

Covid-19 has shone a light on the importance of good end of life care. Sensitive, dignified care at the end of life can be delivered in any setting, including in people's own homes and care homes. It relies on a supported multi-disciplinary workforce and supportive communities. Good palliative care extends to meet the person's and their family's and carers' needs, including care following a bereavement.

Over the course of the next Senedd 170,000 people will die in Wales, including 1,000 babies and children.¹ Of these, around 80 per cent will be 'expected' deaths where the person could benefit from palliative and end of life care.²

In Wales today, 1 in 4 people are missing out on the right palliative care.³

To address this, Hospice UK is calling on the next Welsh Government to take four steps to

Reach every child and adult with palliative care needs

1. Deliver a national end of life care plan that takes a whole system approach
2. Plan to meet increased need for end of life care into the future
3. Resource a sustainable palliative and end of life care sector
4. Build capacity and resilience in communities to care for people at the end of life

Hospice and palliative care in Wales

Each year more than 33,000 people die in Wales, including around 200 children.⁴ Estimates of palliative care need indicate that more than 25,000 of these people will die with a palliative care need each year.⁵ There are around 3,200 babies, children and young people living with life-limiting conditions in Wales and, at any given time, an estimated 1,050 children and young people will have a palliative care need.⁶ This year, hospices in Wales cared for over 12,000 adults and 700 children.⁷

Unmet need and future need for palliative care

Current estimates of unmet palliative care need demonstrate that as many as one in four people are missing out on the right care.⁸ This equates to around 6,600 people in Wales each year. Annual deaths are projected to increase by 25 per cent over the next 20 years,⁹ with people aged 85 and over likely to make up more than half of all deaths.¹⁰ Coupled with this, both adults and children are living longer with more complex needs and multi-morbidities, requiring diverse expertise and skills from the caring workforce.

To sustain current trends in preference for end of life care in the community it is estimated that community palliative care and care home capacity will need to double by 2040 to meet projected future demand.¹¹

What is hospice care?

Hospice care aims to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal condition, as well as their family and carers. It encompasses all elements of palliative and end of life care but places equal emphasis on a person's clinical, physical, emotional, social and spiritual needs.

In addition to inpatient hospice facilities, the majority – 90 per cent – of hospice care in Wales is delivered in the community, including in people's homes or care homes.¹² Hospices aim to provide seamless care by working alongside GPs, district nurses and social care workers. Their work extends to providing training and advice to other health and care professionals and mobilising communities to support people affected by death, dying and bereavement.¹³

Hospice care during Covid-19

At the height of the Covid-19 pandemic hospices were instrumental in ensuring continuity of care for people with palliative care needs. Facilitating rapid discharge and increasing community support meant hospices played a key role in relieving pressure on acute NHS settings by avoiding unnecessary hospital admissions and enabling people to be cared for in their own homes. Hospices have also been central to the provision of care at the end of life for people dying of Covid-19 and by supporting other professionals across NHS and social care to uphold human rights and deliver dignified care to people at the end of life, no matter what the setting.

How is charitable hospice care funded?

Hospice care is free for all who use it but reliant on the goodwill of communities to sustain it. Hospices in Wales receive a total of £5.7million annually from statutory sources. This is in comparison with the £33.3million they fundraise each year.¹⁴

The Covid-19 pandemic shone a light on the unsustainable funding model used for hospice care in Wales. In recognition of the 'essential' and 'core' health service delivered by hospices, the Welsh Government committed up to £6.3million as part of its pandemic response to develop hospice bereavement services and to support those hospices encountering financial difficulty to meet the costs of delivering core clinical hospice care.¹⁵

Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do.

We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

Reach every child and adult with palliative care needs

1. Deliver a national end of life care plan that takes a whole system approach

A whole-system, integrated approach that proactively extends the reach of palliative and end of life care beyond the bounds of specialist care is the surest way of meeting the projected increase in palliative care need and enable more people to achieve what matters to them, by being cared for closer to home and surrounded by their loved ones in the community.

As the current End of Life Care Delivery Plan comes to an end, the next Welsh Government must commit to a new strategic plan to delivering palliative care that places widening access and tackling inequalities at its heart to reach every child and adult who needs palliative care. This requires involving the contributors to meeting palliative care needs from across the whole system to build a clinical network and pathways that lead to wider access to care.

