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DRAFT REPORT

on a European initiative on Alzheimer's disease and other dementias
(2010/2084(INI))

Committee on the Environment, Public Health and Food Safety

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MOTION FOR A EUROPEAN PARLIAMENT RESOLUTION

on a European initiative on Alzheimer's disease and other dementias (2010/2084(INI))

The European Parliament,

- having regard to Article 168 of the EC Treaty,
 - having regard to Article 35 of the Charter of Fundamental Rights of the European Union¹,
 - having regard to the Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities,
 - having regard to the World Alzheimer Report 2009 released by Alzheimer's Disease International (ADI) in the context of World Alzheimer's Day on 21 September 2009,
 - having regard to the Communication from the Commission to the European Parliament and the Council on an European initiative on Alzheimer's disease and other dementias (COM(2009)380 final),
 - having regard to Rule 48 of its Rules of Procedure,
 - having regard to the report of the Committee on the Environment, Public Health and Food Safety (A7-0000/2010),
- A. whereas it is estimated that 35.6 million people worldwide will be living with dementia in 2010 – and that this number is estimated to nearly double every 20 years, to 65.7 million in 2030,
- B. whereas the number of people suffering from neurodegenerative diseases in Europe is estimated to be 8.6 million, with Alzheimer's accounting for the vast majority of those cases; whereas neurodegenerative diseases represent one of the main causes of disability in the elderly, and whereas the number of people suffering from these diseases is expected to rise dramatically by 2020, owing to increased life expectancy and a decreasing ratio of working to retired populations,
- C. whereas the population of Europe is ageing, with persons aged over 80 constituting the fastest-growing cohort in most European countries, and whereas dementia is therefore expected to be one of the main challenges for healthcare systems, including informal care and long-term care facilities, in the coming decades,
- D. whereas the total direct and informal care costs of Alzheimer's disease and other dementias in 2005 amounted to EUR 130 billion for the EU 27 region, or approximately EUR 21 000 per year per person affected by dementia (56% of the costs being generated

¹ OJ C 364, 18.12.2000, p. 1.

by informal care¹),

- E. whereas the bulk of the research effort in this field is carried out by Member States, with a relatively low level of transnational coordination, leading to fragmentation and limited sharing of knowledge and best practice among Member States,
 - F. whereas there is a growing awareness that the impact of neurodegenerative diseases on the population in Europe is of such a magnitude that no Member State is capable of resolving it alone; whereas it is therefore necessary in the EU to significantly strengthen cooperation and coordination of research efforts and the level of financial investment in this area, in order to combat neurodegenerative diseases, particularly Alzheimer's, which is a major challenge for European societies,
 - G. whereas dementia is not only a devastating disorder for the patients themselves, but also a very heavy burden placed on the shoulders of the patients' relatives, given the emotional, physical and financial difficulties faced by the relatives and friends of those affected by all types of dementia,
 - H. whereas, although social awareness and scientific knowledge of Alzheimer's disease have increased dramatically in the past 20 years, therapeutic options are still limited to symptomatic drugs, and diagnosis is still largely based on individual physician experience and subjective judgement,
1. Calls on the Council to declare dementia an EU health priority, and urges the Member States to develop national strategies to provide services and support for people with dementia and their families;
 2. Suggests that the Council and the Commission consider launching a European Year of the Brain in order to raise awareness of brain-related diseases associated with ageing, and measures to prevent them;
 3. Underlines the relevance of early diagnosis for preventive interventions, and the need for epidemiological data to help direct research and action;
 4. Encourages all the Member States to engage actively in the definition, development and implementation of common protocols for early diagnosis and a common research agenda in the field of neurodegenerative diseases, thus reducing the prevailing inequalities between Member States and within Member States as regards diagnosis and treatment; emphasises that standard operational procedures for the assessment of disease markers will be key to drug discovery and to the development of more effective, technology-assisted care of patients with Alzheimer's disease;
 5. Points to the importance of a multidisciplinary approach on 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; believes that early diagnostic tests, research into risk factors and criteria for early diagnosis are crucial; this being the case, sees clear added value in

¹ Alzheimer Europe (2008) Dementia in Europe Yearbook 2008.

conducting large-scale epidemiological and clinical studies in transnational collaboration;

6. Invites the Member States to develop a Strategic Research Agenda establishing medium- to long-term research needs and objectives in the area of neurodegenerative diseases, especially Alzheimer's; takes the view that the strategic research agenda should be further developed towards an implementation plan establishing priorities and timetables and specifying the actions, instruments and resources required for its implementation;
7. Points to the importance of research into the connection between the ageing process and dementia and between dementia and depression in the elderly; encourages the Member States, furthermore, to promote research programmes that give great importance to patient choice and perspective;
8. Calls on the Commission to draw up guidelines for the training of staff who work in whatever capacity with Alzheimer's patients (medical and paramedical professions), and for the training of family carers to ensure competent and effective use of the existing resources;
9. Underlines that the recent advances in imaging and biomarker research have indicated that Alzheimer's disease develops as a result of the deposition in the brain of amyloid beta, a small neurotoxic protein;
10. Stresses the importance of psychological support for patients and their families; emphasises the importance of combining the psychosocial approach to ageing with the results of medical and biomedical research;
11. Encourages Member States to develop services with the core principle of maximising coverage and ensuring equity of access, to benefit people with dementia regardless of age, gender, wealth, disability, and rural or urban residence;
12. Encourages Member States to develop information campaigns for the general public and for specific groups such as schoolchildren, health care professionals and social workers, comparing and exchanging experiences on support measures for family carers, patients' associations and non-governmental organisations by promoting the publication and distribution of information pamphlets concerning the training and organisation of voluntary workers and legal, psychological and health assistants both at home and at day centres by promoting or setting up Alzheimer's associations to enable those concerned to exchange experiences;
13. Instructs its President to forward this resolution to the Council and the Commission, and to the governments and parliaments of the Member States.

