



Llywodraeth Cymru  
Welsh Government

PUBLICATION

# Quality statement for palliative and end of life care for Wales

The quality statement describes what good quality palliative and end of life care services should look like.

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This is our vision for palliative and end of life care delivered in Wales for all who need it by people working closely together, at home when appropriate, determined by what matters to the person and underpinned by what works.

## Quality statement: palliative and end of life care

This Quality statement sets out high-level Welsh Government policy intention for children, young people and adult Palliative and End of Life Care.

It will be supported by the NHS Executive and implemented through a series of health board enabling plans, collaborations with other networks and programmes (such as dementia, cardiovascular, neurological, diabetes and cancer) and the work programme of the National Programme Board for palliative and end of life care. Palliative and end of life care is inextricably linked to bereavement; the Wales Bereavement Framework and the recent UK Commission on Bereavement recommendations will help to provide the best possible experience of bereavement to all people<sup>[glossary]</sup> in Wales.

Around 33,000 individuals die each year in Wales, equivalent to over 1,000 citizens for most local authority areas, or several thousand for Wales's larger cities. Deaths in England and Wales are projected to rise by 27.0% by 2040, with a 53.6% increase in deaths in over those over 85<sup>[footnote1]</sup> associated with a higher complexity of care needs, and an increasing number having more than one serious illness contributing to their need for palliative care. Projections indicate that the need for palliative care will rise substantially over coming years especially at home or in care homes. Some evidence was suggesting pre-pandemic that care homes will be the most likely common place of death by 2040<sup>[footnote1]</sup>, however, evidence continues to emerge post-pandemic that may challenge that prediction.

A large and growing proportion of adults will have a life-shortening illness for a

period of time when care needs are intensive; children are more likely to need long term care often with intensive care episodes. Good palliative care can make a huge difference to the quality of life for people and those who care for them, helping them to live as well as possible and to die with dignity. Anyone requiring palliative and end of life care in Wales should have access to the best possible care. To achieve this, a much broader Programme focus across the spectrum of health and social care and third-sector provision rather than on specialist palliative care services will be required to make this happen as a whole system effort.

There is a need to ensure that equity of palliative and end of life care access is provided for those people who have faced inequality, such as, for example, ethnic minority communities and the LGBTQ+ communities and some pathways will need to be reimagined to incorporate more flexibility and innovation to deliver this.

The Welsh Government's '**More than just words plan**' to strengthen Welsh language in health and care services through the 'active offer' principle should become an integral part of palliative and end of life care provision. Service providers should build on current best practice and plan, commission and provide care based on this principle.

There is a need to develop greater resilience, coproduction and investment within the work and volunteer forces and unpaid carers. This will be underpinned by a review of the distribution of resources and model utilisation taking into account the current financial and economic environment. The principles of Value Based Health and Care will guide our improvements. Continuous citizen involvement will be at the centre of these improvements using the outcomes that matter to people to ensure the choices made about care design and access to services, are co-produced in line with the principles in '**A Healthier Wales**'.

Health Boards and Trusts, along with local authorities and regional partnership boards are responsible for planning services for people facing life shortening

illnesses in line with professional standards, clinical guidance and the quality attributes set out below. 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 National Clinical Framework (NCF)** places specific emphasis on the development of national clinical pathways, and the **Quality and Engagement Act** and **Framework** emphasises the importance of systemic local use of the quality assurance cycle. This Quality Statement will form the basis of a quality assurance cycle for palliative and end of life care to support local improvement in the quality of services and address unwarranted variations in care.

Detailed service specifications will also be developed to support the planning and accountability arrangements for the NHS and partners in Wales; these will be set out in Annex A as they become available.

## Safe

The overall palliative and end of life care direction and ambition including public involvement will be set by the National Programme Board for Palliative and End of Life Care, with a clear account of what should be decided locally, reflecting local circumstances.

National variation and standards in care will be addressed by clinical leaders in palliative and end of life care services working collaboratively across voluntary and statutory services with the National Programme Board for End of Life Care.

Other Welsh Government and NHS end of life care work-streams will work together with the National Programme Board for Palliative and End of Life Care to ensure a whole systems approach to any transformation or reform.

A national quality assurance system for palliative and end of life care including measurement of relevant outcomes and user involvement will provide a systematic approach to improvement, planning and quality.

## Timely

National evidenced-based seamless pathways for how people will access palliative care, including specialist palliative care, will follow the principles set out in the National Clinical Framework.

People from the point of diagnosis or recognition that they are dying, will receive timely, person-centred care, reflecting current knowledge, standards, and guidance to maintain as good a quality of life as possible and to reduce the distress of life shortening illness for the person and those close to them.

Family and carers will be informed and prepared in a timely way about how they can provide care in a safe and supported way and at the level in which they feel able to provide it should they choose to.

Palliative and end of life care access will be underpinned by equity, with active measures to identify and reduce those evidenced inequities including diagnosis, mental health, dementia, age, geography, ethnicity, sexual and gender identity, and poverty and those with Welsh language needs.

People will access good information about dying and end of life care, appropriately communicated and delivered, wherever they are located in Wales at any time.

## Effective

National systematic public engagement and involvement for palliative and end of

life care will be central to decisions on quality and improvements.

A national approach to digital and informatics systems will ensure important clinical/personal information is easily and rapidly accessible to those providing and receiving care in any setting, including where possible across borders, to ensure care is joined up, efficient, timely and reliable with relevant, high quality, standardised data to drive service improvement.

Agreed national outcomes and experience measures for people and where appropriate, for those close to them, will be utilised, ensuring people's self-reported experience should drive forward improvements and share what is 'good'.

