the delivery of palliative care in care homes.

### **Recommendation 6. The Welsh Government Ministerial Advisory Group for Carers should address the specific support needed by carers of people at the end of life.**

The Welsh Government must recognise the crucial role carers play in delivering on their aspiration to deliver more care, including palliative and end of life care, closer to home. The current Ministerial Advisory Group for Carers – and future iterations of this Group – should address the issues facing people caring for adults and children with life-limiting conditions and people at the end of life, including specialist bereavement support. Carers of people at the end of life, and their representatives, should have input to this Group.

### **Recommendation 7. 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.

### **Recommendation 8. The Welsh Government should introduce enhanced mandatory training in palliative care for hospital-based clinical staff.**

More than half of all deaths currently occur in hospitals; ensuring clinical staff are equipped to support patients at end of life is therefore critical. The Welsh Government should work with Health Education and Improvement Wales and external partners, such as the Royal Colleges, to incorporate annual mandatory training in palliative care for all hospital-based clinical staff as part of their Continuous Professional Development.

**Recommendation 9. The Welsh Government and End of Life Care Implementation Board should identify gaps in data collection on adult and paediatric palliative care needs, and take steps to fill these, to ensure service planning and design is based on need.**

Service planning and development for adult and paediatric palliative care must be based on evidence of need if we are to reach more people. In partnership with health boards and charitable hospices, the Welsh Government and End of Life Care Implementation Board should identify gaps in existing data that could meaningfully inform service development. This should include exploring ways to quantify the provision of palliative care in the NHS and charitable sector at primary and secondary care levels – including cross-border provision – and to identify measures that will improve understanding of equal access to palliative care. Working with the NHS Wales Informatics Service, the End of Life Care Implementation Board's Data Subgroup and the All-Wales Managed Clinical Network in Paediatric Palliative Care, the Welsh Government should outline how these gaps will be filled. Relevant data on palliative care use, including the needs of carers, should inform, and be informed by, statutory Population Needs Assessments and Wellbeing Assessments and their resultant plans.

**Recommendation 10. The End of Life Care Implementation Board should support health boards and NHS trusts to improve their accountability by developing consistent reporting criteria to measure progress against meeting national palliative care priorities.**

To better understand whether access to hospice and palliative care in Wales is equal we need the ability to compare delivery and outcomes between health boards and NHS trusts and against national priorities. Appropriate comparison between providers is dependent on developing shared measures. In partnership with health boards and charitable hospices, the End of Life Care Implementation Board should agree shared reporting measures for providers to enable the scrutiny of annual progress. Reporting on common measures between Health Delivery Plans and the proportion of people with diagnoses other than cancer on the Palliative Care Register should form part of this (see Recommendations 1 and 2).



**Recommendation 11. The Welsh Government and End of Life Care Implementation Board should ensure that the funding of charitable hospices is regularly updated to ensure it is based on current local population need and prevalence data.**

- a) Wales is the only nation in the UK to have a mechanism for determining the statutory funding of adult palliative and end of life care, which includes provision for charitable hospice care services. This has supported the development of palliative and end of life care across Wales. The funding of palliative care provided by hospices must continue to be based on estimates of local need. However, the calculation which underpins the formula has not been reviewed since implementation a decade ago. The funding of charitable hospices providing core clinical palliative care services should be calculated based on an up-to-date assessment of the area's population needs, taking account of the ageing population, rurality and the expansion of services to meet underserved groups.
- b) The commissioning of adult and children's palliative care services by health boards from charitable hospices should likewise be funded based on an assessment of current need and prevalence. Contracting, commissioning and Service Level Agreements with charitable hospices should reflect any uplift in the health board's budget.

# Background

## Our inquiry

1. The Cross Party Group on Hospices and Palliative Care received evidence to its inquiry between November 2017 and March 2018. During the course of the inquiry written submissions were received from 26 organisations. Two oral evidence sessions, including one in North Wales, and a roundtable discussion with practitioners, clinicians, families and carers of people needing palliative care, were held.
2. We would like to thank all those who have taken the time to contribute to this inquiry by giving evidence. Lists of those who gave oral and written evidence are included in Annexes A and B to this report respectively. Organisations that contributed to the roundtable discussion are listed in Annex C.

## Context

3. Around 33,000 people die each year in Wales.<sup>1</sup> It is estimated that around 23,000 people in Wales have a palliative care need at any one time.<sup>2</sup> Around 1,000 children and young people in Wales have life-limiting conditions.<sup>3</sup>
4. Palliative care is defined by the National Institute for Health and Care Excellence (NICE) as “the active holistic care of patients with advanced progressive illness.”<sup>4</sup> End of life care is a specific aspect of palliative care for people considered to be in the last year of life.
5. Palliative care is delivered by a multi-disciplinary team, which can encompass colleagues in primary, secondary and tertiary care.<sup>5</sup>
6. Charitable hospices provide care free of charge to those who need it. Hospice UK states:

Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs.<sup>6</sup>
7. The Welsh Government and NHS Wales End of Life Care Delivery Plan 2017-2020 sets out national priorities for developing palliative care. The End of Life Care Implementation Board is tasked with delivering the plan and reports annually on progress.

## Why the Cross Party Group looked at this issue

8. Research from the UK and internationally consistently indicates that access to palliative care is unequal.<sup>7</sup> Across the UK it is estimated that around one in four people who could benefit from palliative care are missing out; this represents around 6,000 people in Wales.<sup>8</sup>
9. Factors known to contribute to unequal access to palliative care are geography, care setting, diagnosis, age, ethnic background and having a spouse or partner.<sup>9</sup>
10. There has been little research that looks specifically at the factors affecting equal access to hospice and palliative care in Wales.

## Terms of reference

11. The inquiry focused its work on the following key areas:

- understand what factors lead to unequal access to hospice and expert palliative care for the population of Wales, considering learning and evidence at both UK and Wales levels;
- consider what actions palliative care providers and interested parties are currently taking to improve access to expert palliative care for all members of their populations;
- explore and understand the barriers palliative care providers and interested parties face in improving access to their services;
- consider what national and local levers would support improving equality of access to hospice and palliative care in Wales.

## Our report

12. Due to the focus of this short inquiry, we have limited our reporting to the evidence we received and made recommendations in specific areas. We have not sought to provide a detailed summary of all of the evidence received.

13. Chapters 1, 2 and 3 primarily refer to adult palliative care but make references to paediatric palliative care where there are shared issues. Evidence received specifically about inequalities in access to paediatric palliative care is addressed in Chapter 4.

# 1. Inequalities in meeting the need for palliative care

## Meeting need, widening access

14. Despite progress since 2008<sup>10</sup> (when the first Palliative Care Implementation Board was established) to widen access to hospice and palliative care in Wales there remains significant unmet need and under-met need.<sup>11</sup> This includes people who are missing out on palliative care entirely and those who do not receive enough to benefit fully from such care.
15. While a range of factors, including location and ethnicity, are known from previous research to affect access to palliative care, evidence submitted to the Group particularly pointed to the impact of diagnosis. People with diagnoses of dementia, heart, lung and renal failure, and neurological conditions, as well as frail, older people are seen to be disproportionately missing out on hospice and palliative care.
16. Poor awareness of what hospice and palliative care can offer – both from a public perspective and from clinicians working in areas other than palliative care – was seen to contribute either to a delay in accessing palliative care or the absence of appropriate end of life care.

