



Care and support  
through terminal illness

# A manifesto for dying well in Wales

Delivering the best end of life experience for all



**D**ying, death and bereavement are inevitabilities that every individual will have to face at some point in their life. Coronavirus has brought them to the forefront of the nation's attention under the most tragic circumstances. Issues surrounding how, where and why people die have become more familiar. Despite this, death remains a taboo subject, with many people reluctant to have open conversations about what matters most to them at the end of life.

**Coronavirus has brought dying, death and bereavement to the forefront of the nation's attention.**

Coronavirus has both highlighted and exacerbated many challenges faced by those who use palliative care services and those working within the sector. Never has it been more important to have a well-resourced health and social care service, with a workforce that feels supported and equipped to deliver accessible and value-based end of life care. A rapidly growing and ageing population, combined with an increase in comorbidities, means that providing high-quality and specialised care is becoming increasingly important; by 2040, the demand for palliative care is set to increase by 42%.<sup>1</sup>

To improve the experience of those living with a terminal illness, their families and carers, the next Welsh Government must make end of life care a key focus for the next parliamentary term. To support this important commitment, Marie Curie has identified three priority areas and specific actions that all political parties should include in their manifestos ahead of the next Senedd elections.

Marie Curie is calling upon the next Welsh Government and statutory partners to:

- ensure equitable access to palliative care services
- identify and meet expectations of everyone approaching end of life
- implement a person-centred and universal bereavement strategy in Wales.

By committing to these three priority areas and implementing the following outlined actions, the next Welsh Government will ensure that everyone affected by dying, death and bereavement has the best possible experience.



Phil Hardman/Marie Curie

# Priority one: The Welsh Government and NHS Wales must ensure equitable access to palliative care services

## Overall ambition

Marie Curie is calling for the development of an accountable NHS Wales governance and implementation framework that works towards eliminating variation across Wales, ensuring everyone in Wales has equitable access to palliative care and support when needed.

## Recommended actions

- The Welsh Government should develop and fully resource a successor to the End of Life Care Delivery Plan, due to come to an end in 2021/22.
- End of life care representation should be included within any new proposed NHS governance structure established during the next parliamentary term.
- A monitoring framework should be established to oversee agreed outcome measures, which feed directly into any new governance arrangements.
- Improvement to the end of life care data infrastructure should be delivered at pace, in particular through the replacement and upgrade of the palliative care reporting system which currently sits as part of the Cancer Network Information System Cymru (CaNISC).

## End of life care plan

Of the 34,000 people who die in Wales each year, at least 75% would benefit from some form of palliative or end of life care.<sup>2</sup> For many reasons however, 25% of people will not have access to the end of life care support that they need.<sup>3</sup> To ensure that everyone has the best possible experience and can be supported to make the best choices around their place of death, end of life care must be a priority of the next Welsh Government.

It is vital that we see the Welsh Government develop a new national strategic approach to end of life care that follows on from the current End of Life Care Delivery Plan, which is due to end in 2021/22. This new strategic approach should be developed in consultation with healthcare professionals,

**The next Welsh Government must develop an End of Life Delivery Plan.**

# 42%

**By 2040, the demand for palliative care is set to increase by 42%.<sup>1</sup>**



experts within health and social care, and individuals and their carers who use or who have used end of life services. It should be bold enough to prompt the necessary shift in how we prioritise end of life care and needs to be well enough resourced to enable successful and sustainable delivery.

At the heart of the plan should be a whole-systems approach to end of life care, which facilitates partnership between national and local stakeholders, and across the private, public and third sectors. Lastly, to ensure accountability and oversee implementation across the whole of Wales, there must be end of life palliative care representation within any new NHS Wales structures that are formed during the next parliamentary term.

### Monitoring framework

Overseeing, funding and supporting the development and implementation of a monitoring framework for palliative care services and end of life patient experience should be a priority for the next Welsh Government. This framework would enable health boards to benchmark services and audit patient outcomes and experience in order to pinpoint where variation exists across Wales, and to monitor progress in eliminating health inequalities. This insight would go a long way to informing the steps that need to be taken to eliminate health inequalities, provide a foundation for sharing best practice and drive service improvement.

Within this monitoring framework, there should be an agreed set of outcome measures that are consistently gathered and recorded across Wales. These measures should be clinically agreed, informed by patients and captured via a new IT infrastructure (see below). The development and implementation of such outcome measures should be included as a priority action in the successor to the current End of Life Care Delivery Plan.



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### Improved data infrastructure

To eliminate variations in care, drive service improvement and deliver the best possible experience for patients, end of life care services in Wales need to be underpinned by fully resourced and continually innovating data infrastructure. Outcome measures identified as part of the monitoring framework previously explained should be collected, submitted and reported in an efficient and systematic way – and most importantly not overburden healthcare professionals.

The current end of life care electronic healthcare record is delivered through CaNISC – a system also used to capture

data on cancer services. CaNISC is no longer fit for purpose, and a business case has been agreed by the current Welsh Government for a new IT system. The first phase of the replacement of CaNISC will take place during the Summer of 2021. The replacement of CaNISC's specialist palliative care functionality, which includes palliative care reporting, is part of phase 2 of the roll out and is not scheduled to take place until 2022. It is imperative that the palliative care elements of this programme are delivered ahead of this proposed timetable and not delayed due to competing NHS priorities taking precedence.



Layton Thompson/Marie Curie

**End of life care services need to be underpinned by continually innovating data and IT infrastructure.**

# Priority two: The Welsh Government and statutory partners must identify and meet the expectations of everyone approaching the end of their life

## Overall ambition

The Welsh Government should work with partners across society to encourage open and honest conversation about death, dying and bereavement so people are aware of what to expect at the end of their life. This would enable those with a terminal illness, their family and carers to make decisions on the type of care they would like to receive, where and from who they would like to receive it.

### Recommended actions

- The Welsh Government should develop an action plan to find out from people of all backgrounds and characteristics what their expectations are at the end of their life.
- The Welsh Government should adopt the *What Matters Most Charter* as best practice for advance care planning.
- The Welsh Government should develop and roll out a bespoke advance care planning digital tool.

## Identifying expectations

Since the foundation of the NHS, people have long had expectations about the care and support they should receive throughout their lives. Over time this has been underpinned by policy, targets and focused resources. Waiting time targets and person-centred care are examples of how such expectations have been reinforced.

But when it comes to the most vulnerable time in our life – the end of our life – all too often people don't know what they should expect. Our healthcare system is based on

the principle of supporting us from cradle to grave, with health and social care policy rightly focusing on preventing ill health. But it is equally important to prioritise those who are terminally ill. This would make it easier for healthcare professionals, patients, their families and carers to have conversations about planning the type of care they would like to receive, including where and from who they want to receive it.

The next Welsh Government should seek to work with partners across Wales to explore what people want and expect at the end of life, recognising that every individual will have different views and priorities. Such work should seek to hear from under-represented and under-served groups in particular, who too often face unwarranted barriers to getting the support they need.

## Advance care planning

New thinking in health services has radically changed the experience of birth and the expectations that go with this – in location, environment and clinical practice. The same shift in thinking needs to occur in end of life care and support. A good death does not only mean clinical support and pain management; it needs to consider individuals' needs more widely. We must adopt a holistic approach to end of life care, otherwise we risk preferences being overlooked.

Advance care planning (ACP) can facilitate this process. It is a discussion that takes place between a health and/or social care professional and an individual who is dying. This gives a person the opportunity to talk about their hopes, fears and their wishes surrounding their last days and what they would like to happen to them after they die.



Phil Hardman/Marie Curie

The *What Matters Most Charter*<sup>4</sup> was developed by a UK-wide group of experts on end of life care, from both charities and health and social care bodies. It aims to change care planning to be more focused on what makes life good for the individual. The charter enables professionals and patients to have conversations centred on their relationships and personal preferences as well as addressing their clinical needs.

Alongside this, palliative care experts in Wales have been calling for an electronic advance care planning tool. This would make it easier to share ACP information across NHS services so that it is available to the right people, in the right place, at the right time. This should include accident

and emergency staff, out-of-hours GPs and paramedics. At present, there is no electronic solution to support ACP and the current system is inefficient and often ineffective.

As outlined above, the NHS Wales Informatics Service (NWIS) has been focusing on a replacement for CaNISC, meaning there have been delays in the development of an electronic ACP data capturing system. It is vital that this digital tool is progressed at pace so that it can be used to its full potential alongside an updated CaNISC system. This is a necessary part of ensuring a continually innovating and data-driven end of life care sector in Wales.

