

National Action Plan for dementia – Alzheimer's disease

**NATIONAL ACTION PLAN FOR DEMENTIA –
ALZHEIMER'S DISEASE**

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Introduction

Dementia is one of the biggest challenges for Public Health. Based on estimations of Alzheimer's Diseases International, nowadays 44 million people are affected by dementia world-wide, a number which will double by 2030 and will hypertriple by 2050. In our country, 200.000 people are affected by dementia and this number is expected to exceed 600.000 by 2050. Despite the scientific methods of the last 25 years the treatment of dementia constitutes a major issue both at national and international level. The stigma, denial and lack of economic resources constitute the main obstacles for integrated care of people affected by dementia.

The World Health Organization, the European Community and the Alzheimer's international organizations have been repeatedly engaged in developing instructions and writing reports concerning the management policies of dementia and its consequences. In the recent G8 Dementia Summit held in London, in December 2013, international economic experts, doctors and politicians appealed to the governments of all countries to render as the major target of public health the prevention of dementia during the next years. Eleven countries materialize at this moment National Action Plans for dementia which determine policies, sections of intervention, priorities and actions, signaling at the same time the necessity and importance for undertaking coordinated measures to satisfy the needs of people affected by dementia.

Within this context, under the continuously increasing socio-economic impact of dementia and as the result of long-term requests of the non-profit Alzheimer Associations in our country, the Ministry of Health set up the National Committee-Working Group which carried out the **National Action Plan for dementia-Alzheimer's Disease 2015-2020**.

The aim of the specific Action Plan is not the complete recording of research and other results in the field of dementia, which would require collective work of many people for a long period of time. The Working Group tried to register fields of deficits and

problems, actions and practices, so as to constitute the base for the development of an integrated Action Plan for dementia and Alzheimer's disease in our country.

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Chapter 1 – Dementia world-wide**1. Epidemiological particulars – Risk factors**

Dementia = = being out of one's mind

Definition: progressive decrease of a person's intellectual faculties

In 2005, 24.4 billion people worldwide had been affected by dementia and 4.6 billion new cases of this disease were appearing every year. As far as the geographical distribution is concerned, in populations aged above 60, the highest prevalence of dementia is noted in North America and Western Europe (6.4% and 5.4% respectively) Latin America follows (4.9%), China and the regions of the Western Pacific (4.0%). The annual incidence (new cases per population of 1000 persons) per geographical region is estimated to 10.5 for North America, 8.8 for Western Europe, 9.2 for Latin America, and 8.0 for China and the regions of the Western Pacific. For all these populations, the risk for developing dementia and Alzheimer's disease, the most frequent cause of dementia, is being increased exponentially by aging and the disease is extremely frequent in over-aged people: 2% of the population aged 65-74 has dementia, a percentage that rises to 19% for ages 75-84 and to 42% for older than 85 years old. Presently in the U.S.A. more than 5 million people suffer from Alzheimer's disease, a number that is expected to amount to more than 13 millions in 2050 [1].

Alzheimer's disease is the most common type of dementia. About 70% (65-85%) of the clinical diagnosis of dementia is attributed to Alzheimer's disease and 70-80% of pathological samples (autopsies) have elements of definite Alzheimer's disease. Moreover, half of the above have co-existing Lewy bodies or vascular lesions. Frontotemporal and vascular dementia follow as far as frequency is concerned. Frontotemporal dementia is more frequently detected to younger ages, 50-60 years old, and it is responsible for about 5-10% of dementias. Vascular lesions – cerebral infarctions are very frequent in the elderly and are noted in around 1/3 of pathological cerebral samples of people with dementia. However pure vascular dementia without co-

existing pathological lesions of Alzheimer's disease or Lewy bodies is relatively rare with an estimated frequency of 2-10%. Other diseases which may be responsible for dementia (e.g. normal pressure hydrocephalus, Jacob-Creutzfeldt disease, Huntington's disease, dementia due to HIV, dementia due to infectious or metabolic causes etc) are quite more rare and are cumulatively responsible for 5-10% of dementias.

The exact causes of Alzheimer's disease are not known, while it is noted that genetic factors may play a determinant role and affect directly the chances for the development of the disease [2]. These factors include 3 genes passed on from parents to children, with 50% probability. However, these genes concern the rare "familial" type of the disease (2-3%), the symptoms of which start at a very young age (e.g. at the age of 50, 40 and/or 30). Genetic factors seem to affect to a smaller degree the frequent "sporadic" type of the diseases from which suffers the 97-98% of people with dementia. However, presently and possibly in the near future, these genetic factors are neither fully known nor modifiable.

At the same time, non-genetic – environmental factors seem to affect the probability for development of the disease. These factors are:

- √ Age, gender,
- √ Down syndrome,
- √ Cardiovascular factors (diabetes mellitus, hypertension, dyslipidemia, obesity),
- √ Smoking,
- √ Nutritional habits,
- √ Traumatic Brain Injuries,
- √ Depression,
- √ Medications (hormones, anti-hypertensive, anti-dyslipidemic, anti-inflammatory etc),
- √ Factors which affect cognitive reserve (IQ, education, occupation, intellectual, social activities, physical exercise etc).

It is clear that cardiovascular factors predispose for cerebral vascular episodes and vascular dementia. However, according to literature, whether these constitute risk factors for Alzheimer's disease, remains unclear. Diabetes mellitus [3,4] Lu, 2009), hypertension [5, 6, 7], dyslipidemia [8,9], and obesity in middle age [10] possibly increase the risk for development of the disease in an older age. Diabetes seems to have the stronger association, since its correlation with Alzheimer's disease has been noted both in epidemiological studies, and in basic science research studies (common mechanisms have been observed between the biology of insulin and that of amyloid – the basic pathological lesion caused by Alzheimer's disease).

Based on the possible association between cardiovascular factors and Alzheimer's disease, it has been hypothesized that drugs that treat these diseases (anti-hypertensives, statins) possibly act protectively [11,12]. Moreover, since Alzheimer's disease is characterized inter alia by high inflammation levels, it has been hypothesized that steroidal anti-inflammatory (cortisone), and non-steroidal anti-inflammatory (NSAIDs) [13] (drugs used widely on everyday basis for treating musculoskeletal and other pains) possibly have positive effect, but studies till now are controversial and a therapeutic role of the specific drugs in the treatment of the disease has not been proved.

Older studies supported that smoking acts protectively against Alzheimer's disease. Yet, more recent studies demonstrate that smoking clearly increase the probability for development of the disease [14,15].

Traumatic brain injuries seem to increase the probability not only for dementia pugilistica, but also for Alzheimer's disease. This applies mainly to more severe injuries that had led to concussion and loss of consciousness for a long period of time (e.g. more than a few minutes or half an hour).

Depression, is conceivably associated with dementia and Alzheimer's disease, through multiple biological mechanisms [16]. Older studies demonstrated that the presence of depression increases the probability for development of Alzheimer's disease a few years later. However, people with Alzheimer's disease manifest symptoms both in the

cognitive sphere, and behavioral – psychiatric ones, out of which the most frequent is depression. For this reason, it is not clear whether depression really increases the risk for Alzheimer’s disease or it simply represents an early manifestation of the disease itself. Furthermore, recent studies demonstrate that depression in middle age possibly leads to increased probability for developing Alzheimer’s disease many decades later [17,18].

The **theory of “cognitive reserve”** suggests that inter-individual differences are observed concerning the ability to fight Alzheimer’s disease [19,20,21]. Many studies demonstrate that people with higher intelligence quotient, higher levels of education, more demanding professions and more leisure time activities (including, intellectual, social and physical activities) [22,23,24,25] have lower probability to develop the disease. Whether these associations are really of etiologic nature (in other words whether a real protection exists) or whether they simply ensue due to methodological errors in scientific studies, constitutes an object for disagreement within the scientific community.

Nutrition is included in the plethora of environmental factors that have been associated with Alzheimer’s disease. However, the results from various relevant studies are conflicting [26]. Higher intake of vitamins (C, E, B6, B12, folic acid), flavonoids, unsaturated fatty acids and fish, moderate consumption of alcohol, intake of antioxidants, anti-inflammatory and food supplements, have been associated with decreased risk for developing Alzheimer’s disease or with slower cognitive decline. Other studies however support that the risk for Alzheimer’s disease or cognitive decline is not associated with the intake of the aforementioned. Recent data suggest that the Mediterranean Diet is associated with decreased probability of developing Alzheimer’s disease [27, 28]. In total, the existing data concerning nutrition are not adequate to develop guidelines and advice of high degree of scientific certainty for particular nutritional habits.

Also, compared with men, women are slightly more likely to be diagnosed with Alzheimer's disease [29], which is probably due to the higher longevity of women, or the reduction of female hormones in old age (estrogens and progesterone). Many studies indicate that estrogens and progesterone may act protectively in the brain and the cognitive functions. However, a recent clinical study has shown that that substitution of estrogen or progesterone in menopausal women not only does not protect against Alzheimer's disease or other cognitive problems, but possibly even acts aggravating [30, 31, 32].

To summarize, the identified risk factors for Alzheimer's disease are the genetic predisposition and age increase, but they are not modifiable. The role of modifiable factors (cardiovascular factors, diet, tobacco use, brain injuries, depression, cognitive reserve) remains unclear and there is no scientific consensus as to their role.

Therefore, avoiding traumatic brain injuries and smoking, prevention and treatment of cardiovascular diseases such as diabetes mellitus, hypertension, dyslipidemia, obesity from middle age or even young age are recommended. Similarly, having as basic principle the WHO's definition for health, aiming at higher levels of education and more demanding professions, as well as intellectual, social and physical activities in combination with traditional but nowadays marginalized Mediterranean diet are recommended in order to prevent suffering from dementia,

2. Types and clinical types of dementia – Behavioral and Psychological Symptoms

Types of dementia

Dementia is the mental abilities decline, caused by degeneration and dysfunction of the human brain neurons. Dementia is the clinical expression of many neurogenerative diseases with Alzheimer's disease being the most frequent one. Vascular dementia,

mixed dementia, frontotemporal dementias, Parkinson's disease dementia and dementia with Lewy bodies follow as less frequent. Dementia may be also caused by a variety of other causes and conditions that affect brain function primarily or secondarily (encephalitis, toxic encephalopathies, brain injuries, space-occupying processes a.o.). In the last years, significant progress has been noticed in the prevention, diagnosis and treatment of Alzheimer's disease and other types of dementia:

1. Scientific knowledge on risk factors and protective factors has increased significantly, thus prevention is achievable to some extent.
2. Diagnosis in the early stages of the disease is possible due to advanced methods (Amyloid PET-positron emission tomography, volumetric MRI, cerebrospinal fluid indicators, genetic testing, comprehensive neuropsychological evaluation). As a result, the application of multiple interventions (pharmacological or not) is feasible.
3. Blood tests can investigate genetic predisposition of several forms of dementia.
4. Currently the available pharmacological treatment of dementia is symptomatic, aiming at maintaining the functionality and quality of life of people with dementia. Furthermore, due to the dramatically increasing prevalence of dementia, the research funds are also increasing and many new drugs are tested clinically.

Alzheimer's Disease

It is a neurodegenerative disease with specific neuroanatomy changes (amyloid plaques and neurofibrillary tangles). Although it is characterized by clinical heterogeneity, its progression is determined. The course of the disease, from the onset of the symptoms to the final stages of the disease, lasts on average 10 years.

The clinical features of Alzheimer's disease include [33]:

1. Disorders of short-term memory, while the long-term memory is affected at the last stages of the disease.
2. Disorders of speech.

3. Decline in executive functions and visual-spatial abilities.

4. Decline in everyday functioning.

Vascular dementia

It is the second most-common form of dementia. It is characterized by impaired judgment thinking and planning, while memory decline is not a characteristic symptom (at least in the initial stages) [34].

Mixed dementia

it is characterized by neuropathological lesions associated with more than one types of dementia (i.e. Alzheimer's disease and vascular dementia, or Alzheimer's Disease and dementia with Lewy bodies) [35]. The clinical symptoms vary depending on the types of dementia involved in the formation of mixed dementia.

Dementia with Lewy bodies

The clinical characteristics of this type of dementia include fluctuation of the mental function (alternation of confusing periods with relatively normal ones), visual hallucinations (particularly detailed) parkinsonism [36,37].

Dementia in Parkinson's disease

It is estimated that 50-80% of people affected by Parkinson's disease will develop dementia symptoms during the progress of the disease. Symptoms include difficulty in thinking, visual hallucinations, delirium, depression, irritability and sleep disorders [38].