## Perception and understanding

*“Public awareness of palliative care is poor and even within the palliative care community we need to break the taboo.”*

(Alison Foster, Betsi Cadwaladr University Health Board,  
in oral evidence, 16 March 2018)

17. Clinicians in primary and secondary care may not identify a need for specialist palliative and hospice care for adults and children leading to missed or delayed care. This was seen, in part, to be a result of poor understanding of the range of services offered by hospice and palliative care providers and the range of potential benefits of such services.
18. Tŷ Hafan Children’s Hospice told the Inquiry there is:  
  
*“a lack of understanding from other clinicians, particularly in the statutory sector, as to the support we can provide to families, their understanding of hospice care as being a building based thing rather than the compendium of services we can provide in the community, at home or even in secondary and primary care settings.”*
19. The medicalisation of life-limiting conditions contributes to a delay in accessing referral to the full breadth of palliative care services, including those that meet the person and their family’s social and emotional needs.<sup>12</sup> Palliative and hospice care services can be delivered in tandem with other medical care, rather than being an ‘either/or’ proposition.







20. Early involvement of hospice and palliative care professionals can support timely and appropriate access to care. The Motor Neurone Disease (MND) Association report that including these key professionals as core members of multi-disciplinary teams contributes to earlier palliative care referrals and better advance care planning.<sup>13</sup>
21. While low public awareness of the benefits of palliative and hospice care, and the stigma surrounding these services, can be barriers to accessing services, movements such as 'Byw Nawr' are working to turn this tide. 'Byw Nawr' is the national campaign that aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. 'Dying Matters' week in May each year sees the coordination of events to promote open discussion about death and dying at national and community levels.

## Diagnosis

22. Hospice and palliative care services work particularly well for people with cancer, and their families, at the end of life. Caring for people with cancer remains an integral part of the work of hospice and palliative care providers but there has been a continued effort in the past 20 years to expand palliative care services to all people who might benefit from this care, regardless of their diagnosis.
23. While deaths from cancer represent 29 per cent of all deaths in Wales, the End of Life Care Implementation Board reports that 76 per cent of all referrals for specialist palliative care (adult) were for people with cancer.<sup>14</sup> People with diagnoses other than cancer therefore continue to be underrepresented in referrals to specialist palliative care.
24. Evidence submitted to the Group noted that people with heart failure and progressive neurological conditions such as dementia, multiple sclerosis and motor neurone disease were missing out on palliative care or are accessing care at a later stage in their disease.
25. Progress is being made to reduce this inequality with NHS and third sector providers seeing year-on-year increases since 2009 in referrals to specialist palliative care for patients with conditions other than cancer.<sup>15</sup>
26. A number of national and local initiatives in Wales to widen access to appropriate palliative care – including specialist palliative care and generalist palliative care delivered by disease specialists – for people with diagnoses other than cancer have been undertaken. This includes work at a national level, under the direction of the End of Life Care Implementation Board, to:
  - create links between the End of Life Care Implementation Board Coordinator with her equivalent roles working on related Welsh Government Health Delivery Plans
  - increase palliative care skills in all areas of health, for example with heart failure nurses embedded within cardiac teams to manage their palliative care caseloads.<sup>16</sup>
27. Hospice-led, local initiatives to reach greater numbers of people with diagnoses other than cancer who could benefit from palliative care are widespread. For example, St David's Foundation, working in Newport, Monmouthshire, Torfaen, Caerphilly and South Powys, have undertaken a deliberate policy of establishing links with services supporting people with diagnoses other than cancer to proactively identify more people who could benefit from their services. Targeted work in partnership with condition-specific groups, such as the work between Hospice of the Valleys and Alzheimer's Society Cymru, is also underway.

The Challenge Project in Blaenau Gwent combines the specialist knowledge of the Hospice of the Valleys and Alzheimer's Society Cymru. Clinical nurse specialists and dementia support workers combine their expertise to support the palliative and end of life care needs of people living with dementia, including by exchanging training information and raising awareness. Families have a single point of contact for information and support.

28. Despite the various initiatives to increase the reach of palliative care for people with conditions other than cancer – including working with clinicians from disease specialisms to raise their understanding of, and skills in, palliative care – there does not appear to be strategic oversight at a national level to drive this forward, and no formal links between Welsh Government Health Delivery Plans have been established or monitored to measure progress in the round.

## Primary care

29. Primary care clinicians, including general practitioners (GPs), play a crucial role in identifying people who could benefit from palliative care, and coordinating and delivering care in the community. The Royal College of General Practitioners (RCGP) cites palliative care as “a core part of general practice.”<sup>17</sup>
30. The Quality and Outcomes Framework, which determines the level of payment GPs receive from the NHS, incentivises maintaining a register of people with palliative care needs, irrespective of age (the GP Palliative Care Register). Palliative Care Registers are seen as a means of identifying and recording people with palliative care needs, and of coordinating multi-disciplinary palliative care.
31. Despite this, the Group heard that not all professionals who should be part of the multi-disciplinary team, such as community pharmacists, are made aware that a person has been included on a Palliative Care Register.
32. As well as coordinating care in the community for people who are receiving specialist palliative care, the process of populating and maintaining the Palliative Care Register encourages the proactive identification of people who may benefit from palliative care. This includes identifying people who may not be in contact with secondary care for specific conditions but who may have a range of advanced conditions and could be approaching the end of life. For example, people with ‘frailty’.
33. While the number of people on Palliative Care Registers has increased across Wales since it was incentivised by the Quality and Outcomes Framework, only 10,013 people – of the 24,000 people estimated to have palliative care needs – were recorded on a register in 2016-17.<sup>18</sup> In their evidence to the Group, the End of Life Care Implementation Board note that many people who are not included on the Palliative Care Register may be cared for and included on different disease registers held by GPs, such as registers for heart failure or dementia.<sup>19</sup>

34. Data held on the register does not clarify whether the register is succeeding in widening access to palliative care by identifying more people who are not already receiving care elsewhere, or identifying people with conditions other than cancer. Metrics in relation to the diagnoses of people on the register are not required as standard by health boards in their contracting arrangements with GP practices.
35. The RCGP told the Group that populating Palliative Care Registers with people who have conditions other than cancer is variable and can be reliant on GP skills and experience:

*“We have to understand it’s not just cancer but other life-limiting conditions – cardiac, renal, dementia. From a GP point of view, it’s extremely difficult to identify those who need to go on to a Palliative Care Register. Whenever you’ve got a life-limiting condition entering a terminal phase it means having a difficult conversation. Some GPs are better at it than others.”*

(Dr Martin O’Donnell, RCGP, in oral evidence 2, 16 March 2018)

Cwm Taf University Health Board’s Macmillan GP Facilitator project has actively promoted the meaningful use of the Palliative Care Register. GPs are supported to identify more people – with cancer and non-cancer diagnoses – approaching the end of life by using the Prognostic Indicator Tool.

