Introduction

We welcome the opportunity to respond to the Equal Opportunities Committee call for views around age and social isolation. We particularly 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.

Scotland’s population is ageing; the number of people aged 75 and over is projected to increase from 420,000 to 780,000 by 2037 (an 86% increase). This shifting demographic, coupled with an increasing average life expectancy means that people are living with more complex needs than before, often with multiple long-term conditions. Audit Scotland¹ estimates that by the age of 65, nearly two-thirds of people will have developed a long term condition and that older people are also more likely to have more than one long term condition with 27% of people aged 75-84 having two or more.

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. But one thing we do know is that they will need care and support for all or part of that time.

Scotland’s 2011 census² showed that single person households are the most common household type, accounting for 35 per cent of all households. These numbers are projected to increase to around 41% (1.15 million) by 2037³. For those above pensionable age, not only are they more likely to have complex and long term conditions, but 25% of men and 61% of women are living alone.

Marie Curie is the UK’s biggest provider of high quality care for people living with a terminal illness. We care for over 7,500 patients across Scotland through our hospices, community nursing services and support services. Every day matters when you’re living with a terminal illness and we want to help people make the most of the time that they have left. As part of this, we need to address the inequities that exist in accessing care and support and address societal responses to death and dying.

Themes

Remote and rural

For people living with a terminal illness, there are often multiple barriers 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 than those living in more densely populated areas. They are more likely to be physically and geographically isolated than those living in urban settings. Terminally ill people in rural Scotland experience barriers to

¹ http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions
² http://www.scotlandscensus.gov.uk/housing-and-accommodation
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.

Rural Scotland accounts for 95% of its total land area, with just under a million people (around 19% of the population) living in rural areas. Pensioners living alone in Scotland account for 15% of households in remote rural areas, and 12% in accessible rural areas compared to 13% in the rest of Scotland. The local authorities with the largest very remote rural areas are the Highlands & Islands, Argyll & Bute, Aberdeenshire and parts of Perth & Kinross, Dumfries & Galloway, South Ayrshire and the Borders.

Remote and rural services

Marie Curie are currently delivering care in remote and rural areas, including Argyll and Bute, Dumfries and Galloway, the Highlands and Aberdeenshire, through partnership working in service delivery and design, and raising awareness with service providers and policymakers. We have an ‘optimal use of rural resource’ workforce model which means that Marie Curie community nurses can deliver a flexible 24/7 palliative care services. This enables high quality end of life care to be delivered even in the smallest island populations and remote areas including Orkney and the Western Isles.

Our work in these areas involves tackling social isolation related to geographical boundaries, but you don’t have to be hard to reach to be socially isolated.

Terminal illness itself is isolating. Having a terminal illness can be incredibly restrictive physically, psychologically, socially, and spiritually – and this can often be the case when a person with a terminal illness is surrounded by friends and family members. What about the people that don’t have these support networks? We are currently experiencing an increase in single person households, and this is estimated to grow. Social isolation and greater need for nursing care will likely grow alongside this.

Symptoms

People living with a terminal illness will often have complex symptoms, symptom and pain management. This will differ according to their specific circumstances and conditions – a few of these are highlighted below:

Chronic Obstructive Pulmonary Disease (COPD)
People with very severe COPD have a number of disabling physical symptoms (especially breathlessness), compounded by comorbidity, psychological distress, and social isolation.

Motor Neurone Disease (MND)
People with MND may experience social isolation due to their complex care needs. They may experience swallowing difficulties, require diet texture modifications which can cause social embarrassment in restaurants. They may experience speech changes which can cause issues with self-image and self-esteem. This may develop into an inability to speak which can cause frustration as they are unable to make themselves understood or heard. Increased

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5 Caring about Dying: Palliative care and support for the terminally ill a guide for donors and grant-makers
6 http://www.bmj.com/content/342/bmj.d142
fatigue may also mean they are unable to leave the house. All of these factors can lead to increased social isolation\textsuperscript{7}.

**Multiple Sclerosis (MS)**

Physical symptoms of MS may include a limp, an unsteady gait, muscle twitches, excessive bathroom usage and sudden exhaustion. This can cause social embarrassment, and that coupled with a physical inability to leave the home unaided can cause social isolation and feelings of not being understood by the general population\textsuperscript{8}.