Frontotemporal dementias

Given that this type of dementia is characterized by behavioral and psychiatric symptoms and cognitive decline is not always obvious, frontotemporal dementia may not be easy to identify. Thus, its prevalence is difficult to be estimated.

There are three forms of frontotemporal dementia: 1. *Behavioral variant*, characterized by changes in personality, apathy, disinhibition and depression symptoms. 2. *Primary progressive aphasia* characterized by difficulty in speech production. 3. *Semantic dementia* during which people lose the meaning of words [39].

Behavioral and Psychological Symptoms of Dementia (BPSD)

The BPSD appear in all forms of dementia [40]. Specifically, in frontotemporal dementia and in dementia with Lewy bodies, they are indicative of specific pathology and are part of the diagnostic criteria. Recent studies have shown that nearly all people with dementia will develop one or more behavioral and psychological symptoms during the course of the disease.

BPSD have significant impact on both people with dementia and their caregivers. Their course is independent of the severity of cognitive deficits and functional impairment, with exacerbations and remissions and high recurrence rate.

BPSD include [41]:

- √ aggression,
- √ depression,
- √ apathy,
- √ increased motor activity,
- √ psychotic symptoms (delirium and hallucinations),
- √ disinhibition,
- √ sleep disorders,
- √ eating disorders.

BPSD constitute the main source of burden for caregivers, causing life quality impairment to people with dementia and their families. Additionally, they contribute significantly to the institutionalization of people with dementia and thus they dramatically increase the cost of care. Family and paid caregivers, usually report that are annoyed more by BPSD and less by the cognitive deficits that people with dementia show.

3. Economic dimensions of dementia

As a disease with significant morbidity burden, dementia is a major problem for the budget not only for the health system, but also for social productivity, and therefore for

national economy in all developed economies worldwide. The reason is that the cost of dementia involves:

1. Direct (medical) costs
2. Indirect costs

The **indirect cost** relates to expenses for the sufferer himself, because of the needs for monitoring costs – follow ups, expenditure of diagnostic tests, medication costs and hospitalization expenses, either in hospital or in a unit of long-term stay, or nursing home. At the same time, the direct costs including the cost of handling the complications of the disease and the comorbid conditions.

Furthermore, the disease entails **indirect - hidden costs**, incurred because of the progressive inability of the sufferer and the constantly growing demand for care and support from the relatives / friendly environment. These costs are the indirect costs of the disease, namely the cost resulting from loss of social production. In the estimation of the indirect costs, productivity losses (loss of income) are included both because of people with dementia inability to work, and their caregivers' absenteeism from work (due to the increasing needs care of the patient) [42,43]. Furthermore, indirect costs are considered the valuation in economic terms or, otherwise, the value of care provided by family / relatives of the person with dementia, even if this is not a direct financial transaction. It is worth noting that according to international literature, the indirect costs of the disease appear larger (or even multiple) of the direct costs, highlighting the full dimension of the disease for national economy.

With a range of coarse calculations, which, however, provide a sufficient magnitude, the cost of dementia worldwide in 2010 was \$ 604 billion, an expenditure which corresponds to about 1% of the World GDP or, alternatively, at a total cost equal to twice the annual GDP of Greece. The annual cost of caring for people with Alzheimer's disease in the USA is comparable to the annual cost of the war in Iraq. With an aging population and the dramatic increase in people with dementia in the absence of preventive or therapeutic methods, the frequency of Alzheimer's disease is increasing.

Provisions on the other hand report that in the next decades, this cost is likely to sevenfold.

Despite the above, at least for the present, investments regarding dementia research are extremely disproportionate worldwide in relation to the cost of the disease.

For instance, in the USA investments for dementia research are about \$ 0.5 billion a year while the cost of the disease is over \$ 200 billion annually.

4. International policy for facing dementia – Action plans of other Countries

Dementia remains one of the most difficult challenges for Public Health. Despite the scientific advances of the last 25 years, dementia treatment constitutes a major issue both at national and international level. The stigma, denial and lack of economic sources are the main obstacles for integrated care of people with dementia. The World Health Organization, the European Community and the Alzheimer’s international organizations have been repeatedly engaged in developing instructions and publishing reports concerning management policies about dementia and its consequences, such as the following:

- 2004: Kyoto Declaration (ADI)
- 2006: Paris Declaration (AE)
- 2008: Alzheimer’s Disease Charter (ADI)
- 2009: European Alzheimer Initiative (EU)
- 2012: WHO Report “Dementia: A public health priority”
- 2013: Global Dementia Charter “I can live well with dementia” (ADI)

Furthermore, on January 19th, 2011, the EU Parliament adopted the resolution **“European initiative on Alzheimer’s disease and other dementias”**, which declares dementia as a “European priority”. The European Parliament urges the Member - States to develop specific national strategies to address the medical and social aspects of dementia and provide services and support to people with dementia and their caregivers.

In the recent G8 summit in London in the autumn of 2013, the commitment to continue and expand the efforts for fighting dementia was countersigned and exhortations recorded for all countries to take initiatives in this direction, particularly in the light of data concerning the burden of morbidity and the economic load of dementia [44]. For this reason, it is proposed each country to increase the national funding for dementia at the level of 1% of the national cost over the next 10 years. In the same Summit international economic experts, doctors and politicians have appealed to the governments of all countries to render the prevention of dementia the major objective of public health in the coming years and they founded the World Dementia Council to achieve these objectives at global level.

All the above recommendations set priorities and suggest ways for the management of dementia and Alzheimer's disease in particular, defining the following commonly accepted areas of action:

- Early diagnosis- prevention
- Information and public awareness
- Equal access for all to diagnosis and treatment
- Development of health and social care services and structures
- Respect of the rights of people with dementia (legislative framework)
- Recognition of the caregivers' burden and the role of families
- Participation of people with dementia and their caregivers in the planning of care services
- Research support.

Worldwide, the development and implementation of National Action Plans is the most effective and powerful tool for the treatment of dementia and meeting the needs of people with dementia, whose number is growing at epidemic rates. Currently, **11 countries are implementing Action** plans [45] (United Kingdom, Australia, Denmark, Finland, France, USA, South Korea, Netherlands, Norway, Luxembourg and Belgium). Many of these already proceed to the next phase of implementation or preparation of the

second updated Action Plan. The existing Action Plans obviously vary, but only in details, while in overall common critical chapters are identified for the treatment of the disease.

Legislation exclusively for Alzheimer's disease does not exist in any country. The model of its integration in the general legislation for mental health is usually followed.

Action plans of other countries

Netherlands

A National Dementia Plan was implemented in 2004-2008, funded with 2.4 million €, extended by 2011. In April 2013, the Dutch Ministry of Health announced that it will finance with 32.5 million € a new Action Plan on Dementia in collaboration with the private sector. The plan focuses mainly on coordination and interconnection between services of health and social care.

Australia

The initiative “Make Dementia a National Health Priority”, 2005-2010, funded with 320 million AUD. A new National Action Framework on dementia is currently under development including areas such as research, early intervention programs and development of integrated care services.

USA

The Action Plan, 2012-2015, was designed with the collaboration of 24 parts, Ministries, professional associations, Academic Institutions, patients’ organizations and it is the result of an exchange of views for several years. The first objective is to enable the prevention and radical treatment of Alzheimer’s disease by 2025.

France

It drew up and implemented the most complete Action Plan, 2008-2013, by state funding of € 1,6 billion. The plan covered all possible sectors and action axes and was implemented rapidly and with strict progress control mechanisms.

United Kingdom

The National Dementia Strategy “Living well with dementia”, 2009-2014, with Funding of 150 million €, focuses on the development of care services of high quality under the responsibility of local government in cooperation with the national government. The involvement of the patients’ organizations in its development and implementation was important.

South Korea

The program "War on Dementia", 2008-2013, with funding of 6.46 trillion won, drawn up with the participation of many associations of health professionals and focuses on training specialists for dementia.

5. Legislation and rights of people with dementia

The treatment of dementia and Alzheimer's disease has as basic legislative foundation, in international law, the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights of the Agreement on Civil and Political Rights of the U.N.

The importance of these texts lays mainly in the establishment of the principle on enjoyment of fundamental rights from everyone, regardless sex determinations, origin, language, religion, therefore whatever other particularities of mental condition. The International Covenant on Economic, Social and Cultural Rights refers also to the recognition of the right of every person to "enjoy the better possible mental health" (article 12) [46].

Within the framework of European law, the Court of Strasbourg (European Court of Human Rights), which acts as the supreme court for the implementation of the European Convention on Human Rights (ECHR), has repeatedly stressed the importance of the rights specifically of the involuntarily hospitalized mental patients. However, its relevant detailed case-law has wider significance for the rights in mental health and, in this respect; it regards people with dementia [47] as well.

The European Convention on Human Rights and Biomedicine (The Oviedo Convention) is the latest version with reference to Human Rights, interested in the issue of dementia. Customized exclusively to issues of medical practice, the Convention provides settings a) for the principle of "consent after information » (informed consent) especially as regards people with dementia without willing ability (Art. 6), b) for the

protection of the patients' privacy (Art. 10), c) for the importance of "advance directives" in the medical care of those who are unable to express will (Art. 9) and d) involving patients in biomedical research (art. 15-17).

As to the protection of personal data and clinical research issues, analytical predictions are in Directives 95/46 and 2001/20 of the EU (currently under revision). The EU legislation applies to EU Member States that have adapted, respectively, their national law.

At the level of national legislations, dementia is treated within the framework of the general mental health policy. Several states have developed national action plans and offer the permanent monitoring institutions for their implementation.

In the USA, action plans exist in more than 40 States. Enough of them have established institutions, such as the standing patient's representative for health issues, the "advance directives – living wills" of the patient, (wishes for his medical treatment, in case he loses the ability of will, which are officially recorded in advance and engage doctors and relatives), the potential access to voluntary or low-cost legal services for the protection of patients' rights. They have also recognized some specific rights such as the right of "productive life", the right of protection from personal or financial exploitation, the rights for their caregivers' training about the constraints and opportunities the law provides, and social rights for people with dementia (insurance policy) [48].

At the level of monitoring, several of the above States have established permanent single-person or collective advisory institutions, commonly referred directly to the Governor and have competences for proposals to improve the legislation, structures, and the public information.

In Britain, the dementia issues are regulated by several key legislations (Mental Health Act - 1983, Mental Capacity Act - 2005, Deprivation of Liberty Safeguards - 2009) [49]. The main direction of this legislation is the minimum possible interference in the lives of people with dementia, only where absolutely necessary and always evaluating

the most appropriate for achieving this objective method (principle of proportionality). The right “to live the way one chooses” is characteristically stressed hereto. In this context; a) a person is considered as principally capable of acting for himself, b) the priority is to enhance the patient’s ability, c) eccentric or irrational decisions do not constitute the only proof of disability, d) the only criterion for the patient’s legitimate representative is the latter’s best interest and e) the least restrictive option for the patient’s autonomy must be preferred.

Among the fundamental rights, for the person with dementia more critical are considered the right to life, the right to physical integrity (protection from torture), the right to personal freedom and security and the right to private and family life.

In particular, the right to privacy includes the free response by any means, the free choice of friends, access to open space, free visits, the ban on research in a private area, confidentiality of medical data, but even the right of isolation for physical needs. The treatment of a person with dementia is also considered important based on his individuality and not his subjection to general and impersonal rules that impose prohibitions on the pretext of “protection”.

In France, the first country in Europe that drew a national action plan for Alzheimer’s disease (2001), the general legislation of the Civil Code and the Public Health Code specifies the law to protect adult persons (5.3.2007). Around this law today’s concerns move about the patients’ rights (in particular on the power of legitimate representatives, including the judiciary supporter). The principle of maintaining independence and enforcing restrictions to the strictly necessary extent applies here as well, while it is noted the lack of predictions for decisions concerning the end of life [50].

Several countries in the EU have developed a National Action Plan (Belgium, Denmark, Netherlands, Ireland, Finland etc.), unlike others (Austria, Germany, Czech Republic, etc). In general, however, the basic guidelines for the patients’ rights, as described above, are admitted by national legislations.

Chapter 2nd – Dementia in Greece

1. Epidemiology – Research – Education

Epidemiological data

There are no adequate epidemiological data on dementia in Greece. By extrapolating using data from other countries, Alzheimer's disease International calculates the prevalence of dementia in Greece in 2010 to 196,000 people. It is estimated that in 2030 it will reach 276,000 people and in 2050 365,000 people [51].

