hospice UK

Manifesto priorities
Senedd Election 2021
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. Of these, around 80 per cent will be ‘expected’ deaths where the person could benefit from palliative and end of life care.

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

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
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**
   - Commit to delivering a new end of life care plan
   - 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**
   - 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 the development of electronic Advance/Future Care Plans

3. **Resource a sustainable palliative and end of life care sector**
   - 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**
   - 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
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\(^\text{14}\).

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\(^\text{15}\).

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.

Further information

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References

2. End of Life Care Board (2018) ‘Report to the Cross Party Group on Hospices and Palliative Care Inquiry’
13. See https://www.compassionate-communitiesuk.co.uk/)