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COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL

on a European initiative on Alzheimer's disease and other dementias

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1. INTRODUCTION AND PROBLEM DEFINITION

1.1. The context

Dementia is a decline in mental ability that usually develops slowly, causing impaired memory, thinking and judgement, and personality may deteriorate. It predominantly (but not exclusively) affects those aged over 60 and is a major cause of disability among the elderly, and the increasing proportion of older people in many populations means that the number of dementia patients is also likely to rise. Dementias are a group of neurodegenerative diseases and are not just a part of the normal ageing process.

The most common type of dementia in the EU is Alzheimer's disease which accounts for around 50-70% of cases, followed by the successive strokes which lead to multi-infarct dementia (around 30%); other forms include Frontotemporal dementia, Pick's disease, Binswanger's disease, Lewy-Body dementia, amongst others. A project, carried out by the European Union patients' platform Alzheimer Europe[1] with the support of the European Commission, also identified the most significant rare forms of dementia[2].

The best available estimates[3] indicate that, in 2006, 7.3 million Europeans (across the 27 Member States) between 30 and 99 years of age were suffering from different types of dementia (12.5 per 1 000 inhabitants). Within this group, more women (4.9 million) than men (2.4 million) are affected. With the increase in life expectancy, especially in developed countries, dementia's incidence has increased dramatically and some current forecasts project a doubling of the number of persons affected every 20 years[4,5].

Of course, dementias do not only affect the people with the condition, but also those who care for them. If we estimate that in every family with a patient, on average three persons directly bear the brunt[6], this means that an estimated 19 million Europeans are directly affected by dementias.

Dementias are very expensive for society as a whole: according to the Dementia in Europe Yearbook (2008), the total direct and informal care costs of Alzheimer's disease and other

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1 http://www.alzheimer-europe.org/

2 http://ec.europa.eu/health/ph_projects/2002/rare_diseases/fp_raredis_2002_a4_03_en.pdf

3 http://ec.europa.eu/health/ph_information/dissemination/echi/docs/dementia2_en.pdf

4 Alzheimer's disease: Scientific, medical and societal implications, Synthesis and recommendations. Collective expert report from INSERM (French National Institute for health and medical research), 2007.

5 First Results from the Survey of Health, Ageing and Retirement in Europe (2004-2007**)** http://www.share-project.org/t3/share/uploads/tx_sharepublications/BuchSHAREganz250808.pdf

6 Alzheimer's disease in real life--the dementia carer's survey http://www.alzheimer-europe.org/?lm2=C5BA5EF2EE10

dementias in 2005 amounted to €130 billion for the EU 27 region (€21 000 per patient/year); 56% of costs were generated by informal care[7].

However, Alzheimer's disease remains under-diagnosed in the EU; according to the available epidemiological data, only half of those suffering from the disease are currently identified[8].

The importance of these conditions has long been recognised at European level, not only by the Commission but also by the Parliament and the Council. Resultant action has included European Parliament Resolutions in 1996 and 1998[9], accompanied by budgetary provision for specific projects in this area[10]. The White Paper "Together for Health: A Strategic Approach for the EU 2008-2013" of 23 October 2007 (COM(2007) 630) outlining the EU Health Strategy[11] identifies the need for neurodegenerative diseases such as Alzheimer's to be better understood in the context of demographic ageing. Most recently, the Council has adopted two sets of Conclusions on combating neurodegenerative diseases and particularly Alzheimer's[12,13], including calls for action by the Commission.

The primary responsibility for tackling dementias lies with the Member States. However, in the area of health under Article 152 of the Treaty, the Community is to encourage cooperation between the Member States and if necessary to lend support to their action. Moreover, Article 165 of the Treaty stipulates that the Community and the Member States shall coordinate their research and technological development activities so as to ensure that national policies and Community policies are mutually consistent. In close cooperation with the Member States, the Commission may take any useful initiative to promote coordination.

