



Care and support  
through terminal illness

# Marie Curie Response

## Mental Health Strategy in Scotland

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### Introduction

1. Marie Curie welcomes the opportunity to respond to the Scottish Government's call for views on the proposed framework and priorities to inform the transform the new mental health strategy in Scotland.
2. Marie Curie's vision is for a better life for people and their families living with a terminal illness. 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.
3. We care for over 8,000 people living with a terminal illness, as well as their families and carers across Scotland. We deliver this care through our hospices, community nursing services and support services. We treat people with all terminal conditions, whether that is terminal cancer, dementia and frailty, MND, or heart failure.
4. We welcome the 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.
5. We particularly want to highlight the need to look closer at how care is delivered for people with mental health issues arising from their terminal illness, and those with severe mental health conditions approaching the end of life.
6. Marie Curie strongly believes 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. The mental health strategy should add the final stage to the strategy and include the priorities, actions and results outlined in this submission.
7. The final mental health strategy should also link with and cross reference the Scottish Government's Strategic Framework for Action on Palliative and end of life care.

### Die Well: Priorities for a new Mental Health Strategy

8. 57,500 people die in Scotland each year. Around 46,000 of these people need some form of palliative care<sup>1</sup>. Palliative care is for people living with a terminal illness where a

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<sup>1</sup> <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

cure is no longer possible. Palliative care aims to treat or manage pain and other physical symptoms and also help with any psychological, social or spiritual needs. The goal of palliative care is to help the person and everyone affected by their illness to achieve the best quality of life.

9. The mental health strategy in Scotland needs to recognise and set out how care and support is delivered for people with mental health issues arising from their terminal illness, and those with severe mental health conditions approaching the end of life. This should be detailed in a fourth life stage in the strategy: Die Well.

### **Mental health issues arising from a terminal illness diagnosis**

10. For many people living with a terminal illness their mental health issues can be very apparent but can often go untreated and unsupported. Access to support can depend on where they live, their condition and the practitioner delivering their care.
11. 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.
12. 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.
13. 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<sup>2</sup> however, owing to underreporting this may be a lot higher. This could mean up to 70 suicides in Scotland each year.

### **People with mental health conditions approaching the end of life**

14. 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. Almost 4,500 people died from mental and behavioural disorders in 2015, including 11 from schizophrenia, schizotypal and delusional disorders, and 20 from mood (affective) disorders, such as bipolar affective disorder and recurrent depressive disorders<sup>3</sup>.
15. 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.

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<sup>2</sup> <https://prod.hsj.co.uk/chronic-illness-link-with-suicide-revealed/5034084.article>

<sup>3</sup> <http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2015/section-6-deaths-causes>

16. The framework proposed for the new strategy focuses strongly on supporting people to stay mentally and physically healthy. What it doesn't acknowledge is that this is not always possible for some people. Illness trajectories for people with terminal illnesses can vary. For people with cancer, there is usually a steady progression and a clear terminal phase; for those with conditions such as heart failure, there may be a gradual decline, with episodes of deterioration and recovery and a relatively unexpected death; and for those with conditions such as dementia or frailty, there may be a long gradual decline<sup>4</sup>. One thing is for certain though, their health will decline and they will die. Many of these people will have longstanding mental health issues or recurrent issues that can mirror these trajectories, often triggered by different points in their physical illness.
17. 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.
18. With Scotland's ageing demography and the number of people expected to die in Scotland to increase by 17% to 63,400 by 2038-39<sup>5</sup> we will need to support more and more people to die well. We expect the demand for services for people with mental health issues at the end of life, to increase alongside this.
19. The strategy should cross reference and link in with the recently published Strategic Framework for Action on Palliative and End of Life Care.

## Support

20. We think there needs to be a range of support available for people at the end of life. This can include access to mental health practitioners including psychiatrists and counsellors, as well as support groups, and access to suitable medication to help with conditions such as depression or sleep deprivation. This also needs to include better communication and understanding between palliative care and mental health teams, and wider education and training to challenge stereotypes and support practitioners.
21. When dealing with terminal illness, speed is of the essence. Whether someone only has a few years or in many cases a matter of months to live, people cannot afford to wait to get the support they need. Wherever possible, support for mental health issues must be fast-tracked or prioritised for people at the end of life.

