

Dementia in Europe Yearbook 2006



Including the Alzheimer Europe Annual Report 2005

This publication has been produced in the framework of the Alzheimer Europe project "European Collaboration on Dementia - EuroCoDe" which received financial support from the European Commission under its programme for community action in the field of public health (2003-2008)

Neither the European Commission nor any person acting on its behalf is responsible for any use that might be made of the following information.

Alzheimer Europe gratefully acknowledges the co-financing it has received from Fondation Médéric Alzheimer for the coordination of the EuroCoDe project and for the work package on social support systems.

The information on the organisation of home care was obtained in the framework of the Alzheimer Europe business plan (2001-2006) and the organisation gratefully acknowledges the support it received from Janssen-Cilag, Lundbeck and Pfizer for the implementation of its business plan programmes.



Table of contents

1 Forewords	6
1.1 <i>Markos Kyprianou, European Union Commissioner for Health and Consumer Protection</i>	7
1.2 <i>Liisa Hyssälä, Minister of Health and Social Services (Finnish Presidency of the European Union)</i>	10
1.3 <i>Karl-Heinz Florenz, Chairman of the Committee for the Environment, Public Health and Food Safety of the European Parliament</i>	12
2 Introduction	14
3 Dementia in Europe – “Comparative Findings”	18
3.1 <i>The prevalence of dementia in Europe</i>	19
3.2 <i>The availability of anti-dementia drugs in Europe</i>	24
3.3 <i>Home care in Europe</i>	34
3.4 <i>European EuroCoDe network organisations</i>	42
4 Dementia in Europe – “National Results”	48
4.1 <i>Austria</i>	49
4.2 <i>Belgium</i>	55
4.3 <i>Bulgaria</i>	62
4.4 <i>Cyprus</i>	67
4.5 <i>Czech Republic</i>	69
4.6 <i>Denmark</i>	75
4.7 <i>Estonia</i>	83
4.8 <i>Finland</i>	89
4.9 <i>France</i>	97
4.10 <i>Germany</i>	104
4.11 <i>Greece</i>	112
4.12 <i>Hungary</i>	117
4.13 <i>Iceland</i>	122
4.14 <i>Ireland</i>	128
4.15 <i>Italy</i>	133
4.16 <i>Latvia</i>	139
4.17 <i>Lithuania</i>	142
4.18 <i>Luxembourg</i>	146
4.19 <i>Malta</i>	152
4.20 <i>Netherlands</i>	158
4.21 <i>Norway</i>	165
4.22 <i>Poland</i>	173
4.23 <i>Portugal</i>	179
4.24 <i>Romania</i>	185
4.25 <i>Slovak Republic</i>	191
4.26 <i>Slovenia</i>	194
4.27 <i>Spain</i>	197
4.28 <i>Sweden</i>	203
4.29 <i>Switzerland</i>	211
4.30 <i>Turkey</i>	218
4.31 <i>United Kingdom</i>	221



Note to the readers of this Yearbook

Help us to improve this publication

The country descriptions in this Yearbook have been obtained through an extensive literature search, as well as from information provided by representatives of our national member organisations and other individual experts. The reports on the different European countries represent our interpretation of the information we were able to obtain and, to the best of our knowledge, are accurate descriptions of the prevalence, reimbursement systems and home care organisation in 31 European countries.

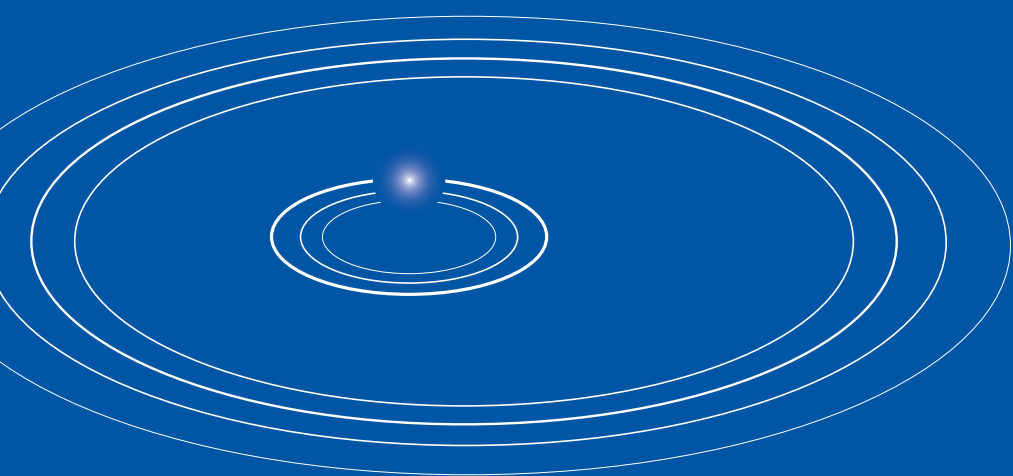
Nevertheless, we are aware that some of the information obtained may have been out-of-date or misinterpreted by us. Also, on some subjects, we were unable to obtain sufficient information in some of the 31 countries to include a detailed report in this first edition of our Yearbook.

Therefore, we invite readers to help us in improving the information contained in this publication. Please feel free to contact us with additional information for those countries for which our reports are incomplete, as well as with any corrections you feel are necessary.

The information contained in this Yearbook will be made available on a website which Alzheimer Europe will create for the dissemination of these results (www.dementia-in-europe.eu) and our aim is to update the online national reports on a regular basis.

Many thanks in advance for your help.

Alzheimer Europe
145, route de Thionville
L-2611 Luxembourg
Tel.: +352-29 79 70
Fax: +352-29 79 72
info@alzheimer-europe.org
www.alzheimer-europe.org
www.dementia-in-europe.eu



Forewords

1.1 *Markos Kyprianou*

European Union Commissioner for Health and Consumer Protection



I am very pleased to welcome this publication by Alzheimer Europe as the European Commissioner responsible for public health.

Both in the former EU Health Monitoring Programme as well as in the current EU Public Health Programme, Alzheimer's disease and other dementias, as well as all neurodegenerative diseases, are a major focus of attention in the European Union public health information and prevention policies. The most important priority for the Commission is to get the necessary recognition for the magnitude of the problem and for the tremendous costs for society. However, the starting point for monitoring neurodegenerative diseases such as Alzheimer's disease at EU level is unsatisfactory because this has not really been taken as a main priority by competent authorities at national level.

The European Commission knows very well that the main network monitoring dementia cases in the EU is Alzheimer Europe. I am very happy that the task of Alzheimer Europe as a non-profit organisation aiming to improve the care and treatment of Alzheimer patients is now extensively supported by the EU Public Health Programme. I am also convinced that the EuroCoDe (European Collaboration on Dementia) Project, with Alzheimer Europe as a Project Leader, will be a major public health success.

Data on the prevalence of Alzheimer's disease and other dementias are nowadays available across the EU thanks to the work realised by Alzheimer Europe. This 'Dementia Yearbook' will provide a comprehensive and complete overview about the present situation of Alzheimer's disease and other dementias in the EU.

Of course, the European Commission has not been inactive facing the dementia problems during the last 10 years. In 1997 and 1998, the European Commission approved a budgetary line for the implementation of measures to help persons suffering from dementia and Alzheimer's disease and for those assisting them on a non professional basis. Several projects were launched in areas such as: Diagnosis and therapy, maintenance such as drug treatment to minimise common co-morbidities associated with dementia (e.g., depression), control of distressing symptoms, information and support to caregivers, ongoing support and counselling, end of life support and counselling in relation to 'palliative care, intermittent assistance with activities of daily living. The results of these projects are publicly available on DG SANCO web site:

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

There was also a project in the framework of the former EU Action Plan on Rare diseases on 'Rare forms of dementia' coordinated by Alzheimer Europe. The objective of the project was to build up a database of information about rare forms of dementia and to make this available to the general public by means of the existing Internet systems of Alzheimer Europe. A very useful new classification system for these forms of dementia has been created. The results of this project are also publicly available on DG SANCO web site:

http://ec.europa.eu/health/ph_projects/2002/rare_diseases/raredis_2002_03_en.htm

In 2005, a new network supported by the EU Public Health Programme was created by Alzheimer Europe to implement the important initiative EuroCoDe (European Collaboration on Dementia), which was selected for funding under the Public Health Programme in 2005. The various guidelines and indicators will be developed by specific working groups comprising representatives of the majority of Member States. The European Commission has high expectations for this project.

The EU Public Health Programme has also priorities in dementia related to risk factors, risk reduction strategies, cost of illness, social support, to develop a healthy brain lifestyle, eHealth activities and supporting the exchange of information and experiences on good practice. It is always necessary to take initiatives able to reduce the differences in quality standards through increased cooperation and by exchanging knowledge and experience about the content and organisation of care.

Although dementia does not only affect older people, the likelihood of developing dementia nevertheless increases with age. Thanks to the work of the European Community Concerted Action on the Epidemiology and Prevention of Dementia group EURODEM, it is possible to estimate how many people in a given country are likely to have dementia, provided that accurate population statistics are available.

From the early EU Framework Programmes, brain research, and in particular research on Alzheimer's disease and other neurodegenerative diseases, have received continuous support. In the 5th Framework Programme (1998–2002), about 20 M€ was invested in research on Alzheimer's disease, mainly through the key action on "The ageing population and their disabilities". In the 6th Framework Programme (2002-2006), up to 250 M€ has been dedicated to brain and neurosciences research. Out of this amount, about € 40 million has been invested to support translational research on Alzheimer's disease, through 1 "Network of Excellence", 3 "Integrated Projects" and 6 "Specific Targeted Research Projects", which are currently underway. Finally, it should also be noted that an ERA-NET specifically dedicated to national public or other bodies responsible for financing or managing research activities on neurodegenerative diseases (including Alzheimer's disease) is funded in order to fight against research fragmentation and to support cooperation and coordination in this field.

Perspectives exist for continued support for research on Alzheimer's disease in the 7th Framework programme. Indeed, in the European Commission's proposal for this programme (2007-2013), collaborative research will include an activity on "Research on the brain and related diseases, human development and ageing", with a particular emphasis on translational research. In addition, research on public health, including mental health, is included as a new area for health research.

I hope that this yearbook will help to reinforce suggestions for common practices in the different areas and stages of the disease. I wish every success to Alzheimer Europe in this important work.

Markos Kyprianou

1.2 Liisa Hyssälä

Minister of Health and Social Services (Finnish Presidency of the European Union)



Care of elderly and sick people is on the agenda of social dialogue. Dementia Yearbook published by Alzheimer Europe is a significant and necessary addition to promoting international dialogue and offers a forum for exchanging experiences and evidence-based information on the rights and care of people with dementia.

It is extremely important to seek answers to ethically challenging questions regarding a good care of persons suffering from dementia. How to meet a person who has no words or ability to decide on his or her affairs, no ego, and who sometimes even needs to be protected against him/herself? Services that are provided at an early stage guarantee people with dementia an active and safe everyday life. Family members and significant others need all possible support to cope. NGOs play an important role in this field.

Prevalence of memory impairments is strongly linked with the changed age structure of populations. With the growing numbers of older people, also the number of people with dementia is increasing in Western countries and also in Japan, among others. In Finland the number of dementia patients is expected to almost double by 2030. It is noteworthy that memory impairments of different levels of severity have even been recorded for working-age Finns (ca 0.25 %).

Dementia is one of the most common factors jeopardizing the continuance of home care. Living in familiar settings is most often the best option, but it requires good multiprofessional community care. Skills and knowledge needed in dementia care, which today require specialisation, are scattered. Therefore we need new models and ways for the treatment of dementia, both in regard to ageing employees and elderly population. I would like to mention as one example the dementia training project of Pielinen-Karelia region in Finland, financed by the Finnish Ministry of Social Affairs and Health and the European Regional Development Fund, which aims at, e.g., modelling a regional dementia development centre. Memory units at health centres also focus comprehensively on patients' affairs.

Prevention, treatment and pharmacotherapy of dementia as well as rehabilitation of patients are developing all the time. It is now possible to diagnose diseases more precisely. We know that unhealthy lifestyles, increased alcohol use, high cholesterol levels, untreated hypertension as well as obesity and lack of exercise are risk factors for the disease. In the future, an early identification, diagnosing and efficient treatments can reduce the need for services or delay it. In the care of dementing diseases

rehabilitative measures are needed all through the disease process and rehabilitation needs change with the progress of the disease.

Let us participate together in improving the life quality of people with dementia. For that we need appreciation, time, professional skills, and close relationships and humour. It is important to meet a person suffering from dementia as an individual, ask his or her opinion and offer different options. We need medical know-how, inclusion in community, and also knowledge of people's life history and cultural background as well as of matters that the person is interested in. It is a proof of professional skill to see the individual in the person with dementia and to find with him or her possibilities for producing wellbeing.

Dr. Liisa Hyssälä

1.3 *Karl-Heinz Florenz*

Chairman of the Committee for the Environment, Public Health and Food Safety of the European Parliament



Alzheimer as a part of dementia is a disease which is growing to be one of the big themes in the western hemisphere. Actually, it is one of the major causes of death in the western countries.

This illness is so malicious because its consequences hit the patients in the most fundamental aspects of their lives - in the most elementary behaviour like talking, thinking, remembering. Alzheimer steals memories - and with these, in fact a whole life. Another cause for the depressing character of this illness is the fact that it does not influence only the patient, but all relatives and friends who have known the ill person before Alzheimer - who are then accompanying the sick persons on their difficult way to living with the illness.

As Chairman of the Committee for environment, public health and food safety in the European Parliament, the vehement fight against Alzheimer is one of my main requests. We have figured out its potential impacts and are working on practicable solutions - solutions for the benefit of the population. It makes me confident to see that there have been big advances in our fight against Alzheimer and dementia in the last years. However, these little steps may not lead astray from the fact that there is still a long way to go to help the Alzheimer patients.

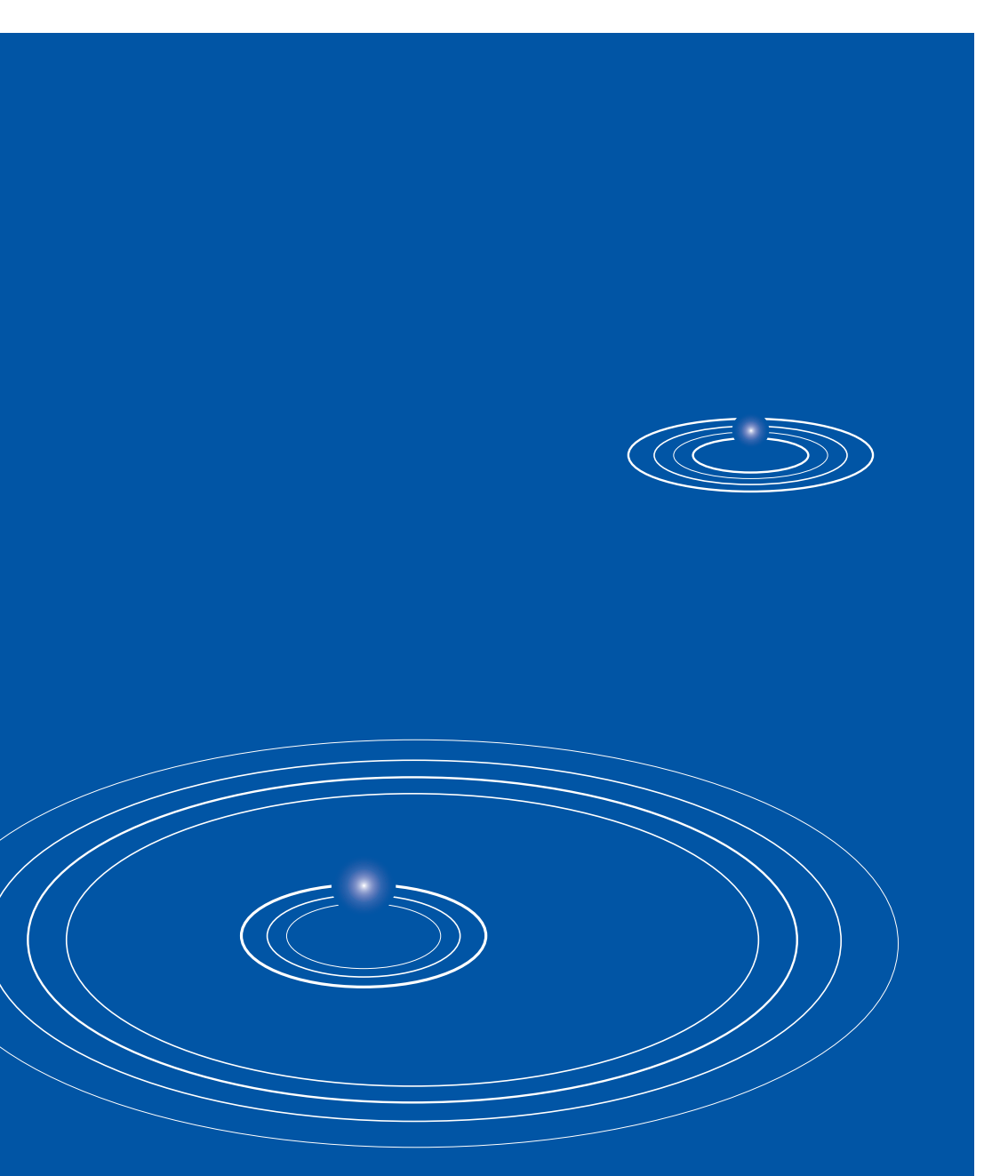
However, not only the sick, but also their relatives and friends have to be accompanied by us. It is the politicians` homework to open the population`s mind for the big burden that living with Alzheimer constitutes. People affected with this illness deserve our respect and gratitude.

This book will be a very important tessera - it will do its share in the battle. I am really looking forward to the discussion concerning the results of the comprised studies and the new impulses that the book will give.

The fight against Alzheimer will be a long one. However, I am convinced that we will win it - if we stand close to both the ill people as well as to their relatives and friends taking care for them - in good and even in bad times.

Karl-Heinz Florenz





Introduction



It gives me great pleasure to present this new publication of Alzheimer Europe. Our “Dementia in Europe Yearbook” has been produced in the framework of our “European Collaboration on Dementia - EuroCoDe” project which receives financial support from the European Commission under its public health programme.

The aim of this project is twofold.

- On the one hand, Alzheimer Europe would like to create a broader European network of all the players active in the field of dementia and to develop an ongoing dialogue between these actors to identify ways of developing synergies and a closer collaboration on a European level.
- On the other hand, the different organisations involved in the project are tasked with carrying out an extensive analysis of the already existing literature in this field in order to develop consensual indicators or guidelines which could provide policy makers on a European and national level with much needed advice on how to improve the care and treatment of people with Alzheimer’s disease throughout the European Union.

The project will look at a variety of different issues such as the prevalence of Alzheimer’s disease and other forms of dementia and existing guidelines on diagnosis, medical treatment and psycho-social interventions in the field of Alzheimer’s disease. Similarly, the project will aim to develop an overview of our current understanding of possible risk reduction or prevention strategies. Finally, the project will highlight the socio-economic cost of dementia in Europe and provide an overview of the different approaches used in European countries to financially support carers of people with Alzheimer’s disease.

This Yearbook, which is the first edition in a series of three, forms an integral part of our project and will present its main findings. This first provides information in three main fields:

- EuroCoDe will result in the development of new consensual prevalence rates and this publication would not be complete without an attempt at describing the real impact of Alzheimer’s disease and other forms of dementia on European citizens. Estimations of the numbers of people affected by the disease are of course an essential tool for policy makers interested in providing the right services and support for people with Alzheimer’s disease and their carers. This Yearbook provides a range of estimates for **the number of people with dementia in Europe**, but also for each of the countries covered.
- EuroCoDe also aims to identify the whole range of support provided by governments to people with dementia and their carers. As a first step towards this aim, Alzheimer Europe concentrated on the question of **the availability of Alzheimer treatments** through national health systems for this first edition of our Yearbook.

The findings of our survey show that there are substantial variations across Europe as to the medicines marketed and/or reimbursed, the dates when these medicines were made available, as well as the rules governing the different national reimbursement systems.

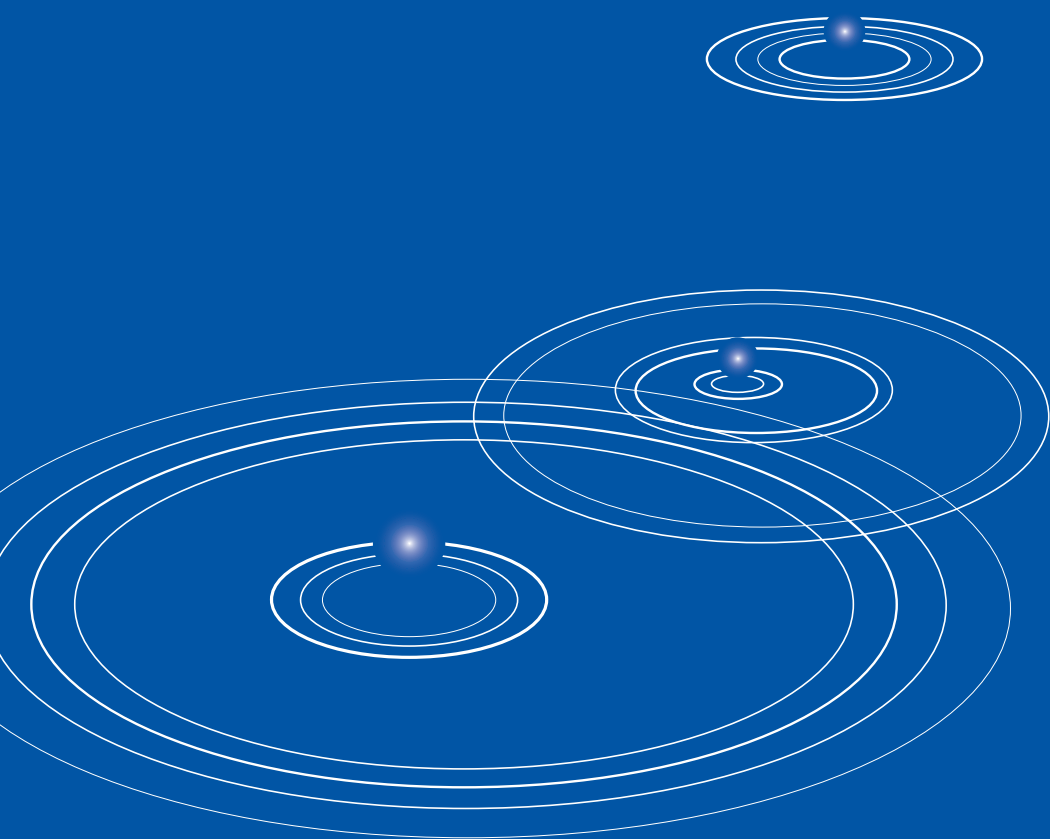
- As a third area, Alzheimer Europe focused on **the provision of home care services** in different European countries. Identified as a main priority by Alzheimer associations in Alzheimer Europe's business plan, the question of home care was examined by representatives of national Alzheimer associations in a two year project. Again, the descriptions of existing systems show great variations as to the kinds of services provided and the possibility of people with dementia and their carers to access them.

Finally, since the project brings together a broad network of European organisations such as Alzheimer Europe (AE), the European Alzheimer's Disease Consortium (EADC), the Interdem network, the European Association of Geriatric Psychiatry (EAGP), the European Federation of Neurological Societies (EFNS), the European Union Geriatric Medicine Society (EUGMS) and the International Association of Gerontology – European region (IAG-ER), we have provided a directory with the contact details of these European organisations, as well as their national members in the different countries covered by our project.

We hope that this Yearbook will contribute to a greater awareness of the public health impact of Alzheimer's disease and will encourage European and national policy makers to give this disease the priority it so justly deserves and to develop clear action plans with the aim of improving the care and treatment of the 5.8 million people with Alzheimer's disease or another form of dementia in the European Union.

Jean Georges
Executive Director
Alzheimer Europe





Dementia in Europe
“Comparative findings”

3.1 The prevalence of dementia in Europe

3.1.1 Introduction

The term “dementia” refers to a range of symptoms commonly found in people with brain diseases which result in the damage and loss of brain cells. Losing brain cells is a natural process but with dementia this occurs at a much faster rate and involves a gradual and slow deterioration of a person’s ability to function, affecting memory, attention, concentration, language and thinking. There are numerous forms of dementia. The most common form is Alzheimer’s disease, sometimes referred to as dementia of the Alzheimer’s type (DAT). Other common forms include dementia with Lewy bodies, vascular or multi-infarct dementia and Pick’s disease, to name but a few. It is also possible to have a combination of different kinds of dementia.

The likelihood of developing dementia increases with age even though it does not only affect older people and old age alone does not cause dementia.

The number of people with dementia in a given population is known as the prevalence of dementia. This can be calculated by applying prevalence rates to population statistics for specific age groups. A number of studies have been carried out in order to determine prevalence rates, generally for 5 year age groups and sometimes for men and women separately. The rates do not usually differentiate between different forms of dementia or different stages of the disease. This is a drawback to existing studies as such information would be of great importance to policy makers responsible for organising the provision of services.

In the framework of the EuroCoDe project, the project partners of Alzheimer Europe are currently carrying out a meta-analysis of existing prevalence studies in the whole of Europe, including the new Member States, in order to devise new consensual prevalence rates for dementia. A database will also be compiled of all European epidemiological studies in this field to-date. They will be classified by research methodology, disease type, age range, date and geographical location etc. This work, which will be carried out in collaboration with a group of European experts, is expected to be finished by the end of 2008.

3.1.2 Examples of major prevalence studies

Meanwhile, in order to provide information on the number of people with dementia in Europe, we have used prevalence rates from two existing studies.

The first is from the European Community Concerted Action on the Epidemiology and Prevention of Dementia group (EURODEM for short).¹ In the course of their work, members of the above-mentioned group pooled data on the prevalence of moderate to severe dementia in several European countries and came up with a

¹ For more details about this study, please refer to the article: Hofman, A. et al. (1991), The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, *International Journal of Epidemiology*, Volume 20, No.3, pages 736-748.

set of prevalence rates for men and women in 9 different age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99). The study included people with dementia who were living at home as well as those in institutions, nursing homes and residential care.

Table 1: EURODEM prevalence rates

Age group	Male	Female
30-59	0.16%	0.09%
60-64	1.58%	0.47%
65-69	2.17%	1.10%
70-74	4.61%	3.86%
75-79	5.04%	6.67%
80-84	12.12%	13.50%
85-89	18.45%	22.76%
90-94	32.1%	32.25%
95-99	31.58%	36.00%

A second, more recent study was carried out by Ferri et al. (2005)² on behalf of Alzheimer’s Disease International (ADI). For this study, 12 international experts conducted a systematic review of published studies on dementia and agreed on prevalence estimates for every World Health Organisation (WHO) world region, for men and women combined, in five year age groups from 60 to 84 years and for people over 85. A DELPHI consensus method was used. This is a technique which makes it possible to derive quantitative estimates through the qualitative assessment of evidence. Where information is scarce, experts can make inferences using data from comparable contexts and express opinions free from peer-group pressure. For our calculations, we used the prevalence rates for Western Europe (Region A) and Eastern Europe (Regions B and C)³.

Table 2: Ferri et al. prevalence rates

Age group	Region A	Region B/C
60-64	0.9%	0.9%
65-69	1.5%	1.3%
70-74	3.6%	3.2%
75-79	6%	5.8%
80-84	12.2%	12.2/11.8%
85+	24.8%	24.7/24.5%

² For more details about this study, please refer to the article: Ferri, C.L., Prince, M. et al. (2005), Global prevalence of dementia: a Delphi consensus study, *The Lancet*, Vol. 366, December 17/24/31, 2005

³ The EURO B category included countries with a low adult mortality rate and the EURO C category, those with a high adult mortality rate.

3.1.3 The population of people with dementia in Europe

The following table shows the number of people with dementia living in Europe using the EURODEM and Ferri et al. prevalence rates on the basis of population statistics obtained from Eurostat (the official statistics office of the European Community)⁴.

Calculations based on the two different sources of prevalence rates provide different estimates of the number of people with dementia in Europe. This is not only because the prevalence rates differ slightly for each age group but also because Ferri et al. did not include prevalence rates for the 30-59 age group, whereas EURODEM did.

Also, as mentioned above, Ferri et al. developed their prevalence rates through a DELPHI approach i.e. based on a consensus statement by experts in the field of dementia and not directly from epidemiological studies.

Table 3: The number of people with dementia in Europe

Country	Age group ⁵	Number of people		Number of people	
		with dementia (EURODEM)	As % of total population	with dementia (Ferri et al.)	As % of total population
Austria	30-94	104,428	1.27	94,441	1.15
Belgium	30-99	140,639	1.35	127,174	1.22
Cyprus	30-99	6,725	0.9	6,054	0.81
Czech Republic	30-99	105,553	1.03	93,973	0.92
Denmark	30-99	68,430	1.26	62,318	1.15
Estonia (2004)	30-99	15,065	1.12	12,955	0.96
Finland	30-99	65,362	1.25	59,360	1.13
France	30-99	847,808	1.36	760,715	1.22
Germany	30-94	1,118,429	1.36	1,010,245	1.22
Greece	30-99	135,566	1.22	123,700	1.12
Hungary	30-89	100,567	1	88,070	0.87
Ireland	30-94	35,381	0.86	31,940	0.78
Italy	30-99	905,713	1.55	820,462	1.4
Latvia	30-99	25,969	1.13	22,509	0.98
Lithuania	30-99	35,298	1.03	30,169	0.88
Luxembourg	30-94	4,857	1.07	4,370	0.96
Malta	30-89	3,427	0.85	3,148	0.78
Netherlands	30-99	183,485	1.13	165,585	1.02

⁴ Unless otherwise indicated, the latest Eurostat figures used are from 2005.

⁵ For an accurate estimate of the numbers of people with dementia in a given country, detailed population statistics with breakdowns in 5 year age groups are necessary. For countries, for which the statistics do not provide this information up to the 95-99 age group, this will result in significant underestimations of the numbers of people with dementia. This is the case in this table for Austria, Germany, Hungary, Ireland, Luxembourg, Malta, Portugal, Switzerland, Turkey and the United Kingdom.

Country	Age group	Number of people		Number of people	
		with dementia (EURODEM)	As % of total population	with dementia (Ferri et al.)	As % of total population
Poland	30-99	350,511	0.92	300,447	0.79
Portugal	30-94	129,916	1.23	119,308	1.13
Slovenia	30-99	21,788	1.09	19,302	0.97
Slovakia	30-99	44,813	0.83	38,232	0.71
Spain	30-99	583,208	1.36	533,388	1.24
Sweden	30-99	138,641	1.54	128,220	1.42
UK (2004)	30-89	660,573	1.11	621,717	1.04
EU25 TOTAL		5,832,152	1.27	5,277,802	1.14
Bulgaria	30-99	87,797	1.13	76,556	0.99
Iceland	30-99	2,845	0.97	2,584	0.88
Norway	30-99	61,077	1.33	56,227	1.22
Romania	30-99	200,893	0.93	172,130	0.79
Switzerland	30-94	97,068	1.31	88,900	1.2
Turkey	30-74	129,715	0.18	78,546	0.11
other countries					
TOTAL		579,385		474,943	
GRAND TOTAL		6,411,547		5,752,745	

From the above table, it can be calculated that the estimated number of people with dementia living in the European Union is between 5.3 and 5.8 million people. This means that between 1.14% and 1.27% of citizens in the European Union are living with a form of dementia.

With the ageing of European societies, these numbers have increased substantially over the past 45 years, both in absolute figures, but equally as a percentage of the overall population. This is likely to increase dramatically in the next 35 years. According to estimations by Ferri et al. (2005), the number of people with dementia over the age of 60 in the EURO A region will increase from 4.9 million in 2001 to 9.9 million in 2040. The increase will be from 1 to 2.8 million and from 1.8 to 3.2 million for the EURO B and C regions respectively.

3.1.4 A word of caution

Estimations of the prevalence of dementia in Europe, as well as in separate countries, are extremely useful but should also be treated with some caution for the following reasons.

They are based on the availability of population statistics which may differ from one country to the next and even from one organisation providing statistics to the next. In some countries, statistics are available for every age group. In others, statistics for some age groups (particularly the oldest) are missing for some or all of the years used in the calculations.

Although there are fewer people in the older age groups, the percentage having dementia is higher. Consequently, this can distort the results, giving the impression that there are fewer people with dementia than there really are. Also, if statistics for a particular age group are available for some years and not for others (within the same country), this could give the false impression of a sudden increase in the number of people with dementia.

Another problem is that if prevalence rates were calculated on the basis of analyses of diagnosed cases, a large number of people with dementia would be excluded from the figures. Furthermore, this would differ from one country to the next depending on the rate of diagnosis in each country. Many people in the early stages of dementia have not yet been diagnosed and some people with dementia will unfortunately never receive a diagnosis.

3.1.5 National reports and charts

More detailed calculations of the number of people with dementia in each country, based on the two sets of prevalence rates from EURODEM and Ferri et al. and the population statistics from EUROSTAT, can be found in the chapters containing information on individual countries.

Calculations can also be made using other prevalence rates and/or population statistics from other sources such as national governments. For this reason and also due to possible limitations linked to making estimates, our calculations are only intended to provide a rough estimate of the number of people with dementia in Europe. The actual number of people with dementia in Europe is likely to be somewhat higher.

3.2 *The availability of anti-dementia drugs in Europe*

3.2.1 Existing treatments for Alzheimer's disease in Europe

No drug treatments can provide a cure for Alzheimer's disease or the other common forms of dementia. However, drug treatments have been developed that can temporarily slow down the progression of symptoms in some people with Alzheimer's disease. Donepezil, rivastigmine and galantamine all work in a similar way and are known as acetylcholinesterase inhibitors. Memantine⁶ works in a different way to the other three.⁷

3.2.1.1 Acetylcholinesterase inhibitors

Research has shown that the amount of a chemical called acetylcholine is diminishing in the brains of people with Alzheimer's disease. Acetylcholine is one of the many chemicals that nerve cells use to communicate and is a neurotransmitter that plays a critical role in memory and learning processes.

Donepezil, rivastigmine and galantamine have a common mode of action as all three drugs prevent an enzyme known as acetylcholinesterase from breaking down acetylcholine in the brain. However, rivastigmine inhibits both acetylcholinesterase and butyrylcholinesterase, the two enzymes that break down acetylcholine in the brain. Galantamine also appears to act on the nicotinic neuronal receptors in the brain, making them release more acetylcholine.

Increased concentrations of acetylcholine lead to improved communication between nerve cells involved in memory and learning, which may in turn temporarily improve or stabilise some of the key symptoms of Alzheimer's disease.⁸

It is possible that one of these drugs might suit a particular individual better than another. The specialist may be able to advise whether there is any advantage associated with a particular drug.

At present acetylcholinesterase inhibitors are only used in people with mild to moderate Alzheimer's disease. They are not effective for everyone and may only temporarily improve memory or delay memory loss. Research is being undertaken to find out whether any of these drugs may be effective in the later stages of Alzheimer's disease.

In February 2006, following a positive opinion from the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency, the European Commission granted rivastigmine EU Marketing Authorization for the symptomatic treatment of mild to moderately severe dementia associated with idiopathic Parkinson's disease (PDD).

⁶ Donepezil is marketed in Europe under the name Aricept, rivastigmine as Exelon, galantamine as Reminyl and memantine as Ebixa or Axura.

⁷ Alzheimer's Society (UK), Information sheet on Drug treatments for Alzheimer's disease - Aricept, Exelon, Reminyl and Ebixa (August 2003)

⁸ Alzheimer's Society (UK), op. cit.

3.2.1.2 Memantine

The action of memantine is different to that of the acetylcholinesterase inhibitors. Memantine blocks another neurotransmitter in the brain known as glutamate. Glutamate is released in excessive amounts when brain cells are damaged by Alzheimer’s disease, causing the brain cells to be damaged further. Memantine is thought to protect brain cells by blocking this release of excess glutamate.

Memantine can temporarily slow down the progression of symptoms in people in the middle and later stages of the disease. This is the first time a drug has been available for this group of people. There is also a suggestion that memantine may slow down the disease process itself.⁹

At first memantine was licensed for the treatment of moderately-severe to severe Alzheimer’s disease, but following a positive opinion from the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency in October 2005, the European Commission granted memantine an extension of the indication to the treatment of patients with moderate to severe Alzheimer’s disease.

3.2.2 Inequalities in access to Alzheimer treatments in Europe

In its Strategic Plan (2006-2010), Alzheimer Europe has provided a clear mission statement for its work. Its core objective is defined as ‘changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services’.

Access by European citizens to existing anti-dementia drugs is of course a key concern of Alzheimer associations throughout Europe and in 2005 and 2006, Alzheimer Europe coordinated a response of its national organisations to the appraisal document of the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom on the treatments available for Alzheimer’s disease. In its response, the organisations expressed their grave concern about the proposal to limit access of UK citizens to treatments which are available to people with Alzheimer’s disease in other European countries.

As a follow-up to this response and as part of its European Commission financed project “European Collaboration on Dementia (EuroCoDe)”, Alzheimer Europe carried out an extensive survey of its members to highlight any inequalities within the European Union with regard to the access of people with Alzheimer’s disease to existing treatments. In its survey, Alzheimer Europe concentrated on finding out which of the available treatments were reimbursed under national health systems in different European countries, but also aimed at quantifying the delays experienced by different countries in granting such reimbursement, as well as any other access restrictions imposed by national health systems for the reimbursement of these medicines.

⁹ Alzheimer’s Society (UK), op. cit.

3.2.3 The reimbursement of Alzheimer treatments in Europe

Reimbursement systems in Europe vary quite considerably, but each European country has a system in place that guarantees that essential medicines are made available to patients at an affordable price which is at least partly underwritten by the national health systems.

The following table shows whether the four drugs available for the treatment of Alzheimer's disease have been authorised (A) and whether they are part of the reimbursement system (R) of the respective countries. However, the table does not give any indications as to the level of reimbursement provided or the access restrictions imposed by the reimbursement systems.

Country	Donepezil		Rivastigmine		Galantamine		Memantine	
	A	R	A	R	A	R	A	R
Austria	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bulgaria	Yes	No	Yes	No	Yes	No	No	No
Cyprus	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Czech Republic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Finland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
France	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Germany	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Greece	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hungary	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Iceland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ireland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Italy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Latvia	Yes	No	Yes	No	Yes	No	Yes	No
Lithuania	Yes	Yes	No	No	Yes	No	Yes	Yes
Luxembourg	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Malta	Yes	No	Yes	No	Yes	No	Yes	No
Netherlands	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Poland	Yes	Yes ¹⁰	Yes	Yes	Yes	No	Yes	No
Portugal	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Romania	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Slovak Republic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

¹⁰ Reimbursement of donepezil is limited to the generic versions of this product.

Country	Donepezil		Rivastigmine		Galantamine		Memantine	
	A	R	A	R	A	R	A	R
Spain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sweden	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Switzerland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Turkey	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No ¹¹

As can be seen from the above table, with the exception of Bulgaria, Latvia and Malta, one or more acetylcholinesterase inhibitors are reimbursed in all the European countries, covered by the Alzheimer Europe survey, even if there may be slight variations as to which of the medicines are available and reimbursed. Memantine, as the more recent drug approved for the treatment of Alzheimer’s disease, has not yet been made subject to a reimbursement decision in Bulgaria, Italy, Latvia, Malta, Norway and Poland. Similarly, most health trusts in the United Kingdom do not cover memantine under the National Health System.

3.2.4 Access and reimbursement restrictions

The question of whether treatments for Alzheimer’s disease are reimbursed under the national health systems provides important information on the existing inequalities in access to treatment in Europe. Nevertheless, it does not provide a complete picture since various conditions imposed by the health systems may impose further restrictions on the access of people with Alzheimer’s disease to existing treatments.

The proposed changes by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom would for example limit the reimbursement of anti-dementia drugs to people in the moderate stages of the disease and exclude people with mild Alzheimer’s disease.

Similarly, some countries have reserved reimbursement to treatment decisions made by specialist doctors or in specialist centres. Some have gone further by also requiring a continuing treatment decision to be made by a specialist doctor. Also, reimbursement may not be made available to people with Alzheimer’s disease living alone or living in nursing homes. Other systems require specific examinations to be carried out prior to a reimbursement decision being made. Finally, there are quite considerable differences between European countries which have defined upper and lower MMSE score limits for the initiation and discontinuation of treatment¹². It is therefore not surprising that a recent article¹³ warned about the “alarming arbitrariness” of these prescription and reimbursement criteria in Europe.

¹¹ Although individual health trusts are free to reimburse memantine, the Scottish Medicines Consortium rejected their use through the NHS and the opinion of the National Institute for Health and Clinical Excellence (NICE) was pending when this publication went to print.

¹² The Mini-Mental State Examination (Folstein et al. 1975) is a quick test which gives an overall estimate of a person’s intellectual capacity and can therefore be used to give a rough assessment of the progress of dementia over time. It gives a score from 30 (full mental capacity) to 0 (severe impairment).

¹³ R.C. Oude Voshaar, A. Burns, M.G.M. Olde Rikkert : Alarming arbitrariness in EU Prescription and reimbursement criteria for anti-dementia drugs, *Int J Geriatr Psychiatry* ; 2006 ; 21 :29-31

Country	Initial treatment decision	Continuing treatment decision	Special examinations required	Upper and lower MMSE scores (ACHI) ¹⁴	Upper and lower MMSE scores (mementine) ¹⁵
Austria	Specialist doctors	Specialist doctors	MMSE	26–10	14–3
Belgium	Specialist doctors	Specialist doctors	Diagnostic protocol	>10	15–0
Bulgaria	No reimbursement				
Cyprus	No information				
Czech Republic	Specialist doctors	Specialist doctors	MMSE	20–13	16–6
Denmark	No restrictions ¹⁶	No restrictions	Diagnostic protocol	None	None
Estonia	No information				
Finland	No restrictions ¹⁷	No restrictions	None	None	None
France	Specialist doctors	No restrictions	None	26–10	15–0
Germany	No restrictions	No restrictions	None	None	None
Greece	Specialist doctors	No restrictions	None	None	None
Hungary	Specialist doctors	Specialist doctors	Diagnostic protocol	26–10	18–0
Iceland	No restrictions ¹⁸	No restrictions	Diagnostic protocol	None	None
Ireland	No restrictions	No restrictions	None	None	None
Italy	Alzheimer Evaluation Unit	Alzheimer Evaluation Unit	Diagnostic protocol	26–10	Not applicable
Latvia	No information				
Lithuania			MMSE	None	20–0
Luxembourg	No restrictions	No restrictions	Diagnostic protocol	26–10	15–0
Malta	No reimbursement				
Netherlands	Specialist doctors	Specialist doctors	Diagnostic protocol	26–10	14–3
Norway	No restrictions ¹⁹	No restrictions	MMSE	> 12	Not applicable
Poland	No restrictions	No restrictions	MMSE	26–10	Not applicable
Portugal	Specialist doctors	Specialist doctors	None	None	None
Romania	Specialist doctors	Specialist doctors	Diagnostic protocol	> 12	> 12
Slovak Republic	Specialist doctors	Specialist doctors	MMSE	24–13	24–13
Slovenia	Specialist doctors	No restrictions	MMSE	26–10 ²⁰	26–10
Spain	Specialist doctors	Specialist doctors	MMSE	None	None
Sweden	No restrictions	No restrictions	None	None	None
Switzerland	No restrictions	No restrictions	MMSE	>10	>3
Turkey	Specialist doctors	No restrictions	None	None	None
United Kingdom	Specialist doctors	No restrictions ²¹	MMSE	30–12	Not applicable

¹⁴ Unless obtained from our member organisations, we included data from R.C. Oude Voshaar et.al., op.cit

¹⁵ Unless obtained from our member organisations, we included data from R.C. Oude Voshaar et.al., op.cit

¹⁶ Although an application for reimbursement can be made by any doctor on behalf of a patient, the diagnosis must have been made by a specialist (neurologist, psychiatrist or geriatrician).

¹⁷ Any doctor can prescribe anti-dementia drugs, but reimbursement can only be made if the diagnosis has been established by a specialist.

¹⁸ Although prescriptions can be filled in by any doctor, the diagnosis needs to be confirmed by a specialist.

¹⁹ Norway specifies that treatment decisions should be made by a doctor with an interest in and knowledge of dementia, but does not restrict treatment decisions to specialist doctors.

²⁰ For patients with MMSE scores higher than 26, more extensive neuropsychological examinations have to be carried out that indicate cognitive decline consistent with Alzheimer's disease.

²¹ The NICE guidance in existence (September 2006) allows general practitioners to continue treatment under shared care protocols.

3.2.5 Market access delays

A final aspect that Alzheimer Europe covered in its survey on the availability of anti-dementia drugs concerned the dates of the market authorisation, product launches and reimbursement decisions in the different countries. While differences in market authorisations already point to significant delays in some countries for the approval of new medicines, these delays are further exacerbated by the time it takes for pricing decisions to be made and for products to be launched, as well as for new treatments to be included in the reimbursement system.

