



*Making dementia a priority:
changing perceptions, practice and policy.*

European Commission Communication on a European initiative on Alzheimer's disease and other dementias (COM(2009) 380) – Alzheimer Europe Position

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1 Introduction

Alzheimer Europe welcomes wholeheartedly the European Commission's Communication on a European initiative on Alzheimer's disease and other dementias (COM(2009) 380). This Communication encompasses the four priorities Alzheimer Europe identified in its Paris Declaration agreed at its General Assembly in 2006 and which has since been endorsed by a large number of European and national policy makers : public health priorities, research and medical priorities, care and social support priorities, legal and ethical priorities.

Alzheimer's disease : a daunting challenge for the Member States

While Alzheimer Europe duly acknowledges that the primary responsibility for tackling dementia lies within the Member States, the organisation appreciates the European Commission's commitment to encourage and support the Member States in engaging in initiatives that will effectively recognise and tackle the health, social, research and economic challenges posed by dementia.

In Europe, dementia affects some 7.3 million citizens aged between 30 and 99 years of age. Within this group, more women (4.9 million) than men (2.4 million) are affected. With the increase in life expectancy, the incidence of dementia is projected to double every 20 years.

Alzheimer's disease, the most common form of dementia is a terminal illness that develops slowly, causes memory, thinking and judgement impairment and may lead to changes in personality. It is the major cause of dependency and it is estimated that on average three persons in every family bear the burden. Consequently, 19 million Europeans are affected by the disease.

Alzheimer's disease is a costly disease: the estimated total direct cost and informal cost of Alzheimer's disease and dementia are estimated to be € 21,000 per patient/year across the the 27 EU Member States (56 % for informal care).

Alzheimer Europe's recent findings show that Alzheimer's disease remains underdiagnosed in the EU. Many inequalities exist as well across the Member States in prevention, access to treatment and provision of services.

To date, no treatment has been found to halt or cure Alzheimer's disease, only treatments that deal with the symptoms of the disease and may improve the quality of life of people with the disease and their carers.

2 Comments on the Communication and proposed actions

2.1 **Public health: Acting early to diagnose dementia and promote well-being in old age**

Alzheimer Europe's Paris Declaration recognises it is important to **raise greater awareness** about Alzheimer's disease, both at national level and European level. This is paramount to empower the population recognise the first signs of the disease, seek early diagnosis and access treatment and services at an early stage. Good physical and mental health that helps avoid cognitive decline must also be widely promoted.

When one combines the growing evidence that mental activity and stimulation reduce the risk of dementia and the Europe 2020 priorities to foster the EU sustainable growth and an inclusive high-employment society, Alzheimer Europe agrees it is important that the EU now engages in **flexible work policies** to enable citizens to be in employment longer, work flexible hours when having to face the new challenge of caring for a dependant elderly

person, receive adequate training to care for a dependant elderly person and possibly use these new skills in the community.

While taking into account the national struggles to balance the pension finances, the EU must consider **appropriate pension schemes** for the citizens who need stop a paid work in order to care for a dependent person.

The stimulation of innovation advocated by the Europe 2020 strategy should **support ICT and assistive technology programmes** that will bring concrete solutions to the very specific needs of people with dementia and their carers.

Particular attention must be paid to the **workforce for health** as a key partner in improving the prevention, diagnosis and treatment of dementia : Alzheimer Europe particularly calls on the national governments to make dementia a compulsory part of medical training and raise awareness among the medical profession about Alzheimer's disease and other forms of dementia. The results of the European Commission's consultation on the European workforce for health calling on health professionals to engage in continual development and update of their skills to improve the quality of health outcomes must be acted upon.

Actions

- To incorporate the 'dementia dimension' into the European Union's ongoing and future actions on health prevention, especially those related to cardiovascular health and physical activity, **health education and new technologies**.
- To produce a set of recommendations which would help the citizens to prevent dementia **and involve Alzheimer associations in disseminating these recommendations at grass-root level**.
- **Raise awareness about dementia among the general public to recognise the early symptoms of dementia, seek early diagnosis, treatment and appropriate support. Involve the Alzheimer associations in designing and promoting these awareness campaigns. Public-private partnerships should also be actively explored.**
- **Identify and promote best practice in early diagnosis of Alzheimer's disease and other forms of dementia.**
- To include the 'dementia dimension' in flexible European **work** policies **and** retirement **policies, as well as** in the framework for action for older people in the European Pact for Mental Health and Well-Being.
- **Evaluate the creation of a European observatory on the healthcare workforce to assist the Member States in planning future workforce capacity, training needs and the implementation of technological developments.**