Research: Deficits and problems

Despite limited resources and adversities, a series of commendable research efforts have been carried out in the past by groups (mainly at the National and Kapodistrian University of Athens and the Aristotle University, but also in other Universities and research bodies) on the prevalence, incidence, risk-protection factors, clinical manifestations, diagnostic biomarkers, genetic profiles and the key biological mechanisms in the knowledge domain of dementias.

Based on research work so far in Greece, the areas which require infrastructure, expansion of research and gathering of more data are the following:

- **Prevalence** (frequency in the population) of dementias in total and of different types of dementias.
- **Incidence** (rate of new cases with dementia over time) of dementias in total and of different types of dementia.
- **Recording specific to the Greek population protective** (e.g. nutrition, genetic factors) **or risk** (e.g. smoking, genetic factors) **factors** concerning the development of dementia.
- **Cost of dementia** (mainly through quantitative studies) and its precise breakdown into categories such as direct, indirect, hospitalizations, medication, comorbidity etc.
- **Mapping of the network and available health services** for people with dementia.

- **Prescription and other therapeutic practices** of health service providers, and the extent to which these comply with or deviate from the international-European recommendations, guidelines and practices.
- **Basic research:**
 - Creation of Centers of Excellence (CoE).
 - Increase the number of basic research direction researchers.
 - Strengthening laboratory material – technical infrastructure (i.e. animal brain imaging center etc).
- **Clinical research:**
 - Creation of Centers of Excellence (CoE).
 - Increase the number of clinical research direction researchers.
 - Creation of an Organization for recording outpatient clinics [clinic registries].
 - Updating and development of population studies [population cohorts].

Despite the scientific achievements of Greek research teams that have produced significant scientific work and participate in international scientific proceedings and efforts (international consortia), the number of these research units is quite restricted for the size of the country. These successful exceptions prove the rule of the following overall image:

- a research community in the field of dementias small in number which must be enriched with many more scientists,
- deficits of research infrastructure that lead to systemic disadvantage of the existing researchers on their ability for more effective and active role in the world scientific proceedings.

Education: Deficits and problems

Despite the economic difficulties that the country faces and the relative lack of resources and infrastructure, institutions such as universities, the Greek Neurological Society, the Greek Psychiatric Society, departments of the NHS hospitals, Non Profit Alzheimer Societies etc., have exhibited significant efforts for educating and informing

doctors, health professionals, caregivers and the public through conferences, meetings, seminars, e-learning and other educational methods. However, the undertaking of initiatives to address major problems and deficits, such as the following is deemed necessary:

- Awareness, information, education and training in the topic of dementia:
 - Of Doctors non specialists in the object of dementia.
 - Of General physicians and Internists who provide primary care and have the initial, the higher number of and the most frequent contacts with people with dementia and their families.
 - Of Doctors of relevant discipline such as Neurologists, Psychiatrists.
 - Of other health professionals (nurses, social workers, physiotherapists, speech therapists and occupational therapists).
 - Raising awareness, informing and educating the general population, including the caregivers of people with dementia, in the topic of dementia should be substantially strengthened.
 - More emphasis should be given on the topic of dementia (at the level of basic and clinical research) in undergraduate studies (education programs in schools for health professionals).
 - There is no medical specialty in Geriatrics.
 - There are no graduate programs (Master) for education in dementia (for Health professionals and social scientists).

There are no official sub-specializations (fellowships) in the field of dementia for Neurologists, Psychiatrists, Geriatricians, such as those in the USA (behavioral neurology, geriatric neurology, geriatric psychiatry).

2. Economic dimensions

In Greece, there are no sufficient data regarding either the cost of dementia, or its breakdown into categories, such as direct, indirect, hospitalizations, medications and comorbidity.

The single, until recently, published study, on the economic burden of Alzheimer's dementia is the research of Kyriopoulos et al. in 2005 [52]. The researchers, with the help of a group of experts using the methodology of a consensus Panel, concluded that the monthly cost for a person with dementia in the autonomy stage was 341 €, in the dependency stage at home 957€, and in the dependency stage in an institution 1.267 €, i.e. an annual cost of about 4092-15204 €, the largest proportion of which relates to the cost of informal care and loss of productivity. Specifically, with respect to the caregivers' time, the dependency stage at home required 168 hours per month from a family member and about 72 hours from a household assistant. The researchers concluded that the professional medical care increases as the person with dementia goes from the stage of autonomy to the stage of dependence at home and decreases as he/she moves to an institution. Institutional care reduces family commitment and increases the total cost of the care of a person with dementia. The above data are confirmed by a recent survey of Kaitelidou et al. that was published in a Greek magazine in 2013 [53].

Simple application of international data in the case of Greece, leads to the conclusion that the total cost of the disease (direct and indirect) most likely exceeds the € 3 billion per year and may be close to € 6 billion annually, if the application uses only data from developed economies, with epidemiological and demographic profile similar to that of Greece. This cost, demonstrates its potential reduction with a rational disease management.

By using as (conservative) estimate the national cost for dementia € 6 billion a year, the Greek State should set itself as a 10-year target to increase the financing of domestic research for dementia at least to €60 million annually.

3. Health care and Social care – Structures and services

It has been recognized by all relevant parties that the issue of dementia was not a priority in the public health sector and there was no systematic mapping of the network of the few available health and social care services for people with dementia in Greece [54]. The current status of care and management of people with dementia in our country is insufficient. There are substantial gaps in the reported services for people with dementia and a significant lack of relevant structures. In the near future, this problem will be more intense, as, according to documented estimates, the number of people with dementia will rise epidemically. This stress the need for direct documented, well-planned and targeted actions aiming, on the one hand the direct improvement of the present condition and on the other hand the management of the increased future needs. Currently, the structures providing health care services for dementia in Greece are the following:

Memory and Cognitive Disorders Clinics and Psychogeriatric Clinics

Special **Memory and Cognitive Disorders Clinics**_(around 20) operate within the framework of Neurological and Psychiatric departments of General Hospitals mainly in Athens, in Thessaloniki and in a few large cities (Patras, Alexandroupoli, Ioannina).

Psychogeriatric Clinics operate in Psychiatric Institutions in Athens, in Petra of Olympos, in Thessaloniki, in Corfu and in Tripoli.

People with dementia in Greece are mainly treated by neurologists, psychiatrists, geriatrists and family doctors who work privately or belong to the PEDY (ΠΕΔΥ) (Primary National Health Network) and offer services such as diagnosis, monitoring, prescribing.

Non-Profit Alzheimer Associations in Greece

The Alzheimer's Associations operating in various Greek cities are non-profit organizations set up by relatives and caregivers of people with dementia, doctors, psychologists and other health professionals. The goal of these organizations is to offer

information and services such as, non-pharmacological interventions for people with dementia and education and support to their caregivers in order to reduce the burden (social, economic, emotional) they experience due to the long-term care they provide to people with dementia. The Alzheimer's Associations, also offer advocacy services and support of the rights of people with dementia and their families. Finally, they are responsible for organizing events about dementia prevention, and timely and accurate diagnosis, aiming at promoting public awareness.

Day-Care Centers

The most integrated services for people with dementia and their caregivers' are offered by the Day Care centers of the program Psychargos under the responsibility of Greek Alzheimer's Associations. These centers were implemented under the operational program "Health – Welfare 2000-2006" co-funded by the European Union and the Ministry of Health and Social Solidarity.

The organizations operating Day Care Centers (11 in total) and 2 boarding homes (for short-term stay) for individuals with dementia are the following:

- Greek Association of Alzheimer's Disease and Related Disorders (Thessaloniki): 2 Day Care Centers
- Athens Association of Alzheimer's Diseases & Related Disorders: 4 Day Care Centers
- Greek Association of Alzheimer's Disease & Related Disorders of Volos: 1 Day Care Center and 1 boarding house.
- "Nestor" Psychogeriatric Association – Athens: 1 Day Care Center and 1 boarding home.
- Association for the Development of Mental Health Community Services for children and adults "Panakeia" in Rodos: 1 Day Care Center.
- Greek Association of Alzheimer's Disease & Related Disorders of Chania: 1 Day Care Center.
- "Iasis", Ano Glyfada, Athens: 1 Day Care Center

Community services

Services like the Open Protection Centers for the Elderly (K.A.P.I.), the Day Care Centers for the Elderly (K.I.F.I.) and the services “Help at Home” provided by many Municipalities of the country offer services to people with dementia and their families’ although not specialized ones.

K.A.P.I. operate in all the Municipalities of Greece and offer:

- Healthcare instructions.
- Physical therapy – Occupational therapy.
- Members’ activity groups that enhance their socialization.
- Training, lectures, cultural events.

K.I.F.I. are daily accommodation units for aged people who are dependent and their family members, responsible for their care (mainly women) work or face serious social, economic or health problems and are unable to respond to care.

K.I.F.I. provide free daily hosting services including:

- nursing care
- care of the practical living needs
- the personal hygiene
- programs for creative activity and skills development

The program “Help at Home” is addressed to senior citizens who are not self-dependent. The program provides counseling and psychological support, nursing care, family assistance and company. Its proper operation is ensured by a specialized and well-organized group of Health professionals.

Long-term care facilities for the elderly in Greece

In our country, services and facilities for long-term care and permanent living for the elderly are provided by public organizations, by Non-Profit Associations (Church, Charitable Institutions etc.) and Profit organizations (private Care Units for the Elderly). However, the Greek society is family-centered, thus in most cases disabled and elderly people are looked after at home by members of their family.

The Care Units for the Elderly in our country cover a small percentage of the existing housing needs and do not have specialized care for people with dementia. There are only a few private nursing homes specializing in dementia.

Social Benefits for people with dementia

Social security covers part of the costs for specific services related to the treatment and movement and cognitive rehabilitation of people with dementia (physical and speech therapy) and for limited periods of time. About long-term care services, the Greek system is mixed and includes funding from the state budget, the social insurance funds, but mainly from private payments.

Pension funds do not provide disability benefits or carers allowances to all insured persons with dementia. According to the unified table for the determination of disability percentages (Official Gazette of the Government of the Hellenic Republic B 1506/4-5-2012) used by the Committees of the Centers for Disability Certification (KEPA), the percentage corresponding to dementia is 67-80%. According to this percentage the person with dementia who is not insured in any pension fund can claim welfare allowance (about 600 € / two months). In the case that the person with dementia is insured, the disability percentage will help him get a reduction of income tax from the public revenue service.

Existing deficits

There is no National Action Plan on dementia and no specific national strategies have been developed in order to address the medical and social impacts of dementia in the Greek territory and organize services and Health and social care structures. Furthermore, there is no cooperation and networking of the existing structures and services for individuals with dementia. As a result provided care is not always efficient and economical advantageous.

In particular:

1. There is no sufficient public awareness thus patients and their caregivers do not always access timely the primary care services. As a consequence, precious time is lost from the appearance of the first symptoms until the diagnosis.
2. The primary care physicians are not sufficiently trained to respond to the significant need for early diagnosis, referral and management of people with dementia. So, the ease and equal access to timely diagnosis, care and treatment depends on the region people with dementia live.
3. Examination protocols of patients with dementia are completely absent at the Emergency Care Unit and inpatient clinics of the General Hospitals. However hospitalization for several comorbidities is very common in old age.
4. There are no Cognitive Disorders Clinics_in every General Hospital of the Regional Units (Prefectural Hospital) despite the decision of PSYCHARGOS plan (Υ5β/Γ.Π./οικ 46769/2012) [6], which follows the basic principle of Social Psychiatry on sectorization of services.
5. There are not enough Day Care Centers to provide non-pharmacological therapies and support for caregivers in most cities, particularly in rural areas and in the islands of Greece.
6. There is no specialized social services network for supporting people with dementia and their caregivers after the diagnosis. Professionals in the existing network of Local Administration Organization structures (K.I.F.I., K.A.P.I., program “Help at Home”) are not trained in the management of dementia cases. Moreover, the distribution of these services and structures is uneven and not spatially correct. Major shortages are in rural areas and in the islands [55].
7. There are no structures for short-term stay of people with dementia which will provide caregivers with the opportunity to rest and relief from their burden.
8. There are no special institutions for palliative care of end-stage patients (hospices).
9. There are only a few care services at home for people with dementia.

10. There are no sufficient benefits, financial aids and other measures that could reduce caregivers' burden, as a special leave for dementia patients' caregivers, discount in tickets of Public Transport, museums, etc.

