

## **Cross Party Group on Dementia**

**Meeting – 26/3/2015**

**Meeting Start Time:** 12.45pm

**Present:** Sue Northrop (Dementia Friendly East Lothian); Amy Dalrymple (Alzheimer Scotland); Susanne Cameron-Nielsen; Lynne Stevenson (Nutricia); Mary Scanlon (MSP); Roderick Campbell (MSP); Shirley Law (DSDC); Jeanette Maitland (NDCAN); Richard Meade (Marie Curie Scotland) and Eilidh Lean (in-house secretariat).

**Apologies:** Dr Fiona McLeod, Dr Seamus McNulty, Dr Jacqueline Wilson, Swaran Rakhra, Anna Buchanan, Mark Hazelwood, Irene Oldfather, Dr Nanette Milne (MSP).

Roderick welcomed and introduced Richard Meade and Amy Dalrymple. He explained that they were giving presentations on end of life care for people with dementia.

### **Presentation from Richard Meade:**

Richard Meade explained why Marie Curie are talking about Palliative Care for people with dementia. He noted that many people believe that Marie Curie is only there to help cancer patients, when in reality, it is for all of those with a terminal illness. This is why Marie Curie has launched a new strategy – they are looking to do more for terminally ill people and their families – policy work and campaigning.

RM explained that Marie Curie recently launched their Living and dying with dementia in Scotland report. He indicated that Marie Curie recently conducted a UK-wide literature review and study, with individual reports for the four constituent nations.

RM then set the scene as it currently stands in Scotland, almost 90,000 people in Scotland are living with dementia and this is set to double by 2031. He explained that over 54,000 people die every year in Scotland, and this number is expected to rise by 5% in the next 15 years and 13% in the next 25 years. The number who die due to dementia are underrepresented – for example, people will die of pneumonia but rarely dementia. Hopefully, we will have more robust data following the introduction of new arrangements on the registration and certification of deaths in Scotland.

RM explained that 30% of those in hospital are within the last 12 months of their life and two-thirds of them have co-morbidities. We know that 60% of people will die in hospital yet the vast majority of people would prefer to die at home. From the evidence available, it would suggest that a considerable number of people with dementia die in hospital.

RM then showed a slide that showed the terminal trajectory typical of cancer and dementia – cancer is fairly predictable, whereas dementia is unpredictable. This is why there are barriers of care for dementia sufferers.

RM then asked what do we mean by palliative care? Palliative care is the active, holistic care of people with advanced progressive illness, involving the management of pain and other symptoms and the provision of psychological, social and spiritual support. He explained that it is often misunderstood – it is associated with cancer and medical care. Lots of evidence that people with dementia would benefit from palliative care. Of 54,000 people who die in Scotland, almost 35-40,000 need palliative care but only 20% of people with dementia are getting it. Whereas 75% of terminally ill cancer patients receive palliative care. He indicated that of those dementia patients who do get palliative care, it is only within the last few weeks of life.

So, why are dementia patients not getting the care?

Dementia isn't diagnosed as a terminal illness by health and social care professionals; gaps in knowledge of identifying dementia patients for palliative care; palliative care consultants don't understand dementia; primary care practitioners struggle to talk about death; issues in identifying dementia as the cause of death.

### **Q&A Session following the presentations**

The meeting was then brought to a close and finished at approximately 14.00.