The specific characteristics of Alzheimer's disease and other dementias single them out as areas where actions taken at EU level can bring added value in supporting Member States. The objective of this Communication is to set out actions providing support to Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care, and research for Alzheimer's disease and other dementias in Europe. For this a Joint Action between the European Commission and the Member States as defined in the Work Plan for the implementation of the Second Health Programme (2008-2013)[14] will be launched in 2010. This will in turn contribute to the overarching goal - an improvement in health outcomes, and therefore a growth in Healthy Life Years, a key Lisbon Strategy indicator[15].

1.2. The issues

There are four key issues that Community action could help to address:

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7 Alzheimer Europe (2008) Dementia in Europe Yearbook 2008

8 Major and Chronic Diseases Report 2007, Task Force on Major and Chronic Diseases, DG SANCO http://ec.europa.eu/health/ph_threats/non_com/docs/mcd_report_en.pdf

9 Resolution of 17 April 1996 on Alzheimer's disease and the prevention of disorders of the cognitive functions in the elderly and Resolution of 11 March 1998 on Alzheimer's disease.

10 http://ec.europa.eu/health/ph_projects/alzheimer_project_full_listing_en.htm

11 See http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm

12 http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/104778.pdf

13 http://register.consilium.europa.eu/pdf/en/08/st13/st13668.en08.pdf

14 Decision No 1350/2007/EC of the European Parliament and of the Council of 23 October 2007 establishing a second programme of Community action in the field of health (2008-13)

15 See http://ec.europa.eu/health/ph_information/indicators/lifeyears_en.htm

– People can act to help prevent dementia, especially vascular dementia and in some extent also Alzheimer's disease, and early diagnosis can ensure that interventions take place while they are most effective. But there is a lack of awareness of the importance of prevention and early intervention throughout the EU;

– There is a clear need for improved understanding of dementias, in particular of Alzheimer's disease and other neurodegenerative types. Yet there is very limited coordination of research, an issue with particular potential for European added value, and a lack of sufficient epidemiological data to help direct research and action in the future;

– There are good practices emerging in different places across the EU with regard to diagnosis, treatment and financing of therapies for these conditions, but they are not being shared throughout the Union. This is all the more important given that the European Union is and will be confronted with staff shortages of formal carers, and problems stemming from a lack of support for informal carers;

– Insufficient attention is being paid to rights of people suffering from a cognitive deficit . There is also a lack of recognition of the mental capital of older people, lack of knowledge and understanding by the general public of what Alzheimer's disease is, and a stigma associated with dementias that can influence the health of these patients.

2. OBJECTIVES AND COMMUNITY ACTIONS

2.1. Acting early to diagnose dementia and to promote well-being with age

Promoting good physical and mental health (e.g. developing a healthy cardiovascular system, encouraging education and learning throughout life) can help to avoid cognitive decline leading to dementia. Prevention is more straightforward for vascular dementia than for Alzheimer's disease because risk factors for strokes are well identified and similar to those for other cardiovascular diseases (such as coronary heart disease). These risk factors include high blood pressure, high cholesterol levels and smoking. Given that half of all dementia cases have a vascular component, control of vascular risk factors could protect against the development of dementia[16]. More targeted research is required in order to better understand what a 'healthy brain lifestyle' is an issue which will increase in importance alongside demographic ageing.

Understanding dementias, both for individual patients and families, and for public authorities, also depends on accurate and consistent diagnosis. Identifying and promoting best practice in early diagnosis of Alzheimer’s disease and other forms of dementia is necessary in order to make best use of available interventions at the most effective early stages. Through earlier diagnosis and intervention it may be possible to delay late-stage progression of the diseases and thus postpone institutionalisation, thereby reducing the high cost of terminal (long-term) care. Progress has already been made at EU level towards developing a basis for early, accurate diagnosis that also allows best use to be made of existing treatments[17]. The

[16] Alzheimer Europe (2008) Dementia in Europe Yearbook.

[17] This includes the Mini Mental State Examination (MMSE) and the EU Project DESCRIPA (*Development of Screening guidelines and diagnostic Criteria for Predementia Alzheimer's disease*) – see http://www.biocompetence.eu/index.php/kb_1/io_2930/io.html.