4. Legislation and rights of people with dementia

The rules of international law cited above apply in our country as well, having binding force for the national legislator. More specifically, the rights of people with dementia - especially personal freedom, personal security, physical integrity, freedom of movement, the right to private and family life and the right to health (including the right to participation in clinical research) - must be approached in the light of the corresponding provisions particularly of the ECHR (European Convention on Human Rights) and the Oviedo Convention, as well as the EU legislation on personal data and clinical research. These rights are also constitutionally acknowledged, with specific provisions [56].

It should be emphasized that special importance have two fundamental principles of the Constitution for the people with dementia concerning the protection of human dignity (Art. 2, par. 1), and the equal protection (Art. 4, par. 1). Starting from these principles, the largest possible autonomy and the corresponding limitation of restrictions for persons with dementia are enforced by legally binding requirements in our legal system. These rights are not specified, however, by the legislator so as to make practically feasible their enjoyment. Some specialization constitute, here, the provisions of Article 28 of the Code of Medical Ethics (Law 3418/2005) [57] as well as those relating to the involuntary treatment provisions of Articles 94 et seq. of Law 2071/1992. However, these provisions pertain to mentally ill persons in general, and do not reflect particular interest of the legislator for the case of dementia.

Dementia is covered by the provisions of the general Law 2716/1999 ("Modernization of Mental Health Services").

According to Article 1:

 ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ, ΥΠΟΥΡΓΕΙΟ ΕΞΩΤΕΡΙΚΩΝ
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“1. The State is responsible for the provision of mental health services designed to the prevention, diagnosis, treatment, care, and to psychosocial rehabilitation and social reintegration of adults, children and adolescents with mental disorders and autism spectrum disorders and with learning problems.

2. Mental Health services are structured, organized, developed and operated in accordance with the provisions of this law, following the principles of sectorization and community psychiatry, priority primary care, out-of-hospital care, deinstitutionalization, psychosocial rehabilitation and social reintegration, continuity of psychiatric care, as well as the information and voluntary assistance of the community in the promotion of mental health ”

Articles 6 to 11, especially 9 (Units and Psychosocial Rehabilitation Programs) have special interest to tackle Alzheimer’s disease and provide for the creation of structures. Specific legislation, related to the disease, is present in normative acts (mostly ministerial decisions) regulating issues, such as the insurance coverage of patients and the establishment of local care centers. Finally, in the “Psychargos” program (National Plan on Mental Health) actions are provided to tackle the disease, but without being binding on the State (these may not be subject of a legal claim, e.g. from people with dementia and their families or by mental health professionals).

5. SWOT ANALYSIS

• Strengths	Weaknesses
<ul style="list-style-type: none"> • Existing community mental health care model in the context of the reform program “PSYCHARGOS”. • Validity of international law on the rights of people with dementia. • The commitment and the role of the family in the care of patients. • Existing Greek Alzheimer’s Associations and Day-Care Centers. • Social services O.T.A., K.A.P.I., K.I.F.I., providing services but not specialized ones. • Development of recent clinical guidelines for the management of people with dementia. • Gradual acceptance of people with dementia by local societies (stigma). 	<ul style="list-style-type: none"> • Significant gaps in <u>Memory and Cognitive Disorders Clinics</u> that do not exist in every hospital, in <u>Day Care Centers</u> for the provision of non-pharmacological therapies and the support of caregivers, in <u>home care services</u>, in long stay structures for people with dementia and in the <u>palliative care services</u> for end-stage patients (hospices). • Geographical inequalities of the existing services, which are gathered in a few large cities (Athens, Thessaloniki). • Lack of a specialized network of social services to support people with dementia and their caregivers after diagnosis. • Lack of networking, interconnection and cooperation among the existing services. • Lack of skilled human resources in dementia issues (doctors and health professionals). • Lack of education, information and awareness for dementia healthcare professionals, particularly the doctors of primary Health Care. • Absence of examination protocols and hospitalization of people with

	dementia.
	<ul style="list-style-type: none"> • Absence of epidemiological data on dementia. • Lack of research structures for dementia (basic and clinical research). • Lack of financial aids and generally measures for the caregivers' burden relief. • Lack of education, information and awareness in the general population.
Threats	Opportunities
<ul style="list-style-type: none"> • The aging of population and the increasing number of patients in the future. • Increase of the total cost of coping dementia due to the increase in the number of sufferers. • Reducing public health expenditures, as a result of the current economic crisis. 	<ul style="list-style-type: none"> • Designating the seriousness of the problem to a social and economic level internationally and the adoption of initiatives to develop policies to prevent dementia and funding the research for its cure. • Reforms in the health sector, particularly in the field of Primary Health Care with the planned development of PEDY. • Utilization of the EU Structural Funds for the funding of actions and programs for dementia. • Establishment of the National Observatory for Dementia and drafting for the first time the National Action Plan for dementia.

Chapter 3 Strategic Planning

1. Vision of the National Action Plan

Building a national and sustainable policy for dementia, for the first time in our country, with the commitment of all stakeholders, i.e. of the Ministry Health, political bodies, academic institutions, health professionals and organizations of persons with dementia aims at:

- The effective treatment of dementia syndromes and the better quality of life for people with dementia and their caregivers.
- The prevention of dementia and the promotion of the population's health.
- The implementation of cost-effective management measures for the dramatically increased number of people with dementia.

2. Principles and Aims of the National Action Plan

The preparation of the National Action Plan on dementia and Alzheimer's disease was based on the principles and values listed below and included in the Principles and Values adopted by the European Union and the World Health Organization.



Furthermore, the National Plan on dementia has the following objectives:

Strategic Objectives of the National Plan for dementia

Political Objectives

- Ensuring inter-partisan consensus on the implementation of the National Action Plan
- Ensuring continuity in its implementation
- Development of monitoring system for implementation progress.

Social Objectives

- Designation and promotion of the important social behaviors and life style that reduce risk factors associated with dementia. Examples include: dietary habits, physical activity, participation in social activities, cognitive exercise.
- Promotion of public awareness to eliminate the stigma associated with dementia.
- Provision of multidimensional and personalized care to the person with dementia, with purpose to improve the quality of his life.
- Provision of palliative care to the patients of the final stage.
- Creation of suitable housing infrastructures with the public-private sector partnership for the long-term retention of people with dementia and relieving the burden of caregivers.
- Safeguarding legislative rights of people with dementia in healthcare.
- Legislative recognition of dementia as a disability, institutionalization of benefits for people with dementia and their caregivers with financial aids and financial reliefs.

Epidemiological Objectives

- Development of an integrated system for recording dementia cases, in order to gather accurate information and design specific policies targeting dementia.

Chapter 4 Axes and Actions of the National Plan

Axis No 1: Registration and classification of people with dementia in Greece

Action 1: National Registry of people with dementia

Description:

The National Dementia Registry aims at the systematic recording of dementia cases and the standardization of the information collected, helping to improve the quality of diagnosis, treatment and care.

Objectives:

- Capturing the true size of the problem in our country - morbidity and mortality data from dementia.
- The provision of comparable data with other European countries.
- Establishing national policies based on valid and reliable data.

Implementation Actions:

1. Preparation of a business plan for the development of the National Dementia Registry
2. Pilot implementation in selected geographical areas
3. Establishment of the National Dementia Registry
4. Development of required IT infrastructure and defining the operating procedures of the National Dementia Registry.
5. Promoting awareness and informing professionals and institutions about the importance and the process of recording people with dementia.

Implementation bodies:

- NATIONAL SCHOOL OF PUBLIC HEALTH
- Center for Disease Control and Prevention (KEELPNO)

Timetable:

- 2015: Development of an Operational Plan for development and operation of the National Dementia Registry in Greece.
- 2016: Pilot implementation in selected geographical areas.

- 2017: Establishment and operation of the National Dementia Registry

Budget:

€ 500.000 in total for the preparation of the operational plan and the pilot implementation of the National Dementia Registry.

Action 2: Classification of people with dementia and provision of financial support based on an algorithm of the disease and the families' financial burden

Description:

For the financial support of people with dementia, their needs should be measured by the severity of the disease and the degree of disability that causes. Moreover, social and economic factors (such as income, marital status, etc.), other criteria (such as accessibility to health care and social care services, family's financial burden, etc.) must be considered. Based on the above factors a system classifying people with dementia in individual categories will be developed.

Thereafter, for each category the amount of financial aid will be determined and a program for providing financial support to people with dementia will be established.

Objectives:

- The development of a classification tool for people with dementia based on equality and social justice criteria.
- The institutional consolidation of financial aids for people with dementia according to their needs and characteristics.

Implementation Actions:

1. Study of international experience and the opinion of healthcare professionals and caregivers for people with dementia (bibliographic research, good practices from other countries, consensus panels with healthcare professionals and caregivers).
2. Design of a classification model for people with dementia (definition of classification criteria)
3. Development of the classification Algorithm
4. Determination of the financial assistance per patient and per classification category.
5. Development of electronic automatic classification tools for people with dementia

6. Establishment of a financial assistance program to people with dementia (initially a pilot implementation in one area and then expansion nationwide)
7. Classification of individuals with dementia from the Disability Certification Centers (KEPA).

Implementation bodies:

- Ministry of Health
- Ministry of Labor
- National School of Public Health
- National Observatory for Dementia

Timetable:

- 2015: Completion of the classification framework for people with dementia – establishment of a financial assistance program for people with dementia.
- 2016: Pilot implementation of the financial assistance program for people with dementia.
- 2017: Nationwide implementation.

Budget:

€100.000 in total for the development of the classification framework for people with dementia

Axis 2: Prevention-Informing and creating public awareness

Action 1: Intervention for the prevention of dementia

Description:

The action involves informing and educating the population about dementia prevention. It also includes the planning and implementation of relevant preventive programs.

Objectives:

- Raising public awareness
- Reducing the frequency of all dementia types in Greece

Implementation Actions:

1. Strengthening of the cooperation between Memory and Cognitive Disorders Clinics, Greek Alzheimer's Associations and the stakeholders of Local Administration Organizations under the supervision of the Ministry of Health and the National Observatory for dementia.
2. Informing and educating the population about the risk factors and their control, the implementation of screening programs in an early stage at national and local level.

Implementing bodies:

- Ministry of Health
- Ministry of Education- Universities
- Medical Scientific Societies
- Local Administration Organizations
- Alzheimer's Associations
- National Observatory for Dementia

Timetable:

- 2015: Preparation and organization of information and prevention programs
- 2016-2020: Implementation of programs on an annual basis per region

Budget:

2.500.000 €in total for the years 2016-2020 (500.000 €per year) for all regions

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ, ΥΠΟΥΡΓΕΙΟ ΕΞΩΤΕΡΙΚΩΝ
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Action 2: Information and public awareness

Description:

The action includes raising awareness and informing the society about dementia, aiming the early diagnosis and treatment of the disease and stigma fighting, by organizing a national information campaign.

Objectives:

- Early diagnosis and treatment of the disease in order to improve the quality of life of people with dementia and their caregivers, and the saving of resources.
- Fighting the stigma.

Implementation Actions:

1. Information campaigns for the public about the benefits of early diagnosis, prevention of dementia and stigma fighting
2. Organization of local conferences, seminars and workshops, which are addressed to the general public.
3. Publication of brochures for the disease and the available structures and services.
4. Training of professional groups that come into contact with people with dementia (civil servants, security forces, priests).

Implementation bodies:

- Ministry of Health
- Ministry of Education- Universities
- Medical Scientific Societies
- National Observatory for Dementia
- Local Administration Organizations
- Alzheimer's Associations

Timetable:

- 2015-2020: Implementation of the annual national information campaign on dementia

Budget:

2.500.000 €in total for the years 2016-2020 (500.000 €/ year)

Axis 3: Support of caregivers for people with dementia**Action 1: Support of caregivers****Description:**

Today great emphasis is given on treating dementia in the community. The stay of the patient at home and the effectiveness of interventions in the community are heavily dependent on the presence of a supportive family environment. Caregivers of people with dementia suffer significant psychological, health and financial burden. Their support at all levels is necessary and imperative. Especially, the seeking of sources of assistance shall be encouraged.

Objectives:

- The preservation of mental and physical health of caregivers.
- The best quality of life for people with dementia and the caregivers.
- Avoiding the institutionalization of people with dementia.

