

# Marie Curie

## Dying Well in Wales lecture series

**Event report: How do we support people to live and die well in Wales by 2040?**



**Marie  
Curie**

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**Gofal a chefnogaeth  
drwy salwch terfynol**

**Care and support  
through terminal illness**

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## Introduction

In July 2021, Marie Curie in Wales held its first lecture series event since the start of the pandemic. The event was held virtually and was attended by 64 colleagues from across Wales representing Welsh Government, health, social care the third sector representatives. The event was kindly chaired by Rhun ap Iorwerth MS.

Research around projections on place of death were presented by Dr Anna Bone, Research Associate from the Cecily Saunders Institute at Kings College London. A response to this research evidence was given by Dr Cliff Jones, GP and End of Life Care lead at the Royal College of GPs, and Dr Idris Baker, Palliative Care Consultant and End of Life Care Clinical Lead for Wales.

This event report provides a summary of the common themes emerging from the event, along with contributions and observations captured from panellists and participants. The discussion that took place is by no means exhaustive; many important issues were not discussed in detail due to time constraints. No comments have been attributed to individuals.

## Context

In 2008, The Sugar Report was published and established the core elements of a specialist palliative care service in Wales. Wales has since been focused in its aim to ensure that good palliative and end of life care is delivered and accessible to everyone who needs it.

Over the last decade, huge efforts have been made by the End of Life Care Board and colleagues across Wales to drive forward the recommendations of the Sugar Report. This includes the development of two Palliative and End of Life Care Delivery Plans.

The clinical governance structures of health and social care systems in Wales will soon be undergoing reorganisation. In March 2021, the Welsh Government launched proposals for a new National Clinical Framework, which sits within planned arrangements for a new NHS Wales Executive function. This clinical framework includes plans to develop a dedicated end of life care programme to sit alongside a newly designed end of life care Quality Statement. These new arrangements will replace the oversight arrangements of the End of Life Care Delivery Plans.

This period of change and progress presents an opportunity for the palliative and end of life care community to come together, share challenges and openly discuss options for driving continuous improvement in palliative and end of life care services, which support people to die well in Wales.

## Evidence and insight

A number of research initiatives have taken place recently which provide context to the changing demands of palliative and end of life care. The Covid-19 pandemic has led to a sustained increase in the number of people dying in community settings and this period has served as a stress test for our current health and

social care systems. Current programmes of work and our collective experience through the pandemic provide us with a platform to understand and consider the demands that will be placed on our systems in the coming years.

### **Impact of population ageing on future demand of end of life care.**

Research by Bone et al estimates that by 2040, annual deaths in England and Wales will rise by 25.4%, from 501,424 to 628,659<sup>1</sup>. Due to the overall increase in deaths, with more deaths happening at older ages, as well as a projected rise in deaths from chronic diseases, palliative care need is set to increase significantly. If age- and sex-specific proportions with palliative care needs remain the same as in 2014, the number of people requiring palliative care in 2040 will grow by 25.0% (from 375,398 to 469,305 people/year)<sup>2</sup>. However, if recent upward mortality trends continue, then 160,000 more people in England and Wales will need palliative care by 2040<sup>3</sup>. This would represent an increase in need of 42% from 2014 to 2040<sup>4</sup>. Predominant illnesses driving increased palliative care need are projected to be cancer and dementia<sup>5</sup>.

Healthcare systems need to start adapting to the age-related growth in deaths from chronic illness and more resource is urgently needed. There needs to be increased specialist palliative care capacity to cope with increasing numbers of patients at end of life with comorbidities and complex conditions. In addition, more primary and secondary care generalists that are aware of advance care planning and symptom management will be key.

### **Trends and future projections on place of death**

Further research from Bone et al found that if recent trends continue, overall deaths in the community are projected to increase by 2040, with hospital deaths (as a proportion of all deaths) expected to decline by more than 50% in the same period<sup>6</sup>. Deaths at home will increase by 88.6% by 2040<sup>7</sup>, while deaths in care homes are projected to increase by as much as 108% by 2040<sup>8</sup>; deaths in the community (care homes, homes and hospices) will nearly double by 2040, and account for 76.0% of all deaths. Care homes are projected to become the most common place of death by 2040.

As such, researchers have concluded that end of life care provision in care homes and the community needs to double by 2040.

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<sup>1</sup> Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

<sup>4</sup> Ibid.

<sup>5</sup> Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017

<sup>6</sup> Ibid.

<sup>7</sup> Bone, A., Gomes, B., Etkind, S. et al, '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, 32(2)

<sup>8</sup> Ibid.