EXPLANATORY STATEMENT

The communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias is a fundamental step on the way towards specific proposals to link up the various existing policies and ways of tackling this type of disease. Fragmented action, the uneven responses that exist in Europe and the prevalence of unequal conditions regarding access and treatment for the disease provide more than sufficient justification for this initiative. Basing itself on four key objectives - promoting early diagnosis and quality of life; improving epidemiological knowledge of the disease and coordinating existing research; supporting solidarity between the Member States through sharing best practices; and, finally, respecting the rights of people living with dementias - the Commission is proposing a series of measures which this report aims to take further. Additional measures are also set out aimed at better incorporating the social dimensions of the disease and their implications. In addition to these aspects, particular attention is paid to health care professionals and providers, action to strengthen the various care systems, and training and support for families and other people coping with dementia on a daily basis.

The context

According to the figures presented by patients' associations, every year 1.4 million citizens living in Europe develop some type of dementia. A new case is diagnosed every 24 seconds. Almost one in 20 people over the age of 65 and one in five over 80 suffer from dementia. It is estimated that more than 8 million Europeans aged between 30 and 99 suffer from neurodegenerative diseases, and scientists anticipate that this number could double every 20 years.

Alzheimer's disease is responsible for more than half of these cases. It is significant that only 3% of people diagnosed have survived for more than 40 years after receiving their diagnosis. In addition to the above figures, emphasis should be placed on the inequalities that remain as regards access to diagnosis and treatment, not only between countries but also within them.

At present neurodegenerative diseases represent one of the main causes of incapacity among the elderly, and the number of people affected is expected to rise significantly. This fact becomes even more important bearing in mind the increase in average life expectancy and the declining ratio between the number of people working and the number of people who are retired.

Many of the factors that lie at the origin of dementias remain unknown. However, it is possible to identify a series of risk factors that increase the possibility of contracting Alzheimer's disease. These include high blood pressure and high levels of cholesterol and homocysteine; low levels of intellectual stimulation, social activity and physical exercise; obesity and diabetes; and serious or repeated cerebral lesions. More recently, studies have shown that Alzheimer's disease can develop as a result of the deposition of a neurotoxic protein in the brain. It seems to have been confirmed that this is not a predominantly hereditary disease, since the number of families in which the disease develops as a result of a

genetic disorder is very low. Alzheimer's is a disease which results from a combination of many different factors.

Early diagnosis and priority to prevention

The symptoms of Alzheimer's disease are often confused with common signs of ageing. Despite the scientific progress that has been made and increasing awareness among health professionals, the number of people diagnosed at a moderate or even advanced stage of the disease is still very high. We also know that the process normally followed in order to reach a diagnosis consists of excluding other conditions. The number of people who have the disease without knowing it remains high.

It is vital to place prevention at the heart of any strategy and to target efforts at obtaining the earliest possible diagnosis.

Patient dignity

As yet no cure has been found for Alzheimer's disease. Current treatments are based on the use of medication that seeks to mitigate or stabilise the symptoms associated with behavioural and cognitive changes among patients. It is possible to delay the effects, but it is not yet possible to prevent progressive neuronal loss. It is therefore vital to step up extra-pharmacological intervention, promoting interventions that improve the well-being of those affected. Helping patients to live with the disease and endeavouring to preserve their autonomy is the way to guarantee a life with dignity for as long as possible.

Even though sufferers share common symptoms, social and economic conditions mean that each patient and their families are affected by the process of the disease in very different ways. For example, it is not uncommon for patients' relatives to be forced to give up their work to care for family members with the disease.

The people affected

People affected by Alzheimer's disease and other dementias, along with their relatives or those with whom they have close ties, face social stigmatisation.

Changes in behaviour and personality resulting from the disease make those affected more and more dependent on other people. It should be stressed that those affected by Alzheimer's disease are not only those who suffer from the disease themselves but also the people around them and the people who care for them. These people tend to be relegated to a second tier in the system that currently prevails. It is only by recognising the complexity of the situation of living with dementia that we can arrive at a fairer approach that acknowledges all those affected.

The structure of the report

The basic approach taken by this report is improved coordination between the Member States and a more effective and solidarity-based response geared to prevention and the treatment of people living with dementias, particularly Alzheimer's, as well as the people around them, whether they be healthcare professionals, service providers or relatives. For any European strategy in this area to work, it is crucial that the various countries give priority to drawing up national action plans.

It is also vital to focus on early diagnosis and prevention and the gathering and processing of epidemiological data on the disease.

Once these fundamental steps have been taken, the various countries should take integrated action ranging from research to healthcare provision. It is important to fill the gaps that still exist in such areas as professional training, support for families (as regards both care and psychological support) and action to raise public awareness of what living with dementia entails.

A European strategy must also seek to safeguard the existence of services that guarantee maximum possible coverage and equal conditions as regards access and treatment for patients, regardless of their age, gender, financial resources or place of residence.

Enhancing the dignity of all patients throughout the process of their disease and reducing existing inequalities must also be priority objectives. This choice implies the wider involvement of the various groups of people concerned, from medical organisations to patients' associations, as their contribution will play a vital part in bringing together the various measures taken and ensuring their effectiveness.