Actions:

1. Establishment of the Annual Caregiver's Day.
2. Organizing and implementing documented and authoritative information and education programs for caregivers of people with dementia at regional and national level, with the cooperation of many bodies.
3. Issue of informational and educational material (manual for caregivers of people with dementia).
4. Implementation of distance learning programs for caregivers of people with dementia.
5. Creation of hotlines (telephone information and assistance service) for caregivers and support of the silver alert service.
6. Creation in large care units for people with dementia of an information center for caregivers staffed by health professionals (psychologists, social workers).
7. Establishment of close cooperation and interconnection of Local Services for dementia with the existing network of the social care structures for the elderly (K.A.P.I.,

K.I.F.I., Friendship Clubs, Care Units for the Elderly, church organizations) with the primary health care services to effectively support caregivers.

Implementation Bodies:

- Ministry of Health
- Centers of Excellence
- Local Administration Organizations (Municipalities)
- Alzheimer's Associations

Timetable:

- 2015: Establishment of the annual Caregiver's Day and design of information and education programs for caregivers of people with dementia.
- 2016-2020: Creation of help lines, information centers for caregivers, cooperation and services interface.

Budget:

€1.000.000 in total for 6 years from 2015 to 2020.

In more details:

- € 50.000 annually for the years 2015 to 2020 for the implementation of distance learning programs for caregivers of people with dementia
- €660.000 in total for the establishment and operation of help lines
- €90.000 in total to support silver alert service.

Axis 4: Treatment of dementia**Action 1: Dementia in Primary Care****Description:**

This action aims at integration of dementia services in Primary Care and at the organization of diagnostic services for early detection and management of dementia.

The measures that are integrated in the framework of this specific action, have as a primary purpose the education of family doctors (general practitioners and internists) of Health Care Centers and Clinics of National Primary Health Care Network (ΠΕΔΥ) and the specialized doctors contracted with ΠΕΔΥ (neurologists, psychiatrists) in dementia. Moreover, emphasis is given on the dissemination of clinical guidelines for dementia, and the interconnection of Primary Care services with the existing Alzheimer's Associations Memory and Cognitive Disorders Clinics, the University Cognitive Disorders Clinics and the General Hospitals Memory and Cognitive Disorders Clinics.

Objectives:

- Ease and equal access for people with dementia and their families to the early diagnosis and treatment.
- Information of people with dementia and their caregivers about the services provided in their area.
- More effective and comprehensive care of people with dementia and their families regardless of their place of residence.

Implementation Actions:

1. Networking-Interconnecting the health professionals and Primary Care services with the Memory and Cognitive Disorders Clinics.
2. Education and training of health professionals providing Primary Care services in issues related to dementia (Axis 7).
3. Dissemination and implementation of clinical guidelines for dementia from the Mental Health Directorate of the Ministry of Health.

4. Establishment of a Regional Service for dementia in every region or at least the appointment of a responsible administration employee for dementia issues, with the responsibility to inform citizens about the available services and structures concerning dementia in their area, as well as the interconnection with health and welfare services of their area. Furthermore, the Regional Services are competent to inform people with dementia and their relatives about the financial aids.

Implementation Bodies:

- Ministry of Health – PEDY (National Primary Care Health Network)
- Regional Health Directorates
- Centers of Excellence for dementia
- Local Administration Organizations (Municipalities)
- Medical Scientific Societies
- National Observatory for Dementia
- Alzheimer’s Associations

Timetable:

- 2015-2018: Education and training of doctors of PEDY and creation of specialized doctors’ registries per region.
- 2018-2020: Organization and operation of a network with doctors and services for people with dementia per administrative region.

Budget:

No additional cost is created.

Action 2: People with dementia at the Emergency Care Units and General Hospitals Departments

Description:

Actions 2 relates to the coordination of the services offered to people with dementia suffering from various co-morbidities and attending to ECUs or when they are hospitalized in the Departments of General Hospitals. The coordination is achieved by creating special examination and treatment protocols and by the designation of a coordinator doctor responsible for dementia cases at every General Hospital. The dementia coordinator will ensure adequate clinical care for people with dementia, by making sure that examination and hospitalization protocols are implemented. For hospitals that already operate Memory and Cognitive Disorders Clinics, the coordinator doctor comes from it.

Objectives:

- Global and comprehensive coverage of all health needs that people with dementia face in General Hospitals.
- Satisfaction of the medical needs of people with dementia who face obstacles for their admission and lack of medical care during hospitalization in the above structures and services.

Implementation Actions:

1. Creation of special examination and treatment protocols for people with dementia.
2. Education and training of health professionals working in Departments of General Hospitals in aspects concerning dementia (Axis 7).
3. Establishment of a coordinator doctor responsible for dementia at every General Hospital.

Implementation Bodies:

- Ministry of Health
- Ministry of Education- Universities

- Medical Scientific Societies
- Centers of Excellence
- National Observatory for Dementia

Timetable:

- 2015-2017: Training of health professionals- Preparation of examination and hospitalization protocols.

Budget

No additional cost is created.

Action 3: Memory and Cognitive Disorders Clinics**Description:**

This action includes the establishment and operation of a Memory and Cognitive Disorders Clinic in every Regional General Hospital (Prefectural Hospitals) as provided in PSYCHARGOS (Ministerial Decision: Υ5β/Γ.Π./οικ 46769/2012 “Ten-year program for the development of units and mental health actions, PSYCHARGOS C (2011-2020)”). Furthermore, it aims to create a sufficient number of such clinics in hospitals of Athens and other major cities, depending on population needs.

The Memory and Cognitive Disorders Clinics should belong administratively to the Neurological or Psychiatric Departments of the Hospitals and provide:

- Diagnosis, treatment and follow up for people with dementia per region in cooperation with doctors of Primary Care.
- Networking, interconnecting and collaboration with health and social care settings of their region, like Health Centers and Primary Care settings, Alzheimer’s Associations, K.I.F.I., K.A.P.I., nursing homes, charities etc.
- Raising awareness of the public, and health professionals’ bodies concerning dementia.
- In regions with difficult access (e.g. islands, mountainous areas, remote villages), the health professionals of the Memory and Cognitive Disorders Clinics should visit periodically the Health Centers. Coverage through Telemedicine services in cooperation with the more proximal Memory and Cognitive Disorders Clinics is recommended.

The recommended minimum staff for each Memory and Cognitive Disorders Clinic is:

- 1 specialist doctor, neurologist or psychiatrist (specialized or with intensive clinical training in Centers of Excellence)
- 1 Neuropsychologist
- 1 nurse or social worker with duties of secretarial support, information and liaison, supplementary to the medical care.

Objectives:

- Creation of infrastructure to provide integrated medical care to people with dementia across the geographical territory of the country and improvement of the accessibility to remote areas (islands, mountain areas, remote villages).
- Providing full diagnostic, treatment and follow up services for people with dementia.

Implementation Actions:

1. Extension of the operation on a daily basis for the Memory and Cognitive Disorders Clinics in Hospitals where these already exist.
2. Establishment of Memory and Cognitive Disorders Clinics in General Hospitals in the seats of the regional units (Prefectural Hospitals).
3. Staffing of the Memory and Cognitive Disorders Clinics either with the existing personnel of the National Health System (NHS), or with newly-appointed one.
4. Interface and cooperation between the Memory and Cognitive Disorders Clinics with doctors and Primary Care structures, to provide information and organization of joint actions and practices.
5. Interface and cooperation between the Memory and Cognitive Disorders Clinics with the Day Care Centers (Axis 4, Action 4).
6. Regular evaluation of the work of the Memory and Cognitive Disorders Clinics under the supervision of the National Observatory for dementia.

Implementation Bodies:

- Ministry of Health
- Regional Health Directorates
- Centers of Excellence for Dementia
- National Observatory for Dementia

Timetable:

- 2015: Selection and assessment of the personnel for staffing the Clinics. Obligation of the hospital administrations for implementation with simultaneous ensuring of resources for their creation.
- 2016-2020: Establishment and staffing of the Clinics.

Budget:

1.800.000 € / year for 60 Memory and Cognitive Disorders Clinics (30.000 € / year / Clinic for payroll of 2 health professionals in addition to the doctor)

Action 4: Day Care Centers for people with dementia**Description:**

The action involves the gradual development of Day Care Centers for people with dementia spatially distributed in cities throughout Greece, and the strengthening of the existing Day Care Centers. At the same time, this action aims at improving the cooperation of Day Care Centers with the existing network of the social care structures for the elderly dealing with people with dementia (K.A.P.I, K.I.F.I, Friendship Clubs, nursing homes, church organizations), healthcare professionals of which will be deployed after training from the Centers of Excellence (axis 7).

Day Care Centers will provide the following services:

- Cognitive rehabilitation (mental empowerment, occupational therapy, art therapy, speech therapy)
- Daily activities for people with dementia
- Physical rehabilitation (gym-physiotherapy)
- Services for Caregivers
- Interface with the community

The multidisciplinary team of the Day Care Centre will include psychologists, nurses, occupational therapists and social workers, in a number proportional to the population needs and the available resources.

The Day Care Centers will interface with the nearest Memory and Cognitive Disorders Clinics of the General Hospitals, their doctors will cover the medical monitoring needs arising.

Objectives:

- Providing integrated health and social care to people with cognitive deficits across Greek territory through:
- Providing non-drug therapies.
- Relief of the caregivers' burden.

- Education and mental support of caregivers.

Implementation Actions:

1. Strengthening the existing Day Care Centers of the PSYCHARGOS program with health professionals of various specialties.
2. Determination of the conditions for the establishment and operation of Day Care Centers from the National Observatory for dementia.
3. Gradual development for a period of the next 10 years of a Day Care Centre for people with dementia in cities of over 20.000 inhabitants (160 in Greece).
4. Establishment and operation of 30 Day Care Centers, from public Organizations, -Local Administration Organizations, Alzheimer's Associations, private organizations etc. until 2020.
5. Cooperation and networking with the existing health and social care structures of the elderly, which effectively deals with people with dementia.

Implementation bodies:

- Ministry of Health
- Local Administration Organizations
- Alzheimer's Associations
- Private organizations
- National Observatory for Dementia

Timetable:

- 2015-2020: Development of 30 Day Care centers for people with dementia in large cities
- 2020-2025: Completion of the Day Care centers development nationwide

Budget:

120.000 €per year for each Day Care Center for the salaries of five health professionals and operating expenses.

Funding may come from national sources (Ministry of Health, National Organization for Rendering Health Services), from European funds, charities and private sources.

Action 5: Hospitality and long stay institutions for people with dementia**Description:**

This action aims at covering the long-term stay needs of people with dementia who are unable to stay at home, even with home care. The certification and continuous evaluation of existing private Nursing Homes is proposed as well as aiding financially through benefits people with dementia and their caregivers in order to use these units. These benefits will be granted according to the criteria of Action 2 of Axis 1, special care should be provided to people who have no insurance coverage.

Residence in private Nursing Homes serve people with dementia who exhibit behavioral disorders and require increased care. Moreover, people with dementia may be hosted for a short period of time so that their caregivers can have a break from their burden. Finally, residence in Nursing Homes aims to provide care to people with dementia with inadequate social support (poor, homeless) until the difficulties that they are facing, are solved.

Objectives:

- Establishment and operation of an adequate network of certified Nursing Homes for the Elderly to cover residence and accommodation needs of people with dementia.
- Improving the quality of the provided care and by extension the quality of life of people with dementia living in Nursing Homes.
- Saving resources by reducing the admission of people with dementia in public and private hospital clinics, due to conditions owed to inadequate care.

Implementation Actions:

1. Assessment of needs for accommodation services of people with dementia (a few days stay or long term stay) in different geographical regions of the country.
2. Establishment of special certification criteria for Nursing Homes that accommodate people with dementia, in order to meet the increased and specific care needs.

3. Continuous monitoring and evaluation of public and private Nursing Homes that host people with dementia.
4. Classification of people with dementia and establishing special financial benefits programs for them and their caregivers (Axis 1 Action 2)

Implementation bodies:

- Ministry of Health
- Local Administration Organizations
- Nursing Homes
- NGOs, Church Organizations
- Social Security Bodies - Private insurance companies
- National Observatory for Dementia

Timetable:

- 2015: Assessment of needs for accommodation and hosting services for people with dementia. Defining quality and certification criteria for Nursing Homes.
- 2016: Evaluation and certification of existing units.
- 2015-2016: Adoption and implementation of a financial aids program for people with dementia.

Budget:

100.000 for the development of a certification system of the Nursing Homes.