Within a new plan, specialists should be recognised as resources of expertise, influence and education to enable more people to be cared for appropriately by generalists and community colleagues.¹⁶ In practical terms, democratising palliative care knowledge and skills means targeted training for the health and care workforce supporting people at the end of life, and facilitating specialist support to generalists. A new plan must, as a priority, address ways to ensure the community workforce has the capacity to meet the increasing need for end of life care in the community, including to enable equal access to children and their families across Wales to be cared for at home. This means embracing technologies that facilitate community nurses to be supported by specialist colleagues or to make the most of community nurses' time; exploring the potential of district nurses and community paediatric nurses with specialist palliative care qualifications; and looking at the wider nursing model in an area that includes both statutory and third sector providers.

A national plan must deliver locally, responding to the demographic needs and the make up of the regional health and care system. Stakeholders across specialist palliative care and the wider community workforce, including the third sector, should be involved as integrated partners with statutory services to coproduce planning frameworks and priorities that understand, measure and meet local population need.¹⁷

The Welsh Government should:

- **Commit to delivering a new end of life care plan that places tackling inequality at its heart**
- **Take a whole system approach by utilising the expertise of specialist palliative care teams to increase the wider health and care workforce's capacity**
- **Increase the capacity of the adult and children's community workforce skilled in palliative care**
- **Strengthen local and regional integration arrangements between health boards, hospices and the wider care sector**

2. Plan to meet increased need for end of life care into the future

Planning to meet all palliative and end of life care needs sustainably is reliant on a robust understanding of the level of population need now and into the future. Prevalence research into children's and adults' needs would be an important first step to enable our health and care system to plan and prepare, and actively seek to identify those people it does not yet reach.¹⁸ Added to this, a robust understanding of where people die – an indicator of need and preference – is

required to support resource allocation and service development where there is evidence of increased need, such as in care homes and in people's own homes.¹⁹

Better data on palliative care need must also be viewed through a health equalities lens. We know that access to hospice and palliative care remains unequal; adequate and timely palliative care is less accessible for BAME, LGBTQ and older people.²⁰ The current outdated Canisc system does not collect sufficient data to understand the demographic characteristics of people accessing care or to understand each person's care journey within and between services. A first step in capturing better patient-level data will be to find a fit-for-the-future informatics solution and individual patient record for palliative care, accessible to the person. Capturing the right data will enable us to shine a light on those groups the sector is not yet reaching early enough or where people fall between services, and will guide the system to make adjustments to reach those groups.

At an individual level, planning our end of life care preferences is part of the solution to ensuring everyone gets access to the care they need and want. Covid-19 has demonstrated the importance of planning for our own care and the benefits this can have by reducing unnecessary emergency admissions, facilitating rapid discharge and keeping people in their community at the end of life, as well as leading to better bereavement outcomes.²¹ Prioritising the facilitation of timely Advance and Future Care Planning and Paediatric Advance Care Plans, including within primary care and with care homes residents, is necessary if we are to ensure more people are supported in the setting of their choice. For this to happen effectively, the commitment within the current End of Life Care Delivery Plan to develop digital Advance and Future Care Plans²² (AFCP) must be realised to enable the sharing of people's care preferences seamlessly across all care services.²³ Public education and awareness raising, including the promotion of public-facing resources, should be prioritised to involve people and their caring networks in a social model approach to AFCP²⁴ and a programme of training for those working across the health and social care sector must be embarked on to facilitate AFCP conversations.²⁵

The Welsh Government should:

- **Support research into the prevalence of need for palliative care, including for children's palliative care**
- **Deliver a modern, palliative care patient record and informatics solution that captures outcomes that matter and equalities data**
- **Make Wales a nation where planning for end of life is the norm, through public facing campaigns, training for the workforce and delivering electronic Advance/Future Care Plans**

3. Resource a sustainable palliative and end of life care sector

As the Covid-19 pandemic has demonstrated, the fragility of the funding arrangements for key partners in the end of life care pathway, such as charitable hospices and care homes, threatens their ability to continue caring when that care is most in need and most under pressure. A piecemeal approach and short term funding solutions restricts these care providers from engaging in the transformation of services needed to meet future end of life care needs.

