



*Alzheimer Europe's main aims are by co-operation
to raise awareness of dementia and to support the
sufferers and their carers.*

Office:

145, route de Thionville
L-2611 Luxembourg

MEP

Tel.: (352) 29 79 70

Fax: (352) 29 79 72

E-mail: info@alzheimer-europe.org

Web-site: www.alzheimer-europe.org

Luxembourg, 3 March 2005

Dear <name of MEP>,

I am writing to you to express our deep concern regarding the preliminary recommendations of the appraisal committee of the National Institute of Clinical Excellence (NICE). In effect, the committee proposes to no longer recommend the use of current treatment options and if these recommendations are put into practice, this would deny tens of thousands of people the only treatment available for their condition.

As Members of the European Parliament, you may be interested in knowing that people with dementia in the United Kingdom already have more limited access to diagnostic services and treatment options than those of other Member States of the European Union, a trend which could potentially be exacerbated by this new guidance.

Furthermore, Alzheimer's associations in the United Kingdom fear that this new guidance could undo years of progress in improving dementia care and result in huge numbers of cases going undiagnosed and people failing to receive adequate support and counselling.

We trust that you share our concerns and those of people within your constituencies. Comments on the preliminary recommendations can be sent to NICE until 22 March 2005 and we are hoping that you will support the efforts of the Alzheimer's Society and Alzheimer Scotland in undoing a potentially disastrous decision.

Should you need any further information on the above, please do not hesitate to contact one of our UK associations.

Yours sincerely

Jean Georges
Executive Director

For further information:

<p>Alzheimer's Society Chief Executive: Neil Hunt Gordon House, 10 Greencoat Place SW1P 1PH London UNITED KINGDOM Phone: +44-20-7306 06 06 Fax: +44-20-7306 08 08 Email: NHunt@alzheimers.org.uk Web: http://www.alzheimers.org.uk</p>	<p>Alzheimer Scotland - Action on Dementia Chief Executive: Jim Jackson Drumsheugh Gardens 22 EH3 7RN Edinburgh UNITED KINGDOM Phone: +44-131-243 14 53 Fax: +44-131-243 14 50 Email: jjackson@alzscot.org Web: http://www.alzscot.org</p>
--	---

People with dementia in the United Kingdom already have more limited access to diagnostic services and treatment options than those of other Member States of the European Union

A recent survey¹ conducted in a number of European countries highlighted a number of areas where the situation of people with Alzheimer's disease in the United Kingdom lagged behind that of those from other European countries.

- The time taken to a diagnosis of Alzheimer's disease after symptoms were first noticed was considerably longer in the United Kingdom (32 months) than in France (24), Poland (23), Spain (18), Italy (14) or Germany (10).
- Fewer carers in the United Kingdom (51%) reported that physicians recommended treatment at the time of diagnosis than those of Germany (78%), France (83%), Italy (85%), Poland and Spain (86%).
- The number of carers who believed that governments did not invest enough in Alzheimer's disease was higher in the UK (87%), than in Italy (65%), Germany (77%), France (80%) and Spain (82%), though lower than in Poland (88%).
- Similarly, physicians had lower expectations from the available drug treatments (68% of respondents agreed or strongly agreed that early treatment can delay the progression of Alzheimer's disease) than their colleagues in Spain (86%), Germany (87%), Italy (91%), France (92%) and Poland (96%).

Alzheimer's associations in the United Kingdom fear that this new guidance could undo years of progress in improving dementia care.

Neil Hunt, chief executive of the Alzheimer's Society, said, ' We are stunned at the proposal that vulnerable people with Alzheimer's disease should not receive treatments that have been proven to work. If these initial recommendations are finally approved thousands of people with dementia will be denied the only drug treatment available to them.

'This seems just another example of the NHS failing to take dementia seriously as a medical condition. Despite the fact that these drugs are proven to work, NICE believes that they aren't good value for money. We know they are. The Society has seven years of evidence that proves that these drugs improve the quality of people's lives. NICE seem to think that people with dementia aren't worth spending money on, but how else can you change someone's life for just £2.50 a day?

¹ "Inequalities in Dementia Care across Europe: An Agenda for Change", edited by David Wilkinson in International Journal of Clinical Practice, March 2005, Volume 59, Supplement 146

'Preventing people who may benefit from receiving a drug treatment that works will see us lose a decade of progress and return to a dark age of dementia care.'

The availability of these treatments has revolutionised dementia care; it has encouraged people to seek an early diagnosis; led to the establishment of memory clinics and improved the quality of life for thousands of people with dementia and their carers.

The Alzheimer's Society is deeply concerned about the impact that this decision could have on these other areas of dementia care. If these drugs are no longer available people will see no incentive in seeking an early diagnosis for what is a degenerative and incurable condition and one that needs a great deal of support and information.

Responding in a similar vein, Jim Jackson, Chief Executive, Alzheimer Scotland said: 'We are devastated that people with Alzheimer's disease could be denied treatments that have been shown to work for many people with this illness. It will be a disaster if the hope that drug treatments have brought is taken away.'

'This could be another example of dementia not being given the priority it requires because it is not fully understood. Alzheimer Scotland calls upon NHS Quality Improvement Scotland to reject the draft guidance from NICE.'

'These drug treatments have led to diagnostic services being improved and recognition that better services throughout the illness are required. The draft guidance would take us back to a time where people with dementia and their families were ignored and left to cope as best as they could.'