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Wise in 5: Palliative and end of life care

Wise in 5 is a snapshot comparative guide to a public policy issue across the nations of the UK and Ireland. It helps you be PolicyWISE (Wales, Ireland, Scotland, England) in 5 (it takes just five minutes to read).

It includes a summary of the latest policy developments across the nations, as well as related research from PolicyWISE, The Open University and PolicyWISE's university partners.

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	Legal right to palliative care	Legal status of advance decisions to refuse treatment	Published government strategy	Published framework for bereavement care
England	⊞	⊞	Adult and children	
Northern Ireland		⊞	Children	
Republic of Ireland		⊞	♻	⊞
Scotland	💡	⊞	♻	⊞
Wales		⊞	Quality statement	⊞

Key	⊞ Yes	💡 Proposed	♻ Update due

Wise in 5: Palliative and end of life care

Overview

According to the World Health Organisation "Palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well."

Palliative care includes the care and support for people with life-limiting conditions over the weeks, months and years following diagnoses.

End of life care refers to the care and support for people in their final weeks or days before death, although sometimes this can be up to the last year of life.

In 2015, palliative care provided in the UK was ranked as the best in the world in The Economist Intelligence Unit's (EIU) 2015 Quality of Death Index. However, a Government report for England published in the same year admitted that "too many people still do not receive good quality care which meets their individual needs and wishes". In the Cross-Country Comparison of Expert Assessment of the Quality of Death and Dying 2021, both the UK and Ireland were included in the list of the best 6 countries for delivering palliative care.

Within the UK, health is a devolved policy area in each nation, meaning the respective governments are responsible for palliative care. Most have a strategy or framework which sets out how they have delegated implementation to NHS bodies and what care should look like in their nations.

In this briefing, strategy refers to a published plan of action.

End of life care refers to the care and support for people in their final weeks or days before death, although sometimes this can be up to the last year of life.

According to Marie Curie, about 90% of all deaths in the UK are of people in need of palliative care. Due to an ageing population, the total number of people needing palliative care is set to increase by 2050.

Reflecting Ireland's relatively young population, estimates are that the need for palliative care in Ireland will nearly double over 30 years (from 2016 to 2046).

According to the latest National Audit of Care at the End of Life in 2019/20, two thirds of hospitals in England and Wales lacked face-to-face specialist palliative care provision eight hours a day seven days a week. This report also showed that patient demand surpasses the recruitment and retention of NHS staff.

The UK Commission on Bereavement recommended that "To ensure an integrated approach to delivery of care before, during and after a death, all Governments in the UK must ensure that there is sustainable funding and effective delivery of palliative care services" in their 2022 report.

The Covid-19 pandemic has had a significant impact on end of life care, including the ability of organisations such as hospices to provide services, as well as the experience of people at the end of life and their families. The Welsh and Scottish Parliaments held inquiries into the impact of the pandemic on communities and care provision and found evidence of notable increases of deaths in private homes compared to the previous five year average and a significant impact on staff of working through the pandemic in end-of-life care.

Nation by Nation

Open University (OU) research

The OU conducts a wide range of research about palliative and end of life care through the Open Thanatology group. Some projects have examined how guidance is understood and implemented and new service developments. Other projects focus on the experience of services users, carers and/or health and social care professionals in a range of contexts, including hospice, remote provision of care, and in-patient settings. Critical analysis of government policy has recommended "a shift away from using the term good death (and related ways of evaluating deaths as good, better, or more appropriate) to outlining what quality end of life care should look like." The OU collaborates with several charities, hospices, and NHS Trusts to conduct research in this field.

Hospice care

According to the Nuffield Trust, although less than 5% of deaths occur in a hospice bed in England more than 300,000 people received care from hospices in the UK in 2020/21. This is a significant number against a backdrop of more than 650,000 deaths in the UK in 2021.

Hospice care is often provided by the charitable sector, funded through a mix of NHS contracts and charitable donations. Hospice UK claim a funding gap of £77m for the UK hospice sector in the financial year 2023-24 in England due in part to high inflation rates.

England

In England, the term 'end of life care' refers to care provided during the last year of life. The first national policy about end of life care for adults was released in 2008 – the End of Life Care Strategy England. This was significant in highlighting that end of life care is not a disease-specific issue but one that is relevant to everyone.

In February 2022 the UK Government accepted a Lords amendment to the Health and Social Care Bill for England (now the Health and Care Act 2022) requiring every part of England to provide equitable specialist palliative care. Integrated Care Boards (ICBs) have a legal requirement to commission palliative care within Integrated Care Systems. NHS England produced statutory guidance to support this, emphasising that palliative and end of life care require a whole systems approach which is flexible to meet people's needs (both adults and children) and that these should be aligned with the "Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026".

A 2022 survey of ICBs in England by Marie Curie (Integrated Care Boards) found that despite the requirement for palliative care now being on a statutory footing, there is a lack of consistent strategic focus, gaps in understanding of population health needs and inequalities, as well as little evidence of workforce planning.

