

Marie Curie Response

Assisted Dying (Scotland) Bill Consultation, question one - *NEUTRAL*

Marie Curie's position on assisted dying

1. Marie Curie maintains a neutral position on assisted dying – we neither campaign for, nor against, a change in the law.
2. Our core mission is to ensure that as many people as possible have access to high-quality care and support when they are dying – including palliative and end of life care. Too often, the debate around assisted dying does not pay sufficient attention to the significant levels of unmet care and support needs that exist among people who are dying and coming towards the end of life in the UK.

What do we mean by a terminal illness?

3. Marie Curie believes someone is terminally ill if they are diagnosed with a condition that will lead to their death. Depending on the condition this could be years, months, weeks or days. It's sometimes called a life-limiting illness.
4. There is no set list of illnesses which are terminal. People who are terminally ill may have a single disease or a number of conditions. Examples of some illnesses which can be terminal include:
 - advanced cancer
 - dementia (including Alzheimer's)
 - motor neurone disease
 - lung disease
 - neurological diseases like Parkinson's
 - advanced heart disease.
5. It can be difficult for doctors to predict how long someone will live for. This can depend on their diagnosis and any treatments they may be receiving.
6. No two experiences of a terminal illness are the same. Sometimes, a person's condition will gradually get worse as the illness progresses. Other people may find that they have times when they feel better and times when they feel worse at different points during their illness.
7. Those who are terminally ill can be supported with a palliative care approach.

What is palliative care?

8. Palliative and end of life care supports people who have a terminal illness. By terminal illness, we mean a disease or condition which will likely result in the person's death. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.
9. Palliative care can be provided in different settings, including in hospital, a hospice, care or nursing homes and a person's own home. Palliative care aims to support a person to

have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for family and friends

10. Palliative care be delivered by a range of professionals ranging from specialist palliative care clinicians and health practitioners, through to GPs, district nurses, and social care staff.
11. The vast majority of care delivered to people when terminally ill and approaching end of life is by generalist health and social care providers, such as district nurses and social care staff in any and all settings. This can be delivered alongside palliative care teams. For those experiences complexities in their care, such as pain and symptom control, they are likely to be referred to specialist palliative care teams, and this can also be in any setting, including hospices.

Dying, death and bereavement in Scotland currently

12. In 2020-21, there were over 63,000 deaths registered in Scotland¹; around 90% of those (56,700) had a palliative care need.
13. However, we know that not everyone who is terminally ill is getting the care and support they need, and this has a direct impact on their quality of life they experience as they approach the end of life. Various evidence suggests that anywhere between a quarter and up to half of all people do not get some or all the care and support they need as they die.
14. This gap in care could grow in the coming years, as by 2040 nearly 63,000 people will die every year needing some palliative care support, which is nearly 11,000 more people a year than now, and 95% of all people who die.
15. We know that more and more people will be dying of more than one condition, with a substantial increase in the number of people dying with dementia and cancer. People will also be significantly likely to be living with lots of different chronic and life-long conditions, as they get older, including frailty and diabetes. This will potentially make their care needs more complex and challenging to meet.
16. Marie Curie research suggests that by 2040 nearly two-thirds of people will be dying in the community either at home or in a care home, until recently most people died in hospital. Scottish Government statistics has shown that the average time a person spends in the community during their last six months of life has been increasing gradually every year for a decade.

A focus on ensuring that everyone who needs palliative care gets it

17. Not everyone who might benefit from palliative care gets access to some or all that care. Although there is no significant piece of evidence to identify exactly how many people miss out on care and what support they need, there is a range of evidence that demonstrates people miss out. The LSE, in 2015, suggested that nearly 11,000 people in Scotland miss

¹ National Records of Scotland: Vital Events Reference Table 2020-21

out on palliative care services². A Sue Ryder report recently suggested that around only 50% of people that need specialist palliative care receive it³.

18. We believe a palliative approach should be introduced as early as possible following a terminal diagnosis or very serious illness where the possibility of it progressing to a terminal condition is high. A palliative approach can be introduced while a person is still receiving curative treatment and can often compliment that care, so it does not need to be a choice between approaches.
19. A palliative approach often starts with a conversation and the beginnings of a care plan. An anticipatory care plan (ACP) can allow patients and healthcare teams to discuss treatments and care options, as well as preferences such as place of care and where a person would prefer to die. It also allows a social and spiritual preferences and wishes to be captured and acted on, as well as help identify any carers.
20. Having an ACP in place can reduce the amount of time a person spends in hospital, including reducing the number of unnecessary hospital admissions, reduce the likeliness of having to go to A&E, and more likely to die in their preferred place of choice.
21. However, currently only 69% of people dying with a terminal illness have an electronic care plan in place in Scotland; with those dying of terminal cancer more likely to have one than those with other conditions⁴.
22. There are considerable inequities and inequalities faced in accessing palliative care for those that need it. Social characteristics including age, sexuality, socio-economic status, gender, as well as diagnosis all determine whether someone accesses the palliative care they need⁵. This is important when considering the introduction of assisted dying as it could lead to unintended consequences, including a disproportionate amount of people from protected social characteristic backgrounds accessing assisted dying as a result of not receiving palliative care and other services that they might need when terminally ill and at end of life.
23. Scottish Government made a commitment in the 2016 Health and Social Care Delivery Plan, that everyone who needs palliative care should have access to it by 2021, including a commitment to ensure that everyone who needs an anticipatory care plan will have one, but despite best efforts this has yet to be achieved.
24. For those who access palliative care many of them receive it late, which can affect their experiences and quality of life including pain and symptom control. Ensuring that people access the care they need from the point they need it can have significant impact on patient outcomes.
25. Marie Curie believes that Scottish Government's focus should be on closing this gap in care urgently to ensure that terminally ill people get all of the care and support they need from the point of their diagnosis, throughout their illness and right up until the end of life.

