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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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PR_INI

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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, and the Council conclusions on public health strategies to combat neurodegenerative diseases associated with age and, in particular, Alzheimer's disease,
- having regard to the findings of Alzheimer Europe's EU project EuroCoDe (European Collaboration on Dementia) (2006/2008) financed by DG Sanco and the World Alzheimer Report 2010 released by Alzheimer's Disease International (ADI) in the context of World Alzheimer's Day on 21 September 2010,
- having regard to the results of EuroCoDe (European Collaboration on Dementia), an Alzheimer Europe European project funded by the Commission,
- 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 the EU strategic objective of promoting good health in an ageing Europe, established on the basis of the Commission White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013', which stresses the need to intensify research in the interests of palliative care and a better understanding of neurodegenerative diseases,
- having regard to its resolution of 9 September 2010 on the long term care of older people²,
- having regard to its resolution of 7 September 2010 on the role of women in an ageing society³,
- 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 (A7-0366/2010),

A. whereas it is estimated that 35.6 million people worldwide will be suffering from dementia in all its forms in 2010, and that this number is estimated to nearly double every

¹ OJ C 364, 18.12.2000, p. 1.

² Texts Adopted, P7_TA(2010)0313

³ Texts Adopted, P7_TA(2010)0306.

20 years, possibly reaching 65.7 million in 2030, (2010 report by Alzheimer's Disease International); whereas the number of sufferers of Alzheimer's disease is underestimated due to difficulties in early diagnosis,

- B. whereas 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 (2010 report by Alzheimer's Disease International); taking into account that neurodegenerative diseases can affect people of all ages but represent one of the main causes of disability and dependence in older people, and that the number of people suffering from these diseases is expected to rise dramatically by 2020 owing to increased life expectancy and a lack of social life among the retired; whereas this figure for the number of people affected almost trebles when the number of informal carers of people with dementia are also taken into account,,
- C. whereas, according to the World Alzheimer Report for 2009, Europe accounts for over 28 % of the total number of persons suffering from dementia, placing it second only to Asia (with 35 %), while of all the world's regions western Europe has the highest proportion of sufferers (19 %),
- D. whereas the population of Europe is ageing, with persons aged over 80 constituting the fastest growing cohort in most European countries; whereas there is a decreasing ratio of working to retired populations and whereas dementia is therefore expected to be one of the main challenges for the sustainability of national social and healthcare systems, including informal care and long-term care facilities, in the coming decades,
- E. whereas according to certain estimates (2010 report by Alzheimer's Disease International) the total direct medical and social care costs of Alzheimer's disease in Europe amount to USD 135.04 billion,
- F. whereas early diagnosis may help to manage healthcare costs across Europe,
- G. whereas the European Union does not currently have at its disposal sufficiently precise statistics concerning dementias, and in particular neurodegenerative diseases, and whereas the estimates vary by up to a factor of three, depending on the study consulted; whereas it is essential, therefore, that European epidemiological studies should be carried out on the basis of common, strictly defined indicators,
- H. whereas the consequences of dementia are both social and economic, affecting all health systems in the Member States,
- I. whereas in order to anticipate the economic and social impact of Alzheimer's and other forms of dementia, it is necessary to invest in scientific research and efficient approaches to care systems,
- J. 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, and whereas research for Alzheimer's Disease is lagging behind research into other major diseases in Europe,