## Our view

**Recommendation 1. The Cabinet Secretary for Health and Social Services should monitor, and have oversight of, progress against shared priorities between the Palliative and End of Life Care Delivery Plan and other Health Delivery Plans.**

A strategic approach to joint working should be taken by the End of Life Care Implementation Board and the Implementation Groups of related Health Delivery Plans, including cancer, heart disease, respiratory health, neurological conditions and the Dementia Action Plan. This is needed to ensure access to expert hospice and palliative care for all people who could benefit from it. Progress towards short/medium term targets and priorities should be included in the End of Life Care Delivery Plan Annual Progress Report. Shared measures should be developed, where appropriate, to facilitate joint working. This should be monitored, overseen and reported on by the Welsh Government/Cabinet Secretary for Health and Social Services.

**Recommendation 2. The Welsh Government and End of Life Care Implementation Board should establish a target for increasing the number of people on General Practice Palliative Care Registers and introduce measures to monitor their effectiveness in supporting adults with all life-limiting conditions.**

For people with life-limiting conditions other than cancer, little is known of the effectiveness of Palliative Care Registers in enabling access to appropriate palliative care and delivering good outcomes. In line with reporting on specialist palliative care referrals, the Welsh Government and End of Life Care Implementation Board should require health boards to establish the proportion of people recorded on Palliative Care Registers who have diagnoses other than cancer. Following this benchmark, ambitious targets should be set to ensure all people who could benefit from expert end of life care, regardless of diagnosis, are recorded on GP Palliative Care Registers.

**Recommendation 3. Charitable hospices and health boards should demonstrate how they promote improved awareness of the breadth of hospice and palliative care services.**

Early access to the full breadth of hospice and palliative care services is dependent both on referral from professionals and the person's readiness to receive this care. Hospices and NHS palliative care providers have a responsibility to educate colleagues across the health and care sector about the role of palliative care, the pathways to access this care, and how to conduct difficult conversations with people being referred. In partnership with the Welsh Government, End of Life Care Implementation Board and 'Byw Nawr', where appropriate, hospices and health boards should also undertake specific work to encourage people in their communities to talk about death, dying and bereavement and to better understand the wider role hospices play in supporting their communities. Important discussions leading to Advance Care Plans should play a part of this.



## 2. Inequalities in achieving care preferences

### A good death in any setting

36. During the course of the inquiry the Group received considerable evidence pointing to inequalities in people's ability to achieve their care preferences. This was often expressed in terms of the care setting.
37. While most people express a preference to be cared for in their usual place of residence – at home or in their care home – more than half (55 per cent) of deaths in Wales occur in hospitals.<sup>20</sup>
38. For this reason, place of death is often used as a measure of quality, with the percentage of deaths in the usual place of residence seen as a proxy for a 'good death'.<sup>21</sup>
39. While using place of death may provide some insight into a person's experience at the end of life (where they have expressed a preference to be cared for at home), it does not necessarily provide insight into quality of care. With appropriate training, support from specialist colleagues and a strategic focus, hospitals can support a 'good death'.
40. A significant number of people will either choose a hospice inpatient setting as their preferred place of death or will receive expert palliative care in a hospice inpatient setting as part of their care journey. Hospice inpatient settings provide short term symptom management or respite care, where the person is then discharged to be cared for in the community, as well as expert end of life care to those who need it. This care is provided at no cost to the person, with hospice services complementing and working in partnership with NHS services and serving the local community's specific needs.





## Achieving preferred place of care and death

### Advance care planning

41. A precursor for enabling an effective measure of whether someone has achieved their preferred place of care or preferred place of death is providing the opportunity for a person to express and record their care preferences. Advance care planning is a process by which this is achieved, with a person's wishes and preferences recorded in an Advance Care Plan.
42. Contributors to the Roundtable told us that if the care preferences recorded in the plan are to be acted on then Advance Care Plans must be accessible to all clinicians who may come in contact with the person. This includes primary and secondary care, acute and emergency care, and other providers such as care homes and hospices. This is supported by research conducted by Macmillan, which found that when staff have a record of a person's care preferences they are twice as likely to die in the place of their choice.<sup>22</sup>
43. Developing electronic Advance Care Plans that can be shared at an all-Wales level with all colleagues and agencies involved in the person's care is central to achieving this. The Group heard that there is some progress in realising this ambition in Wales, with the End of Life Care Board actively exploring ways to see this delivered, but that momentum for this project must be maintained if we are to see more people cared for at the end of life in accordance with their preferences.

### Dying at home

44. Supporting a person to die at home, if that is their preference, involves the coordination of a range of services from across health and social care, often involving public sector, third sector and independent providers. GPs, district nurses, palliative care clinicians such as consultants and clinical nurse specialists from within the NHS or from charitable hospices, as well as domiciliary care staff will be involved. Services, predominantly provided by charitable hospices in Wales, coordinating and delivering care to dying people in their own homes are commonly known as 'hospice at home' services. In addition to services that directly support the person with palliative care needs, families and carers should also have access to appropriate respite and bereavement care.
45. 'A Healthier Wales', the Welsh Government's long term plan for health and social care, sets out a vision of seamless, integrated services that are delivered at home, or as close to home as possible.<sup>23</sup> 'Hospice at home' services will play a central role in delivering this vision by supporting greater numbers of dying people to be cared for by multi-disciplinary teams in their own homes.
46. Systematic research reviews across the UK consistently indicate that people who live alone are less likely to achieve a home death than people who live with a spouse or partner.<sup>24</sup> The round the clock care needed by a person at the end of life often makes a hospice inpatient setting, care home or hospital the only options available to people living alone.

## Carers and communities

47. The British Association of Social Workers Cymru noted that enabling a person to die at home “relies on relatives to provide additional support, who may themselves be elderly and frail.”<sup>25</sup> There is a significant impact on carers that must be considered in realising a person’s preference to be cared for at home.
48. Caring for someone at the end of life will likely impact on a person’s employment, their social and emotional lives, and their finances. The majority of hospices engage a dedicated welfare rights officer and/or social worker to support both the person at the end of life and their family and carers to access the enhanced support they are entitled to.
49. Families and carers of children and young people who attended the Group’s Roundtable highlighted the specific issues affecting them. These carers will often support their child over a number of years. This can have a profound effect on their ability to work and places pressure on their family life, including the lives of siblings.
50. The Social Services and Wellbeing (Wales) Act entitles all carers, including those who care for people at the end of life, to a statutory assessment of their needs. Whilst this legislation provides a framework to support carers of people at the end of life, there does not appear to be reference to the specific needs of this group in national strategies or action plans for carers.
51. The Group heard from select projects working to support carers by upskilling them to care for their loved one at home. These projects have the double benefit of increasing the carer’s confidence and resilience, and of reducing emergency admissions.

Carers often support people to take oral medicines at home but, in the UK, are not routinely able to administer subcutaneous medicines. If a person becomes unable to take their medicine orally, this leads to greater interventions at home from healthcare professionals or, in some cases, to admission to hospice or hospital. For this reason, Cardiff and Vale University Health Board’s ‘Cariad’ study set out to determine the feasibility of training carers in the administration of subcutaneous medicines, to enable people to stay at home for longer. The initial results of the project are positive, with people and carers reporting their satisfaction.

52. Appropriate bereavement support (including pre-bereavement support) for families and carers is essential for carer resilience through and beyond their caring journeys. Despite the importance of this service to those affected by death and dying, contributors to the Roundtable told us of the cut backs in bereavement support, particularly specialist bereavement counselling, from both the statutory and third sectors. Hospices continue to offer this vital service but report increased pressure on the services they provide in response to service closures elsewhere.