Action 6: End of life Institutions**Description:**

Action 6 aims to create structures of Palliative Care for the terminally ill (Hospices). The adequate spatial dispersion, staffing and infrastructure of these centers are essential to ensure high quality care. The use and adaptation of the existing structures (e.g. old hospital buildings) can be a practical solution for the necessary infrastructure.

Objectives:

- Improving the quality of life of end stage dementia patients.
- Savings of resources through reduced admissions of end-stage patients in public and private health care institutions.

Implementation Actions:

1. Developing services for end stage patients by existing palliative care structures for other diseases.
2. Establishment of care protocols and guidelines for the final stage of dementia taking into account the special needs of patients. Training of palliative care structures personnel on care protocols for persons with dementia.
3. Creation of dementia palliative care structures in areas with increased needs.
4. Exploitation and adaptation of existing structures (e.g. old buildings clinics, hospitals with low efficiency).
5. Establishment of increased financial benefit programs for people with dementia and their caregivers to cover the palliative care needs of the final stage (Axis 1 Action 2).

Implementation bodies:

- Ministry of Health
- Local Administration Organizations
- NGOs
- Charitable institutions
- Insurance Funds, Private insurance companies

- National Observatory for Dementia

Timetable:

- 2015: Establish palliative care protocols for end-stage patients with dementia.
- 2015-2020: Creation of at least 2 Hospices for people with dementia with a capacity of 100 beds each.

Budget:

Under the Circular of the Ministry of Health Y5b /G.P.oik.56675 the cost of 80 euros is determined per suffering person from dementia per day.

Therefore, for the final stage of dementia patients, the daily cost is adjusted and for the hospice capacity of 100 beds, the amount of 20.000.000€ is calculated in total, for the years 2016-2020: 4.000.000€annually.

Alternatively, it is proposed to make use of the existing structures and their human resources (hospitals with low efficiency) which can be converted into hospice, so that the cost is significantly reduced.

ACTION 7: Decentralized Care- Care at home**Description:**

This action relates to people with dementia who are unable to move from their home because of serious mobility problems, the advanced stage of the disease or the caregiver's moving weakness. It includes care services in different fields of care, medical, nursing and social, in order to facilitate everyday life and ultimately improve the quality of life of people with dementia and their caregivers.

The home care services are staffed by social workers, health visitors, nurses etc. specialized in care for people with dementia across the whole spectrum of the disease's process and interconnect the homes of people with dementia with Primary Care services.

Objectives:

- Covering the needs of people with dementia and their caregivers who have no access to services.
- Improving the quality of informal care.

Actions:

1. Creation of home care services by those municipalities that are able to organize such services. These services will belong to the Regional Services for dementia (Axis 4, Action 1).
2. Strengthening the interconnection and cooperation of the existing social care structures for elderly with the Primary Care services, combined with the certified training of health professionals from the Centers of Excellence (Axis 7 Action 2).
3. Development of a professional certification scheme for professionals caregivers of people with dementia who without qualifications deal with the care of people with dementia in our country.
4. Training and certification of professional caregivers.

Implementation Bodies:

- Ministry of Health – PEDY (Primary National Health Network)
- Local Administration Organizations
- EOPPEP (National Organization For the Certification of Qualifications and Vocational Guidance)
- Centers of Excellence

Timetable:

- 2015-2020: Creation of care services at home.
- 2015: Development of a professional certification scheme for professional caregivers.
- 2016-2020: Training and certification of professional caregivers.

Budget:

Depending on the available resources of Local Administration Organizations to create home care services.

€500.000 for the training and certification of professional caregivers.

ACTION 8: Telemedicine Services**Description:**

Services provided to people with dementia and caregivers living in remote areas are not comparable to those available in urban centers. The development of modern ICT-telemedicine services helps to deal with the shortages in remote and island areas, by facilitating access to health services and reducing the cost.

Objectives:

- Meeting the care needs of people with dementia and their caregivers in remote areas.
- Reducing service cost.

Actions:

1. Establishment of a Dementia Telemedicine Clinic in remote areas having its seat at the Health Centers or the local Health unit that will interface with Memory and Cognitive Disorders Clinics of the general hospitals.
2. Strengthening of selected home care programs with telemedicine equipment (external mobile telemedicine units) for persons with dementia with limited access to the Telemedicine Clinic.
3. Accelerated education of health professionals who will staff Dementia Telemedicine Clinics.

Implementation bodies:

- Ministry of Health
- Ministry of Education – Universities
- Ministry of Labour
- Local Administration Organizations

Timetable:

- 2015-2020: Creation of 20 Dementia Telemedicine Clinics spatially distributed throughout Greece.

Budget:

20,000 € per clinic in one-off payment

Axis 5: Legislation – Rights of people with dementia and their caregivers’***Action 1: Changes in the valid legislation*****Description:**

This action concerns the adoption of legislation aimed specifically at dementia. The action focuses on system problems and needs that are presented in the analysis of the current situation in Greece in Chapter “Legislation and Rights of Persons with dementia”. An analysis of the current situation in Greece proposes to emphasize:

- In direct service autonomy
- To right to privacy
- To right to health
- In indirect service of autonomy
- In technical legislative directions

Objectives:

- Guarantees regarding the rights of people with dementia and their caregivers must be pointed as the focal issue.
-

Implementation Actions:

1. Setting the special legislative committee to prepare and draft a law.
2. Delivery of the draft law and the explanatory memorandum to the Ministry of Health.
3. Completion of the parliamentary procedure – Adopt the law and publishment in the Official Gazette of the Government.
4. Supervision of its application.

Implementation bodies:

- Ministry of Health
- Parliament

- National Observatory for Dementia

Timetable:

- 1/2015: Setting a special law-drafting committee
- 6/2015: Completion of the draft law and explanatory memorandum
- 12/2015: Completion of the parliamentary procedure of adoption of the Law and publishment in the Official Gazette of the Government.

Budget:

30,000 € One-off remuneration for the 10 members of the special legislative committee. 3,000 €/ member (payment, on the timely delivery).

AXIS 6: Research on Dementia***Action 1: Calls for National Research Programs and Participation in International Research Efforts*****Description:**

This action concerns the issue of invitations for expressions of interest, annually or every two years for research projects in the field of dementia and participation in international research efforts on dementia such as the Joint Program for Neurodegenerative Diseases (JPND).

International and national research programs will relate to basic research, clinical research, translational research, implementation research, etc. As examples of research themes –subjects the following are mentioned: epidemiology, protective factors and risk factors for appearance or prognosis, financial and social impacts of dementia, technological resources and expertise utilized in Greece and internationally, recording and analysis of structures and health service needs, assessment of practices and doctors' habits and other health service providers in the field of dementias, comparative effectiveness research etc. The research programs will have implementation duration of 2-5 years.

Objectives:

- Expand the scientific base (people, infrastructure, know-how etc.) in the area of dementia in Greece.
- Increase the capacity to claim and capital inflow through the equal participation of Greek scientific community in international collaborations, and thus the absorption of competitive European and international research programs.
- Collection of adequate, reliable and valid data and acquisition of the necessary knowledge for designing a unified rational national policy for dementia and its more effective planning.
- Creating new knowledge towards the treatment of dementia, improving the care offered and the quality of life of people with dementia and their caregivers' etc.

Implementation Actions:

1. Ensuring resources from European and national sources.
2. Issue and publication of calls, which will focus on the shortcomings mentioned above.
3. Evaluation and selection of institutions that will implement the programs by use of independent external (outside of Greece) reviewers with adequate remuneration selected by existing lists of external judges of ministries, lists of GGET (General Secretariat of Research & Technology), of universities etc or by delegation of the review process in international organizations and associations.
4. Participation of Greece in all international calls on subjects of Dementia (e.g. participation in the Joint Program for Neurodegenerative Diseases).

Implementation Bodies:

Collaboration of the following under the guidance of the National Observatory for Dementia

- Ministry of Health
- General Secretariat of Research and Technology
- Non-profit Organizations and Research Institutions

Timetable:

- 2015-2020: Scheduling an annual or per two years call of research programs in order to implement 10 projects in the next 2 years.

Budget:

5.000.000€per year.

Action 2: Awards for the best researchers

Description:

The second action of Axis “Research” establishes prizes for the best researchers in the field of dementia, the cost of which will be covered either by public or private bodies (1 for clinical and 1 for basic research).

Objectives:

- Incentive and rivalry among scientists to enhance research.
- Expand the scientific base, i.e. the number of scientists engaged in research on dementia.

Implementation Actions:

1. Ensuring financial resources.
2. Promotion of the process and the importance of these awards.
3. Collaboration of the following implementation organizations for setting criteria and evaluating candidates for the awards each prize type.
4. Assessment of applications by independent reviewers with adequate remuneration selected from existing lists of external judges of ministries, of GGET (General Secretariat of Research & Technology), of universities etc.

Implementation Bodies:

Collaboration of the following under the guidance of the National Observatory for Dementia

- Ministry of Health
- General Secretariat of Research and Technology
- Non-profit Organizations and Research Institutions

Timetable:

- 2015- 2020: 1 award for clinical and 1 for basic research for one year.

Budget:

10.000€[5000 € award]/ year

Axis 7: Education on dementia**Action 1: Clinical and Research Scholarships****Description:**

This action intends to create scholarships for clinical and research expertise in the field of dementia.

Clinical scholarships (fellowships) addressed to physicians, neurologists, psychiatrists, geriatrics, physicians, general practitioners and other specialties. Research Fellowships addressed to physicians, biologists, neuroscientists and other healthcare professionals with an interest in the field of dementia and may have the character of a postgraduate doctoral thesis, postdoctoral education.

The duration of the specializations will be either annual or biennial.

The creation of an initial critical mass of experts, through this action, is essential to set up any further clinical, educational and research effort.

Objectives:

- Increase the number of the specialized and well-trained scientists in the field of clinical care and clinical research for dementia.
- Creation of a core of capable specialists in the field of research on dementia.

Implementation Actions:

1. Collaboration of the implementation organizations with accredited education programs in dementia, towards organizing and ensuring the induction and training of fellows, and towards defining the criteria and conditions for awarding scholarships.
2. Call for 10 clinical fellowships per year for the next 5 years.
3. Call for 5 research fellowships per year for the next 5 years.

Implementation Bodies:

Collaboration with the following under the guidance of the National Observatory for Dementia

- Universities - Research Centres
- Hellenic Neurological Society

- Hellenic Psychiatric Association
- Centres of Excellence for dementia

Timetable:

- 2015-2020: call for 50 clinical fellowships (10 per year).
- 2015-2020: call for 25 research ones (5 per year).

Budget:

30.000 €/ scholarship, e.g. 450.000 € in total for a whole year.

Action 2: Centres of Excellence for dementia**Description:**

The Centres of Excellence for Dementia will be Public or Private ones or a combination thereof and will contribute to the achievement of clinical specialization (fellowship) in dementia. They will also provide the basic educational unit for accelerated clinical education of specialized physicians (Neurologists, Psychiatrists, Geriatricians, General Practitioners, Internists and other specialists) in dementia, who will staff the Clinics of Memory and Mental Functions and other relevant structures. The Centres of Excellence do not necessarily have integration of vertical nature, but may take the structure of a network (e.g. geographically neighboring institutions with complementary structures and capacities but which will, however, demonstrate close cooperation and interaction).

The Centers of Excellence must have:

- Significant educational activity in the field of dementia.
- Significant clinical research activity in the field of dementia.
- Significant research activity and infrastructures in terms of basic research in the field of dementia (e.g. biobanks of biological materials, laboratory infrastructure, etc.). The Centers of Excellence may be or may establish reference laboratories as to some of the diagnostic tests.
- Competent number of human resources with recognized scientific merit and potentialities for education, clinical activity and research in the field of dementia.
- Satisfactory for the implementation of the above administrative and technocratic support.
- In total world-class status and recognition in the field of dementia.

Objectives:

- Promotion and development of clinical and basic research in the field of dementia.

- Training of a sufficient number of experts in the field of dementia to staff the services and structures that are proposed by the National Action for Dementia.

Implementation Actions:

1. Establishing certification criteria of the Centres of Excellence.
2. Call of competition for the development of Centres of Excellence.
3. Evaluation and selection of the bodies that will implement the specific programs by independent external reviewers (outside Greece) with adequate remuneration selected from existing lists of external judges of ministries, of GGET (General Secretariat of Research & Technology), of universities etc. or by delegation of the assessment process in international organizations and associations.
4. Staffing and operation of the Centres of Excellence.
5. Renewal of certification of the Centres of Excellence and evaluation of new candidateCentres every 3-5 years.

