

Marie Curie – Health, Social care and Sport Committee Inquiry into loneliness and isolation, consultation response

Introduction and scale of the problem

We welcome the opportunity to respond to the National Assembly for Wales' Health, Social Care and Sport Committee's call for evidence into loneliness and isolation. We want to highlight the issues of social isolation for people who have a terminal illness and the social difficulties around death, dying and loss that can exacerbate this.

At Marie Curie 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.

The number of older people in Wales' population is growing; people aged 85 and over make up around 2.5% of the Welsh population and this is projected to increase by 87.2% by 2030¹. This shifting demographic, coupled with an increasing average life expectancy means that people are living longer and with more complex needs than before, often with multiple long-term conditions. We also know that the number of people dying each year is anticipated to have risen by 9% by the same time.

Many of these people will be living with a terminal illness. By that, we mean they will have reached a point where their illness is likely to lead to their death. Depending on their condition and treatment, they may live with their illness for days, weeks, months or even years after this point.

Marie Curie is the UK's biggest provider of care for people living with a terminal illness outside the NHS. Our mission is to help people living with a terminal illness and their families make the most of the time they have together by delivering expert care, emotional support, research and guidance.

Across the UK we have nine hospices (including one in Penarth) and around 2,000 community nurses spread across the UK (including around 150 in Wales).

Our hospice in Penarth cost £3.4m to operate during 2015/16 of which £1.4m (42%) came from NHS/Govt funding with the rest coming from fundraising/charitable donations. During 2015/16 our hospice in Penarth provided 9,497 days of care to 472 individual patients.

Our nursing service in Wales cost £3.7m to run during 2015/16 of which £1.8m (49%) was funding from NHS/Govt funding, with the rest coming from charitable donations. Across Wales in 2015/16 our nurses delivered a total of 88,914 hours of care to 2,424 patients.

We run a Helper service in Wales. This service is managed by Marie Curie employees but delivered by volunteers. They are very carefully recruited, trained and supported to offer to companionship, support and friendship to people at the end of their lives. Each helper works with one individual. The resources to run the Helper service come entirely from charitable donations. The Helper service currently operates in Cardiff, Vale of Glamorgan and Rhondda Cynon Taf with plans to further roll out across more of Wales.

¹ www.MarieCurie.org.uk/Atlas

Many people who have a terminal illness will need some support or companionship from other people. Whilst the NHS/Social Services can provide some of this, charity and other third sector providers are needed too.

We cannot look at one aspect of loneliness and isolation, we need to be able to look at cause and effects of the issue. Often this cannot simply be separated.

We know ill health can contribute to social isolation, through physical and mental manifestations in many illnesses. In the case of terminal illnesses, the rate of disease progression is often unpredictable and impaired communication has the potential for an increasingly significant impact on personal relationships and interactions – which we know can lead to increased loneliness and social isolation.

Communication is crucial to addressing and mitigating these effects. We know that communication is important in end of life care. For example, advanced care planning is essential to ensure that people with terminal illnesses have their physical, psychological, social, and spiritual needs assessed and their care planned in a way that meets their wishes. Ensuring that these conversations are held and that care plans are agreed is an important element in reducing the likelihood of loneliness and social isolation. However, we also know that the shared experience and emotional support provided by meeting other people in a similar situation can also reduce isolation.² We need to be able to support people to be able to interact with others who understand what they are experiencing, in addition to providing social support, such as befriending, that counteracts social isolation and loneliness.

Impact of loneliness & isolation

For people living with a terminal illness, there are often multiple barriers to getting the care and support that they need. This is particularly evident in remote and rural settings and people in these communities often do not have the same access to care and support services at the end of life as those living in more densely populated areas. As expected they are more likely to be physically and geographically isolated than those living in urban settings. Terminally ill people in rural areas experience barriers to care that include a lack of appropriate transport, physical and social isolation, a limited out of hours services and limited staff resources and specialist services.³

A significant proportion of the Welsh population lives in smaller settlements: nearly 20% live in villages of less than 1,500 persons compared with 10% in England. Wales also has a relatively low proportion of its population in large settlements: only 26% live in urban areas with a population over 100,000; in comparison, nearly 40% of the English population live in urban areas larger than the largest in Wales. Another feature of the settlement pattern in Wales is the share of the population living in the sparsest rural areas: 15% compared with only 1.5% in England.⁴

We know that the physical and mental deterioration often associated with dementia can often lead to social isolation, depression, and carer burden – especially if there are no community support networks. It is important to remember that Dementia remains a terminal illness. There is also evidence to suggest that men living with dementia are less likely to seek and receive the help and support they need although initiatives such as the ‘Men’s Shed’ programme are part of the means to address this issue.

