



## **Paris Declaration on the political priorities of the European Alzheimer movement**

### **Executive Summary**

Alzheimer Europe and its member organisations call upon the European Union, the World Health Organisation, the Council of Europe and national governments to:

- Recognise Alzheimer's disease as a major public health challenge and to develop European, International and national action programmes,
- Dedicate a European Parliament report and resolution on the state of dementia care, treatment and research in Europe,
- Recognise Alzheimer's disease as a major health scourge within the meaning of Article 152 of the EC Treaty and to develop a Community action programme on Alzheimer's disease,
- Investigate the possibility of providing core funding to Alzheimer Europe for the exchange of information and best practices between national Alzheimer associations.
- Make dementia a compulsory part of medical training,
- Support awareness campaigns targeted at the general public to improve the recognition of the symptoms of Alzheimer's disease,
- Continue to make available existing treatments under their national reimbursement systems,
- Support a survey on the existing inequalities of access to available treatments for Alzheimer's disease,
- Foster pan-European research into the causes, prevention and treatment of Alzheimer's disease and other dementias,
- Increase the funding for Alzheimer's research and support collaboration of national research centres,
- Promote the role of Alzheimer associations towards the medical profession so that people diagnosed are systematically informed about Alzheimer associations and the services they provide,
- Recognise the important contributions provided by Alzheimer associations and to provide financial support to them,
- Recognise the significant burden of carers of people with dementia and to support the development of adequate respite services,
- Develop and support a whole range of services for people with dementia ,
- Adequately support people with dementia and their carers to allow them to make use of existing services,
- Extend the Open Method of Coordination to the question of long-term care and to exchange best practices on a national level,
- Reinforce medical codes to ensure people with dementia are adequately informed about their diagnosis,
- Exchange best practices with regard to national guardianship systems,
- Provide a clear statutory basis for effective advance directives with appropriate safeguards

# Paris Declaration on the political priorities of the European Alzheimer movement

## Public health priorities

1. In 2006, close to 5.4 million citizens in the European Union are living with Alzheimer's disease<sup>1</sup> or another form of dementia<sup>2</sup>. With the ageing of the populations in all the Member States of the European Union, these numbers are set to increase and researchers have predicted a doubling of these figures by 2040 in Western Europe and a trebling of these figures in Eastern Europe<sup>3</sup>.

Alzheimer Europe calls upon the European Union, the World Health Organisation and national governments to recognise Alzheimer's disease as a major public health issue and develop European and international programmes as well as national action plans to adequately respond to the challenges posed by the growing numbers of people with dementia.

2. In 1996 and 1998, the European Parliament dedicated two resolutions<sup>4</sup> to Alzheimer's disease in which it stressed the public health implications of an ageing population and the increase in numbers of people affected by Alzheimer's disease and other forms of dementia. The call for action of the European Parliament expressed in these two resolutions has largely gone unanswered.

Alzheimer Europe calls upon the European Parliament to dedicate a report to Alzheimer's disease outlining the progress achieved since the adoption of its resolutions as well as the priorities for Community action in the coming years.

Alzheimer Europe calls upon the European institutions to recognise Alzheimer's disease as a major health scourge within the meaning of Article 152 of the EC Treaty and to develop a Community action programme on Alzheimer's disease.

3. In its 1996 resolution, the European Parliament welcomed and supported "Alzheimer Europe and other European associations who care for sufferers of Alzheimer's disease and their families". Since then, Alzheimer Europe has been actively promoting the collaboration between national Alzheimer associations and has carried out a number of successful trans-European projects. Despite this proven track record and various calls by the European Parliament, the funding of specific Alzheimer's projects has been discontinued.

Alzheimer Europe calls upon the European institutions to investigate the possibility of providing core funding to the organisation for the exchange of

---

<sup>1</sup> Although Alzheimer's disease is the most common form of dementia, Alzheimer Europe is committed to promoting the quality of life of people living with all forms of dementia. Throughout the declaration, any statement regarding Alzheimer's disease should equally apply to other forms of dementia.

<sup>2</sup> Alzheimer Europe calculated the numbers of people living with dementia by using the EURODEM prevalence rates [Hofman, A. et al. (1991), The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, International Journal of Epidemiology, Volume 20, No.3, pages 736-748] and combining them with the population statistics provided by Eurostat (the official statistics office of the European Union).

<sup>3</sup> C.P. Ferri et al (2005), Global prevalence of dementia: a Delphi consensus study, Lancet 2005; 336: 2112-17

<sup>4</sup> Resolution of 17/04/1996 on Alzheimer's disease and the prevention of disorders of the cognitive functions in the elderly and Resolution of 11/03/1998 on Alzheimer's disease

# Paris Declaration on the political priorities of the European Alzheimer movement

information and best practices between national Alzheimer associations and the development of pan-European projects.

## Research and medical priorities

4. Although scientific progress and the growing awareness of the medical profession have improved the diagnosis of Alzheimer's disease and other forms of dementia, a significant number of people continue to be diagnosed at the moderate and late stages of the disease or even go undiagnosed. A recent survey<sup>5</sup> showed that the delays from symptoms to diagnosis varied considerably between European countries ranging from 10 months in Germany to 32 months in the United Kingdom.

Alzheimer Europe calls upon national governments to make dementia a compulsory part of medical training and to raise the awareness of the medical profession about Alzheimer's disease and other forms of dementia.

5. Amongst the barriers to early diagnosis, carers cited the lack of recognition of the symptoms (70%), the lack of recognition of the severity of the symptoms (61%), the fact symptoms were perceived as normal part of ageing, but also denial and fear<sup>6</sup>.

Alzheimer Europe calls upon the European Commission and national governments to support awareness campaigns targeted at the general public to improve the recognition of the symptoms of Alzheimer's disease and to educate the general public that significant memory loss does not constitute a part of normal ageing. Such awareness campaigns should be conducted in close collaboration with Alzheimer associations and the medical profession. Private-public partnerships involving the pharmaceutical industry should be actively explored.

6. Current treatments for Alzheimer's disease do not cure or halt the disease. Nevertheless, the treatment of the symptoms results in significant improvements in the quality of life of people with dementia and in a reduction of the burden experienced by carers<sup>7</sup>. In some European countries however, the cost-effectiveness of these drugs has been questioned and some of the existing drugs are not available under national reimbursement systems.

Alzheimer Europe calls upon national governments and regulatory authorities to continue to make available existing treatments under their reimbursement systems.

Alzheimer Europe calls upon the European institutions and the European Medicines Agency to support a survey on the existing inequalities of access of European citizens to available treatments for Alzheimer's disease.

---

<sup>5</sup> David Wilkinson et al (2005), Inequalities in dementia care across Europe : an agenda for change, International Journal of Clinical Practice, March 2005, Vol. 59, Suppl. 146

<sup>6</sup> David Wilkinson et al (2005), op.cit.

<sup>7</sup> For a more detailed account of the effects of existing treatments, please consult : Alzheimer Europe (2005) : Alzheimer Europe response to the preliminary NICE recommendations ([www.alzheimer-europe.org](http://www.alzheimer-europe.org))

## **Paris Declaration on the political priorities of the European Alzheimer movement**

7. Despite continued research into Alzheimer's disease and other forms of dementia, the real causes of the disease remain unknown. Similarly, no treatments exist to cure or halt the disease.

Alzheimer Europe calls upon the European institutions to foster pan-European research into the causes, prevention and treatment of Alzheimer's disease in the framework of the 7<sup>th</sup> Community programme for research and development.

Alzheimer Europe calls upon national governments to increase the funding for Alzheimer's research and to actively support the collaboration of national research centres to foster the development of centres of excellence for specific research areas, as well as for rarer forms of dementia.

### **Care and social support priorities**

8. People with dementia and their carers need both medical attention and care. Alzheimer associations have been set up in most European countries and provide people with dementia and their carers with much needed information and support. Yet, a recent survey<sup>8</sup> showed that at the time of diagnosis, only 41% of carers received information on Alzheimer associations and only 18% on available services.

Alzheimer Europe calls upon the medical profession to systematically inform newly diagnosed patients and their carers about the existence of Alzheimer associations and upon European medical organisations to inform their members about the support Alzheimer associations can provide to people with dementia and their carers.

Alzheimer Europe and its member organisations are committed to developing partnerships with the medical profession to provide a holistic approach to people with dementia taking into account both their care and treatment needs.

9. Alzheimer associations provide a range of services. A survey<sup>9</sup> conducted by Alzheimer Europe amongst its members showed that in 24 of the 26 countries covered by the survey, Alzheimer associations provided support groups for people with dementia and their carers. Similarly, training programmes for carers were provided in 23 countries, helplines were operated in 23 countries, day care was provided in 14 countries and home care in 11 countries.

Alzheimer Europe calls upon national governments to recognise the important contributions provided by Alzheimer associations and to provide financial support to these organisations in order to help them to improve the services they give to people with dementia and their carers. Governments should envisage a range of support, such as core support, project funding, VAT exemptions or the tax deductibility of donations.