The following table shows the delays experienced in some countries for the market authorisation, the launch or the reimbursements decisions for three of the Alzheimer medicines.

	Galantamine Market authorisation dates	Memantine Launch dates	Rivastigmine Reimbursement dates
First country	Sweden (03/2000)	Germany, Denmark, Iceland (08/2002)	Switzerland (03/1997)
Within 6 months	Austria, Belgium, Denmark, Finland, Iceland, Ireland, Norway, Switzerland, United Kingdom	Austria, Greece, Ireland, Netherlands, Norway, Sweden, United Kingdom	
Within 6 to 12 months	France, Germany, Greece, Italy, Luxembourg, Poland, Portugal, Spain	Finland, France, Hun- gary, Slovenia, Spain	
Within 1 to 2 years	Czech Republic, Lithuania, Slovak Republic, Slovenia	Belgium, Czech Repub- lic, Poland, Portugal, Ro- mania, Slovak Republic, Switzerland, Turkey	France, Germany, United Kingdom
Within 2 to 3 years		Croatia, Italy, Serbia- Montenegro	Spain, Netherlands
Within 3 to 4 years	Latvia, Malta, Netherlands	Cyprus	Ireland
Over 4 years	Cyprus		Austria, Belgium, Hungary

Although it was impossible to find data for all the countries covered in our survey, the findings point to significant delays in some countries as to the access of people with Alzheimer's disease to treatment options available to patients in other countries. With the decision to centralise market authorisations for drugs for the treatment of neurodegenerative diseases, such as Alzheimer's disease, at the level of the European Medicines Agency, the delays between the Member States of the European Union will disappear.

Nevertheless, due to the pricing discussions in some countries or internal company decisions, the launch dates of products will continue to vary and some people with Alzheimer's disease will have earlier access to new treatments than others.

Similarly, true access to anti-dementia drugs is only obtained by patients, once these drugs are part of the reimbursement system, as otherwise treatment with these drugs may be limited only to those people who can afford to pay for them themselves. As can be seen from the above table, although rivastigmine was authorised through the centralised procedure with European wide marketing authorisation on 12 May 1998, there were significant differences as to the dates when individual countries included this treatment in their reimbursement systems.

For Alzheimer Europe, these differences are unacceptable as the organisation campaigns for people with Alzheimer's disease throughout Europe to have equal access to a high standard of care services and treatment options.

3.2.6 Treatment rates

The Alzheimer Europe survey shows important differences between European countries as to the numbers of people with Alzheimer’s disease having access to existing treatments. Other recent publications similarly aimed at identifying differences as to the numbers of people with Alzheimer’s disease being treated.

A survey conducted by Pfizer amongst 200 carers from 6 different European countries (France, Germany, Italy, Poland, Spain and United Kingdom) showed that a majority of physicians recommended treatment at the time of diagnosis. Nevertheless, there were marked differences between countries, with UK carers reporting that treatment was recommended at the time of diagnosis in only 51% of cases, whereas carers in Poland or Spain reported that this was the case in 86% of cases.

As to the treatment recommended, carers reported mainly prescription medicines (98%), either specific Alzheimer’s treatments (86%) or medication to treat mood and behaviour (61%). Other therapies, such as counselling (29%), day care (26%), cognitive therapy (21%) or support groups (15%) were less often recommended by doctors.²²

Similarly, a recent study by Waldemar²³ et. al. calculated the rates of people with Alzheimer’s disease who receive treatment by combining the Alzheimer Europe prevalence rates with data obtained from International Marketing Services about the sales of donepezil, galantamine, rivastigmine and memantine.

The following table shows the percentage of carers reporting treatment at diagnosis and the percentage of patients treated.

²² D. Wilkinson et. al. Inequalities in dementia care across Europe : An Agenda for Change, *Int J Clin Pract*, March 2005, 59 (Suppl. 146), 17-24

²³ G. Waldemar, K.T.T. Phung, A. Burns, J. Georges, F. Ronholt Hansen, S. Iliffe, C. Marking. M. Olde Rikkert, J. Selmes, G. Stoppe, N. Sartorius, Access to diagnostic evaluation and treatment for dementia in Europe, in press *Int J Geriatric Psychiatry*

Country	Percentage of carers reporting treatment at diagnosis ²⁴	Percentage of patients treated ²⁵
Austria		32
Belgium		30
Bulgaria		6
Czech Republic		9
Denmark		28
France	83	50
Germany	78	26
Greece		97
Hungary		3
Ireland		46
Italy	85	18
Netherlands		8
Poland	86	16
Portugal		33
Slovak Republic		10
Spain	86	40
Sweden		47
Switzerland		28
United Kingdom	51	18

3.2.7 Conclusions

The Alzheimer Europe survey and other studies in this field confirm that people with Alzheimer's disease do not have equal access to existing dementia treatments in Europe. Rather, access is subject to a great many restrictions and there are huge variations in access between European countries.

3.2.8 Acknowledgements

Alzheimer Europe gratefully acknowledges the input of the following individuals without whom it would have been impossible to collect this information:

²⁴ D. Wilkinson, op.cit.

²⁵ G. Waldemar, op.cit.

- ABELA Stephen, Malta Dementia Society, Malta
- ALLARD Patrice, France Alzheimer, France
- BARTSCH Roswitha, Alzheimer Angehörige Austria, Austria
- BEDNARZ Bartosz, Novartis, USA
- BASTIANI Pierluigi de, A.I.M.A., Italy
- BLOM Marco, Alzheimer Nederland, Netherlands
- BYL Brigitte, Janssen-Cilag, Belgium
- ESKILDSEN Thomas, Lundbeck, Denmark
- GRANÖ Sirpa, Alzheimer-keskusliitto, Finland
- GYLFADÓTTIR Guðrún, Social Security Department, Iceland
- HAUKSSON Helgi Johann, FAAS, Iceland
- HENRY Sabine, Ligue Alzheimer, Belgium
- HIMMER Eva, Hungarian Alzheimer’s Association, Hungary
- HOLMEROVA Iva, Czech Alzheimer’s Society, Czech Republic
- ILIEVA Irina, Alzheimer Bulgaria, Bulgaria
- JACQUES Alan, Alzheimer Scotland, United Kingdom
- JANSEN Sabine, Deutsche Alzheimer Gesellschaft, Germany
- JOHANNSEN Peter, Alzheimerforeningen, Denmark
- KLASUPA Ilva, State Agency of Medicines, Latvia
- KOGOJ Ales, Slovenian Alzheimer’s Society, Slovenia
- KOTRAS Nina, GAARD, Greece
- LECLERC Nathalie, Novartis, France
- LONEUX Sylvie, Ligue Alzheimer, Belgium
- O’CALLAGHAN Sarah, Alzheimer Society of Ireland, Ireland
- PETITPRE Jean, France Alzheimer, France
- RAUDSEPP Kristin, State Agency of Medicines, Estonia
- RODRIGO Jesus Maria, CEFA, Spain
- SADOWSKA Alicja, Polish Alzheimer’s Association, Poland
- SALVINI Gabriella, Federazione Alzheimer Italia, Italy
- SCERRI Charles, Malta Dementia Society, Malta
- SELMES Micheline, Fundación Alzheimer España, Spain
- SHARP Samantha, Alzheimer’s Society, United Kingdom
- SPARR Sigurd, Nasjonalforeningen Demensförbundet, Norway
- TARISKA Peter, National Institute of Psychiatry and Neurology, Hungary
- TELARANTA Pirkko, Alzheimer-keskusliitto, Finland
- TSOLAKI Magda, GAARD, Greece
- TUDOSE Catalina, Societatea Alzheimer, Romania
- TRAYKOV Latchezar, Alzheimer Bulgaria, Bulgaria
- WILSON Gillian, Alzheimer Scotland, United Kingdom
- WOLFENBERGER Marianne, Association Alzheimer Suisse, Switzerland
- WORTMANN Marc, Alzheimer Nederland, Netherlands
- ZINKE DOS REIS Maria do Rosario, APFADA, Portugal

3.3 Home care in Europe

3.3.1 Introduction

In 2005, as part of Alzheimer Europe's Business Plan project on home care, short descriptions of home care provisions were prepared for 25 countries within Europe. These reports were written with the help of Alzheimer Europe's member associations and on the basis of recent literature such as the EUROFAMCARE reports²⁶ and information from Ministries and other national sources. Member associations were asked to provide information about relevant legislation, the organisation and funding of home care, the kinds of home care services available and the extent to which carers and people with dementia are consulted with regard to the provision of such services.

It became clear that there were tremendous differences between countries, particularly in terms of State responsibility, funding, the role of families and the actual availability of home care services. Differences were also detected within countries.

A few common issues emerged such as the lack of any specific reference to people with dementia in laws and documents pertaining to the provision of home care services, an emphasis on home care services for the elderly and/or disabled, limited reference to any actual obligation on the part of the State to provide home care services and the involvement of families, voluntary organisations and NGOs.

As much of the information obtained was based on services for elderly and/or disabled people, the following sections will frequently refer to home care services for these two groups. The reports do not specifically address the issue of home care services for younger people with dementia. This will be covered by the next project on social support services for people with dementia (EuroCoDe, WP4), which is funded by the European Commission and should be finalised by 2008.

3.3.2 State responsibility for care of elderly dependant people

In most countries, the State is responsible for providing home care services, either directly or by granting allowances that people can use to purchase them. In Denmark, Norway, Iceland and Sweden, the State is legally obliged to provide such services for the elderly if needed, although in Sweden this is only if a person's needs cannot be met in another way. The services are mainly funded through general taxation.

In some countries, there is no legal obligation to provide home care services but there is a more general, less precise commitment on the part of the State to provide the necessary services to enable elderly people to remain in their homes for as long as possible (Spain, England and Wales, and the Czech Republic) or to provide support for the elderly and disabled (Hungary and Estonia). In Bulgaria and Poland, the

²⁶ <http://www.uke.uni-hamburg.de/extern/eurofamcare/>

State provides some home care services but priority is given to elderly people, on low incomes, living alone. The provision of home care services falls into the category of social assistance and is linked to poverty, age or social isolation in some countries.

Luxembourg, Germany Austria and Belgium (just Brussels and Flanders) have long-term care insurances which cover home care. The actual level of care provided is dependent on the assessed level of need and is subject to the fulfillment of certain conditions. In Switzerland, home care services are also financed through an obligatory care insurance but access to such services is determined by cantonal law.

With regard to legal obligations, the Health Service Executive in Ireland is empowered (under the 1970 Health Act), but not required by law, to provide community care services in Ireland. Consequently, access to such services has been limited and varies from one region to the next. In England and Wales, the State is obliged to provide an assessment of care needs but is not actually obliged to provide the services. In Scotland, on the other hand, people over the age of 65 are entitled to free nursing and personal care as well as increased access to direct payments for home care services.

3.3.3 The role of families in caring for elderly dependant relatives

The organisation and provision of home care services for people with dementia in Europe cannot really be considered in isolation from family carers. In a number of countries, especially those in southern Europe (e.g. Malta, Spain, Portugal, Italy and Greece), there is a cultural tradition of families caring for their elderly dependent relatives. In many cases, this involves daughters and daughters-in-law caring for their parents and parents-in-law, although in some cases, this extends to aunts and uncles. In these countries, there is an actual legal obligation to provide care. The reliance on the family to provide care often means that the provision of home care services by the State is considered as discretionary.

A legal obligation for relatives to contribute towards the cost of care also exists in Austria, Estonia, France and Poland. In Belgium and certain cantons in Switzerland, relatives may sometimes be asked to contribute towards care.

In those countries, where home care services are means tested and/or dependent on an assessment involving an analysis of “available assistance”, families may be obliged to indirectly contribute towards the cost of care or provide it themselves.

3.3.4 Other arrangements for care at home

In Bulgaria, Hungary and Poland, it is possible to draw up a contract with third parties which involves ceding property in exchange for care and/or maintenance. Care

is not normally provided by the State in such cases even if the person lives alone. Another form of home care is family accommodation/boarding out, which is practiced in Portugal. This consists of temporarily or permanently housing elderly dependent people within families. This service is intended for elderly people who do not have a family or for whom insufficient social support prevents them from being cared for in their own homes.

3.3.5 Conditions governing access to home care services

Often people with dementia, who are in need of home care services, fall into the category of assistance for elderly dependent people. Those who are younger may have to apply for assistance based on disability. For countries which have a long-term care insurance, the emphasis is on having a recognized medical condition which creates a situation of dependency necessitating a certain degree of care over a prolonged period of time. In southern countries, priority tends to be given to elderly people with limited financial resources and no family. This, combined with the tradition of family care, means that people do not always apply for the services they need. Also, the availability of appropriate services tends to be unevenly distributed or simply lacking.

3.3.6 The role of voluntary organisations and other NGOs

As appropriate and sufficient home care services for people with dementia are not always provided by the State, the role of voluntary organisations, the Church and other NGOs is very important. In the vast majority of countries, voluntary organisations, NGOs and the Church play a role in providing home care services. Often, these organisations are completely independent, but in some countries, their services are organised and coordinated in collaboration with the State.

One organisation which is active in a number of countries is the Red Cross. In fact, in the Czech Republic, it was instrumental in setting up the first home care services. Similarly, in Greece, the Red Cross provided the first home care services on a small scale in collaboration with other voluntary associations including the Church.

An interesting service, known as the good neighbour scheme, was set up in 1982 by Caritas in Malta. Every elderly person is visited, assessed and invited to participate in this free service. If interested, volunteers then motivate neighbours who keep a friendly and regular watch on the elderly person. Some provide direct help and some alert the relevant authorities in order to organise help.

3.3.7 Kinds of home care services provided

Most home care services can be roughly divided into two categories: those providing assistance linked to a person's residence (e.g. cleaning, shopping, laundry, transport, meals-on-wheels etc.) and those linked to personal care (washing, dressing,

eating, incontinence care, getting in and out of bed, taking medication etc.). These services are available in most countries with a reasonable level of home care service provision.

Measures to enable people to continue living in their own homes for longer such as home adaptations, assistive technology and “telealarm” systems are a little less common. In Poland, France, Malta and Bulgaria, assistance may be provided with small household repairs. In Denmark, volunteers usually help with this.

With regard to supervision for people who cannot cope if left alone for long periods, day and/or night time sitting services and day care centres are available in some countries. All but three countries in this survey (Romania, Spain and Turkey) mentioned day care centres, either for people with dementia or more generally, for elderly people. Quite a few countries (Belgium, the UK, France, Germany, Malta, the Netherlands and Sweden) referred to provisions for night time care in the form of sitting services or night time care centres.

Finally, in a few countries (Bulgaria, Denmark, France, Sweden, Norway and Luxembourg) the importance of social contact and entertainment was recognised. Services were mentioned in connection with leisure activities, social contact, companionship and social needs. In some countries, efforts are made to organise holidays for people with dementia and carers, either together or separately. This is often with the involvement of Alzheimer Associations. In Germany and Luxembourg, carers are entitled, within the long-term care insurance system, to a set number of days holiday per year, during which time a replacement carer is provided.

3.3.8 The extent to which home care services are adapted to actual needs/wishes

People with dementia have various needs which differ from one person to the next and change over time. A flexible set of home care services is therefore needed which can easily be adapted to the needs of each person if and when required. Some countries have a limited range of services which do not take into account the specific needs of people with dementia.

In the Czech Republic, for example, assistance with everyday tasks is not routinely provided. In Romania, home care services only cover nursing care and even that is limited to a certain number of days per year. In the Nordic countries and those which have long-term care insurances the emphasis is on helping people to maintain their independence and continue living at home rather than on whether they qualify for a pre-determined set of services.

Nevertheless, people with dementia do not always receive the services they need or want. This may be because the needs assessment is biased towards physical disability and does not sufficiently take into account other needs such as supervision

and emotional support. Sometimes, sufficient and appropriate services do not exist. This may be especially the case for younger people with dementia or for people with learning disabilities and dementia.

3.3.9 How people with dementia (or carers) pay for services

Usually, people receive services in kind (e.g. organised by the State, NGOs and/or voluntary, charitable or church associations) or an allowance which can be used to pay for or contribute towards the cost of services (either from the State, independent service providers or non-professionals). For services in kind, a contribution from the service user is often required.

Service cheques and personal care budgets exist or are being introduced in a few countries (Belgium, France and the Netherlands). This system gives people with dementia (or carers acting on their behalf) the opportunity to choose the exact services that they want. This also gives them some control over service providers with regard to the quality of the services provided, as the user can always take their custom elsewhere if dissatisfied. Many people like this system but some feel that the organisation and responsibility involved would be too much for them to handle, especially due to cognitive difficulties.

In Denmark, people receiving personal and practical home care services are entitled to change them for others that they would prefer. In a few countries, people can decide whether to have services in kind or money to purchase the services themselves.

3.3.10 The extent to which people with dementia and carers are consulted

In most countries, carers and people with dementia are not routinely consulted about the home care services they receive. There are however a few exceptions.

In Sweden, for example, it is stated in the Law on Health and Medical Services (1982) and in the New Social Legislation (2002) that home care services should be organised in consultation with the people and relatives requesting them. Similarly, in Finland, the Act on the Status and Rights of Social Welfare Clients (2000) states that clients' wishes and opinions must be taken into account when planning and providing social welfare.

Under the Community Care and Health (Scotland) Act 2002, both the views of the person whose needs are being assessed and the views of the carer should be taken into account insofar as it is reasonable and practicable to do so.

At the request of the Danish Ministry of Social Affairs, some communes sent out questionnaires to obtain qualitative and quantitative information on the needs of

the people with dementia and their carers. In England and Wales, the government produced guidelines on community care assessments (Government White Paper, Caring for People, 1989) which emphasise the need to take into account the wishes of individuals and their carers, but this is not a legal obligation.

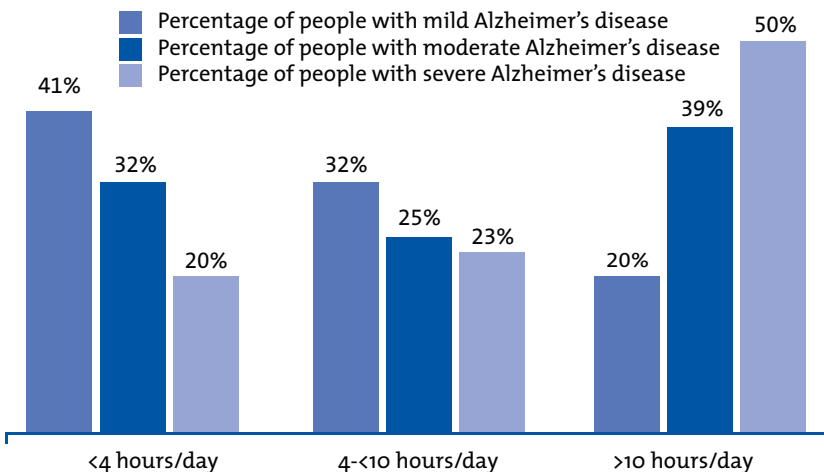
3.3.11 Second AE survey confirms the role of carers and the lack of adequate support

In a separate survey²⁷, recently carried out by Alzheimer Europe, involving over 1,000 carers in France, Germany, Poland, Scotland and Spain, the organisation explored the impact of dementia on carers and assessed the availability of services for them.

The survey confirmed that the majority of people with Alzheimer’s disease were cared for at home (86%), whereas a minority were in nursing or residential care (10%) or living in sheltered housing (1%). There were slight differences between countries, as the percentage of people living at home differed from 63% in France to 97% in Poland.

The results also painted a shocking picture of the level of commitment required from carers. One in five carers of people with Alzheimer’s disease in the mild stages reported that they provided more than 10 hours’ care each day. For carers of people with Alzheimer’s disease in the late stages, one in two reported providing more than 10 hours’ care per day.

Chart 1: Hours per day caring for a person with dementia: current severity



²⁷ Alzheimer Europe (2006): Who cares? The state of dementia care in Europe

It is essential for carers to be able to access adequate home care services to allow them to carry on in their caring role without jeopardising their own health. Unfortunately, the survey also revealed that many carers lack basic support services to help them cope in their caring role. A significant number of people do not have access to essential services such as home help, befriending or respite care. When these services are available, many carers have to pay for them out of their own pockets, as can be seen from the following charts which also provide an overview of the existing differences between the five countries.

Chart 2: Percentage of carers reporting the availability of selected services.²⁸

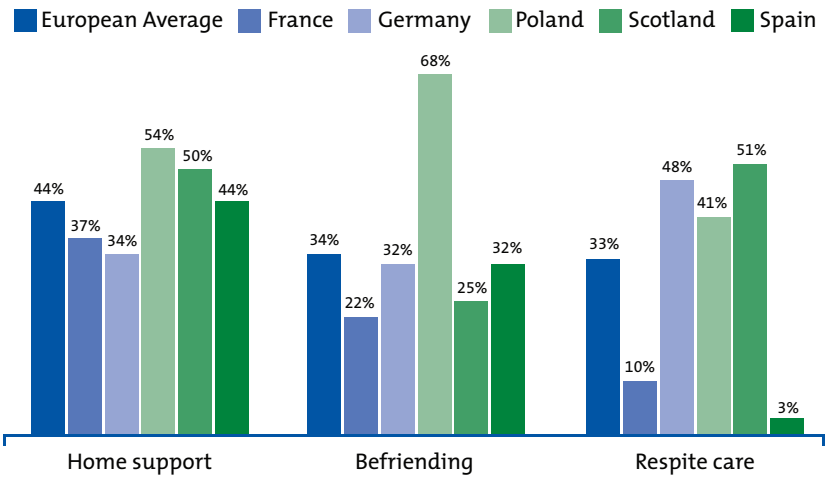
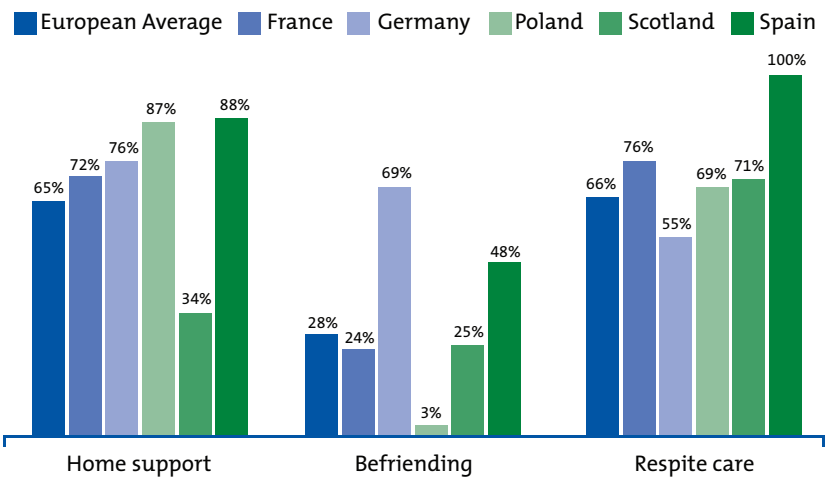


Chart 3: Percentage of carers reporting the need to contribute towards the cost of selected services.²⁹

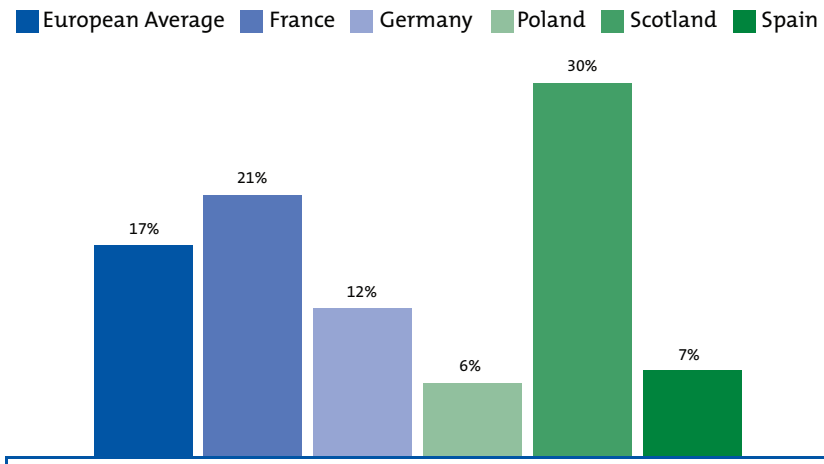


²⁸ Alzheimer Europe (2006) : op.cit.

²⁹ Alzheimer Europe (2006) : op.cit.

Not surprisingly, when asked whether they thought that the level of care for the elderly was good in their country, only about one in five carers agreed with the statement. This percentage varied from 6% in Poland to 30% in Scotland. Also, although carers were not asked specifically about the quality of home care services, these figures provide some information about the degree of satisfaction of carers.

Chart 4: Percentage of carers agreeing with the statement that the care of the elderly was good in their country.³⁰



3.3.12 Conclusion

The two home care surveys carried out by Alzheimer Europe highlighted great disparities in the provision of home care services within Europe and the need for greater support for carers. However, it must be borne in mind that current provisions reflect the historical, economic, political, cultural and religious developments that have taken or are taking place in each country. Nevertheless, this should not prevent governments from recognising and respecting the right of elderly, dependent people to appropriate and affordable home care services. Alzheimer Europe and its member associations urge governments to take the necessary steps and to ensure that home care services are adapted to the specific needs of people with dementia.

³⁰ Alzheimer Europe (2006) : op.cit.

3.4 *European EuroCoDe network organisations*

3.4.1 **Alzheimer Europe**

Alzheimer Europe is a non-profit organisation, which aims to improve the care and treatment of Alzheimer patients through intensified collaboration between its member associations.

The majority of people with dementia live at home and are cared for by their relatives and friends. Although many organisations are active in supporting them, carers often work alone, and lack the know-how and inspiration, which could be given by others.

AE thus hopes, through its activities, to answer a growing need in society, and especially among the community of people affected by the existence of the disease. The exchange of experience and knowledge as well as collaboration on new approaches will stimulate and motivate people with dementia. Further to this, it will ensure that information on best practice in the care of Alzheimer sufferers is available throughout Europe and beyond.

Alzheimer Europe activities are geared towards attaining the following objectives:

- To improve the exchange of information between Alzheimer associations;
- To stimulate the development of projects in the domains of information, support and caregiving for people with dementia;
- To establish contacts between Alzheimer associations in view of setting up and coordinating common transnational projects;
- To arrange for the translation of booklets, pamphlets and other material of interest to various organisations in the member states of the European Union;
- To organise an annual international conference offering participants the possibility to inform themselves about new findings in the fields of research on, and treatment of the Alzheimer's disease.

Alzheimer Europe
145 route de Thionville
L-2611 Luxembourg
Tel: +352 - 29 79 70
Fax: +352 - 29 79 72
info@alzheimer-europe.org
www.alzheimer-europe.org

3.4.2 European Alzheimer’s Disease Consortium (EADC)

The EADC is a fully functional network of European centres of excellence working in the field of Alzheimer’s Disease. It provides a setting in which to increase the basic scientific understanding of the disease and to develop ways to prevent, slow, or ameliorate the primary and secondary symptoms of Alzheimer’s disease. This is done by facilitating large Europe wide research studies. The EADC is funded by the European Commission and as such enjoys the privilege of complete independence and autonomy from the pharmaceutical industry whilst maintaining close working links with it.

The EADC is a network of 45 European centres of excellence working in the field of Alzheimer’s Disease.

European Alzheimer’s Disease Consortium (EADC)
c/o Dr Emma Reynish, Co-ordinator
Department of Internal Medicine and Clinical Gerontology
Toulouse University Hospital
170 Avenue de Casselardit
31300 Toulouse
FRANCE
Tel:+33 - 5- 61 77 76 49
Fax:+33 - 5- 61 49 71 09
reynish.e@chu-toulouse.fr
www.alzheimer-europe.org/eadc

3.4.3 European Association of Geriatric Psychiatry (EAGP)

The EAGP was founded in 1971 as an informal association of psychiatrists, neurologists, neuropathologists, psychologists and sociologists from various European Countries who have a special interest in the psychogeriatric field.

Thus, the EAGP was the first international association concerning the special subject of geriatric psychiatry. Today the EAGP has about 250 members from 26 European countries.

The objectives of the EAGP are research promotion, pre- and post graduate education, further development of geriatric psychiatry and the cooperation with national and international bodies engaged in the field.

The EAGP aims to accomplish its objectives through:

- Organisation of congresses on geriatric psychiatry
- Encouragement of collaboration between all professions concerned with mental health in old age

- Publications in the official organ of the association, the “International Journal of Geriatric Psychiatry“
- Organisation of training courses in geriatric psychiatry
- Fostering of scientific projects

European Association of Geriatric Psychiatry
 c/o Dr. Brigitte Grass-Kapanke
 Rheinische Kliniken
 Psychiatrische Kliniken der Heinrich-Heine-Universität
 Bergische Landstr. 2
 40629 Düsseldorf
 GERMANY
 www.eagp.com

3.4.4 European Federation of Neurological Societies (EFNS)

The EFNS is an organisation that unites and supports neurologists across the whole of Europe.

Currently 40 European national neurological societies are registered members of the EFNS, which represents more than 12,000 European neurologists.

The 10 missions of EFNS are to:

- Broaden the base of clinical neurology in Europe
- Raise public awareness about the importance of the brain and its disorders
- Strengthen the standard, availability and uniformity of neurological services in Europe
- Create and maintain continuing medical education (CME) guidelines and accreditation
- Support and encourage European clinical neuroscience research programmes
- Strengthen the standard, quantity and equality of pre-graduate and post-graduate teaching and training
- Strengthen WFN, EU and WHO relations
- Strengthen the collaboration with related professional and lay organisations
- Organise European Neurology Congresses and Neurological Teaching Courses
- Publish the European Journal of Neurology

EFNS Head Office
Breite Gasse 4-8
1070 Vienna
AUSTRIA
Tel: +43 -1- 889 05 03
Fax: +43 -1- 889 05 03 13
headoffice@efns.org
www.efns.org

3.4.5 European Union Geriatric Medicine Society (EUGMS)

A number of organisations have been supporting a European profile for geriatric medicine and momentum has been building up over the last decade. The European Section of the International Association of Gerontology has been a positive force, and the institution of the Geriatric Medicine Section of the UEMS in 1997 was a defining point. This meant that geriatric medicine was officially recognised in more than eight European countries.

It was felt, however, that there was still a lack of a central focus for continuing professional development and academic matters in the European Union. The first group met to discuss the EUGMS in September 1999 in Paris. After a number of meetings at different European cities, the European Union Geriatric Medicine Society was finally created, and was launched in Paris in August 2001, when its 1st Congress took place.

The missions of EUGMS are:

- To develop geriatric medicine in the member states of the European Union as an independent specialty caring for all older people with age-related disease
- To campaign for the availability of these services to all citizens of the European Union
- To promote education and continuing professional development, and in particular a biennial scientific meeting
- In conjunction with the Section of Geriatric Medicine of the EUMS, to promote geriatric medicine to the European Commission and Parliament
- To promote evidence-based guidelines for the most efficacious prevention and treatment strategies for older people in the European Union

European Union Geriatric Medicine Society (EUGMS)

Marjory Warren House
31 St. John's Square
London EC1M 4DN
UNITED KINGDOM
Tel: +44 -20- 76 08 13 69
Fax: +44 -20- 76 08 10 41
secretariat@eugms.org
www.eugms.org

3.4.6 Early Detection & Timely INTERvention in DEMentia Network (INTERDEM)

INTERDEM is:

- A network that is dedicated to person-centred values and working together with people with dementia and their family carers, by placing them at the centre of research and practice and encouraging their active participation
- A multi-professional network of gerontological research-practitioners who focus on psychosocial (as opposed to neurobiological) approaches to the early recognition and intervention in dementia, throughout Europe
- A network of researchers, practitioners, people with dementia and their carers who have a particular focus on early and timely support, psychosocial intervention and disability prevention in dementia, at the primary / community - specialist care interface.
- Psychosocial researchers, practitioners, people with dementia and families, from the UK, Spain, the Netherlands, Ireland, Italy, Portugal, France, Belgium, Germany, Sweden, Poland and Greece (plus Hong Kong)
- An aim to develop and carry out pan-European psychosocial research and person-centred practice in dementia

Interdem

c/o Dr Esme Moniz-Cook, Coordinator
University of Hull
Institute of Person Centred Research & Practice in Ageing (I.P.C.R.A.)
Coltman Street Day Hospital
Hull HU3 2SG
UNITED KINGDOM
E.D.Moniz-Cook@hull.ac.uk
www.alzheimer-europe.org/INTERDEM

3.4.7 International Association of Gerontology European Region (IAG-ER)

IAG-ER is the European part of the World Organisation: the International Association of Gerontology (IAG) founded in 1952 in Liège by Prof. Brull.

It has three sections:

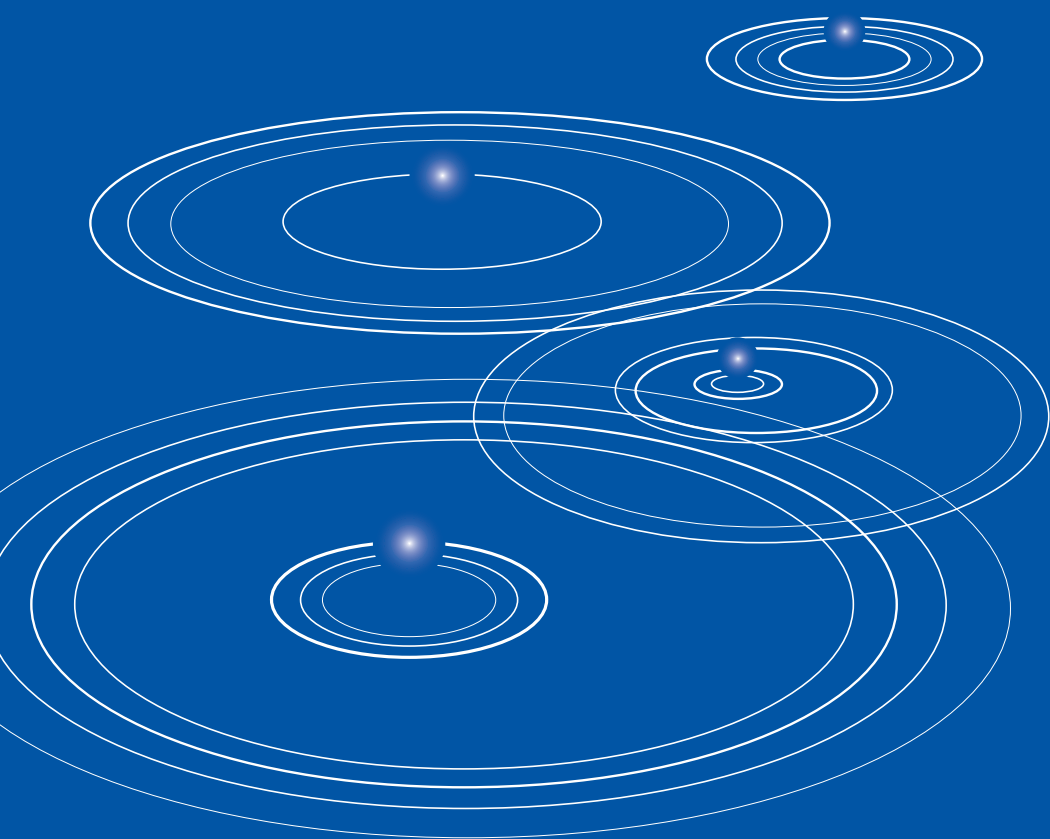
- The biological section
- The medical section
- The behavioural and social section.

The aims are to:

- Promote gerontological research in these fields
- Promote training of highly qualified personnel
- Promote the interests of gerontological organisations in all questions pertaining to international matters
- Promote and assist in the arrangements for holding the European Congresses of Gerontology at four year intervals, separate congresses of the sections, and also of the International Congresses of IAG

International Association of Gerontology European Region (IAG-ER)

c/o Robert Moulías, Chairperson
Hôpital Charles Foix
7 avenue de la République
94205 Ivry sur Seine
FRANCE
Tel.: +33 -1- 49 59 45 04
Fax: +33 -1- 49 59 45 24
robert.moulias@wanadoo.fr
www.iag-er.org



*Dementia in Europe –
“National results”*

4.1 Austria

4.1.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Austria in 2005 as being between 94,441 (Ferri et al.) and 104,428 (Eurodem). This represents 1.15% (Ferri et al.) to 1.27% (Eurodem) of the total population of 8,206,524, which is almost identical to the EU average (i.e. 1.14% to 1.27%).

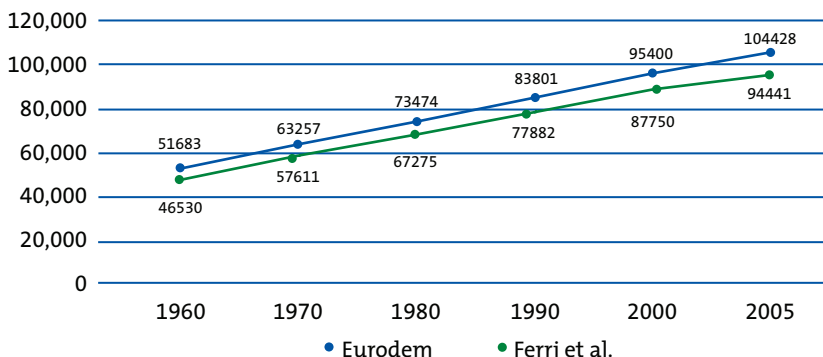
The Alzheimer Europe figures underestimate the number of people with dementia in Austria, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Austria over the age of 94.

Table 1: The number of people with dementia in Austria in 2005

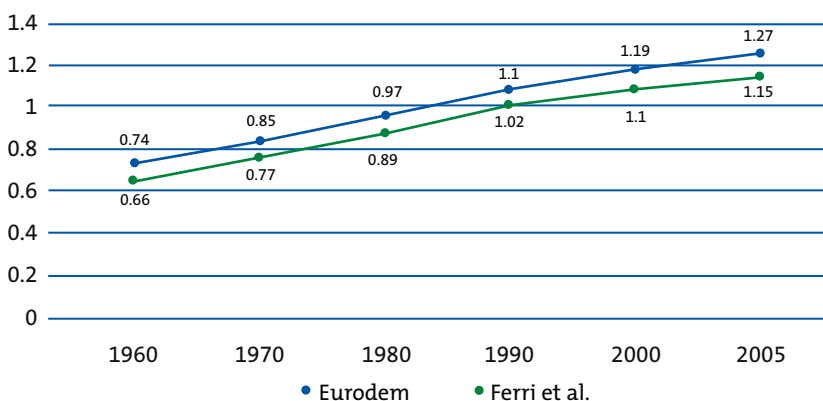
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	2,852	1,601	4,453	
60–64	3,720	1,198	4,918	4,414
65–69	3,777	2,172	5,948	5,572
70–74	6,344	6,754	13,099	11,254
75–79	5,485	11,432	16,918	16,814
80–84	7,966	20,631	28,597	26,663
85–89	3,798	12,717	16,515	29,725
90–94	3,276	10,704	13,981	
Total	37,218	67,210	104,428	94,441

The following charts show a) the increase in the number of people with dementia in Austria from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia doubled between 1960 and 2005.

The number of people with dementia in Austria from 1960 to 2005



The number of people with dementia in Austria as % of the total population from 1960 to 2005



4.1.2 Availability of anti-dementia drugs

4.1.2.1 The availability of medicines in general

Austria keeps a list of pharmaceutical products for which expenses are covered by the health care system. Nevertheless, patients and carers need to cover part of the costs of medicines. This charge is currently set at € 4.60 per item prescribed. For infectious diseases and in cases of need, medicines may be free of charge.³¹

4.1.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Austria and are included on the list of pharmaceutical products that are covered by the health care system.

³¹ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

Prescription is limited to specialist doctors and this applies to both treatment initiation, as well as to continuing treatment decisions. For the prescription of acetylcholinesterase inhibitors, an MMSE is required. Treatment with acetylcholinesterase inhibitors is limited to people with an MMSE between 26 and 10, whereas treatment with memantine is reimbursed for patients scoring between 14 and 3 on this scale.

Medicines for people living alone and for people in nursing homes are also covered by the health care system, nevertheless the Austrian Alzheimer Association pointed out that the treatment of people in nursing homes was limited by the medicines budgets of the nursing homes in question.

The Austrian Alzheimer Association also pointed out that bi-therapy with an acetylcholinesterase inhibitor and memantine was specifically excluded from reimbursement in Austria and that patients would have to pay for one of the drugs in that case.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	26–10	26–10	26–10	14–3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	Nursing home budgets	Nursing home budgets	Nursing home budgets	Nursing home budgets

4.1.3 Organisation of Home care

4.1.3.1 Background information about dementia and home care services

In 1993, the Federal State and the individual provinces made an agreement to further develop common measures by 2010 with regard to the provision of services for those in need of care. This was to include home nursing, elderly care and home help. An interim report dated 31.12.2002 revealed, however, that the provision of mobile services was unevenly distributed. Nevertheless, by December 2002, an additional 1,727 full-time care worker posts had been created (compared to the period 1995 to 1997) within Austria, excluding Vienna. In 2003, there were plans to create a further 2,191 full-time posts by 2010 (Blaha, 2006).

The main providers of home care services are the Red Cross, Caritas, social welfare organisations, relief organisations and “Volkshilfe”.

4.1.3.2 Legislation relating to the provision of home care services

There are two main pieces of legislation of relevance to the provision of home care services. These are the Federal Long-Term Care Allowance Act and the Provincial Long-Term Care Act. Agreements between the federal and provincial authorities were signed in May 1993 and were implemented in January 1994. Consequently, long-term care allowances are uniform throughout Austria. The federal act covers people who are entitled to social security pensions (i.e. 90% of the population) whereas the provincial act covers those who are not i.e. the remaining 10% of the population (Brodsky et al. 2000).

The law governing the assessment of the need for care is the Ordinance on Care Allowance levels (Einstufungsverordnung zum BPGG). The actual financing of care is the responsibility of the 9 provinces, each of which has its own law.

According to Austrian civil law, married couples are legally responsible for each other's maintenance. They can fulfill this obligation by means of payment or the provision of services. Under certain circumstances, children may be held legally responsible for the maintenance of their parents. In Vorarlberg, even grandchildren may be held responsible for the maintenance of their grandparents. According to social assistance laws in most provinces, children may, in certain circumstances, be obliged to contribute towards the costs of community care and residential care for their parents. Numerous decisions have been made by the Supreme Federal Court with regard to the conditions upon which the provisional authorities can demand that relatives contribute towards the cost of care.

4.1.3.3 Organisation and financing of home care services

Coordination centres exist but vary from one province to the next. They deal with medical and non-medical home nursing as well as care services linked to the social insurance.

Eligibility for the long-term care allowance is based solely on the level of disability and the amount of assistance needed. It is not means tested and is financed through general tax revenues not through social insurance contributions. Nevertheless, it should be noted that employee and employer contributions were increased just before the Long-Term Care Allowance Acts came into force (Brodsky et al., 2000).

There are seven levels of disability. Level 1 is the lowest level and intended for people whose disability necessitates between 50 and 74 hours of care per month, whereas levels 4 to 7, are for people who require 180 hours of care or more. Another condition for eligibility is that the person has a permanent need for personal care for at least 6 months. Private physicians are responsible for deciding on eligibility and the level of disability.

People who have been judged eligible for the care allowance are paid a cash benefit on a monthly basis. This is exempt from tax and can be spent in any way that the recipient sees fit e.g. to pay for services or to pay an informal carer. This is intended to enable people to stay at home for as long as possible and to promote self determination and family support. Recipients who are cognitively impaired may have a legal representative appointed to manage the care allowance on their behalf (Brodsky et al., 2000). The vast majority of formal services are provided by NGOs.

With the exception of the long-term care allowance, the financing of care needs is determined by a person’s income, assets and recourse to their children’s income. Despite efforts over the last ten years to harmonise legislation, this is still governed by provincial legislation (Blaħa, 2006).

Although there are no official figures, it is believed that an illegal work market is steadily growing for paid carers from the Czech Republic, Slovakia, Hungary and Poland. They are usually paid between EUR 1,200 and EUR 1,800 for 24 hour in-house care (Hörl, 2005). Discussions are currently being held at the highest level in order to decide whether to legalise this situation. This would result in additional costs for those employing such workers, as they would be obliged to also pay social insurance contributions (Blaħa, 2006).

4.1.3.4 Kinds of home care services available

The kinds of services available include home help, personal care, meals-on-wheels, companionship and laundry. There are also community care centres, sometimes known as pensioners’ clubs, which offer cultural and leisure activities, as well as light meals. Day care centres exist. Some are for all elderly people and some are for specific groups such as people with multiple sclerosis or dementia. It is also possible to apply for subsidies for home adaptations which would facilitate home care.

Carers who find themselves temporarily unable to provide care, due to illness, holidays or other reasons, can ask for a replacement carer. This is only possible for carers of people who are classed as being at disability level 4 or above on the long-term care allowance scale.

4.1.3.5 Consultation with people with dementia and carers

In the framework of the “Qualitätsversicherung in der häuslichen Betreuung” of 2002, people receiving the long-term care allowance, along with their informal carers, were asked during a home visit about their level of satisfaction with the initial contact, the provision of information and referral to services etc. (Blaħa, 2006).

4.1.3.6 Sources

Blaha, M. (2006), Information provided by fax on 11 August 2006

Brodsky, J., Habib, J. and Mizrahi, I. (2000), A review of long-term care laws in five developed countries,

<http://www.wu-wien.ac.at/wwwu/institute/Sozialpolitik/LTC.pdf#search='A%20review%20of%20longterm%20care%20laws%20in%20five%20developed%20countries'>

Hörl, J. (2005), *National Background Report for Austria*, EUROFAMCARE,

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_austria_rc1_a4.pdf

Kodner, D. L. (2003), Consumer-directed services: lessons and implications for integrated systems of care. *International Journal of Integrated Care*, 17 June 2003,

<http://www.ijic.org/publish/issues/2003-2/index.html?000137>

4.1.4 EuroCoDe network organisations

Alzheimer Angehörige Austria

Obere Augartenstrasse 26-28

1020 Wien

Tel: +43 -1- 332 51 66

Fax: +43 -1- 334 21 41

alzheimeraustria@via.at

www.alzheimer-selbsthilfe.at

Österreichische Gesellschaft für Geriatrie und Gerontologie

Sozialmedizinisches Zentrum

Apollo gasse 19

1070 Wien

Tel: +43 -1- 521 03 13 07

Fax: +43 -1- 521 03 13 09

franz.boehmer@wienkav.at

www.geriatrie-online.at

Österreichische Gesellschaft für Neurologie (ÖGN)

Garnison gasse 7/22

1090 Wien

Tel.: +43 -1- 512 80 91 19

Fax.: +43 -1- 512 80 91 80

oegn@admicos.com

www.oegn.at

4.2 Belgium

4.2.1 Prevalence of Dementia

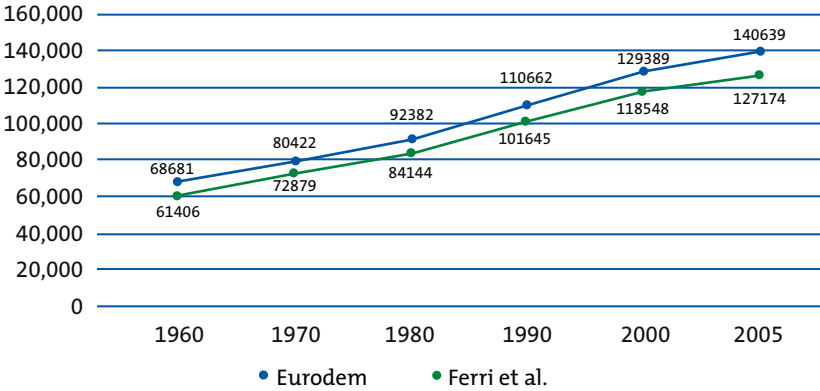
Alzheimer Europe estimates the number of people with dementia in Belgium in 2005 as being between 127,174 (Ferri et al.) and 140,639 (Eurodem). This represents 1.22% (Ferri et al.) to 1.35% (Eurodem) of the total population of 10,445,852. The number of people with dementia in Belgium, as a percentage of the total population, is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Belgium in 2005

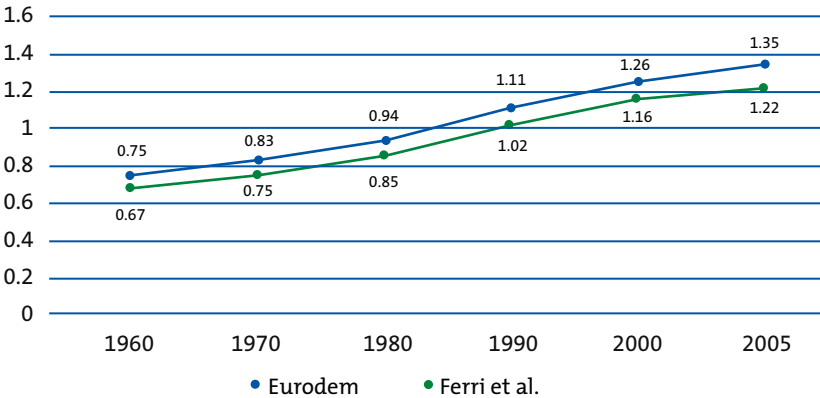
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	3,579	1,983	5,562	
60–64	3,814	1,188	5,002	4,447
65–69	5,055	2,872	7,926	7,410
70–74	9,709	10,080	19,789	16,983
75–79	7,945	15,239	23,184	23,166
80–84	12,276	24,406	36,682	34,413
85–89	5,497	16,100	21,597	40,754
90–94	3,870	13,107	16,977	
95–99	559	3,360	3,919	
Total	52,304	88,335	140,639	127,174

The following charts show a) the increase in the number of people with dementia in Belgium from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia doubled between 1960 and 2005.

The number of people with dementia in Belgium from 1960 to 2005



The number of people with dementia in Belgium as % of total population from 1960 to 2005



4.2.2 Availability of anti-dementia drugs

4.2.2.1 The availability of medicines in general

In Belgium, the reimbursement system has classified drugs into different reimbursement categories.

- Medicines in category A for serious illnesses are fully covered by the system and free of charge for the patient.
- For medicines in category B (useful drugs), the patient is required to pay 25% up to a ceiling of € 10.20.

- For medicines in category C (less useful drugs), the patient is required to pay 50% up to a ceiling of € 17.00. This percentage may go up to 60% or 80% for drugs certain medicines in this group which fall under category CS (ease drugs) or Cx (for example: contraceptives).

For medicines for which an identical generic product exists, the refund by the reimbursement system is reduced by 30%.³²

4.2.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Belgium and are part of the reimbursement system.

Belgium has a very strict treatment protocol for drugs to be reimbursed. Amongst others, it limits the prescription of anti-dementia drugs to specialist doctors, both for treatment initiation and for treatment continuation. An MMSE score of between 24-12 is required for the reimbursement of acetylcholinesterase inhibitors and a score of between 15 and 3 for the reimbursement of memantine.

The Belgian system explicitly limits reimbursement to one class of drugs only, so that patients would not be able to receive bi-therapy under the system unlike some other European countries. According to the Ligue Alzheimer, a significant number of patients and carers have to pay for their Alzheimer medicines, because their general practitioners failed to refer them to a specialist.

The reimbursement system does not impose any restrictions for the reimbursement of people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	24-12	24-12	24-12	15-3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

³² European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.2.3 Organisation of Home care

4.2.3.1 Legislation relating to the provision of home care services

In the Flemish speaking part of Brussels and Flanders, the “zorgverzekering” is the relevant law governing the provision of care services at home and in institutions. It came into force on 1 October 2001. This does not exist in the Walloon region but it is being discussed.

According to the degree of dependency of the person concerned, s/he can receive a fixed amount “A” (least dependent), “B” or “C” (most dependent) for the financing of home care services (federal legislation). The criteria to determine the fixed amount are based on the capacities of the person (e.g. related to getting dressed, moving, incontinence and feeding).

Also at the federal level, there is the health care insurance (which has been improved) and the allowance for assistance to the elderly (which has also been improved).

Adult children are not legally obliged to care for their parents. However, if a parent or in some cases a grandparent needs residential care, the local Public Centre for Social Welfare can claim part of the costs back from the children and exceptionally the grandchildren provided that they have sufficient resources (Declercq and Van Audenhove, 2004).

There is no specific policy for people with dementia. Measures are taken within the framework of financing of long-term care for dependent people. There are also several allowances for handicapped people:

- the income replacement allowance (for people between 21 and 65 years of age): granted if earning capacity is reduced to 2/3 of what a valid person is able to gain on the labour market.
- the integration allowance (for people between 21 and 65 years of age): if, due to reduced autonomy, the person is faced with additional expenses for integration in social life.
- the allowance for assistance to the elderly (over 65 years of age): if, due to reduced autonomy, the person is faced with additional expenses for integration in social life.

4.2.3.2 Organisation and financing of home care services

Nursing home care is financed by health insurances but people may be asked to pay a supplement for certain services offered by freelance nurses. Palliative care and end-of-life care at home are also free but necessitate a prescription from a doctor. A payment of two instalments of EUR 483 may be charged for the hire of equipment and for medication.

Sitting services (which may also offer respite for carers) are not covered by the health service. Therefore there are no set fees and such services are often costly for patients/carers e.g. EUR 18-32 per night and EUR 11-20 per day depending on the patient's needs.

The situation regarding home care services (e.g. help accomplishing certain tasks linked to daily life such as doing the shopping, preparing meals, household tasks and personal hygiene) depends on one's place of residence. In the French and German speaking part of Belgium, such home care services are coordinated and registered. The contribution to be borne by the person requiring the service is means tested but it is also possible to apply to health care insurances for assistance. In the French speaking part of the country, home care services are chiefly regulated by the Decree “Picque” of June 1989, which regulated the establishment and functioning of “centres for the coordination of care and home care services” (Declercq and Van Audenhove, 2004).

In the Flemish speaking part of Belgium (in Brussels and in Flanders) there is the “zorgverzekering” which covers care services at home and in institutions. It is obligatory in Flanders and optional in Brussels. It costs EUR 25 per year and entitles people at home to a payment of EUR 90 per month and people living in an institution to a payment of EUR 125 per month (provided that they fulfil the necessary criteria for payment). “Community care centres” exist in the Flemish part of Belgium, which provide a meeting place for people over 55 and those in need of home care. The idea is to provide information, prevent isolation and make professional care more accessible (Declercq and Van Audenhove, 2004).

In 2004, the government introduced “service cheques”. The cheques are for € 6.20 per hour of help and are tax deductible for the person who purchases them. They can cover in-house activities such as ironing, cooking and cleaning or outdoor activities such as shopping and transportation (Declercq and Van Audenhove, 2004).

For the refunded services, a personal quota (known as a moderating ticket) is borne by the person insured. In 2001, the principle of the “maximum to invoice” was established. It fixes an absolute limit that families should have to pay per year in moderating tickets for essential refundable care. This limit is fixed according to the income of the family.

4.2.3.3 Kinds of home care services available

The kinds of services that are available include home help, sitting services, respite care, day care centres and night care centres etc.

Private and public organisations provide meals services.

Some local authorities organise other forms of help such as transportation and shopping. Such services may be provided by voluntary organisations, municipalities or non-profit organisations (Declercq and Van Audenhove, 2004).

4.2.3.4 Sources

Declercq, A. and Van Audenhove, C. (2004), *National Background Report for Belgium*, EURO-FAMCARE,
http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_belgium_rc1_a4.pdf

Delpérée, N. (2004), *Les aspects sociaux, juridiques et éthiques en cas de démence*, Ligue Alzheimer

Information provided by a member of the Scientific Council of the Ligue Alzheimer (2006).

4.2.4 EuroCoDe network organisations

Alzheimerliga der Deutschsprachigen Gemeinschaft VoE - Patienten Rat & Treff

Aachener Strabe 6

4700 Eupen

Tel: +32 -87- 55 22 88

Fax: +32 -87- 55 76 83

patienten.rat@skynet.be

www.alzheimer.be/alzheimerliga/index.html

Belgische Vereniging voor Gerontologie en Geriatrie

Nieuwpoort Steenweg, 57

8400 Oostende

Tel: +32 -59- 55 34 04

Fax: +32 -59- 51 99 43

jpbaeyens@skynet.be

www.geriatrie.be

Cyclotron Research Centre

Université de Liège

Unité médicale, Bâtiment B 30 - Sart Tilman

4000 Liège 1

Tel: + 32 -4- 366 23 16

Fax: + 32 -4- 366 29 46

eric.salmon@ulg.ac.be

www.ulg.ac.be/crc/fr/esalmon.html

ExpertiseCentra Dementie Vlaanderen

Sint Bavostraat 29

02610 Wilrijk

Jum.verschraegen@dementie.be

www.dementie.be

Ligue Alzheimer

Montagne Sainte Walburge 4b

4000 Liège

Tel: +32 -4- 229 58 10

Fax: +32 -4- 225 86 93

henry.sabine@skynet.be

www.alzheimer.be

Ligue Nationale Alzheimer Liga

Rue Sainte-Catherine 16-18
1000 Bruxelles
Tel: +32 -2- 289 60 12
jan.hertecant@cawmozaiek.be
www.alzheimer.be

Quality of Life and Dementia

Department of General Practice
Academisch Centrum Huisartgeneeskunde
KU Leuven
Kapucijnenvoer 33 Blok J
3000 Leuven

Société belge de gériatrie et gérontologie

CHU Sart-Tilman B35
Service de Gériatrie
Domaine Universitaire du Sart-Tilman
4000 Liège
Tel.: +32 -4- 366 79 93
Fax: +32 -4- 366 82 74
Jean.Petermans@ulg.ac.be
www.geriatrie.be

Société belge de Neurologie - Belgische Vereniging voor Neurologie

Departments of Neuroanatomy & Neurology, University of Liège
Rue de Pitteurs, 20,
4020 Liège
Tel.: +32 -4- 336 51 91
Fax: +32 -4- 225 64 51
jschoenen@ulg.ac.be
www.neuro.be

University Hospital Gasthuisberg

Neurology Department
Herestraat 49
3000 Leuven
Tel: + 32 -16- 34 42 80
Fax: + 32 -16- 34 42 85
rik.vandenberghe@uz.kuleuven.ac.be
www.uzleuven.be/diensten/neurologie/patient/geheugenkliniek/

Vlaamse Alzheimer Liga

Stationstraat 60-62
2300 Turnhout
Tel: +32 -14- 43 50 60
Fax: +32 -14- 43 76 54
vlaamsealzheimerliga@skynet.be
www.alzheimer.be

4.3 Bulgaria

4.3.1 Prevalence of Dementia

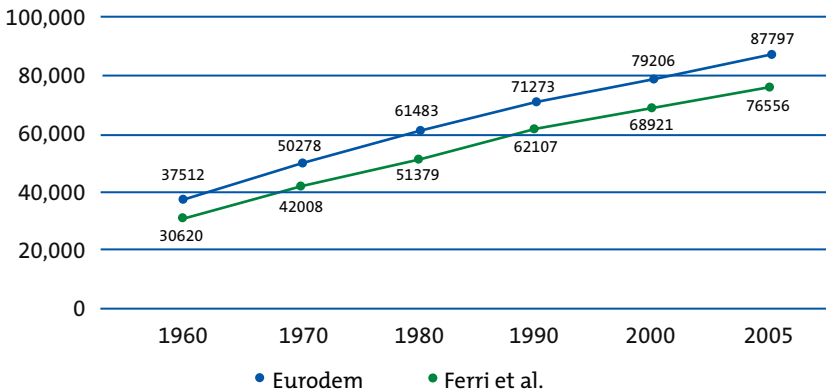
Alzheimer Europe estimates the number of people with dementia in Bulgaria in 2005 as being between 76,556 (Ferri et al.) and 87,797 (Eurodem). This represents 0.99% (Ferri et al.) to 1.13% (Eurodem) of the total population of 7,761,049. The number of people with dementia in Bulgaria as a percentage of the total population is lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Bulgaria in 2005

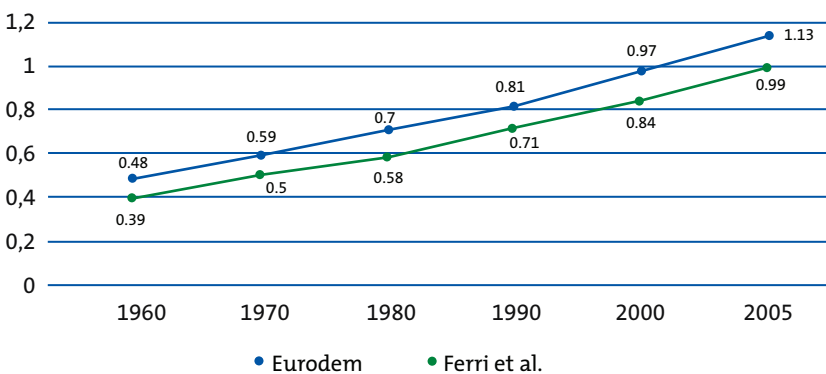
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	2,589	1,490	4,079	
60–64	3,175	1,114	4,289	3,941
65–69	3,866	2,468	6,334	5,233
70–74	7,725	8,699	16,424	12,574
75–79	5,963	11,644	17,607	16,987
80–84	7,994	14,873	22,867	21,488
85–89	3,138	6,775	9,914	16,333
90–94	1,863	3,631	5,494	
95–99	231	559	790	
Total	36,544	51,253	87,797	76,556

The following charts show a) the increase in the number of people with dementia in Bulgaria from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005. This was also the case for the number of people with dementia as a percentage of the total population.

The number of people with dementia in Bulgaria from 1960 to 2005



The number of people with dementia in Bulgaria as % of total population from 1960 to 2005



4.3.2 Availability of anti-dementia drugs

4.3.2.1 The availability of medicines in general

Alzheimer Europe was unable to obtain detailed information on the general reimbursement system of medicines in Bulgaria.

4.3.2.2 The availability of Alzheimer treatments

According to Alzheimer Bulgaria, except for memantine, all anti-dementia treatments are available in Bulgaria, but none of them are part of the reimbursement system in that country and patients and carers need to cover these costs themselves.

4.3.3 Organisation of Home care

4.3.3.1 Legislation relating to the provision of home care services

There are three main pieces of legislation relevant to the provision of home care services in Bulgaria:

- The Social Assistance Act of 19 May 1999 (amended on 29 December 2002 and by the Regulations for Implementation of the Social Assistance Act)
- Regulations for the Social Service of Persons and Families
- Ordinance No. 4 of 16 March 1999

Within Bulgarian cultural tradition, it is considered the duty of families to take care of their elderly relatives even though this is not a legal obligation.

4.3.3.2 Organisation and financing of home care services

The municipalities are responsible for providing home care services which they call family care services. The provision of such services is regulated by the Social Assistance Act as well as by the Regulations for the Social Service of Persons and Families and Ordinance No. 4.

In accordance with the Regulations for Implementation of the Social Assistance Act, family care services assess the needs of each person, state the goals to be achieved and draw up an individual care plan. Every six months, the plan is checked and modified if necessary.

Eligibility criteria for family care services include being over 60, being unable to care for oneself, having no relatives and not having signed a contract for ceding property in return for financial support and/or care. This is stipulated in Ordinance No. 4 of 16 March 1999. The Regulations for the Social Service of Persons and Families cover the provision of family care services to people over 65 years old. However, generally speaking priority is given to people over the age of 75, particularly those living alone or whose income is less than the social pension.

Some people who are eligible for home care services such as cleaning do not take up the offer as they cannot afford the cleaning materials.

4.3.3.3 Kinds of home care services available

Article 5 of the Regulations for the Social Service of Persons and Families mentions the following home care services (amongst others):

- Meals-on-wheels
- Monitoring of health
- Assistance receiving medical assistance
- Provision of bedding, clothes and shoes (according to current standards for people lacking private means living in homes)
- Small repairs in the home and of household appliances (carried out by an electrician or plumber)
- Entertainment and pursuits
- Purchase of food and necessities (using the person’s own money)

Ordinance No. 4 of 16.03.1999 refers to the following home care services:

- Meals-on-wheels
- Personal hygiene (e.g. daily washing, putting on incontinence pads, bathing a few times a week, other tasks linked to personal hygiene)
- Home cleaning (e.g. washing the dishes, cleaning rooms)
- Assistance obtaining necessary aids
- Help with interaction and social contacts (e.g. conversations, strolls, reading)
- Entertainment in and out of the home (e.g. organising celebrations)
- Paying bills (e.g. electricity, heating, telephone) with the person’s own money

Regional (municipal) social assistance centres exist which also provide family care services e.g. day care centres for the elderly and organize social activities.

4.3.3.4 Source:

Dimova, L. and Dimov, M. (2004), *National Background Report for Bulgaria*, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_bulgaria_rc1_a4.pdf

4.3.4 EuroCoDe network organisations

Alzheimer Bulgaria
 16, Bacho Kiro Str.
 1000 Sofia
 Tel: +359 -2- 989 45 39
 Fax: +359 -2- 986 17 65
office@alzheimer-bg.org
www.alzheimer-bg.org

Bulgarian Association on Aging

Blvd.Vitosha 36

1000 Sofia

Tel:+359 -2- 987 68 77

Fax:+359 -2- 87 41 45

medlib@sun.medun.acad.bg

Bulgarian Society of Neurology

Department of Neurology, Blvd. Tzarigradsko shosse, 4 km

1113 Sofia

Tel.: +35 -92- 70 32 98

Fax: +35 -92- 70 93 90

stamenova@mbox.cit.bg

Foundation Compassion Alzheimer Bulgaria

P.O. Biox 380

9000 Varna

Tel: +359 -899- 43 20 79

Fax: +359 -56- 50 58 73

compassion.alz@abv.bg

4.4 Cyprus

4.4.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Cyprus in 2005 as being between 6,054 (Ferri et al.) and 6,725 (Eurodem). This represents 0.81% (Ferri et al.) to 0.9% (Eurodem) of the total population of 749,175. The number of people with dementia in Cyprus as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

A survey was carried out by RAI Consultants Services Ltd in 2004 on behalf of the Cyprus Alzheimer’s Association in order to measure the prevalence and incidence of Alzheimer’s disease in Cyprus. 14,125 people were contacted via a door-to-door survey. Information was eventually collected on 3,001 people over 60 years of age. From this information, a prevalence rate of 12.7% was established for people with dementia over the age of 60 which would mean that there were 14,000 people with dementia in Cyprus. This estimate is just for Greek Cypriots in southern Cyprus.

Table 1: The number of people with dementia in Cyprus in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	239	141	380	
60–64	259	82	342	306
65–69	303	168	471	438
70–74	482	485	967	829
75–79	384	666	1,050	1,056
80–84	575	866	1,442	1,362
85–89	408	746	1,154	2,063
90–94	284	493	777	
95–99	54	89	143	
Total	2,989	3,736	6,725	6,054

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Cyprus since 1960.

4.4.2 Availability of anti-dementia drugs

4.4.2.1 The availability of medicines in general

In Cyprus, medicines are provided by hospitals or institutions. Drugs prescribed are included in an approved list. Patients are required to pay 50% of the costs of treatments on the approved list.³³

4.4.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Cyprus and are part of the reimbursement system. Alzheimer Europe was unable to obtain detailed information on reimbursement restrictions in Cyprus.

4.4.3 Organisation of Home care

Alzheimer Europe was unable to obtain sufficient information to describe the organisation of home care in Cyprus.

4.4.4 EuroCoDe network organisations

Cyprus Neurological Society
Limassol Medical Association,
P.O. Box 50339
3603 Limassol
Tel.: +357 -5- 36 32 86
Fax: +357 -5- 74 63 98
chrisele@spidernet.com.cy

Pancyprian Alzheimer Association
Stadiou Street 31a
6020 Larnaca
Tel: +357-24- 62 71 04
Fax: +357-24- 62 71 06
alzncyprus@yahoo.com

4.5 Czech Republic

4.5.1 Prevalence of Dementia

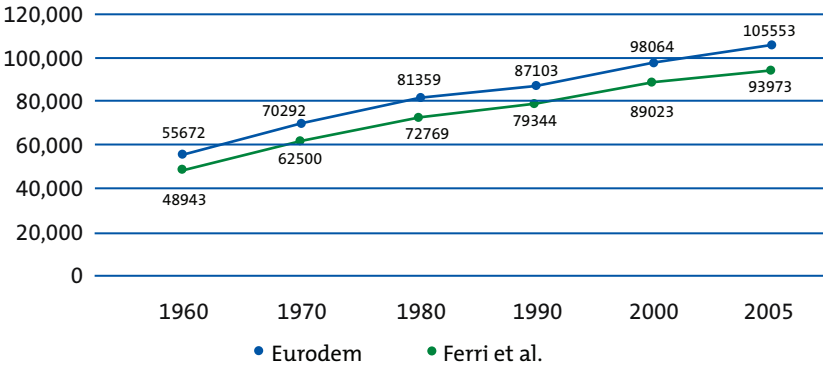
Alzheimer Europe estimates the number of people with dementia in the Czech Republic in 2005 as being between 93,973 (Ferri et al.) and 105,553 (Eurodem). This represents 0.92% (Ferri et al.) to 1.03% (Eurodem) of the total population of 10,220,577. The number of people with dementia in the Czech Republic as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in the Czech Republic in 2005

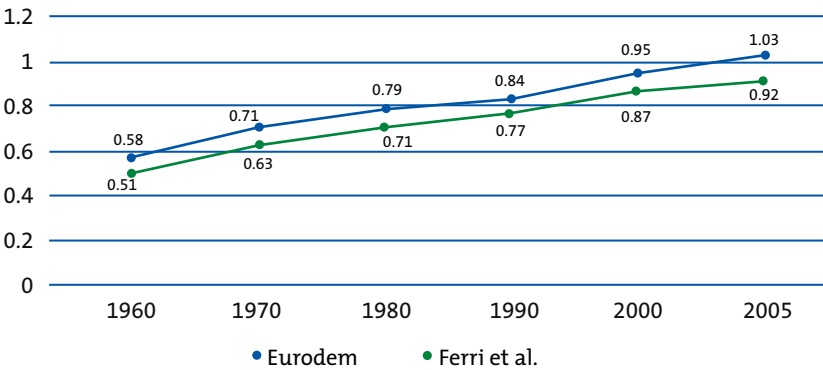
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	3,541	1,986	5,527	
60–64	4,309	1,453	5,762	5,237
65–69	3,992	2,538	6,530	6,220
70–74	7,473	8,870	16,343	14,108
75–79	5,973	13,422	19,394	19,184
80–84	8,319	19,734	28,053	26,208
85–89	3,037	9,488	12,525	23,016
90–94	2,333	7,472	9,805	
95–99	299	1,315	1,615	
Total	39,276	66,277	105,553	93,973

The following charts show a) the increase in the number of people with dementia in the Czech Republic from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia almost doubled between 1960 and 2005. In the same period of time, the number of people with dementia as a percentage of the total population increased from 0.58 to 1.03% (Eurodem).

The number of people with dementia in the Czech Republic from 1960 to 2005



The number of people with dementia in the Czech Republic as % of total population from 1960 to 2005



4.5.2 Availability of anti-dementia drugs

4.5.2.1 The availability of medicines in general

In the Czech Republic, medicinal products are classified into three categories and reimbursement may vary from 0 to 100%. The first category is fully covered and includes the cheapest effective preparations of all essential products. For medicines in the second or third category, patients need to either partly or fully co-finance the costs of the medicines.³⁴

4.5.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in the Czech Republic and are part of the reimbursement system.

³⁴ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

The Czech Republic limits reimbursement of these drugs to prescriptions filled in by specialists (neurologists, psychiatrists and geriatricians) both for initiation and continuation decisions of these treatments. Furthermore, acetylcholinesterase inhibitors are limited to patients with an MMSE score between 20 and 13 and memantine to patients with an MMSE score between 16 and 6.

There are no reimbursement restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	20–13	20–13	20–13	16–6
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.5.3 Organisation of Home care

4.5.3.1 Background information about dementia and home care services

In 1991, the Ministry of Health established and financially supported 40 non-governmental Home Care Agencies. The Czech Catholic Charity, the Czech Red Cross and several individual nurses set up the first private Home Care Agencies. Originally, these were intended mainly for the elderly, the chronically sick and the dying. 1993 saw the creation of the Association of Home Care whose role it was to collect data related to home care and to unite home care personnel.

In 2000, almost 107,000 people received home care services from home care agencies and about 80% of these were elderly people (aged 65 or over) in need of both health and social care (US Dept of Commerce, 2000). In 1995, there were 593 registered home care associations. Of these, 498 provided 24 hour round the clock comprehensive home care, 42 provided comprehensive home care on a limited basis and 53 provided specialised home care services for people with specific diagnoses e.g. neurological diseases, cancer etc.

4.5.3.2 Legislation relating to the provision of home care services

Decree No 182/91 of the Ministry of Labour and Social Care regulates the direct financing from local council budgets of individual social care and assistance. However, legislation on social services, dating from laws passed during the socialist era, persists, some of which has become unclear due to numerous changes that have since been made. The State is not actually obliged to provide social care.

The Volunteer Services Act No. 198 of 24 April 2002 lays down certain conditions for the involvement of volunteer workers in a number of domains including that of providing assistance to the elderly. It also contains provisions for the financial support of organisations which select, register and train volunteers e.g. in the form of pension payments, insurance payments and certain expenses.

Chapter 31 of the Charter of Fundamental Rights and Freedoms, which is contained in article 3 of the Constitution of the Czech Republic, states that “Everybody has the right to protection of his or her health. Citizens are entitled under public insurance to free medical care and to medical aids under conditions set by law.” This right does not, however, extend to social care. According to Holmerová (2004), the division between health care and social care is the main obstacle to the provision of care to the dependent elderly. Fortunately, some NGOs (such as the Diakonie, Charita and Czech Red Cross) and some municipalities provide both health and social care, thereby bridging this gap.

Dependency is defined in several laws but in a different way for each purpose and situation. In Act 100 on Social Security, which covers entitlement to an allowance, one of the criteria for dependency is that the person is over 80. Definitions governing entitlement to technical aids, household adaptations, and exceptional benefits and allowances exclude people with dementia.

With regard to carers in paid employment, the Act on Sickness Insurance (1956) entitles family carers to special leave to care for a sick relative. They receive an allowance of 69% of the average wage for the first 9 days of the sickness. This can only be claimed once for each specific diagnosis. The worker must also reside in the same household as the person who is in need of their care.

4.5.3.3 Organisation and financing of home care services

The health insurance system is currently based on a third party fee-for-service payment model and is compulsory. Health care is reimbursed by the general health care insurance but co-payments are necessary in some cases. Home health nursing services (up to 3 daily visits by a nurse to the patient’s home) are reimbursed if provided by health professionals under contract to the insurance company and if approved by a physician. If more visits are required, patients must pay for them themselves.

Some social services, especially the care in homes for people with disabilities, on the other hand, are financed by the Ministry of Labour and Social Affairs. Some are provided and funded by regional authorities (residential homes) and by municipalities (home help). Clients may have to contribute towards such services depending on their income. Unfortunately, despite the recent increase in the number of providers, there may be a lack of provision of services to people with limited incomes due to a lack of adequate financing.

According to the National Plan on Ageing, one of the aims of the State is to develop a system of integrated home service, as a necessary condition to enable older people to remain home, which should be included in a new concept of health and social care. Nevertheless, in some municipalities, home help is simply not available. When questioned about the lack of home care services, municipalities frequently respond that the family should provide the necessary care or that institutionalisation is recommended (Veselá, 2003 in Holmerová).

Some home care associations recruit lay people, particularly students or elderly people, to assist them in their work. They also cooperate with NGOs, particularly those of elderly people such as Life 90. Some home care associations also provide information, education and practical training in simple as well as more specialised nursing techniques to relatives or people who are close to the patients in order to improve the health, wellbeing and/or quality of life of patients.

There are also social services agencies (about 400 in 2000) which offer some basic personal care (basic nursing care). Unfortunately, as there is no clear separation between health care and social care, problems with financing sometimes occur.

4.5.3.4 Kinds of home care services available

Home health care services may include both skilled and basic nursing care, as well as rehabilitative services, transportation, and counselling. Personal care in the home is usually considered as part of home nursing care. Personal assistance with everyday tasks is not covered by social care legislation and is not routinely provided.

Home help services include housework, shopping, laundry and meals-on-wheels. Some communities also offer a meal service for older people in the dining rooms of schools.

Transportation to and from health services is covered by general health insurance and is therefore free. Some day care centres also provide transport services. There are not many day care centres and many of those that exist are only open for a few hours a day. However, in the last few years, some day care units for people with dementia have been set up. They are usually open for more than 8 hours a day.

Information, counselling and respite care exist in the Czech Republic but are not covered by social care legislation. It is therefore left to the discretion of local

authorities, NGOs and other organisations. Respite care in the form of short stays in respite centres, for example, is provided by the organisation Life go. Respite care at home (“granny sitting”) is provided by the Czech Alzheimer Society.

4.5.3.5 Sources

Act No. 198 of 24 April 2002 on Volunteer Services, amending certain regulations (Volunteer Services Act)

Holmerová, I. (2004), National Background Report for the Czech Republic, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_czech_rc1_a4.pdf

Misconiová, B. (2005), Comprehensive Home Care in the Czech Republic, unpublished report

Topinkova, E. (2005), WHHO-Compendium Text (extract on the Czech Republic), <http://www.nahc.org/WHHO/WHHOcomptext.html>

US Dept of Commerce (2000), Czech Republic: Home Care Medical Equipment, http://www.factbook.net/countryreports/cz/Cz_HomecareMedical_mkt.htm

4.5.4 EuroCoDe network organisations

Czech Alzheimer Society

Centre of Gerontology, Šimůnkova 1600
182 00 Prague 8
Phone: +420 -2- 86 88 36 76
Fax: +420 -2- 86 88 27 88
Martina.Rokosova@gerontocentrum.cz
www.alzheimer.cz

Czech Neurological Society

Videnska 800
140 59 Prague 4
Tel.: +420 -2- 61 08 36 95
Fax: +420 -2- 472 15 14
keller@ftn.cz or neurolog@ftn.cz
www.czech-neuro.cz

Czech Society of Geriatrics and Gerontology

Přednostka Geriatrické kliniky
Praze Londýnská 15
120 00 Prague 2
etopink@vfn.cz
www.cggs.cz

Czech Society of Gerontology and Geriatrics

Šimůnkova, 1600
182 00 Praha 8 -Kobylisy
Tel: +420 -2- 88 36 76
Fax: +420 -2- 88 27 88
gerontocentrum@telecom.cz
www.gerontocentrum.cz

4.6 Denmark

4.6.1 Prevalence of Dementia

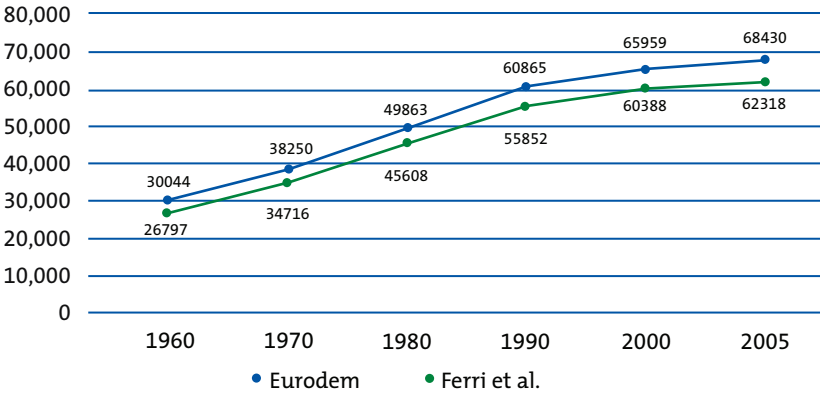
Alzheimer Europe estimates the number of people with dementia in Denmark in 2005 as being between 62,318 (Ferri et al.) and 68,430 (Eurodem). This represents 1.15% (Ferri et al.) to 1.26% (Eurodem) of the total population of 5,411,405. The number of people with dementia in Denmark as a percentage of the total population is almost identical to the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Denmark in 2005

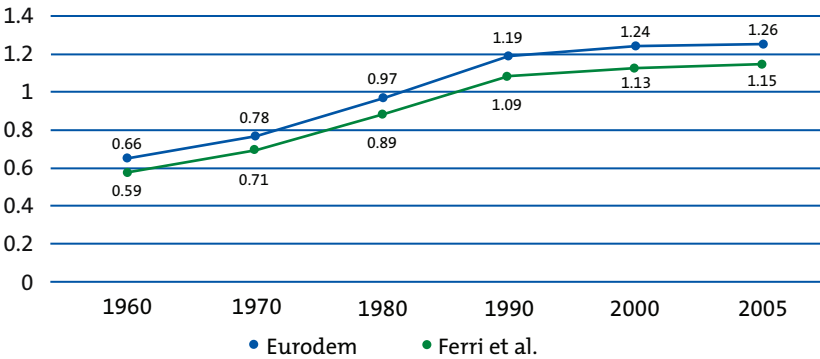
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,875	1,032	2,907	
60–64	2,504	756	3,260	2,875
65–69	2,527	1,373	3,900	3,619
70–74	4,066	3,998	8,064	6,904
75–79	3,430	6,037	9,467	9,514
80–84	5,486	10,191	15,677	14,732
85–89	3,845	10,135	13,980	24,674
90–94	2,294	6,694	8,988	
95–99	377	1,810	2,187	
Total	26,404	42,026	68,430	62,318

The following charts show a) the increase in the number of people with dementia in Denmark from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen from the table, the number of people with dementia rose from 30,044 to 68,430 (Eurodem) between 1960 and 2005. This represents an increase of over 100%. In the same period of time, the number of people with dementia as a percentage of the total population almost doubled i.e. rising from 0.66% to 1.26% (Eurodem).

The number of people with dementia in Denmark from 1960 to 2005



The number of people with dementia in Denmark as % of total population from 1960 to 2005



4.6.2 Availability of anti-dementia drugs

4.6.2.1 The availability of medicines in general

In Denmark, medicines on a special list (essentially all prescription medicines) are covered up to a certain degree depending on the overall total expenditure on medication of a patient during a year.

- If the total expenditure on medicines in a year does not exceed DKK 480 (approx. € 63), the patient covers 100% of the drug costs.
- For total medicines expenditure between DKK 480 and DKK 1,165 (approx. € 156), the patient covers 50% of the costs.
- For total medicines expenditure between DKK 1,165 and DKK 2,730 (approx. € 366), the patient covers 25% of the costs.
- For total medicines expenditure above DKK 2,730, the patient covers 15% of the costs.

Nevertheless, for cases where there is a well documented need for extensive and permanent treatment, the reimbursement rate can go up to 100% of the part of the total co-payment which is in excess of DKK 3,520 (approx. € 472).

Finally, in special cases the health service can contribute to medicines not on the list or contribute fully to medicines for dying persons.³⁵

4.6.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Denmark and are part of the reimbursement system. Reimbursement is dependent on a prior authorisation by the Danish Medicines Agency according to the following procedure.

An application for reimbursement has to be sent to the Danish Medicines Agency and any doctor can apply for reimbursement for a patient. Nevertheless, reimbursement is only granted, if a specialist in neurology, psychiatry or geriatrics has made the diagnosis.

For patients with mild to moderate dementia a CT (or MR scan) of the brain has to be performed first. The physician also has to state that causes other than Alzheimer are excluded.

The system does not provide upper or lower MMSE limits for the treatment with different anti-dementia drugs, but reimbursement is dependent on a clinical grading. Reimbursement for donepezil, rivastigmine and galantamine is only granted to patients in mild to moderate stages and memantine to patients in moderate to severe stages.

The application has to be renewed every 12 to 15 months. Renewal of reimbursement of memantine depends on a statement by the physician that a continuous effect in the individual patient is still observed. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

³⁵ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.6.3 Organisation of Home care

4.6.3.1 Background information about dementia and home care services

In 1987, legislation more or less put a stop to the construction of conventional nursing homes for older people and encouraged the development of independent specialised housing as well as home care services (Leeson, 2004). The current trend is to try to enable people to remain at home for as long as possible.

In Denmark, there is a classification system based on age with people over 60 forming the 3rd age group and those over 80 the 4th age group. There are approximately 700,000 people over the age of 67 in Denmark (the official retirement age). Of these, 172,000 receive long-term home-help and a further 7000 to 8000 people receive temporary home-help. The vast majority of people receiving long-term home-help live in their own homes. (Leeson, 2004). Jarden and Jarden (2002) estimate that there are about 189,000 people over 80 in Denmark. A high percentage of the 4th age group receive home care services.

4.6.3.2 Legislation relating to the provision of home care services

The Law on Social Assistance (1976) states that all communes must provide home help for the elderly. There is no difference between the social protection offered to people suffering from dementia and that offered to people who are dependent. The Social Service Legislation contains a few relevant references (taken from Leeson, 2004):

According to paragraph 67a of the Social Services Legislation, local or regional authorities must determine whether there are any relatives or other people who could represent the older person i.e. in an advocacy role.

Paragraph 71 part 60 states that local authorities should take into consideration the global situation of the older person, including the overall network, when assessing the need for assistance. Relatives are expected to participate in supporting the older person in the home. It is also suggested in part 96 of paragraph 71 that a relative should assist in completing the various application forms and that everyone should be made aware of this possibility.

Paragraph 72 deals with respite care. It states that local authorities are obliged to provide respite help to spouses, parents or other close relatives caring for a physically or mentally disabled person.

4.6.3.3 Organisation and financing of home care services

The Danish healthcare system provides free and equal access to health care to all residents. It is funded through general taxation but access to care is not dependent on a person's financial status. Home care is divided into two categories - long-term or temporary. Long-term home care is provided free of charge but people may be

asked to contribute towards the costs of temporary home care depending on the level of their income (Jarden and Jarden, 2002).

According to the Ministry of Social Affairs (2002), a goal has been established to improve the organisation of dementia care in order to ensure good coordination between local authority services and the provision of treatment and care by the health service. Furthermore, the development of partnerships between the public and voluntary sectors is emphasised, for example in areas such as respite care.

Since 1989, the Integrated Home Service has encouraged medical personnel to work in the home care sector and social workers to work in medical institutions which permits a more flexible approach to home care particularly in times of need. Since 1 July 1989, dependent elderly people have been entitled to permanent and free home help.

Such assistance is offered following an assessment of the functional capacity of the person, of his or her needs and on the basis of the service level determined by the local authority (Ministry of the Interior and Health/Ministry of Social Affairs and Gender Equality, 2002).

In accordance with the Preventive Home Visits to the Ageing Law of July 1996, local authorities are obliged to offer preventive home visits to all citizens over 75 years of age at least twice a year. The aim of these visits is to encourage older people to use their own resources better and consequently allow them to preserve their functional capacities as long as possible and also to be informed of the resources available from the municipality. The elderly person can freely decide whether or not to accept the home visit and can decide which subjects should be discussed.

Since 1 July 2002, people receiving personal or practical services have been entitled to exchange the services that they have been allocated for other services that they would prefer (Ministry of the Interior and Health/Ministry of Social Affairs and Gender Equality, 2002). Since 1 January 2003, older people have had the right to choose the providers of the personal and practical help and assistance to which they are entitled. Local authorities therefore have to ensure that there are several service providers from which to choose. The older person can then decide whether they would prefer the help with personal care and/or practical tasks to be provided by a private person, the local authority or an authorised service provider. This means that a family member could be chosen and would be paid by the local authority. This had been possible for a long time for practical help but it has now been extended to encompass personal care (Jarden and Jarden, 2002).

4.6.3.4 Kinds of home care services available

Local authorities must provide nursing care in service users' homes and offer help and assistance to maintain physical and mental capacity. Such assistance should be provided in such a way that it encourages the participation of the older people

and helps them to manage alone thereby maintaining their autonomy for as long as possible.

Home care services may include 24 hour assistance from a nurse, the provision of meals, the possibility to adapt the home, day care centres, financial assistance and transport facilities. Sometimes this may also include having an alarm system, maintaining the garden and clearing away snow. Certain services, such as minor repair jobs, are not provided by the local authorities. Some voluntary associations offer assistance with such jobs. Otherwise, the person can purchase the services from the private sector.

Meals may be delivered to the home by the local authorities at a subsidised rate. They are sometimes prepared in residential homes and then distributed within the community. Day care centres also have meals facilities.

Local authorities may also provide or finance services aimed at keeping people active or promoting their health. Sometimes, such services are proposed and/or organised by voluntary associations but financed by the local authorities. Such services might include sports activities, tuition/lectures and companionship for older people who are lonely. In 1998, the Social Service Law introduced a yearly budget for the development and expansion of voluntary services (Jarden and Jarden, 2002). DaneAge is an association, with a nationwide network, which offers older people a wide range of activities and opportunities to socialise. It also provides respite care for carers of people with dementia and trains volunteers so that they can provide such services in people's homes. These volunteers are of all ages and from all walks of life (Leeson, 2004). Respite care is also offered by some nursing homes.

4.6.3.5 Consultation with people with dementia and carers

At the request of the Ministry of Social Affairs, 8 communes took part in a project based on home care for elderly people with dementia and their families. Some of the communes sent out questionnaires to obtain qualitative and quantitative information on the needs of the people with dementia and their carers.

The municipality of Vejle organised a project aimed at assessing users' satisfaction with home care services, getting a picture of how resources were used, establishing a common notion of what quality and quality objectives are and drawing up a plan for the achievement of defined objectives. Users, employees and politicians were all involved in the project. Users were involved in drawing up the questionnaires. There were also group and individual interviews for which the elderly-talk-to-elderly method was used. It was felt that involvement of users and an elderly persons council was effective in motivating people. (This project was not limited to people with dementia.) (EFILWC, 2002)

4.6.3.6 Sources:

European Foundation for the Improvement of Living and Working Conditions (EFILWC) (2002), Denmark – http://www.eirpfpimd.ie/living/socpub_cstudies/de3.htm (accessed 31/5/2005)

Jarden and Jarden (2002), Social and health-care policy for the elderly in Denmark, Global Action on Aging, <http://www.globalaging.org/elderrights/world/densocialhealthcare.htm>

Leeson, G.W. (2004), National Background Report for Denmark, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_denmark_rc1_a4.pdf

Ministry of the Interior and Health & Ministry of Social Affairs and Gender Equality (2002), Questionnaire on health and long-term care for the elderly, European Commission http://europa.eu.int/comm/employment_social/social_protection/health_en.htm

Witsoe-Lund, L. and Ibenfeldt-Schultz, L., Le système d'aide et de soins aux personnes âgées atteintes de démence sénile de type Alzheimer au Danemark. In Joël, M.-E. et Cozette, E. (2002), Prise en charge de la maladie d'Alzheimer en Europe, Inserm

4.6.4 EuroCoDe network organisations

Alzheimerforeningen

Skt. Lukas Vej 6,1
2900 Hellerup
Tel: +45 -39- 40 04 88
Fax: +45-39- 61 66 69
post@alzheimer.dk
www.alzheimer.dk

Danish Geriatric Society

Dept. of Geriatrics
Gentofte Hospital University of Copenhagen
Niels Andersens vej 65
2900 Hellerup
SUVDMAo1@gentoftehosp.kbhamt.dk
www.danskselskabforgeriatri.dk

Danish Gerontological Society

Aurehojvej, 24
2900 Hellerup
Tel: +45 -39- 62 76 27
Fax: +45 -39- 62 66 27
DGS@geroinst.dk
www.gerodan.dk

Dansk Neurologisk Selskab (Danish Neurological Society)

Faellessekretariatet, Esplanaden 8c, 3.
1263 Copenhagen
Tel.: +45 -35- 44 84 01
Fax: +45 -35- 44 84 08
bje@dadl.dk
www.dns-neuro.suite.dk

Rigshospitalet

Memory Disorders Research Unit
Department of Neurology 6702
Blegdamsvej 9
2100 Copenhagen
Tel: +45 -35- 45 25 80
Fax: +45 -35- 45 24 46
gunwal@rh.dk

University of Copenhagen

Department of General Practice and Central Research Unit for General Practice

Institute of Public Health

Copenhagen

4.7 Estonia

4.7.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Estonia in 2004 as being between 12,955 (Ferri et al.) and 15,065 (Eurodem). This represents 0.96% (Ferri et al.) to 1.12% (Eurodem) of the total population of 1,351,069. The number of people with dementia in Estonia as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Estonia in 2004

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	408	257	665	
60–64	494	203	697	670
65–69	602	478	1,080	926
70–74	1,009	1,512	2,521	1,954
75–79	688	2,171	2,858	2,679
80–84	704	2,514	3,218	2,883
85–89	420	1,789	2,209	3,844
90–94	280	1,225	1,505	
95–99	42	271	312	
Total	4,646	10,419	15,065	12,955

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Estonia since 1960.

4.7.2 Availability of anti-dementia drugs

4.7.2.1 The availability of medicines in general

In Estonia, patients normally pay EEK 50 (approx. € 3.20) as well as a further 50% of the cost of medicines exceeding that basic amount.

For listed chronic conditions, patients pay EEK 20 (approx. € 1.28) for medicines, whereas the health insurance fund covers either the totality of the remaining costs (for diseases, such as HIV, cancers, tuberculosis and others) or 75% of the remaining costs (for diseases, such as asthma or nephritis amongst others).

Finally, the health insurance fund also covers 90% of extra costs for children up to 10 years of age, persons on an invalidity pension and for people over the age of 63.³⁶

4.7.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are authorised for use in Estonia and with the exception of Exelon, they are part of the reimbursement system and reimbursed at 50%. Alzheimer Europe was unable to obtain detailed information on the specific conditions for reimbursement in Estonia and existing access restrictions.

4.7.3 Organisation of Home care

4.7.3.1 Background information about dementia and home care services

Estonia gained independence in 1918 and again in 1991 after over 40 years' occupation by the Union of Soviet Socialist Republics (USSR). From 1991 to 2000, new principles of social security were formed and new insurance systems were established. In Estonia, there is a high percentage of elderly people, particularly elderly single women living alone.

Since the early 1990s, the Estonian health care system has seen a number of reforms, mainly involving the reorganisation of the public funding system and a reduction in the number of hospitals and beds, whilst at the same time trying to make a more efficient use of funds. Consequently, the Estonian healthcare system has changed from a centralized state-controlled system to a decentralised one and from a state-funded system to one funded mainly through health insurance contributions. However, the health system had difficulty coping with the extent of decentralisation and consequently in the late 1990s, the Ministry of Social Affairs had to re-establish responsibility for overall health care planning (Hit Summary, 2004). Attempts have also been made to improve the quality and accessibility of general medical care services and to reintroduce the system of general practitioners.

The ongoing Estonian healthcare reform plans to reorganise health care so as to create a three levelled system with 4 centres for intensive care, a low concentration of long-term care (mainly in county centres) and dispersed primary health care (general practitioners). It is planned to limit the length of stays in hospitals. Consequently, there is a need to develop home nursing services and home care. There is a need to better coordinate health care and social welfare, particularly between general practitioners and home care and between long-term care, home nursing and home care (Kõre, 2005).

4.7.3.2 Legislation relating to the provision of home care services

The Social Welfare Act of 1995 (consolidated text December 2003) covers the provision of domestic services which are defined as being services provided to persons in their homes which help them cope in familiar surroundings. The Act states that local government authorities shall establish a list of domestic services and the conditions and procedure for their provision.

³⁶ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

§27 deals with the social welfare of the elderly. It states, “ In order to assist the elderly to cope in surroundings familiar to them and to have a life of equal value with other persons, rural municipality governments and city governments and city governments shall:

- Establish opportunities for cheaper alimentation;
- Ensure the accessibility of information concerning services provided and establish opportunities for the use of social services;
- Establish opportunities for interaction and hobbies;
- Ensure the security and independence of the elderly living in social welfare institutions, respect for their private life and the opportunity to participate in decision-making pertaining to their physical and social environment and future.”

In the “Development plan of Estonia’s nursing care network from 2004 to 2015”, it is stated that by 2007, adjustments in legislation based on the conception of nursing care (as well as welfare services) should enter into force.

4.7.3.3 Organisation and financing of home care services

The systems for health care and social welfare are relatively separate. Funding for social welfare comes from local government budgets, the state budget, people who voluntarily engage in social welfare and various other sources. The state budget provides local governments with funds for social welfare but the local governments may also have to use their own budgets for this purpose. Voluntary organisations, churches, foundations, commercial associations and non-profit organisations can all provide social services.

Local administrations are responsible for providing welfare services but this obligation is stated in the Law on Social Welfare of 1995 in very vague terms so the actual provision of services varies from one local administration to the next. The local administrations can provide services themselves or purchase them from private or public organisations. There are over 200 municipalities in Estonia and many of them are very small. For this reason, it is impossible for them all to offer a full range of services. Nevertheless, some of them join together and offer services jointly.

People who are in need of services must contact their local government in order to organise for a social worker to assess their needs and determine the kind of care they will receive (based on their needs and financial situation). Elderly people may be offered a geriatric assessment. Geriatric assessments were introduced in 2004. They consist of a single assessment to determine clients’ needs and to provide them with suitable services covering health care, nursing care and welfare services. The geriatric assessment team is composed of a physician, a nurse and a social worker and an international standardised tool is used for the assessment.

The providers of social services may charge beneficiaries or their families for their services. Children and kinsfolk are legally obliged to take care of their elderly relatives. However, if they are unable to do so or if an elderly person does not have any relatives, the Government must assume responsibility for their care.

In 2001 the Estonian Health Insurance Fund (EHIF) was created and replaced the existing Central Sickness Fund. It covers 94% of the population and is responsible for contracting health care providers, paying for health services and refunding medication costs amongst other things. In 2003, the EHIF started to cover expenses for long-term care, nursing care and some home care (Hit Summary, 2004).

4.7.3.4 Kinds of home care services available

In the Law on Social Welfare, domestic services are defined as services provided to persons in their homes which help them cope in familiar surroundings and it is stated that a list of domestic services and the conditions and procedure for their provision shall be established by local government authorities.

Social care may take the form of cash benefits (including daily allowances for daily living or personal assistance) or benefits in kind. However, services for people in need of assistance are mainly provided in special social care homes.

Services that are specifically provided for people with mental health problems or disabilities are the responsibility of the state. As such, they are managed and financed by the Ministry of Social Affairs and the state budget (Hit summary, 2004).

The Health and Long-term Care in Estonia: National report (Social Welfare Ministry), describes care services as:

- 1) Care by relatives/informal care – care or basic nursing care of an elderly or disabled family member or a relative in home conditions. Local governments offer supporting services to help people taking care of their relatives, e.g. domestic help and interval care, and assistance for establishment and activities of various support groups;
- 2) Family care – care of a person in a suitable family where he/she is not a member of family. Local governments offer supporting services to help the carers and pay a compensation to cover the costs related to caring, which is not a remuneration for work;
- 3) Home services (domestic help) – services offered to people at home, helping them cope in their usual environment, excluding the care that requires physical contact. Long-term supportive service, required continuously for independently living people to enable them to use general public services. Home services comprise, for example, cleaning and care of the housing, procurement of food, pharmaceuticals, other necessities and firewood or other fuel, information and assistance in administrative matters etc.;

- 4) Accommodation or housing service (including adaptation) – supplying a room for around-the-clock accommodation, including rental of accommodation. Adaptation of accommodation for the person to improve the possibility to move in the room and cope independently. In institutional welfare, providing of security must be offered in addition;
- 5) Personal assistance service – helping people with low coping capacity to perform activities, helping them to move around, in issues of personal hygiene, administrative matters at home and outside. Help is provided also in procedures requiring physical contact with the person. The main purpose of the service is to activate the person or maintain his/her capacity to cope;
- 6) Day-care in a welfare institution – supporting a person’s or his/her family’s coping capacity in institutions where the person spends the day. Day-care is provided by day centres where social services, developmental and hobby activities are offered during the day. An elderly or disabled person can visit the day centre as often as he/she wishes (has need for). Specialisation on the day care of the demented is possible. The purpose of day centres is to maintain the welfare and activity of their clients;
- 7) Long-term care in institution;
- 8) Strengthened support care service – improving the capacity of a person to cope independently and/or maintain the quality of life of a person with strong multiple disability by means of treatment, rehabilitation and assistance in everyday life;
- 9) Strengthened supervision care service – maintaining the quality of life of a person with increased level of danger by means of assistance in daily life procedures, in a care unit with enhanced supervision and assistance;

4.7.3.5 Consultation with people with dementia and carers

In the second half of the 1990s, with the help of a Dutch health care quality organisation, satisfaction surveys of patients and employees were launched. It is unclear whether people with dementia took part in these surveys.

According to §32 of the Social Welfare Act of 1995, in the provision of social services, social benefits and other assistance, a person’s wishes shall be considered except in the cases provided for in §§19, 20 and 25 of the said Act. These paragraphs cover people “of unsound mind” who have been placed in social welfare institutions without their consent and presumably do not cover people with dementia still able to live in their own homes.

4.7.3.6 Sources

European Observatory on Health Systems and Policies, Health Care Systems in Transition, HiT Summary for Estonia, WHO Regional Office for Europe, <http://www.who.dk/document/e85516sum.pdf#search='HiT%20summary%20AND%20Estonia'>

Kõre, J. (2005), Possibilities for integration of health and welfare services in Estonia in liberal political and economical circumstances, <http://www.socialeurope.com/pdfs/Venice/presentations/kore.pdf#>

Merle Malvet, Pille Liimal and Kaja Vaabel (2005), Social care and welfare for the elderly and social services, <http://www.parnu.ee/raulpage/welfag7.html#elderly>

Valdja, U. (2005), WHHO-Compendium Text (extract on the Estonia), <http://www.nahc.org/WHHO/WHHOcomptext.html>

Social Welfare Act of 1995, <http://www.legaltext.ee/text/en/X1043K6.htm>

Social Welfare Ministry (2005), Health and Long-term Care in Estonia: National report, April 2005, unpublished report.

Social Welfare Ministry (2005), Developmental plan of Estonia's nursing care network from 2004 to 2015, (<http://www.sm.ee> for Estonian version).

4.7.4 EuroCoDe network organisations

Estonian Association of Gerontology and Geriatrics - EGGA

Lembitu 8

50406 Tartu

Tel: +372 -7- 44 13 40

Fax: +372 -7- 31 86 07

egga@egga.ee

www.egga.ee

Estonian Ludvig Puusepp Society of Neurologists and Neurosurgeons

Dept. Neurology and Neurosurgery, Tartu University,

2 Ludvig Puusepp St.

51014 Tartu

Tel.: +372 -7- 31 85 46

Fax: +372 -7- 31 85 02

sulev.haldre@kliinikum.ee

4.8 Finland

4.8.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Finland in 2005 as being between 59,360 (Ferri et al.) and 65,362 (Eurodem). This represents 1.13% (Ferri et al.) to 1.25% (Eurodem) of the total population of 5,236,611. The number of people with dementia in Finland as a percentage of the total population is almost the same as the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Finland in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,807	996	2,803	
60–64	2,098	660	2,757	2,458
65–69	2,470	1,434	3,904	3,663
70–74	4,156	4,485	8,641	7,428
75–79	3,463	7,230	10,692	10,626
80–84	4,592	11,118	15,710	14,670
85–89	2,675	9,455	12,131	20,516
90–94	1,544	5,682	7,226	
95–99	232	1,266	1,498	
Total	23,036	42,325	65,362	59,360

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Finland since 1960.

4.8.2 Availability of anti-dementia drugs

4.8.2.1 The availability of medicines in general

In Finland, medicines are generally reimbursed at a level of 42% of the cost of medicines. Nevertheless, for serious and chronic conditions, the reimbursement system lists a number of medicines for which the reimbursement can be 72% or 100% of the cost of medicines over the value of € 3 per product which the patient will need to cover out of his/her own funds.

Should the total pharmaceutical expenses of an individual exceed €616.72 in a year, these costs are fully covered without participation by the patient.³⁷

4.8.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Finland and are part of the reimbursement system. The reimbursement system does not provide a list of specific examinations to be carried out, but for Alzheimer treatments to be reimbursed a diagnosis of Alzheimer’s disease must be established by a specialist who will carry out a thorough examination which often includes a CT or MRI scan. There are no upper or lower MMSE limits for the treatment with different anti-dementia drugs. Any doctor can prescribe Alzheimer treatments, but to be reimbursed, the prescription must be accompanied by a statement of a specialist doctor.

There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. In open wards, the normal reimbursement continues, whereas for formal institutional care, the institution will cover the cost of these medicines.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.3 Organisation of Home care

4.8.3.1 Background information about dementia and home care services

In Finland, there are an estimated 300,000 informal caregivers. Only 20,000 of these are official informal caregivers. This number refers to informal care giving in general. The number of informal carers for people with dementia is not specified. Finland has separate legislation on informal care (informal care agreement, financial compensation, required services and respite periods for the family caregiver). In order to provide informal care, the carer and the municipality make an agreement on the provision of informal care. The problem is, however, that the municipalities don’t necessarily have enough financial resources to support informal care giving

³⁷ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

and in different municipalities, inhabitants are not treated on an equal basis when it comes to sorting out the allowance for this kind of support. This means that at present only a proportion of family members providing informal care are receiving an informal care allowance.

This question of informal caregiving is currently under discussion. The detection of informal care, as well as proposals for developing it, have been made to the Government. The Alzheimer Society of Finland (ASF) has made a statement on this developmental work. The ASF pointed out, for example, that financial support should not be the only means of support for informal care giving, but in addition to that services are needed. From the ASF's point of view, financial compensation for the family carer should be combined with other services. Financial compensation makes it possible for many carers to provide informal care.

4.8.3.2 Legislation relating to the provision of home care services

There is national legislation concerning provisions for home care services. In the Constitution of Finland (731/1999) basic rights and liberties of inhabitants are defined. In Chapter 2, §6, the principle of equality is defined; §7 defines the right to life, personal liberty and integrity and in §19, the right to social security is defined. With regard to people with dementia, this means, that no one shall be treated differently from other people on the grounds of disability or age. They have a right to human dignity and those who cannot obtain the necessary means for a dignified life have the right to receive indispensable subsistence and care. Everyone is guaranteed by an Act the right to basic subsistence in the event of illness and disability.

The Social Welfare Act (710/1982) defines social welfare: social services, social assistance, social allowance and related measures intended to promote and maintain the social security and functional ability of the individual, the family and the community. §17 of this Act defines municipalities' responsibilities in organising services (home-help services, support for informal care). In §20, home-help services are defined. In §21, it is stated that home-help services are provided on the grounds of impaired functional capacity, illness or to persons in need of assistance in coping with functions and activities.

In the Social Welfare Decree (607/1983), §9, the way that home-help services are organised is defined: 1) assistance, personal attendance and support provided at home by a trained home helper for house aid for an individual or a family and 2) auxiliary services (meals-on-wheels, maintenance of clothes, bathing, cleaning, transportation and services promoting social interaction).

In the Act on the Status and Rights of Social Welfare Clients (812/2000), it is stated that clients' wishes and opinions must be taken into account in planning and providing social welfare. If a person cannot participate in planning because of their illness, family carers' opinions should be used in order to determine clients' will.

4.8.3.3 Organisation of home care services

The Ministry of Social Affairs and Health in Finland is responsible for general planning, guidance and supervision of services aimed at older people. In Finland, there are 444 municipalities, which are independently responsible for providing social and health care services. According to the Act on Planning and Government Grants for Social Welfare and Health Care (733/1992), municipalities receive financial support from the Government in order to organise these services.

Each municipality organises services independently, which means, for example, that they are responsible for organising home help, housing services, institutional care and support for informal care. The way that services are organised may vary (for example municipalities can provide services independently themselves, they can organise/provide services together with another municipality, or they can provide a voucher to service users so they can buy services from a private service provider).

During the past decade, increasing attention has been paid to the role of different bodies in organising and funding services. The overall policy still holds that the public sector (municipalities) is responsible for organising services. The role of the private sector (including non-governmental organisation/foundations, in which the municipalities often have their representatives) in providing services has also grown. The role of non-governmental organisations is particularly important in the field of housing services (sheltered homes).

In Finland, all inhabitants are legally obliged to have social insurance. This obligatory social insurance is intended to cover everyone for the financial impact resulting from old age, work disability, sickness, unemployment and death of dependents.

However, there is inequality in access to services. Concerning people with dementia, this inequality means that getting first-hand information and adaptation training, for example, depends heavily on which municipality the patient with dementia lives in. The role of service providers from the private sector has therefore become more important and expectations for the future of this sector are high. However, this places people with dementia on an unequal footing due to higher expenses. Private services don't exist in all municipalities. The use of service vouchers is an option for people who need home services. Municipalities can offer these vouchers to their inhabitants in order to buy services from the private sector.

The Government's Target and Action Plan for Social Affairs and Health for 2004-2007 and its recommendations specify the goals relating to social welfare and health care policy. In the plan, the Government sets down for the next four years the development targets and recommendations for social welfare and health care. In this plan, there are guidelines for care and services for elderly people. The main policy aim is to ensure that as many older people as possible are able to live independent lives in their own homes.

These targets and recommendations apply primarily to the municipalities. The plan also includes recommendations for measures through which the central government can support the municipalities in reaching their targets. In order to carry out this policy each municipality is expected to have an up-to-date policy strategy concerning care for older people that safeguards their social rights. The strategy should include a service development programme, the starting point of which is to ensure a good quality of life for older people, their self-determination and independence regardless of their functional capacity. There are relatively few municipalities, which have a special strategy concerning dementia care.

The Six State Provincial Office creates the conditions for the implementation of social and health care services in the province. It also steers and monitors the delivery of these services. The State Provincial Office networks with service providers and users and various organisations across administrative boundaries. In collaboration with municipalities, it supports the development of social and health care services according to national objectives, as well as the implementation of preventive social and health care policy. The State Provincial Office helps ensure equal access to welfare services for every citizen regardless of where they live. The tasks include for example: 1) steering and monitoring of municipal social and health services and preventive work 2) licences for providers of private social and health services and monitoring the practitioners.

Although there is national legislation in place and the Ministry of Social Affairs and Health gives recommendations regarding service provision, actual practices vary widely in the 444 municipalities in Finland because of their independent role. Although there are recommendations to the municipalities on providing care and services, actual practice with regard to testing and evaluation of functional capacity as well as the evaluation of the need for services and so on varies.

In Finland, the main service providers are municipalities (444). Then there are non-governmental organisations (for example The Central Union for the Welfare of the Aged, Finnish Red Cross etc.). In addition to this there are dozens of private service providers, who provide homecare and home services for elderly people.

Home care services provided for the elderly by Finnish local municipalities have been cut by a third over the last decade. It is also estimated that home services are in many cases aimed at people living in sheltered homes, which means that people living in their own homes are often deprived of much needed services. In addition to this, home care does not take sufficient account of the special needs of people with dementia.

4.8.3.4 Financing of home care services

It is estimated, that overall expenses in dementia care for moderate to severe dementia amount to almost EUR 1.7 million per year. This is based on institutional care. Secondary costs are excluded.

Municipalities are responsible for organising services for their inhabitants. Tax revenues finance service provision/organisation. The costs of the services provided by municipalities for their clients are determined by their income. Financial support is dependent on the municipality's age structure and the size of its population. However economic constraints dictate the level of service provided. There are areas/municipalities, especially in eastern and northern Finland where local authorities are experiencing financial difficulties (because of migration, age structure in the municipality and tax revenue).

As mentioned earlier in this paper, municipalities can produce services themselves, or they can buy services from private service providers (which are private firms or Non-Governmental Organisations). Non-Governmental Organisations provide services like sheltered houses and home care. The proportion of costs met by service recipients themselves has increased. There have been discussions whether clients should pay more for these services.

According to a European Commission report (2002), a working group has studied the possibility of introducing long-term care insurance in Finland on a voluntary basis to finance the care of the elderly. This would supplement statutory municipal service provision and other public services.

4.8.3.5 Kinds of home care services available

Home help and home nursing care are the kinds of service, which are also aimed at people with dementia living at home. In Finland, home help and home nursing services in a municipality work together in close collaboration.

In some municipalities, home help services and home nursing have been co-operated for home care units. When organising home care (nursing and services), a written plan is drawn up for each client in which the aims, methods and all providers are defined. In some cases, it includes a plan for rehabilitation as well.

Home help services provide assistance when a person, owing to an illness or reduced capacity, needs help at home in order to cope with routine daily activities. Help is provided by home helpers and practical nurses. They monitor the clients' state of health and provide guidance and advice. Services are also provided in the evening and at weekends. Municipal health centres employ separate personnel, who have trained as specialised nurses, registered nurses and practical nurses. The home nursing service includes giving care, taking samples and performing tests. Nowadays even more demanding nursing is provided at home, because many people want to live at home until the end of their lives. These services also involve supporting family members.

Home-help services cover the performance of or assistance with functions and activities related to housing, personal care and attendance or activities in normal daily life. Support services are intended to help older people to manage socially in

everyday life. Services include the provision of meals, daytime activities, transportation and services, bathing, laundry and cleaning services. Municipalities determine the range and cost of each service. There is no special provision for these kinds of services for people with dementia. Therefore, they are usually a part of the services aimed at elderly people.

4.8.3.6 Consultation with people with dementia and carers

From the Finnish Alzheimer Society’s point of view 1) the number of services available is insufficient and 2) the content of these services does not take into account the needs of people with dementia. The Alzheimer Society of Finland has stressed the importance of specific quality factors with regard to these services:

- 1) The services should be based on a thorough evaluation of the needs of the person with dementia and his/her family carer (life history, family situation, holistic way of evaluation and assessment of functional capacity)
- 2) Rehabilitative way of supporting a person with dementia (recreational activities, plan for care and services)
- 3) Emphasis on clients’ resources – supporting functional capacity
- 4) Flexibility in providing services
- 5) Confidence-building is essential
- 6) The self-determination of a person with dementia should be respected.
- 7) Co-ordination and building networks - continuity and developmental aspects should be taken into account when providing home care and support services.

Please also see the paragraph on the “Act on the Status and Rights of Social Welfare Clients (812/2000)” for information on the need to consult people with dementia and their carers about the provision of social welfare services.

4.8.3.7 Sources:

Information provided by Sirkkaliisa Heimonen (Alzheimer’s Society of Finland)

European Commission (2002), Questionnaire on health and long-term care for the elderly, European Commission:
(http://europa.eu.int/comm/employment_social/social_protection/docs/fi_healthreply_en.pdf)

European Commission (2002), Finland,
http://europa.eu.int/comm/employment_social/missoc/2002/03/finland_en.pdf#search='care%20insurance%20AND%20ofinland' (accessed on 31 May 2005)

Ministry of Social Affairs and Health (1999), Social welfare legislation (Appendix 2):
(<http://pre20031103.stm.fi/english/pao/publicat/welfare/welfare7.htm>)

4.8.4 EuroCoDe network organisations

Alzheimer-keskusliitto (Finnish Alzheimer's Society)

Luotsikatu 4 E
00160 Helsinki
Tel: +358 -9- 622 62 00
Fax: +358 -9- 62 26 20 20
varpu.kettunen@alzheimer.fi
www.alzheimer.fi

Central Union for the Welfare of the Aged

Malmin kauppatie 26
00700 Helsinki

Finnish Association for Dementia Care

Arkadiankatu 19 C
00100 Helsinki
tarja.zhou@dementiahoitoyhdistys.fi

Kuopio University Hospital

Department of Neurology
P.O. Box 1777
70211 Kuopio
Tel: +358 -17- 17 30 12 / +358 -40- 573 57 49
Fax: +358 -17- 17 30 19
hilka.soininen@uku.fi
www.uku.fi/neuro

Societas Gerontologica Fennica

Haartmannink, 4
00290 Helsinki
Tel: +358 -9- 471 22 22/ 457
Fax: +358 -9- 471 40 13
otto.lindberg@hus.fi
www.gernet.fi

Suomen Neurologinen Yhdistys (Finnish Neurological Association)

Department of Neurology
University of Turku
P.O. Box 52
2051 Turku
Tel.: +358 -2- 313 00 00
Fax: +358 -2- 313 27 37
laura.airas@tyks.fi
www.terveysportti.fi/neuro

University of Helsinki

Memory Research Unit
Department of Neurology
PL 300
0029 HUS
Tel: +358 -40- 50 00 826
Fax: +358 -9- 47 17 23 52 or +358 -9- 47 17 23 53
timo.erkinjuntti@hus.fi

4.9 France

4.9.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in France in 2005 as being between 760,715 (Ferri et al.) and 847,808 (Eurodem). This represents 1.22% (Ferri et al.) to 1.36% (Eurodem) of the total population of 62,370,800. The number of people with dementia in France as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in France in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	20,476	11,787	32,263	
60–64	21,014	6,535	27,550	24,485
65–69	26,641	15,319	41,960	39,305
70–74	51,778	54,884	106,663	91,622
75–79	44,313	85,460	129,773	129,629
80–84	74,479	144,573	219,052	205,622
85–89	33,708	91,455	125,162	270,053
90–94	32,716	98,044	130,760	
95–99	5,895	28,730	34,625	
Total	311,020	536,788	847,808	760,715

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in France since 1960.

4.9.2 Availability of anti-dementia drugs

4.9.2.1 The availability of medicines in general

France has different reimbursement levels for medicines depending on the efficacy of the medicines and the seriousness of the disease or symptoms. Reimbursement can thus vary between 30% and 70% with medicines for certain diseases being reimbursed 100%.³⁸

³⁸ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.9.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in France and are fully reimbursed at 100% through the reimbursement system. There are no specific examinations which are specified by the reimbursement system, but reimbursement of acetylcholinesterase inhibitors is limited to people with Alzheimer’s disease with an MMSE score ranging between 26 and 10 and memantine to patients with an MMSE score below 15.

The French system requires the initial treatment decision and prescription to be done by a specialist (a neurologist, psychiatrist or geriatrician), whereas continuing treatment prescriptions can be filled in by general practitioners as well. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments.

France Alzheimer clarified that although the market authorisation for all four products is for Alzheimer’s disease, the French system also has a system of temporary authorisations (“autorisation temporaires d’utilisation”) for diseases for which no treatment is available. Under that system, some people with Lewy body dementia, vascular dementia and Parkinson’s disease dementia also had access to these treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	26–10	26–10	26–10	15–0
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.9.3 Organisation of Home care

4.9.3.1 Background information about dementia and home care services

Home help is intended to provide assistance with everyday tasks to people aged 60 or more to enable them to carry on living in their own homes. The aim of home nursing care services is to prevent, postpone or shorten stays in hospital or residential care institutions.

4.9.3.2 Legislation relating to the provision of home care services

The Elderly Dependency Act of 20 July 2001 introduced the “allocation personnalisée d’autonomie” (individual attendance allowance) known as APA. This allowance, paid to dependent people over the age of 60, is intended to cover the costs of any assistance they need due to the loss of their ability to care for themselves. They must also have their main residence in France and be dependent according to the AGGIR scale (Autonomie Gérontologique – Groupes Iso-Ressources).

According to article L113-1 of the “Code de l’Action Sociale et des Familles”, any person over 65 without sufficient resources may benefit either from home help or a place in a private home or establishment. This home help may take the form of a payment or actual assistance with household tasks (art. L 231-1 of the above-mentioned code).

It is stated in article 205 of the French Civil Code that adult children have a legal obligation to provide maintenance to their parents and other ascendants if in need. This obligation extends to daughters-in-law and sons-in-law in certain circumstances with regard to their parents-in-law (article 206).

4.9.3.3 Organisation and financing of home care services

Home help is partly financed by retirement schemes (depending on the income of the person receiving the service) and partly by social welfare benefits provided by the “département”. Certain services, such as meals-on-wheels and house alarm systems are often financed by regional governments and recipients may have to contribute towards costs. Home nursing care services and other paramedical services, on the other hand, are fully financed by the healthcare system. There is a growing number of freelance nurses. Home care services for elderly people are mainly provided by private non-profit making associations and by municipalities. Many services are provided by volunteers and are therefore cost free.

People who need assistance (but to a lesser extent than that needed by people who are entitled to the individual attendance allowance) receive special allowances or increased benefits to pay for services from third parties (European Commission, 2002).

The Law 2005-841 of 26 July 2005 on Personal Services and Social Cohesion introduced the “chèque emploi service universel” (CESU) which came into force on 1 January 2006. This replaces the “chèque emploi service” and the “titre emploi service”. CESUs can be purchased by individuals and used to pay directly for services required by an individual, including home help for elderly or disabled people, ironing, gardening and general housework. They can be for a predetermined amount or for an amount to be decided by the purchaser. They can also be co-financed by employers much in the same way as luncheon vouchers or holiday vouchers. Employers are entitled to a tax deduction (credit d’impôt) of 25% of their costs. It is also possible for other organisations to finance the CESU such as pension funds and insurance companies (webpublic.ac-dijon, 2005).

The cheques can be purchased from any bank in collaboration with the national office for the collection of social contributions. People or organisations providing the services simply deposit the cheques into a bank account.

The APA can take the form of services or cash and is paid irrespective of whether the person lives at home or in an institution. The allowance is for human and technical assistance, not the provision of care which would be covered by health insurances. People in receipt of the APA can choose whether to pay for a service or to pay for a private person to provide the service (with the exception of spouses). A private person who is paid to provide a service must declare this as a salary. As of 1 January 2006, people with a monthly income of less than EUR 658.4 are not obliged to contribute towards the costs of the APA. People with an income higher than EUR 2,622.34 have to make a contribution of 90% of the costs. Those with incomes between these two amounts have to contribute progressively towards costs.

On Monday 13 September 2004, the Minister of Health, Mr Philippe Douste Blazy, announced his new plan for Alzheimer's disease for the period 2004 - 2007.

A major feature of the new plan is the recognition of Alzheimer's disease as a disease in its own right which means that medication will henceforth be 100% refunded. Douste Blazy also plans to integrate a cognitive evaluation into the "preventative consultations" foreseen for people at the age of 70 according to the Law on Public Health. The aim of these consultations, which will be carried out by a geriatrician, a neuropsychologist and a neurologist, will be to establish a diagnosis of the disease and propose the appropriate care.

100 new memory clinics will be created (in addition to the 238 already existing) and by 2007, 13,000 extra places will be made available in therapeutic day care centres and respite centres, which represents a fourfold increase in available places.

4.9.3.4 Kinds of home care services available

Home nursing care services provide people with the necessary assistance to carry out essential activities of daily life. Jani-Le-Bris (2004) provides a list of the kinds of home care services offered to older people:

- Accompanying the person for a walk, for medical visits and shopping etc.
- Adaptation of flat/house
- Administrative help
- Day or night care at home
- Delivery of medication (especially in rural areas)
- Taking the person to eat in a centre
- Granny sitting
- Hospitalisation at home (HAD)

- Home alarm service
- Household help (cleaning, cooking, shopping, washing, ironing, cleaning windows etc.)
- Keeping the person company (talking, reading etc.)
- Meals-on-wheels
- Mobile library
- Night and day care at home or in an institution
- Paramedical service (nursing, personal hygiene, physiotherapy etc.)
- Repair service for small repairs (i.e. where a craftsperson would be too expensive)
- Respite care
- Social nocturnal emergency services (e.g. buying medication or food)
- Technical assistance (hospital beds, crutches etc.)
- Transportation (special mini-buses from the local authority, informal transportation)

Meals-on-wheels is not as popular in France as in other countries. According to Jani-Le-Bris (2004), the service is considered as leading to or reinforcing social isolation. There is a preference for preparing food together with home-helpers or alternatively, eating out in an institution, home for the elderly or sheltered housing restaurant as many open their doors to older people living at home. The social aspect of meals is highly valued. In cities, take-away restaurants (e.g. Asian and Italian) provide a delivery service, which in areas with a high migrant population, have the advantage of offering older people the kind of food that they are used to.

4.9.3.5 Sources

Agevillage (2006), APA 2006: revalorisations au 1er janvier 2006,

http://www.agevillage.com/Article/index.jsp?ARTICLE_ID=671&SECTION_ID=3

Anonymous (2002), Questionnaire on health and long-term care for the elderly; France's contribution, European Commission

(http://europa.eu.int/comm/employment_social/social_protection/docs/fr_healthreply_en.pdf)

European Commission (2002), France,

http://europa.eu.int/comm/employment_social/missoc/2002/03/france_en.pdf#search=care%20insurance%20AND%20france (accessed on 31 May 2005)

Jani-Le-Bris, H. (2004), National Background Report for France, EUROFAMCARE,

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_france_rc1_a4.pdf

« L'enseignement professionnel tertiaire » website (2005), Le chèque emploi service universel

http://webpublic.ac-dijon.fr/pedago/ecogestpro/Professeurs/Documentation/Economique/PagesEconomiques/cheque_emploi_service_universel.htm

Prieur, C. (2004), Dix mesures contre l'implacable avancée de la maladie d'Alzheimer, *Le Monde* (13/9/2004)

4.9.4 EuroCoDe network organisations

Association France Alzheimer

Boulevard Montmartre 21
75002 Paris
Tel: +33 -1- 42 97 52 41
Fax: +33 -1- 42 96 04 70
directeur@francealzheimer.org
www.francealzheimer.org

CH Pellegrin

Neurologie
Place Amélie Raba Léon
33076 Bordeaux cedex
Jean-Francois.Dartigues@isped.u-bordeaux2.fr
www.isped.u-bordeaux2.fr/ISPED/RECHERCHE/paquid/fr-paquid-accueil.htm

CHU La Grave-Casselardit

Department of Internal and Geriatrics Medicine
170 Avenue de Casselardit
31300 Toulouse
Tel:+33 -5- 61 77 76 49
Fax : +33 -5- 61 49 71 09
vellas.b@chu-toulouse.fr
www.chu-toulouse.fr/alzheimer_ca

CHU Lille

Université de Lille 2
Clinique Neurologique
59037 Lille
Tel:+33 -3- 20 44 57 85
Fax:+33 -3- 20 44 60 28
pasquier@chru-lille.fr
www.lille.inserm.fr/u422/FlandreAlzheimer.html

CHU Montpellier

UNC, Neurologie B
Hôpital Guy de Chauliac
80 Avenue Gaston Fliche
34295 Montpellier cedex 05
Tel: +33 -4- 67 33 60 29
Fax: +33 -4- 67 33 60 36
jacques.touchon@wanadoo.fr
www.alzheimer-montpellier.org/

CHU Nice

Centre Mémoire
Hôpital Pasteur, Pavillon J
30 avenue de la Voie Romaine
06002 Nice
Tel: +33 -4- 92 03 80 02 / 37 993
Fax: +33 -4- 92 03 83 26
philippe.robert15@wanadoo.fr

CHU Tours

37000 Tours
FRANCE
v.camus@chu-tours.fr

Fondation Médéric Alzheimer

30, rue de Prony
75017 Paris
Tel: +33 -1- 56 79 17 91
Fax: +33 -1- 56 79 17 90
fondation@med-alz.org
www.fondation-mederic-alzheimer.org

Hôpital Broca

Service de Gériatrie Clinique
54/56 rue Pascal
75013 Paris
Tel: +33 -1- 44 08 35 02
Fax: +33 -1- 44 08 35 10
francoise.forette@brc.ap-hop-paris.fr
anne-sophie.rigaud@brc.ap-hop-paris.fr

Hôpital Salpêtrière

Centre de Neuropsychologie
Pavillon Paul Castaigne
47 Bd de l'Hôpital
75651 Paris Cédex 13
b.Dubois@psl.ap-hop-paris.fr

Société Française de Gériatrie et de Gériatrie

49, rue Mirabeau
75 016 Paris
Tel: +33 -1- 41 12 87 12
contact@sfgg.org
www.sfgg.fr

Société Française de Neurologie

c/o Hôpital de la Salpêtrière,
47, Boulevard de l'Hôpital
75651 Paris Cédex 13
Tel.: +33 -1- 42 16 18 01
Fax: +33 -1- 44 24 52 47
jean-marc.leger@psl.ap-hop-paris.fr
www.sf-neuro.org

4.10 Germany

4.10.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Germany in 2005 as being between 1,010,245 (Ferri et al.) and 1,118,429 (Eurodem). This represents 1.22% (Ferri et al.) to 1.36% (Eurodem) of the total population of 82,500,849. The number of people with dementia in Germany as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

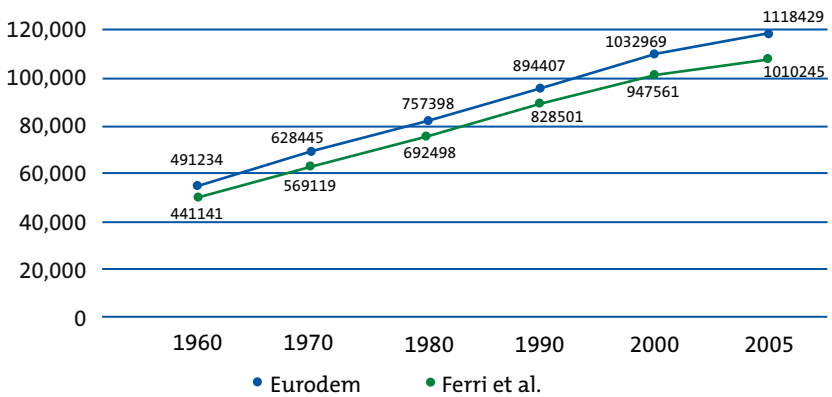
The Alzheimer Europe figures underestimate the number of people with dementia in Germany, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Germany over the age of 94.

Table 1: The number of people with dementia in Germany in 2005

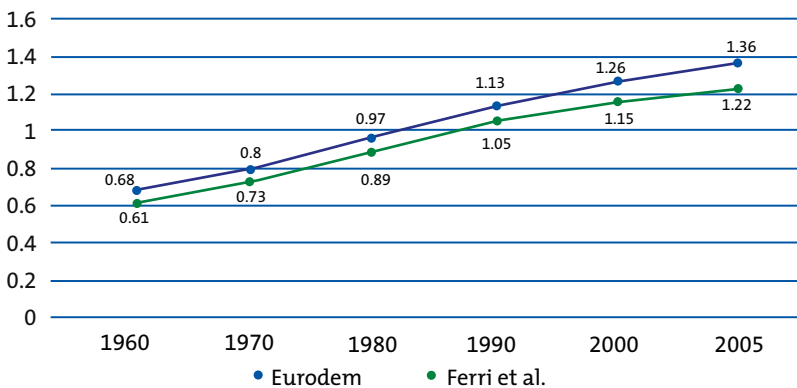
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	28,900	15,772	44,673	
60–64	40,359	12,424	52,783	46,780
65–69	53,702	29,884	83,585	77,871
70–74	75,059	76,570	151,629	130,027
75–79	59,645	121,644	181,289	180,431
80–84	77,746	203,067	280,813	261,771
85–89	37,470	133,498	170,968	313,365
90–94	32,946	119,742	152,688	
Total	405,828	712,600	1,118,429	1,010,245

The following charts show a) the increase in the number of people with dementia in Germany from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005. As a percentage of the total population, the number of people with dementia doubled over the same period of time.

The number of people with dementia in Germany from 1960 to 2005



The number of people with dementia in Germany as % of total population from 1960 to 2005



4.10.2 Availability of anti-dementia drugs

4.10.2.1 The availability of medicines in general

In Germany, patients generally pay 10% of the cost of medicines with a minimum contribution of € 5 per product and a maximum contribution fixed at € 10. Nevertheless, the system also makes exceptions for children and hardship cases for whom no contributions are required.

For some products, the system sets fixed prices. If the cost of the product exceeds this fixed price, a patient is required to also cover the difference in addition to the set prescription charge.³⁹

³⁹ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.10.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Germany and are part of the reimbursement system. There are no specific examinations which are required for medicines to be reimbursed nor does the system provide upper or lower MMSE limits for the treatment with different anti-dementia drugs. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. Also, the German system does not limit treatment initiation or continuation decisions to specialist doctors.

The German Alzheimer Association underlined that due to the introduction of medicines budgets for individual doctors, some doctors were less inclined to prescribe Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.10.3 Organisation of Home care

4.10.3.1 Background information about dementia and home care services

Prior to 1994, the German health and social services system did not cover the risk of dependency. Although the service for public assistance was responsible for this, it was not under any obligation to provide social services to dependent people (Ylief, 2005). Since the introduction of the long-term care insurance, the number of home-based care providers has risen from about 6,000 to 12,500 in 2003 (Theobald, 2004). However, according to Theobald (2004), the long-term care insurance is orientated towards the performance of basic daily activities and as such neglects other aspects of care which are particularly important when caring for people with dementia e.g. general supervision and attention, and social and emotional support. It has also been argued that this orientation presupposes family support or a stable social network which in turn hinders the development of more comprehensive, complex care arrangements (e.g. which might enable people with dementia living alone to continue to do so for longer).

4.10.3.2 Legislation relating to the provision of home care services

The Social Dependency Insurance Act of 26 May 1994 relating to Care Insurance radically changed this situation. It made it compulsory for people to subscribe to the Long-Term Care Insurance (LTCI). People on a higher income, who are consequently not subject to statutory health insurance, are not obliged to subscribe to the long-term care insurance. However, they must prove that they have a private long-term care insurance policy.

Various diseases or disabilities are listed in the care legislation. These include psychiatric illnesses and psychological, physical and mental disabilities such as dementia or other forms of age-related mental decline. In order to be eligible for support or care under the LTCI, a person must have a recognised disease or disability as well as a recognised need for care (Meyer, 2004).

The Act was implemented in two stages: first for home care in April 1995 and then for institutional care in July 1996 (Brodsky et al., 2000). The Complementary Nursing Act was passed in 2002. The aim of this Act was to grant a yearly amount to carers or people with dementia in order to purchase additional services.

4.10.3.3 Organisation and financing of home care services

The LTCI is financed through a tax of 1.7% of the gross wage which is shared equally between the employer and the employee. The LTCI is obligatory for every person who has a health insurance and also for people who are privately insured. The employer is compensated through the designation of one day's holiday as a working day (Brodsky et al., 2000). A person's financial situation and the availability of assistance from the family are not taken into account when judging eligibility. Since 1 April 2004, pensioners have been obliged to pay full contributions to the LTCI. Prior to 2004, pension insurance funds paid half of the cost.

The LTCI covers personal hygiene, nutrition, mobility and housekeeping. There are four levels (I, II, III and special hardship) and a person must need substantial help for at least 6 months to qualify. Within each category, a specific amount is payable for each kind of assistance needed and this differs according to the person providing the assistance/service. For this reason, the allowance can be paid either to the person with dementia so that they can pay carers in cash or directly for services (“Sachleistung”). The following table provides an overview of the payments in Euro for services according to each category:

	Monthly payment for domestic care (cash payment)	Monthly payment for domestic care (professional services)	Monthly payment for nursing home care
Category I	205	384	1,023
Category II	410	921	1,279
Category III	665	1,432	1,432
Special hardship		1,918	1,688

Source: Bundesministerium für Gesundheit (2006)

The allowance granted under the Complementary Nursing Act of 2002 amounts to a maximum of EUR 460 per year and is especially for people who have a significant need for care and supervision beyond that already covered by care insurance provisions. This includes people with dementia. The care allowance can only be used to pay for “day or night-nurses, short-term care, special services of general supervision and care from recognized care providers, and for services from low-level care providers” (Bundesministerium für Gesundheit, 2006).

Non medical home care services are often provided by home health assistants and housekeepers who provide assistance with household chores. Certain services such as shopping and simple household help may also be provided by young men who decide to do community service instead of military service (Payne et al. 1999).

Domestic careworkers from Eastern Europe, taken on to carry out household tasks, sometimes become unofficial carers even though they do not necessarily have the right to work (Meyer, 2004).

4.10.3.4 Kinds of home care services available

The kinds of services covered by the LTCl are:

- Personal hygiene: washing, showering and bathing, dental hygiene, combing, shaving and assistance going to the toilet.
- Nutrition: assistance with eating
- Mobility: assistance getting into and out of bed, standing up, going up and down stairs, leaving and returning to one’s home
- Care of the home: shopping, cooking, cleaning, washing pots, changing and washing clothes, heating the home
- Organised care: respite care, day care and night care
- Various aids: nursing aids and technical aids

4.10.3.5 Consultation with people with dementia and carers

According to Brodsky et al. (2000), the Social Dependency Insurance Act of 26 May 1994 included provisions for quality assessments. Service providers have to undergo external assessment of the quality of the services they provide. People who choose a

cash allowance instead of services have three inspection visits per year from formal service providers who ensure the quality of the services provided, give information on available services and advise informal carers (Brodsky et al., 2000).

4.10.3.6 Sources

Brodsky, J., Habib, J. and Mizrahi, I. (2000), A review of long-term care laws in five developed countries, <http://www.wu-wien.ac.at/wwwu/institute/Sozialpolitik/LTC.pdf#search=A%20review%20of%20longterm%20care%20laws>

Bundesgesetzblatt (14.11.2003) extracted from: Leistungen und Rechengrößen der Kranken- und Pflegeversicherung im Jahr 2004, <http://www.pflege.de/html/pflegeversicherung.html>

Bundesministerium für Gesundheit (2006), Long-term care insurance, http://www.bmg.bund.de/cln_041/nn_617004/EN/Long-term-care-insurance/info-long-term.html (accessed on 8 August 2006)

Meyer, M. (2004), *National Background Report for Germany*, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_germany_rc1_a4.pdf

Payne, K. A. et al. (1999), Resource use by dementia patients and caregivers: an international survey of medical and social services and processes of long-term care, *Annals of Long Term Care, Volume 7, Issue 7*

Theobald, H. (2004), *Care services for the elderly in Germany - infrastructure, access and utilization from the perspective of different user groups*, Arbeitsgruppe Public Health

Forschungsschwerpunkt Arbeit, Sozialstruktur und Sozialstaat, (WZB) <http://skylla.wz-berlin.de/pdf/2004/io4-302.pdf#search='Pflegeversicherung'>

Tschainer, S. (2002), *Das Wichtigste 8. Die Pflegeversicherung*, Deutsche Alzheimer Gesellschaft, http://www.deutsche-alzheimer.de/index.php?id=37&no_cache=1&file=14&uid=224

Ylief, M. et al. (2005), *Rapport international – les aides et les soins aux personnes démentes dans les pays de la communauté européenne*, Qualidem, Universities of Liège and Leuven

4.10.4 EuroCoDe network organisations

Central Institute of Mental Health
Department of Gerontopsychiatry
68072 Mannheim
Tel: +49 -621- 17 03 30 01
Fax: +49 -621- 17 03 30 05
froelich@zi-mannheim.de
www.zi-mannheim.de

Demenz Support Stuttgart GmbH
Hoelderlinstr. 4
70174 Stuttgart
a.rutenkroeger@demenz-support.de

Deutsche Alzheimer Gesellschaft e.V.
Friedrichstr. 236
10969 Berlin
Tel: +49 -30- 25 93 79 50
Fax: +49 -30- 31 50 57 35
info@deutsche-alzheimer.de
www.deutsche-alzheimer.de

Deutsche Gesellschaft für Gerontopsychiatrie und -psychotherapie e.V. (DGPP)

Geschäftsstelle
Postfach 1366
51675 Wiehl
Tel: +49 -2262- 79 76 83
Fax: +49 -2262- 999 99 16
gs@dggpp.de
www.dggpp.de

Deutsche Gesellschaft für Gerontologie und Geriatrie e.V.

Alte Jakobstr. 77
10179 Berlin
Tel: +49 -30- 28 44 99-24
Fax: +49 -30- 28 44 99-34
gs@dggg-online.de
www.dggg-online.de

Deutsche Gesellschaft für Geriatrie e.V.

Geschäftsstelle
Kampstraße 7
30629 Hannover
Tel: + 49 -511- 58 15 84
Fax: + 49 -511- 58 32 84
Email: wegner@gerikomm.de
www.dggeriatrie.de

Deutsche Gesellschaft für Neurologie (DGN)

Neurologische Abteilung, Allgemeines Krankenhaus
St. Georg Lohmühlenstr. 5
20099 Hamburg
Tel.: +49 -40- 28 90 22 67
Fax: +49 -40- 28 90 41 85
info@dgn.org
pevog@prof-p-vogel.de
www.dgn.org

Deutsches Zentrum für Altersfragen

Manfred-von-Richthofenstr. 2
12101 Berlin
Tel: +49 -30- 260 74 00
Fax: +49 -30- 785 43 50
dza@dza.de
www.dza.de

Evangelisches Krankenhaus Elisabethenstift

Klinik Für Geriatrie
Landgraf Georgstr. 100
64287 Darmstadt
Tel: +49 -61- 51 40 33 000
Fax: +49 -61- 51 40 33 009
hanswerner@gmx.de

Friedrich-Alexander-Universität Erlangen-Nürnberg

Poliklinik & Institutsambulanz (Leitung)
Labor für Molekulare Neurobiologie (Leitung)
Klinik und Poliklinik für Psychiatrie und Psychotherapie
Schwabachanlage 6
91054 Erlangen
Tel:+49 -9131- 853 68 96/341 60
Fax:+49 -9131- 853 60 02/363 81
jens.wiltfang@psych.imed.uni-erlangen.de

Georg-August-University

Von-Siebold-Str. 5
 37075 Goettingen
 Tel: +49 -551- 39 95 63
 Fax: +49 -551- 39 66 92

Kuratorium Deutsche Altershilfe (KDA)

An der Pauluskirche 3
 50677 Kohn
 Heiko.Fillibeck@kda.de

Ludwig-Maximilian University

Alzheimer Memory Centre and Geriatric Psychiatry Branch
 Dementia and Neuroimaging Section,
 Dept. of Psychiatry
 Nussbaumstr. 7
 80336 Munich
 Tel: +49 -89- 51 60 58 54
 Fax: +49 -89- 51 60 58 56
 hampel@psy.med.uni-muenchen.de

Private Universität Witten-Herdecke gGmbH

Dialogzentrum Demenz
 Stockumer Str. 10
 58453 Witten
 herglboecklin27@aol.com
 dialogzentrum@uni-wh.de

Rheinische Kliniken Düsseldorf**Kliniken der Heinrich-Heine-Universität Düsseldorf**

Bergische Landstrasse 2
 40 629 Düsseldorf
 Tel: +49 -211- 922 42 53
 Fax: +49 -211- 922 42 66
 www.rk-duesseldorf.de

Technische Universität

Psychiatrische Klinik, Möhlstrasse 26
 81 675 Muenchen
 Tel: +49 -89- 41 40 42 62
 Fax: +49 -89- 41 40 49 23
 alexander.kurz@lrz.tum.de

Universitätsklinikum Eppendorf

Intitut fuer Medizin-Soziologie
 Martinist. 40
 20246 Hamburg
 Tel: +49 -40- 428 03 45 28
 Fax: +49 -40- 428 03 40 56
 doehner@uke.uni-hamburg.de
 www.dggg-online.de

University of Munich

Alzheimer Therapiezentrum der Neurologischen Klinik Bad Aibling
 Kolbermoorerstr. 72
 83043 Bad Aibling

4.11 Greece

4.11.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Greece in 2005 as being between 123,700 (Ferri et al.) and 135,566 (Eurodem). This represents 1.12% (Ferri et al.) to 1.22% (Eurodem) of the total population of 11,082,751. The number of people with dementia in Greece as a percentage of the total population is slightly below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Greece in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	3,760	2,111	5,870	
60–64	4,168	1,396	5,564	5,048
65–69	6,045	3,644	9,689	9,148
70–74	12,191	12,408	24,599	21,093
75–79	9,669	16,210	25,879	26,093
80–84	12,266	18,823	31,089	29,357
85–89	7,143	11,447	18,591	32,961
90–94	4,806	6,734	11,540	
95–99	1,074	1,671	2,745	
Total	61,121	74,445	135,566	123,700

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Greece since 1960.

4.11.2 Availability of anti-dementia drugs

4.11.2.1 The availability of medicines in general

The Greek system provides for different levels of participation in patients to the cost of medicines. As a general rule, patients should pay 25% of medicines prescribed by a doctor. Nevertheless, for certain diseases such as Parkinson's disease or Crohn's disease, this contribution by patients is lowered to 10%. Similarly, the contribution is reduced to 10% for retired persons receiving the minimum pension.

Finally, for certain chronic conditions such as cancer or diabetes, medicines are fully covered. The same is true for medicines during pregnancy or for medicines necessary for employment accidents.⁴⁰

4.11.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Greece and are part of the reimbursement system.

Greece requires the initial treatment decision to be taken by a neurologist or psychiatrist, but does not have any restrictions for continuing treatment decisions which can be made by any practitioner. Also, Greece does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits.

Finally, the Greek system reimburses medicines for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Neurologists or psychiatrists	Neurologists or psychiatrists	Neurologists or psychiatrists	Neurologists or psychiatrists
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.11.3 Organisation of Home care

4.11.3.1 Background information about dementia and home care services

Home help services were originally developed on a small scale by the Greek Red Cross and other voluntary associations such as the Church. The Greek Red Cross also provides training to volunteers, including training in nursing skills and personal care. Nowadays, there are many organised agencies providing home care services but this is in the private sector and they are not supervised by the State.

Some local authorities provide home care services but such services are not provided uniformly throughout the country. This is further complicated by a lack of avail-

⁴⁰ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

able information on entitlement and availability of services. The majority of older people continue to live at home either with their families or alone. Families play a key role in providing care for which they receive no direct support from the State.

However, in the last two decades the State has taken measures to increase community care services for older people so that they can remain in their own homes for as long as possible thereby enabling them to maintain their independence and enhance their quality of life. These measures include the creation of open care community centres for older people (KAPIs) and the help at home programme.

4.11.3.2 Legislation relating to the provision of home care services

The transfer of responsibility for the management and operation of KAPIs to local authorities occurred as a result of article 68 of Law N.1416/84. The relevant law concerning the home help for the elderly programme is Law N.2082/92.

Invalidity is measured in terms of the percentage of disability of the whole person. Carers are not legally entitled to any benefits but there are invalidity supplements for people in need of constant care.

It is stated in the Constitution and in Civil Law that the family is responsible for the care of dependent relatives of all ages but also that the State will care for the health of citizens and will adopt special measures for the protection of young people, the elderly and invalids, as well as for assistance to the needy. Consequently, if a family is unable to care for a dependent relative, the dependent person is taken care of by the Social Security system.

For carers in paid employment, labour legislation allows them to take up to 6 days' unpaid leave to fulfill their caring obligations.

4.11.3.3 Organisation and financing of home care services

There is no long-term care insurance in Greece. Financial assistance is mainly in the form of discretionary tax rebates to family carers. Some family carers use supplementary pensions for incapacity or dependency to help towards the costs of caring.

Some local authorities provide home help services to elderly dependent people, most of whom are poor and isolated but they are not obliged to do so. Discretionary grants and benefits are also available in some areas. However, these provisions are dependent on the financial resources of individual local authorities and are not based on an official policy.

Open care community centres for old people were set up as a pilot scheme by voluntary organisations funded by the State. In 1982, local authorities assumed responsibility for the KAPIs and the State continued to be the main financial contributor. A "Help at Home" programme for older people was started in 1992 under the auspices

of the Ministry of Health and Welfare involving a number of KAPIs and local authorities. In some areas, the Help at Home programme supports family carers (mainly women) by providing supervision during part of the day so that the carer can take up or maintain paid employment.

Where community care services exist, they are free at the point of use. They are currently funded through central government. Some services are partly funded by EU special programmes e.g. some of the KAPI home care services.

4.11.3.4 Kinds of home care services available

KAPI centres aim to provide the necessary support to enable people to live independently in their own homes for as long as possible. Most offer the following services:

- Preventive medical services
- Physiotherapy programmes
- Ergotherapy programmes
- Health education
- Recreational activities

Many KAPI centres collaborate with the Help at Home project which offers a range of services to elderly people who are unable to manage on their own, i.e.:

- Social services (counselling and psychosocial support, information on rights and health issues)
- Health care services
- Family assistance (assistance with housework, personal care and eating, as well as befriending)

A few community centres are run by voluntary bodies or directly by local authorities (e.g. the centres for love and friendship in Athens). They are fairly similar to the KAPI centres but do not offer health care services. A number of day care centres have been set up since the establishment of the National Social Care System in 1998. These are closely linked to the KAPIs.

In some areas, local authorities and many parishes of the Orthodox Church provide free meals at home to people in need. In many areas, neighbours, friends and volunteers offer sitting services but the main source of respite care is still through acute admissions to hospitals. In Thessalonika and Athens, there is a 24-hour tele-alarm system linked to family, neighbours, the police or the ambulance service.

4.11.3.5 Sources

Daniilidou, N., Economou, C., Zavras, D., Kyriopoulos, J. and Georgoussi, E. (2005) Health and social care in aging population: the case of an integrated care institution in Greece, <http://www.integratedcarenetwork.org/publish/articles/000004/article.htm>

Mestheneos, E., Triantafyllou, J. and Kontouka, S. National Background Report for Greece, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_greece_rc1_a4.pdf

Sissouras, A., Ketssetzopoulou, M. et al. (2002), Providing integrated health and social care for older persons in Greece, (Procare report), National Centre for Social Research (EKKE), <http://www.imsersomayores.csic.es/documentos/documentos/procare-providinggreceia-01.pdf#search='Procare%20National%20Report%20Greece'>

4.11.4 EuroCoDe network organisations

Aristotle University of Thessaloniki

Memory and Dementia Centre
3rd University Department of Neurology
Despere 3
54621 Thessaloniki
Tel: +30 -2310- 99 23 56 or +30 -2310- 23 42 39
tsolakim@med.auth.gr

Greek Association of Alzheimer's Disease and Related Disorders

Terma Dimitriou Charisi - Ano Toumba
543 52 Thessaloniki
Tel: +30 -2310- 92 58 02
Fax: +30 -2310- 92 58 02
alzheimer@the.forthnet.gr
www.alzheimer-hellas.gr

Hellenic Association of Gerontology and Geriatrics

23 Kanningos Street
10677 Athens
Tel: +30 -210- 381 16 12
Fax: +30 -210- 384 03 17
hagg@otenet.gr
www.gerontology.gr

Hellenic Association of Neurology

10, Alkmanos Str.
115 28 Athens
Tel.: +30 -210- 724 70 56
Fax: +30 -210- 724 75 56
neurolog@hellasnet.gr

4.12 Hungary

4.12.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Hungary in 2005 as being between 88,070 (Ferri et al.) and 100,567 (Eurodem). This represents 0.87% (Ferri et al.) to 1% (Eurodem) of the total population of 10,097,549. The number of people with dementia in Hungary as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the number of people with dementia in Hungary, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Hungary over the age of 89.

Table 1: The number of people with dementia in Hungary in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	3,277	1,935	5,211	
60–64	3,985	1,515	5,500	5,171
65–69	4,151	3,107	7,257	6,158
70–74	7,610	10,153	17,762	13,699
75–79	5,940	14,678	20,619	19,600
80–84	8,554	20,789	29,343	26,499
85–89	3,705	11,169	14,875	16,944
Total	37,221	63,346	100,567	88,070

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Hungary since 1960.

4.12.2 Availability of anti-dementia drugs

4.12.2.1 The availability of medicines in general

In Hungary, in-patient medicines are free of charge for patients. Out-patient medicines on the official list are covered basically by the Health Insurance Fund by 50 to 100%. This percentage depends on a decision made by a professional body for each type of drug.

Elderly people with a low income and disabled people can receive a special card which entitles them to free medication. Finally, victims of employment injuries and occupational diseases also receive medicines free of charge.⁴¹

4.12.2.2 The availability of Alzheimer treatments

Except for galantamine, anti-dementia drugs are available in Hungary and are part of the reimbursement system (50% reimbursement). Prescriptions both for treatment initiation and for treatment continuation need to be filled in by specialist doctors. There are no restrictions governing the access of people living alone or in nursing homes to available Alzheimer treatments but continuous treatment must be guaranteed.

Since 1999 there have been several national guidelines for the diagnosis and treatment of Alzheimer’s disease. The 2006 guideline has been accepted by the Ministry of Health and prescribes a number of diagnostic examinations (MMSE, Laboratory tests and either a CT or MRI scan).

Since 2003, special dementia centres have been set up (at the time of print, the number of these centres was 84) which are led by neurologists or psychiatrists. Physicians of these centres have the right to prescribe donepezil, rivastigmine and memantine with reimbursement.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Not applicable	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Not applicable	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	Not applicable	Diagnostic protocol
MMSE limits	26–10	26–10	Not applicable	18–0
People living alone	Caution against use	Caution against use	Not applicable	Caution against use
People in nursing homes	No restrictions	No restrictions	Not applicable	No restrictions

4.12.3 Organisation of Home care

4.12.3.1 Background information about dementia and home care services

Home help services in Hungary were organised as early as the late 1960’s, primarily to care for the elderly, patients with chronic conditions and the homebound.

⁴¹ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

In the past, many citizens in Hungary considered health and social services as a right of citizenship. Consequently, this led to lengthy hospital stays and less need for home care services from the family. According to Sovenyi et al. (2005), in 1993 one in five Hungarians spent an average of 12.4 days in the hospital.

The health care system has moved from centralised Semashko state control to a more pluralistic, decentralised model. It is mainly funded through social insurance contributions. The government has agreed to introduce a 1% nursing care insurance based on the German long-term care insurance system (Széman, 2004).

4.12.3.2 Legislation relating to the provision of home care services

In the past, adult children had financial obligations towards their parents according to Hungarian law. However, under the Local Government Act of 1990 and Act III of 1994 on Social Services, municipalities acquired responsibility for the elderly and disabled people, as well as for social care. The Act on Social Welfare of 1993 made it possible, in certain cases, for family carers to receive a fee for providing care (Széman, 2004).

4.12.3.3 Organisation and financing of home care services

Since 1993, each municipality has been required to meet local needs for home care, with contributions from the central budget based on the municipality’s population size and number of inactive and unemployed persons. According to Széman (2004), this budget only covers about 80% of costs. The services are provided by professional caregivers and volunteers, as well as specialist nurses who provide home nursing services under a doctor’s orders. Efforts are being made to establish a separate home care and nursing service and to expand the insurance-based system of delivery to the non-profit agencies. (Sovenyi, 2005).

Social care is funded through the welfare sector and not the health sector. The State relies heavily on cooperation with foundations, associations and church organisations. The practice of paying “gratitude money” persists in Hungary. Many elderly people feel that it is necessary in order to receive proper treatment. Some doctors even demand advance payments of “gratitude money”.

Under Hungarian law, an elderly person can sign a maintenance contract with a person of their choice whereby the appointed carer inherits the old person’s flat or house in exchange for caring for the elderly person. In the past, this led to cases of abuse but modern contracts with more safeguards now exist. Some people sign maintenance contracts with trusted neighbours (Széman, 2004).

4.12.3.4 Kinds of home care services available

Social care includes home care nursing for medical problems and home care social support e.g. the provision of medication and meals, house cleaning and assistance in maintaining personal hygiene. Help with laundry and shopping is also included but much of this is also carried out by voluntary associations.

Transport to the doctor's is also the responsibility of local authorities but this service does not extend to transport to other places such as to church, social gatherings or even to the hospital for medical examinations. Fortunately, some NGOs provide such services.

Home nursing care is provided if prescribed by a doctor. In practice, many trained home help workers also provide home nursing care. The vast majority of home help workers are in fact trained nurses but the strict division between health and social care forbids this so both the elderly and the care workers sometimes falsify the records. The Maltese charity organisation provides integrated home care covering both home help and home care.

Clubs for the elderly exist where people who are still partly able to care for themselves can go during the day. In these clubs, elderly people can profit from 1 to 3 meals per day, have a bath and take part in activities (Széman, 2004).

4.12.3.5 Consultation with people with dementia and carers

The opinions of people with dementia and their carers, with regard to the quality of the services they receive, are not routinely sought by professional home care providers.

4.12.3.6 Sources

Sovenyi, K., Szegedi, G. and Druskoczi, T. (2005), <http://www.whho.org/WHHOcomptext.html#anchor569287>

Széman, Z. (2004), National Background Report for Hungary, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_hungary_rc1_a4.pdf

4.12.4 EuroCoDe network organisations

Institute of Psychiatry and Neurology

Húvösvölgyi street 116
1021 Budapest
Hungary
Tel: +36 -1- 391 53 00
Fax: +36 -1- 391 53 05

Hungarian Association of Gerontology

Kossuth L.u. 6.
2510 Dorog
Tel: +36 -1- 33 51 31 41
Fax: +36 -1- 33 51 31 49
informacio@geronto.hu
titkarsag@sztborbala.hu
www.geronto.hu

Memory Foundation

Pf. 105

1277 Budapest

Tel: +36 -1- 325 62 99

Fax: +36 -1- 325 62 99

memoryfound@freemail.hu

University of Debrecen

Egyetem tér 1

4032 Debrecen

Tel: +36 -52- 41 20 60

Fax: +36 -52- 41 64 90

rector@admin.unideb.hu

4.13 Iceland

4.13.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Iceland in 2005 as being between 2,584 (Ferri et al.) and 2,845 (Eurodem). This represents 0.88% (Ferri et al.) to 0.97% (Eurodem) of the total population of 293,577. The number of people with dementia in Iceland as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Iceland in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	96	52	148	
60–64	91	28	118	105
65–69	99	52	151	139
70–74	197	182	379	324
75–79	167	267	434	439
80–84	261	401	663	626
85–89	182	373	555	953
90–94	100	214	315	
95–99	19	64	83	
Total	1,212	1,633	2,845	2,584

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Iceland since 1960.

4.13.2 Availability of anti-dementia drugs

4.13.2.1 The availability of medicines in general

In Iceland, medicines are divided into 4 main categories depending on their type and category. Payments by patients for medicines can vary from 0 to 100% of their overall cost, again depending on the category of the medicine. Patients only pay this co-payment to the pharmacy with the rest of the costs being paid to pharmacies by the health insurance.

- Category 1: Essential medicines used for the treatment of life threatening and chronic conditions such as diabetes, cancer and psychotic disorders are reimbursed 100%.
- Category 2: Medicines of great therapeutic value for well defined and chronic diseases such as hypertension, asthma, psoriasis and depression are partly reimbursed
- Category 3: Medicines of lesser therapeutic value such as medicines for arthritis or hormone replacement therapy in menopause are also partly reimbursed
- Category 4: Medicines for which the indication is too broad or not well defined as well as medicines for minor conditions (tranquillisers, analgesics, antibiotics and lipid regulating drugs) are not generally reimbursed.

Medicines in categories 1, 2 and 3 are on the positive list, but products not on the positive list may be reimbursed in individual cases, when certain criteria are fulfilled ⁴².

4.13.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Iceland. They are included in category 4 and are thus not part of the positive list. Nevertheless, reimbursement is possible under the following criteria.

People that have been diagnosed by a specialist can receive a special drug card which allows them to have their medicines reimbursed. For treatment with acetylcholinesterase inhibitors, the specialist needs to diagnose a patient with either Alzheimer’s disease or Lewy Body dementia according to the ICD 10 criteria. For treatment with memantine, patients need to score at least five points on the GDS (Global Deterioration Scale).

Although diagnosis needs to be done by a specialist, it is possible for general practitioners to prescribe treatment with either class of drugs. A follow-up of the patient needs to be done every year and the drug card will not be renewed if a patient has deteriorated by more than two points on their MMSE scores and if carers do not believe the medicines had any results.

The Icelandic reimbursement system does not have any specific restrictions for the reimbursement of Alzheimer treatments for people living alone or in nursing homes.

⁴² European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.13.3 Organisation of Home care

4.13.3.1 Background information about dementia and home care services

According to the “Icelandic National Health Plan to the year 2010” published by the Ministry of Health and Social Security in 2004, “With the appropriate services and support it is fair to assume that more people would be able to stay longer at home. (...) It is important to emphasise the need to maintain and enhance physical and mental abilities, in order for senior citizens to be able to stay as long as possible in their own homes.”

Methods to achieve this are outlined. These include:

- the need to strengthen and increase cooperation and coordination of home help and
- the need to increase the availability of day care and health centre home services, in which the emphasis should be on round-the-clock, 7-day service and short-term hospitalisation.

The Ministry has set itself a target, namely that by 2010 “more than 70% of citizens over the age of 80 will retain their health to the extent that they can with the appropriate support services, continue to live in their homes and participate in daily life.”

4.13.3.2 Legislation relating to the provision of home care services

In Iceland, there are a few laws which specifically deal with issues related to the elderly. The first was enacted in 1982 and was then revised in 1989 and 1999. The underlying principle of these laws is that the elderly should be respected. The laws also state that the elderly have a legal entitlement to the services that they need

and that consequently the state must ensure that their needs are met in a way that is relevant and economically feasible (Jónsson and Pálsson, 2005).

The purpose of the Act on the Affairs of the Elderly, No.125 of 31 December 1999 (Act no.125 of 1999) is stated as being “to ensure that the elderly are able, for as long as possible, to enjoy a normal domestic life and that they are assured the required institutional services when needed.” An elderly person is defined as being a person aged 67 or older.

This legislation, combined with the high cost of nursing home care and the desire of many elderly people to continue living in their own homes, has resulted in an increased demand for home care services (Johnson and Olafsdottir, 2005).

Home care in Iceland includes health care and social services. The former is in the hands of health care centre employees pursuant to the Act on Health Care Services. The latter is handled by municipalities or the parties with which the municipalities have contracted, pursuant to the Act on Municipal Social Services.

4.13.3.3 Organisation of home care services

In each health care centre district there is a service council for the elderly. This service is responsible for ensuring that the elderly receive the services they need, that they are informed of the options available to them and that their needs for institutional care are assessed (Act no.125 of 1999, article 8).

Home nursing services are usually provided by community health centres. Such care is organised on a regional basis. Other kinds of home care services (sometimes referred to as homemaker services) are organised by the social services sector, also on a regional basis.

4.13.3.4 Financing of home care services

The national health insurance finances home nursing care almost entirely. It is paid for by the state through the central government’s budget. Social services for the elderly (including home care and days care) are paid for by county councils which are funded by local governments. Nursing in the home is therefore free. Payment for other home care services is related to income. Therefore, clients may have to pay a small contribution towards the costs of such services. There are no cash benefits for home care.

People attending day care centres must pay up to a maximum amount of one full basis pension (i.e. EUR 217 per month) (MISSOC, 2005).

People who are in need of care can obtain a reimbursement for care costs along with their pension provided that they are on a very low pension. If eligible, the amount is calculated on the basis of each individual case in terms of percentages (35%, 70%, 90% or 120%) and paid to the person with dementia. In July 2001, this amounted to EUR 75, EUR 149, EUR 192 and EUR 256 respectively.

Spouses may be entitled to special compensation amounting to 80% of the flat rate state pension for providing care at home if they:

- have suffered a loss of income as a result of stopping full-time employment;
- have incurred extra expenses linked to day care or paid home help;
- are on a low income e.g. if the spouse has no income.

4.13.3.5 Kinds of home care services available

Chapter IV, article 13 of the Act no.125 of 1999 provides the following examples of geriatric services (which would also be available to elderly people with dementia).

- Home care services provided to the elderly residing at home. The service shall be based on case-by-case assessments of service needs and shall be geared to support for self-help. Home care services shall be provided in the evening, at night and on week-ends if necessary. An effort shall be made to organise and co-ordinate the health care and social aspects of the home care services with the welfare and needs of the elderly person in mind.
- Service centres for the elderly which are operated by municipalities to ensure that senior citizens are provided with company, nourishment, exercise, recreation, entertainment and health surveillance. Service centres may work independently or in connection with other services enjoyed by the elderly.
- Day-care centres for the elderly as a supporting measure for those who require supervision and care on a regular basis in order to continue to live at home. Day-care centres for the elderly shall provide nursing services and be fitted with facilities for exercise and medical services. Transportation services shall be provided to and from the home of the individual, as well as health assessments, exercise, recreation, social support, education, counselling and assistance in the activities of daily life.
- Serviced apartments for the elderly which may be privately owned, rented or residential rights apartments. Prior to the construction of serviced apartments for the elderly, construction permits must be obtained from the Minister for Health and Social Services pursuant to Article 16. Serviced apartments for the elderly shall be fitted with security systems and a choice of varied services, such as catering, laundry and cleaning and access to social activities. Payment for services provided shall be governed by the provisions of Article 20. The residents of serviced apartments shall be entitled to the same home and watch services as other residents of the municipality.

4.13.3.6 Consultation with people with dementia and carers

The “Icelandic National Health Plan to the year 2010” mentions the objective of ensuring that every health care institution establishes a formal quality development procedure and follows its own plan with regard to quality issues and that over 90% of patients should be satisfied with the health care services they receive. It is not clear to what extent this would apply to the provision of home care services for people with dementia.

4.13.3.7 Sources

Act on the Affairs of the Elderly, No.125, 31 December 1999 (with amendments up to Act No.38/2004), http://eng.heilbrigdisraduneyti.is/media/Laws%20in%20english/Act_on_the_Affairs_of_the_Elderly.pdf#search=Act%20on%20the%20Affairs%20of%20the%20Elderly%20AND%20Iceland

Alzheimer Europe (2001), Equality in the Provision of Care at Home, Alzheimer Europe

Health information Unit of WHO Regional office for Europe, Highlights on Health in Iceland, <http://www.who.dk/document/E72496.pdf>

Johnson, P. and Oafsdottir, T. (2005), WHHO-Compendium Text (extract on Iceland), <http://www.nahc.org/WHHO/WHHOcomptext.html>

Jónsson, P. V. and Pálsson, H. (2005), Toward informed and evidence-based elderly care: the RAI experience in Iceland, <http://www.milbank.org/reports/interRAI/Iceland.html>

MISSOC (2005), Comparative tables: Iceland, http://www.europa.eu.int/comm/employment_social/missoc/2002/is_part12_en.htm

The Ministry of Health and Social Security (2004), The Icelandic National Health Plan to the year 1020, abridged version, <http://www.heilbrigdisraduneyti.is/media/Skyrslur/heilbenska5mai.pdf#search='Icelandic%20National%20Health%20Plan'>

4.13.4 EuroCoDe network organisations

F.A.A.S.

Austurbrún 31

104 Reykjavík

Tel: +354 -533- 10 88

Fax: +354 -533- 10 86

faas@alzheimer.is

www.alzheimer.is

Icelandic Neurological Society

Landspalinn (National University Hospital)

Department Rehabilitation Medicine,

101 Reykjavík

Tel: +354 -560- 16 61

Fax: +354 -560- 15 19

alberts@landspitali.is

4.14 Ireland

4.14.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Ireland in 2005 as being between 31,940 (Ferri et al.) and 35,381 (Eurodem). This represents 0.78% (Ferri et al.) to 0.86% (Eurodem) of the total population of 4,109,173. The number of people with dementia in Ireland as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the number of people with dementia in Ireland, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Ireland over the age of 94.

Table 1: The number of people with dementia in Ireland in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,321	738	2,059	
60–64	1,357	399	1,756	1,537
65–69	1,493	789	2,282	2,108
70–74	2,544	2,368	4,912	4,195
75–79	1,947	3,483	5,430	5,451
80–84	2,893	5,320	8,214	7,720
85–89	1,952	4,838	6,790	10,928
90–94	1,087	2,851	3,938	
Total	14,593	20,787	35,381	31,940

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Ireland since 1960.

4.14.2 Availability of anti-dementia drugs

4.14.2.1 The availability of medicines in general

Approved medicines prescribed by GPs are free of charge for persons with full eligibility. Similarly, no charge is required from people under the age of 16 who are suffering from a mental handicap or a mental illness as well as persons suffering from specified long-term illnesses for the treatment of the illness in question.

Finally, under the drugs payment scheme, no individual or family is required to pay more than € 85 per month for approved prescribed medicines.⁴³

4.14.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Ireland and are part of the general system described above. There are no specific examinations which are required for medicines to be made available to patients, nor does the system provide upper or lower MMSE limits for the treatment with different anti-dementia drugs. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. Finally, prescriptions can be filled by any doctor and are not limited to specialists, be it for treatment initiation or continuation decisions.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.14.3 Organisation of Home care

4.14.3.1 Background information about dementia and home care services

Home care services for people with dementia comprise community nursing services and home help services. (O’Shea, 1999). Although home support services exist to some degree in each region, it has been reported that 87% of those caring for people with dementia in the home could be categorised as receiving a low level of domiciliary support (Ruddle and O’Connor, 1993). The public health nursing service is not adequately resourced, nor is the service adequately supported by back-up services.

The home help service is regarded as a key service in home care for older people. The home help service is still a discretionary service, which contributes to variability of provision and eligibility across the country. (Lundstrom and McKeown, 1994) The service is generally not available out of hours or in an emergency. A further issue is that the home help service is generic, with few, if any of the workers trained in the management of dementia. In addition, there are a significant number of pro-

⁴³ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

viders operating in the provision of home help type services including statutory and non-statutory (NGO) provision. This in turn leads to large inequities and variances in services. The Alzheimer Society of Ireland provides home respite services specifically for people with dementia – however, it is not comprehensive in terms of the number of hours support each person receives or in the geographic spread.

Most long-term care in the community is informal care provided by family members and friends in the community. There are an estimated 50,000 carers in Ireland looking after someone with one of the six specified symptoms of dementia; for example 25,000 carers are looking after someone with marked forgetfulness on a regular or occasional basis, while 15,000 are looking after someone with confusion to the point of interfering with everyday life (O’Shea, 2001). The overall median daily provision of care provided by family carers to people with dementia is 10 hours (ibid). This estimate is in line from other surveys on care provision for people with dementia (Ruddle and O’Connor, 1993).

4.14.3.2 Legislation relating to the provision of home care services

With regard to legal obligations, the Health Service Executive is empowered (under the 1970 Health Act) but not obliged or required by law to provide community care services in Ireland. Access to such services has been limited and variable within and among the regions as a result. Families are not under any legal obligation to care for their elders. There is no legally defined definition of dependency. Therefore, dependency is assessed differently according to the care group concerned and the area using a variety of different scales (McMahon and Barron, 2004).

4.14.3.3 Organisation of home care services

There is a dearth of community and home-based services for people with dementia and their carers. Services available are largely provided by the non-statutory agencies (NGOs), of which there is a plethora. However, the state also provides home care services directly in particular the public health nursing, and in some cases, home carers and home helps. In the majority of cases the state is providing some of the funding for the services to the NGOs.

Home helps are provided on the basis of assessed need, taking into account medical and family circumstances. In practice, it appears that people who are living alone are more likely to receive home help. Recipients may be asked to contribute to the cost of the service if they are deemed to have sufficient means to do so.

In general, home help services managed by the statutory bodies are organised by the four regional areas as defined by the Health Service Executive. A programme manager administers the service within their region. Within each region there is a director of community care and the area would be further broken down into areas having local area administrators/superintendent public health nurses. This

area administrator directly manages the public health nursing staff through the Superintendent public health nurse. The public health nurse locally either manages and assigns local home helps or liaises with a home help organiser (also employed by the community service) who would send in a home help to a home where required.

In the case of an NGO, clients are either referred to the home help organiser within the voluntary organisation or the referral will come to the organisation, which then reassigns it to a statutory home help organiser.

4.14.3.4 Financing of home care services

In ‘An Action Plan for Dementia’ (O’Shea, 1999), figures were given as to the overall and individual cost of care for a year for a person with dementia in 1997. It was estimated that the overall total cost of dementia care for the year in Ireland was €314m (lower estimate) (adjusted for inflation, the 2006 baseline estimate is just under €400m). That is equated to €10k per person per year of which €1.5k was attributed to community care and €7k was attributed to the cost of family care.

According to a report by the National Council on Ageing and Older People (O’Shea, 2000), family care accounts for 57% of the overall cost of care rising to 64% if family care is valued on the basis of home help replacement cost. By contrast, the inadequate provision of community care is evident by the fact that only 6% of the cost of dementia is attributable to community care services.

For carers, the principal financial support is the Carer’s Allowance. This is a means-tested benefit. In addition, carers may receive an annual respite care payment and they are also entitled to free schemes i.e. free travel, free TV license, telephone and electricity/gas allowances). The Carer’s Allowance is only given to people who look after someone full time and as a result they are unable to work in the open labour market. Many people do not claim this benefit as they slightly reduce their hours rather than completely give up work (McMahon and Barron, 2004).

4.14.3.5 Kinds of home care services available

Community Care services are defined as community nursing, home helps, respite services, day care centres and meals services together with paramedical services such as physiotherapy, occupational therapy, chiropody and speech therapy.

In addition to the above, it may be possible to benefit from home nursing aids, special lifting aids, special toilet aids, special beds, training for carers in lifting and toileting and continence advice. “Meals-on-wheels” is solely provided by voluntary groups with funding from statutory agencies. On average, those in the home in receipt of the service are supplied with meals three times a week.

4.14.3.6 Sources

Lawlor, B et al. (1994), Prevalence of mental illness in an Elderly community dwelling population using AGECT. *Irish Journal of Psychological Medicine*, 11, 4 (157-159)

McMahon, M. and Barron, B. (2004), *National Background Report for Ireland*, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_ireland_rc1_a4.pdf

O'Shea, E. and O'Reilly, S. (1999), *An Action plan for Dementia*, National Council on Ageing and Older People: http://www.ncaop.ie/publications/research/intros/intro_54_Action_Plan.pdf

O'Shea, E. (2001), *The costs of caring for people with dementia and related cognitive impairments*, National Council on Ageing and Older People: http://www.ncaop.ie/publications/research/intros/Intro_60_Costs_Dementia.pdf

Ruddle, H. and O'Connor, J. (1993) *Caring without Limits? A Study of Carers*. Dublin: The Alzheimer Society of Ireland.

Lundstrom, F. and McKeown, K. (1994) *Home Help Services for Elderly People in Ireland*, Dublin, National Council for the Elderly

4.14.4 EuroCoDe network organisations

Alzheimer Society of Ireland

Alzheimer House, Northumberland Avenue 43
Dún Laoghaire Co.
Dublin
Phone: +353 -1- 284 66 16
Fax: +353 -1- 284 60 30
info@alzheimer.ie
www.alzheimer.ie

Dementia Services Information & Development Centre

St James Hospital
Dublin 8

Irish Gerontological Society

Dr. Denis O'Mahony
Department of Geriatric Medicine
University Hospital, Wilton,
Cork
Tel: +353 -21- 492 23 96
Fax: +353 -21- 492 28 29
omahonyd@shb.ie
www.gerontology.ie

Irish Neurological Association

c/o Raymond P Murphy, MD; Department of Neurology
Tallaght Hospital
Dublin 24
Tel: +353 -1- 41 40 61/7
Fax: +353 -1- 41 40 67
raymond.murphy@amnch.ie

Irish Society of Physicians in Geriatric Medicine

webmaster@ispgm.ie
www.ispgm.ie

4.15 Italy

4.15.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Italy in 2005 as being between 820,462 (Ferri et al.) and 905,713 (Eurodem). This represents 1.4% (Ferri et al.) to 1.55% (Eurodem) of the total population of 58,462,375. The number of people with dementia in Italy as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Italy in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	20,357	11,510	31,867	
60–64	24,847	8,026	32,873	29,523
65–69	32,946	19,004	51,949	48,687
70–74	58,722	61,544	120,266	103,255
75–79	48,714	93,418	142,131	142,026
80–84	75,771	150,812	226,583	212,561
85–89	38,285	103,985	142,270	284,410
90–94	34,264	94,267	128,531	
95–99	5,553	23,690	29,243	
Total	339,458	566,255	905,713	820,462

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Italy since 1960.

4.15.2 Availability of anti-dementia drugs

4.15.2.1 The availability of medicines in general

Medicines in Italy are included in one of the three following groups:

- Group A is for medicines termed “essential” for the treatment of more serious diseases and conditions and are free of charge for people insured except for the fixed amount for the prescription.
- Group C is for other medicines and for over-the-counter medicines. For these medicines, the cost is borne in totality by the insured person.

- Group H is for medicines free of charge but limited to use in hospitals or out of hospitals according to the laws of the Italian regions.⁴⁴

4.15.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Italy and with the exception of memantine are reimbursable under strict conditions. The Italian government launched the Cronos project in 2000 to assess the impact of a multi-level therapeutic approach which included a two year free-of-charge treatment with acetylcholinesterase inhibitors.

Reimbursement is limited to persons participating in this project and requires a diagnostic assessment in one of the 503 Alzheimer Evaluation Units set up for this project. The first six months of the treatment are provided free of charge by the pharmaceutical companies manufacturing the medicines. The project provides specialists with a diagnostic protocol they need to follow. Treatment with acetylcholinesterase inhibitors is open for people with an MMSE score between 26 and 10 and memantine for people with MMSE scores below 14.

There are no specific restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	No ⁴⁵
Initial treatment decision	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Not applicable
Continuing treatment decision	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Not applicable
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Not applicable
MMSE limits	26–10	26–10	26–10	Not applicable
People living alone	No restrictions	No restrictions	No restrictions	Not applicable
People in nursing homes	No restrictions	No restrictions	No restrictions	Not applicable

4.15.3 Organisation of Home care

4.15.3.1 Background information about dementia and home care services

In 1978, the National Health System was set up in Italy. In the same year, Local Health Authorities (USL) were created which were controlled by the municipalities. However, it was not until 2000 that a legal framework and financial basis for a national development of social services was established. Meanwhile, care for the elderly was

⁴⁴ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

⁴⁵ Certain Italian regions may have different reimbursement rules. In Trentino for example, memantine can be reimbursed.

entrusted to general practitioners, community care services organised by municipalities and associations. According to Nesti et al. (2003), “at least until the 1990s, Italy had no clear concept of the problems inherent to elderly people with care needs, nor was it clear which services were required to maintain their health.”

There is still a strong emphasis on support from the family. Care of the elderly is traditionally considered as a kind of “social duty” by the family, especially the women on whom the main burden of care falls. According to Auser (2001), “it is generally accepted as normal and legitimate that the community and institutions should become involved in caring for elderly family members only after the family resources – often interpreted in a very extended sense (up to the third degree of kinship) have run out (in Polverini et al. 2004).

Demand for home care services has nevertheless increased significantly but supply has been fairly limited. The percentage of over 65 year-olds using home care services in Italy is very low (i.e. 1% of the population) compared to other countries e.g. 5.5% in the United Kingdom, 6.5% in Germany and almost 10% in Scandinavia (Minguzzi in Polverini et al. 2004). Moreover, there have been considerable differences in the development and distribution of home care services, particularly between the north and south of the country. There are also differences between the populations. For example in the north, elderly people tend to live in better conditions; on the islands, such as Sicily and Sardinia, there is a higher percentage of chronic diseases and disability (Nesti et al. 2003). Services tend to be fragmented and public expenditure on health services is fairly low.

4.15.3.2 Legislation relating to the provision of home care services

Reform of the National Health System began in 1992 with the Health Care Decree no. 502/1992, followed by the “Objective: Ageing Persons” project (the National Plan for Welfare), Law no. 328/2000 relating to the creation of an integrated care and social services system and finally the Guidance and Co-ordination related to Health and Social Integration Act of 2001.

The objective of the National Plan for Elderly People was to better co-ordinate medical and social services so as to ensure their integration within the home care services system. Related services are intended to promote the well-being of elderly people and to help them to maintain their autonomy.

Every person in Italy, with insufficient financial resources, irrespective of age, can ask for “alimony” from his/her family. According to articles 433, 438 and 443 of the Civil Code, relatives can fulfil this obligation either by paying money every month or by accepting and supporting the person in their own home (Polverini et al., 2004).

4.15.3.3 Financing of home care services

In Italy, citizens must purchase a ticket in order to have access to services within the National Health Service. People who are over 65 years old and those suffering from an officially recognised chronic and disabling disease do not have to pay.

The regions have legislative powers over health and welfare but home care services are financed entirely by Local Councils. Such services are generally rendered to people on low incomes. Elderly people may have to contribute towards costs using their pensions, vouchers and care payments. Those with extremely limited financial resources may be exempt from making these partial payments. According to Dogliotti et al. (1999), there is a die-hard cultural misconception in Italy that care is not considered as a right to be claimed by each and every citizen, but rather as a concession from above, similar to some sort of 'charity' (in Polverini et al., 2004, p.57).

According to Nesti et al. (2003), national surveys have revealed that 15% of families caring for an elderly relative employ informal carers on a private basis for more than 20 hours per week. These carers are often immigrants and the amount paid per month ranges from approximately EUR 500 in the South to EUR 800 in the North (Salvini, 2006). In some cases, families use the vouchers that they are given for services to contribute towards the cost of private care.

4.15.3.4 Kinds of home care services available

A care system was set up in the framework of the National Plan for Elderly people which includes⁴⁶:

Home Care (community care): with social importance (home help, meals and personal care); with health importance (medical, rehabilitative and/or nursing care); integrated.

Integrated Home Care Services: is a combination of integrated and coordinated health and social activities which seek to keep an elderly person at home as long as possible. Health services are medical care (Geriatric, Psychiatry), nursing, rehabilitation, medicines and prosthesis supply. Social services are: personal care, meals, house work, laundry, administrative services.

Day Centres: semi-residential structure, within the District, which hosts disabled elderly people for a short-term period (they are open during the day, 5 days a week, 7 hours a day, and admit 20 elderly persons). They provide healthcare services (prevention, therapy, and rehabilitation), and social care services (personal care and promotion of personal autonomy, entertainment, job therapy, and social activities).

Nursing homes: residential structure, organised into small groups ("nuclei"), which provides healthcare, social care, and functional rehabilitation for people with disabilities. Patient care can be extensive or intensive. The first area comprises temporary accommodation for long-term care and rehabilitation (while hospitalisation is limited only to the acute stage). The second area comprises intensive rehabilitation, with high medical importance, plus a hospice for terminal patients which provides palliative care (reduction of pain; social protection for patients and their family; family support). Doctors, nurses, social workers and psychologists are available at the Nursing Home.

⁴⁶ Extract from the report "Providing integrated health and social care for older persons in Italy" (Nesti et al., 2003)

4.15.3.5 Sources

European Foundation for the Improvement of Living and Working Conditions (EFILWC) (2002), Italy – http://www.eirpfpimd.ie/living/socpub_cstudies/de3.htm (accessed 31/5/2005)

Information provided by Gabriella Salvini (2006)

Nesti, G. et al. (2003), *Providing integrated health and social care for older persons in Italy*, Procure (<http://www.imersomayores.csic.es/documentos/documentos/procare-providingitaly-01.pdf>)

Polverini, F., Principi, A., Balducci, C., Melchiorre, G., Sabrina Quattrini, M.,

Gianelli, V. and Lamura, G. (2004), *National Background Report for Italy*, EUROFAMCARE. http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_italy_rc1_a4.pdf

4.15.4 EuroCoDe network organisations**A.I.M.A.**

Ripa di Porta Ticinese 21
20143 Milano
Tel: +39 -02- 89 40 62 54
Fax: +39 -02- 89 40 41 92
aimanaz@tin.it
www.alzheimer-aima.it

Federazione Alzheimer Italia

Via Tommaso Marino 7
20121 Milano
Tel: +39 -02- 80 97 67
Fax: +39 -02- 87 57 81
info@alzheimer.it
www.alzheimer.it

Laboratory of Epidemiology and Neuroimaging

IRCCS San Giovanni di Dio - FBF
via Pilastroni 4
25125 Brescia
Tel: + 39 -030- 350 13 61
Fax: + 39 -027- 00 43 57 27 or + 39 -030- 353 35 13
frisoni@master.cci.unibs.it
www.centroAlzheimer.it

Società Italiana di Gerontologia e Geriatria - S.I.G.G.

Via G. C. Vanini 5
50129 Firenze
Tel: +39 -055- 47 43 30
Fax: +39 -055- 46 12 17
sigg@sigg.it
www.sigg.it

Società Italiana di Neurologia (SIN)

Italian Neurological Society
c/o Conventur Siena
Via di Città 56
53100 Siena
Tel: +39 -0577- 28 50 40
Fax: +39 -0577- 28 93 34
convent@tin.it
www.neuro.it

Università Cattolica del Sacro Cuore

Department of gerontological, geriatric and psychiatric sciences
Largo A. Gemelli, 8
00168 Rome
Tel: +39 -06- 30 15 42 38
Fax: +39 -06- 30 15 48 59
bernabei@rm.unicatt.it
roberto_bernabei@rm.unicatt.it

Università di Genova

Clinical Neurophysiology Service
Dept. of Endocrinological and Metabolic Sciences
Viale Benedetto XV, 6
16132 Genoa
Tel: +39 -010- 353 84 40
Fax: +39 -010- 555 68 93
guido@unige.it

Università di Perugia

Medical School
Institute of Gerontology and Geriatrics
Department of Clinical and Experimental Medicine
via Brunamonti
06100 Perugia
Tel: +39 -075- 578 38 39 / 37 22
Fax: +39 -075- 573 02 59
u.senin@unipg.it

University of Rome La Sapienza

Department of Psychiatric Science and Psychological Medicine
P.le Aldo Moro 5
00185 Roma
Tel: +39 -064- 991 22 12
Fax: +39 -064- 45 16 22

4.16 Latvia

4.16.1 Prevalence of Dementia

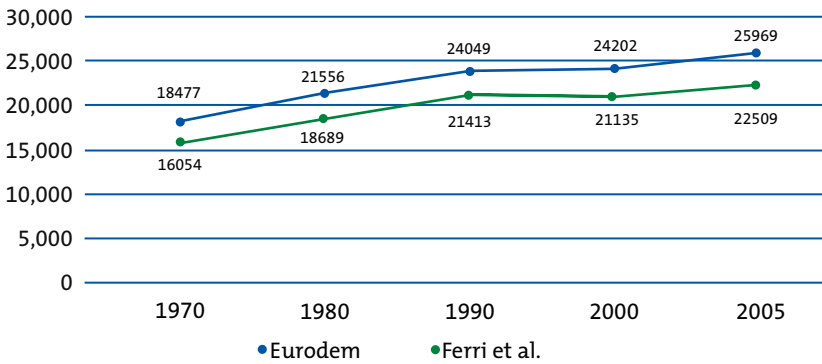
Alzheimer Europe estimates the number of people with dementia in Latvia in 2005 as being between 22,509 (Ferri et al.) and 25,969 (Eurodem). This represents 0.98% (Ferri et al.) to 1.13% (Eurodem) of the total population of 2,306,434. The number of people with dementia in Latvia as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Latvia in 2005

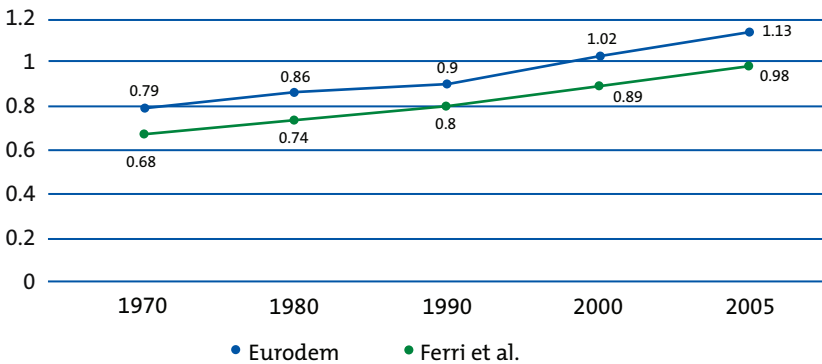
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	713	440	1,154	
60–64	857	358	1,215	1,173
65–69	1,079	864	1,943	1,668
70–74	1,637	2,529	4,166	3,233
75–79	1,206	3,845	5,051	4,731
80–84	1,211	4,712	5,923	5,478
85–89	633	2,833	3,466	6,226
90–94	492	2,011	2,503	
95–99	99	449	547	
Total	7,927	18,041	25,969	22,509

The following charts show a) the increase in the number of people with dementia in Latvia from 1970 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia steadily but only slightly increased between 1970 and 2005. In fact, the calculations based on Ferri et al.’s prevalence rates actually indicate a slight drop in 2000. As a percentage of the total population, the number of people with dementia increased from 0.68% to 0.98% or from 0.79% to 1.13% (depending on the prevalence rates used) between 1970 and 2005.

The number of people with dementia in Latvia from 1970 to 2005



The number of people with dementia in Latvia as % of total population from 1970 to 2005



4.16.2 Availability of anti-dementia drugs

4.16.2.1 The availability of medicines in general

Medicines in Latvia are included in one of four categories which determine the reimbursement rates:

- Medicines without which it is not possible to maintain life functions are reimbursed at 100%.
- Medicines without which there would be difficulties in ensuring a patient's life functions are reimbursed at 90%.
- Medicines without which the current health status could not be maintained are reimbursed at 75%.
- Medicines which are necessary to improve a patient's health condition are reimbursed at 50%.⁴⁷

4.16.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are marketed in Latvia, but none of them are part of the reimbursement system.

4.16.3 Organisation of Home care

Alzheimer Europe was unable to obtain sufficient information to describe the organisation of home care in Latvia.

4.16.4 EuroCoDe network organisations

Latvian Neurologists Association
7th Clinical Hospital of Riga
Hipokrata Str. 2
1038 Riga
Tel: +371 -7- 53 63 92
Fax: +371 -7- 53 95 24
neiroasoc@gails.lv

4.17 Lithuania

4.17.1 Prevalence of Dementia

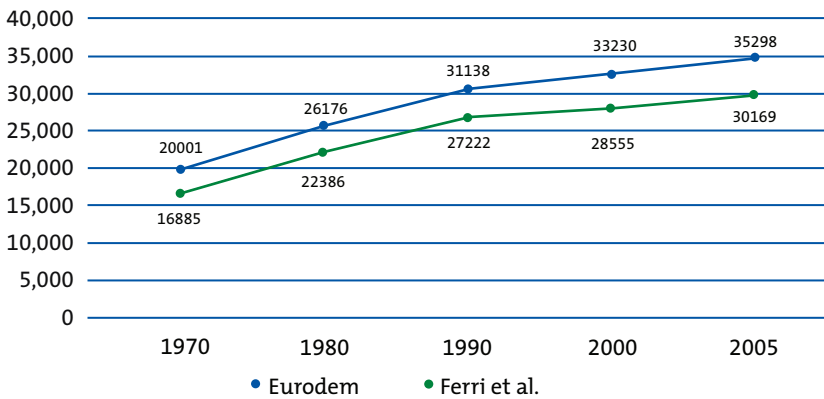
Alzheimer Europe estimates the number of people with dementia in Lithuania in 2005 as being between 30,169 (Ferri et al.) and 35,298 (Eurodem). This represents 0.88% (Ferri et al.) to 1.03% (Eurodem) of the total population of 3,425,324. The number of people with dementia in Lithuania as a percentage of the total population is well below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Lithuania in 2005

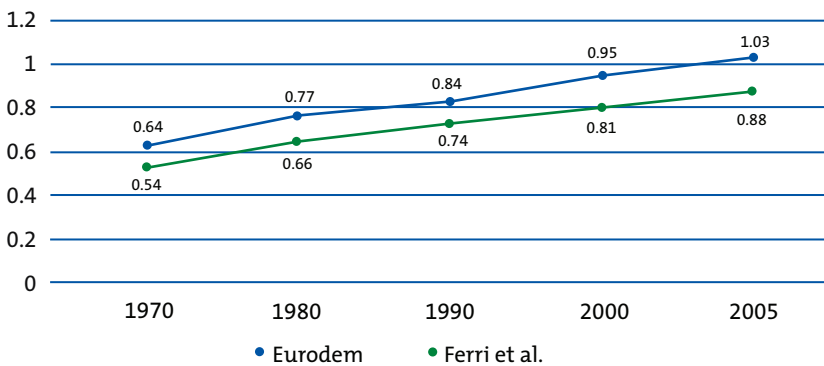
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,065	658	1,723	
60–64	1,159	476	1,635	1,572
65–69	1,416	1,112	2,528	2,162
70–74	2,413	3,538	5,951	4,608
75–79	1,752	5,084	6,836	6,437
80–84	2,009	6,227	8,236	7,399
85–89	946	3,529	4,475	7,991
90–94	674	2,403	3,076	
95–99	280	557	837	
Total	11,714	23,584	35,298	30,169

The following charts show a) the increase in the number of people with dementia in Lithuania from 1970 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia rose from 20,001 to 35,298 between 1970 and 2005 (Eurodem).

The number of people with dementia in Lithuania from 1970 to 2005



The number of people with dementia in Lithuania as % of total population from 1970 to 2005



4.17.2 Availability of anti-dementia drugs

4.17.2.1 The availability of medicines in general

Medicines in Lithuania are fully covered for children under 18, persons with group 1 disability and for hospital treatment. 50% of the price of medicines is covered for old-age pensioners, persons with group 2 disability and other persons entitled to a social insurance protection.

Finally, the Lithuanian system prescribes reimbursement levels for medicines for specific diseases on a special list for which reimbursement can be 50%, 80%, 90% or 100% depending on the disease.⁴⁸

⁴⁸ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.17.2.2 The availability of Alzheimer treatments

In Lithuania, only donepezil and memantine are part of the reimbursement system. People with an MMSE score between 20 and 0 can qualify for the reimbursement of donepezil. The same information for memantine was not available. There are no restrictions in Lithuania for the reimbursement of these treatments for people living alone or in nursing homes.

Alzheimer Europe has no information on whether there are special requirements in Lithuania as to which doctors can prescribe Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	No	No	Yes
Initial treatment decision	No information	Not applicable	Not applicable	No information
Continuing treatment decision	No information	Not applicable	Not applicable	No information
Required examinations	MMSE	Not applicable	Not applicable	No information
MMSE limits	20–0	Not applicable	Not applicable	No information
People living alone	No restrictions	Not applicable	Not applicable	No restrictions
People in nursing homes	No restrictions	Not applicable	Not applicable	No restrictions

4.17.3 Organisation of Home care

Alzheimer Europe was unable to obtain sufficient information to describe the organisation of home care in Lithuania.

4.17.4 EuroCoDe network organisations

Alzheimer Association Lithuania

Balio Sruogos g. 36-14
10220 Vilnius
andriuliene@alzheimer.lt

Kaunas University of Medicine

Geriatric Clinic
Micevicius g
44307 Kaunas
juramac@takas.lt

Lithuanian Neurological Association

Vilnius University Santariskiu Klinikos Hospital

Santariskiu 2

2021 Vilnius

Tel: +37 -02- 36 52 21 or +37 -02- 36 52 22

Fax: +37 -02- 36 52 20

neuro@lux.lt

4.18 Luxembourg

4.18.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Luxembourg in 2005 as being between 4,370 (Ferri et al.) and 4,857 (Eurodem). This represents 0.96 % (Ferri et al.) to 1.07% (Eurodem) of the total population of 455,000. The number of people with dementia in Luxembourg as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

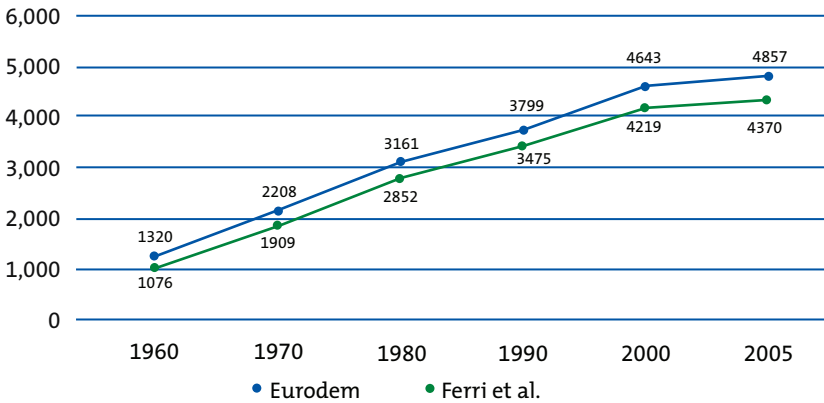
The Alzheimer Europe figures underestimate the number of people with dementia in Luxembourg, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Luxembourg over the age of 94.

Table 1: The number of people with dementia in Luxembourg in 2005

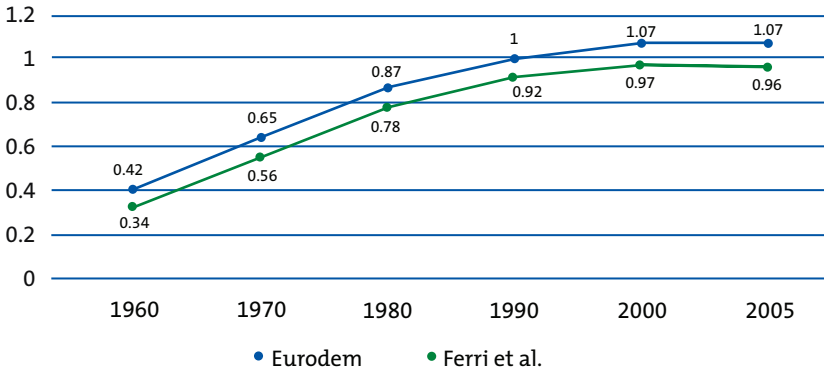
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	164	90	254	
60–64	163	50	213	188
65–69	194	110	304	284
70–74	358	366	724	621
75–79	290	558	848	847
80–84	334	825	1160	1082
85–89	187	621	807	1,348
90–94	113	434	547	
Total	1,803	3,054	4,857	4,370

The following charts show a) the increase in the number of people with dementia in Luxembourg from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than trebled between 1960 and 2005.

The number of people with dementia in Luxembourg from 1960 to 2005



The number of people with dementia in Luxembourg as % of total population from 1960 to 2005



4.18.2 Availability of anti-dementia drugs

4.18.2.1 The availability of medicines in general

Medicines in Luxembourg can fall under one of four different reimbursement systems:

- Normal reimbursement of medicines amounts to 80% of their cost,
- Preferential reimbursement is 100%,
- Reduced reimbursement is 40% and
- Certain medicines are not reimbursed.⁴⁹

⁴⁹ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.18.2.2 The availability of Alzheimer treatments

In Luxembourg, all anti-dementia drugs are available and are part of the normal reimbursement system (80%). Reimbursement is nevertheless dependent on prior approval by the medical control unit of the social security ministry. Any doctor can fill in this application for reimbursement, but specific information needs to be provided to see whether a patient fulfils the DSM IV definition of Alzheimer's disease. In practice, most applications are filled in by neurologists or psychiatrists. A reimbursement decision is made for six months only, after which a follow-up examination is necessary and treatment continuation is possible.

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores below 15.

There are no restrictions in Luxembourg for the reimbursement of these treatments for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	26–10	26–10	26–10	15–0
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.18.3 Organisation of Home care

4.18.3.1 Background information about dementia and home care services

In 1991, a Consultative Commission was set up to look into the possibility of creating a dependency insurance scheme. Users, carers and voluntary as well as private organisations were all invited to participate in the consultation which eventually led to the introduction of a dependency insurance in 1999. This was part of the government's dual policy to support elderly and disabled people in their own homes for as long as possible whilst at the same time developing user-oriented care strategies.

Between 1998 and 2003, 17,933 requests for assistance were registered by the Ministry of Social Security. Of these, 83.2% were from people over 70 and of the accepted applications, 62.6% were from people in need of home care (Ferring and Weber, 2005).

4.18.3.2 Legislation relating to the provision of home care services

The Law of 19 June 1998 (“Assurance Dépendance”) led to the introduction of an obligatory dependency insurance on 1 January 1999 (sometimes referred to as long-term care insurance or “LTCI”). This covers expenses linked to the care of elderly residents in old people’s homes or assistance at home.

4.18.3.3 Organisation and financing of home care services

The dependency insurance is financed by people (whether they are Luxembourg residents or simply commuters from the surrounding countries) who contribute to the Luxembourg sickness insurance. For the monthly contribution, each person pays 1% of their total gross income (less a quarter of the minimum social salary). There are plans to increase this to 1.4% in the near future (Di Bartolomeo, 2006). For Luxembourg residents, investments, rental and other sources of income are also included in the calculation for annual contributions.

Before home care services are provided, a person must have a needs assessment which involves a medical examination and an evaluation of their level of dependency. This is organised by the “Cellule d’Evaluation et d’Orientation” (CEO) which is comprised of a multidisciplinary team under the authority of the Ministry of Social Security. According to the dependency insurance law, a person is considered as dependent if due to a disease or a physical or mental disability, he or she regularly needs a considerable amount of assistance from a third party in order to carry out basic daily tasks (i.e. at least 3,5 hours per week).

The final decision concerning entitlement to services and the amount of services to be provided is taken by the Union of Sickness Funds (“Union des caisses de maladie”) based on information about the assessment carried out by the CEO. The Union of Sickness Funds is responsible for:

1. the individual classification of dependency, as well as the attribution, reduction and suppression of the different benefits and services;
2. the payment of nursing services, the elaboration of nursing contracts and the negotiation of the monetary value of nursing services;
3. negotiation with service providers concerning the provision of nursing aids (Ferring and Weber, 2005).

Dependent people receive a nursing allowance of € 23,85 per hour which can be used to finance informal care e.g. provided by a relative, friend or significant other. However, if the estimated amount of care to be provided is between 7 and 14 hours per week, at least half of the services must be provided by help networks e.g. “Hëllef Doheem”. If the person is in need of more than 14 hours of services per week, such services must be completely provided by the help networks (Ferring and Weber, 2005).

In addition to services provided by informal carers and the established help networks, there are about 23 associations, registered with the Ministry of Family Affairs, which operate on a voluntary basis.

4.18.3.4 Kinds of home care services available

The person appointed to provide care is responsible for assisting and supporting the dependent person in performing basic acts of living or partially or totally performing these acts for the dependant person. This could include:

- Help with tasks that are essential for daily living:
 - o Personal hygiene – washing, brushing teeth, skincare and going to the toilet
 - o Nutrition – preparing meals for special needs, assistance with eating and drinking
 - o Mobility – getting up, going to bed, changing position, getting dressed and undressed, standing up, going up and down stairs, going out and returning to one's home.
- Help with domestic tasks:
 - o 2.5 hours per week of domestic assistance (extended to 4 hours in case of special needs, e.g. with washing clothes in case of incontinence)
- Support:
 - o Individual support, e.g. stimulating and motivating the person to do activities
 - o Group support, e.g. gym, manual work, going on walks
 - o The dependency insurance also covers special equipment (e.g. beds, wheelchairs etc.) and adaptation of a person's home (e.g. special doors, chair lift etc.)
- Respite care:
 - o Every year, the person in need of care receives twice the amount of his/her nursing allowance which can be used to finance a stand-in person for three weeks' respite care.

4.18.3.5 Sources:

Di Bartolomeo, M. (2006): information given in speech at the "Cross Atlantic Exchange to advance long-term care" conference held on 13 September 2006 in Bruxelles (organised by AARP and the European Commission)

EFILWC (2002), *Dependency insurance in Luxembourg*, www.eurofound.ie/living/socpub_cstudies/lu1.htm

Ferring, D. and Weber, G. (2005), *National Background Report for Luxembourg*, EUROFAMCARE. http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_luxembourg_rc1_a4.pdf

Hartmann-Hirsch, C. et al. (1999), *L'Assurance Dépendance; guide pratique*, Ministère de la Sécurité Sociale

Horsburgh & Co. S.A. (2005), *Assurance Dépendance*, www.horsburgh.lu/assurdepend.html

4.18.4 EuroCoDe network organisations

Association Luxembourg Alzheimer

B.P. 5021
1050 Luxembourg
Tel.: +352 42 16 76-1
Fax: +352 42 16 76-30
info@alzheimer.lu
www.alzheimer.lu

Association Luxembourgeoise de G erontologie et de G eriatric

13 Rue Prince Jean
9052 Ettelbruck
Tel: +352 26 82 1
Fax: +352 268 222 40
jean-claude.leners@santel.lu

Soci t  Luxembourgeoise de Neurologie asbl

23-25, rue de l'Alzette,
4011 Esch-sur-Alzette
Tel: +352 54 44 49-1
Fax: +352 54 78 86
alexbis@pt.lu

4.19 Malta

4.19.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Malta in 2005 as being between 3,148 (Ferri et al.) and 3,427 (Eurodem). This represents 0.78% (Ferri et al.) to 0.85% (Eurodem) of the total population of 402,668. The number of people with dementia in Malta as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

It should be noted that due to the lack of availability of statistics from EUROSTAT for 2005 for the 90+ age group, these calculations probably underestimate the number of people with dementia in Malta. Statistics from the Maltese government indicate that there were 1,492 people aged between 90 and 100 in 2004. Using EURODEM prevalence rates, this would represent 319 people with dementia, which would bring the total number of people with dementia in 2005 to at least 3,746.

Table 1: The number of people with dementia in Malta in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	136	76	212	
60–64	147	47	194	174
65–69	176	104	281	264
70–74	276	315	590	509
75–79	214	406	620	620
80–84	329	582	911	857
85–89	196	423	619	724
Total	1474	1,953	3,427	3,148

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Malta since 1960.

4.19.2 Availability of anti-dementia drugs

4.19.2.1 The availability of medicines in general

According to information from the website of the Health Division (Ministry of Health)⁵⁰, the government supplies medicines free of charge to all in-patients in government hospitals. Medicines are supplied for free from government pharmacies and district clinics to entitled persons. There are two schedules under the Social Security Act Cap. 318 to grant free medicines:

- Schedule II (referred to as the Pink Card), entitles households with low total income (means tested) to medicines listed in the Government Formulary, subject to completion of certain requirements (e.g. hospital consultant’s signature in the case of certain medicines). A Pink Card can also be issued for people with tuberculosis, leprosy or poliomyelitis and their after effects. People with diabetes can also benefit from this schedule.
- Schedule V (referred to as the Yellow Card), entitles people with diseases listed under the fifth schedule of the Social Security Act to free medicines for that condition irrespective of financial position. These include many chronic diseases such as malignancy, cancers, chronic cardiovascular and respiratory disease, endocrine diseases, schizophrenia and others. Certain conditions such as stroke, dementia and depression are not included. The list was last updated in 1999.

Other persons entitled to free drugs (who are issued a Grey Card that has the same function as the Pink Card) are members of religious orders, inmates of charitable institutions, certain grades of employees in the Health Division, certain grades of employees in the police and armed forces, prisoners, and persons injured on government duty.

4.19.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Malta. Alzheimer’s disease is not on the list of covered diseases (schedule V) and anti-dementia drugs thus need to be funded through out-of-pocket payments. Prescriptions can be effected both by specialists and family doctors.

4.19.3 Organisation of Home care

4.19.3.1 Legislation relating to the provision of home care services

According to the Maltese Civil Code (Book first of persons, art. 2), a married person who is in need of help with daily living can rely on maintenance from his/her spouse provided that they still live together. Maintenance is defined in article 19, paragraph 1 as including food, clothing, health and habitation. Children are bound to maintain their parents or other ascendants who are indigent. However, neither of the spouses can claim maintenance from their children if such maintenance could be provided by the other spouse (art. 5.3). No one is legally obliged to care for unmarried people or widows with no children. The State would be responsible for their care.

The main legislation that governs home care in Malta is the Social Security Act (Cap. 318). This law deals with the provision of benefits, assistances and pensions to the poor, sick, elderly and the unemployed. A Carer’s Pension is payable to “all unmarried or widowed persons who are taking care, on their own of a parent who is bed-ridden or confined to a wheel-chair”. A legal notice entitled State Financed Services Rate Regulations (L.N. 259 of 2004) determines the amount that an elderly person residing in state financed homes shall contribute to Government for his/her care

and upkeep. Care is classified as Level 1 care, where residential care with only minimal basic care is provided and Level 2 care where the residential service provided includes such level of care that goes beyond minimal basic care as certified by the Interdisciplinary Assessment Team within the Elderly and Community Services Department.

4.19.3.2 Organisation and financing of home care services

As Malta is small (316 km² with a population of 400,000), all policies are promulgated and passed by the national government. There are consequently no formal regional or district tiers of health care.

Nevertheless, there are 68 local councils. They do not have any policy making power but many have an elected person who is responsible for monitoring the provision and quality of services for the elderly. Although it is the responsibility of the national government to provide day-care centres, it is often on the initiative of local councils which in many cases also provide and furnish the actual building.

The health care system is publicly financed through general taxation and is free at the point of delivery although users may have to make out-of-pocket payments. Private healthcare is fairly common (Ministry of Health, 2002).

In 1987, the Government set up a Department for the Care of the Elderly which is responsible for taking care of the special needs of the elderly. The aim, in providing these services, is to enable elderly people and those with special needs to remain living within the community for as long as possible. Community services for the elderly and for people with special needs are heavily subsidised by the State. People receiving such services pay a nominal fee based on their income (Ministry of Health, 2002).

Requests for the homecare help service must be accompanied by a medical report. This is sent to the Department for the Elderly and Community Services, which then arranges for a social worker to visit the applicant in their home in order to assess their needs. The number of hours granted is dependant on each person's needs.

4.19.3.3 Kinds of home care services available

There is a wide range of home care services for the elderly in Malta.

There are 13 day centres mainly for people who are over 60 years of age. Priority is given to elderly people living alone, those who are not involved in social activities and those who could be at risk spending long hours on their own. The centres, which are open 5 days a week, offer physical education, social and creative activities and sometimes educational talks on relevant issues e.g. health, home safety and welfare services. Intergenerational activities are encouraged and outdoor activities are organised twice monthly. People attending day centres are required to pay a nominal fee (ranging from Lm 1 to Lm 2.5 a month depending on how many times they attend the centre) with an additional 50 cent charge being made for couples.

The handyman service offers a range of about 70 different repair jobs e.g. linked to plumbing, carpentry, transportation of objects, electrical work etc. The service is free of charge to senior citizens holding the Pink Form and Special ID Card (which are granted on a means-tested basis and entitle holders to free medication and certain other benefits). People who do not have such cards have to pay for the service. This usually amounts to Lm 1- Lm 2 depending on the job required. In all cases, the person receiving the service must pay for any necessary materials.

The homecare help service provides non nursing care, personal assistance and help with light domestic work to older people i.e. over 60. The services are adapted to each person's individual needs. People over the age of 85 are given priority. Other criteria include having special needs and the ability to live a relatively independent life in one's own home if given assistance, being terminally ill or living alone with no formal or informal family support network. There is a nominal fee of Lm 1 per week for a single person and Lm 1.50 in the case of more than one person benefiting from the service. The preparation of meals incurs an additional charge of 50 cents for a single person and 75 cents for more than one person.

The incontinence service is available to people over 60 years of age or younger people with special needs. Incontinence pads/diapers are heavily subsidised in order to permit people with this problem to continue living in the community. Nevertheless, there is a charge which ranges from 7 cents to 11 cents each.

Meals-on-wheels are provided 7 days a week by the Maltese Cross Corps (a non-governmental organisation) and the Catholic Action Movement in collaboration with the Department for the Elderly and Community Services. People over 60 years of age and people with disability, who are unable to prepare their own meals, can benefit from this service. Each meal costs 95 cents (approx. EUR 2.2). When delivering the meals, the specially trained staff ask whether the elderly person needs anything and keep an eye on the person's home environment. They are expected to report anything unusual to the organisers of the service.

The social work unit provides psychological counselling, guidance and assistance to certain categories of elderly people including those with dementia and those living alone with a high level of dependency. The unit “deals with social casework, provides advocacy for clients, facilitates self-help management and develops action plans, performs crisis intervention work, provides assessments for residential homes, home care help service and assessments of Carer's Pension for the Department of Social Security, and liaises with the geriatric, general and rehabilitation hospitals, the Health Department, police, Local Councils and other community organizations.” A medical report is necessary to benefit from this service. Once approved, either the social worker visits the person in their own home or the person has a meeting with the social worker at the offices of the Department.

The telecare service is designed to enable subscribers to call for help when needed. This gives older people, those with special needs and also their friends and relatives a feeling of security and encourages subscribers to carry on living in their own homes. The service is available to elderly couples/people living alone aged 80 and over, people over 70 suffering from a chronic illness, people of any age living alone who are afflicted by a life threatening illness and people who are afflicted by a life threatening illness whose carers would benefit from the service. In case of emergency, the elderly person just needs to press a button on the unit itself or on a pendant worn round the neck and a call is made to the Control Centre which has full medical details as well as the contact details of the person, the doctor and two relatives, friends or neighbours who have a key. The service costs Lm 1 per month for single people and Lm 1.16 for two people living together.

The Malta Hospice Movement offers a comprehensive range of services to terminally ill people, most of whom are elderly. This includes home care, day therapy, spiritual support, night and day nursing in the home, respite care, assistance with bathing and hairdressing.

Respite care is mainly provided at Zammit Clapp Hospital, a specialised geriatrics assessment and rehabilitation hospital and at St. Vincent de Paul Residence, a residential complex. Both these units are state-run and free. However, places are limited and an application has to be submitted beforehand. Respite can also be organised in residential homes run on a profit-making basis, as well as in church-run residential homes.

Voluntary associations offering services for the elderly in the community include Caritas Malta, the Catholic Action Movement, the Legion of Mary, the Social Action Movement and the St Vincent de Paul Society. In 1982, Caritas set up the "good neighbour scheme". Every elderly person is visited, assessed and invited to participate in this free service. If interested, the volunteers motivate neighbours who then keep a friendly and regular watch on the elderly person. Some provide direct help and some alert the necessary authorities in order to organise help.

A number of grants are available to the elderly for home adaptations or improvements.

The Independent Living Advice Centre is an organisation run by volunteers which promotes the use of technical aids to enable frail and elderly people with disabilities to manage daily activities and retain their independence.

4.19.3.4 Sources

Department of Information (2004). Legal Notice 259 of 2004: State Financed Services Rate Regulations. <http://www.doi.gov.mt/EN/legalnotices/2004/05/LN259.pdf>

Information provided by Charles Scerri and Stephen Abela (2006).

Malta Hospice Movement website: <http://www.hospicemalta.org> (accessed in November 2005)

Ministry of Health (2002), *Public Health Report: Malta 2002*, Department of Health Information:
<http://www.sahha.gov.mt/showdoc.aspx?id=41&filesource=4&file=publichealthreport2002.pdf>

Ministry of Health website (Department of the Elderly and Community Services):
<http://www.gov.mt/frame.asp?l=2&url=http://www.sahha.gov.mt> (accessed in November 2005)

Ministry of Justice (2004). Laws of Malta: Social Security Act. Cap 318. Accessed on 7th June 2006
from http://docs.justice.gov.mt/lom/legislation/english/leg/vol_7/chapt318.pdf

Troisi, J. (2004), *National Background Report for Malta*, EUROFAMCARE.
http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_malta_rc1_a4.pdf

Zammit Clapp Hospital (2004). Annual Report 2004.
http://www.sahha.gov.mt/showdoc.aspx?id=2&filesource=4&file=zchannualreport_2004.pdf

4.19.4 EuroCoDe network organisations

Malta Dementia Society

University of Malta
c/o Room 135, Department of Pharmacy
MSD 06 MSIDA
info@maltadementiasociety.org.mt
www.maltadementiasociety.org.mt

Maltese Association of Gerontology and Geriatrics MAGG

European Centre of Gerontology
University of Malta.
Msida MSD 06
Tel: +356 -2- 340 22 37/38
Fax: +356 -2- 131 95 26
magg@um.edu.mt
soc.um.edu.mt/magg

4.20 The Netherlands

4.20.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in the Netherlands in 2005 as being between 165,585 (Ferri et al.) and 183,485 (Eurodem). This represents 1.02% (Ferri et al.) to 1.13% (Eurodem) of the total population of 16,305,526. The number of people with dementia in the Netherlands as a percentage of the total population is a little lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

We would like to point out that the Dutch Alzheimer Association has cautioned against the use of these prevalence rates (in particular the data from Ferri et al.), as the organisation feels that these rates underestimate the size of the problem in the Netherlands as identified by the National Health Council, which published data on the prevalence of dementia in the Netherlands and estimated that there were 193,912 people with dementia in the Netherlands in 2005.

Nevertheless, in order to provide comparative data between the different countries, Alzheimer Europe includes here the calculations based on the Eurodem and Ferri prevalence rates.

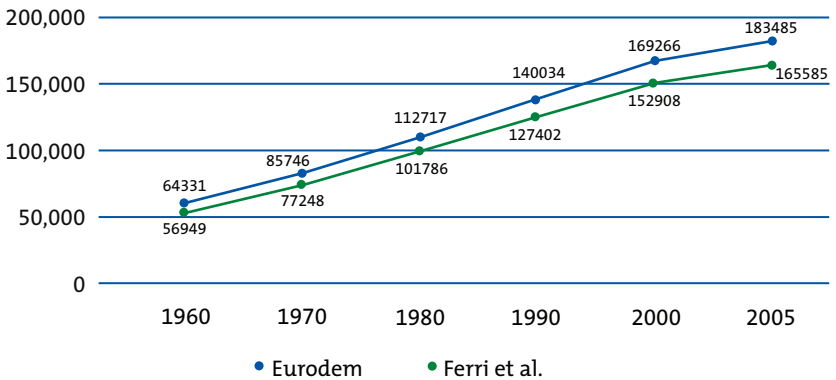
Table 1: The number of people with dementia in the Netherlands in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	5,857	3,224	9,081	
60–64	6,531	1,930	8,462	7,417
65–69	7,132	3,837	10,969	10,163
70–74	12,156	12,132	24,288	20,808
75–79	9,572	17,988	27,560	27,576
80–84	14,434	29,225	43,659	40,940
885–89	8,530	25,975	34,505	58,682
90–94	4,637	15,750	20,387	
95–99	702	3,873	4,574	
Total	69,551	113,934	183,485	165,585

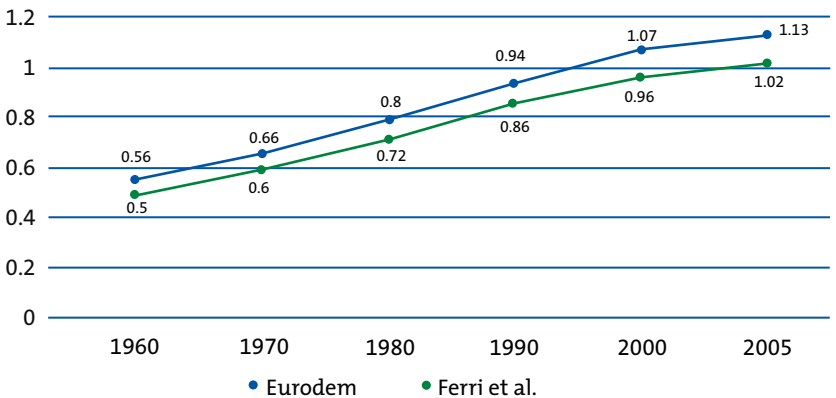
The following charts show a) the increase in the number of people with dementia in the Netherlands from 1960 to 2005 and b) the number of people with dementia as

a percentage of the total population in the same years. As can be seen, the number of people with dementia almost trebled between 1960 and 2005. As a percentage of the total population, the increase was just over 100%.

The number of people with dementia in the Netherlands from 1960 to 2005



The number of people with dementia in the Netherlands as % of total population from 1960 to 2005



4.20.2 Availability of anti-dementia drugs

4.20.2.1 The availability of medicines in general

The health insurance system in the Netherlands is a mixture of private and public insurance schemes. In 2006, there was a huge change in the system. Hospital and GP care, drugs and other short-term care is now insured by private insurance companies, within the framework of public rules about acceptance, settlement of bad risks and price. Long-term care is still part of public insurance.

Only pharmaceutical products with a marketing authorisation are added to a positive list by the health ministry.

Products with a reference price are listed in annex 1a. If a reference price cannot be allocated to a product it will be placed in annex 1b. When deciding about the reimbursement of products in annex 1b the therapeutic value of the product is considered. If the therapeutic value of a product is low it will not be considered eligible for reimbursement. Some drugs in the positive list are classified into annex 2. These drugs are reimbursed only if certain criteria are fulfilled. The criteria could be, for example, that the prescription must be written by a specialist physician.⁵¹

4.20.2.2 The availability of Alzheimer treatments

With the exception of donepezil, anti-dementia drugs are available in the Netherlands and are part of the reimbursement system. Since these drugs are on annex 2 of the positive list, certain criteria need to be fulfilled prior to reimbursement. Only specialist doctors can initiate and continue treatment and the reimbursement system provides a clear diagnosis and treatment protocol.

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores between 14 and 3.

There are no restrictions in the Netherlands for the reimbursement of these treatments for people living alone. Although there are no restrictions in theory for the access of people in nursing homes, the Dutch Alzheimer’s organisation stresses that reimbursement remains problematic, since the cost of treatment would need to be covered by the budgets of the nursing home and may thus be dependent on a positive decision of the home in question.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	No	Yes	Yes	Yes
Initial treatment decision	Not applicable	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Not applicable	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	Not applicable	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	Not applicable	26–10	26–10	14–3
People living alone	Not applicable	No restrictions	No restrictions	No restrictions
People in nursing homes	Not applicable	No restrictions	No restrictions	No restrictions

⁵¹ Martikainen J, Rajaniemi S. Drug reimbursement systems in EU Member States, Iceland and Norway. Helsinki: The Social Insurance Institution, Finland, Social security and health reports 54, 2002. 130 pp. ISBN 951-669-612-0.

4.20.3 Organisation of Home care

4.20.3.1 Legislation relating to the provision of home care services

The new Health Insurance Act which came into force on 1 January 2006 abolished the former distinction between private and public health insurance. The act made it compulsory for every person residing or paying tax in the Netherlands to take out a health insurance. Every healthcare insurance company in the Netherlands, having agreed to provide services under the new Act, is obliged to accept any person who applies for insurance. People pay a nominal premium directly to the health insurer as well as an income-related contribution. The latter is levied by the Inland Revenue Service.

Under the Health Care Insurance Act, which also came into force on 1 January 2006, people may receive an allowance if the nominal premium is particularly high in relation to their income.

The Exceptional Medical Expenses Act of 14 December 1967 (implemented on 1 January 1968) – AWBZ – covers costs for the care of long-term chronic illness that are not covered by the Health Insurance Act. A basic principle of the AWBZ is that people should be helped to live at home for as long as possible. The AWBZ originally covered costly long-term institutional care but the scope of the act was extended to cover other services such as home nursing in 1980 and home help in 1989. Health insurance companies are designated by the Ministry of Health, Welfare and Sport to implement the AWBZ.

4.20.3.2 Organisation and financing of home care services

Care provided under the Health Insurance Act and the AWBZ is divided into “products”. Home care and residential/nursing care for people with physical and/or mental disabilities are considered Medical Expenses Act products. A product consists of one or more functionally defined categories of care. There are seven broadly-defined categories of care:

- Domestic help
- Personal care
- Nursing
- Supportive guidance (e.g. help organising one’s daily life, day care etc.)
- Activating guidance (helping the person to adapt their behaviour or learn new skills)
- Treatment (care linked to a health condition e.g. rehabilitation after a stroke)
- Accommodation (e.g. sheltered housing, constant supervision, institutionalisation)

AWBZ is funded through a compulsory premium, a co-payment and general taxation. The compulsory premium is integrated into the income tax structure but it is the employer who pays the largest share. The amount of the co-payment depends on the type of service, the income of the person who needs it, whether they are over 65, whether they live at home or in an institution and whether they live alone or cohabit. There is, however, a maximum weekly co-payment for all forms of home care.

To be considered eligible for care, it is necessary to be assessed by an organisation called CIZ (Centrum indicatiestelling zorg). CIZ determines how much and what kind of care a person is entitled to receive. Once a person's entitlement has been established, the person is free to choose care in kind, a personal care budget or a combination of the two.

Care in kind means care services provided directly by a health care provider. This is arranged in consultation with the client who can use one or more care providers. A personal care budget is an amount of money granted to the client to purchase care independently. The client is free to purchase the care services from a health care provider but also from any person willing to provide the service e.g. a friend, relative or neighbour etc. Clients receiving a personal care budget are obliged to provide regular justification of their expenditure. The personal care budget is quite popular. The number of people with a personal care budget increased from 5,400 in 1996 to 65,000 in 2003 (Beukeman quoted in van Vliet and Oudenampsen, 2004).

