Marie Curie Briefing

Scottish Labour Debate – Mental Health



Photograph by Margaret Mitchell

Donna's story

Donna, 56, has experienced multiple hardships throughout her life, financial insecurity being just one. She is a single parent with caring responsibilities. She has experienced a series of bereavements over the last decade, including the sudden death of her son:

> **"I don't think I could be hurt any more than I have been hurt."**

Donna lives with multiple chronic conditions, some of which, like COPD, she has had for many years, while others are new. Together, her conditions cause her a lot of pain and breathlessness and she has low energy;

> **"I struggle to leave the house, to get dressed."**

Because she is housebound much of the time, she struggles with isolation:

> **"I feel like a prisoner in my home. I really feel like that. Nobody to go and see, I just need to sit here, basically."**

Donna's story is part of **Dying in the Margins,** a research study by University of Glasgow and Marie Curie which examines barriers to, and experiences of, dying at home for terminally ill people, their families and carers living with financial hardship and deprivation, including mental health. **Donna experiences multiple, cross-cutting issues which impact her mental (and physical) health as a result of dying, death and bereavement**, including isolation and loneliness and bereavement, but services are disjointed meaning she does not get all of the support she needs.

Mental health and dying, death and bereavement – key issues

Psychological and spiritual support is an essential part of the palliative care people affected by dying, death and bereavement receive, yet for many mental health needs are under identified and undertreated.

Key issues which impact the mental health of people affected by dying, death and bereavement:

1. **People diagnosed with a terminal illness are at increased risk of mental health challenges**, **yet their needs are under-identified and treated** leading to poorer quality of life, and increased pressure on health and social care systems

2. **Social isolation and loneliness impact mental health *and* physical symptoms at the end of life**. However, loneliness and end of life remains an area which is significantly under-researched

3. **Carers of terminally ill people experience poor mental health both during their caring role and after the cared for person has died** as a result of the physical, emotional and financial burden of caring

4. **Financial concerns are a continual worry for people affected by terminal illness**, the double burden of income loss and increased expenditure brought on by a terminal illness, such as higher energy bills and home adaptions, leave people struggling to make ends meet, and force those who were already on the threshold below the poverty line having a significant impact on mental health

5. **Grief is a significant contributor towards a person's mental state and wellbeing**, and can start even before a person has died, as well as following their death

Marie Curie is calling for Scottish Government to:

1. **Embed mental health and bereavement support for people affected by dying, death and bereavement, which must synergise across Government directorates and strategies:**
   - **Palliative Care Strategy**
   - **Mental Health and Wellbeing Strategy**
   - **National Care Service**

2. **Deliver mental health support as part of sustained investment for palliative care, especially in community settings**

3. **Facilitate more open conversations about dying, death and bereavement to support positive physical and mental wellbeing**

Under-identification and under-treatment of mental health challenges in people affected by terminal illness

There is substantial evidence that **psychosocial suffering is under identified and under treated in palliative care patients, despite psychiatric disorders and psychological symptoms being extremely common** amongst people receiving palliative care support[1].

This may be because of under-recognition of mental health needs, a belief that mental health issues are expected in palliative care patients and subsequently minimised, a lack of mental health assessment guidelines in palliative care and a lack of psychologists and psychiatrists in palliative care teams[2].

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

[1] O'Malley, K et al *Mental Healthcare and palliative care barriers;* BMJ Journals
[2] O'Malley, K et al *Mental Healthcare and palliative care barriers;* BMJ Journals

diagnosis. Terminal illness can exacerbate existing mental health conditions or illnesses, or generate a new diagnosis:

> **People living with a mental health condition or illness usually have a 15-20 year shorter life expectancy, and are more likely to develop terminal and chronic Illnesses, as well as being at higher risk of co-morbidities[3],[4].**
>
> **Anxiety and depression levels are high among those diagnosed with a terminal illness with the likelihood of major depression in certain groups of people who are terminally ill could be as high as 77%[5].**

Anxiety and stress due to uncertainty around the future and feelings of hopelessness are common. Often, people withdraw from society or their usual lifestyles, whether a result of physical symptoms or reasons associated with mental health.

Donna's story also highlights that people affected by terminal illness face significant barriers to accessing the mental health and bereavement support they need because social determinants of health, including social security, housing, and health and social care (including palliative care).

> **Mental health challenges, in addition to challenges associated with a terminal illness, not only impact individuals and their quality of life, but it also increases reliance on health and care systems which could be avoided with appropriate community mental health and bereavement support.**

People with advanced progressive illness, including terminal illness, are also likely to develop psychological co-morbidities, such as fear of dying, being a burden to others, and existential distress[6].

Acceptance and Commitment Therapy (ACT) is a mindfulness-based behavioural therapy aimed at improving wellbeing and promoting values-based living and acceptance of their condition or illness, also helping terminally ill people cope with a range of challenges brought on by their illness.

There is evidence for its effectiveness for people with a range of psychiatric disorders and health problems, and evidence in palliative care settings is emerging[7],[8].

