Current Status regarding Dementia in Greece – Towards the Implementation of the Greek Dementia Strategy

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Dementia in Greece

- 200,000 people with dementia
  89% cared for at home - 400,000 caregivers
- Dementia the most pressing medical, social and economic challenges
- Annual cost of dementia in Greece 6 billion euros
- Dementia programmes since 2006 but so far limited resources
- Few services operated by Alzheimer’s Associations and funded by the State or European Union
Dementia in Greece

- 13 Day Care Centers run by AAs (Underfinanced, provide services for only 5,000 people with dementia)
- 3 respite care facilities
- 15 Memory Clinics (Medical Schools, NHS, NGOs)
- 28 Alzheimer’s Associations (awareness campaigns, screening programs, programmes for carers, non-pharmacological interventions, seminars for health professionals, scientific research)

National Strategic Plan for Dementia
Alzheimer’s Associations in Greece

• Greek Association of Alzheimer's Disease and Related Disorders – Thessaloniki 1995
• Volos 1998
• Xanthi 1998
• Chania 1999
• Larissa 2000
• Athens Association of Alzheimer’s Disease and Related Disorders 2002
• Heraklion 2002
• Rodos 2008
• Chalkida 2008

Greek Alzheimer’s Federation 2007
Memory Walks 2008 - 2014
Dementia in Greece - Deficiencies

- Compared to the existing needs, the services provided are woefully inadequate, large areas of the country which are not covered by any specialist services or facilities
- The major problem is the total lack of social care facilities, long stay institutions and end of life centres throughout the country
- There are no tax allowances or financial benefits for people with dementia and caregivers
- Primary health care services and hospital Emergency departments do not have the necessary expertise
- There is no legislative framework for Dementia
- Continued stigma surrounds Alzheimer’s Disease
- Impact of the economic crisis on patients and carers

7 November 2012: Withdrawal of full reimbursement for anti-dementia drugs

National Strategic Plan for Dementia
Formation of the National Working Group

• Earnestly pursued by all stakeholders for many years
• In November 2013 the Minister of Health assigned a national working committee to design, organise and develop a National Dementia Strategy
• The working group consisted of specialized doctors and other health professionals, caregivers, lawyers, health economists and members of the Alzheimer’s Associations
• In September 2014 the working group finalized and presented the first draft of the strategy to the Ministry of Health
• 26 September 2014: launch event attracted over 2000 delegates
Towards a Greek Dementia Strategy

The working group has been involved with the following:

- Collecting a large amount of data through literature and examining other countries strategies, policies and procedures
- Recording and analysing the current situation and listing the existing resources and deficiencies in Greece in collaboration with Ministries, local authorities, Universities, NGOs, Institutions etc.
- Organizing two waves of consultation:
  - 1500 questionnaires distributed to the Alzheimer’s Association members, patients, families and health professionals all over Greece
  - Three focus group consultations conducted during May-July 2014. These included academia and scientific experts, health professionals unions, politicians, industry, stakeholder groups and interested parties involved in the management of dementia
Figure 2. Type of needs expressed (%) by caregivers of patients with dementia

Legal issues: 80.1%
Financial benefits: 66.15%
Social services: 43.06%
Medical services: 42.7%

Evaluating the Needs of Dementia Patients’ Caregivers in Greece: A Questionnaire Survey

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Greek Dementia Strategy recommendations

Key priorities of the strategy are to raise public and professional awareness, promote early diagnosis and intervention and improve the quality of life of people with dementia and their caregivers. The strategy is centered around 10 core areas and for each one a set of actions is defined. These are listed below:

- Improve public awareness and engagement - reduce stigma
- Improve prevention, early diagnosis and effective treatment
- Establish a national dementia registry to design policies and improve care
- Create services for carers and families in all parts of Greece
- Enhance residential/institutional care, care at home
- Effectively integrate care pathways and promote coordination of social and medical care
- Reinforce education and training for healthcare professionals
- Establish research programmes that embrace innovative technologies
- Create legislation to support patients’ needs and rights
- Effective implementation-monitor progress- update
In December 2014 the Greek Parliament enacted a law to ensure the implementation of the strategy. This law, supported by the entire Greek political spectrum, authorises the establishment of an independent strategic public institution: the National Observatory for Dementia and Alzheimer’s disease. The Observatory will act under the guiding principles of respect, support and promotion of patients’ rights.

The Observatory has an interdisciplinary profile, engaging health professionals, scientists, caregivers and other members with specific expertise. Their five-year mandate will be renewable once and its operation may not be affected by governmental changes.
National Observatory for Dementia Objectives

• Ensure the implementation and subsequent updates of the National Dementia Strategy
• Provide official guidance to the Parliament, the Ministry of Health and other public authorities on legislative and policy measures related to dementia
• Coordinate and promote the work of public and nongovernmental agents and associations, in order to ensure efficient services to patients and their caregivers
• Provide specific guidance for organizing and promoting the national policy in research and education
The strategic plan has been discussed in two subsequent sessions and approved by the Standing Committee of Social Affairs of the Greek Parliament.

All parties agreed that «the basic principles, directives and priorities of the strategy constitute the basis for developing specific regulations on dementia at a national level»

They also acknowledged the key role of the National Observatory in monitoring the implementation of the plan, designing relevant policies, and ensuring a permanent dialogue between the patient organizations, the clinical and research community and the public authorities.
Greek Dementia Strategy implementation

1. A national dementia registry is underway by the Greek National Health Service Organisation-funding available from the National Strategic Reference Framework 2014-2020

2. A rating system to measure the burden of dementia on families is being developed by the National School of Public Health taking into account socioeconomic and family status, place of residence, access to health and social care services etc. This will be used by the State to accordingly establish financial benefits for persons with dementia and their carers–funding available from the National Strategic Reference Framework 2014-2020

3. Dementia Day Care Centers in collaboration with Municipalities throughout the country – funding available from the National Strategic Reference Framework 2014-2020
Following steps for the future

- Major challenge is unquestionably financial!

- We have to balance the needs, set priorities and focus on targets that can be met currently.

- Our major goal is to build a broader base of engaged people, expand leadership at a national level and implement the Strategy in a collaborative way.