## Better End of Life Programme

The Marie Curie Better End of Life Programme reinforces the increasing shift towards more deaths happening at home and within community settings. The programme seeks to understand the outcomes and experiences of people affected by death, dying and bereavement in the UK and to propose a policy agenda aimed at ensuring that everyone has the best possible end of life experience. The programme is a multi-year collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, University of Hull, and the University of Cambridge.

The first research [report](#) from the programme, published in March 2021, explored the ongoing impact of the Covid-19 pandemic on dying, death and bereavement in the UK<sup>9</sup>. It looks back at 2020, and also brings to light lessons learned for the future of palliative and end of life care and bereavement support.

As well as outlining key Covid-19 specific challenges around lack of PPE, medicines and equipment, the report highlights key learning around the impact that sustained increase in deaths at home can have on people's experience of dying. Even outside of pandemic peaks in 2020, there was an increase of 40% of people dying at home in the UK compared to the five-year average.

## Emerging themes from event

The following discussion synopsis is set against the presentation of the preceding research and demonstrates areas of consensus that emerged from participants and panellists. Many of these themes are interlinked.

### A multi-disciplinary approach

The most referenced challenge during the session was the need for an integrated, multidisciplinary team (MDT) approach to deliver ongoing improvements to palliative and end of life care across Wales.

MDT working is essential to provide better quality and integrated care, which would benefit both patients, their loved ones, and professionals. MDT working should include representation from GPs, palliative care, geriatricians, community nursing, social care, care homes and third sector. However, concerns exist that whilst the benefits of MDT are well known, the reality of barriers and pressures within systems means that true MDT working is often challenging and varies across Wales.

Participants observed that due to workforce challenges, it is common for district nursing colleagues to be unable to attend MDT meetings. Yet, district nurses are fundamental in an effective system of providing care to people dying at home and other community settings.

With more insight into the current state of working between primary care, community, third sector services, and specialist palliative care colleagues, it is important to explore how communication between teams and within the sector can be improved. It is vital that the barriers to effective MDT working are identified and

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<sup>9</sup> Sleeman, K., Murtagh, F., Kumar, R., O'Donnell, S., Cripps, R., Bone, A., McAleese, J., Lovick, R., Barclay, S. & Higginson, I., *Better End of Life 2021: Dying, death and bereavement during Covid-19, Research report*, Marie Curie, April 2021

analysed to rebuild a robust approach which ensures partners are able to effectively deliver the best end of life care experience possible.

**Potential next step 1:** Explore a new End of Life Care Programme workstream around multi-disciplinary team approaches.

## Care coordination

Issues around care coordination were another challenge raised by many. Building on this discussion, anecdotal evidence was provided of how implementing key worker roles, both through dedicated clinical nurse specialists and through disease specific key workers, improved care coordination in services. Nonetheless, it was also agreed that palliative and end of life care is more complex than disease-specific care, in terms of the variety of physical needs and the more holistic interventions needed. If coordinators in end of life care are to be explored, any professional appointed to this role must have understanding of the entire patient pathway and strong presence within MDTs to ensure all aspects of care are considered and communicated to the patient.

Discussion around the benefits of information and support coordination hubs also took place, as these types of services have been seen to lead to better integration of services. Another example of good practice raised was the concept of a 'gold card', implemented in various regions in England as part of the Gold Standards Framework<sup>10</sup>. This system allows the patient to ring up their GP practice or other care providers and mention the gold card. This in turn triggers a specific pathway, ensuring that the person's needs are met in the context of end of life. One area with a 'gold card' system in place saw hospital deaths decrease from 49% to 14% and an increase from 22% to 44% in home deaths<sup>11</sup>. It was suggested that similar interventions be explored here in Wales

**Potential next step 2:** Explore initiatives which provide a single point of access and communication to patients who are dying, and their loved ones, with a view to develop a universal solution to ensure provision of seamless and integrated patient experience.

## Workforce and training

Challenges around the acute workforce were highlighted, with clinical nurse specialists (CNS) under more and more pressure, both within hospital and in supporting community teams. The CNS nursing crisis that existed pre-pandemic, due to retirement and work fatigue, will only continue to add pressure to workforce shortages in the future.

Whilst it was acknowledged that specialist palliative care providers are vital in delivering the best possible care, more focus was placed on workforce shortages in community settings. There was consensus that a lack of community nursing and social care support will only increase in the future. Inevitably, this will also place immense pressure on unpaid carers, families and loved ones. Steps must be taken to create more care

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<sup>10</sup> <https://www.goldstandardsframework.org.uk/cross-boundary-care-training>

<sup>11</sup> Gold Standards Framework. *Improved coordination in GSF Cross Boundary Care Sites and attainments of GSF Accredited teams* [Online]. Available from: <https://www.goldstandardsframework.org.uk/cross-boundary-care-training>

capacity in the community, as well as increasing and solidifying support available for unpaid carers.

