



Marie
Curie

Gofal a chefnogaeth
drwy salwch terfynol

Care and support
through terminal illness

Public attitudes to death and dying in Wales

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Executive Summary

We all hope for the best possible end of life experience for ourselves and our loved ones. However, that doesn't necessarily mean that we have given a lot of thought to what this looks like, had conversations about our wishes with loved ones or professionals, or – as a society – that we provide the care and support that dying people need in their final years, months, weeks, and days.

In 2021, during the Covid-19 pandemic, Marie Curie commissioned a survey company, Opinium, to coordinate a survey across the UK, designed by the Marie Curie Research Centre (MCRC) at Cardiff University. The survey asked members of the public to give their views on a range of end of life issues including their fears, how they had planned for death and dying, their preferences around end of life care, their understanding of key terms, attitudes to survival versus quality of life, and more.

The survey questions were based on those developed and delivered by MCRC in a 2018 Wales study. Both the 2018 and 2021 surveys had more than 2,000 respondents each across Wales, and all the responses in both surveys were analysed by MCRC with further support from the PRIME (Primary Care and Emergency Care) Centre Wales.

This means we have two rich datasets which show us how the Welsh public understand and approach issues relating to death and dying, as well as their expectations for care and support at the end of life.

We are at a critical moment for improving palliative and end of life care in Wales, as the Welsh Government and its partners across the NHS, social care and the third sector are planning a refreshed approach to the delivery of palliative and end of life care through the development of a new All Wales End of Life Care Programme.

A recent review of progress made against the recommendations of the 2008 Sugar Review for the delivery of Specialist Palliative Care in Wales rightly celebrates success¹. But it also acknowledges the opportunity to look towards the new National Programme for End of Life Care, to broaden the agenda, and continually improve outcomes for people who are dying and their loved ones over the next ten years.

“Going forward, person-focused end of life care lies in the diversity of our services, diversity in the range of our professionals engaged in our specialist services, and with the integration of the wider provision of end-of-life care.”

End of Life Care Board: Review of Specialist Palliative Care Service in Wales 2010 - 2021

By better understanding public attitudes towards death and dying – including the care and support people hope to receive – we believe this report will help Wales face into the challenges ahead, and to provide a palliative and end of life care system which is fit for the future so that everyone who dies in Wales has the best possible end of life experience.

Key findings from the survey include:

The public believe that end of life care should be a priority for the NHS in Wales.

Four out of five people think that end of life care should be given equal priority in the NHS as care for people in any other stage of life. Awareness is low about the availability of services and there are mixed views on their quality. But more positively, three quarters of respondents think that people who are dying are treated with dignity and respect by health and social care professionals in Wales.

Being free of pain, with loved ones, and dying with dignity are people's top priorities for their end of life experience.

People were more likely to prioritise these over dying at home, which could have important implications for measuring how well services are performing and meeting people's needs and wishes. Access to a trained carer and privacy are top priority needs that people would want to have met as they approach the end of life.

People's worst fears about dying are being helpless and dependent on others.

Over 70% of people fear being helpless and dependent more than they fear death – reinforcing the importance of doing everything we can to ensure that people have their voice heard in the care they receive. Quality of life also matters a great deal to people at the end of life. More than three-quarters of people (78%) say that if they were severely ill, the quality of their life would be more important than the length of their life.

Most people feel that as a society we do not talk enough about death and dying.

But the vast majority (86%) say that there is nothing to prevent them talking about this at a personal level with family and friends, and they would feel comfortable having these discussions.

There is a huge gap between the proportion of people who say that they feel comfortable talking about death and dying, and the proportion who have actually done so.

Most people (92%) think it is important to express future health and care preferences in advance of serious illness and dying, and their main reason for doing so is to lessen the burden on family and friends. However, just 16% of respondents have done this. Only one in five people have made financial arrangements for their funeral and less than half have talked to someone about whether they want their body to be buried, cremated, or donated for medical or scientific purposes. Worryingly, more than half (55%) of people who are in their last years of life say they don't know where to find information on how to plan their care in advance.

Continued on next page...



Philip Hardman/Marie Curie

In Wales, our ability to engage in talking about and planning for death is hampered by poor understanding of terminology.

Most people are unaware of technical terms such as Advance Care Planning and Advance Directive. Even for more widely recognised terms such as palliative and hospice care, about a third (29%) of people are not familiar with them. Many of these terms are in common use within health and social care working environments but are not well understood by patients and families, thereby excluding the people for whom open conversations are most important. Even so, people are willing to be involved in treatment decisions – most respondents (74%) feel confident as a patient to be involved in decision-making about life-supporting technology.

The latest official projections predict that by 2038, at least 40,000 people will die each year in Wales.² Research suggests that, if current trends continue, by 2040 the number of people who need palliative care in England and Wales will rise by more than 40%.³

With the number of people dying in Wales increasing, and mounting pressures on health and social care services, the evidence in this report offers a unique opportunity to support the public discourse on dying, death and bereavement and inform innovation and ongoing development of services for people at the end of life.

We need to see three principal changes to improve end of life care for the future, as set out in the discussion section of this report.

Firstly, **end of life care should be as much of a policy priority as care and support at any other phase of people's lives**; secondly, **we need a better public discourse about dying, death and bereavement**; and finally, **people must be listened to more closely about their own preferences for their end of life care**.



Layton Thompson/Marie Curie

Marie Curie's policy recommendations to make these changes happen in Wales are:

1 We need to treat end of life care as just as much of a priority as care and support at any other phase of people's life

Ensure that timely implementation and effective oversight arrangements are put in place around the new End of Life Delivery Programme for Wales. With the previous commitment to the publication of the new Programme in April 2022, we expect a clear action plan highlighting a strategic approach that is bold enough to prompt the necessary shift in how we prioritise end of life care. This action plan must include a clear timetable, a commitment to sustainable funding, and sufficient number of staff to enable successful delivery. The Programme must be able to support integrated services and be geared towards meeting the needs of all people in Wales who would benefit from palliative care

Introduce a national survey of bereaved people so their experiences inform future end of life care policy and strategies. The survey shows that bereaved carers and people in the last years of life often have a different perspective on end of life services and issues to the general population, highlighting the importance of experiential knowledge. A regular survey of bereaved people in Wales would give healthcare professionals and government a better understanding of the experiences of people at the end of their lives and those close to them. The survey design should allow us to understand the experiences of people with different characteristics and backgrounds.

