

Dementia and End of Life Care

Westminster Hall debate on the barriers of care related to Dementia and Alzheimer's disease – 12 April 2016

What is the purpose of this briefing?

To provide you with further information ahead of the Westminster Hall debate tabled by Jim Shannon MP on Tuesday 12 April 2016, 9.30 am - 11.00 am.

What is Marie Curie's position?

People with dementia often have very high levels of palliative care need. Palliative care helps control symptoms and keeps people living as well as possible in the final stages of their lives. Frequently the need for palliative care in people with dementia goes unrecognised. Research by the London School of Economics (LSE) shows that people with conditions other than cancer and those over the age of 85 are less likely to receive palliative care.

The number of people living with dementia is increasing each year. This means that palliative care need among people with dementia will also grow. The current system must change to meet not only the present need among people with dementia but to meet future demand. Marie Curie is committed to working with a range of partner organisations to promote a stronger focus on dementia as a terminal condition and in particular the barriers which prevent many people with dementia from accessing and receiving appropriate high quality palliative care at the end of their lives.

The challenges of a dementia diagnosis and end of life care

- **Our ageing population means that over the coming decades, a growing number of people will experience the different forms of dementia.** Between 2003 and 2013 the percentage of deaths from dementia and Alzheimer's disease rose from 4.7% to 12.2% for women and from 2% to 6.2% for men. An estimated one in three people over the age of 65 years who die will have some form of dementia.
- **Debates about dementia focus almost exclusively on early stages of the condition, on diagnosis and on the search for a cure, with little reference to its final stages.** Dementia is a terminal condition which means that equal emphasis must be placed on the care which is provided to people with dementia and the support which is available to their families and carers. We must be realistic and acknowledge that the eradication of dementia is, at present, a medium to longer term project rather than a short term goal. It is important that we provide high quality care and support to people living with the disease now.
- **Lack of timely and appropriate diagnosis and recognition of dementia as a terminal condition leads to ineffective advance care planning.** Timely diagnosis has a major potential impact on subsequent access to support, treatment and appropriate care. The ultimate cause of death is often attributed to an infection or other common illness and is stated as such when the death is formally



registered.

- **Because of the condition's emphasis on symptom management, inequality of access is a major concern.** There is a current under-use of both hospice and specialist palliative care. These services need to be made available by giving their staff and volunteers the training and skills to deliver services to people with dementia.
- **Inappropriate admission to and inconsistent care in hospitals reduces the quality of care experienced by people with dementia.** Hospitals are very difficult places for people with dementia, even more so because the condition is not adequately identified during admission. The experience leads to poor pain management and ultimately causes unnecessary disruption for a person with dementia in the final days and weeks of life and negatively impacts on survival times.

What need to be done?

We believe that the Government and NHS England should work together to ensure the following actions become a priority and help people with dementia to access the high quality end of life care they are entitled to:

- **Remove barriers.** Ensure that these people are supported to live their lives as they want for as long as they can, and, when they approach the last weeks and months of their lives, they are able to access the most appropriate care, advice and support.
- **Transform core services.** Enhance the role of palliative care for people with dementia much earlier in the development of the condition and replicate examples of excellent links between local palliative care services and care homes and hospital services across the country.

We would be grateful if you could raise these points during the debate. If we can provide any further information, then please do get in touch.

About Marie Curie

Marie Curie is the leading charity for people with a terminal illness and their families. We:

- Provide direct care to people in our nine hospices across the UK and in their own homes;
- Offer a dedicated information and support service to people affected by terminal illness;
- Run the UK's largest research programme into improving care for people with a terminal illness and their families;
- Campaign to ensure that everyone living with a terminal illness and their families and carers get access to the care and support they need.
- Work as part of the end of life care coalition to ensure everyone can get high quality care at the end of life.

For more information contact:

Scott Sinclair
Head of Policy & Public Affairs
Marie Curie
020 7599 7116
scott.sinclair@mariecurie.org.uk