Hospices

Hospices deliver a 'core clinical' and 'essential'²⁶ statutory service by supporting people with the medical component of their palliative and end of life care needs. This would otherwise need to be delivered by the NHS. Coupled with the additional pressures of the pandemic, the projected

increase in deaths due to our ageing population and the complexity of people's needs from the prevalence of multi-morbidities means hospices will need to reach more people with more complex care into the future. Enabling hospices to expand their reach is essential if they are to continue relieving pressure on acute NHS services by enabling people approaching the end of life to be cared for in their community.

In addition to services considered core clinical, Covid-19 has demonstrated the wider essential services that hospices provide but which are entirely reliant on fundraised income. For example, bereavement care, which hospices are in a unique position to deliver, and other preventative services, such as support for carers, day hospice and respite or short break care for children.

For children with palliative care needs, respite and short break care is the service families report valuing most and is central to the children's hospice offering.²⁷ Short breaks are generally recognised as primarily meeting a social care need, both for the child to experience age appropriate play, socialisation and development opportunities, but also to meet carers' needs. For many children accessing short breaks, the hospice is the only setting offering the integrated health and social care provision required to meet their specific ongoing health needs. Whilst short break care is a recognised, assessed need for most children with life-limiting conditions and their families, it is rarely commissioned by either health or social care providers, leaving families to rely on the charitable provision of care.²⁸

Despite the importance of these services to the Welsh health and care system, hospices need to fundraise £33.3 million each year to continue caring. Services the public consider to be essential are being propped up by charitable donations from communities across Wales and, whilst communities have been generous, the pandemic has shown community fundraising to be fragile, with events cancelled and charity shops restricted. This leaves hospices with little scope to plan, innovate, expand or, in some cases, maintain their care offering. A funding solution that enables a sustainable hospice sector to thrive must be reached going forwards.

Social care for older people

Palliative care is at the crux of integrated health and care. For adults with palliative care needs, receiving their palliative and end of life care closer to home is almost entirely reliant on access to appropriate social care. This is particularly true of the older population – often those who are frail or have a diagnosis of dementia – who are supported to remain independent through personal care provided by domiciliary care workers in their own homes or for people who are resident in care homes. With 16 per cent of all deaths occurring in care homes²⁹ and three quarters of care home residents thought to be in their last year of life,³⁰ social care, and care homes in particular, are significant providers of end of life care. The role of care homes in the provision of end of life care is only set to increase with projections indicating the need to double capacity by 2040 if we are to maintain the current preference for care at home at the end of life.³¹

Successive administrations have debated how we will pay for social care to meet the needs of our ageing population.³² As yet, there has been no commitment on a way forward, only agreement that the current funding model is unsustainable. Unless a settlement to fund social care into the future is arrived at, care homes and domiciliary care agencies will not have the capacity or resource to enable people to remain in the place they call home at the end of their lives. This is coupled with the inequality people face in the funding of their end of life care; people who receive a component of their end of life care from social care services and who contribute financially to their care will indirectly pay for part of their end of life care. This is in comparison with those who receive end of life care in a social care setting funded through continuing health care or those who receive their end of life care in a health setting.

The next Welsh Government should:

- **Work with the hospice sector to deliver a sustainable and fair settlement to meet the palliative care needs of children and adults**
- **Address the social care needs of children with life-limiting conditions by resourcing short break care**
- **Resource social care providers, including care homes, appropriately to meet future need for increased capacity in the community**

4. Build capacity and resilience in communities to care for people at the end of life

Wales has the stated ambition of becoming the first Compassionate Country in recognition of the vital role compassionate and dignified care plays within strong and resilient communities.³³ Compassionate Communities projects that support people with terminal and life-limiting conditions and their carers are known to make the difference between a peaceful death at home and an emergency hospital admission at the end of life.³⁴ At a local level, Compassionate Communities are transformative; they integrate primary care with the proactive involvement of social care interventions early on – such as to people discharged from hospital – and draw on the involvement of community development initiatives to support people with preventative, informal care. As Compassionate Community initiatives at primary care cluster level continue to evaluate positively, a national commitment to taking forward this model of care, tailored to meet local need, is needed to achieve a truly Compassionate Cymru.