2 We need a better public discourse around dying, death and bereavement

Adopt a public health approach to encourage more open conversations about death and dying across the whole population. A programme of research aimed at improving public literacy around death and dying is needed to underpin a public health approach promoting openness, access, and community resourcefulness in meeting our end of life needs. As well as tackling taboos, this approach should seek to improve public understanding of technical terms related to palliative and end of life care and increase public awareness of the health and care services available, what they can offer, and how to access them at the end of life. It should also include action to encourage and support Advance and Future Care Planning in a willing population. Compassionate Cymru can provide resources and examples of how local communities in Wales can play a stronger role in supporting people at the end of life.

End of life services should meet the needs of the whole population. This must include people with protected characteristics and those who face additional barriers to accessing palliative and end of life care services. It requires concerted action to tackle inequities in access to and quality of care – we need to listen to and learn from the voices of individuals and communities with direct experiences of inequality.

3 We need to listen more closely to people about their preferences for their end of life care

Outcome measures for end of life care services should reflect what matters most to patients and their families.

A more holistic approach is needed to measuring performance in end of life care that focuses on the full range of a person's wishes, needs and preferences for the end of their life – and responds flexibly as these change over time. With the development of the new End of Life Care Programme for Wales, we have an opportunity to introduce a new measurement framework which focusses on the impact that services have on patients and their families, rather than on the activities that services delivers.

Ensure that NICE Quality Standards (QS13) in relation to end of life care and Advance and Future Care Planning are delivered.

This means that people approaching the end of life should feel satisfied that they have been able to discuss, record and review their needs and preferences if desired. It also means that this conversation should cover all aspects of a person's care and support, and it should be conducted in accordance with best practice as set out in the What Matters Most Charter and Advance and Future Care Planning (AFCP) guidance developed by Welsh Government and NHS Wales colleagues.

Develop and roll out bespoke digital tools to support Advance and Future Care Planning.

An electronic AFCP tool will help support this information to be efficiently and securely shared across NHS services so that it is available to the right people, in the right place, at the right time. This should be developed and implemented across healthcare settings as soon as possible, including emergency and out-of-hours services, to ensure that people's needs and wishes at the end of life are known and acted upon.

Further research is needed into several areas related to our survey findings.

Future research should inform how we align the ambitions of the End of Life Programme with evaluations of clinical care which reflect public priorities and patient perspectives on what matters most. We also need to understand how patients and families engage with services so that we can better integrate health and social care services locally to deliver the care needed, and how best to include patients and the public in quality improvement projects.



Philip Hardman/Marie Curie

Introduction

Before the pandemic, the number of people dying each year in Wales was steadily increasing.⁴ In 2019, there were 33,183 deaths in Wales, compared with 31,439 in 2014, and 31,005 in 2009⁵. In 2020, this rose to 37,399, reflecting the devastating impact of Covid-19 on the population. Similar effects were observed across the other UK nations. This significantly heightened need for and pressure on health and social care services, including palliative and end of life care services.

Even without the effects of the pandemic, the UK's ageing population means that the longer term trajectory is towards an increasing number of deaths per year. The latest official projections predict that by 2038, at least 40,000 people will die each year in Wales⁶. Research suggests that, if current trends continue, by 2040 the number of people who need palliative care in England and Wales will rise by more than 40%.⁷

In this context it is particularly important to think about the support people receive at the end of life – and how we ensure that everyone receives the care they need, and have their preferences heard and responded to. Too often, we don't even talk about issues of dying and death – making it all the harder to prepare for it.

Members of the public were asked to give their views on a range of end of life issues including their fears, how they had planned for death and dying, their preferences around end of life care, their understanding of key terms, attitudes to survival versus quality of life, and more.

A total of 8077 UK adults participated in the 2021 survey, including 2005 in Wales. The number of respondents from Wales was boosted for the purposes of comparison with the previous version of the survey, in which 2,210 people participated⁸. This means that in Wales we have a wealth of data, including rich qualitative data from the free text responses, which can help us to better understand what the public think about end of life issues. The headline findings are presented in this report, with all quotes taken from respondents in Wales unless otherwise specified.

The responses were analysed by the Marie Curie Research Centre at Cardiff University with further support from the PRIME (Primary Care and Emergency Care) Research Centre at Cardiff University.

Further information about the survey methodology is available in our previous publication, [Public Attitudes to Death and Dying in the UK.](#)

1.1 Our Survey Research

In 2021, during the Covid-19 pandemic, Marie Curie commissioned a commercial survey company, Opinium, to coordinate a survey across the UK based on the questions used in our previous 2018 and 2019 surveys in Wales and Northern Ireland.

What do people think about end of life care?

End of life care is recognised as a priority for the NHS

The survey findings show that most people recognise end of life care as a priority for NHS Wales, regardless of the age of those needing care.

Nearly four out of five (79%) respondents agreed or strongly agreed that end of life care should be given equal priority in the NHS as care for people in any other stages of life. The same proportion (79%) agreed or strongly agreed that end of life care for older people should be given equal priority in the NHS as care of people in other age groups.

People have mixed views on the quality and accessibility of services

The survey asked respondents to indicate the extent to which they agreed with statements around the adequacy of end of life services.

Over half of respondents (56%) did not agree or did not know whether there are adequate health and social care services available for people approaching the end of life. In their comments, some respondents raised concerns about the availability of NHS resources. Others said that they believed the NHS is doing a 'good job'.

"The provision here is very spotty; some aspects are wonderful, others markedly less so. Standards need to be consistently high."