Increasing workload and ongoing pressures in primary care also means that more planning is needed to ensure that patients are visited regularly. The time taken to build relationships with individuals is becoming less; examples of district nurses visiting patients in their last days of life and meeting them for the first time, is not uncommon. Contributors talked of ‘borrowing’ nursing support from neighbouring primary care clusters due to staff shortages. The Covid-19 pandemic has undoubtedly exacerbated this situation.

People who are dying receive care and support from a wide range of professionals. Palliative care specialists play a critical role, but most day to day care is in fact provided by the non-specialist workforce. Participants discussed the importance of ongoing palliative and end of life care education and training for these non-specialist teams, with a particular focus on those working in social care and care home settings. Whilst it was recognised that many professionals working in these settings already receive high quality training, it is not universal, and gaps exist in training, education, and experience (see next section: care homes and change in place of death).

**Potential next step 3:** The new end of life care programme should work alongside Health Education and Improvement Wales to develop a training programme to deliver ongoing palliative and end of life care education and training for all of those involved in the care of dying patients, across care settings.

## Care homes and change in place of death

The discussion around care homes focused heavily on the need to ensure that the system wraps around the needs of the patient and the care home, rather than the care home and patient having to adjust to meet the demands of the system.

It was highlighted that people go to care homes because they have specific health and care needs – residents are a specific cohort of people that need additional support due to increased complexity, and this needs to be factored into planning for the future. This reinforces the earlier point of needing to develop new MDT models which involve care home representatives. It is worth mentioning that rurality and stretched capacity was highlighted as a specific challenge here when it comes to care home and GP collaboration.

In highlighting the need to train care home staff to recognise signs of deterioration, the ‘Six Steps Wales’ care home programme was mentioned as a successful initiative. Programmes like this have made good progress in training and educating care home colleagues, but as with other successful interventions, it is important to ensure that the offer is universal and available consistently to all.

Advance and Future Care Planning discussions are particularly valuable in supporting good deaths in care homes (as well as other settings). Where these interventions are used, patients and their loved ones feel better supported and have better outcomes, this is particularly true of those who have dementia. The All-Wales Care Decisions Guidance (CDG) for Last Days of Life was also raised during the session. Although there are signs that this guidance is used and implemented at varying rates in different settings across Wales, the framework and guidance would be particularly valuable in care homes and raising awareness of the

guidance and providing training on its use would be a beneficial exercise.

Finally, the group agreed that there is often a negative perception surrounding care homes, exacerbated by the Covid-19 pandemic. This tied into a wider discussion around perceptions of 'the right place to die'. It was acknowledged that the 'best' place to die is wholly dependent on the person and the situation. Whilst a home death is sometimes believed by some to be the holy grail of a 'good' death, it is important to acknowledge that acute medical wards support thousands of people to die well in hospital. Furthermore, there are groups of people that for many reasons are unable to die at home or choose to die in other settings, and we must ensure our system is prepared to support all circumstances.

**Potential next step 4:** The End of Life Care Programme must pay specific attention to the needs of care homes in supporting their patients and residents to die well. A specific workstream on care homes should be considered, taking into consideration MDT working and care coordination. Strategic care home representation on the new End of Life Care Programme Board should be explored.

### **Compassionate communities and unpaid carers**

Conversations about care in the community inevitably moved to unpaid care provided by family, loved ones and friends. Panellists and participants were quick to note that informal support is often as important, if not more important than medical intervention. It was acknowledged that unpaid carers often feel unnoticed and undervalued.

Community support networks are essential for any holistic system of care. If we want to enable more people to receive care in the place of their choice, we must not consider community support networks to be on the periphery of service delivery, but a fundamental part of the jigsaw. This must include investing and delivering on the ambitions laid out in the Compassionate Cymru initiative and exploring solutions such as local coordinators, linking where possible with primary care and community-based teams.

The role of community pharmacies and their knowledge of the local population was also highlighted. As well as providing expert advice on medications, community pharmacists can capitalise on their formal and informal relationships to be vigilant of potential issues and signpost to additional support. Their role in the community serves to relieve pressure on colleagues in primary care, freeing GP, and other primary care colleagues to provide care to those who have more complex needs.

**Potential next step 5:** Welsh Government and the End of Life Care Board should consider the role that unpaid carers play in the end of life care system. The new End of Life Care Programme should ensure that they are respected, better supported and all relevant priorities in the new Strategy for Unpaid Carers should be acted upon<sup>12</sup>.

**Potential next step 6:** Social movements such as Compassionate Cymru take time to establish and grow momentum. This initiative is an important part of the end of Life Care infrastructure in Wales with the potential to transform dying and bereavement experiences. Continued investment and recognition by the new End of Life Programme is vital.

<sup>12</sup> <https://gov.wales/strategy-unpaid-carers-html>

**Potential next step 7:** The role of community pharmacists must be recognised as part of the wider public health approach to dying, death and bereavement. The revision of the new community pharmacy contract should take into consideration the added value that pharmacists can bring in ensuring people have the best end of life experience possible.

## Bereavement

Participants noted that it is not only the physical effects of the pandemic that we need to be considering, but the psychological too. The level of bereavement in Wales has of course increased with Covid-19, with the increasing scale and complexity of bereavement cases having been acknowledged. This must be planned for and the National Bereavement Framework will be a good first step when it is published.

In line with this event briefing, it is anticipated that the National Bereavement Framework will consider the importance of community support and the place of bereavement care within a Compassionate Cymru context. However, we must now see the framework acknowledging and acting on the complex experiences of people who have been bereaved during the pandemic.

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 getting support from friends and family<sup>13</sup>. The research highlights limited access to professional bereavement services, including for those identified as most vulnerable in their grief. When published, the full results of this research should be reviewed and considered by the Welsh Government to inform any future action, especially when it comes to the delivery of the National Framework for Bereavement Care.

**Potential next step 8:** Welsh Government should commit to reviewing the full findings of the Marie Curie Palliative Research Centre's work on the experience of people who have been bereaved during the Covid-19 crisis, and ensure that this is reflected in any future work under the National Framework for Bereavement Care.

## Potential next steps

Everyone agrees that dying, death and bereavement is everyone's business. Whilst our primary and specialist palliative care colleagues are experts in compassionate medical interventions and supportive holistic palliative treatments, there is a role for us *all* during this next stage of planning.

Foundations have been laid since the publication of the Sugar Report and the newly published Review of Specialist Palliative Care in Wales 2010 – 2021 gives us an important insight into the progress that specialist palliative care in Wales has made during that time. But it is now time to plan for the next phase.

The Dying Well in Wales event gave us the opportunity to come together and discuss common issues that we all believe need addressing. This event briefing brings to light the areas where consensus was found – in

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<sup>13</sup> <https://www.medrxiv.org/content/10.1101/2021.06.11.21258575v1>

terms of challenges faced and potential next steps for us all to consider in the coming months. It is now the responsibility of Welsh Government, colleagues across health, social care and the third sector to oversee the development of the new End of Life Care Programme and ensure that we plan carefully for what the future holds.

Only then can we make it possible for everyone to die well in Wales by 2040.

### **Summary of potential next steps:**

1. Explore a new End of Life Care Programme workstream around multi-disciplinary team approaches.
2. Explore initiatives which provide a single point of access and communication to patients who are dying, and their loved ones, with a view to develop a universal solution to ensure provision of seamless and integrated patient experience.
3. The new end of life care programme should work alongside Health Improvement and Education Wales to develop a training programme to deliver ongoing palliative and end of life care education and training for all of those involved in the care of dying patients, across care settings.
4. The End of Life Care Programme must pay specific attention to the needs of care homes in supporting their patients and residents to die well. A specific workstream on care homes should be considered, taking into consideration MDT working and care coordination. Strategic Care Home representation on the new End of Life Care Programme Board should be explored.
5. Welsh Government and the End of Life Care Board should consider the role that unpaid carers play in the end of life care system. The new End of Life Care Programme should ensure that they are respected, better supported and all relevant priorities in the new Strategy for Unpaid Carers should be acted upon.
6. Social movements such as Compassionate Cymru take time to establish and grow momentum. This initiative is an important part of the end of Life Care infrastructure in Wales with the potential to transform dying and bereavement experiences. Continued investment and recognition by the new End of Life Programme is vital.
7. The role of community pharmacists must be recognised as part of the wider public health approach to dying, death and bereavement. The revision of the new community pharmacy contract should take into consideration the added value that pharmacists can play in ensuring people have the best end of life experience possible.
8. Welsh Government should commit to reviewing the findings of the Marie Curie Palliative Research Centre's work on the experience of people who have been bereaved during the Covid-19 crisis and ensure that this is reflected in any future work under the National Framework for Bereavement Care.

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