

## Alzheimer Scotland Palliative Care Initiative (2009)

This exciting year-long initiative is a partnership project between Alzheimer Scotland, Dumfries and Galloway NHS and The University of the West of Scotland and is funded by the Scottish Government and NHS Education Scotland (NES).

It builds on Alzheimer Scotland's previous work in raising the profile and understanding of the need of people with dementia in the later stages of the illness and their relatives.

Firstly through the Lighting up Lives<sup>i</sup> report (2004 -2006) which identified the unmet palliative care needs of people in this stage of the illness living in Dumfries and Galloway and was funded by the Big Lottery Fund

Secondly through the Beyond Barriers Project (2007- 2009) this was a partnership between Alzheimer Scotland, the Care Commission and Dementia Services Development Centre Stirling and was funded by the Scottish Government. The Beyond Barriers Project has recently won a Mental Welfare Commission Principles into Practice Award for Carer Support and Involvement. The Mental Health (care and treatment) 2003 Act is underpinned by a number of important principles and these principles should be the gold standard of all mental health care not just for those people who are detained under the Act

The aim of the Beyond Barriers project was to develop current care practice by supporting staff *and* relatives to meet the palliative care needs of people in the later stages of dementia living in care homes and recognised that this process maybe protracted and last up to two years.

The training consisted of an innovative three-day course for both care staff *and* relatives and a further five half-day sessions of supported learning for staff to enable them to implement their learning in practice.

The focus of the course placed communication at the heart of the sessions. It acknowledged the importance of person centred care and examined how a palliative care approach could enhance quality of life at this stage of the illness. An open approach was adopted that dying *with* dementia or *of* dementia will occur. It accepted that dementia is non-curative and for those people who reach the later stages of the illness it will be terminal. It also recognised that there were important lessons to be learnt from this project in managing the care of people with dementia who will die of other unrelated illnesses at any stage of their dementia.

Outcomes of this work have been: -

- the development of workbooks linked to knowledge evidence requirements for Health and Social Care SVQ
- a greater understanding or the importance of involving relatives in such a programme of education
- a greater understanding of the palliative care needs of people with dementia

- the importance of providing supported learning to enable change in practice to occur

The aim of the Alzheimer Scotland Palliative Care Initiative will be to develop the knowledge and understanding of a palliative care approach to care for people with dementia and their families to a much wider audience including health and social care professionals.

The Review of palliative care services in Scotland August 2008 identified that ‘specialist palliative care should be available to patients with complex needs while general provision should be available to all.’ One of the key messages from the report identified ‘that most palliative care is provided by generalist staff in hospitals, care homes or in-patient’s own homes. But palliative care needs are not always recognised or well supported. Generalists need increased skills, confidence and support from specialists to improve the palliative care they give to patients and their families’<sup>ii</sup>

The Initiative will therefore: -

- develop the Beyond Barriers workbooks to meet the wider needs of health and social care professionals
- ensure that the workbooks reflect the Living and Dying Well Action Plan<sup>iii</sup>
- gain SVQ accreditation for the workbooks
- publish the workbooks
- identify staff providing education within all NHS, voluntary and all social care settings
- provide a free two-day course for up to 60 of the identified trainers. The aim of the first day of the course will be to equip them with the knowledge and skills to deliver the course. This will be followed up by a further day of supported learning.
- there will also be the opportunity for the trainers to participate in an Action Learning Set, this will be optional as it will not be free.

Initially there will be a small pilot session. The courses will then be rolled out throughout Scotland and will be delivered by experienced members of the Alzheimer Scotland Learning Development Team

The University of the West of Scotland will externally evaluate the Initiative.

If any one would like more information about the project please contact [jhenderson@alzscot.org](mailto:jhenderson@alzscot.org) or telephone 01387 261303.

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## Alzheimer Scotland SQA Centre



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<sup>i</sup> [www.alzscot.org/pages/policy/palliativecare](http://www.alzscot.org/pages/policy/palliativecare).

<sup>ii</sup> Audit Scotland *Review of palliative care services in Scotland* August 2008 ISBN: 978 1 906752 [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)

<sup>iii</sup> The Scottish Government *Living and Dying Well a national action plan for palliative and end of life care in Scotland* 2008 ISBN: 978-0-7559-5889-4