² [Caring about Dying: Palliative care and support for the terminally ill a guide for donors and grant-makers](#)

³ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

⁴ Welsh Assembly Government (2005). *Rural Development Plan for Wales, 2007 to 2013: The Strategic Approach*. pp. 61–63.

It was encouraging to find that a joint event held between Marie Curie and Alzheimer's Cymru recently in Llanelli engaged well with men, suggesting that gender is not necessarily a barrier to accessing help but that the way in which it is designed and provided needs careful thought.

Addressing problems of loneliness & isolation

There are three specific Marie Curie programmes that which helps deal with loneliness & isolation:

2.1 Caring for Carers

Caring for a loved one with a terminal illness can be both physically and emotionally challenging and at times, financially stressful. Research has shown that becoming a carer increases the risk of loneliness.⁵ Carers and family members are at increased risk for depression and social isolation as well as physical illness and injury related to the demands providing care. Additionally, research has also shown that social isolation is often among the symptoms of grief following bereavement. The onset of loneliness can happen gradually and this is often exacerbated by specific life events, especially one associated with loss or bereavement.⁶

Every month in our Penarth Hospice we run an event called 'Careers Café' this is a very informal event where cares can come in for a tea or coffee either as a respite break or to seek advice from both Marie Curie staff and/or from other cares or from former careers who attend.

As mentioned a similar event began in Llanelli in October 2015, run in conjunction with Alzheimer's Cymru.

2.2 Helper programme

The Marie Curie Helper Service provides one-to-one emotional support, companionship and information about relevant local services to people living with terminal illnesses, and their families and carers through the use of volunteer helpers.

The Helper service specifically aims to:

- Fill the gap in meeting the emotional support needs of terminally ill people, and those of their carers
- Provide carers with support to enable them to continue caring
- Reduce social isolation faced by some terminally ill people and their carers
- Support people throughout the terminal phase of their illness, usually within the last 12 months of life

Our Helpers visit people in their homes, offering a few hours of their time each week to provide company and support to people with a terminal illness, and their families and carers, to help them to cope with more confidence. This service is available from the time of a person's terminal prognosis and for their families after bereavement.

⁵ ibid

⁶ <http://www.iriss.org.uk/resources/preventing-loneliness-and-social-isolation-older-people>

The Marie Curie helper service is relatively new and currently operates across Cardiff, The Vale of Glamorgan and in the Rhondda Valley. Over time we hope to expand this when resources and volunteers allow.

2.3 Information and Support line

Launched in March 2015, Marie Curie's Information and Support line (0800 090 230) offers free support, help and advice for patients, relatives and carers regarding terminal illness, death and dying as well as bereavement/support. 9,936 calls were received in the 2015/16 financial year, whilst most of the calls were for general support and practical day-to-day care matters 17% were for emotional support and 6% for help with bereavement.

Many of the calls have been from people just looking for someone to talk to (these calls come from both people who are terminally ill and relatives/carers) rather than enquiring about a specific problem. The call centre has received calls from people with a terminal condition who are phoning up simply to let others know how they're doing.

Loneliness and isolation with regards to Palliative Care

Whilst the remit for the consolation does not specify specific scenarios, Marie Curie would like to draw the committee's attention to the following:

Loneliness and Isolation is also an increased risk factor in people not receiving palliative care when they need it. Research shows that there are significant differences between palliative care patients and people who die without access to palliative care⁷.

Therefore, we need to ensure that everyone with a terminal illness gets the care they need, when they need it. Recent research in primary care has shown that 1 in 4 people and up to 8 out of 10 non-cancer patients with a terminal illness are not accessing palliative care and those that do are getting it very late into their care. Often support for people earlier than the last weeks of life is patchy, as is bereavement aftercare. Lack of access to professional and support services can cause complex social and psychological issues for people and their families.⁸

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⁷ Mergam, A. N., Pepersack, T., & Petermans, J. (2007). [Risk factors for not benefiting from palliative care in end-of-life geriatric patients]. *Revue medicale de Bruxelles*, 29(5), 481-485.

⁸ http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf