

Henry Simmons

Personal Statement

RE: NICE TECHNOLOGY APPRAISAL: Donepezil, galantamine, rivastigmine and memantine for Alzheimer's Disease (part review of TA111)

In support of my nomination I would like to add the following personal statement.

Alzheimer Scotland is the leading Scottish charity that represents and supports the interests of people with dementia, their families and informal carers. We have over four thousand members across Scotland, eight hundred staff and five hundred volunteers. Our mission is to ensure that no one goes through the experience of dementia on their own.

We estimate that there are 69,550 people with dementia living in Scotland. Alzheimer Scotland both provides direct services and campaigns, lobbies and seeks to influence all levels of local and national government to ensure that their rights and the rights of their families and carers are upheld. We work very closely and effectively with a range of partner organisations, for example recently we supported the Alzheimer's Cross Party Group in the Scottish Parliament to develop a Charter of Rights for People with Dementia and their Families, which has been widely adopted and received the support of the Scottish Government.

We provide the only national 24 hour Dementia Helpline, which can be a critical lifeline that helps many individuals and families cope. We have just launched our own self-funded network of 19 Alzheimer Scotland Dementia Advisors who will support individuals and families to cope with the impact of dementia throughout the various stages of their journey and will work with communities and organisations to help them become more dementia friendly and inclusive. We fund a Dementia Nurse initiative that provides three year funding to Health Boards in order to employ nurse consultants who will help shape and improve practice in our general hospitals and improve the experience for people with dementia. We also fund a small number of Research Fellowships, which at present includes three university science-based projects and one clinical research fellowship with the newly-developed Scottish Clinical Research Network.

Central to our work has been the involvement of people with dementia. We have supported and funded the work of the internationally-renowned Scottish Dementia Working Group, employing a small team to support this group and ensure that their voices are heard at all levels of Scottish society, and crucially within our own organisation and policy development process.

The scale, scope and contact of our organisation across the spectrum of dementia practice and directly with people with dementia, their families and friends helps to ensure that in

my role as Chief Executive I am as well informed, guided and supported as possible in order to properly represent their interests. I believe that this would be a useful asset to the appraisal process and team.

This also means that we can formulate a very unique pan Scottish view on the use of donepezil, galantamine, rivastigmine and memantine. We hear first hand the difficulties that some people experience accessing these medications, the varying forms of prescribing practice and the impact that this can make on the lives of people with dementia and their families. We also hear the views from many people about how much of a difference these medications have made to their lives and how valued they are in helping them cope with their experiences of dementia. Within our services we can see how people progress with or without being prescribed donepezil, galantamine, rivastigmine or memantine in the mild to moderate stages of their journey. We can access the views of people with dementia on these matters quickly and effectively and we can contribute our substantial experience of supporting people to deal with these matters over many years to this appraisal process.

Our ability to engage in positive partnerships and dialogue whilst holding a critical or challenging view is well evidenced for example in our role within the development of the first National Dementia Strategy. Our ability to understand, reflect and present a broad view is a valued role that we can bring to this process.

In recent years we have also been responsible for a number of substantial and highly regarded studies and reports that have significantly influenced Scottish Policy. Publications such as The “Dementia Epidemic” and “Meeting our Needs” brought into sharp focus the growing demographic changes and shortfall in service provision. We also have a high public profile and we are frequently engaged with the media with regard to dementia and to the wider demographic challenges and policy issues facing Scotland today.

In relation to direct contact and support of people with dementia we have around 800 staff delivering a wide range of community-based support services. Alongside this we have been attempting to develop new ways of thinking and working. It is within this area that we believe the effective use of medication plays a crucial role and why we have a very strong interest in this review.

Our new approaches and models centre on the principles and practices of “Personalisation”. We believe that this offers people with dementia and their families the opportunity to shape their own support, making the services they use fit and enhance their lives. Developing a greater ethos of self-management must include how best to use medication and the potential impacts and benefits that are associated with that.

We view personalisation as potentially encompassing a new way forward for early intervention in dementia care. The lack of early, preventive support to help people maintain skills and social networks leads to many people with dementia losing contact with friends and family, leaving them increasingly dependent on paid support. The widespread lack of post-diagnostic support also denies them the opportunity to plan

ahead while they have capacity to make decisions. Personalised services are creatively and flexibly designed around the individual, to mesh with and enhance the natural support their friends and family can provide.

I believe that there is a very real and meaningful changing context that needs to be understood in relation to this appraisal. People recently diagnosed with dementia and their families, particularly when the diagnosis is timely have a very different set of expectations. Social policy is shifting towards greater self-directed support, choice and control. These are critical factors in understanding the needs of people with dementia from a holistic and current contextual perspective.

I believe that I can bring this wider practice context and understanding of emerging relevant social policies as well as service user expectation to the appraisal process in such a way as to enhance and inform the process.

Henry Simmons
Chief Executive
Alzheimer Scotland
2/12/09