Wales

In Wales, the Palliative and End of Life Care definition includes, 'the care and support of people and their families with progressive life shortening conditions, particularly those who may be in the last year of life, and including the various elements often described as palliative care, end of life care or the last days of life.'

In October 2022, the Welsh Government published their vision for palliative and end of life care which sets out quality attributes of services being safe, timely, effective, person-cantered, efficient and equitable. Responsibility is with Health Boards and Trusts, local authorities and regional partnership boards in line with professional standards, clinical guidance and the quality attributes. They will work closely with the third sector, charitable hospices, care homes, domiciliary care agencies, local authorities, Compassionate Cymru, informal carers/families and friends to deliver and continually strive to improve services for all people across all services in Wales. The Welsh Government's 'More than just words plan' to embed Welsh language in health and care services through the 'active offer' principle including as part of palliative and end of life care provision.

Scotland

The Scottish Government have stated "End of life care addresses the medical, social, emotional, spiritual and accommodation needs of people thought to have less than one year to live. It includes a range of health and social services and disease specific interventions as well as palliative and hospice care for those with advanced conditions who are nearing the end of life",

The Scottish Government is currently developing a new palliative and end of life care strategy to replace the current Palliative and end of life care: strategic framework for action 2016 – 2021. The strategy group are working to the following overarching aims:

- everyone in Scotland receives well-coordinated, timely and high-quality palliative care, care around death and bereavement support based on their needs and preferences including support for families and carers

- Scotland is a place where people and communities can come together to support each other, take action, and talk openly about planning ahead, serious illness, dying, death, and bereavement

In March 2024, Miles Briggs MSP for Lothian Region brought forward a proposed Bill which seeks to enshrine a legal right to palliative care in Scotland (as there is in England) to ensure that everyone who would benefit from palliative care is able to receive it. The right would apply to all people living with terminal illness(es) residing in Scotland and would provide equitable access to the palliative support, which is right for them, when and where they need it.

Northern Ireland

At present, Northern Ireland does not have an overarching palliative and end of life care strategy, with the most recent document published in 2010. Organisations including Hospice UK have called for this to be renewed.

There is a more recent strategy for children's palliative care covering the period from 2016 to 2026. The Cancer Strategy for Northern Ireland 2022-2032 does include a section on palliative and end of life care, and the Department of Health Advance Care Planning sets out voluntary process for people to plan for personal, legal, clinical and financial planning.

According to the All-Ireland Institute of Hospice and Palliative Care study "What do the public know about palliative care and advance care planning in Northern Ireland?" participants' understanding of palliative care is quite low, with only 1 in 5 participants describing palliative care accurately. In particular there were three misconceptions, that palliative care is only relevant in the last six months of life, palliative care does not address psychological issues or help people to participate in daily activities. The authors recommend the normalising of early conversations about end-of-life care and challenging the assumptions that are made about the role of palliative care through public health campaigns.

Republic of Ireland

The argument that the right to palliative care should be recognised in Ireland within wider international frameworks is discussed in the media here.

Currently, specialist palliative care is provided by the Health Service Executive in conjunction with the voluntary sector. The 2020 Programme for Government committed to update the current Palliative Care Policy for Adults from 2001 by mid-2021, including to improve the experience of palliative care patients, and to increase the number of specialist beds and staff. The Department of Health carried out a public consultation in Autumn 2021 to obtain the views of those who work in the field of palliative care, interested organisations and members of the public. The findings of the consultation were that while palliative care is good in Ireland, there are issues relating to access depending on location, age, or diagnosis, that services and workforce planning are under-resourced, and that training on a palliative care approach should be available for all healthcare staff. Responses to the consultation also pointed to the need to raise public awareness about palliative care and how it can be accessed.

International

UK developments are often used as good practice example for other nations, in terms of policy direction, language used to talk about the issues, and specific interventions/service models.

According to the World Health Organisation people living in low- and middle-income countries are less likely to receive palliative care. They cite that barriers to palliative care include:

- a lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer to patients and health systems;
- cultural and social barriers, such as beliefs about death and dying;
- misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life.

Wise up – 5 policy points to takeaway

1. Strategies for the delivery of palliative care should be published, reviewed, and updated for both adults and children by each administration across the UK and Ireland.
2. Workforce planning needs to recognise the ageing population and the increase in people living with complex health needs.
3. The introduction of a legal right to palliative care (including hospice-care) needs to be accompanied by suitable resources.
4. There should be exploration of the benefits of discussions around the quality end of life care instead of the inherent subjectivity linked to a “good death”.
5. Research on how policies or strategies are implemented is vital for informing future policy and service delivery. Research should uncover how to improve understanding of population needs and reduce inequalities in provision or access to end of life care.

This briefing was led by Professor Erica Borgstrom, Professor of Medical Anthropology and Lead for Open Thanatology based in the School of Health, Wellbeing and Social Care with support from the PolicyWISE team.

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Wise in 5

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