- K. whereas Alzheimer Europe's recent findings show that Alzheimer's disease remains underdiagnosed in the EU and that many inequalities exist across the Member States in regard to prevention, access to treatment and provision of appropriate services,
- L. whereas current research suggests that diet may be a significant causal factor in the development of Alzheimer's disease and therefore the prevention of dementia through modifiable interventions should be a priority and particular attention should be given to preventative factors such as a healthy diet, promoting physical and cognitive activity and controlling cardiovascular risk factors such as diabetes, high cholesterol, hypertension and smoking,
- M. 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 for Member States and the EU to strengthen significantly cooperation and coordination of innovative and multidisciplinary clinical research efforts into the causes, prevention and treatment of Alzheimer's disease, of information sharing and the level of financial resources in this area, in order to combat neurodegenerative diseases, particularly Alzheimer's, which is a major challenge for European societies,
- N. whereas this European initiative is not intended to replace existing national plans to combat Alzheimer's disease and other forms of dementia, but should instead be used as a means of coordinating European research in this area more effectively,
- O. whereas dementia is a devastating disorder for the patients themselves but can also, if adequate services of good quality are not provided, become a very heavy burden placed on the shoulders of the patients' relatives and carers, due to the emotional, physical and financial difficulties faced by the relatives and friends of those affected by all types of dementia; whereas in every family with a patient, on average three persons directly bear the brunt, meaning that an estimated 19 million Europeans are directly affected by dementias,
- P. whereas there is a shortfall in capacity in institutional care for people suffering from Alzheimer's disease, and that shortfall will worsen in the future; whereas there is a shortage of healthcare professionals and social workers caring for people suffering from Alzheimer's, and that shortage will increase in future; whereas at the same time it is clear that the best thing for such people is to assist them to remain in their familiar environment at home,
- Q. whereas, in connection with the care of dementia sufferers and support for carers, the European Union and the Member States must pursue a threefold objective: provide high-quality care for sufferers, ensure that carers can take advantage of periods of respite tailored to their needs, and ensure that sufferers can be looked after at home or in high-quality, innovative care facilities,
- R. whereas modern telemedicine services can deliver very effective support for patients suffering from Alzheimer's, and for their carers, and can thus contribute to a better quality of life for patients in their familiar environment and provide a good alternative to institutional care,

- S. whereas there is a stigma attached to Alzheimer's disease and public attitudes towards the illness and the persons affected by it leave sufferers and their families and relatives isolated; whereas the overall approach to the problem is still the wrong one, leading those affected and their relatives to their social exclusion; whereas, therefore, there is a need for better understanding of the stigma, prejudice and discrimination associated with dementia whilst research is also needed on how to prevent social exclusion and encourage active citizenship so as to maintain the dignity and respect of the people with dementia at the core of any action,
- T. whereas enhancing the quality of the patients is often linked to the emotional lives of the patients' relatives,
- U. whereas Support Groups represent a suitable space for group thinking to support and share the 'conscious responsibility' of the patients' relatives.
- V. whereas Alzheimer's and the other forms of dementia should not be perceived as a normal problem faced by individuals as part of the ageing process without them being entitled to suitable treatment, medical assistance and specialised care,
- W. whereas, although social awareness and scientific knowledge of Alzheimer's disease have increased substantially, underlining in particular how the disease is characterised not only by clinical dementia but also by the onset of pre-dementia earlier in time, therapeutic options are still limited to symptomatic drugs; whereas there are currently striking disparities between and even within Member States and shortcomings in terms of staff training and qualifications and the availability of equipment needed for diagnosis and research and whereas the diagnosis of Alzheimer's often takes place years after the onset of the disease, thus delaying any possible treatment to slow down the disease,
- X. whereas recent advances in the use of reliable biomarkers for Alzheimer's disease have stimulated the development of new criteria defining Alzheimer's disease as a clinical entity encompassing not only a phase affecting memory and cognition, but also an earlier phase,
- Y. whereas Alzheimer's disease and the other forms of dementia do not affect just the elderly, but may also be developed by young people; whereas access to diagnostic services, research and care, support and accommodation should be improved for young sufferers,
- Z. whereas raising greater public and professional awareness about Alzheimer's disease, both at national and European level, should empower the population to recognise the first signs of the disease, seek early diagnosis, and access treatment and services at an early stage,
- AA. whereas a greater focus on the pre-dementia phase of Alzheimer's disease could contribute to supporting the development of appropriate therapeutic interventions capable of slowing down the disease's progression, and ultimately delaying patients' entry into severe Alzheimer's, i.e. the most debilitating form of the disease,