Implementation bodies:

- National Observatory for Dementia
- Ministry of Health
- Ministry of Education – Universities
- Educational Institutions and bodies of Health

Timetable:

- 2015-2017: Establishment and operation by a minimum of one, to a maximum of three Centres of Excellence.

Budget:

150,000 €/ Centre of Excellence / year.

Action 3: Specialization on dementia

Description:

Action 3 concerns the designing of the official medical sub-specialization in dementia for Neurologists, Psychiatrists, Internists, General practitioners, in Greece.

The Centres of Excellence will undertake the training and certification in clinical specialization in cooperation with corresponding Scientific Societies (Hellenic Neurological Society, Hellenic Psychiatric Association).

Objectives:

- Creation of a core of capable specialists, a crucial mass of qualified people in the clinical care setting for dementia, to enhance clinical, educational and research effort.

Implementation Actions:

1. Configuration of standard and homogeneous, uniform for all Centers of Excellence training program lasting one year.
2. Approval by the plenum Central Health Council of the new specialization acquisition process in dementia.

Implementation Bodies:

- Ministries of Health – Central Health Council
- Ministry of Education – Universities
- Centres of Excellence for dementia
- Scientific Societies (Hellenic Neurological Society, Hellenic Psychiatric Association, etc.).

Timetable:

- 2017-2020: Completion of the program in 18 specialized doctors (6 per year).

Budget:

30,000 €/ trainee, i.e. 180.000 €/ year.

Action 4: Enhancing undergraduate education in dementia**Description:**

The action involves the strengthening and expansion of undergraduate education in disciplines related to dementia and in particular the increase of the respective educational allocated time during studies in Medical School, Nursing, Biological, Pharmaceutical Departments, Psychology Departments and others. The above undergraduate courses can be core or elective courses, practical training programs, etc.

Objectives:

- Increasing the number of graduates of these Departments that will deal with dementia either professionally or for research purposes and strengthening of the scientific field.
- Increasing the knowledge and familiarity with dementia.

Implementation Actions:

1. A call for expressions of interest to higher education institutions to expand their curricula in the academic field of dementia.
2. Evaluation of applications and selection of educational institutions that will undertake these specific projects.

Implementation Bodies:

- Ministry of Health
- Ministry of Education
- Higher Education Institutions

Timetable:

- 2016-2017: Planning and commencement of 10 new undergraduate courses / courses in disciplines related to dementia

Budget:

€50.000/year: €5.000/course - 10 courses / year.

Action 5: Training in dementia during the Medical Specialty**Description:**

The action aims to improve the medical residency education (knowledge and skill) of the trainee residents in the specialties of Neurology, Psychiatry, Internal Medicine and General Medicine. It includes the mandatory exposure to people with dementia (clinical rotation) for a specific time period of three months, in Neurological - Psychiatric Clinics with Clinics of Memory and Mental Function.

Objectives:

- Improving the medical residency education (knowledge and skill) for dementia.
- Expanding the medical clinical knowledge and competence in multiple medical specialties, mainly to those which have more contact with people with dementia.

Implementation Actions:

1. Cooperation between scientific bodies for the establishment of the integration process in the residency curriculum of the Neurology, Psychiatry, Internal Medicine, General Medicine specialties, of the 3-month training in related dementia issues.
2. Approval of the Central Health Council (KESY).

Implementation Bodies:

- Ministry of Health - Central Health Council (KESY)
- Ministry of Education
- Scientific Societies (Hellenic Neurological Society, Hellenic Psychiatric Association, etc.).
- National Observatory for Dementia

Timetable:

- 2015-2017: Identification of the clinics of Neurology - Psychiatry that simultaneously offer the qualification of (a) granting the medical specialty and (b) clinics of Mental Functions and integration of this mandatory rotation in the education curricula of the residencies mentioned hereinabove.

Budget:

No additional cost is created.

Action 6: Training Specialized physicians and other Health professionals on dementia

Description:

This action focuses on training and strengthening knowledge about dementia through the organization and operation of accelerated training (duration 3 months) in the Centres of Excellence for dementia. It is addressed to specialized Neurologists, Psychiatrists, Internists and General Practitioners, and other health professionals who will staff the Clinics of Memory and Mental Functions.

Objectives:

- Improving medical clinical training (knowledge and skill) in dementias.
- Expansion of the medical clinical knowledge and skill in multiple medical specialties, particularly those that will come into greater contact with people with dementia.
- Create a core of capable, familiar with dementia health professionals who will staff the Cognitive Disorders Clinics and other relevant structures.

Implementation Actions:

1. Determination from the Centres of Excellence of the number of trainees they may accommodate or educate, and the educational material.
2. Proclamation and implementation of educational programs.

Implementation bodies:

- Centres of Excellence for dementia
- Ministry of Health
- Ministry of Education

Timetable:

- 2016-2020: Organization and implementation of educational programs.

Budget:

No additional cost is created.

Chapter 5th Implementation Procedure –**Budget of the National Action plan**

The “National Action Plan for dementia – Alzheimer’s disease” registers the country’s needs in the field of dementia and suggests the directions and actions that will lay the foundations for improving the level of health and life of people with dementia and their caregivers. However, in achieving the objectives set for our country in the field of dementia the framework and implementation procedures should be determined regarding political supervision, planning, coordination and monitoring of the implementation of the National Action Plan. Moreover, a continuous evaluation and monitoring of the implementation of the National Action Plan and continuous cooperation of stakeholders with the political leadership of the Ministry of Health is required.

In this context, the **political supervision** of the National Action Plan is exercised by the respective political leadership of the Ministry of Health, to which the National Observatory for dementia is accountable. Moreover, the National Observatory for Dementia – Alzheimer’s diseases is established in the Ministry of Health, with purpose to support permanently the policy of the Country for the treatment of the disease and to protect the rights of the patients and their families’. The National Centre for Dementia – Alzheimer’s diseases exercises inter alia the following competences:

1. It prepares the National Strategy Plan for the disease, which is submitted for approval to the Commission of Social Cases of the Parliament.
2. Monitors the implementation of the National Strategy Plan by the authorized health care services all over the Country, draws up the relevant annual report submitted to the Minister of Health and the competent Parliamentary Committee.

Finally, during the preparation of the National Action Plan the competent Commission proceeded to the assessment of the actions proposed, shown in details below. For the implementation of the National Action Plan all the possible **sources of funding** will be

exploited such as the EU Structural Funds and particularly the Partnership Agreement (PA), the state budget, Corporate Social Responsibility, sponsorships etc.

Funding – Estimated budget for the period 2015-2010

The total budget of the operations of the National Action Plan for dementia amounts to 51.600.000 €. In particular, the budget of each axis and the partial actions is presented in the following table.

AXIS I. RECORDING AND CLASSIFICATION OF PATIENTS WITH DEMENTIA IN GREECE		
ACTIONS	ACTION TITLE	BUDGET
Action 1	National record of people with dementia	500.000€
Action 2	Classification of people with dementia and provision of economic aids according to an algorithm of the disease and of the families burden	100.000€
TOTAL:		600.000€

AXIS II. PREVENTION - INFORMING AND AWARENESS OF THE PUBLIC		
ACTIONS	ACTION TITLE	BUDGET
Action 1	Intervention for the prevention of dementia	2.500.000€
Action 2	Awareness and informing the public	2.500.000€
TOTAL:		5.000.000€

AXIS III. CAREGIVERS SUPPORT		
ACTIONS	ACTION TITLE	BUDGET
Action 1	Caregivers Support	1.000.000€
TOTAL:		1.000.000€

ACTIONS	ACTION TITLE	BUDGET
Action 1	Dementia in Primary Care	-
Action 2	People with dementia in Emergency Departments and the Departments of General Hospitals	-
Action 3	Memory and Mental Function Clinics	9.000.000€
Action 4	Day care centers for people with dementia	21.600.000€
Action 5	Hospitality and long stay structures for people with dementia	100.000€
Action 6	Final stage structures	20.000.000€

Action 7	Decentralized Care- Home care	500.000€
Action 8	Telemedicine Services	400.000€
	TOTAL:	51.600.000€

AXIS V. LEGISLATION , PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS' RIGHTS		
ACTIONS	ACTION TITLE	BUDGET
Action 1	Changes in the Current Legislation	30.000€
	TOTAL:	30.000€

AXIS VI. RESEARCH FOR DEMENTIA		
ACTIONS	ACTION TITLE	BUDGET
Action 1	Proclamations of National Research Programs and participation in International Research Efforts	30.000.000€
Action 2	Awards for best researchers	50.000€
	TOTAL:	30.050.000€

AXIS VII. EDUCATION		
ACTIONS	ACTION TITLE	BUDGET
Action 1	Clinical and Research Fellowships	2.250.000€
Action 2	Centers of Excellence for dementia	1.500.000€
Action 3	Specialization in dementia	540.000€
Action 4	Enhancing undergraduate education in dementia	50.000€
Action 5	Training in dementia when completing Medical Specialty	-
Action 6	Training of qualified doctors and other health professionals in dementia	-
	TOTAL:	4.340.000€

	TOTAL BUDGET 2015-2020:	92.620.000€
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Literature

1. Alzheimer's, Disease International. *2011 Alzheimer's Disease Facts and Figures*. 2011; Available from: http://www.alz.org/downloads/Facts_Figures_2011.pdf .
2. NIH. NIH consensus development conference statement on preventing Alzheimer's disease and cognitive decline. 2010; Available from: http://consensus.nih.gov/2010/docs/alz/ALZ_Final_Statement.pdf .
3. Forum, A.R. Alz Risk Factor Overview Diabetes Mellitus. [cited 2012; Available from: <http://www.alzrisk.org/riskfactorview.aspx?rfid=3> .
4. Lu, F.P., K.P. Lin, and H.K. Kuo, Diabetes and the risk of multi-system aging phenotypes: a systematic review and meta-analysis. *PLoS One*, 2009. 4(1): p. e4144.
5. Forum, A.R. Alz Risk Factor Overview Blood Pressure. [cited 2012; Available from: <http://www.alzrisk.org/riskfactorview.aspx?rfid=1>.
6. Skoog, I., et al., 15-year longitudinal study of blood pressure and dementia. *Lancet*, 1996. 347(9009): p. 1141-5.
7. Stewart, R., et al., Change in blood pressure and incident dementia: a 32-year prospective study. *Hypertension*, 2009. 54(2): p. 233-40.
8. Beerli, M.S., et al., The effects of cardiovascular risk factors on cognitive compromise. *Dialogues Clin Neurosci*, 2009. 11(2): p. 201-12.
9. Shepardson, N.E., G.M. Shankar, and D.J. Selkoe, Cholesterol level and statin use in Alzheimer disease: I. Review of epidemiological and preclinical studies. *Arch Neurol*, 2011. 68(10): p. 1239-44.
10. Whitmer, R.A., et al., Obesity in middle age and future risk of dementia: a 27 year longitudinal population based study. *BMJ*, 2005. 330(7504): p. 1360-.