Commission will support further work in order to develop these best practices for early diagnostic procedures for Alzheimer's disease and other dementias.

Furthermore, there is growing evidence that mental activity and stimulation (through lifelong learning as well as through social interactions) reduces the risk of developing dementia, including Alzheimer's disease. Conversely, inactivity appears to be a risk factor. There is evidence to suggest that when people come to retire and do not make appropriate adjustments, retirement acts as a catalyst for age-related cognitive decline[18]. This could be countered by more flexible retirement or post-normal retirement employment (also contributing to the sustainability of pension schemes), as well as other adjustments in health and social care systems.

A European Pact for Mental Health and Well-being was established by the EU high-level conference "Together for Mental Health and Well-being" of 13 June 2008[19]. Its launch is an opportunity to take this dimension of the disease into account, providing a framework for awareness-raising activities and the exchange of good practices in addressing Alzheimer challenges, as a strand complementing the Pact's focus on mental health, well-being, and disorders.

The European Commission launched in 2007 the "Communication on Ageing Well in the Information Society" of 14th June 2007 (COM(2007) 332)[20] with a number of concrete actions. These include specific actions in the Information and Communication Technologies (ICT) part of the FP7, , as well as large scale pilot projects with regions under the Competitiveness and Innovation programme specifically addressing ICT solutions for elderly people with cognitive problems and mild dementia and as well as their carers. In addition, a joint research and innovation programme has been launched[21] between the EU and 23 European countries on new ICT products and services for ageing well, where solutions in support of Alzheimer's disease can be developed.

- 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.
- To produce set of recommendations, which would help the citizens to prevent dementia diseases.
- To include the 'dementia dimension' in flexible European policies on retirement and in the framework for action on older people in the European Pact for Mental Health and Well-being.

18 http://www2.ulg.ac.be/crepp/papers/crepp-wp200704.pdf
19 http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/pact_en.pdf
20 http://ec.europa.eu/information_society/activities/health/docs/policy/interop-com2007-332-final.pdf
21 Decision No 742/2008/Ec of the European Parliament and of the Council of 9 July 2008, OJ L 201/49 of 30.7.2008.

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

Reliable prevalence and incidence data on dementias are also essential if Member States are to be able to make appropriate plans and provision, taking into account the major consequences for public finances across Europe. The Commission will continue to work towards reliable prevalence and incidence data according to age and based on the "European Collaboration on Dementia (EuroCoDe)" project[22] methodology. In particular, the Commission will develop actions under the Health Programme on better prevalence data, risk factors and how to address them, and validation of new criteria for early diagnosis. In the future, the planned European Health Examination Survey (EHES)[23] will also be able to provide valuable information through its cognitive test module, providing data with a strong predictive value on the evolution of this problem. Synergies will be sought within the Seventh Framework Programme for research and technological development (FP7)[24], with particular reference to the Health Theme of the specific Programme "Cooperation", which has research on the brain and related diseases as a dedicated research area and research into ageing as a cross-cutting issue.

Community research efforts in this area have been stepped up in FP7 within the Health Theme through the areas of brain research and public health research, covering issues such as understanding disease mechanisms, patient mental health, prevention strategies for healthy ageing, and equality of access to care. In the face of the major challenges to public health presented by Alzheimer's disease and other dementias, promising areas of research may be supported, in particular by fostering increased coordination between fundamental and clinical research. Examples of areas of potential interest are research into the pathophysiology of the disease, including epidemiological and clinical trials, research in health economics, the social sciences and humanities to help understanding of the psychological and social aspects of the disease, and research into social care models including sharing of best practices in the training of dementia caregivers, reflecting the broad consensus that patient care should not be limited to pharmacological treatment but should also include non-pharmacological approaches.

Within the Health Theme of the specific Programme "Cooperation", the third activity entitled "Optimising the delivery of health care to European citizens" provides for European public health research to contribute to building the necessary basis both for informed policy decisions on health systems and for more effective strategies of health promotion, disease prevention, diagnosis and therapy. To date, two calls for proposals have addressed the impact of ageing, resulting in projects that will entail research on health systems and long-term care of the elderly, organisation of dementia care, a road map for ageing research, ageing cohorts, and health outcome measures and population ageing. Further research should be developed in the light of these projects as well as Member States' priorities.