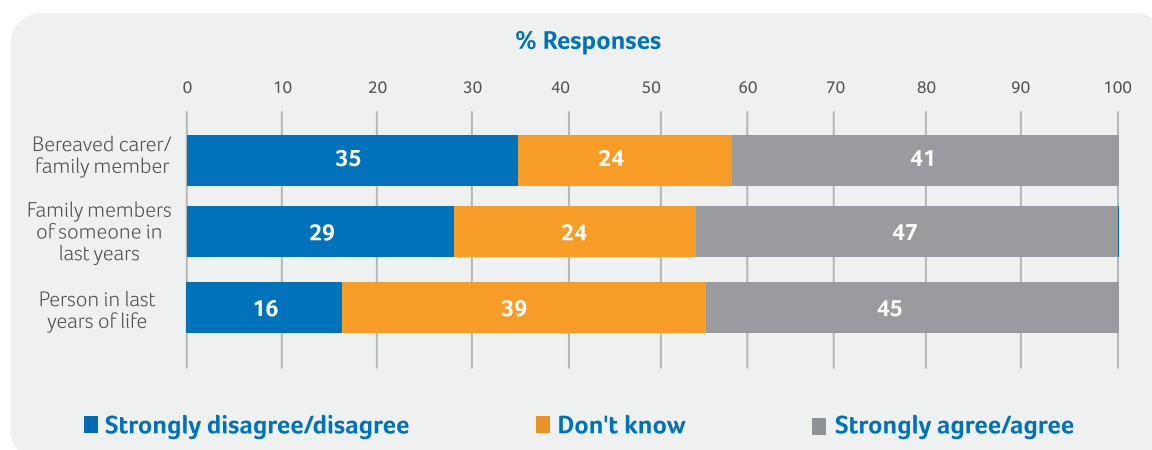
Bereaved carers and family members were more likely to disagree that services are adequate and accessible. Over a third (35%) disagreed that adequate services were available for people approaching the end of life, and one in seven (14%) indicated that people approaching the end of life were not able to access end of life care facilities. Respondents who reported being in the last years of life were more likely to say that they didn't know.

More positively, most respondents think that people who are dying are treated with dignity and respect by health and social care professionals in Wales. About three quarters of bereaved carers (77%) and family members of someone in their last years of life (74%) agreed this was the case.

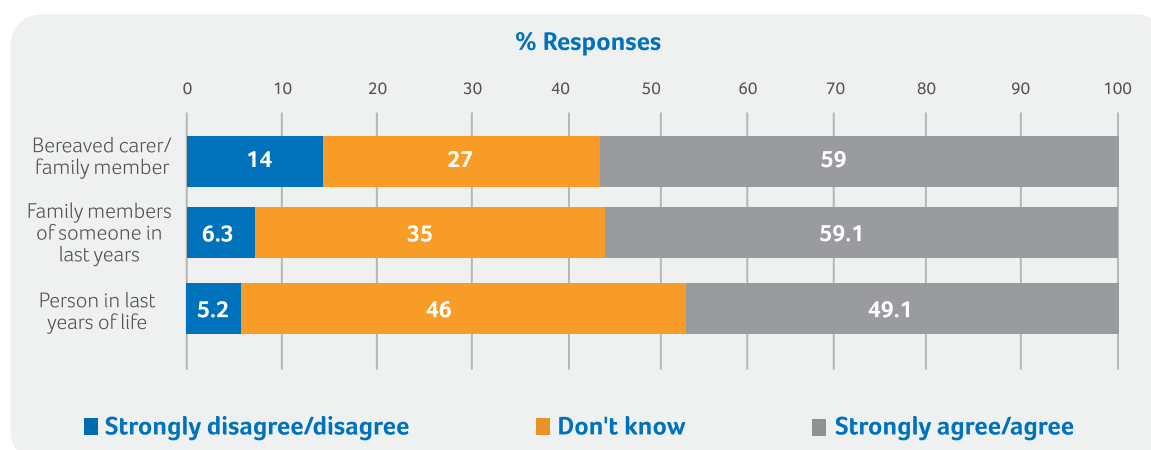


Philip Hardman/Marie Curie

To what extent do you agree that there are adequate health and social care services available for people who are approaching end of life



To what extent do you agree that people who are thought to be approaching end of life are able to access end of life care facilities



Having supported their dying loved one at the end of life, bereaved carers and family members have valuable experiences of and perspectives on services that can help us to understand what works well and what needs to improve. Healthcare professionals tend to answer these questions more positively than other groups.

It is therefore important to create meaningful and sensitive opportunities for both bereaved carers and people with terminal illness to share their views, so that these can inform decisions about service design and delivery.

What matters most at the end of life?

Being free of pain and symptoms and the company of loved ones are top priorities

Respondents were asked to select the three most important personal priorities they would like to be managed during their final days, and last year of life. The survey revealed that people's top priority was being free of pain and other symptoms. This was closely followed by being in the company of loved ones and being able to maintain personal dignity and self-respect.

For people's final days of life, the three top ranked overall priorities for individuals in the Wales were:

1. Being free of pain & other symptoms **47%**
2. The company of loved ones **45%**
3. Being able to maintain personal dignity & self-respect **36%**

Top three personal priorities for the final days of life (%)



“It should be personal to the person, and their wishes should be respected however much other people may not agree with it.”

Just over a quarter of respondents (27%) said being in their home would be one of their top three priorities. This challenges the assumptions that are sometimes made about people’s preferences, with service quality indicators often based on place of death with the preferred option of home.

Respondents who reported that they were in the last years of their life shared the same top three priorities, however being at home ranked slightly higher in fourth place.

“I would be sad spending my last few days in hospital and would rather be home with my pet and loved ones.”

When asked about the final year of life, the top three priorities remain constant, but some of the lower-ranked priorities shift with slightly more respondents wishing to be at home (30%) or to be involved in decisions about their care (22%).

Research suggests that people’s preferences for the end of their life often depend on prior experience and knowledge of palliative care, their own fears around death, and their personal experiences of health and care services.⁹

“Everyone has the right to a peaceful, dignified death, as pain free as possible and their family with them where they feel happiest.”

However, there are gaps in research evidence related to many aspects of death and dying, and the complexity of public

attitudes suggest a need to continuously revisit current assumptions, and current policies and practices.¹⁰

Access to a trained carer is a top priority need

Respondents were asked to select the top three priority needs that would need to be managed during their final years of life. The options offered focused on practical needs, as opposed to the holistic priorities that were covered by the questions above.

In Wales overall, the top priority needs to be managed in the final years of life were:

- | | |
|---|-----|
| 1. Having a trained carer nearby | 62% |
| 2. Having privacy | 59% |
| 3. Having access to professionals for last minute concerns about my family or legal affairs | 49% |

These top priority needs were the same for respondents who reported being in their last years of life.