## Education

22. The proposed framework outlines developing a range of evidence-based programmes to promote good mental health, particularly focusing on prevention and early intervention for infants, children and young people. However, there is no mention of working with Education to develop inclusion within the National Curriculum of Excellence or to ensure provision of mental health awareness, capacity building and resilience in both primary and secondary education. These should be available for all children, not just for those at risk of developing mental health conditions. This will address issues of stigma and discrimination surrounding mental health, and help children and young people develop coping mechanisms to help support mental wellbeing.

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<sup>4</sup> <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC557152/>

<sup>5</sup> <http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based/list-of-tables>

23. In particular, we believe that support for bereaved children is vital to protecting and promoting good mental health. A parent with a child under 18 dies every four hours in Scotland and around 11 children are bereaved of a parent every day in addition to those who are bereaved of a sibling or affected directly by their own life-threatening condition<sup>6</sup>.
24. Too many bereaved children in Scotland are not getting the support and help they need, which can impact on long-term outcomes. We would like to see a review of the National Curriculum for Excellence to ensure that there are appropriate references to death, dying, bereavement and grief, as well as support for teachers to deliver lessons in these issues in classrooms.
25. We welcome the First Minister's commitment in the Programme for Government to appoint a new national coordinator of childhood bereavement services to review and advise on steps to improve support. We hope this national co-ordinator will link in with the mental health strategy.

### Education and training for staff/professionals

26. However, education and training for health and social care staff is also important to ensure that anyone who experiences mental health issues gets the care and support that they need. The proposed framework makes no reference to training of staff in generalist roles in primary or secondary care, or of promoting and maintaining good links between mental health and specialist psychiatry teams, and other specialities.
27. In our experience, patients with mental health issues or cognitive impairment often do not receive treatment that is appropriate for them when they are admitted to hospital. This becomes considerably more complex when people are already receiving pain control or other medication to relieve their physical symptoms at the end of life.
28. Good communication is vital when discussing care and support for people living with a terminal illness. However, often staff are not comfortable discussing end of life or mental health issues and can lack the appropriate skills and competence to have these conversations. All staff should have access to this type of training and support to ensure these conversations are undertaken sensitively.
29. Mental health support is also a crucial part of care when people are deteriorating physically. In our experience, mental health teams can sometimes lack the skills and knowledge to support people when they are physically and mentally deteriorating because of their terminal illness. More needs to be done to raise awareness of palliative care and anticipatory care planning skills across the mental health workforce. This needs to be throughout the person's life, death and into bereavement. The mental health strategy should promote strong links between specialist mental health teams and other community services.
30. We would like to see specific mention of the importance of anticipatory care planning for people with mental health issues in the Die Well section of the mental health strategy. This should link to recommendations from the national review of primary care out-of-hours services and work on living well in communities.

31. Currently, mental health advance statements, that form part of the Mental Health Act, are not linked with the Key Information Summary (KIS) - an electronic information system managed by GPs that forms the centralised collection of information about a patient, to communicate care and treatment wishes. There is also no guidance for clinicians about what care is appropriate or wanted in an acute deterioration situation and this needs to be included in the mental health strategy.
32. Marie Curie believes there should be preventative population-wide education and training, built into each life stage in the proposed framework. We believe that both mental health and palliative care, including end of life care and bereavement training, should be a standard, mandatory part of education across all health and social care staff. This should also be a core part of university curriculums for caring professions and as a core part of continuing professional development. This will enable all staff to strengthen and develop their skills and knowledge of the specific circumstances and challenges of providing services for people at the end of life and those with mental health issues.

## Public Health

33. A key commitment within the Scottish Government's Strategic Framework for Action on Palliative Care is to support greater public and personal discussion of bereavement, death, dying and care at the end of life.
34. We believe this should be coupled with work detailed above in primary and secondary education. This will proactively help children and young people develop coping mechanisms to help support mental wellbeing when they face death, dying and bereavement. A public conversation will help children to build coping mechanisms, and help tackle stigma surrounding, death, bereavement and associated mental health problems in adults too.
35. In Scotland over 200,000 people are significantly affected by the death of a loved one<sup>7</sup>. People need to know how to help and support each other at times of increased mental and physical health needs and during bereavement. There needs to be support from public health professionals to educate and support the public about mental health issues of people who are living with a terminal illness, and at the end of life.
36. This should promote public and professional awareness, understanding and knowledge of ways to improve death, dying and bereavement and promote awareness of mental health issues at the end of life. It should also promote public dialogue around these issues and encourage effective planning for better death, dying and bereavement at all stages of life.
37. This should be included in the Die Well life stage of the mental health strategy and should link with the Scottish Government's proposed public health strategy to address these issues. There should also be a focus on supporting research in the strategy.