**Dementia**

Dementia and other neurologically disabling illnesses present similar community end-of-life care issues. Physical and mental deterioration often lead to social isolation, depression, and carer burden – especially if there are no community support networks.

Physical manifestation of symptoms can often have a direct impact on the mental health of people with a terminal illness. This in itself can cause and exacerbate social isolation and depression, but coupled with the realisation and acceptance of their terminal diagnosis, these feelings are significantly heightened. This becomes considerably more complex in the current societal climate, where there are social difficulties around talking about death, dying and loss.

**Familial, societal and policy considerations**

We need to be able to have honest and open conversations about death and dying – at a family and a societal level. Far too often families do not talk about death and dying even when a family member is terminally ill. Research suggests that some terminally ill patients aren’t even aware that they have a terminal diagnosis and that GPs find such conversations difficult with their patients.

This is also true at a policy level. For example, the Scottish Government’s vision set out in its 2020 Vision for Health and Social Care is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting. The Quality Strategy also sets out how the Government plans to make NHS Scotland a world leader in healthcare quality, providing person-centred, clinically effective and safe healthcare services and achieve its 2020 vision. However, there is currently no reference to terminal illness, dying or death in the Scottish Government’s 2020 vision. How can we expect to change societal attitudes to death and dying if we do not talk about it at a policy and country-wide level. We hope this is addressed in the current planned refresh of the 2020 Vision.

**Palliative Care**

Social isolation is also an increased risk factor for 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 care\textsuperscript{9}.

Therefore, we need to ensure that everyone with a terminal illness gets the care they need, when they need it. This means addressing the inequity between malignant and non-malignant terminal illness. Recent research in primary care has shown that 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


\textsuperscript{8} http://www.msstrength.com/multiple-sclerosis-and-isolation/

is bereavement aftercare. Lack of access to professional and support services can cause complex social and psychological issues for people and their families.\(^{10}\)

The Scottish Government has committed to publishing a new strategy this by the end of 2015, which Marie Curie welcomes. The new strategy must look to develop a societal response to the issue of caring for terminally ill people. It must focus on addressing the inequities of care across diseases and settings.

**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.\(^{11}\) 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. We welcome the recent development of the Carers (Scotland) Bill to ensure every carer in Scotland is supported.

Additionally, research has also shown that social isolation is often among the symptoms of grief following bereavement. The onset of loneliness can often happen gradually and this is often exacerbated by specific life events, especially one associated with loss or bereavement.\(^{12}\)

**Bereavement support**

Marie Curie nurses provide bereavement support to families and carers, providing both practical assistance and emotional support before, during and following bereavement. Over the next five years we plan to increase this support both within our hospices and through the Marie Curie Nursing Service, which operates in 31 local authority areas in Scotland. We will also research the unmet need for individually tailored bereavement support and look at our role in addressing this need in the future.

**Helper Service**

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.

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\(^{10}\) [http://www.ncpc.org.uk/sites/default/files/Public\_Health\_Approaches\_To\_End\_of\_Life\_Care\_Toolkit\_WEB.pdf](http://www.ncpc.org.uk/sites/default/files/Public\_Health\_Approaches\_To\_End\_of\_Life\_Care\_Toolkit\_WEB.pdf)

\(^{11}\) Ibid

The Helper service is currently delivered in Fife and we are currently expanding the service to make it available in Grampian and Lothian.

**Causes and impacts**

We cannot look at one aspect of social 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. However, inversely we also know that loneliness and isolation also have significant negative impact on health\(^{13}\).

Communication is crucial to addressing and mitigating these effects. We know that communication is important in end of life care; 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 accordingly to reduce incidences of 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.\(^{14}\) 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.

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13 March 2015

\(^{13}\) [http://www.ucl.ac.uk/anthropology/people/academic_staff/d_miller/mil-28](http://www.ucl.ac.uk/anthropology/people/academic_staff/d_miller/mil-28)  
\(^{14}\) [Caring about Dying: Palliative care and support for the terminally ill a guide for donors and grant-makers](http://www.ucl.ac.uk/anthropology/people/academic_staff/d_miller/mil-28)