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No. 094220-1/1

National Action Plan for dementia – Alzheimer’s disease

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

ΕΛΛΗΝΙΚΗ ΔΗΜΟΚΡΑΤΙΑ, ΥΠΟΥΡΓΕΙΟ ΕΞΩΤΕΡΙΚΩΝ
ΜΕΤΑΦΡΑΣΤΙΚΗ ΥΠΗΡΕΣΙΑ
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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 live affected by dementia world-wide, a number which will be doubled by 2030 and will be hypertripled by 2050. In our country, 200.000 people live affected by dementia and this number is expected to exceed the 600.000 by 2050. Despite the scientific methods of the last 25 years the resolution of dementia constitutes a major issue both at national and international level. The stigma, denial and lack of economic sources constitute the main obstacles for all-round 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 of 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.

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Within this context, under the continuously increasing socio-economic impact of dementia and as the result of long-term needs 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

Άνοια = α (στερητικό) + νους = loss of mentality

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 effect (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



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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 – necrotomies) have elements of the final Alzheimer's disease. Moreover, half of the above have co-existing lesions of the type of 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 frequently enough to aged people and are met to around 1/3 of pathological cerebral samples of people with dementia. However a mere vascular dementia without co-existing pathological lesions of Alzheimer's disease

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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 enough more rare and cumulatively they are responsible for 5-10% of dementias.

The exact causes of Alzheimer's disease are not known, while it is noted that genetic factors may have a determinant role and affect directly the possibility for the onset of the disease [2]. These factors include 3 genes passed on from parents to children, with 50% possibility. 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



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and/or 30). Genetic factors seem to affect in a smaller degree the frequent “sporadic” type of the diseases from which suffers the 97-98% of people with dementia. However, presently and also in the short-term, these genetic factors are neither fully known nor modifiable.

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

- √ Age, gender,
- √ Down syndrome,
- √ Cardiovascular factors (diabetes mellitus, hypertension, dyslipidemia, obesity),
- √ Smoking,
- √ Nutritional habits,
- √ Head traumatic injuries,
- √ Depression,
- √ Medication (hormones, anti-hypertensive, anti-dyslipidemic, anti-inflammatory etc),
- √ Factors which affect the mental reserve (IQ, education, profession, intellectual, social activities, physical exercise etc).

It is clear that cardiovascular factors predispose for cerebral vascular episodes and vascular dementia. However, if these constitute risk factors for Alzheimer’s diseases,

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remains unclear according to literature. 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 less strong correlation, since its correlation with Alzheimer’s disease has been presented both in epidemiological researches, and in basic 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).



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Based on the possible correlation of cardiovascular factors with Alzheimer's disease, it has been hypothesized that drugs that treat these diseases (anti-hypertensive, 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 (SAIDs) (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 positive action 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 possibility for development of the disease [14,15].

Cerebral traumatic injuries seem to increase the possibility 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, possibly, correlates with dementia and Alzheimer's disease, through multiple biological mechanisms [16]. Older studies demonstrated that the presence of depression increases the possibility for development of Alzheimer's disease a few years later. However, people with Alzheimer's disease manifest symptoms both from the cognitive field, and behavioral – psychiatric ones, out of which the most frequent is depression. For this reason it is not clear if depression really increase the risk for Alzheimer's disease or it simply represents an early onset of the disease itself.

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Furthermore, recent studies demonstrate that depression in middle age possibly leads to increased possibility for developing Alzheimer's disease many decades later [17,18].

The **theory of “cognitive reserve”** suggests that differences are observed from person to person concerning the potentiality for fighting Alzheimer's disease [19,20,21]. Many



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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 less possibilities to develop the disease. If these correlations are really etiologic ones (in other words if real protection exists) or they simply ensue due to methodological errors in scientific studies constitute an object for disagreement within the scientific community.

Nutrition is included in lots of environmental factors that have been correlated with Alzheimer's disease. However, the results from various relevant researches are controversial [26]. Higher intake of vitamins (C, E, B6, B12, folic acid), flavonoids, unsaturated fatty acids and fish, moderate consumption of alcohol, intake of anti-oxidants, anti-inflammatory and food supplements, have been correlated with decreased risk for developing Alzheimer's disease or with slower mental impairment. Other studies however support that the risk for Alzheimer's disease or mental impairment is not correlated with the intake of the aforementioned. New data denote that Mediterranean Diet possibly correlates with the decreased possibility for developing Alzheimer's disease [27, 28] as well. In total, the existing data, concerning nutrition are not adequate so as to develop guidelines and advice, of high degree of scientific certainty, for particular nutritional habits.

Also, women are slightly more likely to be diagnosed with Alzheimer's disease [29] compared with men, which is probably due to the longer life 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 protects against Alzheimer's disease or other mental problems, but probably acts aggravating [30, 31, 32].

To summarize, the identified risk factors for Alzheimer's disease are the genetic



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predisposition and age increase, but they are not modifiable. The role of modifiable factors (cardiovascular factors, diet, tobacco use, head injuries, depression, cognitive reserve) remains unclear and there is no scientific consensus as in their meaning.

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

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

Types of dementia

Dementia is the loss of pre-existing mental abilities, as the result of degeneration, dysfunction and destruction of the human brain neurons. Dementia constitutes the clinical expression of many neurogenerative diseases and Alzheimer's disease is the most frequent one. Vascular dementia, mixed dementia, frontotemporal dementias, Parkinson's disease dementias and dementia with Lewy bodies follow as less frequent. Also, dementia may be 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.).

During the last years significant progresses have been made in the prevention, diagnosis and treatment of Alzheimer's diseases and the other types of dementia:

1. Our knowledge of risk factors and protective factors has increased significantly, which allows some degree of prevention.

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2. The diagnosis in early stages is feasible with advanced methods (PIB PET-positron emission tomography, volumetric MRI, cerebrospinal fluid indicators, genetic testing, structured neuropsychological tests), to permit the application of multiple interventions, medicinal or not.
3. There are blood tests to investigate genetic predisposition of several forms of dementia.
4. We used rugs as symptomatic treatments, and help maintain the functionality and quality life of people with dementia and their caregivers. Furthermore, due to dramatically increasing prevalence of dementia, the funds for research rise and many new drugs are tested clinically at this time.

Alzheimer's Disease

It concerns a neurodegenerative disease with specific neuropathological changes (amyloid plaques and neurofibrillary tangles) that evolves in a specific deterministic manner, characterized by clinical heterogeneity. Since the onset of the symptoms to the final stages of the disease takes on average 10 years.

The clinical picture of Alzheimer's disease includes [33]:

1. Disorders of short-term memory, while the long-term memory is affected at the last stages of the disease.
2. Disorders of comprehensibility of speech and expression.
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 behind Alzheimer's disease. Characterized by the presence of impaired judgment or ability to organize thought and



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targeted behavior, while amnesia is not a characteristic symptom at least in the initial stages [34].

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Mixed dementia

This type of dementia is defined by the presence of neuropathological lesions linked to more than one causes of dementia occur simultaneously in the brain (Alzheimer's disease and vascular dementia usually, and dementia with Lewy bodies) [35]. The clinical picture varies depending on the type 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 (pathognomonic and particularly detailed) and Parkinson's symptoms [36,37].

Dementia in Parkinson's disease

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

Frontotemporal dementias

The prevalence of frontotemporal dementia is especially difficult to be estimated since it may not be easily identified, provided that behavior disorders and psychiatric symptoms prevail which cover the mental impairment. 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



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by difficulty in speech production. 3. *Semantic dementia* during which the sufferer by dementia loses the meaning of words [39].

Behavioral and Psychological Symptoms of Dementia (BPSD)

BPSD appear in all forms of dementia [40]. Specifically, in frontotemporal dementia and in dementia with Lewy bodies they are pathognomonic and form part of the diagnostic criteria. Recent studies have shown that nearly all people with dementia will

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develop one or more behavioral and psychological symptoms during the course of the disease.

BPSD cause significant impacts 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,
- √ psychosis (delirium and hallucinations),
- √ disinhibition,
- √ sleep disorders,
- √ eating disorders.

BPSD constitute the main source of burden for caregivers, causing impairment of life quality to sufferers and their families. Additionally they contribute greatly to the institutionalization of people with dementia and thus they dramatically increase the cost of care. The caregivers, family and professionals, usually report that are annoyed more by BPSD and less by the existence of cognitive deficits in people with dementia.



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3. Economic dimensions of dementia

As a disease with significant morbidity burden, dementia is a major problem for the budget not only of the health system, but also of social productivity, and therefore of national economy, for all developed economies worldwide. The reason is that the occurrence of dementia involve:

1. Direct (medical) costs
2. Indirect costs

The **indirect cost** relates to expenses for the sufferer himself, as a result of the needs for monitoring costs – follow ups, expenditure of diagnostic tests, medication costs and

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hospitalization expenses, either in hospital or in a unit of long-term hospitalization, or nursing at 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 and **indirect - hidden costs**, incurred as a result 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 of the resulting loss of social production. In the estimation of the indirect costs, productivity losses (loss of income) are included both of the person's with dementia, due to his inability to work when the disease appears theoretically during working age, and his caregivers in the form of absenteeism from work due to the increasing needs for custody and care of the patient [42,43]. Furthermore, in indirect costs are taken into account and 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



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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 the research for dementia are extremely disproportionate worldwide in relation to the cost of the disease.

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

4. International policy for treating 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 the resolution of dementia constitutes a major issue both at national and international level. The stigma, denial and lack of economic sources constitute the main obstacles for all-round 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



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writing of reports concerning the management policies of 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 effects of dementia and can 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 concern the burden of morbidity and the economic load of dementia [44]. For this

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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.



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All the above recommendations set priorities and suggest ways for the treatment 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 structures and health and social care services
- 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
- Support of the research.

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.



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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, prepared in collaboration with 24 parts, Ministries, professional associations, Academic Institutions, patients’ organizations and after 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.



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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



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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

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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.



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In Britain, the dementia issues are regulated by a number of 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 live 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

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hereto. In this context; a) a person is considered as principally capable of acting for himself, b) the first 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 o 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



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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.

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Chapter 2nd – Dementia in Greece

1. Epidemiology – Research – Education

Epidemiological data

There are no adequate epidemiological data on dementia in Greece. By reducing 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 the 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, impact, risk-protection factors, clinical manifestations, diagnostic biomarkers, genetic profiles and the key biological mechanisms in the cognitive subject 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:

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- **Prevalence** (incidence in the population) of Dementias in total and individually in different types of dementias.
- **Impact** (growth rate of young people with dementia over time) of Dementias in total and partially in different types of dementia.
- **Recording specific to the Greek population protection** (e.g. nutrition, genetic factors) **or aggravating** (e.g. smoking, genetic factors) **factors** concerning the development of dementia.
- **The cost of dementia** (mainly through quantitative studies) and its precise division 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 services providers, and the extent to which these comport with or deviate from the international-European recommendations, guidelines and practices.

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- **Basic research:**
 - Creation of Centers of Excellence (CoE).
 - Increase the number of basic research researchers.
 - Strengthening laboratory material – technical infrastructure (animal brain imaging center).
- **Clinical research:**
 - Creation of Centers of Excellence (CoE).
 - Increase the number of clinical research direction researchers.
 - Creation of an Organization for recording outpatients' 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



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efforts (international consortia), the number of these research units are 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 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 the country faces and the relative lack of resources and infrastructure, institutions such as universities, the Greek Neurological Society, the Greek psychiatric Society, clinics 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, it is deemed necessary the undertaking of initiatives to address major problems and deficits, such as the following:

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- Awareness, information, education and training in the object of dementia:
 - Doctors non specific in the object of dementia.
 - General physicians and Internists who provide primary care and have the initial, the more and most frequent contacts with people with dementia and their families.
 - Doctors with cognate discipline such as Neurologists, Psychiatrists.
 - Other health professionals (nurses, social workers, physiotherapists, speech therapists and occupational therapists).
 - By raising awareness, informing and educating the general population, including the caregivers of people with dementia, the object of dementia



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should be substantially strengthened.

- More emphasis should be given on the object 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 (which could concern Health professionals and social scientists).
- There are no official specializations (fellowships) in the object of dementia for Neurologists, Psychiatrists, Geriatricians, as indicatively are in the USA (behavioral neurology, geriatric neurology, geriatric psychiatry).

2. Economic dimensions

In the Greek area, there are no sufficient data available regarding the cost of dementia, nor its division into categories, such as direct, indirect, hospitalizations, medications and comorbidity.

The unique, until recently published study, which was carried out on the economic burden of Alzheimer's dementia is the research of Kyriopoulos et al. in 2005 [52]. Researchers with the help of a group of experts under the methodology of the consensus

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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 dependence 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



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dementia goes from the stage of autonomy to the stage of dependence at home and decreases as it 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 with a Greek magazine in 2013 [53].

Simple reduction of international data in the case of Greece, leads to the conclusion that the total cost of the disease (direct and indirect) rather exceeds the € 3 billion per year and may be close to € 6 billion annually, if the reduction uses only data from developed economies, with epidemiological and demographic profile similar to that of Greece. This expense, demonstrates the potential reduction of the cost of 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 tragic lack of relevant structures. The problem will be intensified in the

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future even more, since according to documented estimates, the number of people with dementia will rise epidemically, a fact that stresses the need for direct documented, well-planned and targeted actions with purpose, on the one hand the direct improvement



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of the present condition and on the other hand the management of the increased future needs.

In the present, the structures providing health care services for dementia in Greece are the following:

Clinics of Memory and Mental Functions and Clinical Psychogeriatric Clinics

Special Clinics of Memory and Mental Functions (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 Nursing homes for Chronic Diseases in Athens, in Petra of Olympos, in Thessaloniki, in Kerkyra (Corfu) and in Tripoli.

People with dementia in Greece are mainly served by neurologists, psychiatrists, geriatrists and family doctors who are either self-employed 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 Non Profit 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 societies is to offer information and services such as, non-drug therapies for people suffering from the disease and education and support to caregivers in order to lighten the burden (Social, economic, emotional) they experience as a result of the long-term care of people with dementia. The Non Profit 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 prevention events, timely and accurate diagnosis of dementia, with purpose to promote the public's awareness and sensitization.



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Day-Care Centers

The most complete services for people with dementia and their caregivers' are rendered by the Day Care centers of the program Psychargos under the responsibility of the Non Profit Alzheimer's Associations of Greece. 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 houses (for short-term stay of several days) for individuals with dementia are the following:

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

Community services

Structures like K.A.P.I. (Open Protection Centers for the Elderly), the Day Care Centers for the Elderly (K.I.F.I.) and also the services "Help at Home" provided by many Municipalities of the country render services to people with dementia and their families' although not specialized ones.

K.A.P.I.'s are in all the Municipalities of Greece and offer:

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- Care and instructions for Medical-pharmaceutical care.
- Physical therapy – Occupational therapy.

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- Groups of self-activity of the members that enhance their activation.
- Training, lectures, cultural events.

K.I.F.I.'s are Day accommodation units for aged people who cannot be self-served perfectly and whose family environment that cares them, mainly women, works or face serious social and economic problems or health problems and is unable to respond to care.

K.I.F.I. provide free Day and intra-day hosting services including:

- nursing care
- care to satisfy 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 fully self-sufficient. The program provides counseling and psychological support, nursing care, family assistance and company. The smooth operation of the program 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 entities, from Non-Profit Associations (Church, Charitable Institutions etc.) and Profit associations (Care Units for the Elderly). However, the Greek society is family-centered and disabled and elderly people are looked after in a great percentage at home by members of their family.



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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 funds cover part of the costs for specific services related to the treatment and the kinetic and mental rehabilitation of people with dementia (physical and speech therapy) and for limited periods of time. With regard to long-term care services, the

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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 to all insured persons with dementia of all stages disability of benefits for attendants. 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% and by this percentage may the person with dementia when he is not insured in a fund to claim welfare allowance (about 600 € / two months). If he is insured in a fund, by the percentage disability achieves 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, so that the provided care is efficient and economical advantageous.

In particular:



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1. There is no sufficient awareness of the community, with the result that timely access for patients and caregivers in primary care services is not possible and thus precious time is lost from the first symptoms of the disease until the diagnosis.
2. The primary care physicians are not sufficiently trained to respond to the significant need for early identification, referral and management of people with dementia. So, the ease and equal access to timely diagnosis, care and treatment regardless of the region where they reside, is not assured.
3. Examination protocols of patients with dementia are completely absent at the Emergency Care Unit and inpatient clinics of the General Hospitals, when hospitalized for several comorbidities, very common in old age.
4. There are no Memory and Mental Function Clinics in every General Hospital in the seats of the Regional Units (Prefectural Hospital) despite Υ5β/Γ.Π./οικ 46769/2012 [6] decision of PSYCHARGOS plan, which follows the basic principle of Social Psychiatry on sectorization of services.
5. There are no required Day Care Centers for providing non-drug therapies and support of caregivers in almost all cities, 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 OTA (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.

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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 generally relief measures of the caregivers' burden, as a special leave for a caregiver of a person with dementia, discount in tickets of Public Transport, museums.

4. Legislation and rights of people with dementia

The rules of international law cited above apply in our country as well and bind 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 participation in clinical research) - must be approached in the light of the corresponding provisions particularly of ECHR (European Convention on Human Rights) and the Oviedo Convention, as EU legislation on personal data and clinical studies.

These rights are included in the Constitution, in specific articles [56].

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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), for equality (Art. 4, par. 1). Starting from these principles, we ensure the greatest possible autonomy and enforcement of fewer restrictions on the person with dementia 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 (as applicable). However, these provisions generally pertain to mentally ill and did not attract the interest of the legislator to the case of dementia.



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Dementia is one of the provisions of the General Law 2716/1999 (“Modernization of Mental Health Services”).

According to Article 1:

“1. The State is responsible for the provision of mental health services designed to prevent, diagnose, treat, 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, according to 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 and 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 diseases and provide for the creation of structures. Specific legislation, related to the disease, is present in regulatory acts (mostly ministerial decisions) and regulates individual issues, such as insurance coverage of patients and the establishment of local care centers. Finally, in “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

<ul style="list-style-type: none">• Strengths	Weaknesses
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<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.• Current Non Profit-Alzheimer’s Disease 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 functions clinics</u> that do not exist in every hospital, in <u>Day Care Centers</u> for the provision of non-drug therapies and the support of caregivers, in <u>home care services</u>, in 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 (ΠΥΦ).• Absence of examination protocols and hospitalization of people with
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	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 PHC 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.



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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 with the target:

- 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.





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

Strategic Objectives of the National Plan for dementia

Political Objectives

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

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Social Objectives

- Designation and projection of social norms and behaviors that are determinant to address risk factors associated with dementia. Examples include: dietary habits, physical activity, participation in social activities, mental exercise.
- Education of society, so that the stigma associated with dementia to be eliminated.
- 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 and care.
- Legislative recognition of dementia as a disability, institutionalization of the coverage of people with dementia and their caregivers with financial aids and financial reliefs.

Epidemiological Objectives

- Development of an integrated system for recording dementia cases in our country, in order to gather prompt information and the targeted policy-making to address dementia.



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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 standardizing the information to be 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.
- A rational national policy-making based on valid and reliable data.

Implementation Actions:

1. Preparation of a business plan for the development of the National Dementia Registry

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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. Creating awareness and informing professionals and institutions about the importance and the recording process of 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

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Budget:

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



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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 must be considered as determined by the severity of the disease and the degree of disability that causes. Also, social and economic factors must be considered, as income, marital status, etc., other criteria such as accessibility to health care and social care services, family's financial

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burden, etc. Based on the above factors a classification framework for the people with dementia will be developed which it will classify them in individual categories. Thereafter, for each category the amount of financial assistance will be determined and a program for providing financial support for 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)



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7. Classification of individuals with dementia from the Disability Certification

Centers (ΚΕΡΑ).

Implementation bodies:

- Ministry of Health
- Ministry of Labour
- 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



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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 the prevention methods of dementia. It also includes the planning and implementation of relevant preventive programs.

Objectives:

- Informing the population
- Reducing the frequency of all dementia types in Greece

Implementation Actions:

1. Strengthening of the intersectoral cooperation between the Memory and Mental Functions Clinics with the Non Profit Organizations for Alzheimer's disease 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 the methods for its testing, 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
- Non Profit Companies for Alzheimer's disease
- National Observatory for Dementia

Timetable:

- 2015: Preparation and organization of information and prevention programs

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• 2016-2020: Implementation of programs on an annual basis per region

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Budget:

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

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Action 2: Information and creating the public awareness

Description:

The action involves the creation of awareness and informing the whole society for dementia, with the purpose of prompt diagnosis and treatment of the disease and fighting the stigma by organizing a relevant national information campaign.

Objectives:

- Early diagnosis of the disease and dealing with it at an early stage 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 general population about the benefits of early diagnosis, prevention of dementia and fighting the stigma.
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

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- Ministry of Education- Universities
- Medical Scientific Societies
- National Observatory for Dementia
- Local Administration Organizations
- Non Profit Associations for Alzheimer

Timetable:

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

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Budget:

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

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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 and financial burden and burden of their physical health. 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.



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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.,

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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
- Non Governmental Organizations for Alzheimer's disease

Timetable:

- 2015: Establishment of the annual Caregiver's Day and design of information and education programs for caregivers of people with dementia.



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- 2016-2020: Creation of help lines, creation of 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 in primary care and concerns the organization of prompt diagnostic services and management of people with dementia in primary care.



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The actions that are integrated in the framework of the 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 special doctors contracted with National Primary Health Care Network (ΠΕΔΥ) (neurologists, psychiatrists) in matters relating to dementia. Moreover, emphasis is given on the dissemination of clinical guidelines for dementia, and the interconnection of primary care services to the existing Memory and Mental Function Clinics of the Day Care Alzheimer Centers already operating under the framework of Psychargos, the University Clinics of Memory and Mental Functions per Region and as well with the establishing Memory and Mental Function Clinics in General Hospitals.

Objectives:

- Ease and equal access for people with dementia and their families in 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 Mental Functions Clinics.
2. Education and training of health professionals providing primary care services in issues related with dementia (Axis 7).

3. Dissemination and implementation of clinical guidelines for dementia from the Mental Health Directorate of the Ministry of Health.



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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 to provide financial aids for people with dementia.

Implementation Bodies:

- Ministry of Health – PEDY (National Primary Care Health Network)
- Regional Health Directorates
- Centers of Excellence for dementia
- Regions
- Medical Scientific Societies
- National Observatory for Dementia
- Non Profit Associations for Alzheimer’s Disease

Timetable:

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

Budget:

No additional cost is created.



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

Description:

Action 2 relates to the coordination of the services offered in when people with dementia suffer from various co-morbidities and come for examination to ECUs or are hospitalized in the Departments of General Hospitals. The coordination is achieved by creating special examination and treatment protocols, and by the establishment of a coordinator doctor responsible for dementia at every General Hospital, who will ensure adequate clinical care for people with dementia, by observing the examination and hospitalization protocols. At hospitals which have Memory and Mental Functions Clinics, the coordinator doctor is the trained doctor of the Clinic.

Objectives:

- Global and comprehensive coverage of the needs of people with dementia for health services provided by General Hospitals.
- Meeting 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 particular Departments of General Hospitals in matters 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

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- Medical Scientific Societies
- Centers of Excellence

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- National Observatory for Dementia

Timetable:

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

Budget

No additional cost is created.



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Action 3: Clinics of Memory and Mental Functions

Description:

The action includes the establishment and operation of a Memory and Mental Functions Clinic in every General Hospital in the seats of the regional units (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 Special Memory and Mental Function Clinics should belong administratively to the Neurological or Psychiatric Departments of the Hospitals and provide:

- Diagnosis, treatment and attendance of people with dementia per region in cooperation with doctors of primary care.
- Networking, interconnecting and collaboration with health and social care structures of their region, like Health Centers and other structures of Primary Care, Non-Profit Alzheimer’s Associations, K.I.F.I., K.A.P.I., nursing homes, charities etc.
- Information of the public, bodies and health professionals concerning dementia.
- In regions with difficult access (e.g. islands, mountainous areas, remote villages), the periodic visit at Health Centers is recommended or the coverage through Telemedicine services in cooperation with the more proximal Memory and Mental Function Clinics.



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The recommended minimum staff for each Memory and Mental Functions 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.

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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).
- Coverage of the needs of people with dementia for diagnostic, attendance and treatment services.

Implementation Actions:

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



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6. Regular evaluation of the work of the Clinics of Memory and Mental Functions 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

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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 Clinics of Memory and Mental Functions (30.000 € / year / Clinic for payroll of 2 health professionals in addition to the doctor)



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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 accelerated training from the Centers of Excellence (axis 7).

Day Care Centers are being proposed to provide the following services:

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

The Interdisciplinary Group 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 Mental Function 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.

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- 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.

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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, OTA -Local Administration Organizations, Non Profit Alzheimer Companies, 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
- OTA (Local Administration Organizations)
- Non Profit Societies for Alzheimer's disease
- Private bodies
- 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, EOPYY (National Organization for Rendering Health Services), OTA), from European funds, charities and private sources.



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Action 5: Hospitality and long term stay structures for people with dementia

Description:

The action is about covering the long term stay needs of people with dementia who are unable to stay at home, even with care at home. The certification and continuous evaluation of the Care Units for the Elderly is being proposed and the strengthening of people with dementia and their caregivers by providing financial aids in order to use these units. These aids will be granted according to the criteria of Action 2 of Axis 1 and special care should be provided to people who have no insurance coverage.

Hospitality in the long stay structures serves people with dementia who exhibit behavioral disorders and require increased care. Moreover, people with dementia are hosted for a short time so that their caregivers can have rest breaks. Finally, the hospitality in the long term stay structures 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 Care Units for the Elderly to cover the accommodation and hospitality 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 Care Units for the Elderly.
- Saving resources by reducing the admission of people with dementia in public and private hospital clinics, due to unhealthy 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.



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2. Establishment of special certification criteria for the Care Units for the Elderly that accommodate people with dementia, to meet the increased and specific care needs.
3. Continuous monitoring and evaluation of the Care Units for the Elderly that host people with dementia.
4. Classification of people with dementia and establishing special financial assistance programs for them and their caregivers (Axis 1 Action 2)

Implementation bodies:

- Ministry of Health
- OTA
- Care Units for the Elderly
- 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 of the care units for elderly for their hospitality and stay.
- 2016: Evaluation and certification of existing units.
- 2015-2016: Adopt and implement a financial aids program for people with dementia.

Budget:

100.000 for the development of a certification system of the Care Units for the Elderly.

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Action 6: Structures of the final stage

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 buildings of clinics) can be a practical completion of 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 from existing palliative care structures for other diseases.
2. Establishment of care protocols and guidelines for the final stage of dementia taking into account the specialized needs of patients. Training of palliative care structures personnel to care protocols for persons with dementia.
3. Creation of palliative care structures - for people with final stage dementia in areas with increased needs.
4. Exploitation and adaptation of existing structures (e.g. old buildings clinics, hospitals with low efficiency).



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5. Establishment of increased financial aid 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
- OTA
- Regions
- Charitable institutions

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- Insurance Funds, Private insurance companies
- National Observatory for Dementia

Timetable:

- 2015: Establish palliative care protocols for end-stage patients
- 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) and be converted into hospice, so that the cost to be significantly reduced.



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ACTION 7: Decentralized Care- Care at home

Description:

The 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, medicine, nursing and social to facilitate everyday life and ultimately improving 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, with access barriers to infrastructures and services.
- Improving the quality of informal care.



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Actions:

1. Creation of home care services by those municipalities which have the ability, which 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 ("Help at Home", K.A.P.I, K.I.F.I, Friendship Clubs, Care Centers for Elderly, church organizations) with the primary health care services, combined with the certified training of health professionals from the Centers of Excellence (Axis 7 Action 2).
3. Configuration of a professional certification scheme for professionals, caregivers who without qualifications are dealing with the care of people with dementia in our country.
4. Training and certification of professionals, caregivers .

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Implementation Bodies:

- Ministry of Health should PEDY (Primary National Health Network)
- OTA
- EOPPEP (National Organization For the Certification of Qualifications and Vocational Guidance)
- Centers of Excellence (CoE)

Timetable:

- 2015-2020: Creation of care services at home.

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- 2015: Configuration of a professional certification scheme for professional caregivers.
- 2016-2020: Training and certification of professional caregivers.

Budget:

Depending on the available resources of OTA to create home care services.

€ 500.000 for the training and certification of professional caregivers.

ACTION 8: Telemedicine Services

Description:

Providing services to people with dementia and caregivers of people with dementia living in remote areas are not comparable to those available in urban centers. The development of modern telecommunications technology-telemedicine-helps to face shortages in remote and island areas not, in facilitating access to health services and reduce the cost of services.



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Objectives:

- Meeting the care needs of people with dementia and their caregivers in remote areas that do not have special services for people with dementia.
- Reducing the cost of services.

Actions:

1. Creation of an External Telemedicine clinic in remote areas having its seat at the Health Centers or the local Health unit that will interface with Memory Clinics and Mental Functions of the general hospitals.
2. Strengthening of selected home care programs with telemedicine equipment (external mobile telemedicine units) for persons with dementia who face access barriers at the External Telemedicine Clinic.
3. Accelerated education of health professionals who will staff both External Telemedicine Clinics and external mobile telemedicine units.

Implementation bodies:

- Ministry of Health
- Ministry of Education – Universities
- Ministry of Labour
- OTA

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Timetable:

- 2015-2020: Creation of 20 External telemedicine clinics spatially distributed throughout Greece.

Budget:

20,000 €/ per clinic in one-off payment

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Axis 5: Legislation – Rights of people with dementia and their caregivers'

Action 1: Changes in the valid legislation

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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:

- To be the focal point so as to guarantee the rights of people with dementia and their caregivers.
-

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 the application.

Implementation bodies:

- Ministry of Health
- Parliament

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- 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 publication 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).



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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 as the Joint Program for Neurodegenerative Diseases (JPND).

Like international and national research programs relating to basic research, clinical research, translational research, implementation research, etc. As examples of research objects –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 (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.



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- 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.

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Implementation Actions:

1. Ensuring resources from European and national sources.
2. Issue and publication of notices, which will focus on the shortcomings mentioned above.
3. Evaluation and selection of instruments to implement the programs by independent external assessors (outside of Greece) with adequate remuneration selected by existing lists of external judges, ministries, lists GGET (General Secretariat of Research & Technology), universities etc or by delegation of the crisis 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:

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- 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.

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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 clinic 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 judges with adequate remuneration selected from existing external judges, ministries lists, GGET (General Secretariat of Research & Technology), universities etc.

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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 tender scholarships for clinical and research expertise in the field of dementia.

Clinical scholarships (fellowships) addressed to doctors, neurologists, psychiatrists, geriatrics, physicians, general practitioners and other specialties. Research Fellowships addressed to doctors, 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.



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Objectives:

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

Implementation Actions:

1. Collaboration of the implementation organizations with accredited education programs in dementia, to organize and ensure the induction and training of fellows, and to define 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

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- 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.



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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 resident doctors (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

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are not necessarily the appropriate integration of vertical nature, but may take the network structure (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 subject of dementia.
- Significant clinical research activity in the subject of dementia.
- Significant research activity and infrastructures in terms of basic research in the subject of dementia (e.g. biobanks of biological materials, laboratory physical infrastructure, etc.). The Centers of Excellence may are 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 subject of dementia.
- Satisfactory for the implementation of the above administrative and technocratic support.
- Entirely world-class status and recognition in the field of dementia.

Objectives:

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

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- Training of a competent number of experts in the subject area 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.

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2. Call to tender for the development of Centres of Excellence.

3. Evaluation and selection of the bodies who will implement the specific programs by independent external judges (except of Greece) with adequate remuneration selected from existing lists of external judges, ministries, GGET (General Secretariat of Research & Technology), 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 presentation of new candidates for the Centres 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, by a maximum of three Centres of Excellence.

Budget:

150,000 € / Centre of Excellence / year.

Action 3: Specialization on dementia

Description:

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Action 3 concerns the designing of the official medical 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 capable core of 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.



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Action 4: Enhancing undergraduate education in dementia

Description:

The action involves the strengthening and expansion of undergraduate education in disciplines about dementia and in particular the increase of the respective educational time at the Medical School, Nursing, Biological, Pharmaceutical Departments, at the Psychology Departments and others. The above undergraduate courses can be core or elective courses, job 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 the subject of 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



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Budget:

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

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Action 5: Training in dementia during the Medical Specialty

Description:

The action aims to improve the medical clinic education (knowledge and skill) of the trainee specialists in the specialties of Neurology, Psychiatry, Internal Medicine and General Medicine. It includes the mandatory contact with 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 clinical 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 education 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:

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• 2015-2017: Identification of the clinics of Neurology - Psychiatry with the parallel option (a) granting the specialty and (b) clinics of Mental Functions and integration of this mandatory rotation in the education curricula of the specializations mentioned hereinabove.

Budget:

No additional cost is created.

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Action 6: Training Specialist doctors 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 qualified 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 capable core familiar with dementia health professionals who will staff the Clinics of Memory and Mental Functions and other relevant structures.

Implementation Actions:

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

Implementation bodies:

- Centres of Excellence for dementia

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- Ministry of Health
- Ministry of Education

Timetable:

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

Budget:

No additional cost is created.

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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

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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.

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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€

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	TOTAL:	5.000.000€
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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€

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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

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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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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



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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.

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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".



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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:

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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



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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.

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6. The avoidance of general provisions with reference to the enabling provisions, which
would weaken the regulatory effectiveness of the law.

(Words: 18.900)



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

The translator: Mitropoulou Eleni

29th January 2017

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