Marie Curie Briefing

Assisted Suicide (Scotland) Bill Stage One

Marie Curie understands the importance of this Bill to those that are advocating for and against it.

We believe that it is critical to highlight that the issue of assisted suicide/dying is only one part of a much wider debate on end of life in Scotland.

Too many terminally ill people are not receiving the care they need at the end of life, which can have a detrimental impact on the quality of life they have in their last years and months. Marie Curie believes that this is not fair and action needs to be taken now.

Key Facts:

- It is estimated that 35,000-40,000 people in Scotland need palliative care each year.
- Yet, only 12,050 patients were on the palliative care register in Scotland in 2013-14
- Marie Curie commissioned research estimates that nearly 11,000 people in Scotland are missing out on palliative care every year.
- Over 50% of people die in hospital, but the vast majority would like to die at home.
- The number of people dying in Scotland is due to increase by 13 per cent over the next 25 years.
- Those with diseases other than cancer, such as dementia, chronic obstructive pulmonary disease (COPD), and heart failure are much less likely to be accessing palliative care.
- People living alone, without the support of a carer, those over 85, people from BAME communities are all less likely to be accessing palliative care.
- Half (50%) of UK adults say that their loved one's pain not being managed would be a top concern when caring for a terminally ill loved one, followed closely by not having access to 24/7 care and support (44%).
- It is estimated that 30% of people in Scottish hospitals are in their last year of life.
- People in the last 6 months of life spend anywhere between 10 and 22 days in hospital.
- Carers say seven out of every 10 people with a terminal illness in the UK do not get all the care and support that they need.

The focus of end of life care policy must be on addressing this unmet need and ensuring that the thousands of people who miss out on palliative care each year get it.

The Scottish Government is currently developing a new Strategic Framework for Action on palliative and end of life care, which Marie Curie supports.

Marie Curie believes that the Scottish Government should commit to ensuring that everyone who needs palliative care has access to it by 2020.

Marie Curie's Assisted Suicide position

- We strongly endorse the right of the competent patient to refuse consent to any medical treatment.
- We commend the developing use of Advance Decisions (or their equivalent) to refuse treatment.
- We strongly commend the continued development and growth of end-of-life care services in hospices, hospitals and the community.
- We are not seeking a change in the law to permit euthanasia or physician assisted suicide.

Caring for people with a terminal illness

Someone has a terminal illness when they reach a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live for days, weeks, months or even years after this point.

This is an issue that will affect many of us at some time during our lives, whether it is caring for a loved one or our own care in the future.

A palliative care approach is often recommended for people with a terminal illness who are approaching the end of their lives. This is the active, holistic care of people with advanced progressive illness. A palliative care approach can be delivered by a wide range of settings, including hospices. This can include specialist palliative care and more generalist care.

Barriers to care

People with a terminal illness other than cancer, such as dementia, COPD or heart failure are less likely to be referred to palliative care. However, even those with terminal cancer are not certain to access palliative care with studies suggesting that 25% of cancer patients do not receive palliative care in Scotland.

We need to acknowledge that people with all terminal illnesses can benefit from access to palliative care and end of life care.

People from single person households are much less likely to access palliative care than those with a live-in carer or spouse. Spouses/Partners/ may act as advocates or coordinators, as well as carers, helping someone who is terminally ill to navigate their way through different services.

However, carers often report feeling unsupported and left out of the conversation about their loved one's care, as well as finding a lack of information to help them prepare for the reality of a loved one dying at home and bereavement support after they have died.

Those over 85 are less likely to access palliative care than younger age groups. Yet, evidence suggests that older people are just as likely to benefit from palliative care as younger age groups. This difference in access might be explained because of the perception of older people and dying and belief in there being less of a need.

Studies also suggest that those living in Scotland's most deprived communities are also less likely to be accessing palliative care.

Access to care can also be difficult if you have a disability, are from a black or minority ethnic background or if you are LGBT. The same is true if you're homeless or in prison.

Ineffective coordination of care between services such as health and social care or general and out-of-hours practice and between different organisations can lead to unnecessary delays for care and support. In order to make sure that people living with a terminal illness get the same high quality person centred care we need all integrated boards to put palliative care at the heart of their strategic plans.

The Palliative and end of life care Priority Setting Partnership found that people living with a terminal illness, carers and health and social care professionals have indicated that out-of-hours care and equal provision of care are the two major areas they would like to see more research in. There is still too little research carried out in palliative and end of life care.

We need to examine the training and support given to professionals to ensure that they can provide high quality, person-focused care for people with a terminal illness. This must involve improving generalist care for people with different terminal illnesses. We need to build links between specialists such a cardiologists and neurologists and professionals in palliative care. This will create greater understanding of the benefits and facilitate clear pathways for patients.

Professionals often struggle to communicate with people and families when talking directly about the fact that someone is going to die. If professionals do not provide the appropriate information, people may feel unsure about what services they need and unable to make decisions that benefit them. We need to empower health and social care professionals to have those important conversations and we need to encourage families to have those conversations too.

Cost Effective

Providing more services in the community will reduce pressure on hospital beds, meet people's wishes and has the potential to be a more efficient and effective use of NHS resources.

A review by the London School of Economics has estimated that providing palliative care to those that need it could potentially generate net savings of more than £4million in Scotland.

The Nuffield Trust has estimated that the NHS could be able to realise potential savings of nearly £500 per person by enabling people at the end of life to be cared for in the community or at home. Not only does this mean that the person gets the care they prefer, but it is likely to save valuable statutory funds to be reinvested elsewhere, as well as relieve the pressure on acute services, such as A&E.

Further information:

We are happy to provide further information to support this call for evidence. For more information, please contact:

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Care and support through terminal illness