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22 http://ec.europa.eu/health/ph_projects/2005/action1/action1_2005_10_en.htm

23 http://ec.europa.eu/health/ph_information/dissemination/reporting/report_en.htm

24 Decision No 1982/2006/EC of the European Parliament and of the Council of 18 December 2006 concerning the Seventh Framework Programme of the European Community for research, technological development and demonstration activities (2007-2013) (OJ L 412, 30.12.2006, p. 1) and Council Decision 2006/971/EC of 19 December 2006 concerning the specific programme 'Cooperation' (HEALTH) implementing the Seventh Framework Programme of the European Community for research, technological development and demonstration activities (2007 to 2013) (OJ L 54, 22.2.2007, p. 30).

First steps are being taken to promote cooperation in public research efforts targeting key priorities related to neurodegenerative diseases, in particular Alzheimer's, at European level through a Joint Programming approach[25]. This approach involves Member States engaging voluntarily and on the basis of a variable geometry in the definition, development and implementation of a common strategic research agenda (SRA) based on a communal vision of how to address today's major societal challenges. Neurodegenerative diseases have been identified by Member States as an area where the social demand is high and where a common initiative, implemented through Joint Programming, would improve hugely on the current fragmented efforts in the European Research Area. Currently, resources are split between numerous and diverse funding agencies spread over the 27 EU Member States and without a strong alignment to policy making. This creates the risk of wasteful duplication of public research funding at EU level. A joint European effort is therefore needed to develop a common vision of research needs and measures to be implemented in this field in order to promote the cooperation at EU level, design and upscale novel approaches commensurate with scientific, medical and social unknowns, avoid unnecessary duplication of efforts and increase the efficiency and effectiveness of national and Community R&D spending.

To this end, alongside this Communication, the Commission is presenting a proposal for a Council Recommendation on a pilot Joint Programming initiative on combating neurodegenerative diseases, in particular Alzheimer's, for pooling and coordinating the efforts of European basic and clinical researchers in this field. The purpose of this Recommendation is to develop a new approach, through cooperation and collaboration between national research programmes, for more effectively tackling common European challenges in the area of neurodegenerative diseases, in particular Alzheimer's disease, hence making better use of Europe's limited public R&D funds. The approach would entail Member States to develop a common vision of how research cooperation and coordination at European level can contribute to better understand, detect, prevent and combat neurodegenerative diseases, in particular Alzheimer´s, and to develop and implement a strategic research agenda to realise this vision. It invites the Commission to provide complementary supporting measures to support the pilot Joint Programming initiative, which would include the support to the management structure and the establishment of the SRA, the provision of data, information and analysis on the state of the art in this field in Member States and at European level.

- Actions:

- To improve epidemiological data on Alzheimer's disease and other dementias, implementing the conclusions of the EuroCoDe Project;
- To use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive deficiencies;
- 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.

[25] Council conclusions concerning a common commitment by the Member States to combat neurodegenerative diseases, particularly Alzheimer's.
http://register.consilium.europa.eu/pdf/en/08/st13/s13668.en08.pdf.

2.3. Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering dementia

The 'Open Method of Coordination' for Social Protection, Social Inclusion and Long-Term Care with associated activities (peer review process, conference, theme for the next joint report) can provide a platform for sharing best practice, in particular with regard to standards of care and for the financing of social protection for people with neurodegenerative conditions and their families. Furthermore, best practice on how to optimise support for family members that care for persons suffering from Alzheimer's disease and other forms of dementia should also be shared. Alongside this the Commission will also support the development of good practices, where needed, by providing information on how ongoing Community programmes (in particular, the Structural Funds) can help finance such developments in Member States.

