

## **We need to talk about Palliative Care**

### **Alzheimer Scotland**

#### **Introduction**

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website ([www.alzscot.org](http://www.alzscot.org)) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to the Health and Sport Committee's Inquiry into Palliative Care.

Alzheimer Scotland is currently in the latter stages of developing an important policy report that will include a model of care for people with advanced dementia and people at end of life who have dementia. The report will be published in autumn 2015. The model will be based on the approach of the Eight Pillars Model of Integrated Community Support<sup>1</sup> which is currently being tested in five areas of Scotland, as part of the Scottish Government's second National Dementia Strategy. The model and the report have been informed by a wide ranging consultation, from October 2014 to June 2015, with people with dementia, carers and former carers of people with dementia, and clinical and social care professionals at all levels in the voluntary, public and private sectors.

Alzheimer Scotland's comments to the Committee's Inquiry are therefore informed by our research and consultation about advanced dementia and end of life with dementia. We will be happy to share the report with committee members once it is complete; we hope you will agree, along with the many stakeholders we spoke to over the course of our consultation, that this is an important piece of work in identifying how our health and social care system can best support people with dementia and the people close to them – something that the system all too often currently fails to do.

#### **Key Issues**

We aim, here, to set out the key issues for regarding palliative care as they affect people with dementia and carers. These have been informed by Alzheimer Scotland's research in the development of our forthcoming report. We hope that this is useful for committee members and would be happy to explore this further in discussion.

---

<sup>1</sup> [http://www.alzscot.org/campaigning/eight\\_pillars\\_model\\_of\\_community\\_support](http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support)

## Advanced dementia

One of the key impacts as dementia progresses is the increasingly physical nature of the experience. Advanced dementia presents a range of potential symptoms that impact on mobility, bodily function, resilience and physical wellbeing. Many of the manifestations of advanced illness can be seen as resulting from a complex interplay of the increasing cognitive impairment and diminishing physical robustness.

The range of physical, psychological and social issues in advanced dementia requires a bio-psychosocial approach in understanding and responding to the individual experience. An individual's personality, life experience, physical and psychological health and social context will have an influence on how they respond to the symptoms of dementia and in turn the approach to support required.

Defining the point at which a person can be said to have reached advanced dementia is complex – there is no particular set of symptoms that signify this and the pattern of declining cognitive and physical function is neither fixed nor predictable.

Given the unique nature of the individual experience and the influence of a wide range of factors it is more appropriate to consider the level and complexity of care needs in understanding when advanced illness is being experienced.

Age at the onset of dementia is the main predictor for life expectancy. There is a great deal of uncertainty in understanding when a person with dementia is actively dying<sup>2</sup>.

## Responses

Health care practitioners have a key role in responding to the increasing physical nature of advanced dementia and the influence of co-morbid conditions.

Issues relating to nutrition and hydration are highly prevalent in advanced dementia and at end-of-life.

Psychological symptoms are common during the advanced illness and at end-of-life; increasing cognitive decline makes it more difficult to respond to these symptoms.

---

<sup>2</sup> Murray S, Kendall M, Boyd K & Sheikh A (2005) Illness trajectories and palliative care *BMJ* 330:1007-1011

Communication changes in advanced dementia makes the responses of others of key importance in ensuring the person remains socially connected.

Not everyone with advanced dementia will be in older age groups – in addition to early onset dementia, people with learning disabilities are at increased risk of developing dementia at a younger age.

### **Day-to-day care**

Evidence points to the highest proportion of people with advanced dementia living in a care home with a smaller number continuing to live at home. It also shows that hospitals are an important context for end-of-life care in dementia. When a person continues to live at home during advanced illness much of their care is likely to be provided by those closest to the person<sup>3</sup> - if the person is living in a care home their day-to-day caring will be provided by care workers.

Those providing care require support in understanding and responding to the changing and challenging needs of the person and their condition. They also need to be appropriately supported in providing care and for their own wellbeing to be recognised and addressed. We therefore need to consider the needs of both those who provide care informally due to a close relationship with the person, and paid care staff to ensure that they are adequately supported, trained and resourced to provide quality care.

### **Palliative Care**

There is currently no planned and coordinated approach to providing the care required to support people living with advanced dementia in the community. This can result in crisis interventions in response to medical emergency and the breakdown of the caring relationship.

Palliative care was developed as a response to cancer when active treatment was no longer applicable - care models and access routes reflect these origins. A palliative care approach would seem highly relevant in dementia with its focus including (1) the management of pain and other distressing symptoms (2) support for the emotional, practical and spiritual issues in serious illness and (3) involving and supporting the family through illness and bereavement.

The presence of communication and psychological issues are a significant consideration in responding appropriately to advanced dementia. It is suggested that communication issues alongside ethical and legal concerns can make practitioners reluctant to take a palliative care approach when faced

---

<sup>3</sup> This is often the spouse, partner, adult children or other close relationship

with difficult decisions<sup>4</sup>. Extending a palliative care approach to dementia also raises concerns about the level of need this will create and whether practitioners have the appropriate skills<sup>5</sup>. Review of evidence in palliative care has shown the symptoms of dementia are not effectively addressed and the dying phase can often go unrecognised<sup>6, 7</sup>.

Despite the difficulties outlined above there is potential for a palliative care approach to be an important aspect of supporting people living with advanced dementia. However, the extension of palliative care in itself cannot be considered a ready-made response to advanced dementia. Rather it has an important supporting role for those already providing care in dementia, alongside the other specialists required in responding to the most complex phase of the illness.

Palliative care specialists are skilled in assessing and managing pain and other distressing symptoms. Dementia care practitioners have key skills in responding to communication difficulties and psychological symptoms of dementia. A planned and coordinated approach is required to harness the contribution of both specialities in responding to the complexity of advanced dementia. There is a need to bring together the expertise of dementia care practitioners and palliative care specialists in responding to advanced dementia.

### **Next Steps**

These are the relevant issues that will be identified in Alzheimer Scotland's forthcoming report. Alzheimer Scotland will ensure that committee members receive a copy of the report, which we hope will be of interest. We look forward to further discussion of the issues raised

**Alzheimer Scotland  
16 September 2014**

---

<sup>4</sup> Dixon J, King D, Matosevic T, Clark M & Knapp M (2015) *Equity in the provision of palliative care in the UK: review of evidence*

<https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf> (accessed May 2015)

<sup>5</sup> Hospice UK (2015) *Hospice enabled dementia care: the first steps*

<http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care> (accessed August 2015)

<sup>6</sup> Birch D & Draper J (2008) A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia *Journal of Clinical Nursing* 17(9)1144-1163

<sup>7</sup> Rowlands C & Rowlands J (2012) Challenges in delivering effective palliative care to people with dementia *Mental Health Practice* 16(4)33-36