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This response was submitted to the [Health and Social Care Committee](#) consultation on [mental health inequalities](#)

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Ymateb gan: | Response from: Marie Curie

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Health and Social Care Committee: Inquiry into mental health inequalities

Response on behalf of Marie Curie Cymru, February 2022
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Response does not need to be kept confidential.

About Marie Curie

Marie Curie is the UK's palliative and end of life care charity. We work hard to enable people who are dying, and their loved ones and carers, to have the best possible experience at end of life. We offer expert care across Wales, in people's communities, in their own homes, and in our Cardiff & the Vale Hospice. Our free information and support service, based in Pontypool but operating across the UK, also gives guidance and support to families with any matters relating to dying, death and bereavement.

We are the largest charitable funder of palliative and end of life care research in the UK. Our Wales Policy and Research team work inside and outside of the Senedd to encourage and influence the changes that are needed to ensure more people in Wales have the best possible end of life experience.

Introduction

We welcome the opportunity to respond to this Health and Social Care Committee inquiry into mental health inequalities. This response is founded on the evidenced link between mental health challenges and a terminal illness diagnosis, and the mental health related impacts of caring for someone at the end of their life, including bereavement. **Please see the end of this document for 5 recommendations that the Health and Social Care Committee should consider going forward.**

To ensure that Wales becomes the world's first Compassionate Country, as pledged in the Compassionate Cymru charter in 2018, we must ensure that those at the end of their life and their loved ones receive appropriate mental health care and support. This must include bereavement support being seen in parity with mental health support.

We welcome Welsh Government's recent decision to move bereavement into Deputy Minister Lynne Neagle's mental health portfolio and hope to see this translate into bereavement being given the focus and priority it deserves. We were also delighted to see the publication of the National Framework for Bereavement Services in October 2021 and look forward to our continued engagement with the bereavement steering group to ensure that the framework is implemented in practice.

Mental health challenges while living with a terminal illness

We know that those diagnosed with a terminal illness are at an increased risk of mental health challenges – whether their diagnosis is the primary cause, or whether existing mental health issues are exacerbated by their diagnosis. Anxiety and depression levels are high among those diagnosed with a terminal illness; according to one study, the likelihood of

major depression in certain groups of people who are terminally ill could be as high as 77%[1]. Anxiety and stress due to uncertainty around the future and feelings of hopelessness is not uncommon. Often, we see people withdrawing from society or their usual lifestyles, whether a result of physical symptoms or reasons associated with mental health.

Mental health challenges in addition to challenges associated with a terminal illness not only impact individuals and their quality of life, when they should be making the most of their time left, but it also increases reliance on health and care systems which could otherwise be avoided with appropriate and person-centred mental health support.

Loneliness at end of life

Marie Curie in Northern Ireland has recently published a report focusing on loneliness and terminal illness, the first report of its kind[2]. Although the links between loneliness and worsened mental and physical health are well evidenced, there is a severe lack of research when it comes to the impact of loneliness on someone's end of life experience.

Although the report is focused on Northern Ireland, many lessons can be learnt from these recent findings. For instance, loneliness and isolation not only has a significant impact on mental health, but physical symptoms at end of life too. Marie Curie colleagues find that people who are diagnosed with a terminal illness can become more withdrawn and lose interest in self-care, and even life, which creates an enormous burden on psychological wellbeing and physical symptoms. Some studies have evidenced loneliness as a risk factor for increased pain in certain groups of people with terminal illness, including cancer patients[3] and those with COPD[4]. Furthermore, some groups are more at risk of suffering from loneliness, including those over 75 years, women, and those living in more deprived areas[5]. People with conditions that may lead to neurological decline can also be adversely affected. For example, people with dementia may be unable to take part in social activities and feel misunderstood[6].

As previously mentioned, mental health effects of living with a terminal illness can also increase reliance on health and social care systems. One estimate on the monetary impact of severe loneliness in the UK is £9,530 per person per year[7].

Mental health while supporting someone at the end of their life

Those caring for someone at the end of their life frequently raise worries about their mental health. Ensuring carers receive support during this time is vital and if it is not received, a carer may risk falling into crisis[8]. Carers Wales found that in 2021, 30% of carers in Wales categorise their mental health as bad or very bad, and only 25% define their mental health

[1] Fine, R.L., 2001. Depression, anxiety and delirium in the terminally ill patient. *Baylor University Medical Center Proceedings*, 21 (2).