Community care, home care, residential care and day care are labour-intensive sectors in which staff costs account for the majority of the overall expenditure. Labour supply in these areas is a major preoccupation for Member States, particularly in view of the medical, nursing and social care staff shortages. Provision of special training to nurses and family members of Alzheimer patients should be promoted. Therefore, the Commission will explore the scope for supporting cooperation on development of concepts and solutions both nationally and at European level, promoting a holistic approach for care. It will also focus on developing quality frameworks for medical and social care services for people with dementias through the Health Programme.

The empowerment of national and international Alzheimer's associations and relevant patients' organisations should ensure that patients and their representatives are duly consulted. It's an objective of the second Health Programme and existing national dementia strategies. The EU's PROGRESS Programme (2007-2013)[26] combating social exclusion and discrimination, promoting gender equality and the integration of people with disabilities will continue to provide support to organisations representing patients and relatives.. Facilities provided by the EU Disability Action Plan (DAP) 2003-2010 will also be used as appropriate.

- Actions:

- To map the existing and emerging good practices related to treatment and care for persons suffering from Alzheimer's disease and other forms of dementia and to improve the dissemination and application 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.
- To use facilities provided for in the EU Disability Action Plan (DAP) 2003-2010 to support patients' organisations.

[26] Decision No 1672/2006/EC of the European Parliament and of the Council of 24 October 2006 establishing a Community Programme for Employment and Social Solidarity — Progress.

2.4. Respecting the rights of people with dementias

The image of Alzheimer's disease and other dementias in European society is a negative one, often associated with fear and helplessness that can influence the health of these patients. The gradual loss of capacity makes it difficult for people with dementia to maintain their place and active participation in society. Carers may also experience social exclusion resulting from the effects of dementia on their loved ones. However, maintaining social contact and remaining active helps preserve autonomy and physical and mental well-being for longer, minimising the need for assistance and preventing social isolation and depression.

The disclosure of the diagnosis to people with dementia is of great significance in allowing them to take an active part in decisions affecting their lives. 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[27]. In any case, it is imperative to allow the person suffering from dementia to articulate his or her preferences, insofar as they are capable to do so.

The Commission can contribute to political leadership in recognising the rights of elderly people with cognitive disorders. It has organised the first-ever European Conference on Prevention of Neglect and Abuse of Elderly People (2008). It also envisages establishing a European Network with the most relevant public and private stakeholders for rights and dignity of people with dementia who should formulate recommendations on dignity, autonomy and social inclusion as a means to preserve physical and mental health of these people. This should contribute to political leadership in the EU for reducing the stigma associated with Alzheimer's disease and other dementias and contributing to the well-being of these patients. The proposed European Network should also contribute to sharing best practices on respecting the rights of vulnerable adults and tackling patient abuse.

- Action:

- To establish, using the facilities provided by the Health Programme, a European Network for rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable adults and tackling patient abuse.

3. CONCLUSIONS AND NEXT STEPS

Public health, research, social protection, and rights and autonomy constitute the four dimensions of action that should respond to a reality in our societies. The European population is ageing and it is the responsibility of all to ensure that people can age with dignity, keeping in good health for as long as possible and enjoying the same rights as everyone else. The Commission intends to use, for the purposes of this Communication, the

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

different legal instruments at its disposal (Health Programme, Seventh Framework Programme, EU Disability Action, Open Method of Coordination and Statistical Programme) in an integrated way that permits a high level of efficiency and coordination, and optimum use of resources. Community action can help to support the Member States in addressing the issue of dementias as European society ages. Ultimately, the Community can undertake these supportive actions, but success in meeting this challenge will mostly depend on the primary role of Member States and civil society.

To this end, the Commission will also help support the World Alzheimer's Day (21 September) through European and national initiatives. Working in partnership and on the basis of the measures set out in this Communication, the Commission will thereby contribute to a collective effort seeking to maximise health in an ageing society throughout Europe.

The Commission initiative on Alzheimer's disease and dementias should aim at fostering cooperation at an international level with all interested countries and in close collaboration with the World Health Organisation. International cooperation is already an integral part of the Framework Programmes for Research.

The Commission will produce by 2013 an implementation report on this Communication - addressed to the European Parliament and to the Council- at the end of the Joint Action between the European Commission and the Member States implementing the actions of this Communication.