



Marie Curie briefing

Inequities in palliative care – Mental Health

Care and support
through terminal illness

11,000 people who need palliative care in Scotland each year are not accessing it. 1 in 4 people who die in Scotland miss out on the care they need. This isn't good enough and needs to change. We fully support the Scottish Government's Strategic Framework on Palliative and End of Life Care and the vision that everyone who needs palliative care has access to it by 2021.

Certain groups of people receive less palliative care than others with a comparable need. These are people who are over the age of 85, are from black, Asian and minority ethnic (BAME) backgrounds, identify as lesbian, gay, bisexual and transgender (LGBT), are from more deprived areas, are socially isolated or live alone, are homeless, have mental health needs, or are living in prisons.

Key points – Mental Health

- Four in five people who die need some sort of palliative care.
- More than one in three people are affected by a mental health problem in Scotland each year¹.
- Mental health issues can be very apparent for many people living with a terminal illness, but can often go untreated and unsupported.
- People can often develop mental health issues as a result of their terminal illness diagnosis. At least ten per cent of suicides in Britain are linked to terminal or chronic illness.
- There are many people with severe mental health conditions, such as bipolar affective disorder and schizophrenia approaching the end of life who are not getting the care they need. Nearly 500 people died in 2014 of a mental health or behavioural disorder (not including dementia or suicide).
- 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.

Evidence Base

There is very little research in Scotland, and the UK, 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. More than one in three people are affected by a mental health problem in Scotland each year². These aren't mutually exclusive categories. The effects aren't always quantifiable and people with mental health problems are often under or unreported.

¹ <http://www.bbc.co.uk/news/uk-scotland-35576995>

² <http://www.bbc.co.uk/news/uk-scotland-35576995>

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 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. It can even lead to suicide. According to research carried out by Demos, [at least ten per cent of suicides in Britain are linked to terminal or chronic illness](#)³ however, owing to underreporting this may be a lot higher. This could mean [up to 70 suicides in Scotland each year](#). There needs to be a range of support available. This can include access to psychiatrists and counsellors or other mental health practitioners, as well as support groups, and suitable medication to help with conditions such as depression or sleep deprivation.

It is also 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. [Nearly 500 people died in 2014 of a mental health or behavioural disorder \(not including dementia or suicide\).](#)

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.

A recent study in Dutch mental health facilities in 2016 found that only thirty-six percent of nurses had experience with providing palliative care to psychiatric patients with physical co-morbidities. It found that little attention for palliative care within mental health facilities was a problem and that the provision of palliative care for psychiatric patients needs to be improved⁴.

Marie Curie would like to see:

- a [Die Well](#) life stage added to the mental health strategy to fully address the mental health needs of people approaching the end of life.
- 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.
- better communication and understanding between palliative care and mental health teams, and wider education and training to support practitioners in palliative care and anticipatory care planning skills.
- More 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.

³ <https://prod.hsj.co.uk/chronic-illness-link-with-suicide-revealed/5034084.article>

⁴ <https://www.ncbi.nlm.nih.gov/pubmed/27530547>

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