53. Communities also have a role to play in supporting people at the end of life and their carers. Death and dying is increasingly being recognised as a Public Health issue, with decision-makers understanding that a population-approach is appropriate in some circumstances. Hospices have been central to mobilising the support of volunteers and organising ‘compassionate communities’ models in Wales.<sup>26</sup>

At the heart of ‘compassionate communities’ thinking is the belief that death and dying is everyone’s concern. Compassionate communities are communities that provide support to people who are dying, and their carers. They develop models to support their communities based on local need and experience. Nightingale House Hospice in Wrexham supports a network of community groups across North East Wales. Each village or community group takes the lead on its initiative by determining how it will support its local area, based on the group’s skills and interests and the specific needs of their locality.

### Care out-of-hours

54. Access to seven days a week adult specialist palliative care services has been established across Wales under the leadership of the End of Life Care Implementation Board. To support this, consultant advice is available to healthcare professionals, including out-of-hours GPs, on a 24/7 basis, using an all-Wales rota, though this resource is not always utilised to its full potential.
55. Due to the highly specialist nature of paediatric palliative care, it has not been possible to establish the same level of access out-of-hours as for adult palliative care. An interim arrangement is in place that provides out-of-hours advice to clinicians from three paediatric palliative care consultants. The Chair of the all-Wales Paediatric Palliative Care Network and Implementation Group told the Group that a long term solution to this has not yet been implemented, despite a plan being put forward utilising the skills of specialist nurses:

*“although we have a specialist palliative care nurse in each health board she [sic] is not yet made available to participate in an all-Wales out-of-hours advisory rota, which is what was intended.”*

56. Delivering palliative care at home relies on access to care out-of-hours. GPs, coordinating palliative care in the community, are responsible for alerting the GP out-of-hours service to the adults on their Palliative Care Register. This ensures that these people’s needs are prioritised in the event of needing out-of-hours care.
57. Contributors to the Roundtable discussed the impact of the gaps in out-of-hours GP provision. In recent months, two health boards have failed to provide GP out-of-hours cover in their areas due to staff shortages.<sup>27</sup> This leaves people at the end of life who are in their own homes without appropriate palliative care.

58. Various models of out-of-hours care that ease pressure on the out-of-hours GP service were shared with the Group, with contributors to the Roundtable emphasising the benefits of taking a prudent approach to out-of-hours care by making the best use of the skills within a multi-disciplinary team.

Paul Sartori Hospice at Home in Pembrokeshire have a 24/7 on-call system for patients, staff and wider health and social care colleagues. During out-of-hours periods Paul Sartori's registered nurses are some of the only trained nurses on duty in the county and provide invaluable advice to colleagues such as district nurses, as well as providing hands-on care to people with acute needs.

The Airedale Gold Line out-of-hours service in Yorkshire is a nurse-led service exclusively supporting people with identified palliative care needs. Nurses engage with people and carers by phone and Skype and are able to deal with the majority of calls without the need for the out-of-hours GP to make a home visit.

59. The Royal Pharmaceutical Society, in their contribution to the Roundtable, emphasised the role of formal out-of-hours pharmacy services in improving access to medicines for people at the end of life and pointed to the clinical expertise a pharmacist can bring to the out-of-hours multi-disciplinary team.
60. The Wales Audit Office report into GP out-of-hours services notes that the service is poorly integrated with other key services, which could affect access to the right service at the right time, including palliative care. The report points to the roll-out of the new 111 service as an opportunity to improve triaging of out-of-hours calls and for health boards to review their services.<sup>28</sup>

Communities also have a role to play in enabling care to be delivered in exceptional circumstances where formal services are not in operation. Informed by their personal experience and as healthcare professionals, a recently bereaved family in North East Wales is facilitating a solution to enable care professionals to reach people approaching the end of life in times of adverse weather, such as heavy snow. By creating a network of 4x4 drivers and taking advantage of the immediacy of social media, this family aim to mobilise the community to facilitate the transportation of healthcare workers visiting people at home when they are most needed. Similar community-led services operate in other areas of the UK but, as yet, no service operates in Wales.

## Care homes

61. The Older People's Commissioner noted that equality of access to hospice and palliative care is integral to upholding the human rights of older people and has made care homes the focus of a number of recent reviews.<sup>29</sup>
62. Increasingly, people are entering care homes at an older age, with multi-morbidities and frailty. This often means that people move to a care home in the last months, or even weeks, of life. While palliative care is increasingly the mainstay of care homes, Age Cymru told the Group that care homes are not always appropriately resourced to deliver good palliative and end of life care.<sup>30</sup>
63. Care Forum Wales pointed to the inequality inherent in this, citing the discrepancy in specialist support provided to people in their own homes in comparison with people in care homes:

*“In some parts of Wales it is still the case that you can be supported to die at home unless you call a residential home your home.”*

(Mary Wimbury, Care Forum Wales, in oral evidence, 16 March 2018)

64. Access to appropriately skilled and trained staff remains a barrier to providing good palliative care in care homes. This can lead to inappropriate transfers to hospital for residents, which has the doubly negative impact of increasing pressure on acute services and leading to fewer people achieving their care preferences.
65. Training for care home staff from specialists – both from health boards and hospices – is ongoing. Upskilling of care home staff is seen by the hospice movement as a key part it can play in increasing equal access to palliative care:

*“It's a challenge for hospices – they are specialist centres... There is a lot of work improving skills in local care homes, for example. Hospices, which hold those specialist skills, have a responsibility to educate staff in establishments such as these.”*

(Trystan Pritchard, Hospices Cymru, in oral evidence, 16 March 2018)

Betsi Cadwaladr University Health Board, in partnership with Macmillan, is leading on a project to upskill the care home workforce in North Wales. Using the 'Six steps to success' programme, 20 care homes across the region have benefited from this training to date, with a reported reduction in hospital admissions in the last year of life from 23 per cent to eight per cent.



66. While the impact of the changing demographic is a challenge for care homes, it brings opportunities too. Acquiring palliative care skills can be seen as an investment in the future of the business.
67. Despite the number of initiatives supporting care homes to improve palliative care skills, and the benefits of doing so, Care Forum Wales explained that workforce shortages and financial constraints make backfilling rotas to release staff for training prohibitive.<sup>31</sup>
68. Proposed solutions to this barrier involved using commissioning as a lever to incentivise the provision of a better trained workforce and the utilising of pooled budgets by Regional Partnership Boards.<sup>32</sup> A recent survey on the role of specialist palliative care teams – from NHS and hospices – with care homes in Wales recommended greater specification of the care home setting in the commissioning and contracting of community palliative care services to ensure care home residents have the same access to palliative care as people living in their own homes.<sup>33</sup>
69. End of life care needs to be seen as a core role of care homes, with the resources and access to specialist support provided accordingly.

## Hospital

70. The dual motivation – of patient preference and easing pressure on acute services – to keep people at the end of life out of hospital wherever possible means that a considerable focus should be given to the delivery of palliative care in community settings and on enabling people to remain in their usual place of residence wherever possible.
71. Admission to hospital can, however, be necessary and appropriate for people with palliative or end of life care needs and will continue to be the preferred place of care for some people. With more than half of all deaths occurring in hospital, ensuring good end of life care in all hospitals at all times is an objective that must be realised.