AB. whereas the development of effective disease-modifying agents (as opposed to purely symptomatic agents) represents an area of critical and urgent unmet need for patients with Alzheimer's disease,

AC. whereas, furthermore, the diagnosis of Alzheimer's disease delivered in almost 70 % of cases of dementia fails to take full account of the variety of cerebral lesions encountered in sufferers and of the fact that young and elderly sufferers do not show the same pathological and clinical picture,

1. Calls on the Council to declare dementia to be an EU health priority and strongly urges the Member States to develop specific national plans and strategies for Alzheimer's disease in order to deal with the social and health consequences of dementia and to provide services and support for people with dementia and their families, as has been done in several Member States where the "Alzheimer's and similar diseases" plan launched in 2008 has made it possible to coordinate medical and social care and clinical and basic research into these diseases at national level;
2. Welcomes the EU Joint Programming initiative promoted by the Member States in order to boost research on Alzheimer's and other neurodegenerative diseases and encourages 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;
3. Calls on the Council and the Commission to take account of the concept of dementia when preparing future actions in the area of preventive health policy, notably in relation to its interaction with cardiovascular illnesses, mental health, physical activity, education in the field of health and new technologies;
4. Calls on the Member States to provide EU citizens with lifestyle information with a view to delaying or preventing the onset of Alzheimer's and other forms of dementia, by promoting the concept of 'a healthy lifestyle for a healthy brain';
5. Suggests that the Council and the Commission consider launching a European Year of Mental Health, complementing World Alzheimer's Day on 21 September, in order to raise awareness of brain-related diseases associated with ageing and of ways to detect and identify early symptoms of such diseases, with public information campaigns on their prevention as well as about the treatment of cerebral vascular accidents; The European year should be also a place to promote the exchange of good practices in European countries;
6. Points out that (a) the increasingly ageing population and b) 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; the European Union should therefore adopt in its long-term strategy the policy of firm promotion of the principle of prevention (in terms of medical practices as well as in terms of encouraging

healthier lifestyles). Health indicators will contribute to significant improvement of the economic indicators;

7. Calls on the Council and the Commission to 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;
8. Suggests that the Commission consider promoting a 'Carers Day' to raise awareness of and recognise the crucial role of formal and informal carers across Europe;
9. Stresses that discovering effective interventions that prevent the onset of or delay Alzheimer's progression must take on an all encompassing urgency;
10. Calls on the Council and the Commission to act to 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;
11. Underlines the primality of prevention as well as the relevance of early diagnosis for effective interventions; underlines the need and calls on the Member States to improve epidemiological and clinical data to help direct research, rehabilitation and action, in particular during the asymptomatic phases and before the onset of incapacity;
12. Notes that at present there is no specific policy on the prevention of Alzheimer's disease, and calls, 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;
13. Is convinced that the early diagnosis tests recently proposed by the International Working Group on the New Criteria for Alzheimer's Disease, research into risk factors and the definition of early-diagnosis criteria are vitally important;
14. Encourages all the Member States to engage actively in 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 and the sharing of best practices in the area of research into neurodegenerative diseases, thus reducing the prevailing inequalities between Member States and within Member States as regards diagnosis and treatment; points out 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;
15. Encourages Member States to ensure that drugs able to slow the onset of Alzheimer's are

made available to all patients suffering from the disease and not only patients who are diagnosed with severe cases of Alzheimer's;

16. Encourages the Commission to draw up guidelines for the development and implementation of common early diagnostic services based on a multidisciplinary assessment of the patient's state of memory and an adapted notification and information system to provide patients and their families with the best possible framework in which to approach the onset of the disease;
17. Encourages the Member States to establish specialist centres and to provide satisfactory medical equipment (including magnetic resonance imaging, whose contribution to dementia research is indisputable) nationwide;
18. Calls on the Council and the Commission to take account of the rapid spread of dementia and Alzheimer's, and their impact, when drawing-up action plans for research;
19. Urges the Member States to develop policies for facilitating access to research funding in the field of dementia and Alzheimer's, including research into prevention, on a basis proportionate to these illnesses' economic impact on society;
20. 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; believes that research on the validation of new diagnostic criteria, the development of early screening tests, and the identification of risk factors for the progress of the disease from the pre-dementia phase to the advanced stages is crucial; recommends that representatives of patients, healthcare organisations and medical-service providers be involved in this process; sees, this being the case, clear added value in conducting large-scale epidemiological and clinical studies on the basis of transnational collaboration;
21. Recognises the current importance of the European Union's support, totalling EUR 159 million, for 34 projects on neurodegenerative diseases; considers it essential, nevertheless, in the context of the forthcoming 8th RDFP, to address the fragmented nature of research, particularly that on Alzheimer's, and to include projects in the insufficiently explored fields of non-drug, behavioural and cognitive therapies;
22. Regards early diagnostic tests, research into risk factors and early diagnosis criteria as crucial; sees, this being the case, clear added value in conducting large-scale epidemiological and clinical studies on the basis of transnational cooperation; regards the European Health Examination Survey, which will be able to provide valuable information, through its cognitive test module, on the number of people with early-stage cognitive deficiencies, as equally important;
23. Calls 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, in the areas of medical and social research, health, employment and social policies;

24. Calls on the Member States to develop long-term policies and action plans in the field of care and prevention which anticipate and address social and demographic trends, and to focus on the support provided to the families of patients for whom they are caring, thereby affording social protection to vulnerable persons suffering from dementia;
25. Stresses the importance of preventing Alzheimer's disease by encouraging a healthy lifestyle, including staying mentally and socially engaged, promoting good diets and exercising;
26. Invites the Member States to develop a Strategic Research Action Plan establishing medium- to long-term research needs and objectives in the area of neurodegenerative diseases, including care provision needs, especially in the area of Alzheimer's. These action plans should focus on enhancing the potential of young researchers and supporting innovative research approaches based on a public-private partnership; recommends fostering the development of centres of excellence for specific research areas and involving representatives of patients, carers organisations and public/private healthcare providers;
27. Invites the Member States to cooperate with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda;
28. Calls on the Member States to develop 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;
29. Invites European Institutions to support as far as possible Alzheimer Europe's Dementia Research Observatory as a useful tool for the dissemination of best practices and research results to patients and their carers;
30. Points to the importance of research into the connection as well as the distinction between the ageing process and dementia, between dementia and depression in older people, and between gender differences and the various types of dementia; encourages the Member States, furthermore, to promote specific healthcare and research programmes that give great importance to patient choice and perspective, and to formulate recommendations centered on the core principles of dignity and social inclusion, thereby promoting the autonomy and self determination of patients;
31. Calls on the Member States to devote suitable resources to healthcare for Alzheimer's patients and to exchanges of information and networking with regard to the results obtained;
32. Stresses 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; encourages the Member States to create forms of partnership with those organisations and support for their activities; calls 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;