> **Such preliminary evidence suggests that ACT can improve anxiety, depression, sleep, physical symptoms and quality of life for people with advanced progressive illness; and is beneficial for caregivers and health and social care professionals[9],[10].**

The impact of social isolation and loneliness on the mental and physical health of people experiencing dying, death and bereavement

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 end of life experience. A recent Marie Curie report found loneliness and isolation has a significant impact on mental health, but also physical symptoms at end of life:

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[3] Hinricks, K et al *Help me understand; providing palliative care to individuals with serious mental illness* SAGE Journals
[4] St John's Hospice, The Importance of Mental Health in Palliative Care
[5] Fine, R.L., 2001. Depression, anxiety and delirium in the terminally ill patient. *Baylor University Medical Center Proceedings*, 21 (2).
[6] Gibson-Watt, T, Gillanders, D, Spiller, J, Finucane, A *Acceptance and commitment therapy (ACT) for people with palliative care needs, their caregivers and staff involved in their care: a systematic scoping review* BMJ Palliative Care
[7] Gibson-Watt, T, Gillanders, D, Spiller, J, Finucane, A *Acceptance and commitment therapy (ACT) for people with palliative care needs, their caregivers and staff involved in their care: a systematic scoping review* BMJ Palliative Care
[8] Davis, E et al *Is higher acceptance associated with less anticipatory grief among patients in palliative care?* Journal of Pain and Symptom Management
[9] Gibson-Watt, T, Gillanders, D, Spiller, J, Finucane, A *Acceptance and commitment therapy (ACT) for people with palliative care needs, their caregivers and staff involved in their care: a systematic scoping review* BMJ Palliative Care
[10] Davis, E et al *Is higher acceptance associated with less anticipatory grief among patients in palliative care?* Journal of Pain and Symptom Management

"Particularly during the pandemic, there's been an increasingly worrying impact on people's wellbeing, including social isolation, feelings of being overwhelmed, loneliness and increasing anxiety around diagnosis and prognosis. All of these factors greatly impact on the overall condition of our palliative patients and their loved ones."

Marie Curie Nurse

Some research has evidenced loneliness as a risk factor for increased pain in certain groups of people with terminal illness, including cancer patients[11] and those with COPD,[12] like Donna.

There are also more vulnerable groups at risk of suffering from loneliness, including those over 75 years, women, and those living in areas of deprivation (as highlighted by Donna's story for Dying in the Margins)[13].

Carers of terminally ill people are also at significant risk of experiencing poor mental health while both during their caring role and after the cared-person has died:

> **Carers are almost seven times more likely to suffer from loneliness[14]; emotional support is vital for sustained mental health and wellbeing, and ultimately people's ability to continue as a carer**.
>
> **Sustaining carers' mental health not only has a positive impact on the carer and the cared for person, but also helps relieve pressures on the health and social care system but supporting terminally ill people to remain at home.**

The impact of grief and bereavement on mental health

> **"I suffered PTSD and a breakdown had to change my job because I couldn't cope"** – woman in her 50s whose husband died of a brain clot (evidence given to the Commission on Bereavement)
>
> **"Family zero. Friends zero. Community zero. Pretty much left to it with disabled children to manage"** – man aged between 40-50 whose wife died (evidence given to the Commission on Bereavement)

Grief is a significant contributor towards a person's mental state and wellbeing, and can start even before a person has died, as well as following their death. Bereavement can be an exceptionally isolating and lonely experience. Where available, support from family, friends and communities can play a critical role in providing comfort and connection through grief.

Marie Curie is a supporting partner of the Commission on Bereavement, an independent Commission established examine bereavement support needs across the UK, both now and in the future. In Scotland, the Commission found that in 2020 and 2021:

- 130,000 people died causing an estimated 650,000 bereavements. This was an additional 64,000 bereavements compared to what would have been predicted based on a five year average 2015-19

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

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

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

[14] Carers UK, 2019. Getting Carers Connected.

- Over a quarter (28%) of adult respondents to the Commission's consultation received no support from family and almost half (46%) received no support from friends following bereavement
- 40% of adult respondents who wanted formal bereavement support did not receive it

The pandemic has not only exacerbated existing challenges around bereavement and complicated grief, it has also demonstrated the need to consider how well services are equipped to support people through a bereavement, and/or wider mental health challenges.

Marie Curie research has projected that by 2040, 10,000 more people will be dying with palliative care needs, meaning a significant increase in the need for mental health and bereavement support. Government must act now to equip services with the resources they need.

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2. **Deliver mental health support as part of sustained investment for palliative care, especially in community settings**

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About Marie Curie in Scotland

Marie Curie is here for people living with any terminal illness, their families and carers. We offer expert care and guidance through our two **Hospices** in Edinburgh and Glasgow, and **Marie Curie Nursing Service** in 31 out of 32 Local Authorities.

Our **volunteer-led Helper service** provides companionship and support to those affected by terminal illness and has a presence across all 32 Local Authorities, as well as our **Information and Support lines**, including dedicated bereavement line, which provide emotional support and practical and clinical information about terminal illness. Marie Curie is also the biggest charitable funder of **palliative care research** across the UK.

In 2021-22, Marie Curie Scotland cared for 8,660 people at the end of life. With more and more people dying in the community throughout the pandemic, demand for our community nursing services has remained extremely high.

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Marie Curie
Care and support through terminal illness