Philip Hardman/Marie Curie

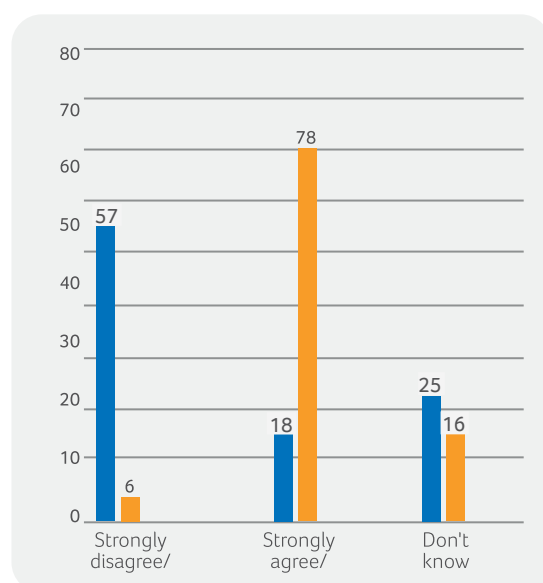
Quality of life matters a great deal

Survey respondents were asked to indicate the extent to which they agreed with statements around treatment and care preferences.

More than three-quarters (78%) of respondents either strongly agreed or agreed that if they were severely ill, the quality of their life would be more important than the length of their life. This was similar (79%) for respondents who reported being in the last few years of life.

"Quality of life is so much more important than quantity but medical care misses this out completely."

Agreement with statements about death and dying (%)



If I was severely ill with no hope of recovery, I would want to be kept alive at all costs

If I was severely ill with no hope of recovery, my quality of life would be more important than the length of life

Aligned to this, more than half of respondents (57%) said that they would not want to be kept alive at all costs.

Many peoples' views about quality of life versus survival will change over time, particularly with diminishing health. Given full information about the extent of disease, many express a preference for quality of life

over survival^{11 12} but individual definitions of quality of life may vary according to life stage or personal characteristics.

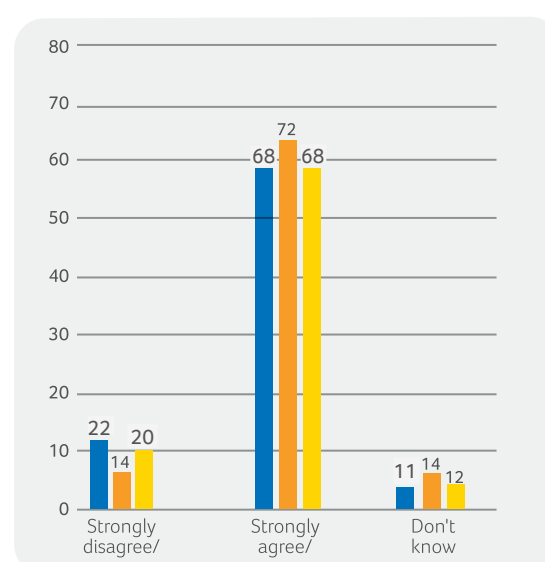
Most respondents (72%) either strongly agreed or agreed that their preferences around death and dying should take priority over the wishes of their next of kin or their doctor's advice.

People fear being helpless and dependent, and in pain

The survey questions asked respondents to indicate the extent to which they agreed with statements around fear of dying.

Almost three-quarters (72%) either strongly agreed or agreed that they feared being helpless and dependent more than they feared death. This was even higher (77%) for respondents in their last years of life. More than two-thirds (68%) of respondents also either strongly agreed or agreed that they fear pain and other physical symptoms, and fear leaving their loved ones.

Preferences about death, dying and end of life (%)



I fear dying because I have to leave my loved ones

I fear being helpless and dependent more than I fear death

I fear pain and/or other physical symptoms

How do people plan for the end of life?

Most people are happy to talk about death and dying

The survey questions asked respondents to indicate the extent to which they felt comfortable discussing death and dying.

Around half (53%) of respondents thought that as a society in Wales we do not talk enough about death and dying.

“Death is a part of life and will inevitably happen to all of us. Trying to find comfort in acceptance will be achieved by talking about death more.”

This was considerably higher for bereaved carers, with two-thirds (66%) saying that we do not talk enough about these topics. This suggests that existing social taboos around talking about death and dying may have particularly strong negative effects on this group, with their needs to talk going unmet.

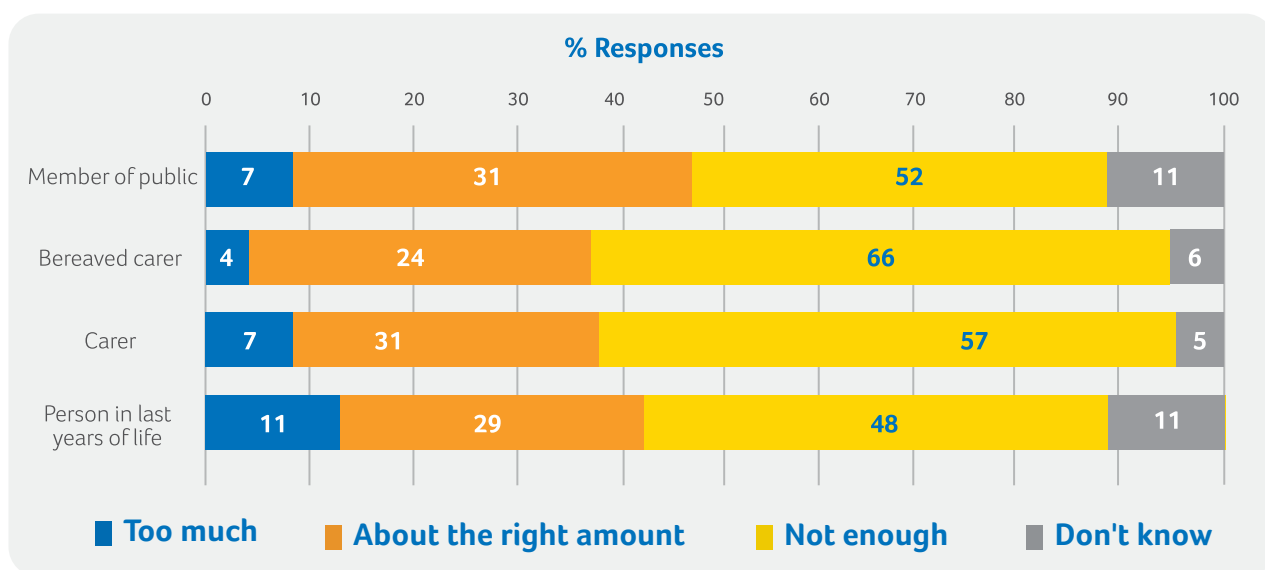
Carers were also more likely to think that as a society we do not talk enough about death and dying (57%).

Just under one third of respondents (31%) thought that we talked about death and dying the right amount. Previous research has found that people often feel that society is generally disinterested in or disapproving of talking about dying and death, as this is a sensitive topic.¹³

Though most people felt that as a society we do not talk enough about death and dying, the vast majority (86%) of respondents said that there is nothing to prevent them talking about this.

“I think that people should treat death as being normal, we all have to face it. Not enough is done in families to talk about the subject and peoples wishes for funerals.”

As a society, how much do we talk about death and dying?



However, respondents did describe challenges or barriers to discussing or making plans in their comments. These include a lack of awareness and understanding about how to engage in these conversations, and an unwillingness to prepare for death when it seems far away.

"I'm only likely to make preparations when I reach a point where death is approaching so I'm not making preparations for sudden or accidental death. I do have concerns about the work involved for relatives if the latter situation arises."

"It's very hard to engage with, and I don't know how or where I would express those preferences."

At a personal level with family and friends, most respondents (67%) reported feeling either very comfortable or comfortable discussing death and dying in general.

In terms of specific conversation topics, even more respondents reported feeling very comfortable or comfortable discussing their:

Three-quarters of respondents (74%) also indicated feeling very comfortable or comfortable selecting someone to decide on treatment decisions when they are unable to do so themselves.

"My husband and I have discussed our personal choices and I'm confident that he would respect my wishes and act on my behalf if required."

By contrast, only 54% of respondents felt very comfortable or comfortable discussing the arrangement of their virtual possessions, such as social media accounts, with family and friends, with 30% of respondents indicating they "don't know". This was similarly low for people in their last years of life (52%), carers (52%) and bereaved carers (57%). A relatively recent issue, this highlights that care of virtual possessions may require particular attention within end of life care planning.

The fact that most people reported being comfortable talking about issues of dying and death, makes it all the more notable that – as we shall see – most people have not in fact done so, or made plans for their end of life care.

- | | | |
|-----------|---|------------|
| 1. | End of life wishes around treatment and care | 74% |
| 2. | End of life wishes around death | 76% |
| 3. | Funeral arrangements, | 75% |
| 4. | Financial affairs | 76% |

There is low awareness of palliative care and Advance Care Planning terminology

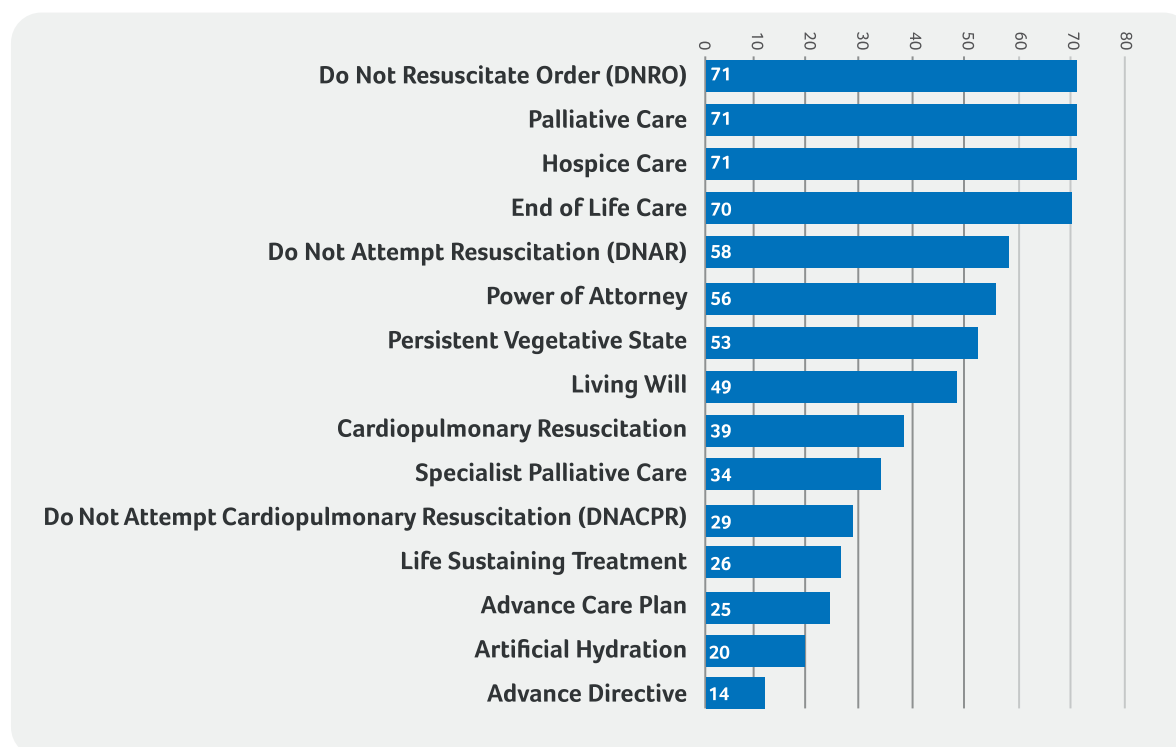
The survey asked respondents to indicate which end of life terms they were familiar with from a list. This list of 15 terms included, for example, Advance Care Plan (a way for you to think, discuss, decide, document and share with your healthcare team what matters most to you at the end of your life) and Advanced Directive (which consists of a Living Will and a medical power of attorney). Three-quarters (75%) of respondents in Wales reported being unaware of the term Advance Care Plan and 86% were unaware of the term Advance Directive.

The terms which were most familiar to respondents were Do Not Resuscitate Order (DNRO), Palliative Care and Hospice Care, although around a third of respondents (29% for each) were unfamiliar with their meaning.

Definitions of advance care planning, palliative care, supportive care, hospice care, and other elements of end of life care and treatments vary¹⁴. Sentences, phrases and terms can mean different things to different people and this can influence their decision making, which becomes especially important in advanced disease and towards end of life, when shared engagement in key discussions is needed.^{15 16}

Adopting a public health approach to palliative care could encourage more open conversations about death and dying and should seek to improve public understanding of technical terms related to palliative and end of life care. The public health approach to palliative care is explained on page 20.