[2] Marie Curie, 2021. Experiences of loneliness among people at the end of life and their carers in Northern Ireland.

[3] Jaremka, L M et al., 2014. Pain, depression and fatigue: Loneliness as a longitudinal risk factor. *Health Psychology*, 33 (9).

[4] Marty, P K et al., 2019. Loneliness and ED visits in chronic obstructive pulmonary disease. *Mayo Clinical Proceedings: Innovations, Quality & Outcomes*, 3 (3).

[5] Marie Curie, 2021. Experiences of loneliness among people at the end of life and their carers in Northern Ireland.

[6] Ibid.

[7] Campaign to End Loneliness, 2020. The psychology of loneliness: Why it matters and what we can do.

[8] Sue Ryder and Marie Curie, 2020. *Life After Death: supporting carers after bereavement.*

as good or very good[9]. Unsurprisingly, over two-thirds of carers in Wales (69%) reported that their mental health had worsened over the pandemic[10].

For people who are caring for loved ones at end of life, the journey can often be unpredictable, with strong possibilities of someone deteriorating more rapidly than initially expected. People with dementia for example, can have a complicated and unpredictable end of life experience. There are some symptoms of dementia that may suggest a person is approaching their final weeks or days, but in other instances, someone can live with these symptoms for months[11].

People with a terminal illness may also need to be admitted to a care home, hospital or hospice as their condition deteriorates. Their carer may experience a feeling of loss of identity and even a sense of bereavement as their role of supporting their loved one had previously been all-encompassing. End of life carers also know there is a finite period for their caring role, even if they do not know how long that will be. Many primary carers are still of working age and their instinct can lead them to give up employment to focus on caring. This increases the caring pressure, increases financial pressure and adds additional burden when caring comes to an end and they need to seek employment.

Carers often prioritise looking after their loved one, over their own physical and mental wellbeing. Carers can be reluctant in accepting or asking for support and/or respite for a variety of reasons, including fear the person will die while they are absent and a belief that they have a duty to care. It also not uncommon for carers to feel a sense of guilt when accepting support or respite. All of these factors and lack of support for carers - whether practical support or emotional support - leads to exhaustion of the carer and worsened mental health.

In addition to many carers finding it difficult to accept help and support, respite opportunities have become even rarer during the pandemic, with support services closed or scaled back. Psychological support, support groups and respite services have all been affected – for instance, Marie Curie's face to face Carers Café which offered informal emotional support to carers has been suspended for the time being. We know that carers are almost seven times more likely to suffer from loneliness[12] and this emotional support is vital for sustained mental health and wellbeing, and ultimately people's ability to continue as a carer. Therefore, sustaining carers' mental health not only has a positive impact on the carer and the loved one, but also allows more people to stay out of hospitals and care homes when this is safe and preferred by those involved.

Bereavement

A recent survey found that more than half of bereaved people experience high or severe vulnerability in their grief[13]. The following section provides evidence on the mental health impact of bereavement and inequalities that exist within this group regarding access to support. It is largely drawn from our recent *UK Commission for Bereavement (UKCB): Wales Stakeholder Event,* held on 9 December 2021. There were approximately 45 attendees at

[9] Carers Wales, 2021. State of Caring Report.
[10] Carers Wales, 2021. State of Caring Report.
[11] Marie Curie. *Caring for someone with dementia at end of life* [Online]. Available from: https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/dementia [Accessed 22 December 2020].
[12] Carers UK, 2019. Getting Carers Connected.
[13] Marie Curie, 2021. New research shows UK faces post-pandemic bereavement crisis and lasting legacy of grief [Online. Available at: New research shows UK faces post-pandemic bereavement crisis and lasti (mariecurie.org.uk) [Accessed 23 February 2022].

the event, ranging from health and social care professionals, bereavement support workers, funeral directors, third sector colleagues, and individuals attending in a personal capacity. The event sought to explore the following themes in detail: public attitude towards death, dying and bereavement, practical matters after a death, accessing bereavement support, inclusivity and diversity of bereavement support, and impact of the pandemic. Discussion was not limited to these themes and attendees were encouraged to raise any topics they felt had been missed. The full report on the event can be found here and these findings from Wales will inform a UK-wide report published by the UK Commission for Bereavement in September 2022.

