

Everyone should have the right to palliative care

Manifesto priorities

2016–2021



Care and support
through terminal illness

Ahead of the elections to the National Assembly for Wales in May 2016, Marie Curie would like to see political parties and candidates commit to the following key priorities in their manifestoes to help improve the lives of those living with a terminal illness and their families and carers.

We want the next Welsh Government to:

1. commit to ensuring everyone who needs palliative care has access to it by the end of the next Assembly
2. take a public health, compassionate communities approach to developing new services for those living with a terminal illness
3. commit to a bi-annual survey of bereaved people to provide a fuller picture of end of life care in Wales

Setting the scene

Marie Curie believes everyone should have the right to the palliative care they need. Yet we know from our research that, even with all the care and support the NHS and its partners provide, 6,200 people across Wales who need palliative care miss out on it each year because their needs are not recognised and they are not referred on to the right services.

We know there are many barriers to people accessing the care they need, including the type of condition they have, and a lack of awareness around what palliative care is and what services are available.

With an ageing population, more and more people will need access to palliative care in the years to come. We urge the next Welsh Government to build on the good work already done to ensure that the growing numbers of people who will benefit from palliative care have access to it.

1. Everyone should have a right to palliative care if they need it

There are still too many people nearing the end of their lives not getting the palliative care they need.

Seven out of 10 carers say people with a terminal illness do not get the care and support they need.*

People with terminal conditions other than cancer, such as dementia, heart failure or chronic obstructive pulmonary disease, are much less likely to get the right care. The same is true of those aged over 85, people from poor or rural backgrounds, and members of the BAME and LGBT communities. This simply must improve.

We would like to see the next Welsh Government commit to ensuring that everyone who needs palliative care has access to it by the end of the next Assembly term in 2021.

2. A public health, compassionate community approach to care at the end of life

We would like to see the next Welsh Government lead a campaign which recognises that care and support for people who are dying is a public health issue that affects us all and has wide ramifications for communities.

Most of us want to die at home surrounded by people we care for and things we know. To do this we will need lots of support in the community. Some should be provided by social services, some through the NHS. But do we really want to professionalise all end of life care in the community?

An alternative is to put in place resources to support people who want to help friends and neighbours who are at the end of their lives. Much remains to be done to support carers of people at the end of their lives.

Far too little is also done to provide bereavement support to people who have lost a loved one. This can lead to mental illness and physical ill health, as well as issues with employment and the ability to remain independent.

This kind of approach will help death and dying be understood and managed compassionately by and within communities.

3. Survey of bereaved people

We want to see the introduction of a bi-annual survey of bereaved people in Wales, so healthcare professionals and government have a better understanding of the experiences of people at the end of their lives and their carers.

This survey should be in a format which allows us to understand the experiences of people with different characteristics and backgrounds.

The information gained from these surveys should be used to inform future end of life care policies, strategies and delivery plans.

* On behalf of Marie Curie, Ipsos MORI interviewed a quota sample of 1,067 adults aged 16-75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last three years. This sample was screened from a nationally representative sample of 6,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using i:omnibus, Ipsos MORI's online omnibus between 3 and 29 October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience.

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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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