

Marie Curie briefing

Mental health and terminal illness

For many people living with a terminal illness their mental health issues can be very apparent but can often go untreated and unsupported.

People can often develop mental health issues as a result of their terminal illness diagnosis, but there are also people with severe mental health conditions who are approaching the end of life who are not getting the care they need.

Carers for people living with a terminal illness can be in a very vulnerable position and highly exposed to psychological distress, both during caregiving and following the death of a loved one, which can go unsupported.

Mental health issues arising from a terminal illness diagnosis

For people living with terminal illness depression can occur anytime such as following diagnosis, as their disease advances and pain increases, or as their independence becomes more limited. It is more likely if a person experiences more symptoms of their disease, such as swallowing difficulties, sickness or bladder and bowel problems.

At Marie Curie many people we support experience anxiety which can lead to varied reactions such as insomnia, restlessness, being agitated, sweating, heart palpitations, panic, worry and tension. The fear of dying itself often creates anxiety and can lead to other mental health issues. Left unsupported this can have serious implications. Not only causing a detrimental impact on the quality of life a person has before they die, it can also see their condition worsen.

People with mental health conditions approaching the end of life

It is vital to consider how palliative care might support someone approaching the end of life with severe mental health conditions such as schizophrenia, bi-polar disorder or clinical depression. This could be their main condition or alongside another physical condition.

There is a lack of data available to show how many people with severe mental health issues need palliative care. However, we know that people with severe mental disorders tend to die earlier on average than the general population. The majority of these deaths are due to chronic physical medical conditions such as cardiovascular, respiratory and infectious diseases. Existing psychiatric symptoms can be made worse by a physical illness.

Die Well: Priorities for a new Mental Health Strategy

Marie Curie welcomes the Scottish Government commitment to a new ten year mental health strategy. However there are a number of issues associated with mental health and support toward the end of life that need to be addressed in this strategy, which we believe are not currently covered in the draft framework.

We strongly believe that there should be 4 stages within the new mental health strategy: Start Well, Live Well, Age Well and **Die Well**. The strategy needs to ensure that people at the end of life, or living with a terminal illness, are able to access support for mental health problems to support them to die well. There should also be additional support for their families and carers through the

course of their condition and bereavement support. We believe the Scottish Government should add this final stage to the mental health strategy.

The new mental health strategy must consider the support needed for everyone living and importantly, dying, with mental health issues. It is absolutely vital that everyone living with a terminal illness and at end of life have as good a quality of life as possible in the time that they have left. The only way to get this right is by ensuring we properly support their mental health, as well as their physical health.

Recommendations

We believe a Die Well life stage should be added to the mental health strategy to fully address the mental health needs of people approaching the end of life. This should include:

- Support for families and carers of people with a terminal illness or at the end of life through the course of their condition and support during bereavement.
- Include mental health, death, dying and bereavement in the National Curriculum of Excellence, alongside support for teachers to deliver lessons on this in primary and secondary care.
- Links with the new national coordinator of childhood bereavement services.
- Public health approaches to help educate and support the public about mental health issues of people who are living with a terminal illness, and at the end of life.
- Support more research to show how many people with severe mental health issues need palliative care, and how mental health needs are supported for people who are diagnosed with a terminal illness.
- Raise awareness of palliative care and anticipatory care planning skills across the mental health workforce.
- Develop strong links between specialist mental health teams and other community services.
- Include mental health and palliative care, including end of life care and bereavement training, as a standard, mandatory part of education across all health and social care staff – including work to support staff to have difficult and sensitive conversations.
- Include mental health and palliative care, including end of life care and bereavement training as a core part of university curriculums for caring professions and as a core part of continuing professional development.
- Links to the Strategic Framework for Action on Palliative and End of Life Care, proposed Public Health strategy and other Scottish Government strategies.

About Marie Curie

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our 4 volunteer led Helper services. We also provide nationwide support through our information and support service including our national helpline.

Last year we provided care for over 8,000 people living with a terminal illness, as well as their families and carers across Scotland. Our vision is for a better life for people and their families living with a terminal illness. We treat people with all terminal conditions, whether that is terminal cancer, dementia and frailty, MND, or heart failure. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

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