Familiarity with end of life care terms (%)



Not everyone is confident they have access to information to plan in advance for the end of life

Despite a lack of familiarity with advance care planning terms, almost half (47%) of respondents reported that they know where to find information on how to plan in advance for care at the end of life. **Worryingly, more than half (55%) of people in the last years of life said they did not know where to find this information.**

Nearly three-quarters (73%) of respondents either agreed or strongly agreed that if they were to make plans for the end of their life, they know who among friends or family they could discuss it with.

"I have already spoken to my family about what I want if I become too ill. I have a living power of attorney in place together with a DNR. I have paid for my funeral and have discussed it at length with my family."

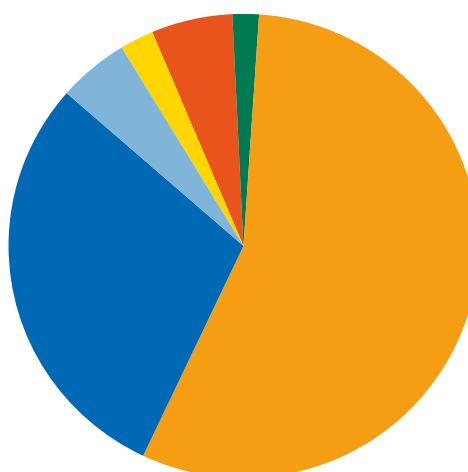
Over half (56%) of those surveyed either agreed or strongly agreed that if someone close to them were to die, they know where to find support.

There is a large gap between intention and action in Advance Care Planning despite the perceived benefits

The survey questions asked respondents to indicate the most important benefits of advance care planning, as well as their intentions and behaviours towards engaging in Advance Care Planning.

Nine out of ten respondents (92%) thought it was either quite important or very important to express future health care preferences in advance of serious illness and dying.

Importance of expressing future healthcare preferences in advance of serious illness and dying



59% Very important

33% Quite important

3% Not that important

1% Not at all important

4% Don't know

1% Other

The most commonly identified benefit of this was to lessen the burden to family members and friends (34%), followed by reducing stress around planning and making decisions about care (30%). Interestingly, only 15% of respondents thought the most important benefit of advance care planning was preventing them from having treatment they don't want.

“[It] would help take the stress away from loved ones making decisions and would ensure your wishes are known.”

Most respondents report feeling very comfortable or comfortable discussing their end of life wishes with doctors and nurses (75%), and very comfortable or comfortable with their family member or loved one discussing their end of life wishes with them (71%). They also want to be involved in decisions about their care: Most respondents (74%) either strongly agreed or agreed that they would be confident as a patient to be involved in decision-making around using life-supporting technology.

Despite most people reporting feeling comfortable discussing their end of life wishes, just 16% of respondents have formally expressed their future health care wishes and preferences. Similarly, only 16% have talked to someone about their end of life care wishes.

“I intend to live for many more years, but I have a will, paid for funeral & 2 lasting powers of attorney in place to make things easier for my family.”

Only one in five (22%) have made financial arrangements for their funeral. Around half of respondents indicated that they intend to have these important conversations and plan for their end of life, but they have not yet done so.

There is a large gap between intention and actions in making end of life arrangements, despite people seeing the benefits of making plans. However, some end of life arrangements seem to be more accessible. Many people stated that they had already talked to someone about whether they want their body to be buried, cremated, or donated (42%) and made a decision about organ donation (47%). This may indicate that these are areas which could lead to a broader Advance Care Planning conversation.

“So that you are not given treatments and procedures you do not want, and get treated at a location of your choosing ie a hospice rather than a hospital.”



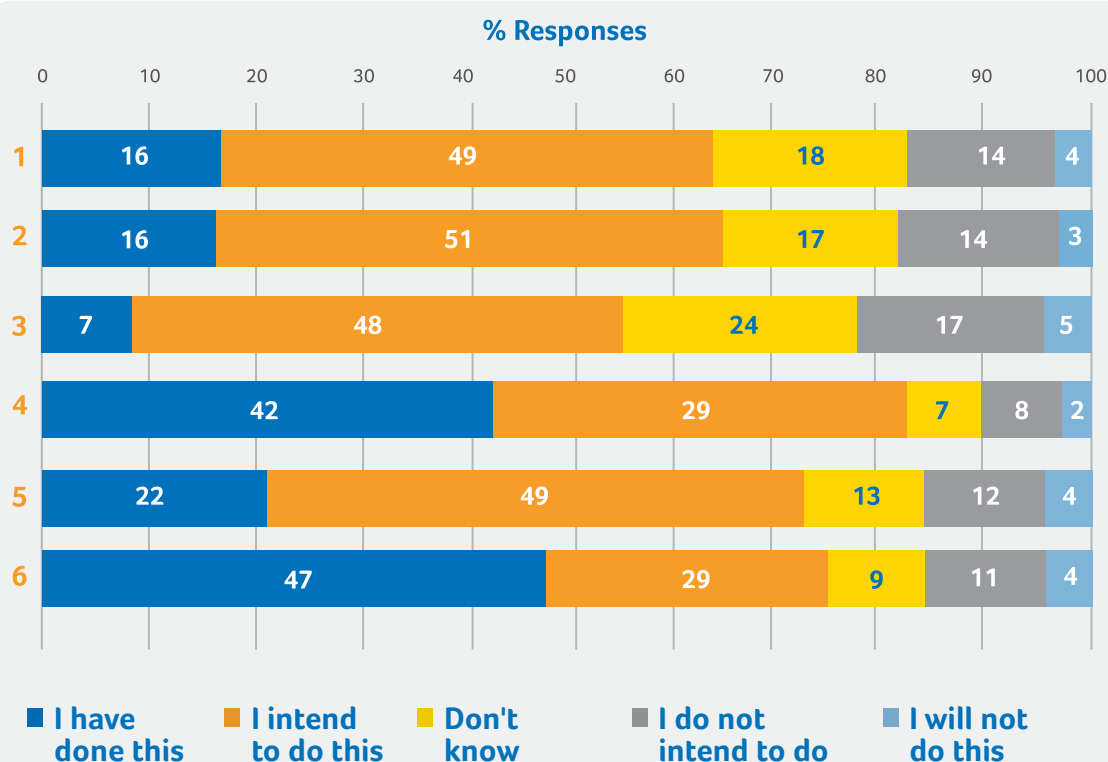
75%

Feel very comfortable discussing their end of life wishes with doctors and nurses



Philip Hardman/Marie Curie

Advance Care Planning intentions



1. Formally expressing my future health care wishes and preferences (e.g making a Living Will)

2. Talking to someones about my End of Life Care wishes

3. Talking to my doctors/nurses about my End of Life Care wishes

4. Talking to someone about whether I want my body to be buried or cremated or donated

5. Making financial arrangement for the funeral

6. Making a decision on organ donation (opt-in or opt-out)

In terms of supporting family members or friends to plan their end of life arrangements, only 17% of respondents have asked a family member or friend whether they have made a living will and only 16% have asked what type of care and support they would want at the end of their lives. About a quarter of respondents (between 21% and 32%) say they do not intend to or will not have these important conversations with their friends and family, emphasising an important area for public awareness campaigns.

“I have chosen to discuss my wishes and arrangements with others. I would not ask them about their choices as I believe it is up to them to speak to me if they wished.”

The numbers of people who are in their last years of life who have made plans are worryingly low. Only one in five (22%) have formally expressed their future healthcare preferences or talked to someone about their end of life care wishes, and only one in ten have talked to a doctor or nurse about their end of life care wishes.

More work is needed to increase public awareness of which health and care services are available, what they can offer, and how to access them at the end of life. By adopting a public health approach to palliative care these points could be addressed. This would also encourage and support higher levels of Advance Care planning.

Who makes advance care plans?

The survey responses can help us to understand the personal circumstances and social characteristics of those who reported having made advance plans for their care.

- Respondents who had formally expressed their future healthcare preferences, for example through a Living Will, were more likely to be over 75 years old. Nearly a quarter (24%) of people in this age group had done so.

- Respondents who were in the last years of life, or were working as health and care professionals or within healthcare research, were more likely to have talked to someone about their end of life wishes compared with members of the public, carers or bereaved carers. Interestingly age and gender seem to have little effect here, with about 16% of men and women, and 13–17% of people in all age groups (from 18–25 to 75–84) having had these conversations.

- Women (44%) were slightly more likely than men (39%) to have talked to someone about what they want to happen to their body after death. The likelihood of having had this conversation steadily increases with age, from 26% in people aged between 18 and 25 years, to 56% in those aged over 75 years.

What is a public health approach to palliative care?

Public health approaches to palliative care seek to address low levels of awareness of death and dying in the population. They focus on early intervention and social solutions, such as building compassionate communities and education programmes. Public health approaches to palliative care seek to alter attitudes to health, death, dying and loss and improve death literacy within communities, so that they have the skills and knowledge about what to do and where to find support in a palliative and end of life care context. More information about compassionate communities is available through [Compassionate Cymru](#).

The impact of Covid-19

While the survey did not ask specific questions relating to Covid-19, some themes around the impact of Covid-19 on attitudes to death and dying were evident in the free-text responses.

Some respondents described how they felt that the pandemic has led to higher awareness of certain aspects of death and dying, which could result in greater understanding of the need to be prepared.

"I think this last year has taught us about death in so many ways and the need to be prepared"

"I believe Covid has made people think a little more but there should be more on social care and financial implications long term"

Some respondents felt that the pandemic had changed how we talk about death for the better, leading us to talk more and be more open, which has created positive opportunities to introduce discussions in new environments, such as the workplace. However, others felt that this increased presence of death in everyday life would mean that people were less willing to talk about these issues right now. Some expressed concerns that illnesses and deaths that are not Covid-related are not given the same amount of attention.

"I think it has got better due to Covid. Workplaces offering wills like they do pensions."

"With this pandemic death has been so much of everyday life for so long I think at the moment it's not something people want to talk about"

"It seems a bit taboo, unless it's Covid related no one in the media is interested."



Philip Hardman/Marie Curie

Across the UK, survey respondents who had experienced the death of loved ones reflected on the difficulties and suffering of this time. For people who had been bereaved in Wales, respondents shared how the pandemic and the lockdown restrictions in place to control the spread of Covid-19 had resulted in end of life preferences not being met, prevented loved ones from saying goodbye, and impacted on the quality of care that hospitals could provide.

"I cared for my partner for ten years [...]. He was very ill the last two years and we discussed end of life, he had a DNR in place and he wanted to die at home. Sadly he had to go to hospital during the lockdown and died alone there as I wasn't allowed to be with him due to covid restrictions. It's difficult to live with now knowing that and I don't get a second chance. But I think under normal circumstances it's important to discuss these things as I did."

"My husband died last year; Covid meant that he did not get the best care [in hospital] but he was able to die at home as he wished. The palliative care he received was wonderful, and made his last week's much easier."

While Covid-19 has clearly increased and normalised talking about death and dying, which participants viewed positively, it has also enhanced the suffering surrounding death and dying. Participants reported the difficulties and hardship of watching loved ones die from a distance due to Covid-19 restrictions, and the fears and worries about death and dying that these challenges have caused.



Layton Thompson/Marie Curie

6. Discussion and conclusion

With the number of dying people set to increase, and continued pressures on health and social care services, these survey findings offer a unique opportunity to support the public discourse on dying, death and bereavement and inform the ongoing development of services for people at the end of life in a way that reflects people's needs and expectations.

We need to see three principal changes to improve end of life care for the future. Firstly, end of life care should be as much of a policy priority as care and support at any other phase of people's lives; secondly, we need a better public discourse about dying, death and bereavement; and finally, there must be closer listening to people about their own preferences for their end of life care.

1 We need to treat end of life care as just as much of a priority as care and support at any other phase of people's life

The vast majority of respondents (79%) believe that end of life care is of equal importance to any other NHS provision, and yet it is not wholly funded by the NHS and is not available to all. Phase two of the End of Life Care Programme review of funding of specialist palliative care in Wales should take into consideration historic funding models and ensure services across all settings are fit for meeting the demands of increased need for palliative care in the future. The survey findings show only half of the population are confident that there are adequate health and social care services to meet the needs of people at the end of life in Wales.

A significant proportion of end of life care services across communities in Wales rely on charitable fundraising – and the impact of the pandemic on charity income brings into sharp relief the precarity of this situation.