Who is at disproportionate risk?

At the UKCB Wales event, attendees highlighted some specific communities and groups of people who appear to be excluded, at a disadvantage, or unable to access appropriate bereavement support. The groups discussed below is by no means an exhaustive list and there will be other communities and groups in Wales that are facing challenges when accessing the support that they need when it comes to bereavement. More research and understanding of this are necessary to achieve a truly equitable bereavement framework in Wales.

Excluded groups that were discussed in breakout rooms include ethnically diverse communities, people who are neurodiverse, people with learning disabilities and the LGBTQ+ community. The specific needs of carers, older single women, and the challenges facing people who live in rural areas were also raised. Lastly, those who live in more deprived areas and face socio-economic related issues were mentioned.

In discussing how we make our bereavement support offers more suitable and more accessible for more people, conversation focused on the need to avoid pursuing a one-size-fits-all approach and to focus instead on a needs-based approach. Proactive effort needs to be made to reach seldom-heard groups or groups that perhaps do not relate or identify with the support currently being offered. We need to be focusing on supporting people on a case-by-case basis, in a way which suits the individual.

Black, Asian and minority ethnic communities

Black, Asian and minority ethnic communities may be put off by the secular nature of bereavement support in the UK, which fails to reflect certain religious or cultural norms. The traditions and rituals around death for some communities are important and the support we offer needs to consider this. Ensuring a body can return to its home country was cited as an example here. Faith leaders who are already trusted and respected in their communities could help ensure that the bereavement support we offer meets multi-cultural needs and is welcoming to all.

People with learning disabilities

People with learning disabilities and those who find it more difficult to process language, such as people who are neurodiverse, may need specific and direct interventions. Currently, attendees noted that these groups are not referred to further bereavement support because there is a misconception that they will not benefit from standard services. Concern was also expressed with regards to the expansion of support provided online and how this may not be effective or welcomed by people with learning disabilities or those who are neurodiverse.

Unpaid carers

Unpaid carers have more specific needs than most when it comes to bereavement. They may need additional help preparing for practical matters after death, particularly in relation to finances when it comes to Carer's Allowance and entitlement to bereavement leave. These conversations should be a part of any bereavement support they receive pre- and post-death.

Older people

Covid-19 has deepened existing inequalities when it comes to older carers as older people have been disproportionately affected by Covid-19 deaths. The close link between loneliness and isolation and their impact on the bereavement process were also highlighted here.

People living in rural areas

The challenges associated with rurality are common in Wales due to the sparse layout of the country in some areas. Unfortunately, many attendees noted the lack of support services in north and west Wales, particularly with regards to more holistic support that is delivered outside of hospitals. As there is not the same coverage of support in communities, healthcare professionals and providers are unsure where to signpost individuals for further support. This is complicated further by huge waiting lists for the few services that are in place. The importance of capitalising on community infrastructure and local support networks were raised when it comes to rurality.

Child bereavement

Bereavement scoping review by MCPCRC 2019 found that there are inequities in the type of death, with more services available for adult death, and low service provision for pregnancy loss and stillbirth

Impact of the pandemic: Study on bereavement through the pandemic by Marie Curie Palliative Care Research Centre

A national study of bereavement during Covid-19 across the UK is underway, including a survey investigating grief experiences, support needs and use of bereavement support by people bereaved during the pandemic[14]. This has evidenced the exceptionally difficult sets of experiences associated with bereavement during the pandemic, and the high level of disruption to end of life care and support, death and mourning practices, and social support networks.

The survey findings show the devastating effects the pandemic has had on end of life interactions, with 93% of participants reporting restricted funerals, and 64% reporting that they were unable to say goodbye how they would have liked. Deaths in hospitals and care homes increased the likelihood of a person being unable to visit a loved one prior to their death to say goodbye.