² Dixon J, King D, Matosevic T et al. (2015) Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie.

³ Von Petersdorff, C et al (2021). Modelling demand and costs for palliative care services in England: A final report for Sue Ryder.

⁴ Finucane. A et al: Electronic care coordination systems for people with advanced progressive illness: a mixed-methods evaluation in primary care. British Journal of General Practice <https://bjgp.org/content/70/690/e20>

⁵ Dixon J, King D, Matosevic T et al. (2015) Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie.

26. There should also include a robust commitment to data collection to establish a true level of unmet need in Scotland for those living with and dying of a terminal illness, across the full journey of care and in all care settings. This should include a commitment to establishing quality of experience as much as receipt of a service or support.

Enshrining Palliative Care in law and as part of the assisted dying process

27. Marie Curie supports the principle of a human right to palliative care for those terminally ill and approaching the end of life.
28. The consultation suggests that where assisted dying has been introduced there has been an increase in investment in palliative care services. Any increase in investment in palliative care would be welcome. However, palliative care is never delivered in isolation and is not a single point of contact. When done well it is carried out from the point of diagnosis to the time of death and includes different types of support and at different levels, at different times. It also works in partnership with statutory partners including primary care and social care services, as well as community volunteer groups. Simply investing in palliative care will not necessarily ensure that all the needs of those people who are terminally ill and approaching the end of life are met.
29. There is no guarantee that with this proposal and subsequent legislation that there will be any increase in overall investment to support terminally ill people. Any investment that was forthcoming would not only need to be for palliative care but also include support for other social and healthcare settings which support terminally ill people.
30. There is also currently no significant evidence base to show how much extra investment would be needed to fill the current gap in unmet need for those who are terminally ill and at end of life. Alongside this, there is also limited evidence to specify the true level of unmet need. This information is urgently needed regardless, but most particularly were the Scottish Parliament to consider progressing legislation for assisted dying.
31. If assisted dying were introduced without measures such as the ones described above, there is a risk that some people who could have had their suffering palliated through effective care and support, could choose assisted dying simply because the services and support they need are unavailable.

Data used to estimate limits to palliative care in Scotland

32. Data used in the consultation that suggests a limit to palliative care has some serious limitations, which need to be considered. The Office of Health Economics (OHE)'s estimate that 591 terminally ill people die annually without their pain being relieved when in receipt of palliative care. However, this estimate for Scotland is based on English data, which has been calculated using the VOICES survey of bereaved carers⁶. The survey used is completed by carers at least six months following the death of the person they were caring for. Although the views of bereaved carers are very important, they are not the views of those experiencing symptoms, who may have had different perspectives of their experiences. Six months have also passed from the point of experience to the collection of those experiences, which can impact on the accuracy of recall.
33. There is no substantial evidence base in Scotland to demonstrate the quality of palliative care that people experience. There is limited evidence from service evaluations and other sources, such as Care Opinion, but not enough to judge with confidence the quality of care

⁶ Zamora, B., Cookson, G., Garau, M., 2019. Unrelieved Pain in Palliative Care in England. OHE Consulting Report. London: Office of Health Economics

terminally ill people experience from the point of the diagnosis, throughout the care and at the point of end of life. This is a serious gap in knowledge and makes it difficult to draw any conclusions about the limitations of palliative care or other interventions that support someone at the end of life.

34. We believe that before any legislation is introduced or debated robust research should be carried out to ascertain the quality of palliative care in Scotland across all settings and in all communities, and throughout all points of someone's care. We also believe that further research needs to be carried out to specifically ascertain a true level of unrelieved pain for those in receipt in palliative care and what that looks like from both a clinical and social perspective.

Public support for assisted dying

35. The opinion polling data being used to show support for assisted dying were all commissioned by organisations campaigning for the law. This brings in some questions around the validity around the assumed levels of support taken by the consultation.
36. The issue of terminal illness, dying, death and bereavement is often far from simple with complexities and nuances that can be hard to capture in opinion polling. People's wishes and views toward dying, death and bereavement change over time, particularly as it might relate to the shortening their lives through assisted dying. Evidence suggests terminally ill people can change their minds when they are in receipt of palliative care⁷. In Oregon for example, data there shows that since 1997, 2,895 people have received prescriptions under the assisted dying law, with 1,905 people (66% of the total) recorded as having died from ingesting the medications. While there is more than one explanation for this discrepancy – for example, information was not available for all patients prescribed with the drugs when the last report from the Oregon Health Authority was published – some of the patients are likely to have changed their minds and opted not to take the medication. In 2020, for instance, 18% of those prescribed with life-ending drugs did not take them and later died from other causes⁸. These are important nuances that must be factored in the deliberations of this legislation.

⁷ Prevalence, course and associations of desire for hastened death in a UK palliative population: a cross-sectional study Price A, Lee W, Goodwin L, et al. *BMJ Supportive & Palliative Care* 2011;1:140-148. <https://spcare.bmj.com/content/1/2/140>

⁸ Oregon Health Authority Public Health Division (2021). Oregon Death with Dignity Act: 2020 data summary

About Marie Curie

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 2019-20, [Marie Curie Scotland](#) cared for over 8,500 people at the end of life. In 2020-21, with more and more people dying in the community throughout the pandemic, we have seen a 16.5% rise in our community nursing services.

Further information:

