

Parliamentary Briefing

Palliative care in light of the Parliamentary and Health Service Ombudsman's report *Dying without Dignity*

22 June 2015

Purpose of this briefing:

To provide peers with more information about Marie Curie's position on *Dying without Dignity* and campaigning activity ahead of Lord Farmer's Oral Question on the Health Service Ombudsman's report. **The question is scheduled to be answered at 2.30pm on 23 June 2015.**

Marie Curie's Position on *Dying without Dignity*:

Dying without Dignity was published on 20 May 2015. Marie Curie welcomed the report as a stark illustration of what can happen to people with a terminal illness when they are failed by staff without adequate training and let-down by a system that struggles to provide effective support outside normal hours.

What we are keen to emphasise is that the harrowing stories contained in the report are not rare. Research from the London School of Economics, commissioned by Marie Curie and published earlier this year, shows that **each year around 110,000 people who need palliative care are missing out**, many of whom are people with an illness other than cancer or people over the age of 85. These perceptions also reflect the views of carers. In a recent survey of 1,067 carers in the UK, seven out of 10 (68%) said that people with terminal illnesses don't get all the care and support they need¹.

This means that each year a large number of people are struggling to live with a terminal illness, without the help they need to manage their symptoms and improve their quality of life. Poor care also leaves a legacy with carers, family and loved ones. We think this is simply not good enough.

What you can do to help:

On 23 June 2015, Marie Curie is publishing a new report called *Triggers for Palliative Care* that identifies some of the barriers that is preventing 110,000 people accessing palliative care each year. One of the key barriers is the lack of training that doctors and nurses receive in identifying which patients need palliative care and how to support them.

In a survey by Ipsos Moriⁱⁱ on behalf of Marie Curie of 500 UK clinical professionals, over a third (39%)ⁱⁱⁱ said that a lack of relevant experience amongst staff delivering care is a barrier to meeting the needs of terminally ill people and over half (55%)^{iv} considered better identification of an illness as terminal to be highly important in improving the quality of patient care.



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As such, we are calling for every healthcare professional to receive further training and development in palliative care to ensure that everyone with a terminal illness gets the care and support they need. No one should have to do without palliative care when they have a terminal illness.

If you are able to speak to Lord Farmer's question on Tuesday, we would be very grateful if you could highlight that:

- The experiences in *Dignity in Dying* are not rare – 110,000 people miss out on palliative care each year and this leads to failings in care that affect both terminally ill people and their families and loved ones.
- Our new report, *Triggers for Palliative Care*, highlights that a lack of training in identifying and providing care to people with a terminal illness is one of the key reasons that people miss out on palliative care – and healthcare professionals agree.
- All healthcare professionals need on-going training and development to ensure that they identify people with a terminal illness and refer them to palliative care services.
- If this problem is not tackled soon then it will likely get worse. By 2040 there will be 100,000 extra people dying per year, which means more people will be missing out on palliative care.

About Marie Curie

Marie Curie is the UK's leading charity for people with any terminal illness. The charity helps people living with a terminal illness and their families make the most of the time they have together by delivering expert hands-on care, emotional support, research and guidance.

Marie Curie employs more than 2,700 nurses, doctors and other healthcare professionals, and with its nine hospices around the UK, is the largest provider of hospice beds outside the NHS.

ⁱ On behalf of Marie Curie, Ipsos MORI interviewed a 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 3 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 3rd and 29th October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience.

ⁱⁱ On behalf of Marie Curie, Ipsos MORI interviewed an online sample of 500 clinical professionals from across the UK. Interviews were conducted between 12th and 31st March 2015. The sample was made up of the following specialisms: Hospital Based Physicians, General Practice, Oncology Nursing and Specialist Nursing, Anaesthesiology and Hospice and Palliative medicine

ⁱⁱⁱ To the question, 'which of the following do you believe are barriers in meeting the needs of terminally ill people', over a third (39%) say that a lack of relevant experience amongst staff delivering care is a barrier to meeting the needs of terminally ill people

^{iv} To the question, 'to what extent do you consider each of the following to be important to you, or not in terms of in improving the quality of care for people with a terminal illness' on a scale of one to ten where one means it is not at all important and ten means it is very important: over half (55%) rated (8 out of 10 score of importance) better identification of an illness as terminal by healthcare professionals. Nearly a third (32%) gave a score of 9 or 10, with 14% giving the highest score of 10 (very important)

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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.

mariecurie.org.uk

Charity reg no. 207994 (England & Wales), SC038731 (Scotland) A003



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