Alzheimer Scotland welcomes the opportunity to provide comments on the draft budget and spending review. The focus of the Committee’s scrutiny is of particular relevance to people with dementia and their carers. Preventative support is essential in enabling people with dementia to remain in the community for longer. The majority of care for people with dementia is provided by unpaid carers; they should be assisted from an early stage in their caring role, as the system is reliant upon their continued support.

There has been significant progress in policy with the National Dementia Strategy in relation to acute care. However, given the Strategy has two key priorities; to improve the response to dementia in general hospital settings and improved post-diagnostic information and support, we ask for more support for the latter.

We had hoped for investment in post-diagnostic support as part of the Reshaping Care for Older People Change Fund. However, only a minimal sum was spent directly on people with dementia and their carers from the initial allocation of the fund. In recent months local health and social care partnerships have begun to consider this and we hope that next year each partnership develops a local strategy for investment in post-diagnostic support for people with dementia.

We are concerned at the inconsistencies in both development and delivery of post-diagnostic support for people with dementia across Scotland. Whilst there are examples of very good services, these are the minority. The experience of many is to receive the diagnosis of a terminal illness, be told there is nothing that can be done and simply to come back to see the doctor if things get worse.

Post-diagnostic support for people with dementia is a national policy objective and the utilisation of the Change Fund should not be the determining factor in delivering it. Post-diagnostic support for people with dementia and their carers should receive direct mainstream funding. We are asking the Scottish Government for a minimum one year guarantee to provide consistency across Scotland.

Alzheimer Scotland believes that every person diagnosed with dementia should receive a minimum guarantee of one year’s post-diagnostic support with a named and well trained person. With some additional training there is already a range of professionals who could do this. Community Psychiatric Nurses, Occupational Therapists, Social Workers and Link Workers all have the skills and abilities; they simply do not have the time and are not empowered to reach beyond the limitations of their roles at the present time. This support should be as personalised as possible with five main elements:
• Assist the person to come to terms with the illness, understand the implications and manage their symptoms.
• Help maintain the person’s community connections and natural supports.
• Help to plan for their future decision-making, sorting out legal issues and power of attorney.
• Work with families and link them to positive community peer and educational support.
• Help to plan the shape of their future care.

There are around 82,000 people with dementia in Scotland; as our population ages the number is set to double within 25 years. We can begin to respond to this increase in a positive way by providing support from an early stage in the illness. Approximately 9,000 people should be diagnosed each year at current levels of dementia incidence.

A systematic review by the Department of Health\(^1\) found that investing in early identification and intervention in dementia improved quality of life, delayed the need for institutionalisation and provided a strong financial case for the identification, treatment and support of people with dementia. There is a clear economic argument for proper post-diagnostic support; we estimate that to fund one year’s post-diagnostic support for one person, which best evidence suggests can be expected to delay admission to residential care for between 2-4 years, would cost as little as £1,000-£1,500 per year – but could save as much as £60,000 - £70,000 in latter years.

Investment in post-diagnostic support has to be a key element of future planning for every local health and social care partnership. If we fail to make this investment the system will break down due to the volume of people who end up in crisis and who will be fast tracked towards reactive institutional care.

Please contact me if you would like to discuss these issues further.

Henry Simmons
Chief Executive
Alzheimer Scotland
17 October 2011