Research into adult and paediatric palliative and end of life care is promoted, facilitated, and invested in as a funded programme. This will include the dissemination of findings and links to policy and service development to improve quality of life, influence care, and make the best use of resources.

## **Person centred care**

Any modernisation or transformation of the design and delivery of palliative and end of life care will build on what we already know from existing research to prioritise the voice of the public, patients and those close to them and will be co-produced to focus it on the outcomes that matter.

People and their families' preferences for place of care, place of death, and place after death and those factors most important to them are identified, respected, and achieved when possible – that might be short break services for children and young people, care at home (including care home), hospital, hospice, the secure estate, or other place of care.

A national approach to providing accessible information (including consideration

of both Welsh and other language needs) around dying and the care that can be expected will ensure that the public and patients and informal carers are adequately informed of the support and systems that are available to them.

People, approaching the end of their lives and their families and carers are treated with dignity and respect and have their personal beliefs and needs, including Welsh language (and other language need) and any spiritual or religious beliefs, considered as part of their core care.

Nationally agreed evidenced-based seamless pathways, careful planning and close collaboration is in place between services for transition from paediatric and young persons to adult services.

Digital technology will be used to support high quality clinical care in all settings, making care more equitable and reducing the need for unplanned change of care setting.

## **Efficient**

All people identified as having palliative care needs will be given the opportunity and support for conversations with someone well placed to discuss their personal needs, wishes and preferences for care at the end of life, through regularly reviewed Advance and Future Care Planning.

People can have 24/7 single point of access to co-ordinated care, medication, and advice about end of life care, wherever they are located in Wales to reduce distress and the likelihood of unwarranted admission to secondary care.

All efforts will be made to recognise dying in a timely manner and communicate this to those close to the person. The All Wales Care Decisions Guidance for the Last Days of Life is recommended to support best practice interventions and to emphasise a partnership approach with informal carers of the dying person

wherever this is appropriate.

Adult and paediatric palliative care services including statutory and voluntary, across care settings are measured and held accountable using national metrics that reflect the quality of care, including accessibility, its outcomes, and people's experience of it.

The National Bereavement Framework and pathways and the recommendations of the UK Commission on Bereavement sets out clear guidance for our services around bereaved people. This will improve timely and equitable access and signposting to the appropriate level of pre and post bereavement services to reduce the burden of grief on caregivers and family members.

## **Equitable**

A 'single Wales offer' or service specification of 'what good looks like' and what structures and models of integration should be in place from both specialist and generic, adult, and paediatric palliative and end of life care services will help define and determine the types of services, the health and care outcomes and the workforce needed to provide and deliver palliative and end of life care.

Children and young people with life-shortening conditions and their families should be able to access 'wrap around' care that offers therapeutic services which enable them to live their best lives and reach their full potential.

Children and young people with life-shortening conditions and their families should be able to access 'wrap around' care that offers therapeutic services which enable them to live their best lives and reach their full potential.

People's priorities for place of care, such as care closer to home (including care homes) for the growing number of people who will need and want it, will be reflected in workforce planning and in investment.

Development of an end- of-life care learning culture and framework for the health and social care workforce to enhance skills and competencies will build confidence in the workforce in providing palliative and end of life care in all care settings. The impact of language on the quality of care should also be a core element of all training programmes.

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### Example Metrics (evolving list)

### Cross- working groups

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- Referrals and clinician interactions
  - Social care
  - National Audit of Care at the End of Life (NACEL)
  - Workforce Training across care settings
  - Voluntary hospice services interventions
  - National Outcome measures – Patient-Reported Outcome Measures (PROMS) and Patient-Reported Experience Measures (PREMS)
  - Health Inspectorate Wales / Care Inspectorate Wales
  - Citizen Voice Body (Community Health Council)
  - National palliative and end of life care patient Feedback System
  - Single Cancer Pathway (SCP)
  - Unsolicited feedback including compliments/ concerns, incident reporting and adverse events
  - All Wales Care Decisions Guidance for the last days of life audit data
- Third Sector organisations
  - Faith and Belief Groups
  - Primary and community care
  - Other Programmes and Networks
  - Shared decision making/ public-citizen activation systems

# Glossary

## Palliative and end of life care

Palliative and End of Life Care 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.’

## People

Throughout this document people includes children, young people, and adults

## Pathways

The common journey/route a person takes through health care services. An NHS Pathway is a clinical tool used for assessing, triaging and directing people through healthcare services. Care pathways can provide patients with clear expectations of their care, provide a means of measuring patient's progress, promote teamwork on a multi-disciplinary team and facilitate the use of guidelines.

## Patient Reported Experience Measures (PREMs), Patient Reported Outcome Measures (PROMs)

Used to assess the quality of healthcare experiences, focusing on patients. These measures help healthcare providers, commissioners and other stakeholders to make informed changes to their services.

## Quality statement

High-level statement of intent for what “best” looks like for palliative and end of life care services.

## Service specifications

Written guidelines that set out details on how specific services will be delivered and measured.

## NHS Executive

The bringing together of 4 national bodies to work as one single national team to help deliver priorities across the NHS:

- NHS Wales Health Collaborative
- Improvement Cymru
- the NHS Delivery Unit
- Finance Delivery Unit

## Annex A: service specifications

The NHS Executive will support the local implementation of nationally agreed, optimised clinical pathways. These will be added as they become available as set out in the implementation plan

# Footnotes

[1] Bone 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. Palliative Medicine 2018 Feb;32\(2\):329-336.](#)

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