## Carers and families

38. Much of the care for people living with a terminal illness will be delivered in the home by family members and policy initiatives are aimed at supporting carers to care for an individual at home for as long as possible. Family carers play a critical role in end of life care for those people living with a terminal illness, enabling people to be cared for and

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<sup>7</sup> <http://www.gov.scot/Resource/0049/00491388.pdf>



die in their place of choice<sup>8</sup>. Recent research suggests that people with spouses or partners are those most able to die at home. They are also more likely to have experience better pain control<sup>9</sup>. This highlights the very important role carers play in providing support to people living with a terminal illness and at the end of life.

39. However, becoming a family carer of someone with a terminal illness can be a challenge. Caring for someone at the end of life can be both physically and emotionally demanding, and is often accompanied by a carer struggling to come to terms with the loss of a loved one<sup>10</sup>. Caring for someone at the end of life can involve symptom management, personal care, attending to household duties, and negotiating financial and employment concerns among others – all alongside psycho-social distress. Often people providing this care do not self-identify as carers and as a result do not access the support that they need. Good mental health is paramount to ensuring that carers are able to continue in their caring role, and ensuring people have the resilience and coping mechanisms following the death of a loved one.
40. Research shows that 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<sup>11</sup>. This distress can include depression, anxiety, complicated and prolonged grief. A study of family carers of patients with advanced cancer showed that more than 50% of the carers had depression scores approaching clinical depression.
41. Family carers also report high levels of mental health problems during bereavement. Research shows that 10-15% of the bereaved individuals suffer chronic distress and depression for years after the loss. While grief is seen as a normal experience after major loss, between 10-20% of bereaved persons (10-20%) experience prolonged grief, where a normal grief adjustment does not occur and the person experiences debilitating grief for a longer period. These people then also suffer from an increased risk of adverse health effects<sup>12</sup>.
42. Being the informal carer for someone who has a terminal illness, when someone is dying, can also be a very isolating experience. A family member may unexpectedly find themselves in a carer position, and be balancing other home and familial responsibilities, work and other commitments. Often carers in this situation become ambivalent about their own needs and are reluctant to identify that they themselves need support<sup>13</sup>. This often means that these carers are not aware of, or accessing, support that they need.
43. Research shows that mental preparation during a caring role can help prevent prolonged post-bereavement psychological distress<sup>14</sup>. This would suggest that additional support for carers during the caring role could help increase resilience and promote better mental health outcomes post-bereavement.

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<sup>8</sup> [http://www.jpsmjournals.com/article/S0885-3924\(12\)00750-6/pdf](http://www.jpsmjournals.com/article/S0885-3924(12)00750-6/pdf)

<sup>9</sup> Equity in the provision of palliative care in the UK: Review of Evidence, London School of Economics (2015)

<sup>10</sup> <http://www.biomedcentral.com/1471-2296/15/48>

<sup>11</sup> <http://www.sciencedirect.com/science/article/pii/S0272735816000039>

<sup>12</sup> [http://ac.els-cdn.com/S0885392413003679/1-s2.0-S0885392413003679-main.pdf?\\_tid=d00746c0-0ba6-11e6-b6d7-00000aacb35f&acdnat=1461672356\\_df7580d1eff907cda93d2f93c311f9cd](http://ac.els-cdn.com/S0885392413003679/1-s2.0-S0885392413003679-main.pdf?_tid=d00746c0-0ba6-11e6-b6d7-00000aacb35f&acdnat=1461672356_df7580d1eff907cda93d2f93c311f9cd)

<sup>13</sup> <http://www.biomedcentral.com/1471-2296/15/48>

<sup>14</sup> <http://www.sciencedirect.com/science/article/pii/S0272735816000039>

## Recommendations

44. Marie Curie believes that the mental health strategy is missing one key pillar, which means that many people with mental health issues may not get the care and support they need at the end of life. We would like to see the addition of a Die Well life stage to the mental health strategy to fully address the mental health needs of people approaching the end of life.
45. As outlined in this response, this should include care and support for people with mental health issues arising from a terminal illness, and people with severe mental health conditions approaching the end of life. The following should be reflected in the Die Well life stage of the mental health strategy for Scotland:
- 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 within the National Curriculum of Excellence, alongside support for teachers to deliver lessons on this in primary and secondary care.
  - Links between the new national coordinator of childhood bereavement services and the mental health strategy.
  - 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 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.

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