2.2 Research: A shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research

Alzheimer Europe's Paris Declaration calls upon the European institutions to foster pan-European research into the causes, prevention and treatment of Alzheimer's disease. The understanding of Alzheimer's disease and other dementias still needs to be comprehensively addressed. The Declaration thus calls on an increase in the funding for Alzheimer's research and active collaboration of national research centres to foster the development of centres of excellence for specific research areas, as well as for other forms of dementia.

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The data on epidemiology gathered during the European Collaboration on Dementia (EuroCoDe) project now need to be further used and refined as a clearer picture of the epidemiology of Alzheimer's disease would greatly help the Member States make appropriate plans and provisions.

Community action enhances research into dementia : the EU 7th Framework Programme, the Innovative Medicines Initiative, the Joint Programming Initiative on combating neurodegenerative diseases, in particular Alzheimer's disease.

Research in health economics, social science and humanities, non-pharmacological approaches is also needed to understand the psychological and social aspects of the disease.

Alzheimer Europe and its national member organisations have an important role to play in disseminating research results to people with dementia and their carers who eagerly await such news, as well as the general public. Alzheimer associations need to do so in a realistic fashion without raising false hopes. For this reason, Alzheimer Europe hopes to develop, over time, a Dementia Research Observatory, to collect, disseminate and comment on research developments.

Actions

- To improve epidemiological data on Alzheimer's disease and other dementias, implementing the recommendations of the EuroCoDe project. ***To do so, the European Commission should benefit from the expertise of the network set up by Alzheimer Europe within the framework of EuroCoDe and invite this group to refine its findings.***
- To use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive defects.
- ***To foster research in health economics, social science and humanities and non-pharmaceutical approaches to understand the psychological and social aspects of dementia.***
- To adopt a proposal for a Council Recommendation on a pilot Joint Programming initiative on combating neurodegenerative diseases as a pilot, in particular Alzheimer's disease. *(Since the publication of this Communication, this initiative has started. Alzheimer Europe would welcome regular feed back on this initiative and offer to be a partner).* ***To involve representatives of patient and carer organisations and healthcare providers appropriately in the pilot project for Joint Programming of research in this field.***
- ***Support Alzheimer Europe's Dementia Research Observatory as a useful tool between the research community and the patients.***
- ***Foster the development of centres of excellence for specific research areas, as well as for rarer forms of dementia.***
- ***To take up the European Parliament call in its Resolution on the Joint Programming of research to combat neurodegenerative diseases, in particular Alzheimer's disease, to launch a European Year of the Brain in order to raise awareness of brain-related diseases associated with ageing, and measures to prevent them.***

2.3 **Social protection: Supporting national solidarity with regard to dementia : sharing best practices for care of people suffering from dementia**

Alzheimer Europe's Paris Declaration stresses the important role played by the Alzheimer associations in providing people with dementia and their carers with information and support. However, Alzheimer Europe's work shows that – at the time of diagnosis - less than half of the carers received information on Alzheimer's associations and only 18 % received information on available services.

The Paris Declaration also calls on the Member States to develop and support a whole range of tailored services for people with dementia. This ranges from memory clinics, diagnostic centres to adequate home care, day care, residential care and palliative care.

This call offers **new economic and social perspectives** that need to be addressed within the context of the Europe 2020 strategy. As people live longer, it is expected that there will be an increasing number of older people with severe disability and in need of long-term care. With the expected reduction in availability of informal carers, it is important to have a European **health workforce tailored to the very specific needs of people with dementia and their carers**.

The development of **respite services** is another priority area of the Paris Declaration. It is essential that, when the Working Time Directive is reviewed, due attention be paid to the very specific requirements of people with dementia who need continuity in the care they receive. This may imply respite carers having different work patterns than those currently catered for by the current working time regulations.

Financing of long-term care must also be considered. The Open Method of Coordination should be used to exchange best practices between the different EU countries.

End-of-life care is another area which Alzheimer Europe has explored. The organisation's '*End-of-life care for people with dementia*' report is aimed at everyone with an interest in providing good quality end-of-life care to people who have dementia. Many of the report recommendations are dependent upon an effective financing, organisation and coordination of end-of-life care, including multidisciplinary trained professionals and appropriate care facilities in all geographical areas.