At the height of the pandemic, an additional 196,000 people in Wales became unpaid carers, many of whom will be caring for people in the last years of life.³⁵ Covid-19 has taught us the importance of connected and collaborative communities in addressing health inequalities, reducing loneliness and isolation and for the wellbeing of people and carers affected by death, dying and bereavement.³⁶ Support has been seen in two main areas: firstly practical tasks, such as the deliveries of essential goods, and secondly, forming social connections despite physical distancing.³⁷ As restrictions to daily life continue, the impact on carer resilience and the isolation of individuals must be addressed. With an additional 40,000 people registering to volunteer during the first national lockdown in addition to our well-established voluntary and community networks, Compassionate Cymru must capitalise on this renewed energy to care within our communities and its preventative benefits to health and wellbeing.

Resilient networks and communities that reach out to others are also known to improve the bereavement experience, particularly in the Welsh context.^{38,39} Every community across Wales will have been affected by Covid-19 and each of us will know someone affected directly by a bereavement during the pandemic. Restrictions on visiting loved ones and changes to funeral arrangements have hampered our ability to process bereavements as we would in normal times – both for people dying of Covid-19 and those who have died from other causes. Many people have died on wards surrounded by caring staff but without their family and loved ones by their side. While investment in technology has gone some way to bridge the gap,⁴⁰ we have an ever-increasing number of people who are coming to terms with the death of a loved one in uncharted territory.

Trauma and complex grief responses, known to be more prevalent in response to sudden deterioration and death such as is the case for many people dying of Covid-19, are anticipated as the country recovers.⁴¹ Commitments to address gaps in bereavement provision identified by the National Bereavement Scoping Review prior to the pandemic, including unequal access to care across the country and long waiting lists for specialist support,^{42,43} must now be revised, updated and uplifted to meet the increased need for bereavement care that will emerge within our communities as we respond to the pandemic.

The next Welsh Government should:

- **Lead on the involvement of communities in planning to meet wellbeing needs through Compassionate Cymru and integrated primary care cluster models**
- **Appropriately resource bereavement care to meet need through and beyond Covid-19**

Further information

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³ Hospice UK (2016). 'Hospice care in the UK 2016: scope, scale and opportunities'.

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⁸ Hospice UK (2016). 'Hospice care in the UK 2016: scope, scale and opportunities'.

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¹¹ Bone, Anna E. *et al* (2017) 'What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death' <https://doi.org/10.1177/0269216317734435>

¹² Hospice UK (2020). 'Hospice care in Wales 2019'.

¹³ See <https://www.compassionate-communitiesuk.co.uk/>

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¹⁵ <https://gov.wales/sites/default/files/publications/2020-05/maintaining-essential-health-services-during-the-covid-19-pandemic-summary-of-services-deemed-essential.pdf>

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¹⁷ Hospice UK (2020) 'Hospice UK Future vision programme – discovery phase'

¹⁸ See, for example, the work on children's palliative care needs in Scotland as an impetus to identify unmet need in the population, supported by research L. Fraser (2015) 'Children in Scotland requiring palliative care: identifying numbers and needs' (University of York)

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²⁰ Cross Party Group on Hospices and Palliative Care (2018) 'Inequalities in access to hospice and palliative care'.

²¹ See, for example, statistics for Pembrokeshire, where one third of care home residents have an ACP as a result of targeted ACP development projects and where 52 per cent of people die in their usual place of residence in comparison with the national average of 40 per cent (based on ONS figures, 2016).

²² <https://gov.wales/written-statement-advance-care-planning>

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- ⁴⁰ <https://www.digitalcommunities.gov.wales/blog/2020/04/13/key-care-providers-given-digital-devices/>
- ⁴¹ <https://www.cruse.org.uk/get-help/coronavirus-dealing-bereavement-and-grief>
- ⁴² <https://gov.wales/written-statement-scoping-study-bereavement-services-welsh-government-response>
- ⁴³ Marie Curie Palliative Care Research Centre (2019) 'A scoping survey of bereavement services in Wales: end of study report'.