European initiative on Alzheimer’s disease and other dementias

2010/2084(INI) - 30/11/2010

The Committee on the Environment, Public Health and Food Safety adopted the own-initiative report drafted by Marisa MATIAS (GUE/NGL, PT) on a European initiative on Alzheimer’s disease and other dementias.

Members recall that it is estimated that 35.6 million people worldwide will suffer from dementia in all its forms in 2010, and that this number is estimated to nearly double every 20 years, possibly reaching 65.7 million in 2030.

The number of people suffering from dementia in Europe is estimated to be 9.9 million, with Alzheimer’s accounting for the vast majority of these.

According to certain estimates, the total direct medical and social care costs of Alzheimer’s disease in Europe amount to USD 135.04 billion.

In this context, Members call on the Council to **declare dementia to be an EU health priority**.

Welcoming the EU Joint Programming initiative promoted by the Member States in order to boost research on Alzheimer’s and other neurodegenerative diseases, Members encourage the Commission to continue launching activities to tackle health-related, social, technological, and environmental challenges for the treatment of Alzheimer’s and other neurodegenerative diseases.

Members call on the Council and the Commission for the following measures:

As regards awareness raising:

- consider launching a European Year of Mental Health, complementing World Alzheimer’s Day on 21 September;
- recognise the role of patients’ associations in the area of neurodegenerative diseases and to involve them in information and prevention campaigns and support measures for dementia sufferers and in the preparation of research programmes;
- consider promoting a ‘Carers Day’ to raise awareness of and recognise the crucial role of formal and informal carers across Europe;
- raise public awareness in the Union concerning dementia, facilitating recognition of the early symptoms of dementia with a view to early diagnosis and the corresponding treatment and appropriate support.

On the issue of prevention:Members note that at present there is no specific policy on the prevention of Alzheimer’s disease, and call, therefore, for the establishment of such a policy, including at European level, to be based on the need to maintain an environment conducive to patients’ physical and intellectual activity and a **diet** consistent with that recommended by the European Platform for Action on Diet, Physical Activity and Health and on the promotion of all policies to reduce smoking, both active and passive. They also call for:

- account to be taken of the concept of dementia when preparing future actions in the area of preventive health policy;
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early diagnostic tests to be carried out and for large-scale epidemiological and clinical studies on the basis of transnational cooperation to be conducted.

Parliament points out that the increasingly ageing population and the mounting pressure on public finances and private productivity due to increased expenses for this ageing population will create a structural problem for the Member States.

Amongst the **proposed national actions**, Members outline the following:

- the definition, development and implementation of common protocols for early diagnosis, to establish biomarkers with a view to building on the emergence of new therapies for both dementia and pre-dementia,and to define a common research agenda in the field of neurodegenerative diseases;
- the availability of **drugs** able to slow the onset of Alzheimer's to all patients suffering from the disease and not only patients who are diagnosed with severe cases of Alzheimer's;
- the setting up of **specialist centres** and to provide satisfactory medical equipment (including magnetic resonance imaging, whose contribution to dementia research is indisputable) nationwide;
- the development of policies for facilitating access to research funding in the field of dementia and Alzheimer's;
- the development of long-term policies and action plans in the field of care and prevention which anticipate and address social and demographic trends,
- the development of action plans aimed at improving the well-being and quality of life of patients suffering from Alzheimer's and other dementias, and that of their families;
- strengthened cooperation with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda;
- the development of action plans aimed at improving the well-being and quality of life of patients suffering from Alzheimer's and other dementias, and that of their families;
- drawing up common guidelines for the training of staff who work in whatever capacity with Alzheimer's patients (medical and paramedical professions);
- the development of healthcare and social services with the core principle of maximising coverage and ensuring equity of access and equality;
- the development of healthcare and social services with the core principle of maximising coverage and ensuring equity of access and equality in general;
- the development of personalised pathways for multiprofessional and multidisciplinary care and support coordinated by a single reference person from the moment the diagnosis is notified;
- the development of diverse, innovative and high-quality facilities to offer respite to carers, such as accommodation and temporary reception centres;
- the promotion, on a voluntary basis, the practice of free memory screenings for those population groups that according to scientific data have a high risk of developing Alzheimer's disease or other dementia illnesses.

Overall, Members call for the setting up of measures to strengthen research, improving access to diagnosis and access to drugs (notably for new treatments).

Member States are urged to improve public and professional awareness of dementia among healthcare skilled/semiskilled professionals, healthcare policy makers and media. The report stresses the importance of preventing Alzheimer's disease by encouraging a **healthy lifestyle**.

On the issue of **early detection**, Parliament encourages all the Member States to engage actively in the definition, development and implementation of common protocols for early diagnosis. It points to the importance of a multidisciplinary approach to ways in which cooperation and coordination in the field of

research at European level can improve knowledge, diagnosis, treatment, prevention, and social research into the welfare of patients and their families and carers. It regards early diagnostic tests, research into risk factors and early diagnosis criteria as crucial.

On a budgetary level, Parliament recognises the current importance of the European Union's support, totalling EUR 159 million and considers it essential, in the context of the forthcoming 8th RDFP, to address the fragmented nature of research, particularly that on Alzheimer's. Members call on the Member States to devote suitable resources to healthcare for Alzheimer's patients. They emphasise the scale of the medical costs entailed by Alzheimer's disease and other dementias and that it is important to find viable solutions which take into account: the direct medical costs (comprising health system costs: specialist costs, medicinal products, medical examinations and regular check-ups); the direct social costs (comprising the cost of formal services outside the medical system: community services, home care, provision of food, transport, and placement of patients in specialist residential centres for the care of the elderly, where they can receive medical assistance); and informal costs (comprising the costs associated with reduced productivity in the event of a prolongation of working life, and loss of output as a result of early retirement, leave for medical reasons or death).

Members call on the Commission, the Council and Member States to take into account the specific needs of women, who account for twice the number of sufferers and a disproportionate number of carers.

Members stress the importance of **home help for patients** and for the elderly, and the vital contribution made by non-profit and voluntary organisations in the care of Alzheimer's patients and those suffering from other age-related diseases. It encourages the Member States to create forms of partnership with those organisations and support for their activities. They call on the Member States, in addition, to give due credit and recognition to the role played by the **informal care** provided by the relatives of those suffering from these diseases. Parliament emphasises that the dignity of people with Alzheimer's needs to be preserved and the stigma and discrimination against them needs to be eliminated.

Members call for recognition of **Alzheimer associations** as prime partners and for them to be involved in: (1) defining prevention recommendations and best practices and disseminating these at grass-root level; (2) providing much needed information and support to people with dementia and their carers; (3) presenting the needs of people with dementia and their carers to policy makers; (4) fostering partnerships with the medical profession to provide a holistic approach.

Lastly, the Council, the Commission and the Member States are called upon, in conjunction with Parliament, to foster the autonomy of persons with dementia and promote their dignity and social inclusion through the action plan in the field of health.