Actions

- To map the existing and emerging good practices related to treatment and care for people living with Alzheimer's disease and other forms of dementia and to improve the dissemination of such practices (using, when possible, the Structural Funds).
- To develop, by means of the Open Method of Coordination, quality frameworks for medical and care services for people with dementias. ***The Open Method of Coordination must include exchange of best practices regarding the financing the long-term care.***
- ***Implement the EU 2020 flagships 'A new jobs agenda' and 'New skills for new jobs'***
- ***To recognise Alzheimer associations as key partners in providing much needed information and support to people with dementia and their carers and foster partnerships with the medical profession to provide a holistic approach to dementia care.***
- ***To use the recommendations contained in Alzheimer Europe's report 'End-of-***

life care for people with dementia' to address end-of-life issues.

- To use facilities provided for in the EU Disability Action Plan (DAP) 2003-2010 to support patient organisations **and to use the Public Health Programme to provide an operating grant to the activities of Alzheimer Europe.**

2.4 Rights and autonomy: Respecting the rights of people with dementias

Alzheimer Europe's Paris Declaration encapsulates the organisation's commitment to promote the autonomy and self-determination of people with dementia. This includes the all too often neglected disclosure of diagnosis. Alzheimer Europe calls for the education of medical professionals on how to disclose a difficult diagnosis.

The Declaration has also identified guardianship systems as a priority to be dealt with. The organisation calls on the Council of Europe and national governments to exchange best practices with regards to national guardianship systems.

A few years ago, Alzheimer Europe dedicated a project to the promotion of the use of advance directives and other forms of advance statement for people with dementia. The findings of the organisation's '*The use of advance directives by people with dementia*' should be used to exchange and promote best practice between the EU Member States. It is also important that in the present context of citizens mobility (citizens spending an increasing time abroad), advance directives are recognised between the EU countries.

Also, thanks to the initial support of the German Ministry of Health, Alzheimer Europe was able to establish a European Dementia Ethics Network comprised of ethics experts from different European countries with the aim of exchanging views on the ethical aspects of dementia care and treatment, collecting and contrasting existing ethical positions and, where possible, developing consensual statements.

Actions

- ***To support***, using the facilities provided by the Health Framework programme, ***the European Dementia Ethics Network which would*** formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable people and tackling patient abuse.
- ***To extend the Open Method of Coordination to the field of legislation of rights of people with dementia, including the issue of guardianship systems.***

3 Conclusion

The implementation of the European Commission's Communication on a European initiative on Alzheimer's disease and other dementias must answer the diverse needs of the people with Alzheimer's disease, their carers, those in the medical profession and the research community. It must empower the Member States to tackle in a timely manner the social, medical and legal aspects of dementia.

The dignity and respect of the people with dementia must remain at the core of any action.

Alzheimer Europe is keen to continue contributing towards the European policy debate by providing robust and up-to-date information, engaging its member associations at grass-root level and facilitating the dissemination of the information.

It is crucial that the role of Alzheimer Europe be further recognised. Alzheimer Europe thus calls on the EU and national policy makers to recognise the important role of Alzheimer associations and provide them with regular financial support.

Actions

- ***Work with the European Commission to set European activities and awareness campaigns around World Alzheimer's Day***
- ***Invite the Commission to recognise Alzheimer Europe, the umbrella organisation representing 40 Alzheimer associations in the EU, plus Norway, Iceland, Turkey and Switzerland, to be well placed to spread the information and best practices between the national organisations and the development of pan-European projects.***
- ***To do so, the European institutions should investigate the possibility of providing regular core funding to the organisation and encourage the Member States to follow suite at national level.***

4 References

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4.2 EU Institutions

4.2.1 European Parliament

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4.2.2 European Commission

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4.2.3 Council Conclusions

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- Conclusions on research joint programming : initiative on combating neurodegenerative diseases (Alzheimer's), Competitiveness Council meeting, December 2009 (http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/intm/111721.pdf)

4.2.4 European Economic and Social Committee

- Opinion of the European Economic and Social Committee on the Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias COM(2009) 380 final, December 2009 (http://www.eesc.europa.eu/sections/soc/public_health.htm)

4.3 Websites

- www.alzheimer-europe.org
- www.neurodegenerationresearch.eu/