---

<sup>8</sup> Alzheimer Europe (2006) : Who cares? The state of dementia care in Europe

<sup>9</sup> Alzheimer Europe (2005) : The Alzheimer Movement in Europe, published in the 2004 Annual report of the organisation.

## **Paris Declaration on the political priorities of the European Alzheimer movement**

10. The care of people with dementia impacts the quality of life of carers significantly. In a recent survey<sup>10</sup>, a significant proportion of carers declared that they spend more than 10 hours a day caring, ranging from 20% of carers of people with dementia in the early stages to 50% of carers of people with dementia in the later stages.

Alzheimer Europe calls upon national governments to recognise the significant burden of carers of people with dementia and to support the development of adequate respite services.

11. The availability of adequate care services for people with dementia poses a challenge in a number of European countries. When asked about the availability of necessary services<sup>11</sup>, a majority of carers were unaware of existing services or felt that services were unavailable for them. Thus, only 44% of carers knew of home support services, 42% knew of day care, 34% of residential care, 33% of respite care and only 8% knew of appropriate palliative care. It is therefore not surprising that only 17% of respondents of the survey agreed with the statement that the level of care of the elderly was good in their country.

Alzheimer Europe calls upon national governments to develop and support a whole range of services for people with dementia which respond to their specific needs. This ranges from memory clinics and diagnostic centres, to adequate home care, day care, residential care and palliative care.

12. The care of people with dementia also constitutes a significant financial burden for carers of people with dementia. In a recent Alzheimer Europe survey<sup>12</sup>, 88% of carers reported that they had to contribute financially to residential or nursing home care, 66% to respite care, 65% to home support and 55% to day care.

Alzheimer Europe calls upon national governments to adequately support people with dementia and their carers to allow them to make use of existing services.

Alzheimer Europe calls upon the European institutions to extend the Open Method of Coordination to the question of financing of long-term care and to exchange best practices in this field between the different European countries.

### **Legal and ethical priorities**

13. Alzheimer Europe and its member organisations are committed to promoting the autonomy and self-determination of people with dementia. The disclosure of the diagnosis to people with dementia is of paramount importance for people with dementia to take an active part in decisions affecting their lives. Yet, the Alzheimer Europe survey revealed that the disclosure rates varied greatly between European countries with 80% of people being informed in Scotland, whereas only 23% of people were similarly informed in Spain.

---

<sup>10</sup> Alzheimer Europe (2006) : Who cares? The state of dementia care in Europe

<sup>11</sup> Alzheimer Europe (2006) : Who cares? The state of dementia care in Europe

<sup>12</sup> Alzheimer Europe (2006) : Who cares? The state of dementia care in Europe

## Paris Declaration on the political priorities of the European Alzheimer movement

Alzheimer Europe calls upon national governments and the medical profession to reinforce the provisions in medical codes of practice regarding the disclosure of diagnosis and to educate medical professionals on how to disclose a difficult diagnosis to patients.

14. Unfortunately, cognitive abilities steadily decline and there generally comes a time when the person with dementia can no longer manage entirely alone and where he/she will need help in making decisions of varying importance, such as financial management or medical decisions. Assistance could be provided by a guardian/lawful representative, but national laws differ widely as discovered by Alzheimer Europe when it carried out its Lawnet projects<sup>13</sup>.

Alzheimer Europe calls upon the Council of Europe and national governments to exchange best practices with regard to national guardianship systems. In particular, Alzheimer Europe advocates for national laws which give the opportunity to people with dementia to nominate guardians or legal representatives which may represent and support them in both their financial management and in healthcare decisions.

15. A guardian or legal representatives can provide much needed support to people with dementia, yet he/she should act in the best interests of the person with dementia and taking full account of their previously expressed wishes. Advance directives would facilitate the work of legal representatives and would also provide guidance for people with dementia who do not have a legal representative<sup>14</sup>.

Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness. Alzheimer Europe expects governments to set up appropriate systems for the registration, use and review of advance directives.

---

<sup>13</sup> Alzheimer Europe (2002) : Comparative analysis of legislation in Europe relating to the rights of people with dementia (available on [www.alzheimer-europe.org](http://www.alzheimer-europe.org)).

<sup>14</sup> For more information on advance directives, please consult: Alzheimer Europe (2005) : Position paper on advance directives (available on [www.alzheimer-europe.org](http://www.alzheimer-europe.org)).