*“Sometimes people do need to be admitted and need acute care – if they need that then it’s important that they get the right care at the right time”*

(Alison Foster, Betsi Cadwaladr UHB in oral evidence, 16 March 2018)

72. The Group heard of approaches taken across Wales to support good end of life care in hospitals – this ranged from upskilling clinicians in A&E in the Betsi Cadwaladr University Health Board to ensuring that at least 10 per cent of all nurses on hospital and acute wards in Cardiff and Vale University Health Board were appropriately trained in palliative care. Despite an appetite to upskill clinicians in palliative care skills and approaches, there does not appear to be a coherent or strategic approach to achieving this.

## Workforce

73. Contributors to the Inquiry emphasised workforce pressures across the board that contribute to unequal access to achieving care preferences. More than 50 per cent of today's healthcare workforce will still be working in the health service in 15 years' time,<sup>34</sup> which makes upskilling the care workforce, including generalists and social care workers, vital and achievable if Wales is to meet the challenge of providing for greater palliative care needs.
74. The Welsh Government and End of Life Care Implementation Board have placed great emphasis on improving the availability of 'hospice at home' and care in the community as one way of improving access to hospice and palliative care with limited resource.<sup>35</sup> 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.<sup>36</sup>
75. Workforce pressures were also cited as impacting on the ability of healthcare workers to provide care using the full range of their skills and expertise. The Royal College of Occupational Therapists described how they are forced to take a "risk management approach" to their caseloads by tending to offer only an equipment loan service to palliative care patients rather than utilising the full potential of the rehabilitative approach – an approach which could enable them to maintain their independence in the longer term.<sup>37</sup>
76. Greater training and development opportunities for all health and social care workers regularly working with people with palliative care needs is essential if the pressure is to be eased on acute services. The Royal College of Nursing (RCN) pointed to the "limitations" on training and development in palliative care for nurses throughout their careers and also to the often cursory education in palliative care as part of initial training. In oral evidence to the Group, Dr Sally Anstey of the RCN proposed that palliative care is an essential skill needed by all nurses and thus mandatory continuous professional development in palliative care is required.

## Our view

**Recommendation 4. Health boards should demonstrate how they consider end of life care needs in determining their out-of-hours coverage and work cooperatively to resource paediatric 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 health board areas, including contributing resource to provide all-Wales coverage. This should include:

- a) Appropriately resourcing and promoting the 24/7 specialist advice line for adult palliative care and directing out-of-hours clinicians – whether GPs, nurses or pharmacists – to this service to support adults with palliative care needs, including (but not limited to) people on Palliative Care Registers.
- b) Working cooperatively with the End of Life Care Implementation Board and children's hospices to secure sustainable out-of-hours coverage for paediatric palliative care by ensuring that appropriate consultant cover is available and that paediatric palliative care nurses are released to contribute to the on-call nursing rota.

**Recommendation 5. Regional Partnership Boards should make use of pooled budgets to support the delivery of palliative care in care homes.**

An integrated approach between health and social care is needed to meet the increasing demand for palliative care in care homes. Regional Partnership Boards are best placed to lead and facilitate a strategic approach to improving access to appropriate palliative care for the people in their areas. Pooled budgets to support palliative care provision within care homes should be utilised, including for capacity building in the care home workforce and in-reach services as appropriate. In reporting on the progress against delivering pooled budgets in improving integration for older people and other groups, Regional Partnership Boards should demonstrate how they have supported the delivery of palliative care in care homes.

**Recommendation 6. The Welsh Government Ministerial Advisory Group for Carers should address the specific support needed by carers of people at the end of life.**

The Welsh Government must recognise the crucial role carers play in delivering on their aspiration to deliver more care, including palliative and end of life care, closer to home. The current Ministerial Advisory Group for Carers – and future iterations of this Group – should address the issues facing people caring for adults and children with life-limiting conditions and people at the end of life, including specialist bereavement support. Carers of people at the end of life, and their representatives, should have input to this Group.

**Recommendation 7. 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.

**Recommendation 8. The Welsh Government should introduce enhanced mandatory training in palliative care for hospital-based clinical staff.**

More than half of all deaths currently occur in hospitals; ensuring clinical staff are equipped to support patients at end of life is therefore critical. The Welsh Government should work with Health Education and Improvement Wales and external partners, such as the Royal Colleges, to incorporate annual mandatory training in palliative care for all hospital-based clinical staff as part of their Continuous Professional Development.

### 3. Inequalities and strategy

77. The Welsh Government and NHS Wales published the Palliative and End of Life Care Delivery Plan in 2017. This follows from previous strategies and working groups on palliative care in Wales since 2008. The End of Life Care Implementation Board oversees the work of each health board in achieving the aims set out in the Welsh Government's Delivery Plan.
78. Whilst progress in the field is evident, the Group heard of regional variations and inconsistencies that could be addressed at a national level.

#### Leadership, coproduction and accountability

79. The introduction of the Integrated Medium Term Plans (IMTPs) ended the requirement for all health boards to submit major health condition delivery plans, including the End of Life Care Delivery Plan, to the Welsh Government. Instead, the Welsh Government NHS Planning Framework 2017/20 notes that organisations are expected to “plan for these important services and reflect the key areas of intended improvement in their three year plans.”<sup>38</sup>
80. Some health boards and NHS Trusts have continued to publish a local End of Life Care strategy and all approved IMTPs make reference to palliative care. However, the level of detail on palliative care planning in IMTPs is variable and there is a risk that streamlining as part of the IMTP leads to palliative care being seen as a lesser priority by health boards.
81. With each health board setting out their plans for developing palliative and end of life care in line with national priorities differently within IMTPs or local strategies – and to greater or lesser degrees – comparison between health board areas can be difficult. Hospice UK noted that benchmarking and comparison would be facilitated by establishing national measures which could be reported to the End of Life Care Implementation Board annually.<sup>39</sup>
82. A co-productive approach to planning and strategising for palliative care at a health board level, including in the development of the IMTP, was advocated by several contributors. Third sector and independent providers told us they are often excluded from strategy setting, service planning and early conversations about commissioning.