**The *What Matters Most* charter aims to make end of life care more focused on what makes life good for the individual.**

# Priority three: The Welsh Government and statutory partners must oversee the delivery of a person-centred and universal bereavement strategy in Wales

## Overall ambition

To see the implementation of a universal strategy for bereavement services in Wales, currently in development, to ensure that anyone who has lost a loved one has timely and equal access to person-centred support when needed.

### Recommended actions

- The Welsh Government must follow through with the implementation of the national strategy for bereavement services that is currently being developed and ensure this is rolled out across all health boards.
- The Welsh Government should commit to review and act on the findings of the Marie Curie Palliative Research Centre's work on the experience of people who have been bereaved during the coronavirus crisis.

## Implementation of the National Strategy for Bereavement Services in Wales

The benefits of pre- and post-bereavement support for people of all ages are clear. Bereavement can affect both physical and mental health and can even impact on mortality.<sup>5</sup> We have heard a great deal about how the country will recover economically from coronavirus, but there has been less focus on how we will recover socially – including how we will respond to the pandemic as a mass bereavement event.

In 2019, a Welsh Government-funded study by the Marie Curie Research Centre

in Cardiff University looked into the type of bereavement support available across Wales.<sup>6</sup> It found that there was unwarranted variation across the country with regards to accessibility and type of support available, and that many bereavement services were encountering similar challenges due to a lack of a clear framework. Other major problems include access to funding and inability to meet demand.

We are pleased with the commitment and progress from the current Welsh Government in developing a universal bereavement strategy for Wales and a new set of bereavement standards through the End of Life Care Delivery Board.<sup>7</sup> A new and fully resourced strategy would help establish clear referral pathways and effective risk and needs assessments, improve training for staff and volunteers, and see the development of an updated directory of available bereavement support across Wales. To see such progress, the next Welsh Government must prioritise this work and provide clear leadership to encourage collaborative working between all health boards, communities and the third sector.

### The experience of people who have been bereaved during coronavirus

Cardiff University has recently received funding to explore the delivery of end of life care and bereavement support during and beyond the coronavirus pandemic.

The first report of interim data identified high levels of emotional support needs, as well as difficulties experienced by people getting support from friends and family.<sup>8</sup> The research highlights limited access



to professional bereavement services, including for those identified as most vulnerable in their grief.

A lack of available information on bereavement support options was also identified, with researchers recommending that more information be routinely provided following a death, that there be an increase in public information on bereavement support options, and that more signposting by GPs needs to take place. The research also makes early recommendations for increased resourcing and for steps to be taken to tackle social isolation amongst the bereaved.

The full results of this research, when published, should be reviewed and considered by the Welsh Government for any future action, especially in light of the delivery of the National Bereavement Strategy.

*“How will we respond to the pandemic as a mass bereavement event?”*



## What can you do to help?

As a Member of the Senedd, you can help by working with your party to encourage a new national conversation and supporting the work of the Compassionate Cymru movement. This seeks to create a new narrative around community empathy, directly supporting its citizens to address the negative impacts attributed to dying, death, bereavement and loss.

For more information about this follow Compassionate Cymru on twitter  
**@BywNawr**

Follow us on social media and tweet your support **@MarieCurieCymru**

Email our Policy and Public Affairs team so we can help you better support your constituents with issues associated with dying, death and bereavement  
**bethan.edwards@mariecurie.org.uk**



Phil Hardman/Marie Curie

## Marie Curie services

The UK's leading end of life charity, Marie Curie is here to support everyone in the UK through all aspects of dying, death and bereavement. Our nurses care for people in their homes and in our hospice, giving much-needed respite to overstretched carers. They provide a lifeline at one of the most frightening and upsetting times any family will face. Last year, our nurses cared for almost 36,000 people.

When you're dealing with the shock of a terminal illness, the stress of caring for someone you love, or the pain of

bereavement, information you can trust is very precious. Our online information and support line help people in their hour of need to feel reassured, informed and empowered to face what's happening in their lives.

Contact our support line on **0800 090 2309** for advice and support about any issue related to dying, death and bereavement.

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**For more information:**

**Lowri Griffiths**

Head of Policy and Public Affairs  
Marie Curie (Wales)

E: [lowri.griffiths@mariecurie.org.uk](mailto:lowri.griffiths@mariecurie.org.uk)

**Bethan Edwards**

Policy and Public Affairs Officer  
Marie Curie (Wales)

E: [bethan.edwards@mariecurie.org.uk](mailto:bethan.edwards@mariecurie.org.uk)

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Please note photos without PPE were taken before the coronavirus pandemic

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