33. Stresses the need for actions which do not just focus on drug-based treatment of Alzheimer's once the condition has developed, but also on preventative measures, including diet and nutrition, to reduce the chances of developing Alzheimer's; calls for extensive research into the effects of diet and nutrition on Alzheimer's and for advice, including nutritional advice, on preventing the disease to be developed and disseminated to the public through awareness raising campaigns;
34. Underlines that research in health economics, social science and humanities, and non-pharmacological approaches is also needed to understand the psychological and social aspects of dementia;
35. Sees that the diagnosis of early symptoms of memory disorders should be one of the focal areas in occupational healthcare;
36. Urges the Commission, the Council and the Member States to consider establishing safety standards applicable to institutions specialising in care for the elderly, to the communities to which they belong and to home care arrangements;
37. Invites Member States, in close cooperation with the Commission and in conjunction with research organisations, to draw up common guidelines for the training of staff who work in whatever capacity with Alzheimer's patients (medical and paramedical professions), and for the training and monitoring of family and other informed carers to ensure competent and effective use of the existing resources; points out that the need for skilled people working with persons with dementia is increasing rapidly;
38. Calls on Member States to consider opportunities offered by the EU 2020 strategies 'A new jobs agenda' and 'New skills for new jobs' to strengthen the future workforce capacity related to looking after people suffering from Alzheimer's and other types of dementia; new skill-specific jobs need to be promoted across Europe to look after an increasingly dependent ageing population;
39. Calls on the Commission to leverage the resources of the flagship initiative 'Innovation Union' in the Europe 2020 Strategy and the planned pilot partnership on active and healthy ageing (to be launched by early 2011) to tackle dementia in Europe;
40. Underlines that the recent advances in imaging and biomarker research open the way to detecting silent molecular processes and early signs of Alzheimer's disease by using, for example, a marker which is currently being studied that will make it possible to view amyloid plaques, one of the two lesions associated with this disease, in the brain;
41. Recognises the vital contribution families, carers and communities play in enabling suffering patients to realise their potential and asks the Member States to support family, carers and community life;
42. 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; advocates the need for research in the fields of the health economy, social-humanistic aspects and non-pharmaceutical approaches to treatment, in order to gain an understanding of the psychological, economic and social

aspects of dementia and to promote the use of existing technologies (e-health, ITC, assistive technologies, etc.);

43. Recommends that the Commission examine how EU initiatives in the field of rights of people with dementia, including the use of advance directives (living wills) and the issue of guardianship systems, can be extended;
44. Encourages Member States to consider reducing the use of antipsychotic medication in their action plans to aid Alzheimer's sufferers, given that while these drugs are currently commonly prescribed to combat the effects of dementia, their beneficial effect has been shown to be limited, and they have moreover contributed to excess deaths every year as a result of their prescription;
45. Emphasises that the dignity of people with Alzheimer's needs to be preserved and the stigma and discrimination against them needs to be eliminated;
46. Encourages Member States and the Commission to develop new policy-based incentives to facilitate the dissemination of information and market access strategies for innovative therapies and diagnostic tests addressing the current unmet needs of patients with Alzheimer's disease;
47. Encourages the Member States to develop healthcare and social services with the core principle of maximising coverage and ensuring equity of access and equality, to encourage the development of integrated services delivery in communities and at home, to benefit people with dementia regardless of age, gender, ethnicity, wealth, disability, and rural or urban residence; encourages Member States to take action to tackle those factors which impact unequally on the health of the population in a way which is avoidable; encourages the Commission and the Member States to further develop the collection of data on health inequalities;
48. Calls on the Member States to be aware of the preventative treatment that helps slow the onset of dementia as well as ensuring access to affordable, quality care for sufferers; highlights for Member States that such services need to be protected at a time of fiscal consolidation across Europe;
49. Calls on the Member States to set up an interconnected European network of centres of reference where expertise in the diagnosis, treatment and care of dementia and Alzheimer's would be concentrated and by means of which information and data could be exchanged and evaluated between the Member States;
50. Encourages the Member States to develop personalised pathways for multiprofessional and multidisciplinary care and support coordinated by a single reference person from the moment the diagnosis is notified, in order to facilitate home-based care through increased use of multi-purpose and specialised home help and care services, home automation and new information and communication technologies;
51. Calls on the Member States to develop diverse, innovative and high-quality facilities to offer respite to carers, such as accommodation and temporary reception centres, and to monitor the health of carers by, for example, providing them with appropriate medical

care and psychological or social support;