11. McGuinness, B., et al., Blood pressure lowering in patients without prior cerebrovascular disease for prevention of cognitive impairment and dementia. *Cochrane Database Syst Rev*, 2009(4): p. CD004034.
12. McGuinness, B., et al., Statins for the prevention of dementia. *Cochrane Database Syst Rev*, 2009(2): p. CD003160.
13. Martin, B.K., et al., Cognitive function over time in the Alzheimer's Disease Anti-inflammatory Prevention Trial (ADAPT): results of a randomized, controlled trial of naproxen and celecoxib. *Arch Neurol*, 2008. 65(7): p. 896-905.
14. Anstey, K.J., et al., Smoking as a risk factor for dementia and cognitive decline: a meta-analysis of prospective studies. *Am J Epidemiol*, 2007. 166(4): p. 367-78.
15. Rusanen, M., et al., Heavy smoking in midlife and long-term risk of Alzheimer disease and vascular dementia. *Arch Intern Med*, 2011. 171(4): p. 333-9.
16. Butters, M.A., et al., Pathways linking late-life depression to persistent cognitive impairment and dementia. *Dialogues Clin Neurosci*, 2008. 10(3): p. 345-57
17. Saczynski, J.S., et al., Depressive symptoms and risk of dementia: the Framingham Heart Study. *Neurology*, 2010. 75(1): p. 35-41.
18. Dotson, V.M., M.A. Beydoun, and A.B. Zonderman, Recurrent depressive symptoms and the incidence of dementia and mild cognitive impairment. *Neurology*, 2010. 75(1): p. 27-34
19. Stern, Y., What is cognitive reserve? Theory and research application of the reserve concept. *J Int Neuropsychol Soc*, 2002. 8(3): p. 448-60
20. Scarmeas, N. and Y. Stern, Cognitive reserve: implications for diagnosis and prevention of Alzheimer's disease. *Curr Neurol Neurosci Rep*, 2004. 4(5): p. 374-80
21. Scarmeas, N. and Y. Stern, Cognitive reserve and lifestyle. *J Clin Exp Neuropsychol*, 2003. 25(5): p. 625-33

22. Scarmeas, N., et al., Influence of leisure activity on the incidence of Alzheimer's disease. *Neurology*, 2001. 57(12): p. 2236-42
23. Scarmeas, N., et al., Association of life activities with cerebral blood flow in Alzheimer disease: implications for the cognitive reserve hypothesis. *Arch Neurol*, 2003. 60(3): p. 359-65
24. Scarmeas, N., et al., Physical activity, diet, and risk of Alzheimer disease. *JAMA*, 2009. 302(6): p. 627-37
25. Sofi, F., et al., Physical activity and risk of cognitive decline: a meta-analysis of prospective studies. *J Intern Med*, 2011. 269(1): p. 107-17
26. Luchsinger, J.A., J.M. Noble, and N. Scarmeas, Diet and Alzheimer's Disease. *Curr Neurol Neurosci Rep*, 2007. 7(5): p. 366-372
27. Scarmeas, N., et al., Physical activity, diet, and risk of Alzheimer disease. *JAMA*, 2009. 302(6): p. 627-37
28. Scarmeas, N., et al., Mediterranean diet and risk for Alzheimer's disease. *Ann Neurol*, 2006. 59(6): p. 912-921
29. Plassman, B.L., et al., Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology*, 2007. 29(1-2): p. 125-32.
30. Shumaker, S.A., et al., Conjugated equine estrogens and incidence of probable dementia and mild cognitive impairment in postmenopausal women: Women's Health Initiative Memory Study. *Jama*, 2004. 291(24): p. 2947-58
31. Shumaker, S.A., et al., Estrogen plus progestin and the incidence of dementia and mild cognitive impairment in postmenopausal women: the Women's Health Initiative Memory Study: a randomized controlled trial. *Jama*, 2003. 289(20): p. 2651-62

32. Espeland, M.A., et al., Conjugated equine estrogens and global cognitive function in postmenopausal women: Women's Health Initiative Memory Study. *Jama*, 2004. 291(24): p. 2959-68
33. Guy M. McKhann et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging – Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 2011,7:263 – 269
34. Sachdev P, Kalaria R, O'Brien J, Skoog I, Alladi S, Black SE, Blacker D, Blazer DG, Chen C, Chui H, Ganguli M, Jellinger K, Jeste DV, Pasquier F, Paulsen J, Prins N, Rockwood K, Roman G & Scheltens P. Diagnostic Criteria for Vascular Cognitive Disorders: A VASCOG Statement. *Alzheimer Dis Assoc Disord*, 2013
35. Zekry D, Hauw JJ, Gold G. Mixed dementia: epidemiology, diagnosis, and treatment. *J Am Geriatr Soc*. 2002;50:1431-8
36. McKeith IG, Dickson DW, Lowe J, et al. Diagnosis and management of dementia with Lewy bodies: third report of the DLB consortium. *Neurology* 65:1863–1872, 2005
37. Ballard C, Aarsland D, Francis P, Corbett. A Neuropsychiatric symptoms in patients with dementias associated with cortical Lewy bodies: pathophysiology, clinical features, and pharmacological management. *Drugs Aging*. 2013,30:603-11
38. Emre M, Ford PJ, Bilgiç B, Uç EY. Cognitive impairment and dementia in Parkinson's disease: Practical issues and management. *Mov Disord*. 2014,15;29:663-72
39. Miller BL. Frontotemporal dementia. Perry DC, *Semin Neurol*. 2013 ;33:336-41
40. Aalten P, Verhey FR, Boziki M, Brugnolo A, Bullock R, Byrne EJ, Camus V, Caputo M, Collins D, De Deyn PP, Elina K, Frisoni G, Holmes C, Hurt C, Marriott A,

Mecocci P, Nobili F, Ousset PJ, Reynish E, Salmon E, Tsolaki M, Vellas B & Robert PH. Consistency of neuropsychiatric syndromes across dementias: results from the

European Alzheimer Disease Consortium. Part II. Dement Geriatr Cogn Disord., 2008. 25(1), 1-8

41. Lyketsos CG, Carrillo MC, Ryan JM Khachaturian AS, Trzepacz P, Amatniek J, Cedarbaum J, Brashear R & Miller DS.. Neuropsychiatric symptoms in Alzheimer's disease. *Alzheimer's and Dementia*, 2011. 7, 532-539.

42. Rice DP, Fillit M, Max W, Knopman DS, Lloyd JR, Duttagupta D, Prevalence, Costs, and Treatment of Alzheimer's Disease and Related Dementia: A Managed Care Perspective *Am J Manag Care* 2001;7:809-818.

43. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist* 1995;35:771-791.

44. Fox, N.C. and R.C. Petersen, The G8 Dementia Research Summit--a starter for eight? *Lancet*, 2013. 382(9909): p. 1968-9

45. Alzheimer's Disease International. Dementia Plans. Available from:

<http://www.alz.co.uk/alzheimer-plans>

46. Art. 11, 15 of the European Social Charter (Law 1426/1984), and Article 4 of the Additional Protocol concerning care (health and social) of the elderly. See also series of articles of the Charter of Fundamental Rights of the European Union (art. 3, 20, 21, 25, 26, 34, 35). It should be noted that psychiatric ethics documents (Declaration of Hawaii II, etc.), as well as soft law texts on the treatment and rights of mental patients (especially Recommendations in European Law) have interpretative significance for the law of dementia.

47. Luberti vs Italy (1984 / appeal No. 9019/80), Winterwerp vs Netherlands (1979 / appeal No. 6301/73), Varbanov vs Bulgaria (2000 / appeal No. 31365/96) and a complete list of this jurisprudence in, P. Bartlett, R. Sandland, *Mental Health Law. Policy and Practice*, Oxford U.P., 2013, xxii, xxiii.
48. Alzheimer's Association, *State Alzheimer's Disease Plans*, http://act.alz.org/site/DocServer/STATE_AD_PLANS.pdf?docID=4641
49. Bartlett, Sandland, *ibid.*, *passim*.
50. J. Ankri, C. Van Broeckhoven, *Evaluation du plan Alzheimer 2008 - 2012. Rapport*, Paris 2013, p. 64 et seq.
51. Alzheimer 's Disease International. *Dementia in Greece - A Summary Report*. 2012
52. Kyriopoulos C, Vandorou F, Zavras A, N Daniilidou. *The cost of Dementia of Alzheimer's type in Greece. Dementia: Medical and Social Challenge*. Tsolaki M, Kazis A. (ed.) University studio press. Thessaloniki 2005
53. Kaitelidou D. et al. *Socio-economic impacts of Alzheimer's disease in Greece: Pilot study. Treatment and research*. Apr.2013
54. Blanakis N. *Psychiatric Care and Human Rights in Greece*. Publisher: Odysseas, 2004
55. Sakka P., et al. *Alzheimer patients caregivers' survey in Greece*, ICAD, Vienna, 2009
56. Art. 5, par. 1, 2, 5, Art. 7 par. 2 art. 9 par. 1, section b, Art. 9A.
57. E. Fytraki [Art. 28 Private Law Code - Analysis], in: S. K. Vidali - Th. K. Papachristou (ed.), *Medical Ethics. By article analysis of the Law 3418/2005*, Sakkoula, Athens - Thessaloniki 2013.

Annex**Recommendations to reform legislation**

Given the weakness of the existing legislation to specify and ensure the rights of people with dementia and their caregivers' the elaboration and establishment of direct service of the autonomy of persons with dementia is recommended.

These provisions must ensure:

1. The personal safety.

The legislator should reconsider the case of involuntary hospitalization of people with dementia. The peculiarity of dementia over other mental illnesses should be recognized. It is proposed to establish a legislative report on medical protocols for the accurate estimation of the need for involuntary hospitalization to avoid compromising the patients' rights.

Furthermore, the current legislation to address domestic violence can be complemented with an explicit reference to the protection of individuals with dementia and the possible enlargement of the option by the competent public prosecutor, after documented complaints of third parties.

2. The legal capacity.

The legislator needs to evaluate the application up to date of the institution of judicial solidarity. There is general lack of awareness of patients' associations and doctors' as well, while it is noted marked aversion in the office of the guardian, reluctance of expert doctors (motivation deficiencies) and bureaucratic delay in the process.

The freedom to appoint a supporter from a wider circle of volunteers (not excluding attending doctors), and the binding force of a patient's prior desire concerning the supporter's face should be considered especially.

Moreover, aiding the relevant judicial judgment by internationally recognized protocols on the onset of disease symptoms and their consequences, it would be useful to be predicted explicitly.

Finally, the legislator should consider broadening the circle of experts and the establishment of a single list for all courts.

3. The right of privacy.

The legislation should explicitly refer to the protection of the patients' privacy. The indicative reference to the law of privacy responses (phone calls, letters, e-mail), the personal relations of the person with dementia, the right to be left alone will enhance both the patient's autonomy and the sense of caregivers' responsibility, delimiting their "power" depending on the stage of the disease and the kind of symptoms.

4. The right to health.

The recognition of the widest control of health issues from the patient as possible is also an important issue. As in other legislations as well, our country should introduce as well the institution of "advance directives".

The sufferer from dementia, already in the early stages of the disease, should be able to set, binding on third parties, whether the person wishing to act on his behalf with regard to health in general (proxy consent), or and directly specific medical procedures that accepts or denies (living wills), for the period during which he/she will no longer be able to decide. The establishment of the institution requires a reliable recording system of the "instructions" and direct access of the attending doctors and relatives to this, the details of which will be defined more specifically in the legislation.

5. The freedom of movement of the patient.

The legislator needs to balance this right with the security of public traffic, providing a mechanism for mandatory annual driving rating, from the time of first diagnosis of possible symptoms of the disease, regardless of whether the patient has exceeded a certain age limit or not. The responsibility for this assessment should belong to the patient himself/herself (to protect medical confidentiality), by express provision, however of severe sanctions against offenders.

Indirect service autonomy

The elaboration and establishment of provisions for indirect service of the patients' autonomy are suggested, so as to create a safe environment to serve their daily needs. These provisions must ensure:

1. The caregivers' support.

The needs of the caregivers require time "breaks", with their smooth temporary substitution by public structures (e.g. Day Care Centres) without disrupting the patient's daily care. A caregivers' relevant right should be explicitly mentioned in the law, so there is a minimum of institutional commitment to the development of such structures.

2. The social care for people with dementia.

Unlike other chronic diseases, dementia involves a large part of the population, it is therefore necessary to avoid piecemeal relevant regulations and overregulation in the allowance policy field. Therefore it is necessary in this case a firm policy concerning benefits and health care to be legislated, in connection with the degree of disability.

The legislator must explicitly exclude repetitive confirmation of disability, when the disease has been already onset, the nature of which is to be deteriorated gradually. This control is not considered necessary and conceals unjustified suspicion to the patient. Instead, periodic checks on the possible increase in the disability rate are imposed.

Legislative drafting directions

It would be good the form of the inclusion of these issues in the legislation, to follow certain guidelines:

1. The conservation settings in the wider context of mental health law, but in a separate section of this law. This will avoid fragmentation, which weakens the implementation. On the other hand, the utilization of mental health facilities will not be disturbed.
2. The authority protecting the patients' rights should be preceded, as a basic guideline.
3. The immediate binding of those regulations not accompanied by costs should be ensured, particularly in terms of the patients' rights in their daily lives, even with sanctions provision (e.g. administrative).
4. The provision of the objectives and priorities on options either expensive or requiring new structures (e.g. Clinics of Memory and Mental Functions, Planned Day Care Centres, research, education, etc.), with a precise description and duties of the responsible bodies.
5. The explicit recognition of the general competence of the Observatory for dementia.
6. The avoidance of general provisions with reference to the enabling provisions, which would weaken the regulatory effectiveness of the law.

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True translation from the attached Greek unattested, unsigned, computerized document.

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