For care in kind, people may receive a bill or have the co-payment deducted from other state allowances. Co-payments for people receiving a personal care budget are deducted from the total amount that the person would otherwise receive.

4.20.3.3 Kinds of home care services available

Home care services are organised around the afore-mentioned categories of care. Examples include: home nursing (e.g. giving advice on how to cope with an illness, dressing wounds, administering medication), personal care (e.g. assistance with dressing, bathing, personal hygiene, eating and drinking), home help and house-keeping (e.g. cleaning, tidying and preparing meals), day care, respite care, night care and assistive devices.

A special service called "Alpha Care" consists of home care that is provided by housewives. It is less expensive but limited to 16 hours per week. Nursing care is limited to 3 hours per day except in exceptional circumstances (Brodsky et al. 2000).

4.20.3.4 Possible future developments

A Social Support Act is currently being debated. If passed, it is likely to absorb cover for domestic help, supportive care and activating care, currently provided under the AWBZ, as well as certain grant schemes under the AWBZ concerning support to eld-

erly people requiring assistance from relatives and friends outside the professional setting. According to van Vliet and Oudenampsen (2004), the consequences of the possible future transfer of cover for certain services to the Social Support Act is that these services will become the responsibility of the local government and will no longer be part of the services that budget-holders can purchase themselves.

4.20.3.5 Sources

Brodsky, J., Habib, J. and Mizrahi, I. (2000), A review of long-term care laws in five developed countries, <http://www.wu-wien.ac.at/wwwu/institute/Sozialpolitik/LTC.pdf#search=%20review%20of%20longterm%20care%20laws>

Ministry for Health, Welfare and Sport (2005), Health insurance in the Netherlands; the new health insurance system from 2006:

http://www.minvws.nl/images/health-insurance-in-nl_tcm11-74566.pdf

Van Vliet, K. and Oudenampsen, D. (2004), Integrated care in the Netherlands,

<http://www.verwey-jonker.nl/images/dynamisch/D3551878.pdf>

Visser-Jansen, G. and Knipscheer, C.P.M. (2004), National Background Report for the Netherlands, EUROFAMCARE: http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_netherlands_rc1_a4.pdf

4.20.4 EuroCoDe network organisations

Vrije Universiteit Amsterdam

Alzheimer Centre
Dept of Neurology, Vu medisch centrum
PO Box 7057
1007MB Amsterdam
Tel: +31 -20- 444 32 22
Fax: +31 -20- 444 07 15
p.scheltens@vumc.nl
www.alzheimercentrum.nl

Alzheimer Nederland

Kosterijland 3, Postbus 183
3980 CD Bunnik
Tel: +31 -30- 659 69 00
Fax: +31 -30- 659 69 01
info@alzheimer-nederland.nl
www.alzheimer-nederland.nl

Knowledge Centre of Psychiatry in the Elderly

Oude Arnhemseweg 260
3705 BK Zeist
Tel: +31 -30- 693 76 10
contact@elderlypsychiatry.com
www.elderlypsychiatry.com

Nederlandse Vereniging voor Neurologie

Dutch Society of Neurology
Secretariat of the Dutch Society of Neurology
P.O. Box 20050
6502 LB Utrecht
Tel: +31 -30- 282 33 43
Fax: +31 -30- 280 38 79
bureau@neurologie.nl
www.neurologie.nl

Nederlandse Vereniging voor Klinische Geriatrie

Postbus 2704
3500 GS Utrecht
Tel: +31 -30- 298 51 69
Fax: +31 -30- 298 51 70
info@nvkg.nl
www.nvkg.nl

Nederlandse Vereniging voor Gerontologie

P. O. Box 222
3500 AE Utrecht
Tel: +31 -320- 22 42 95
Fax: +31 -320- 23 63 57
nig@nig.nl
www.nvgerontologie.nl

University Hospital Maastricht

Department of Psychiatry and Neuropsychology
PO Box 5800
6202 AZ Maastricht
Tel: +31 -43- 387 75 37
Fax: +31 -43- 387 54 44
f.verhey@np.unimaas.nl
www-np.unimaas.nl/maas/maas.html

University Hospital Nijmegen

Department of Geriatric Medicine
PO Box 9101
6500 HB Nijmegen
m.olde-rikkert@czzoger.azn.nl
UMC Nijmegen

4.21 Norway

4.21.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Norway in 2005 as being between 56,227 (Ferri et al.) and 61,077 (Eurodem). This represents 1.22% (Ferri et al.) to 1.33% (Eurodem) of the total population of 4,606,363. The number of people with dementia in Norway as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Norwegian Alzheimer Association uses prevalence rates developed by Ott⁵² et al which would result in greater numbers of people with dementia in Norway (i.e. 66,758).

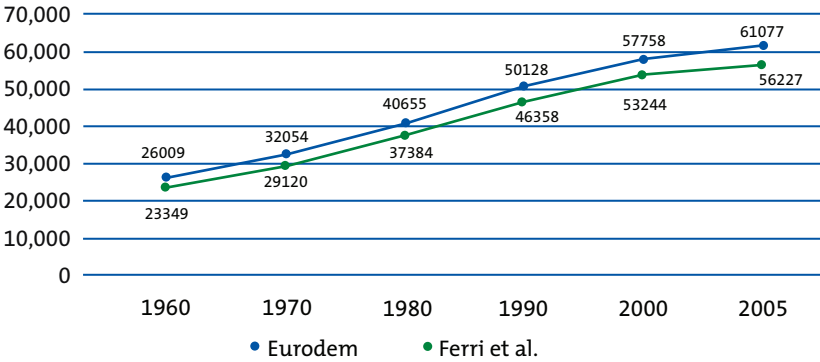
Table 1: The number of people with dementia in Norway in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,580	860	2,439	
60–64	1,765	526	2,291	2,013
65–69	1,779	979	2,758	2,565
70–74	3,248	3,184	6,432	5,506
75–79	3,047	5,347	8,394	8,437
80–84	5,442	10,038	15,480	14,549
85–89	3,737	9,996	13,733	23,157
90–94	2,001	5,808	7,809	
95–99	320	1,421	1,741	
Total	22,919	38,158	61,077	56,227

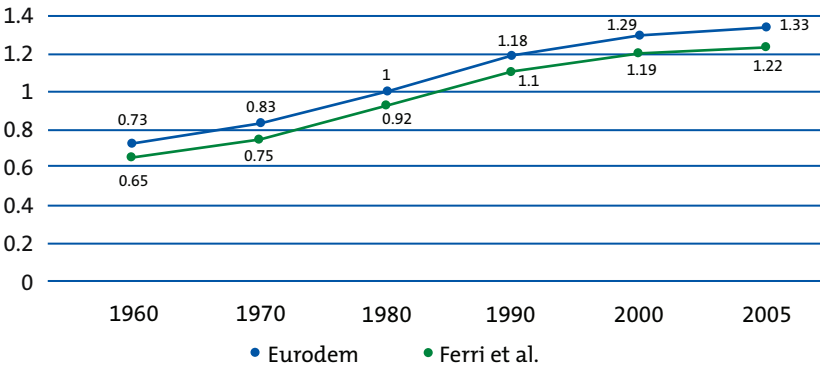
The following charts show a) the increase in the number of people with dementia in Norway from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005, rising from 26,009 in 1960 to 61,077 in 2005 (Eurodem).

⁵² Ott, A., Breteler, M.M., van Harskamp, F., Stijnen, T. & Hofman, A. 1998, “Incidence and risk of dementia. The Rotterdam Study”, *Am.J.Epidemiol.*, vol. 147, no. 6, pp. 574–580

The number of people with dementia in Norway from 1960 to 2005



The number of people with dementia in Norway as % of total population from 1960 to 2005



4.21.2 Availability of anti-dementia drugs

4.21.2.1 The availability of medicines in general

The Norwegian system differentiates between important and less important medicines.

For less important medicines, the patient pays the full cost, even if they have been prescribed by a doctor. Nevertheless, under certain conditions, it is possible for patients to claim a refund of 90% of all costs exceeding NOK 1,600 (approx. € 200).

For drugs on the important medicines list, patients are required to pay 36% of the cost. This only applies to the cost of drugs up to a ceiling of NOK 500 (approx. € 63) for a three months' period. Costs over that ceiling are fully covered by the reimbursement system and no costs are incurred by the patient. Similarly, pensioners in receipt of a minimum pension do not need to pay cost-sharing charges for important medicines.⁵³

⁵³ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

4.21.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Norway, but memantine is not on the list of important medicines and is thus not reimbursed. Nevertheless, the Norwegian Alzheimer’s association explains that it is possible for doctors to fill out a form for memantine indicating that the drug is important and needs to be taken over a long period of time. In such cases, memantine can be partially reimbursed with a part of the costs borne by the patient.

Norway does not limit the prescription of anti-dementia drugs to specialist doctors, since the rules only state that the physician must have an interest in and knowledge about dementia. A diagnosis of Alzheimer’s disease and an MMSE score over 12 are the only requirements for the reimbursement of acetylcholinesterase inhibitors. Also, the Norwegian system reimburses medicines for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	No
Initial treatment decision	No restrictions	No restrictions	No restrictions	Not applicable
Continuing treatment decision	No restrictions	No restrictions	No restrictions	Not applicable
Required examinations	MMSE	MMSE	MMSE	Not applicable
MMSE limits	> 12	> 12	> 12	Not applicable
People living alone	No restrictions	No restrictions	No restrictions	Not applicable
People in nursing homes	No restrictions	No restrictions	No restrictions	Not applicable

4.21.3 Organisation of Home care

4.21.3.1 Legislation relating to home care services:

People in Norway are not legally obliged to provide care for their parents.

National legislation obliges the health and social services to provide home care services to those who need them. However, there is no specific reference to people with dementia.

Act no. 66 of 19 November 1982 on Municipal Health Services describes the duties of the health services as follows:

1. The promotion of health and prevention of illness, injuries and physical defects
2. Diagnosis and treatment of illness, injuries or physical defects.

3. Medical rehabilitation.
4. Nursing and care outside health institutions.

The municipalities have to provide the following services:

1. General medical practices
2. Physiotherapy
3. Nursing, including home care services.

§ 1-3a. The municipality shall plan, organise and provide the services regulated in the law. The people receiving care shall

- feel safe, respected and have a foreseeable situation
- be able to take care of themselves as long as possible
- have their basic physical needs taken care of
- receive adequate help with meals and have enough time to eat in peace
- receive help with personal hygiene and bodily functions
- receive help, if needed, to dress and undress
- be able to follow the natural rhythm of the day, avoiding unwanted stays in bed
- have the possibility for privacy and self-determination
- be able to have social contact
- be able to participate in suitable activities both indoors and out of doors
- have necessary medical check-ups, treatment, rehabilitation and care
- have necessary dental check-ups and treatment (Axel Wannag, 2000).

Act no. 81 of 13 December 1991 on Social Services, Chapter 1, Section 1-1, states that the purpose of the Act is:

- to promote financial and social security, to improve the living conditions of disadvantaged persons, to contribute to greater social equality and to prevent social problems.
- to ensure that each individual has the possibility to lead an independent, active and meaningful life together with others

Chapter 4, Section 4-1 describes the aims of social services as being to provide information, advice and guidance in order to resolve or prevent social problems. If the social services are unable to provide such assistance, they must, if possible, make sure that others do.

The Social Services consist of (section 4-2 in the Act):

- practical assistance and training to people who need it due to illness, disability, age or for other reasons
- short-term care in order to relieve carers with a particularly heavy burden
- support to individuals and families who need it due to disability, age or social problems
- institutional care for those who need it due to disability, age or other reasons
- financial aid to carers with a particularly heavy burden

People who are unable to care for themselves are entitled to help (Section 4-2, a-d).

The legal right to necessary health services is also underlined in the Patients’ Rights Act of 1999 (Ingebretsen and Eriksen, 2004).

4.21.3.2 Organisation and funding of home care services

Home care services for the elderly and disabled are organised, managed and financed by the municipalities. Users may have to pay a fee for some of these services. The size of the fee varies from one municipality to the next.

Most of the municipalities (80%) offer services 24 hours a day. Approximately 155,000 people received home care services in 1999 (European Observatory on Health Care Systems, 2002).

“Report No. 20 to the Parliament (1996-97), Plan of Action for Care of the Elderly; Security - Respect - Quality” is a four-year plan of action for nursing and care services run by the local authorities. The main aim of this plan was to develop local services for nursing and care by:

- providing services that ensure the elderly a secure and, as far as possible, a fulfilling and independent life;
- enabling the elderly to live in their own homes as long as possible;
- making sure that the services have sufficient capacity

This was achieved through general guidelines including:

- ensuring high-quality nursing and home care services
- developing an integrated, flexible range of services
- providing equal facilities nationwide, independent of a person’s place of residence, income or resources
- ensuring greater participation and freedom of choice to service users

According to Ingebretsen and Eriksen (2004), the goals of this action plan, which include the strengthening of home-based care, have to a large extent been achieved, albeit with considerable regional variations. This has led to more home-based care.

It should be noted, however, that Norway is a very sparsely populated country with great variation between municipalities in terms of socioeconomic structure, population etc.

The provision of services is based on a person's needs regardless of whether they live alone or with a spouse/family. In this way, the assessment is based on the condition of the person requiring assistance and not on the ability or willingness of relatives to provide services or meet needs. In practice, however, elderly people living alone are sometimes given priority (Ingebretsen and Eriksen, 2004).

In June 1998, the Norwegian parliament adopted the National Programme for Mental Health. Implementation of this programme started in 1999 and will run until 2008. A document entitled "Mental Health Services in Norway – prevention, treatment, care" produced by the Norwegian Ministry of Health and Care Services can be found at: <http://odin.dep.no/filarkiv/233840/MentalHealthWeb.pdf>

4.21.3.3 Kinds of home care services available

Home care services typically include:

- Leisure activities
- Assistance handling personal finances
- Ensuring that medication is taken
- Housework
- Cooking
- Shopping
- Personal hygiene
- Getting dressed and undressed
- Technical aids

Day care centres exist but are not statutory.

4.21.3.4 Consultation with people with dementia and carers

Although no specific reference is made to people with dementia in the National Programme for Mental Health, reference is made to the ICD classification Foo-Foog (organic, including symptomatic, mental disorders). The report emphasises the importance of the patients' perspective (referred to in the report as the "user"):

"Fundamental for the reform of mental health care in Norway is the emphasis placed on the users' views and perspectives on services. The experience and knowledge possessed by users and their relatives, is unique and necessary in improving and optimising services and treatment. Participation is also vital for empowerment and for the ability to master one's own life. This is of great value and a central vision of the National Programme for Mental Health.

Users and close relatives should be involved at all levels in the decision-making process. At the system level this implies organised participation by users and relatives in planning processes, legislation, implementation of treatment programmes etc. It is of major importance that users’ perspectives are taken into consideration in decision-making throughout the services (political, administrative and professional) and at all levels (Ministry, municipalities, hospitals etc.). Accordingly, national as well as local authorities should be co-operating with users’ organisations and unions in these matters. At the individual level, the policy implies a legal right to participate in the management of necessary services.” (Norwegian Ministry of Health and Care Services, 2005, p.6)

It is further stated that patients’ needs must guide the provision of services and that cooperation with patients and their families is required at all levels.

4.21.3.5 Sources

Anonymous, Security – respect – quality, Action plan for care of the elderly 1998 – 2001, Health Care Systems in Transition, HiT Summary, Norway, European Observatory on Health Care Systems, <http://www.observatory.dk>

Information provided by Inger Jorun Edvardsen and Maija Juva (2006).

Ingebretsen, R. & Eriksen, J. (2004), National Background Report for Norway, EUROFAMCARE, http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_norway_rc1_a4.pdf

Ministry of Health and Social Affairs website
(<http://odin.dep.no/hod/engelsk/publ/handlingsplaner/030005-990070/dok-bn.html>)

Norwegian Ministry of Health and Care Services (2005), Mental Health Services in Norway, prevention – treatment – care, Helse- og Omsorgsdepartementet
(<http://odin.dep.no/filarkiv/233840/MentalHealthWeb.pdf>)

Wannag, A. (2000), Caring for the carers; a review of issues (notes from conference), <http://www.phcttb.org/projects/Qualityofcare.htm> - accessed on 29/4/2005

4.21.4 EuroCoDe network organisations

Nasjonalforeningen Demensforbundet

Oscarsgatan 36A, Postboks 7139 Majorstua
0307 Oslo
Tel: +47 -23- 12 00 00
Fax: +47 -23- 12 00 01
post@nasjonalforeningen.no
www.nasjonalforeningen.no

Norsk Neurologisk Forening - Norwegian Neurological Association

Nevrologisk Forening, Nevrologisk poliklinikk,
Ullevål sykehus
0407 Oslo
Tel: +47 -22- 11 86 50
Fax: +47 -23- 01 59 49
espen.dietrichs@klinmed.uio.no
www.nevrologi.no

Norwegian Geriatric Society

Department of Internal Medicine

Aker University hospital

0514 Oslo

mortenmowe@hotmail.com

www.legeforeningen.no/index.db2?id=17882

Norwegian Gerontological Society

Norwegian Centre for Dementia Research

Ullevaal Hospital, KGR

0407 Oslo

Tel: +47 -22- 11 77 28

Fax: +47 -23- 01 61 61

toril.utne@nordemens.no

www.nordemens.no

4.22 Poland

4.22.1 Prevalence of Dementia

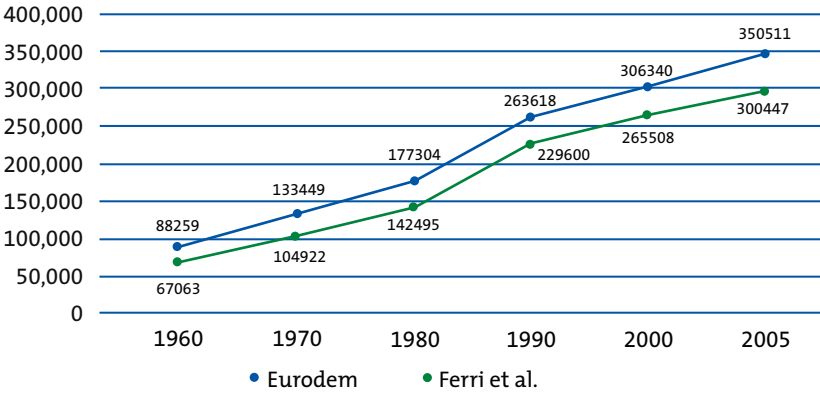
Alzheimer Europe estimates the number of people with dementia in Poland in 2005 as being between 300,447 (Ferri et al.) and 350,511 (Eurodem). This represents 0.79% (Ferri et al.) to 0.92% (Eurodem) of the total population of 38,173,835. The number of people with dementia in Poland as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Poland in 2005

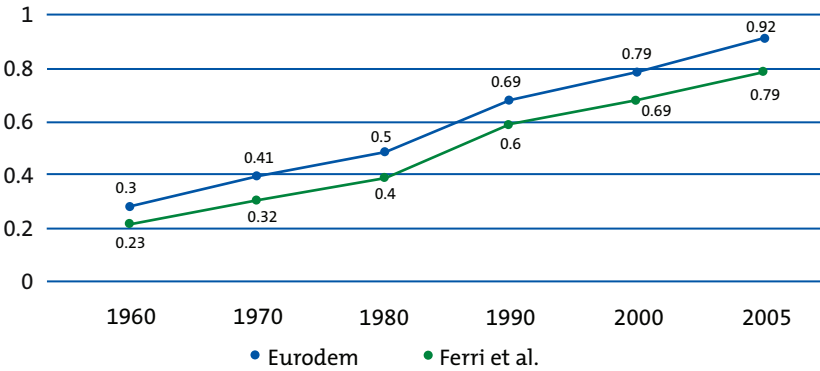
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	12,583	7,248	19,831	
60–64	10,785	3,896	14,681	13,604
65–69	14,496	9,831	24,326	20,302
70–74	26,116	32,651	58,766	45,196
75–79	19,232	46,452	65,683	62,524
80–84	23,670	59,260	82,930	77,380
85–89	10,711	34,807	45,518	81,441
90–94	7,719	24,493	32,212	
95–99	1,314	5,249	6,563	
Total	126,625	223,886	350,511	300,447

The following charts show a) the increase in the number of people with dementia in Poland from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than trebled between 1960 and 2005, rising from 88,259 in 1960 to 350,511 in 2005 (Eurodem). The sharper increase between 1980 and 1990 might be partly explained by the fact that up to 1980, population statistics from EUROSTAT were only available up to the age of 84.

The number of people with dementia in Poland from 1960 to 2005



The number of people with dementia in Poland as % of total population from 1960 to 2005



4.22.2 Availability of anti-dementia drugs

4.22.2.1 The availability of medicines in general

Medicines in Poland can fall under one of three different reimbursement systems:

- For basic medicines patients pay a fixed price up to a maximum of 0.5% of lowest salary,
- For special additional medicines, patients pay 30% or 50% of the cost,
- For all other medicines, patients pay the totality of the cost.

Hospital medicines are free of charge.⁵⁴

4.22.2.2 The availability of Alzheimer treatments

In Poland, all anti-dementia drugs are available, but only donepezil and rivastigmine are part of the reimbursement system. Recently, generic versions of donepezil have become available in Poland and reimbursements is limited to those generic versions.

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores below 14.

There are no restrictions in Poland for the reimbursement of these treatments for people living alone or in nursing homes. Also, prescriptions can be made by any doctor whether for treatment initiation or treatment continuation.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	No
Initial treatment decision	No restrictions	No restrictions	Not applicable	Not applicable
Continuing treatment decision	No restrictions	No restrictions	Not applicable	Not applicable
Required examinations	MMSE	MMSE	Not applicable	Not applicable
MMSE limits	26–10	26–10	Not applicable	Not applicable
People living alone	No restrictions	No restrictions	Not applicable	Not applicable
People in nursing homes	No restrictions	No restrictions	Not applicable	Not applicable

4.22.3 Organisation of Home care

4.22.3.1 Legislation relating to the provision of home care services

During the Communist era, there was a comprehensive programme of health care benefits organised and provided by the State. In 1999, the Health Insurance Act introduced an obligatory health insurance system. Membership of a health insurance fund is now compulsory and citizens pay a tax-deductible premium of 7.5% of their personal income.

Direct reference to “care of the elderly” can be found in article 2, point c of the Act on Social Care of 1923. The new Act on Social Care of 1990 does not contain a specific reference to care of the elderly. Nevertheless, it is stated in article 3 of the new law that social assistance is granted to people and families in particular situations, e.g. in case of disability and/or prolonged sickness. Disability is defined in article 2a as “a physical, psychological or mental state causing a lasting or periodical restriction of independent existence”.

Children are legally obliged to provide for their elderly or disabled parents and this can be enforced in court if necessary. According to article 908 of the Civil Code, a person can make an agreement with someone to exchange the ownership of property for help and nursing in case of sickness (Dz.U. 64.16.93)

The right to receive care can be found in article 17 of the Act on Social Care (Dz.U. 98.64.414) which states that “1. People living alone, who because of age, sickness or other reasons require the help of others, and do not receive it, have the right to help in the form of care services. 2. Care services can be also received by people, who need help, which family cannot provide.”

Article 14, point 3 of the Act on Family, Nursing and Parental Benefits (Dz.U. 98.102.651) grants people over the age of 75 the automatic right to a nursing benefit regardless of their state of health. People over 75 living in institutions are not entitled to this benefit.

4.22.3.2 Organisation and financing of home care services

Generally speaking, the State policy concerning assistance to the elderly concentrates on financial assistance to those who are the most socially and economically weak which means that the health needs of elderly people on low incomes often go unmet. Benefits and services are also provided on the basis of the level of disability.

The local authorities are responsible for organising social assistance. They do this through Social Care Centres. A variety of services are provided by different organisations. Some services, such as washing, bathing and personal hygiene, are performed by health care workers (e.g. community care nurses). Meals are distributed thanks to the Polish Red Cross, the Polish Committee on Social Welfare and NGOs. Some of the meals come from canteens in care homes and schools.

It is stated in article 18 of the Social Care Act that “Care services include help in providing for daily needs, hygiene care, nursing care recommended by a physician and if possible providing social contacts...” Services are also organised and provided through Community Care Centres, which are public institutions. Staff in these centres are responsible for finding people with low incomes in need of assistance. They also organise the provision of care by making contracts with NGOs, private companies and public institutions. Sometimes, the social workers in these centres provide the services themselves but the centres also open their doors to NGOs and self-help groups.

The nursing benefit for people over 75, mentioned in the previous section, is extremely low and would not in fact even cover the most basic needs of nursing care.

4.22.3.3 Kinds of home care services available

A variety of home care services exist including:

- Managing the household
- Preventing social exclusion/promoting social integration
- Doing small repairs e.g. electrical appliances
- Laundry
- Transport
- Day care centres

Day care centres usually offer 4 to 8 hours of care per day to elderly people. In these centres, the elderly can have a hot meal, take part in various activities and receive care from a nurse. Unfortunately, the number of day care centres is steadily decreasing.

4.22.3.4 Sources

Balicki, M. Leder, S. and Piotrowski, A. (2000), Focus on psychiatry in Poland: Polish mental health care system, *The British Journal of Psychiatry*, 177: 375-381

Błędowski, P., Pędich, W. et al. (2004), National Background Report for Poland, EUROFAMCARE: http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_poland_rc1_a4.pdf - main source of information

4.22.4 EuroCoDe network organisations

Institute of Psychiatry and Neurology

Sobieskiego 9
02-957 Warsaw

Polish Alzheimer’s Association

ul. Hoza 54/1
00-682 Warsaw
Tel: +48 -22- 622 11 22
Fax: +48 -22- 622 11 22
alzheimer_pl@hotmail.com
www.alzheimer.pl

Polish Neurological Society (PNS)

Department of Neurology
Medical Academy
Jaczewskiego 8
20-950 Warsaw
Tel: +48 -81- 742 54 20
Fax: +48 -81- 742 54 20
Neurolog@asklepios.am.lublin.pl
www.neurologiapolska.pl

Polish Society of Gerontology

Medical Academy - Dep. Gerontology
Ul. Kilinskiego 1
15-230 Białystok
Tel: +48 -85- 742 20 21
Fax: +48 -85- 742 25 39
geronto@amb.ac.bialystok.pl

Psychogeriatrya Polska - Foundation of Mental Health

ul. Nożownicza 4/8

50-119 Wrocław

Tel: +48 -71- 343 21 52

Fax: +48 -71- 343 21 55

sekretariat@psychogeriatrya.fozp.org.pl

www.fozp.org.pl

Wrocław Medical University

Ul. Pasteura 10

50-367 Wrocław

Tel: +48 -71- 784 10 01

Fax: +48 -71- 784 01 09

rektor@am.wroc.pl

4.23 Portugal

4.23.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Portugal in 2005 as being between 119,308 (Ferri et al.) and 129,916 (Eurodem). This represents 1.13% (Ferri et al.) to 1.23% (Eurodem) of the total population of 10,529,255. The number of people with dementia in Portugal as a percentage of the total population is slightly below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the number of people with dementia in Portugal, as it was impossible to obtain sufficiently detailed population statistics for the number of people in Portugal over the age of 94.

Table 1: The number of people with dementia in Portugal in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	3,448	2,016	5,464	
60–64	3,997	1,366	5,363	4,892
65–69	5,296	3,211	8,507	8,040
70–74	9,728	10,484	20,212	17,375
75–79	7,600	14,681	22,281	22,254
80–84	11,275	20,598	31,873	29,964
85–89	6,583	16,009	22,592	36,784
90–94	4,086	9,537	13,624	
Total	52,013	77,903	129,916	119,308

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Portugal since 1960.

4.23.2 Availability of anti-dementia drugs

4.23.2.1 The availability of medicines in general

The Portuguese system provides five different levels of participation of patients in the cost of medicines. Depending on the situations⁵⁵, the state contributes, 100% (only in very special situations defined by a Health Minister decree, when the drugs are indispensable to sustain life), 95% (level A) 70% (level B), 40% (level C) or 20%

⁵⁵ Infarmed (National Pharmacy and Medicines Institute) has no general criteria to decide the level of reimbursement of any drug. There are diseases whose drugs (specific or not) are all totally reimbursed. Usually they follow a cost/benefit evaluation. A drug can be excluded from the reimbursement system based on its excessive cost. Infarmed has a large discretionary power in this matter.

(level D) of the cost of medicines, and patients or carers are only required to pay the remaining costs. The degree of contributions is fixed in several official lists drawn up by the health services.

The contributions by the State can be increased by 10% for generic medicines and by 5%, in the level A (95%) and in the levels B, C and D by 15%, for pensioners whose annual total income is less than 14 times the minimum wage.⁵⁶

4.23.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Portugal and are part of the reimbursement system. They are classified as level C drugs and the State covers 40% of their costs.

Portugal limits both initial and continuing treatment decisions to neurologists and psychiatrists. It does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits.

Finally, the Portuguese system reimburses medicines for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.23.3 Organisation of Home care

4.23.3.1 Background information about dementia and home care services

In Portugal, until a few years ago, the extended family played a key role in the care of elderly and disabled people. Nowadays, like in other southern European countries, this situation is changing. Demographic and economic changes have led to the increasing isolation of elderly people (especially in big cities) and to a decrease in the number of large families. Also, Portugal has a high percentage of women in paid employment. In the past, these women were the primary carers of elderly and disabled people. The above-mentioned changes have had an impact on policies, as well as on the services provided to elderly people.

⁵⁶ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

There are financial and service-based forms of support but they are still poorly developed. Support provided within the public and non-profit making sector is primarily aimed at supporting the less well-off social groups and elderly people without families. According to Sousa and Figueiredo (2004), promoting individual autonomy is not a central policy aim of the State – “instead assumptions of dependency relationships are pervasive in policy in respect of both cash transfers and care provisions.” They describe Portugal as a country with a strong and explicit ideological commitment to the family, but a low profile as far as family policy is concerned. As caring for the elderly and dependent people is considered a family obligation, there is very little pressure from families to obtain support services from the State.

The large majority of support services for elderly and dependent people exist within the Social Security system, which provides support in the form of money and services. Home care is in the process of expanding due to the Integrated Support Plan for the Elderly, a joint venture between the Ministry of Health and the Ministry of Employment and Social Security.

4.23.3.2 Legislation relating to the provision of home care services

Article 64 of the Portuguese Constitution states:

“the right to health protection is guaranteed through a national health service (NHS) which is universal, general and, depending on the socio-economic status of citizens, largely free of charge.”

According to article 2003 of the Civil Law Code, descendants (to the 2nd degree) are responsible for providing any indispensable care in terms of sustenance, housing and clothing to their parents. If the family cannot provide such care, the Social Security takes over responsibility.

Home care services are a social solution consisting of individualised care for people and their families, who cannot assure their basic needs and/or daily living activities, in a permanent or temporary way, due to sickness, handicap, advanced age or other reasons (Despacho Normativo n° 62/99 de 12 de November).

Due to demographic changes, the number of people with chronic diseases has increased and the lack of long-term and palliative care is now more visible. Portugal now has new social and health needs which demand new and diverse solutions.

These solutions should be adjusted to different groups of dependent people and to the different stages of the disease. At the same time, they should facilitate the autonomy and involvement of patients. The involvement of families, as well as support for the reconciliation of professional and family obligations, should be reinforced.

4.23.3.3 Organisation and financing of home care services

Portugal is divided into five Health Regions, each of which is administered and managed by an autonomous Regional Health Administration. Each region provides some social services through the Social Security System. Municipalities are increasingly organising home care services. However, the main providers of services are the Misericórdias (independent charitable organisations) and private welfare institutions, which are financed by the State.

Insofar as informal home care is concerned, the main service providers are women (75%). Men who provide informal home care are usually husbands caring for their wives.

Networks of care exist which are made up of units and teams providing continued healthcare and/or social support and palliative care. These units belong to community services such as hospitals, health centres, social security districts and local services, the solidarity network and local authorities.

There are three main benefits:

- **Dependency Supplement:** This is a benefit, granted by the Social Security Department, to pensioners in need of care which can be used to help pay for services or to receive services in kind.
- **Handicap Pension:** This is a benefit granted by the Social Security Department to people who are no longer able to work due to a handicap (which has been officially recognised by the “handicap verification services”).
- **Technical Aid Supplement:** This benefit, which necessitates a medical prescription, can be granted by the Social Security Department, Misericordias or other institutions for technical aids such as incontinence products, articulated beds and pillows etc.

4.23.3.4 Kinds of home care services available

Out of 3,828 services providers for elderly people, 1,288 are for home care services. 38,022 people benefit from home care services, with an average of 29.5 clients per service provider. Most of these clients are over 74 years old and 57% are women.

Depending on specific needs, services may include meals, cleaning and tidying the home, personal care, company and recreation, small repairs in the home, shopping, transport and laundry, etc. The following table shows the percentage of the aforementioned home care service providers providing various home care services:

Activities	%
Meals-on-wheels	98
Personal hygiene and comfort	97
Laundry	95
House cleaning	93
Health care (co-operation)	78
Companion (going outside)	72
Animation	62
Shopping	60

Another form of home care is family accommodation. This consists of temporarily or permanently housing elderly dependent people within families. This service is intended for elderly people who do not have a family or for whom insufficient social support prevents them from being cared for in their own homes.

There are also some temporary centres for emergency accommodation and night centres for elderly people who have sufficient capacity to perform their daily living activities but require some assistance during the night.

4.23.3.5 Sources

European Commission (2002), Portugal:

http://europa.eu.int/comm/employment_social/missoc/2002/03/portugal_en.pdf#search=care%20insurance%20AND%20portugal (accessed 31 May 2005)

Jacob, Luís (2004), Os serviços para idosos em Portugal, Dissertação de Mestrado, ISCTE

Sousa, L. and Figueiredo, D. (2004), *National Background Report for Portugal*, EUROFAMCARE: http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_portugal_rc1_a4.pdf (main source of information)

Ylief, M. et al. (2005), *Rapport international – les aides et les soins aux personnes démentes dans les pays de la Communauté européenne*, Qualidem, Universities of Liège and Leuven

4.23.4 EuroCoDe network organisations

APFADA

Av. Ceuta Norte, Quinta do Loureiro, Lote 2, lojas 2

1350-410 Lisboa

Phone: +351 -21- 361 04 60

Fax: +351 -21- 361 04 69

Alzheimer@netcabo.pt

www.alzheimerportugal.org

C.E.O. Hospital Magalhaes Lemos

Porto /Instituto de Cieccias Biomedicas Abel Salazar

Univ Porto

Rua Prof Alvaro Rodrigues

4149-003 Porto

Sociedade Portuguesa de Geriatria e Gerontologia (Portugal)

Av. Joao XXI, 64-3 DT

1000 Lisboa

Tel: +351 -795- 11 53 456

Fax: +351 -795- 11 18 456

socpgeriatria@mail.telepac.pt

Sociedade Portuguesa de Neurologia

Rua D. Manuel II, 33, sala 41

4050-345 Porto

Tel: +351 -226- 00 15 53

Fax: +351 -226- 00 15 53

spn.dir@spneurologia.org

www.spneurologia.org

4.24 Romania

4.24.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Romania in 2005 as being between 172,130 (Ferri et al.) and 200,893 (Eurodem). This represents 0.79% (Ferri et al.) to 0.93% (Eurodem) of the total population of 21,658,528. The number of people with dementia in Romania as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Romania in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	7,045	4,043	11,088	
60–64	7,259	2,564	9,823	9,045
65–69	10,321	6,748	17,069	14,158
70–74	17,687	20,344	38,030	29,142
75–79	13,279	26,326	39,605	38,174
80–84	16,015	31,677	47,692	44,747
85–89	6,006	14,849	20,856	36,863
90–94	4,727	9,518	14,246	
95–99	788	1,696	2,484	
Total	83,127	117,766	200,893	172,130

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Romania since 1960.

4.24.2 Availability of anti-dementia drugs

4.24.2.1 The availability of medicines in general

A positive list of medicines to be reimbursed is compiled annually by the Ministry of Health and the National Health Insurance. This list determines which prescription drugs are covered by health insurance funds. The list is based on recommendations from the College of Physicians and the College of Pharmacists.

The reimbursement list applies to inpatients and outpatients. In fact, there are two lists: one containing substances that are 100% reimbursable for people suffering from one or more of a list of diseases (cancer, tuberculosis, diabetes, etc.); the other containing other substances on which the reference price system is applied and of which 70% of the reference price is reimbursed.⁵⁷

4.24.2.2 The availability of Alzheimer treatments

With the exception of galantamine, all other anti-dementia drugs are available and reimbursable in Romania. Unlike other countries, donepezil is also indicated for the treatment of vascular dementia and can be reimbursed in those cases as well.

Treatment initiation and treatment continuation are restricted to specialists only (neurologists, psychiatrists or old age psychiatrists). The National Health Insurance approved guidelines that are in existence in Romania which prescribe a series of examinations that need to be carried out when making a diagnosis (neuropsychological tests, CT or MRI scans and laboratory tests). For Alzheimer medicines to be reimbursed, these tests need to be carried out and included in a medical report.

Until recently, the system did not prescribe any upper or lower treatment limits, but in some areas of the country, the Romanian Alzheimer Society reports that health insurance offices have restricted reimbursement to people with Alzheimer's disease with an MMSE score over 12.

Although there are no restrictions for people living alone or for people living in nursing homes, the Romanian Alzheimer Society reports difficulties for these people in accessing medication due to a lack of social support.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Not applicable	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Not applicable	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	Not applicable	Diagnostic protocol
MMSE limits	Over 12	Over 12	Not applicable	Over 12
People living alone	No restrictions	No restrictions	Not applicable	No restrictions
People in nursing homes	No restrictions	No restrictions	Not applicable	No restrictions

4.24.3 Organisation of Home care

4.24.3.1 Legislation relating to the provision of home care services

There are several laws which relate to home care services (but only medical services). There are also laws regarding people with handicaps which also cover people with dementia.

There are two laws regulating the activity of personal assistants i.e. Law 519/12.07.2002 and Romanian Government Decision no. 427/2001 regarding the approval of Methodological Norms for working, rights and responsibilities of personal assistants for people with handicaps.

4.24.3.2 Organisation and financing of home care services

4.24.3.2.1 Medical home care services

Medical home care services are provided on the basis of contracts signed between the National Health Assurance Company and people or organisations accredited to provide such services, by GPs or specialists who recommend medical home care, taking into account the state of health of the person in need (who must have a health assurance) and the person's dependency grade. There are 3 dependency grades: totally dependent, partially dependent and independent.

All Romanian citizens who have a health assurance can access medical home care but only for 56 days per year (art. 2, annex no.27, order.1220/24.12.2003). In the past, people were entitled to medical home care for as long as it was needed. This was limited to 14 days maximum in 2003 and then extended to 56 in 2005.

A person can apply for medical home care (not for a personal assistant, but for medical personnel – nurses) on the following conditions:

- they have been previously hospitalised for their disease
- the specialist/GP recommends medical home care
- the doctor who made the recommendation has a contract with the National Health Assurance Company
- The medical home care providers (most of them NGOs) should also have a contract with the National Health Assurance Company

Patients are offered a basic medical services package containing 23 types of medical interventions.

4.24.3.2.2 Personal assistants

In order to be provided with a personal assistant, a person has to obtain a grade one handicap certificate. For a person with dementia, the following procedure applies:

1. Diagnosis of dementia from a specialist (psychiatrist, neurologist) and a form describing the evolution and symptoms. The specialist should demonstrate that the patient needs permanent supervision and recommend either the necessity of a personal assistant or institutionalisation in a long-term institution.
2. An Expertise Commission for Persons with Handicap will examine the patient and his/her medical documents and will decide on the grade of handicap.
3. The patient or the family should find a person willing to become the personal assistant. The personal assistant will be paid by the local authorities. Personal assistants must complete training programmes offered by local authorities.
4. The patient's condition is periodically revised by the Commission.

Personal assistants are considered and treated like staff hired by the local authority. They are paid for 8 hours' work per day. They have to have a daily schedule and present an activity report every week. Their activity should be monitored by representatives of the Social Protection Departments, but the Romanian Alzheimer Society stresses that this is not always the case.

4.24.3.2.3 Certified carers

There are two types of certified carers (as they appear in the Romanian Occupational Code): home carers for people who are ill and home carers for elderly people. They are certified on the basis of Government Ordinance. 129/200 and they are legally certified by the Ministry of Employment. Their training should be organised by providers who have been accredited by the National Council for the Professional Training of Adults.

In the Romanian Job Monitor, issued by the Ministry of Employment, it is specified that a person can become a certified carer after attending a six-month training program. In order to be certified, home carers for people who are ill should attend 720 hours of training, and home carers for elderly people should attend 620 hours of training. This is the longest training in the field. Most people who are interested in it cannot afford to pay for it and the authorities are unable to organise it.

Once they are trained however, they can be hired by different organisations (state social departments, NGOs, private sector) or they can become authorised personnel in the field (i.e. they can be self-employed and pay their taxes). Such training courses are only organised by NGOs within different specific projects and the carers have a chance of being hired afterwards.

Private companies avoid having certified carers because the training period is too long and expensive. Most of the private companies work with untrained personnel; they only recommend "carers" and require a fee from the carer and from the beneficiary. Then the patient or the family illegally pays the carer. Taxes on wages are so high that only rich people can afford to hire a carer legally.

4.24.3.3 Kinds of home care services available

Family members complain that there are no specific home care services for people with dementia.

Available services include:

- State services – described above
- Services offered by NGOs – most of them are specialised in elderly care; some of them even refuse to offer services to people with dementia
- Private services – they offer home care for people with dementia but they do not have trained staff even if there are specific accreditation regulations

4.24.3.4 Consultation with people with dementia and carers

The Romanian Alzheimer Society is not aware of any specific obligation to obtain service users’ views about such services. It has found such specifications only in a guide issued by the Romanian Government in collaboration with the Ministry of Health and Social Protection and the National Institute for Preventing and Combating Social Exclusion of Persons with Handicap – “Occupational standards for personal assistants” author Dr. Verginia Cretu, 2003.

No specific reference is made to people with dementia.

Moreover, the Romanian Alzheimer Society is not aware of any initiatives by service providers to obtain and assess the opinions of people with dementia and carers about the quality of home care services.

4.24.3.5 Source

Information provided by Eugen Stefanut (2006).

4.24.4 EuroCoDe network organisations

“Ana Aslan” International Academy of Aging

“Ana Aslan” International Foundation

Piata M. Kogalniceanu no 1, Bloc 1, Sc. 1, Apt.17

Sector 5 - Bucharest

Tel: +40 -21- 312 46 96

Fax : +40 -21- 312 46 96

office@brainaging.ro

aslan@brainaging.ro

www.brainaging.ro

Romanian Society of Gerontology and Geriatrics

9 Caldarusani St.

78178 Sector 1 Bucharest

Tel: +40 -1- 223 71 91

Fax: +40 -1- 223 14 80

srggaa@yahoo.com

Romanian Society of Neurology
University Hospital Bucharest
Department of Neurology
Splaiul Independentei 169, sector 5,
7625 Bucharest
Tel: +40 -1- 637 66 30
Fax: +40 -1- 312 81 02
ovalbajenaru@xnet.ro

Societatea Alzheimer
Bd. Mihail Kogalniceanu 49, sc. A et. 1 apt. 8 sector 5
70603 Bucharest
Tel: +40 -21- 334 89 40
Fax: +40 -21- 334 89 40
contact@alz.ro
www.alz.ro

4.25 Slovak Republic

4.25.1 Prevalence of Dementia

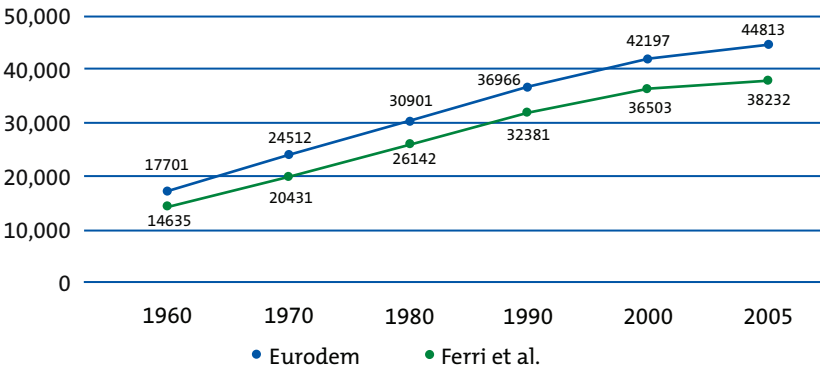
Alzheimer Europe estimates the number of people with dementia in Slovakia in 2005 as being between 38,232 (Ferri et al.) and 44,813 (Eurodem). This represents 0.71% (Ferri et al.) to 0.83% (Eurodem) of the total population of 5,384,822. The number of people with dementia in Slovakia as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Slovakia in 2005

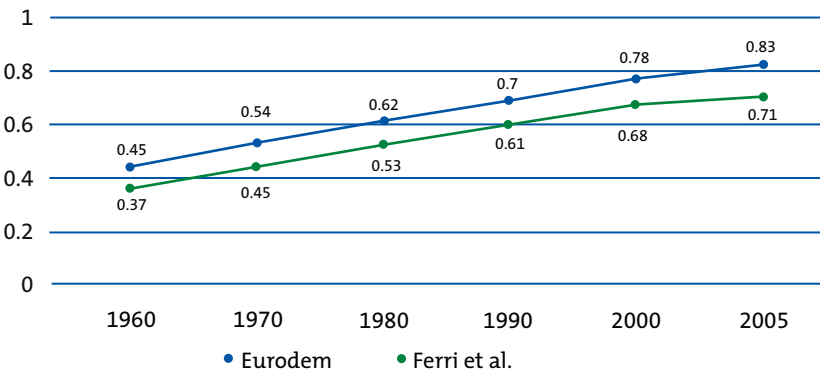
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	1,793	1,028	2,821	
60–64	1,657	619	2,276	2,129
65–69	1,731	1,236	2,967	2,498
70–74	3,099	4,074	7,173	5,529
75–79	2,380	5,763	8,143	7,751
80–84	3,427	8,100	11,527	10,769
85–89	1,357	3,856	5,213	9,557
90–94	1,085	2,862	3,947	
95–99	177	568	745	
Total	16,707	28,106	44,813	38,232

The following charts show a) the increase in the number of people with dementia in Slovakia from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005. The percentage of people with dementia out of the total population steadily increased during this time but did not quite double.

