



Care and support
through terminal illness

Marie Curie Briefing

Scottish Government Debate: *Taking Scotland Forward – Delivering a Healthier Scotland*

Marie Curie is the UK's biggest provider of high quality care for people living with a terminal illness. 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.

Key Points

Ensuring people living with a terminal illness and at the end of life get the care and support they need is vital in order to deliver a healthier Scotland.

Over the course of the next five years of the Scottish Parliament, Marie Curie believes that the Scottish Government and the Parliament must focus on the following key issues to improve care and support for people living with a terminal illness and for their families and carers.

Everyone who needs palliative care should have access to it

- The Scottish Government has committed to ensuring that everyone who needs palliative care has access to it by 2021 in its new Strategic Framework for Action on Palliative Care (December 2015). This is a very welcome, but ambitious target as currently around 11,000 people each year who die miss out on the palliative care they need. The Parliament must ensure that this remains a high priority as no one should miss out on the care they need, especially as they approach the end of life.
- A key commitment within the Framework is to support greater public and personal discussion of bereavement, death, dying and care at the end of life. To facilitate this we would like to see the Scottish Government lead by example and host a debate in the Scottish Parliament before the end of this year.
- The previous health committee of the Scottish Parliament carried out an inquiry into palliative care. The inquiry's conclusions and recommendations informed the development of the Scottish Government's Framework. In its legacy paper the health committee recommended that the new Health and Sport Committee review progress on the inquiry's recommendations. We would urge the new committee to plan for this by the end of the year to coincide with the anniversary of the inquiry's report.

Supporting bereaved children and young people

- Many children and young people are missing out on support after a bereavement. Marie Curie has called for the introduction of a national co-ordinator for childhood bereavement services to review and advise on steps to improve bereavement services. The SNP

committed to this in their manifesto and we would like to see the Scottish Government implement this as soon as possible.

- Children and young people need to be more aware of and resilient to issues relating to bereavement and grief. Marie Curie would like to see a review of the National Curriculum for Excellence to ensure that there are appropriate references to bereavement and grief, as well as support for teachers to deliver this in classrooms.

Getting health and social integration right for those

- Palliative care is now the responsibility of the new health and social care partnerships and must be an early priority. Partnerships must ensure that work is done to identify palliative care needs for all communities and terminal conditions in their localities. They must also put in place plans and services to meet any unmet need, as well as measure progress toward the Scottish Government's 2021 target. Finally partnerships must demonstrate that patient outcomes are being met.
- The third sector is a key part of the integration of health and social care. At present it is unclear how well this is working. In order to ensure that the third sector is playing its full part in integration in every partnership area we would like to see the Scottish Government pledge to review progress and report to Parliament on it by the first anniversary of integration in April 2017.

Ensuring a palliative approach in the next National Dementia Strategy

- In March the previous Scottish Government published its priorities for the third national dementia strategy, which included a commitment to palliative and end of life care for people with advanced dementia. Marie Curie would urge the Scottish Government to ensure that access to palliative care is a significant component of the third dementia strategy when it is published later this year.

Carers

- Supporting carers of those living with a terminal illness is essential if the person is to have the best chance of receiving the care they need and want, as well as the chance to be cared for at home and die there, if that is their wish. Regulations to support the Carers (Scotland) Act, passed in the last parliament are due to be drafted in this new parliament. They must make reference to the needs of carers of those living with a terminal illness as well as include guidance on post carer and bereavement support.

A social security system fit for those living with a terminal illness

- Getting social security right will be a key element to ensuring a healthier Scotland. Many people living with long term and terminal illnesses will rely on social security to support them, as will their carers. Marie Curie supports the establishment of a new Scottish Social Security Agency and the proposed principles of the Scottish social security system. To support this we would like to see a fast track system retained for those who are terminally ill, so that they receive their benefits (Including Personal Independence Payment, Disability Living Allowance and Attendance Allowance) as quickly as possible.
- We also believe that Carers Allowance should be fast tracked for those caring for someone with a terminal illness. We hope that the new Scottish Government will commit to this as

early as possible. Fast tracked Adult Carers Support Plans were agreed under the Carers (Scotland) Act, so fast tracked benefits would be a logical accompaniment.

- Far too many families in Scotland face funeral poverty following the death of a loved one. The Funeral Payment, which is available to support people struggling to pay for a funeral, is due to be devolved to the Scottish Government. The current Funeral Payment cap is £700 (plus burial/cremation). Last reviewed 13 years ago, the cap fails to take into account the rising cost of funerals – an 80% increase in the last decade¹. The average cost of a funeral in Scotland is £3,550². The new Scottish Government must continue its commitment to replace/change the Funeral Payment to make it a fairer benefit. Marie Curie believes that the Funeral Payment should be set at the level of the average funeral cost and be available to all those that qualify for it.
- The previous Scottish Government also committed to organising a national funeral poverty conference and round table discussions between Scottish Ministers and stakeholders to promote action. We believe that this conference should happen before the end of year.

Supporting Information

54,000 people die every year in Scotland and around 40,000 of them will need some of palliative care. Many of whom have been living with a terminal illness, such as terminal cancer, heart disease, dementia, motor neurone disease, frailty. In many cases they will be facing a combination of two or more of these conditions.

We know that around 11,000 people every year who need palliative care services do not get them.

The population of Scotland is expected to rise to record levels of around 5.7 million by 2039¹. The average age of the population is also expected to rise and people at older ages are expected to live longer than ever before. In fact, the number of people in Scotland aged 75 or over is due to increase by 85% by 2039. As people are living longer they are more likely to have more complex needs and develop long-term and multiple conditions.

With this ageing population, the number of people living with a terminal illness and at end of life missing out on palliative care could rise significantly if we do not act now to change things.

People living with a terminal illness need a combination of health and social care services. These will be met by a diverse range of providers and informal unpaid carers (family and friends) in a wide number of settings. We want to ensure that people receive consistent, timely and appropriate care and support across Scotland. This includes joined up working between health and social care services, primary, secondary and community care, and between public, independent and voluntary sector partners.

We believe that everyone who needs palliative care should have access to it from the point of need.

¹ Rising Funeral Costs – The Elephant in the Room (2015). The Royal London Mutual Insurance Society Limited: London

² Cost of Saying Goodbye: Burial and Cremation Charges in Scotland 2015. The Scottish Association of Citizens Advice Bureaux: Edinburgh

What is palliative care?

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 to care can be delivered by a wide range of settings, including hospices.

Key Facts – Palliative Care in Scotland

- Nearly 11,000 people who need palliative care in Scotland each year are not accessing it.
- It is estimated that around 40,000 of the 54,000 people who die each year need some palliative care.
- The number of people dying in Scotland is due to increase by 13% over the next 25 years.
- Over 50% of people currently die in Scottish hospitals, but the majority would prefer to die at home or in a homely setting.
- 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.
- People with a non-cancer terminal diagnosis are significantly less likely to be identified for palliative care.
- Those over the age of 85, those that live alone, those from Black, Asian and Minority Ethnic communities, and those from deprived communities are all less likely to access palliative care.
- 2,500 parents die leaving 4,100 bereaved children every year in Scotland³
- There are currently 24,000 bereaved children in Scotland⁴.

Further information:

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³ The Child Bereavement Network – <http://childhoodbereavementnetwork.org.uk/media/16090/KeystaticsonChildhoodBereavement>

⁴ *ibid*