***“There has been no clear strategy for us in North Wales. Hospices need to be part of the planning process.”***

(Iain Mitchell, St Kentigern Hospice, in oral evidence, 16 March 2018)



## Funding

83. Since 2009 key clinical roles in the provision of adult specialist palliative care in the third sector have been supported by the Welsh Government and NHS Wales through the Welsh Funding Formula. The aim of the Funding Formula is to ensure the NHS provides a core level of clinical expertise. These posts are frequently deployed in charitable hospice settings. Further to this, Baroness Finlay of Llandaf, in her capacity as a former clinical lead on the End of Life Care Implementation Board stated:

*“The purpose of the funding formula was to provide equity across all sectors, provide access to seven-day specialist palliative care, with consultant advice available 24/7 to other healthcare professionals.”*

(Baroness Finlay, End of Life Care Implementation Board,  
in oral evidence, 17 January 2018)

84. The Funding Formula has not been revised since implementation.
85. Paediatric palliative care is not subject to the Funding Formula.
86. Third sector providers, including children’s hospices, are further funded through Service Level Agreements and commissioned services. Children’s hospices receive significantly less than adult hospices from statutory sources.<sup>40</sup>
87. Hospices provide a range of services to people, their families and carers, not all of which are considered core NHS clinical provision. The statutory contribution to the funding of charitable hospices does not contribute to the full range of care provided by hospices nor to their management and overheads. This means that a significant proportion of third sector provision is funded from charitable sources.
88. Services developed in line with population need must be funded accordingly. Estimates of population need informed the Funding Formula for charitable hospices in 2009. However, this data has not been reviewed in light of current prevalence or the forecasting of our aging population. Baroness Finlay, who was instrumental in developing this funding model, told the Group:

*“The database of the funding formula should be repopulated, looking at the changes in populations in some parts of Wales, in the light of the needs assessment data and the numbers of staff (as Whole Time Equivalent) currently in post and the funding spent by each health board on palliative care services in both voluntary sector and NHS services.”*

(Baroness Finlay, in oral evidence, 17 January 2018)

## Service development

89. An ad hoc approach to service development without a strategic overview contributes to inequalities in access to hospice and palliative care. Aneurin Bevan University Health Board told us:

*“In a rush to fill the perceived gaps in service provision, services have developed without adequate overall strategic management. There has not been a whole systems approach in terms of establishing population needs, demands and overall strategic objectives.”*

90. Service planning informed by a thorough assessment of population need can support an equalities approach to the provision of palliative care. Whilst statutory population needs assessments have been introduced by the Wellbeing of Future Generations (Wales) Act and the Social Services and Wellbeing (Wales) Act to inform health and care planning, an assessment of palliative care need has not featured in assessments under these frameworks.
91. Population Needs Assessments under the Social Services and Wellbeing Act are required to assess the extent of carer support needs. For carers of people at the end of life this will include bereavement support and counselling services.

## Data and intelligence

92. Existing population level demographic data can support hospices and palliative care providers by indicating the likely prevalence of palliative care needs in their areas and by highlighting demographic features of their population that may affect how and why people access their services. The Group, however, heard of the difficulties collecting and coordinating data on palliative care use, both for adult and paediatric services.
93. Individual patient level data on specialist palliative care use is recorded on CaNISC.<sup>41</sup> While CaNISC can provide insight into the number of specialist palliative care services provided at health board and national levels it cannot provide an accurate figure of the number of people receiving specialist palliative care as many people will access more than one service, including from different providers. Limited capacity at NHS Wales Informatics Service means that tackling this data deficiency has not been prioritised.
94. Data on the number of people on the Palliative Care Register is available at a GP practice level. However, the disconnect between primary and secondary care IT systems means there is no way of determining from national data sources whether a person is recorded both on the Palliative Care Register and on CaNISC.
95. As such, there is no way of assessing who in Wales receives some form of palliative care, whether specialist or generalist, or who is only receiving palliative care from generalists, whether that is within primary care or secondary care, either as total numbers or in terms of their characteristics (such as ethnicity, diagnosis, and combinations of these factors).

96. NHS Wales Informatics Service is building the Welsh Clinical Portal, a care record across organisational and geographical boundaries, allowing information to be shared between GPs, social care and hospitals. Putting the person at the centre is rightly the priority in developing this care record. However, there is an opportunity here to facilitate the better collection of service use, including palliative care.

## Our view

**Recommendation 9. The Welsh Government and End of Life Care Implementation Board should identify gaps in data collection on adult and paediatric palliative care needs, and take steps to fill these, to ensure service planning and design is based on need.**

Service planning and development for adult and paediatric palliative care must be based on evidence of need if we are to reach more people. In partnership with health boards and charitable hospices, the Welsh Government and End of Life Care Implementation Board should identify gaps in existing data that could meaningfully inform service development. This should include exploring ways to quantify the provision of palliative care in the NHS and charitable sector at primary and secondary care levels – including cross-border provision – and to identify measures that will improve understanding of equal access to palliative care. Working with the NHS Wales Informatics Service, the End of Life Care Implementation Board's Data Subgroup and the All-Wales Managed Clinical Network in Paediatric Palliative Care, the Welsh Government should outline how these gaps will be filled. Relevant data on palliative care use, including the needs of carers, should inform, and be informed by, statutory Population Needs Assessments and Wellbeing Assessments and their resultant plans.

**Recommendation 10. The End of Life Care Implementation Board should support health boards and NHS trusts to improve their accountability by developing consistent reporting criteria to measure progress against meeting national palliative care priorities.**

To better understand whether access to hospice and palliative care in Wales is equal we need the ability to compare delivery and outcomes between health boards and NHS trusts and against national priorities. Appropriate comparison between providers is dependent on developing shared measures. In partnership with health boards and charitable hospices, the End of Life Care Implementation Board should agree shared reporting measures for providers to enable the scrutiny of annual progress. Reporting on common measures between Health Delivery Plans and the proportion of people with diagnoses other than cancer on the Palliative Care Register should form part of this (see Recommendations 1 and 2).

**Recommendation 11. The Welsh Government and End of Life Care Implementation Board should ensure that the funding of charitable hospices is regularly updated to ensure it is based on current local population need and prevalence data.**

- a) Wales is the only nation in the UK to have a mechanism for determining the statutory funding of adult palliative and end of life care, which includes provision for charitable hospice care services. This has supported the development of palliative and end of life care across Wales. The funding of palliative care provided by hospices must continue to be based on estimates of local need. However, the calculation which underpins the formula has not been reviewed since implementation a decade ago. The funding of charitable hospices providing core clinical palliative care services should be calculated based on an up-to-date assessment of the area's population needs, taking account of the ageing population, rurality and the expansion of services to meet underserved groups.
- b) The commissioning of adult and children's palliative care services by health boards from charitable hospices should likewise be funded based on an assessment of current need and prevalence. Contracting, commissioning and Service Level Agreements with charitable hospices should reflect any uplift in the health board's budget.

## 4. Inequalities specific to paediatric palliative care

97. Evidence submitted to the Group stressed the distinct differences between paediatric and adult palliative care. Children using paediatric palliative care services are often severely disabled, with rare congenital conditions for which there is no cure, and which mean their life will be significantly shortened. Thus, paediatric palliative care tends to be delivered over a long period of time, often from identification in early childhood, at birth or at neonate stage, until the child's death or transition into adult services. This means that while end of life care is a core service provided by children's hospices, including the associated support for families, a considerable proportion of care provided by children's hospices is in the form of respite and short breaks.
98. Adult and paediatric palliative care share common principles in serving different users. The organisational structures and legal frameworks in which they operate are very different given the needs of their users. Increasingly, young people are living longer with life-limiting conditions, necessitating a transition from paediatric to adult palliative care.

### An all-Wales approach

99. The relatively small numbers of children and young people with palliative care needs in Wales (estimated to be around 1,000)<sup>42</sup>, coupled with a high degree of specialism, mean that paediatric palliative care is coordinated at an all-Wales level to ensure its viability. The End of Life Care Implementation Board has oversight of this all-Wales service with delivery coordinated by the all-Wales Paediatric Palliative Care Network and Implementation Group, sitting on the Board.
100. While paediatric representation on the End of Life Care Implementation Board is welcomed, contributors told the Group that paediatric palliative care is not always prioritised and is poorly resourced in comparison with representation from the adult sector.<sup>43</sup>
101. Children's hospices reiterated this position, noting that an all-Wales strategic vision was needed by the End of Life Care Implementation Board:

*“There is a lack of strategic development of [children's hospice] services [...] and a lack of clear focus and direction for hospice provision, all of which inhibit the hospices from developing to be able to deliver the services across Wales.”*

(Tŷ Hafan in written evidence)<sup>44</sup>





## Delivering locally

102. Equal access across Wales is an ambition of the End of Life Care Implementation Board and children's hospices alike yet the Group heard of barriers in achieving this. 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.
103. Bringing care closer to home is a strategic priority for children's hospices. Solutions being trialled include closer partnership working between statutory services and children's hospices, such as satellite services where hospice staff are located in health board premises.<sup>45</sup>
104. The Group heard of the impact that drawing on a small number of appropriately qualified clinicians has on delivering access to care for children and young people across all areas of Wales. Together for Short Lives highlighted that only one consultant session is funded in North Wales, and none in Powys; this is not sufficient to meet need.<sup>46</sup> Increase in this cover is expected in July 2018, with a proposed interim arrangement funded until 2020. A sustainable arrangement beyond this has not yet been secured.
105. 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. As with adult palliative care, the majority of families would choose for their child to be cared for at home. Enabling a child to be cared for appropriately, especially at the end of life, is dependent on local arrangements, despite efforts to deliver this care at an all-Wales level.

106. 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.
107. 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. The Chair of the all-Wales Paediatric Palliative Care Network told us how this impacts equality of access:

*“there are still areas in Wales where [our services] would not be able to support a child to die at home. That’s because of a shortage of community paediatric nurses. These are trained in paediatric care, but not in palliative care per se.”*

(Dr Richard Hain, in oral evidence, 17 January 2018)

108. 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 (i.e. seven to ten 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.
109. 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.

Raising awareness and the profile of paediatric palliative care nursing has been at the core of the joint work between the Royal College of Nursing and Tŷ Hafan. As part of the RCN in Wales Nurse of the Year Awards, Tŷ Hafan sponsor the ‘Suzanne Goodall Paediatric Nursing Award’, which aims to recognise a registered children’s nurse who has made an outstanding contribution to the care of children or young people with lifelong and/or life-limiting illness.

## Pathways to hospice care

110. Children's hospices told the Group of their ambition to reach every child or young person in Wales with a life-limiting condition. For that to happen, children must be identified in a timely manner, either through referral from statutory partners or through active case-finding.
111. Despite academic estimates indicating that there are as few as 1,000 children and young people with life-limiting conditions in Wales, there is no central register or database recording these that could support case-finding by providers:

*“For children there’s no register. There’s no palliative care register for children at all. There’s less than a thousand children with life-limiting conditions in Wales but there’s no single point of reference or source for that.”*

(Andy Goldsmith, Hope House/Tŷ Gobaith Children's Hospice,  
in oral evidence 16 March 2018)

112. 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.<sup>47</sup>
113. 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.
114. Tŷ Hafan told us that there is “no one clear plan or referral pathway for families with children with life-limiting conditions into hospice care.” Referral is dependent on whether the child has been referred to statutory tertiary care and the knowledge and awareness of clinicians in this setting about children's hospice care.<sup>48</sup> 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.<sup>49</sup>

With the aim of raising awareness amongst clinicians working in the statutory sector, Tŷ Hafan has developed a model allowing professionals to visit the hospice if they are considering a referral to the service. Tŷ Hafan's consultant and clinical nurse specialists are available to support the referring clinicians and to facilitate earlier access to the hospice for the children, young people and their families who could benefit. As part of its current strategy, the hospice is actively working to improve links with paediatric teams at health board and local authority levels.

Aware that it was not reaching all children who could benefit from hospice care, Claire House Hospice (located on the Wirral) has stationed one of its paediatric palliative care nurses at Alder Hey hospital. This supports children who require end of life care at hospital to get the best care they can and facilitates earlier referrals by doctors at the hospital to the hospice. Claire House works with its Welsh hospice colleagues to ensure referrals are made to the most appropriate provider, enabling care as close as possible to home.

## Transition

115. 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.
116. The Chair of the all-Wales Paediatric Palliative Care Network told us that young people face a "perfect storm" if they are suffering from a life-limiting condition because the transition from children's to adult services often coincides with the progression from requiring chronic palliative care to acute end of life care.<sup>50</sup>
117. An all-Wales Paediatric Palliative Care for Transition post was established in 2016 to address some of the concerns regarding care at this juncture.
118. Despite this, carers and families attending the Roundtable told us 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.
119. 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.<sup>51</sup>
120. Inflexibility within organisations and age-related cut-offs – particularly in light of the small numbers of young people with life-limiting conditions in transition – is a further barrier that impacts access to appropriate palliative care for this group. For example, some services at Noah's Ark Children's Hospital have unilaterally declared that they will not take children over 16 years of age, without having ensured that there are appropriate alternatives.<sup>52</sup> This rigidity is in contrast to recent legislation, such as the Additional Learning Needs and Education Tribunal Act, which aims to extend support for young people up to the age of 25, where this is appropriate.



## Our view

Several of our recommendations featured in the preceding chapters refer to issues facing both paediatric and adult palliative care. Please see **Recommendations 3, 6, 8, 9, 10, 11**.

Of these recommendations, there are some specific areas where we have felt it necessary to detail the actions needed to improve access in paediatric palliative care. These are as follows:

### Recommendation 4. Health boards should demonstrate how they consider end of life care needs in determining their out-of-hours coverage and work cooperatively to resource paediatric 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 health board areas, including contributing resource to provide all-Wales coverage. This should include:

- b) Working cooperatively with the End of Life Care Implementation Board and children's hospices to secure sustainable out-of-hours coverage for paediatric palliative care by ensuring that appropriate consultant cover is available.

### Recommendation 7. 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.

- 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.



# Annex A

## **Oral evidence presented to the Cross Party Group on Hospices and Palliative Care on 17 January 2018, Tŷ Hywel**

End of Life Care Implementation Board:

- Professor the Baroness Illora Finlay of Llandaf, All Wales Clinical Lead for Palliative Care 2008-17
- Steve Ham, Chair of the End of Life Care Implementation Board and CEO Velindre NHS Trust
- Dr Richard Hain, Chair of the all-Wales Paediatric Palliative Care Network and Implementation Group

Hospices Cymru:

- Trystan Pritchard, Chair and CEO St David's Hospice
- Rob Jones, CEO Tŷ Hafan
- Tracy Jones, Tŷ Hafan

## **Oral evidence presented to the Cross Party Group on Hospices and Palliative Care on 16 March 2018, Glyndŵr University**

Royal College of General Practitioners:

- Dr Martin O'Donnell

Royal College of Nursing:

- Dr Sally Anstey, Cardiff University
- Dinah Hickish, St Kentigern Hospice
- Carys Stevens, Hywel Dda University Health Board

Care Forum Wales:

- Mary Wimbury

Betsi Cadwaladr University Health Board:

- Alison Foster

Presentations received from

- Sophie Thomas, Paul Sartori Foundation
- Fiona Redmond
- Tracy Livingstone, Nightingale House Hospice

Supplementary oral evidence received from:

- Andy Goldsmith, Hope House
- Trystan Pritchard, St David's Hospice and Chair of Hospices Cymru
- Jan Sutherland-Oak, Claire House

# Annex B

## Written evidence received

Age Cymru  
Alzheimer's Society Cymru  
Aneurin Bevan University Health Board  
BASW Cymru  
BHF Cymru  
Bracken Trust  
Breast Cancer Care Cymru  
Care Forum Wales  
Cwm Taf University Health Board  
End of Life Care Implementation Board  
Dr Richard Hain  
Hospice of the Valleys  
Hospice UK  
Hospices Cymru  
Macmillan Cancer Care Cymru  
Marie Curie  
MNDA  
MS Society  
Dr Martin O'Donnell  
Older People's Commissioner for Wales  
Fiona Redmond  
Royal College of General Practitioners  
Royal College of Nursing  
Royal College of Occupational Therapists  
Together for Short Lives  
Tŷ Hafan

# Annex C

## **Organisations and attendees of Cross Party Group on Hospices and Palliative Care Inquiry Roundtable 14 February 2018, Tŷ Hywel**

Age Cymru

Aneurin Bevan University Health Board

British Heart Foundation

British Liver Trust

British Lung Foundation

Cardiff and Vale University Health Board

Cwm Taf University Health Board

Dreams and Wishes

End of Life Care Implementation Board

Hope House/Tŷ Gobaith Children's Hospice

Hospice of the Valleys

Hospice UK

Marie Curie

Macmillan Cancer Care Cymru

MNDA

Paul Sartori Foundation

Royal Pharmaceutical Society Cymru

Royal College of Nursing

St David's Foundation

Together for Short Lives

Tŷ Hafan

# References

1. Welsh Government and NHS Wales (2017). *End of life care: annual statement of progress: December 2017*.
2. Welsh Government (2017). *Palliative and end of life care delivery plan: March 2017*.
3. Skone J, Longley M and Rogers C (2015). *Palliative care for children and young people in Wales: meeting future needs*. Welsh Institute for Health and Social Care University of South Wales.
4. NICE. *Palliative care – general issues*. Available at: <https://cks.nice.org.uk/palliative-care-general-issues#!topicsummary> (accessed 3 May 2018).
5. Staff within the multi-disciplinary team may hold specialist qualifications in palliative care. For a fuller definition of what is known as ‘Specialist Palliative Care’ and ‘Generalist Palliative Care’, please see, for example, <https://www.england.nhs.uk/wp-content/uploads/2016/04/specilst-palliatv-care-comms-guid.pdf>
6. Hospice UK. *What is hospice care*. Available at: <https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care> (accessed 3 May 2018).
7. See, for examples, ‘Dixon J et al (2015). *Equity in the provision of palliative care in the UK: review of evidence*, p.4. Personal Social Services Research Unit, London School of Economics and Political Science’ (available at: <http://www.pssru.ac.uk/publication-details.php?id=4962>) and ‘Marie Curie Cancer Care and the Bevan Foundation (2014). *Death and dying in Wales: an analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life*’.
8. Hospice UK (2016). *Hospice care in the UK 2016: scope, scale and opportunities*.
9. Dixon J et al (2015). *Equity in the provision of palliative care in the UK: review of evidence*, p.4. Personal Social Services Research Unit, London School of Economics and Political Science’ (available at: <http://www.pssru.ac.uk/publication-details.php?id=4962>)
10. Evidenced in ‘Welsh Government (2017) *Palliative and end of life care delivery plan: March 2017*’, for example.
11. Hospice UK (2017). *Hospice care in Wales 2017*.
12. British Association of Social Workers Cymru written evidence.
13. Motor Neurone Disease Association written evidence.
14. End of Life Care Board report to the CPG Hospices and Palliative Care 2018.
15. End of Life Care Board report to the CPG Hospices and Palliative Care 2018.
16. End of Life Care Board report to the CPG Hospices and Palliative Care 2018.
17. Royal College of General Practitioners written evidence.
18. Welsh Government and NHS Wales (2017). *End of life care: annual statement of progress: December 2017*.
19. EOLC Board written evidence.
20. ONS *Mortality Statistics 2016*. Report commissioned by Paul Sartori Foundation.
21. Note: while this measure can provide some insight into whether, at a population level, people are likely to be achieving their care preferences, reporting on place of death does not always provide insight into the reality of an individual having achieved their care preference. Some people will continue to choose hospital or an inpatient hospice as their preferred place of care and/or death and some people change their minds as they approach the end of life.

22. Macmillan Cancer Support (2018). *Missed opportunities: advance care planning report*.
23. Welsh Government (2018). *A healthier Wales: our plan for health and social care*.
24. See, for example, 'Dixon J et al (2015). *Equity in the provision of palliative care in the UK: review of evidence*, p.4. Personal Social Services Research Unit, London School of Economics and Political Science' (available at: <http://www.pssru.ac.uk/publication-details.php?id=4962>).
25. BASW Cymru written evidence.
26. For an introduction to 'Compassionate communities' see, for example, Professor Allan Kellehear of Bradford University's lecture from February 2017 as part of Marie Curie Cymru's lecture series, available at: <https://www.mariecurie.org.uk/policy/campaigns/marie-curie-wales-lectures>
27. Abertawe Bro Morgannwg University Health Board GP out-of-hours closures in November 2017; Hywel Dda University Health Board closures in March 2018.
28. Wales Audit Office (2018). *GP out-of-hours service*.
29. Older People's Commissioner written evidence.
30. Age Cymru written evidence.
31. Care Forum Wales oral evidence.
32. Age Cymru written evidence.
33. Newman A et al (2018). *Results of a survey of support to adult care homes in Wales: a specialist palliative care provider perspective*. Marie Curie Palliative Care Research Centre.
34. Wales NHS Confederation (2018). *Retaining our staff – a key to success in difficult times*.
35. End of Life Care Implementation Board funding allocation for Hospice at Home in 2014-15.
36. Oral evidence 1, 17 January 2018.
37. Royal College of Occupational Therapists written evidence.
38. Welsh Government (2017) NHS Wales Planning Framework 2017/20.
39. Hospice UK written evidence.
40. Hospice UK (2017). *Hospice accounts: analysis of the accounts of UK charitable hospices for the year ended 31 March 2016*. (Please note that the comparison refers to adult and children's hospices in Wales.).
41. CaNISC is the Welsh software for recording cancer patient data, retrofitted to record data for all patients receiving specialist palliative care. CaNISC does not record paediatric palliative care activity.
42. Skone J, Longley M and Rogers C (2015). *Palliative care for children and young people in Wales: meeting future needs*. Welsh Institute for Health and Social Care University of South Wales.
43. Together for Short Lives written evidence.
44. Tŷ Hafan written evidence.
45. Tŷ Hafan written evidence.
46. Together for Short Lives written evidence.
47. Tŷ Hafan written evidence.
48. Tŷ Hafan written evidence.
49. Together for Short Lives written evidence.
50. Dr Richard Hain written evidence.
51. RCGP written evidence and Claire House Hospice oral evidence.
52. Dr Richard Hain written evidence.



