

# Marie Curie Local Government Elections 2017: Manifesto Priorities

Ahead of the Local Government elections in May 2017, Marie Curie would like to see political parties commit to the following 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.

Local Councillors will work to ensure that:

1. Health and Social Care Partnerships fully engage with and involve the third sector, service users and carers with key strategic decisions, strategic planning and budgeting decisions concerning care and support for people in communities.
2. People living with a terminal illness get quick access to social care support and that packages of care are responsive to their needs if their situation changes.
3. Carers and young carers who are caring for someone with a terminal illness are supported and involved in decisions about their loved ones' care and get fast-tracked support.
4. There are local bereavement support services for carers, during illness and following the death of the person they care for.
5. Burial and cremation costs are as fair and transparent as possible, and steps are taken to alleviate funeral poverty.

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our five volunteer led Helper services. We also provide nationwide support through our information and support service including our national support telephone line. Last year we provided care for over 8,000 people living with a terminal illness, as well as their families and carers across Scotland.

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 due to increase by 13% over the next 25 years, this problem will get worse unless we act now.

### Integration

Palliative care is now the responsibility of the Health and Social Care Partnerships. Partnerships must ensure that work is done to identify palliative care needs for all communities and people with terminal conditions in their local areas. They must also put in place plans and services to meet any unmet need, as well as measure progress toward



Care and support  
through terminal illness

the Scottish Government's target that everyone who needs palliative care will get it by 2021. 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. We need to make sure that the third sector is fully involved in the design and development of integrated services.

Marie Curie supports the Scottish Government commitment to double palliative care services in the community by 2021, as set out in the Health and Social Care Delivery Plan. We urge Integration Joint Boards to set out how they will achieve this.

## Social Care Support

Between March 2015 and the end of September 2016, 683 people died in hospital in Scotland after being declared medically fit to leave. Social care is an integral part of palliative care. It can mean the difference between being able to stay at home, get out of hospital, remain connected to families and communities, living the life people want to with some element of independence and control, and dying the way they want to. All things that people tell us they want to do. Without good, supportive, adaptive and flexible social care though, even the small things can become impossible.

In 2016, Marie Curie, the Association of Palliative Care Social Workers, Hospice UK and MND Scotland launched *Dying to Care: A report into social care at the end of life*. These frontline organisations providing care and support for over 20,000 people in Scotland, called for a new approach to social care accentuating the need make sure people living with a terminal illness, and their carers, get the social care support they need to allow them to make the most of the time they have left. We need to make sure that people living with a terminal illness get quick access to social care support and that packages of care are responsive to their needs if their situation changes. Local Authorities also need to ensure that they follow current COSLA guidance and waive care charges for terminally ill people.

## Carers

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. These carers can often have very specific needs and requirements which need to be considered in the care and support available to them. 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 at a time of increased psychological stress. Often people providing this care do not self-identify as carers and as a result do not access the support that they need.

The Carers (Scotland) Act will be enacted from on April 1, 2018. The provisions in the Act include duties on local authorities to provide support to carers, and to ensure that support plans available to carers will be fast-tracked for those caring for someone living with a terminal illness. We need to make sure carers and young carers who are caring for someone with a terminal illness are supported and involved in decisions about their loved ones' care.



Care and support  
through terminal illness

## Bereavement support

Bereavement support helps families to adjust to their loss and to address new challenges. People who have spent weeks, months and in many cases years caring for their loved one suddenly find that their realities and daily routines change. Their central role as a carer has gone, as are the professionals who have provided support. The provisions in the Carers (Scotland) Act state that new information and advice services for carers in local areas must also provide information and advice about bereavement support, including, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights. We need to make sure there are local bereavement support services for carers, during illness and following the death of the person they care for.

We also know that 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 has been included in its Programme for Government 2016/17. We look forward to this being implemented as soon as possible.

## Funeral Poverty

We believe everyone should get a dignified and respectful funeral, which does not force their loved ones into significant and harmful debt. It is estimated that 1 in 10 families cannot afford to pay for a funeral they are responsible for. For some families the physiological and emotional strain the cost of a funeral can put on them can be overwhelming and directly affect their grief.

We need to make sure burial and cremation costs are as fair and transparent as possible, and steps are taken to alleviate funeral poverty. We are asking Scottish Councils to do more to ensure burial and cremation costs are kept as reasonable as possible.

## Contact

Richard Meade  
Head of Policy & Public Affairs  
[richard.meade@mariecurie.org.uk](mailto:richard.meade@mariecurie.org.uk)

0131 561 3904  
@RichardMeade13

@MarieCurieSCO

Susan Lowes  
Policy & Public Affairs Manager  
[susan.lowes@mariecurie.org.uk](mailto:susan.lowes@mariecurie.org.uk)

0131 561 3902  
@SusanLowes3



Care and support  
through terminal illness