52. Calls on the European Union and the Member States to strengthen research, improve access to diagnostic services and adapt care and support services to the needs of young sufferers;
53. Encourages the Member States to provide patients with access to new treatments whose therapeutic effectiveness has been verified and established, and to do so as soon as possible after they become available;
54. Urges the Member States to improve public and professional awareness of dementia among healthcare skilled/semiskilled professionals, healthcare policy makers and media, resulting in better recognition of the symptoms of Alzheimer's disease and understanding of the disease and its care; the awareness must focus on different components such as diagnosis, treatment and appropriate support;
55. Reminds the Commission of the 2006 Bowis report calling on employers to introduce 'Mental Health at Work' policies as a necessary part of their health and safety at work responsibility, with a view to ensuring the best possible incorporation into the labour market of persons with mental disorders, and that these policies should be published and monitored within existing health and safety legislation; reminds the Commission that Parliament is still waiting for these policies to be published;
56. Emphasises 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);
57. Encourages the Member States to develop information campaigns for the general public and for specific groups such as schoolchildren, healthcare 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 – including online – on 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; highlights the importance in all awareness and education campaigns of the ability to recognise the symptoms of dementia;
58. Encourages the Member States to promote, 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;
59. Encourages the Member States and the Commission to promote consideration of the needs of and an ethical approach to sufferers in order to guarantee respect for human dignity,

and to consider the legal status of people suffering from neurodegenerative diseases with a view to providing a legal framework for the deprivation of liberty and legal protection for sufferers;

60. Calls 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, and 4) fostering partnerships with the medical profession to provide a holistic approach; points out that in order to do so, the European institutions should investigate the possibilities of the European Public Health Programme providing regular core funding to European Alzheimer Associations and encourage Member States to support Alzheimer associations at national level;
61. Encourages Member States to develop support groups for healthcare professionals working in institutions, for relatives of hospitalised patients, for relatives assisting the patient at home and for healthcare professionals working in the home healthcare service;
62. Calls on the Council, the Commission and the Member States, 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, and to provide information on best practices as regards respect for the rights of the vulnerable and combating the mistreatment of dementia patients;
63. Calls on the Commission and the Council to foster the development, in connection with the implementation of research projects, of partnerships between public institutions and between private and public institutions, thereby harnessing facilities, resources and experience in the private and public sectors to combat the effects of Alzheimer's and of other types of dementia;
64. Points out that considerable progress still needs to be made in the area of access to therapeutic trials for patients with Alzheimer's and similar diseases in order to ensure that the new molecules are effective; emphasises that this problem should be addressed in the next revision of the EU Directive on clinical trials on medicinal products (2001/20/EC);
65. Calls on the Member States, in the light of the destructive impact of Alzheimer's on the memory and the mental faculties, to devise national strategies enabling the authorities responsible for financial aid to sufferers also to monitor such aid so as to ensure that it is used exclusively to benefit the sufferers;
66. 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.

RESULT OF FINAL VOTE IN COMMITTEE

Date adopted	30.11.2010
Result of final vote	+: 48 -: 0 0: 1
Members present for the final vote	Elena Oana Antonescu, Kriton Arsenis, Pilar Ayuso, Paolo Bartolozzi, Sergio Berlato, Milan Cabrnoch, Martin Callanan, Nessa Childers, Chris Davies, Anne Delvaux, Bas Eickhout, Jill Evans, Elisabetta Gardini, Gerben-Jan Gerbrandy, Julie Girling, Nick Griffin, Françoise Grossetête, Jolanta Emilia Hibner, Dan Jørgensen, Jo Leinen, Corinne Lepage, Peter Liese, Linda McAvan, Radvilė Morkūnaitė-Mikulėnienė, Gilles Pargneaux, Andres Perello Rodriguez, Mario Pirillo, Pavel Poc, Vittorio Prodi, Frédérique Ries, Anna Rosbach, Oreste Rossi, Dagmar Roth-Behrendt, Carl Schlyter, Richard Seeber, Theodoros Skylakakis, Catherine Soullie, Salvatore Tatarella, Sabine Wils, Marina Yannakoudakis
Substitute(s) present for the final vote	Marisa Matias, Judith A. Merkies, Miroslav Mikolášik, Bill Newton Dunn, Rovana Plumb, Bart Staes, Csaba Sándor Tabajdi, Giommara Uggias, Thomas Ulmer