

Everyone should have the right to palliative care

Scottish Parliament Manifesto Priorities

2016–2021



Care and support
through terminal illness

Ahead of the Scottish Parliament elections in May 2016, Marie Curie would like to see political parties commit to key priorities in their manifesto to help improve the lives of people living with a terminal illness and their families and carers.

Marie Curie believes everyone should have a right to palliative care when they need it.

The next Scottish Government will:

1. commit to ensuring that everyone who needs palliative care has access to it by the end of the next Parliament (2021)
2. lead a public health campaign to encourage open and honest conversations to tackle the taboos surrounding death and dying
3. introduce a new national co-ordinator for childhood bereavement and review the role of the Curriculum for Excellence in supporting issues of grief and bereavement in children
4. ensure that any existing benefit devolved or new benefit introduced to the Scottish Parliament must include a system of fast tracking for those that qualify and are living with a terminal illness, and their carers

Setting the scene

The UK is a world leader in caring for people living with a terminal illness through palliative care and end of life care. However, not everyone that needs palliative care is currently getting it. Marie Curie research suggests that nearly 11,000 people in Scotland miss out on the palliative care they need every year. With the number of people dying in Scotland each year due to increase by 13% over the next 25 years, this problem will get worse unless we act now. Evidence suggests that investment in palliative care services is almost completely offset by savings in the acute setting.¹

Making sure everyone that needs palliative care gets it

Marie Curie would like the next Scottish Government to commit to ensuring that everyone who needs palliative care has access to it by the end of the next Parliament (2021).

Those with terminal conditions other than terminal cancer, such as dementia, heart failure or chronic obstructive pulmonary disease, are much less likely to get the palliative care they need. Those aged over 85, as well as people from poor and rural backgrounds,

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

and those from black, Asian and minority ethnic communities are also less likely to be able to access the palliative care they need. This must improve.¹

The delivery of the new Strategic Framework for Action on Palliative and End of Life Care, due to be published in 2015, will be paramount to achieving this and the next Scottish Government must work to ensure that it is implemented in full and properly resourced.

Having an open and honest conversation

We would like to see the next Scottish Government lead a public health campaign to encourage open and honest conversations about death, dying and bereavement across Scotland.

Fifty-four thousand people die in Scotland each year, yet far too many of us simply do not talk about death and dying. Talking about death and dying can help empower us to be more supportive of one another in our homes and communities. It can enable people to plan when time becomes short so that what matters to them becomes the focus of their care and support.

Bereaved children need more help and support

There are currently 24,000 bereaved children in Scotland. A parent with a child under 18 dies every four hours in Scotland.² Eleven children are bereaved of a parent every day in addition to those who are bereaved of a sibling or affected directly by a life-threatening condition of their own. Marie Curie believes that too many bereaved children in Scotland are not getting the support and help they need, which can impact on long-term outcomes, including educational attainment. A range of providers deliver childhood bereavement services, but we need leadership to ensure all children can access them from the point of need.

We want the next Scottish Government to appoint a national co-ordinator for childhood bereavement. Death, dying, grief and bereavement in the Curriculum for Excellence should be reviewed, with additional support given to teachers to ensure that this is delivered in every classroom.

Getting benefits right for people living with a terminal illness and their carers

Far too many people living with a terminal illness are not currently getting the benefits they need to support themselves. We want to see all those living with a terminal illness get the support that they need and is available to them, including financial assistance.

We believe that any new benefit introduced or existing benefit devolved to the Scottish Parliament must include a system of fast tracking for those living with a terminal illness that qualify. Carers and family members of those living with a terminal illness must also receive fast tracked benefits for those they qualify for. Benefits should look to mitigate the cost of living with a terminal illness, and prevent any fall into poverty and social isolation at the end of life.

² <http://www.childhoodbereavementnetwork.org.uk/media/16090/KeystaticsonChildhoodBereavementOct2014.pdf>

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We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

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