Experiences of end of life care and early bereavement support varied widely. While 22% of participants said they were always involved in decisions about the care of their loved one, another 22% said they were never involved, and 18% had not been informed at all about their loved one's approaching death. More than a third of participants felt 'not at all' supported by professionals immediately after the death, demonstrating the strain which the

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[14] Of more than 700 participants, over half were bereaved following the death of a parent, the majority of deaths occurred in hospital, and nearly in four in ten of those who died had Covid-19 as their confirmed cause of death. Men and people from ethnic minority backgrounds were under-represented in the survey participants. First publications available at www.covidbereavement.com.

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health system was under in the early months of the pandemic. Communication problems were widely reported, including difficulty getting information about family members and being misinformed about their condition or hospital policies.

There were positive examples of compassion and kindness, being able to visit, and feeling well informed. Deaths that occurred in hospices or at home and deaths that were expected increased the likelihood of the bereaved person being involved in care decisions and feeling well supported by healthcare professionals after the death. However, compared with all other types of deaths, bereavement due to Covid-19 decreased the likelihood of being involved in decisions and feeling well supported, while increasing the likelihood of being unable to say goodbye.

These experiences had a strong emotional and psychological impact on bereaved people, often resulting in distress, guilt, unanswered questions, and regret. The inability to grieve collectively or find respite in usual social activities due to lockdown restrictions and fear of contagion exacerbated this. As a result, 60% of participants had high or fairly high needs for help to deal with their feelings about the way their loved one died, and about half had high or fairly high needs for help with loneliness and social isolation. This isolation was particularly prevalent among those bereaved by Covid-19 and bereaved partners.

Most people were supported by friends and family, though one in five felt uncomfortable asking for this support, and many experienced challenges talking openly about their feelings over the phone. Problems relating to workplaces were commonly described. These included perceived insensitivity from managers and colleagues, and a disinclination to take leave from work at a time of financial uncertainty. While those who were home-working or furloughed experienced isolation, frontline workers faced difficulties managing their grief alongside high pressured public-facing roles. Parent participants described a lack of time and space to grieve amidst lockdowns and school closures, though most children seemed to be coping well with family-based support, with schools and teachers often providing an additional valued source of support. About a quarter of parents who felt their children needed additional bereavement or mental health support reported barriers to accessing this, including a lack of availability, delays, and preferences for face-to-face treatment.

Three quarters of survey respondents with high emotional support needs or vulnerability were not accessing bereavement counselling or mental health support. Of those who had tried to access services, half experienced difficulties. Those bereaved in non-hospice settings were less likely to be given information about how to access services, suggesting a missed opportunity in other settings for providing this sort of information.

The researchers have made a series of recommendations based on these findings to inform the planning of end of life care and bereavement services into the future:

- Improve communication with families at the end of life, enabling contact with patients as far as possible and better support after a death
- Increase resourcing, provision and tailoring of services to meet the diverse needs and backgrounds of bereaved people
- Raise awareness and understanding of bereavement support options, with information provided proactively online and in community settings, and GPs better resourced to signpost to appropriate support
- Expand provision of informal community-based support to help with high levels of loneliness and social isolation, including longer-term educational and social initiatives

Recommendations for the Health and Social Care Committee to consider

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RECOMMENDATION 1: Welsh Government must continue to consider bereavement as part of the wider mental health agenda.

RECOMMENDATION 2: Discussion of emotional and psychological support must be a part of advanced and future care planning (AFCP) discussions, both for the patients and loved ones. This includes ensuring that any AFCP tools that are used includes prompts for these conversations.

RECOMMENDATION 3: Healthcare professionals and allied healthcare professionals should be offered adequate training with regards to spotting the signs of poor mental health and psychological/emotional support needs (in both patients and loved ones), as well as knowing where to signpost people for further support.

RECOMMENDATION 4: Bereavement support must be person-centred to ensure everyone gets the support they need. In order for everyone to feel that they can access support, no matter their ethnicity, their background, whether they have a disability, or any other protected characteristics, we need to ensure that the help that's available can be tailored and personalised to suit everyone's needs.

RECOMMENDATION 5: Creating compassionate communities, increasing societal discussion around mental health, and acknowledging bereavement as a mental health challenge, must be a part of our strategy to eliminate mental health inequalities. Raising awareness of the challenges that can be faced and where to access support is vital.