Over a third (35%) of bereaved carers disagreed that adequate end of life care services are available. This was a substantially higher level of disagreement than for other groups, which highlights the need for incorporating experiential knowledge into service development. One way of doing this would be to introduce a national survey of bereaved people in Wales to give policymakers and healthcare professionals a better understanding of the experiences of people at the end of their lives and those close to them. The survey design should allow us to understand the experiences of people with different characteristics and backgrounds.

It is positive that over three-quarters of people believe that people at the end of life are treated with dignity and respect, but there is far less confidence in the capability of services to meet people's cultural, spiritual or religious needs. This suggests more work is needed to ensure that services reflect the diversity of the Welsh population.

2 We need a better public discourse around dying, death and bereavement

The results highlight the longstanding issues around communication and the language surrounding death and dying. A general lack of awareness of key terminology obstructs individuals' ability to engage in effective planning around end of life. Only 16% of respondents reported having created a plan expressing their priorities and preferences for the end of their life, although 92% of people consider it important.



35%
Over a third of bereaved carers disagreed that adequate end of life care services are available.

We often assume that dying is a “taboo” topic which people are uncomfortable discussing. The results of this survey challenge this – finding that most people report being ‘comfortable’ discussing issues related to dying. However, the results also show a huge gap between the proportion of people who say they are in principle comfortable to discuss death and dying, and the proportion of people who have actually done so. This may indicate the need for more holistic consideration of why people haven’t had conversations about dying, rather than assuming that this is simply because they are uncomfortable doing so. As one respondent said: ‘It’s very hard to engage with, and I don’t know how or where I would express those preferences.’

The results of the survey also highlight a likely related problem around understanding of end of life care terminology, with 29% of people unfamiliar with palliative and hospice care, 75% unfamiliar with Advance Care Plans, and 86% unfamiliar with Advance Directives. Many of these terms are in common use within health care working environments but are not well understood by patients and families¹⁷ thereby excluding the people to whom open conversations are most important.

NHS Wales is in a key position to tackle these barriers to understanding and engagement in end of life care planning. In recent years, strategic thinking and research on Future Care Planning has endorsed an approach centred on offering individuals different planning formats to suit them, as well investing in education and awareness, and encouraging explanation and shared understanding of these poorly understood services and procedures.¹⁸ Experts have recommended a centralised electronic repository for the various forms and guidance documents available. Making this available both to healthcare providers and patients could

help activate patients to fill in their own documents, and ensure these are readily accessible within NHS Wales systems.

The legacy of the pandemic may also usher in change. Respondents noted that the pandemic has increased the likelihood of people facing sudden and unexpected deaths, showing the importance of discussing end of life needs and wishes in advance. Some respondents thought that Covid-19 had been a catalyst for these conversations. Sadly, others described their difficulty and suffering when forced to be distant from dying relatives.

3 We need to listen more closely to people about their own end of life preferences and recognise that these will differ from person to person and may change over time

The findings are an important reminder that we need to listen to people about their own preferences for end of life care, and not make assumptions. Most importantly, we must recognise these will vary from person to person, and may change for an individual over time, particularly as they approach the point of death.

For example, many quality indicators for services are based on place of death with the preferred option of home. However, the survey results challenge the assumptions that have sometimes been made about patient needs, and preferences. Caring for people at home at the end of life often brings its own challenges – it may not meet the need for rapid pain control, access to equipment or trained carers¹⁹, and can bring disruption to the home environment²⁰, whilst laying the burden of caring on family members, many of whom are elderly



29%
Of people are unfamiliar with the terms "palliative" and "hospice care"

Many survey respondents feared becoming helpless and dependent, and suffering pain above all else, which may become more likely with disease progression and complex clinical needs²². These issues, and others, may be difficult to mitigate in the home setting with the added problem of unprepared carers, although there are ongoing initiatives to better understand and support carers²³.

The survey results also indicate a strong preference for many people for quality of life over survival. This is significant in terms of indicating widespread support for the goals of palliative care, and challenges the provision of treatments at end of life which prioritise longevity over quality of life²⁴. However, one of the consequences of not discussing terminal prognosis and patient priorities can be excess treatment and unfulfilled needs²⁵, even though most respondents say they are comfortable with these difficult conversations.

6. Conclusion

Overall, the results of this survey demonstrate a range of broad, societally entrenched issues that require policy change and a public health approach. Some of these, such as peoples' preferences for end of life care including place of death, challenge the way our services are currently set up and should be further interrogated. Others, such as the clear gap between intention and completion in Advance and Future Care Planning require the community to come together to deliver direct action.

Respondents' preferences for quality of life over survival is another important topic. Previous research has shown that too often patients' priorities and preferences are not taken into account when medicine's primary focus is on clinical management at the expense of patient-centred care²⁶. The result is often avoidable harm from

treatment toxicities and a misunderstanding by patients as to both the intention of treatment, and their terminal diagnosis. Suffering pain is the top fear of respondents so minimising needless side effects is important, as is recognising the role that specialist palliative care professionals have in managing symptoms that are routinely experienced by those who are dying.

As ever, we should be mindful that perspectives may change as disease progresses and levels of need increase. Those who identified as being in their last few years of life, or as caring for someone with terminal illness, had different perspectives to the general population. Some of the results reinforce historical issues that are yet to be resolved, such as the barriers caused by palliative care and end of life terminology that may only be understood through direct experience. This is a language that needs to be understood by everyone, no matter what their age or life circumstances. and will only become normalised as people become used to talking about and planning for death.



Ben Gold/Marie Curie

Marie Curie's policy recommendations for meeting these challenges are listed in full at the front of this document. In summary:

1 We need to treat end of life care as just as much of a priority as care and support at any other phase of people's life

- Ensure that timely implementation and effective oversight arrangements are put in place around the new End of Life Delivery Programme for Wales.
- Introduce a national survey of bereaved people so their experiences inform future end of life care policy and strategies.

2 We need a better public discourse around dying, death and bereavement

- Adopt a public health approach to encourage more open conversations about death and dying across the whole population.
- End of life services should meet the needs of the whole population.

3 We need to listen more closely to people about their preferences for

- Outcome measures for end of life care services should reflect what matters most to patients and their families.
- Ensure that NICE Quality Standards (QS13) in relation to End of Life Care and advance and future care planning are delivered.
- Develop and roll out bespoke digital tools to support Advance and Future Care Planning.
- Further research is needed into several areas related to our survey findings.



Layton Thompson/Marie Curie

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