The number of people with dementia in Slovakia from 1960 to 2005



The number of people with dementia in Slovakia as % of total population from 1960 to 2005



4.25.2 Availability of anti-dementia drugs

4.25.2.1 The availability of medicines in general

In Slovakia, medicines are included in a list specifying whether patients being prescribed these medicines are fully or partially refunded for their costs. The Slovak system does not differentiate between different groups of people based on age or income.⁵⁸

4.25.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Slovakia and are part of the reimbursement system.

Treatment initiation and continuation is limited to specialists and the reimbursement system requires specialists to carry out an MMSE of patients. Patients with

⁵⁸ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

MMSE scores between 24 and 13 can receive one of the four anti-dementia drugs. Unlike most other European countries, memantine is thus available for people with mild to moderate Alzheimer’s disease and not for severe Alzheimer’s disease.

There are no restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	24–13	24–13	24–13	24–13
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.25.3 Organisation of Home care

Alzheimer Europe was unable to obtain sufficient information to describe the organisation of home care in the Slovak Republic.

4.25.4 EuroCoDe network organisations

Slovak Alzheimer Society

Dúbravská cesta 9
842 45 Bratislava
Tel: +421 -2- 62 41 41 43
Fax: +421 -2- 62 41 41 43
alzheimers@alzheimers.sk
www.alzheimer.sk

Slovak Neurological Society

Neurologická klinika IVZ, NsP Ruzinov,
Ruzinovská 6,
826 06 Bratislava
Tel: +421 -7- 23 31 48
Fax: +421 -7- 23 64 33
lisy@ivzba.sk
lisy@spamba.sk

Slovak Society for Gerontology and Geriatrics

Department of Geriatrics, Faculty of Medicine
Comenius University, Dumbierska 3
831 01 Bratislava
Tel: +421 -7- 37 36 28
Fax: +421 -7- 37 36 28

4.26 Slovenia

4.26.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Slovenia in 2005 as being between 19,302 (Ferri et al.) and 21,788 (Eurodem). This represents 0.97% (Ferri et al.) to 1.09% (Eurodem) of the total population of 1,997,590. The number of people with dementia in Slovenia as a percentage of the total population is slightly lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Slovenia in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	716	388	1,104	
60–64	799	259	1,058	951
65–69	942	572	1,514	1,431
70–74	1,604	1,976	3,581	3,096
75–79	1,115	2,834	3,949	3,877
80–84	1,317	3,911	5,228	4,860
85–89	558	2,101	2,659	5,087
90–94	503	1,751	2,254	
95–99	73	369	443	
Total	7,626	14,162	21,788	19,302

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Slovenia since 1960.

4.26.2 Availability of anti-dementia drugs

4.26.2.1 The availability in medicines in general

The Slovenian system has three lists of medicines, a positive, an interim and a negative list.

Medicines on the positive list are reimbursed at a level of 75%, those on the interim list at a level of 25% and medicines on the negative list need to be paid for entirely by patients themselves.

Drugs used during hospital treatment and drugs for children, mental disorders and some other diseases are free of charge.

According to the Slovenian Alzheimer’s society, the vast majority of people (more than 90 %) pay an additional voluntary insurance (€ 20,7 monthly) which covers several medical costs. Amongst other things, this voluntary insurance guarantees 100 % reimbursement for medicines on the positive and interim lists.

4.26.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Slovenia and all four are on the interim list and available for reimbursement.

In Slovenia, the initial prescription of anti-dementia drugs can only be done by a specialist doctor (psychiatrist or neurologist), whereas there are no restrictions for continuing treatment decisions. A diagnosis of Alzheimer’s disease and an MMSE score between 10 and 26 are requirements for the reimbursement of any of the anti-dementia drugs. Nevertheless, the Slovenian Alzheimer association also explains that for patients with an MMSE over 26, reimbursement is possible if further more extensive neuropsychological tests show cognitive decline of a patient consistent with Alzheimer’s disease. The Slovenian system reimburses medicines for people living alone or in nursing homes.

Unlike most other European countries, memantine is available for people with mild to moderate Alzheimer’s disease, but not for severe Alzheimer’s disease.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialists	Specialists	Specialists	Specialists
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	10–26	10–26	10–26	10–26
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.26.3 Organisation of Home care

Alzheimer Europe was unable to obtain sufficient information to describe the organisation of home care in Slovenia.

4.26.4 EuroCoDe network organisations

The Alzheimer's Disease Association of Slovenia

Studenec 48

SI - 1260 Ljubljana Polje

Tel: +386 -1- 528 39 95

Fax: +386 -1- 587 25 90

zzppd@mail.ljudmila.org

www.ljudmila.org/zzppd

Slovene Society of Neurology

University Medical Center

Department of Neurology

Zaloska 2

1525 Ljubljana

Tel: +386 -1- 522 23 11

Fax: +386 -1- 522 22 08

anton.mesec@kclj.si

4.27 Spain

4.27.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Spain in 2005 as being between 533,388 (Ferri et al.) and 583,208 (Eurodem). This represents 1.24% (Ferri et al.) to 1.36% (Eurodem) of the total population of 43,038,035. The number of people with dementia in Spain as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

However, on the basis of a door to door survey carried out by Jesús de Pedro in 2003, Fundación Alzheimer España estimate the population of people over 65 to be 6,900,000 and the prevalence rate to be 12%. This would mean that 850,000 people over the age of 65 had dementia, of which they estimate that between 380,000 and 390,000 would have Alzheimer’s disease.

Table 1: The number of people with dementia in Spain in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	14,907	8,300	23,207	
60–64	15,691	5,014	20,705	18,539
65–69	19,283	11,148	30,430	28,530
70–74	40,119	41,066	81,185	69,629
75–79	32,819	59,789	92,608	92,853
80–84	48,543	87,735	136,278	128,150
85–89	31,200	80,563	111,763	195,687
90–94	19,253	50,114	69,367	
95–99	3,980	13,685	17,665	
Total	225,795	357,413	583,208	533,388

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the numbers of people with dementia in Spain since 1960.

4.27.2 Availability of anti-dementia drugs

4.27.2.1 The availability of medicines in general

Medicines are free of charge for hospital treatment, persons over 65 years of age with insufficient means of victims, as well as for victims of employment injuries and occupational diseases.

Otherwise, patients need to contribute 40 % of the price of medicines or 10% for certain special medicines with a maximum limit of € 2.64.⁵⁹

4.27.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Spain and are part of the reimbursement system.

Treatment initiation and continuation is limited to specialists and the reimbursement system requires specialists to carry out an MMSE of patients. Reimbursement with acetylcholinesterase inhibitors is limited to people with Alzheimer's disease with an MMSE score of 23 and below and with memantine for an MMSE score of 17 and below.

There are no restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	Below 23	Below 23	Below 23	Below 17
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.27.3 Organisation of Home care

4.27.3.1 Background information about dementia and home care services

In Spain, the provision of home care services is in the stage of development with about 20% of communes offering such services. However, this is not sufficient to cover demand and it is estimated that only about 1% of the elderly receive home care services provided by the government. The main aim of social services network is to keep elderly people in their homes for as long as possible.

⁵⁹ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

The vast majority of elderly dependent people have to rely on services provided by informal carers. Care of elderly and dependent people tends to be seen as a family obligation. However, according to a survey carried out in 2001, only 24% of the population believe that children will continue to bear the responsibility for caring for their elderly parents in the future and the number of elderly people living alone is steadily increasing (Larizgoitia Jauregi, 2004).

4.27.3.2 Legislation relating to the provision of home care services

The Spanish constitution states that all citizens are entitled to “health protection”. The General Health Law of 1986, which saw the creation of the National Health System, also states that access to health services is a citizen’s right.

In the Spanish Civil Code (Book 1), it is stated that the spouse and children of elderly dependent people are responsible for their maintenance and care which covers everything that is essential for sustenance, shelter, clothing and medical assistance. The extent of the maintenance to be provided depends on the means of the providers and the needs of the dependent person. The obligation to provide maintenance comes to an end when the provider dies or when their wealth has fallen to such a level that continuing to do so would mean having to neglect their own needs or those of their family.

Brothers and sisters also have an obligation to provide maintenance but they come after spouses and descendants, but this obligation is limited to what is absolutely necessary (Kerschen et al., 2005).

Citizens’ do not have a legally established right to social services. The provision of such services is at the discretion of the Autonomous Administration. Access rights are governed by legislation at the level of the autonomous communities.

The main criterion of the social service network is to keep the elderly in their own environment for as long as possible. The main social services are therefore aimed at maintenance in the home. There is also a residential type network. These services generally concentrate on attending the dependent elderly who live alone. The need is also recognised to help subjects with few resources.

4.27.3.3 Organisation and financing of home care services

Health care services are organised by the autonomous communities. Each community has a Health Service and draws up a Health Plan which outlines which activities are necessary in order to meet the objectives of its own Health Service. Amongst other services provided by the health services of the autonomous communities, there is primary care which includes health care in the home and care specifically for the elderly.

Home care services are free for people who are on the minimum pension. People who have an income twice as high as the minimum pension must pay for the services whereas those on an intermediary income must pay a certain amount which is calculated on the basis of their income.

Health care is funded exclusively through general taxation and not through social security contributions. Home social services are financed jointly by the Ministry of Social Affairs, the regional ministries of Social Welfare and the municipalities. Home visits by general practitioners and primary care nurses are funded through the Public Health Service. In addition to government provided services, voluntary associations and not-for-profit associations such as the Red Cross also provide social home care services (Carrillo, 2005).

4.27.3.4 Kinds of home care services available

Home care services include primary care social services, social work, assistance with household tasks, meals-on-wheels and tele-alarm services. However, these services are not available in all the autonomous communities.

In practice, home care services are more or less limited to household tasks (which also includes laundry and shopping). This seems to be based on the choice of the elderly people many of whom think that personal care should be carried out by the family. This opinion seems to be shared by carers who often prefer to receive formal assistance with household tasks rather than personal care (Valderrama et al., 1997 in Larizgoitia Jauregi, 2004).

Meals-on-wheels is a services that is only available in the cities of Malaga and Cordoba Andalusia) and in the city of Lerida (in Catalonia). Tele-assistance and tele-alarm services are offered in at least 10 of the autonomous communities. In Andalusia, Castilla-Leon, Valencia, a service exists which consists of helping to adapt the home to the needs of the dependent person. (Imsero 2004 in Larizgoitia Jauregi, 2004).

4.27.3.5 Sources

Esteban Carrillo (2005), *WHO International Compendium of Home Health Care*:
<http://www.nahc.org/WHHO/WHHOcomptext.html>

Kerschen, N. et al. (2005), Long-term care for older persons. In Long-term care for Older People – conference organised by the Luxembourg Presidency with the Social Protection Committee of the European Union, Luxembourg, 12-13 May 2005

Larizgoitia Jauregi, A. (2004), *National Background Report for Spain*, EUROFAMCARE:
http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_spain_rc1_a4.pdf

Yliff, M. et al. (2005), Rapport international – les aides et les soins aux personnes démentes dans les pays de la Communauté européenne, Qualidem, Universities of Liège and Leuven.

4.27.4 EuroCoDe network organisations

C.E.A.F.A.

C/ Pedro Miguel Alcatarena nº 3
E-31014 Pamplona (Navarra)
Tel: +34 -902- 17 45 17
Fax: +34 -948- 26 57 39
alzheimer@cin.es
www.ceafa.org

Fundació ACE

Cl Marques de Sentmenat 35-37
7014 Barcelona
Tel: +34 -93- 430 47 20
Fax: +34 -93- 419 35 42
ace@fundacioace.com

Fundación Alzheimer España

Pedro Muguruza 1 6c
28036 Madrid
Tel: +34 -913- 43 11 65
Fax: +34 -913- 59 54 50
alzheuro@yahoo.es
www.fundacionalzheimeresp.org

Fundación INTRAS

Santa Lucia 19
47005 Valladolid
Tel: +34 -983- 39 96 33
Fax: +34 -983- 21 75 65
www.intras.es

Hospital Clinic Universitari

Neurology, Alzheimer & memory Research Center
ICMSN, Villarroel, 170
8036 Barcelona
Tel: +34 -932- 27 54 14
Fax: +34 -934- 51 82 40
rbleasa@clinic.ub.es

Hospital Clinico San Carlos

Department of Geriatrics
28040 Madrid
Tel: +34 -91- 330 33 06
Fax: +34 -91- 330 33 06
jribera.hcsc@salud.madrid.org

Hospital Sant Jaume

Institut Català de l'envelliment
Fundació Universitària, Vinculada UAB
Casa Convalescència, St Antoni M Claret
08041 Barcelona
tsalva@catsalut.net or
18581asc@comb.es

Hospital Universitario Reina Sofia

Servicio Neurología
Cordoba
Avd/Menendez Pidal S/N
1400 Cordoba
Tel: +34 -95- 701 04 82
fernansanzlo@hotmail.com

Sociedad Española de Geriátría y Gerontología

Príncipe de Vergara, 57-59 - 1º

28006 Madrid

Tel: +34 -91- 411 17 07

Fax: +34 -91- 564 79 44

segg@segg.es

www.segg.es

Sociedad Española de Neurología

Via Laietana, 57, ppal. 2a

08003 Barcelona

Tel: +349 -3- 342 62 33

Fax: +349 -3- 412 56 54

secre@sen.es

www.sen.es

University of Navarre Medical School

Alzheimer Centre

Department of the Neurology, Memory Disorder Unit

C.U.N., Avda Pio XII 36

31008 Pamplona

Tel: +34 -948- 29 62 80

Fax: +34 -948- 29 65 00

tgisla@unav.es

4.28 Sweden

4.28.1 Prevalence of Dementia

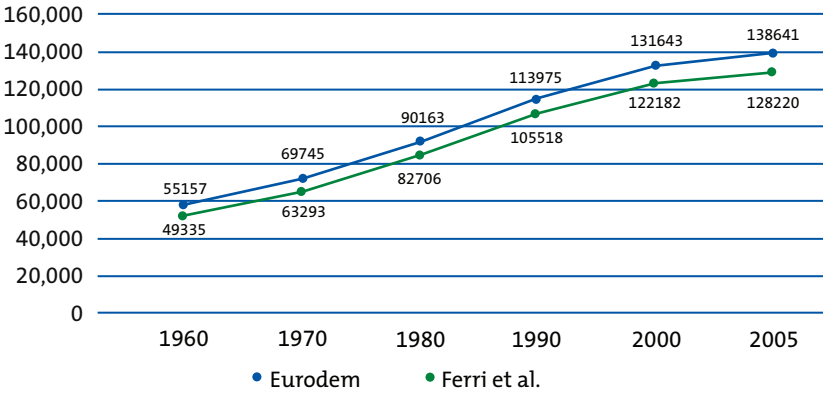
Alzheimer Europe estimates the number of people with dementia in Sweden in 2005 as being between 128,220 (Ferri et al.) and 138,641 (Eurodem). This represents 1.42% (Ferri et al.) to 1.54% (Eurodem) of the total population of 9,011,392. The number of people with dementia in Sweden as a percentage of the total population is considerably higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Sweden in 2005

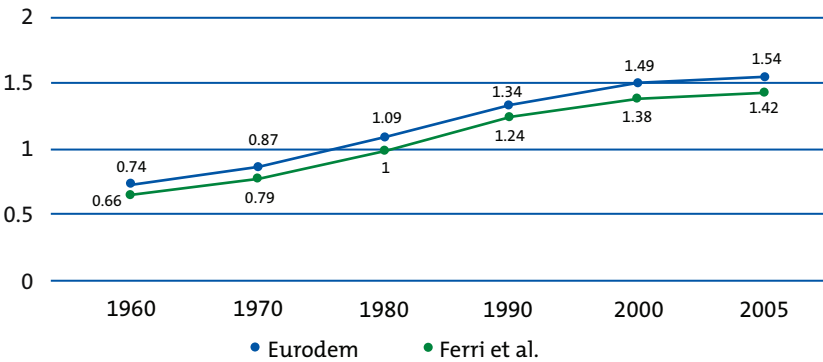
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	2,997	1,637	4,634	
60–64	4,278	1,258	5,536	4,846
65–69	4,325	2,309	6,635	6,139
70–74	7,416	7,231	14,647	12,535
75–79	6,875	11,882	18,757	18,873
80–84	12,776	21,636	34,412	32,413
85–89	9,095	21,512	30,607	53,413
90–94	5,260	13,722	18,982	
95–99	829	3,601	4,431	
Total	53,851	84,790	138,641	128,220

The following charts show a) the increase in the number of people with dementia in Sweden from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005.

The number of people with dementia in Sweden from 1960 to 2005



The number of people with dementia in Sweden as % of total population from 1960 to 2005



4.28.2 Availability of anti-dementia drugs

4.28.2.1 The availability of medicines in general

In Sweden, medicines on a special list are covered up to a certain degree depending on the overall expenditure on medication of a patient during a twelve month period.

- If the expenditure does not exceed SEK 900 (approx. € 63), the patient covers 100% of the drug costs.
- For expenditure between SEK 901 and SEK 1,700 (approx. € 181), the patient covers 50% of the costs.
- For expenditure between SEK 1,701 and SEK 3,300 (approx. € 351), the patient covers 25% of the costs.

- For expenditure between SEK 3,301 and SEK 4,300 (approx. € 458), the patient covers 10% of the costs.
- Costs above SEK 4,300 are totally covered by the healthcare system.⁶⁰

4.28.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Sweden and are part of the reimbursement system.

Treatment initiation and continuation is limited to specialists and the reimbursement system requires specialists to carry out an MMSE of patients. Alzheimer Europe was unable to obtain information on the MMSE limits for the reimbursement of the four medicines in question.

There are no restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.28.3 Organisation of Home care

4.28.3.1 Legislation relating to the provision of home care services

The Ministry of Health and Social Affairs in Sweden is responsible for general planning, guidance and supervision aimed at older people. The overall policy is that people have the possibility to live independently and safely in their own homes as long as they wish with support and home-care if needed. The targets are established by the Swedish Government and Parliament.

The care of older people, which includes the care of people with dementia, is regulated by three laws. Each law regulates in a different way what the public sector can expect in relation to the individual and what kind of rights the individual has. The laws are as follows:

⁶⁰ European Commission (2006): MISSOC – Mutual information system on social protection : Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland : Comparative tables

- the Law of Health and Medical Services (HSL) 1982:763;
- the New Social Service Legislation (SOL) SFS 2002:453 (which came into force on 1 January 2002); and
- the Law of Support and Service to Certain Persons with Handicap (LSS) 1994 which is a law of rights and carefully specifies the obligations of municipalities and county councils as well as individual rights. Only younger people, under 65 years, with dementia have a right to receive help from a personal assistant instead of home care.

The HSL includes an obligation of health service authorities to provide home care services if the needs cannot be met in any other way. Much of the care is carried out by families (informal caregivers). However, there is no statutory obligation for children to care for or financially support their parents. In the Social Service Legislation there are rules which state that the municipalities shall give those who need it, i.e. elderly people and those with disabilities, the kind of support they need which among other things includes home care services. There is no specific reference made to people with dementia. Moreover, there is no national, legally binding definition of dependency in Sweden. People with dementia are covered by the categories “elderly” and “people with disability”. Home care includes medical, rehabilitation and social work which a person may need at home.

According to the SOL, municipalities should support relatives. An important means of support for people with dementia, to enable them to live at home, is day care which can provide stimulation and ensure the safety of people with dementia, as well as providing relief for the relatives. However, day care is not compulsory.

The municipalities are independently responsible for providing social and home care. Social legislation provides a legal framework which gives the municipalities freedom to develop the law according to local conditions and political decisions. They can therefore interpret their obligations differently. Many municipalities have developed their own informal guidelines on service provision with the result that in some areas, for example, elderly people who only need help with cleaning are no longer eligible for home-help. Some have introduced means testing for some services. (Thorslund et al., 2001)

4.28.3.2 Organisation and financing of home care services

In Sweden, the welfare of the elderly is divided between three levels of government:

- at national level: the Parliament/Government (responsible for establishing policy aims and directives by means of legislation and economic steering measures)
- at regional level: the county councils (responsible for the provision of medical and health care)
- at local level: the municipalities (responsible for meeting the social services and housing needs of the elderly) (Regeringskansliet, 2002)

In 1992, the Swedish government implemented the Community Care Reform (known as the Ädelreform) which involved the decentralisation of responsibility and resources for the care of the elderly from regional to local governments. (Regeringskansliet, 2002)

Half of the municipalities, 144 of 290, in the country have now taken over responsibility for health and medical care in ordinary living. In the other municipalities, the county councils are responsible.

The municipalities are responsible for organising service and home care for their inhabitants. They can provide services themselves or they can buy from private providers.

The local authorities are obliged to have insight into and keep control of both their own and private type of care. Support from voluntary organisations is limited. The municipalities are responsible for providing assistive devices for the elderly.

Since an increasing number of people with dementia remain at home in their usual environment for an increasingly long period of time during the course of the disease, specially developed care and support measures are needed that target them and their close relatives. In a number of municipalities, there are clear plans and strategies for how the municipalities can provide individual adapted care for people with dementia. In many other areas, both knowledge regarding the needs of people with dementia and their relatives and the activities and resources offered to meet these needs are insufficient.

The fees charged for home help are determined by the amount of help needed and a person's income. Nevertheless, people receiving home care only pay a fraction of the actual cost. Also, since 1 July 2002, there has been a maximum fee for elderly patients resident in the municipalities. (Regeringskansliet, 2002)

The provision of services is based on an assessment of the person's housing, services and care needs. This is usually carried out by a municipal care manager, or as is often the case for elderly people, by an interdisciplinary care planning team (Johansson, 2004).

4.28.3.3 Kinds of home care services available

Entitlement to aid, insofar as this concerns the care of elderly people, includes amongst other things help in the home with services and personal care if the needs cannot be satisfied in other ways. The type of home care provided can be divided into different services which involve practical help with running of the home, cleaning and laundry, help with purchases and other important errands, as well as cooking and help eating. Help with care means personal help with tasks which are needed in order to satisfy the person's physical, mental and social needs. It may

be help with eating or drinking, getting dressed and moving, help with personal hygiene, activities to break isolation, measures to ensure that the person feels safe and secure at home, or a safety-alarm (which only people with mild dementia can use). It is possible to get home care and medical care every day of the week, in the evening and at night. In 1997, 28 percent of those receiving home help received it in the evenings and at night.

In addition to home help, other municipal services for the elderly include transportation services, foot care, meals-on-wheels, security alarms, housing adaptations and disability support, etc. (Regeringskansliet, 2002).

4.28.3.4 Consultation with people with dementia and carers

§29 of the Law of Health and Medical Services HSL and chapter 3, §5 of the New Social Legislation SoL, states that home care services should be organised in consultation with the people and relatives who are asking for a special kind of assistance. A decision made in accordance with the social law can be appealed if the decision is wholly or partially against the person's wishes.

In 2002, the Government decided to set up a working group to compile the knowledge available about the situation of people with dementia and their relatives. Its objective was to try to provide a comprehensive overview of the current situation.

The group has presented a national view of how dementia care has evolved in Sweden during recent years and the areas that it is important to prioritise and develop in the next few years. This report entitled "På väg mot en god demensvård" (On the way towards good dementia care) was published by the Ministry of Health and Social Affairs in 2003. This report has led to a number of different projects in the Municipalities and County Councils.

There are no national facts about users' satisfaction but many local studies have been done which show that people are generally satisfied with home care. General satisfaction is however a blunt measure for services and care. The failings become much clearer with specific questions. Another problem is that many people cannot answer the questions because of their disease. Often the questionnaire or interview is answered by the relative even though users and relatives' opinions about care often differ. In 2003, the Swedish Dementia Association published an extensive study of the situation of caregivers.

In studies where users have been asked how important a certain fact is, the answer is very often that having the same member of staff is important for their safety. A common experience is that staff is in a hurry. There is no time to talk and be together socially. Questions which are given the highest evaluation are those concerning treatment and accessibility. It is also important to be aware of the needs of people with dementia and their relatives and to understand the experience and needs

of people with dementia in particular. In some communities, specially organised home-care for people with dementia has been started.

Support for people with dementia in their own homes varies greatly from one community to the next. In the inquiry into dementia in 2002, 9% of the communities said that they had specially arranged home care for people with dementia. In certain cases, there is specific planning and a strategy on how the communities should treat and give individually designed care to people with dementia. Elsewhere, knowledge about people with dementia and their relatives is insufficient.

However, a great deal of education/training for staff working with people with dementia has been organised. Awareness about the importance for staff providing care and support to persons with dementia to have the requisite knowledge has increased. They have to know how to behave towards people with dementia, how to stimulate them, what attitude to have when handling challenging behaviour and how to make the most of a person’s remaining capacity.

4.28.3.5 Sources

Information provided by Inge Ploby (2006).

Johansson, L. (2004), National Background Report for Sweden, EUROFAMCARE.

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_sweden_rc1_a4.pdf

Regeringskansliet/Socialdepartementet (2002), Answer to questionnaire on health and long-term care of the Elderly – Sweden, European Commission

(http://europa.eu.int/comm/employment_social/social_protection/docs/sv_healthreply_en.pdf)

Thorslund, M. et al. (2001), Care for elderly people in Sweden. In *Aging: Weisstub, D.N. et al. (Eds.), Caring for our Elders*, Kluwer Academic Publishers

4.28.4 EuroCoDe network organisations

Alzheimerföreningen i Sverige

Sunnanväg 14 S Box 4109

227 22 Lund

Tel: +46 -46- 14 73 18

Fax: +46 -46- 18 89 76

info@alzheimerforeningen.se

www.alzheimerforeningen.se

Demensförbundet

Drakenbergsgatan 13 nb

117 41 Stockholm

Tel: +46 -8- 658 52 22

Fax: +46 -8- 658 60 68

rdr@demensforbundet.se

www.demensforbundet.se

Gothenburg University

Institution for Nursing Science and Health

Sahlgrenska Academy

Arvid Wallgrens Backe Hus 1

413 45 Goteborg

h.wijk@telia.com; helle.wijk@fhs.gu.se

Karolinska Institutet

Dept of Clinical Neuroscience
Occupational therapy & Elderly Care Research, Huddinge Hospital, PO Box B84
141 86 Stockholm
Tel: +46 -8- 585 854 74 or +46 -8- 585 836 17
Fax: +46 -8- 585 854 70 or +46 -8- 585 836 10
b.winblad.kaspac@neurotec.ki.se
www.ki.se

Lund University

Department of Health Sciences
P.O. Box 157
22100 Lund
Anna-Karin.Edberg@omv.lu.se
anna-karin.edberg@med.lu.se

Malardalens Hogskola

Department of Caring & Public Health Sciences
P.O. Box 883
721 23 Vasteras
eva.gotell@mdh.se

Malmö University Hospital

Clinic of Neuropsychiatry
SE-205 02 Malmö
Tel: +46 -40- 33 40 35 or 46 -31- 343 23 82
Fax: +46 -40- 33 46 04
magnus.sjogren@medfak.gu.se

Swedish Gerontological Society

Stockholm Gerontology Research Center
P.O. Box 6401
S-113 82 Stockholm
Lars.Andersson@cns.ki.se

Swedish Neurological Society

Department of Neurology
Karolinska Universitetssjukhuset Solna
171 76 Stockholm
Tel: +46 -85- 177 00 00
Fax: +46 -85- 177 33 99
magnus.la.andersson@kus.se
www.svls.se/sektioner/ne

Swedish Society for Geriatric Medicine and Gerontology

Geriatriska kliniken, Universitetssjukhuset,
581 85 Linköping
anne.ekdahl@lio.se
www.sfgg.se

4.29 Switzerland

4.29.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Switzerland in 2005 as being between 88,900 (Ferri et al.) and 97,068 (Eurodem). This represents 1.20% (Ferri et al.) to 1.31% (Eurodem) of the total population of 7,415,102. The number of people with dementia in Switzerland as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

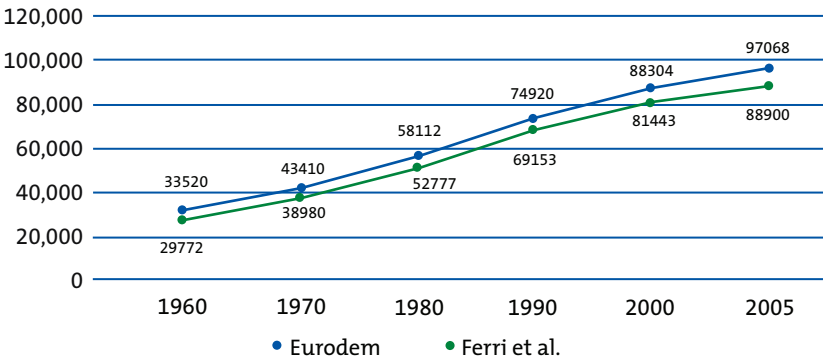
The Alzheimer Europe figures underestimate the number of people with dementia in Switzerland, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Switzerland over the age of 94.

Table 1: The number of people with dementia in Switzerland in 2005

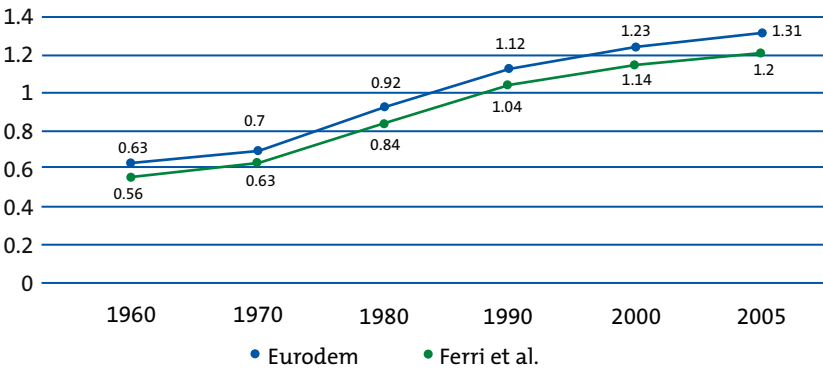
Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	2,639	1,477	4,116	
60–64	3,151	973	4,124	3,658
65–69	3,302	1,886	5,189	4,855
70–74	5,865	6,112	11,977	10,281
75–79	4,868	9,363	14,231	14,218
80–84	7,995	15,329	23,325	21,901
85–89	5,535	14,230	19,765	
90–94	3,777	10,565	14,342	
Total	37,132	59,936	97,068	88,900

The following charts show a) the increase in the number of people with dementia in Switzerland from 1960 to 2005 and b) the number of people with dementia as a percentage of the total population in the same years. As can be seen, the number of people with dementia more than doubled between 1960 and 2005.

The number of people with dementia in Switzerland from 1960 to 2005



The number of people with dementia in Switzerland as % of total population from 1960 to 2005



4.29.2 Availability of anti-dementia drugs

4.29.2.1 The availability of medicines in general

The Federal Office for Social Insurance draws up a positive list of pharmaceuticals for which the compulsory health insurance system will pay (the specialty list). Maximum prices are also set for these products.⁶¹

4.29.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Switzerland and are part of the reimbursement system.

Treatment decisions can be made by any doctor whether it is for treatment initiation or treatment continuation. The Swiss system requires the doctor to carry out an MMSE at the time of diagnosis, as well as a first follow up examination after three

⁶¹ WHO, Pharmaceuticals in Switzerland, accessed September 2006: http://www.who.dk/pharmaceuticals/Topics/Overview/20020414_8

months which can then be followed by examinations every six months. Treatment with acetylcholinesterase inhibitors should be discontinued if the MMSE score falls below 10 and with memantine for MMSE scores under 3.

There are no restrictions for the reimbursement of people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	>10	>10	>10	>3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.29.3 Organisation of Home care

4.29.3.1 Background information about dementia and home care services

According to the Swiss Health Survey carried out in 2004, there are 78,000 people aged 65 to 79 and 120,000 people over 80 years of age requiring home care. This represents 29% and 45% respectively of all those receiving home care.

25,700 people receiving home care are considered by their carers to have dementia (results of a national survey carried out by the Association Alzheimer Switzerland in 2004, published in “Vivre avec la maladie d’Alzheimer en Suisse, Les chiffres-clés 2”).

28,000 people, equivalent to 10,000 full time posts, work in the home care services domain. Over 90% are directly involved in providing care services. They mostly consist of qualified nursing staff, health care auxiliaries, home aids, care assistants and trained household aids.

Since the Federal Law on Health Insurance came into force in January 1996, health insurances have been obliged to refund part of the costs of prescribed care. At the same time, providers have found themselves obliged to reduce costs and increase efficacy. This has led to a wave of mergers which is still continuing. The number of care organisations (including those covering home care) has been reduced by about 50% since 1995. This has entailed a reduction in costs e.g. regrouping offices and vehicles. Most of the 700 state-approved local organisations of aid and home care are

attached to one of the 26 cantonal associations of aid and home care which in turn are members of the Swiss Association of aid and home care services.

4.29.3.2 Legislation relating to the provision of home care services

In Switzerland, legislation exists at federal, cantonal and communal level.

The legal basis of Spitex organisations can be found in the federal law on health insurance (LaMal), (art. 35).

A definition of care is provided in article 7 of the federal law “RS 832.112.31 ordonnance du DFI sur les prestations dans l’assurance obligatoire des soins en cas de maladie”. Such care is divided into categories, i.e. instructions and advice, examinations and care, and basic care.

The organisation of care and home care is determined by the federal law “RS 832.102 ordonnance sur l’assurance-maladie”.

4.29.3.3 Organisation and financing of home care services

Irrespective of age, any person, who is in need of care due to illness/disease, accident, disability, limitations due to age or maternity, can request the organisation of aid and home care within their home region. The necessity for the care and a needs assessment are required conditions for access. From the beginning of 2006 at the latest, there will be a standard assessment tool for carrying out needs assessments known as the RAI-Home-Care (Resident Assessment Instrument – Home Care).

Home care services are organised on an ad hoc basis in the cantons. There is no obligation at federal level to provide such services, although there may be within a canton. Patients are free to decide whether to be cared for at home or in an establishment. However, the insurance companies will no longer pay if a person remains in hospital when it is no longer necessary.

The costs for care services are fixed by federal law. Home care services are recognised and financed through an obligatory care insurance according to conditions determined by federal law. Access to care services is also determined by cantonal law.

The tariffs requested from clients for home care services do not generally cover the costs. The difference is covered by federal, cantonal or communal grants. Some people take out supplementary insurances to cover the part that they have to pay.

Home care services are divided into two categories - those that are refundable and those that are not. Those that are refundable cover care which has been prescribed and for which an assessment has been carried out. For these services, the “ordonnance sur les prestations de l’assurance des soins” (OPAS) has the following hourly prices:

- Basic care for simple and stable conditions (Fr 30 to Fr 47)
- Basic care for unstable and complex situations as well as for examination and care (Fr 45 to Fr 68)
- Assessment of needs and advice on medical prescription (Fr 50 to Fr 73)

The amount refunded by the insurance companies is determined by a price convention which is negotiated every year by the insurance companies and the cantonal aid/home care associations.

Generally speaking, carers and relatives are not legally responsible for the health care of their parents. With regard to the financing of care, there are exceptions in certain cantons or communes where close relatives, who are well off, may be required to financially contribute towards care.

4.29.3.4 Kinds of home care services available

A wide variety of services are available within the domain of home care services. Basic services include care and health care services, family support, household help and social accompaniment. Other services vary according to the local aid and home care organisations.

Basic services:

- Assessment and advice – services financed by the health insurances in accordance with the federal law (LAMal)

Additional relevant services:

- Rental of auxiliary aids
- Home meals service
- Meal at midday/day care centre
- Transport service
- Holidays in homes for the elderly
- Advice in case of respiratory problems
- Advice on nutrition and diabetes
- Home pedicure
- Home hair dressing
- Home ergotherapy
- Social advice
- Accompanying the dying and their relatives/friends
- Help switchboard
- Cleaning service
- Gardening service

The various branches of the Association Alzheimer Switzerland also offer different services e.g. support at home (in the Canton of Geneva, in collaboration with the Red Cross and Pro Senectute), the Alz'Amis (in the canton of Vaud) etc. To be precise, these are psycho-social support services and not nursing care services. They are financed by the beneficiaries of the Association and through a grant from the Federal Office of Social Insurance.

Palliative care is quite well developed in Switzerland. In addition to specialised hospitals and units, there are also Mobile Palliative Care Teams which provide palliative care at home (Stuckelberger and Wanner, 2005).

4.29.3.5 Consultation with people with dementia and carers

There are no legal obligations or formalities concerning consultation with people with dementia.

The Association Alzheimer Switzerland is currently organising, in collaboration with the Association Suisse des Services d'Aide et de Soins à Domicile, a series of regional conferences/debates on the theme: Living with Alzheimer's disease at home – yes, but how?

4.29.3.6 Sources

Enquête nationale, Vivre avec la maladie d'Alzheimer en Suisse, Les chiffres-clés 2, La prise en charge actuelle.

Information provided by Marianne Wolfensberger (2006).

Statistique de l'aide et des soins à domicile (Spitex) 2004 de l'Office fédéral des assurances sociales (www.bsv.admin.ch)
www.spitex.ch

Stuckelberger, A. and Wanner, P. (2005), National Background Report for Switzerland, EUROFAMCARE: (http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_switzerland_rc2_a4.pdf)

4.29.4 EuroCoDe network organisations

Association Alzheimer Suisse

Rue des Pêcheurs 8
1400 Yverdon-les-Bains
Tel: +41-24-426 20 00
Fax: +41-24-426 21 67
info@alz.ch
www.alz.ch

Geriatrische Universitäts Klinik

Kantonspital Basel
Hebelstrasse 2
4031 Basel
hannes-b.staehelin@unibas.ch
www.memoryclinic.ch

Schweizer Neurologische Gesellschaft - Société Suisse de Neurologie - Swiss Society of Neurology

Service de Neurologie, CHUV
1010 Lausanne
Tel: + 41 -21- 314 12 15
Fax: + 41 -21- 314 12 85
paul-andre.despland@chuv.hospvd.ch

Swiss Society of Gerontology - SGG-SSG

Hôpital Bern Ziegler
Morillonstrasse 75
3001 Berne
Tel: +41 -31- 970 77 98
Fax: +41 -31- 970 78 05
info@sgg-ssg.ch
www.sgg-ssg.ch

University of Geneva

HUG, Belle Idée
Département de Gériatrie
3, Ch. du Pont-Bochet
1226 Thônex-Genève
Tel: +41 -22- 305 65 00
Fax: +41 -22- 305 61 25
jean-pierre.michel@hcuge.ch

University of Zurich

Psychologisches Institut Lehrstuhl Gerontopsychologie
Schaffhauserstrasse 15
8006 Zurich

4.30 Turkey

4.30.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in Turkey in 2005 as being between 78,546 (Ferri et al.) and 129,715 (Eurodem). This represents 0.11% (Ferri et al.) to 0.18% (Eurodem) of the total population of 71,607,500. The number of people with dementia in Turkey as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures significantly underestimate the number of people with dementia in Turkey, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Turkey over the age of 74.

Table 1: The number of people with dementia in Turkey in 2005

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	20,454	11,268	31,722	
60–64	15,042	4,763	19,805	17,690
65–69	17,089	9,730	26,818	21,736
70–74	25,701	25,669	51,370	39,120
Total	78,286	51,430	129,715	78,546

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in Turkey since 1960.

4.30.2 Availability of anti-dementia drugs

4.30.2.1 The availability of medicines in general

The majority (about 75 percent) of drug purchases throughout the country are reimbursable through public sector agencies such as the Pension Fund, and the Social Insurance Agency.⁶²

4.30.2.2 The availability of Alzheimer treatments in Europe

All four anti-dementia drugs are available in Turkey and are part of the reimbursement system. Patients must have a medical report showing that they have Alzheimer's disease. These reports can only be given in clinical centres and by specialists, but once there is such a report other physicians can also prescribe. The Turkish system does not require any specific examinations to be carried out, nor does it impose upper or lower MMSE scores for reimbursement.

Finally, there are no restrictions for the reimbursement of people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.30.3 Organisation of Home care

4.30.3.1 Background information about dementia and home care services

There is legislation in Turkey which regulates home care provided by private institutions. This legislation covers home care services in general for all types of patients. It does not specify conditions for old people or people with dementia, or refer to their specific needs. There is work in progress by the Social Services Department to improve shortcomings and to issue new legislation covering the social aspects of home care.

4.30.3.2 Source

Information provided by Murat Emre (2006).

4.30.4 EuroCoDe network organisations

Alzheimer Vakfı

Halaskargazi Caddesi No:115/4

Harbiye-İstanbul

Tel: +90-212- 22 44 189

Fax: +90-212- 29 60 579

alzheimervakfi@ttnet.net.tr

www.alz.org.tr

Geriatrics Society of Turkey

Billur Sokak 29/9

Kavaklıdere

Ankara

Tel : +90 -312- 305 13 93

Fax: +90 -312- 467 11 40

ykutsal@hacettepe.edu.tr

www.geriatri.org

Turkish Neurological Association

Mesrutiyet Cad. 48/7,

06420 Kızılay

Ankara

Tel: +90 -312- 435 59 92

Fax: +90 -312- 431 60 90

info@noroloji.org.tr

www.noroloji.org.tr

4.31 United Kingdom

4.31.1 Prevalence of Dementia

Alzheimer Europe estimates the number of people with dementia in the United Kingdom in 2004 as being between 621,717 (Ferri et al.) and 660,573 (Eurodem). This represents 1.04% (Ferri et al.) to 1.11% (Eurodem) of the total population of 59,699,828. The number of people with dementia in the United Kingdom as a percentage of the total population is slightly lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the number of people with dementia in the United Kingdom, as it was impossible to obtain sufficiently detailed population statistics of the number of people in the United Kingdom over the age of 89.

Alzheimer Scotland, for example, estimates the number of people with dementia in Scotland as 62,000 in 2004, based on national 2004 population projections, which would yield a higher UK figure of 756,500 in 2004. This figure was calculated on the basis of prevalence rates provided by Harvey⁶³ and Hofman⁶⁴, and population statistics provided by the Government Actuary Department. The latest estimate of the Alzheimer’s Society for the UK is 750,000, similar to the Scottish estimate.

Table 1: The number of people with dementia in the United Kingdom in 2004

Age group	Eurodem			Ferri et al.
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30–59	19,752	11,332	31,084	
60–64	22,958	7,155	30,113	26,779
65–69	27,900	15,246	43,147	40,076
70–74	49,535	48,850	98,385	84,242
75–79	41,481	73,924	115,405	115,880
80–84	67,465	124,673	192,137	180,577
85–89	40,812	109,490	150,302	174,162
Total	269,903	390,670	660,573	621,717

Since Alzheimer Europe was unable to obtain detailed and complete population statistics for certain years, it was impossible to provide reliable information on the evolution of the number of people with dementia in the United Kingdom since 1960.

⁶³ Harvey R (1998) *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome* London Dementia Research Group, Imperial College School of Medicine

⁶⁴ Hofman A, Rocca WA, Brayne C, Breteler MMB et al (1991), The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, *International Journal of Epidemiology* 20(3) 736-48 (EURODEM)

4.31.2 Availability of anti-dementia drugs

4.31.2.1 The availability of medicines in general

Free prescriptions are generally available to children under the age of 16 (25 in Wales), people aged 16 to 19 but still in full education (England and Scotland only), people over the age of 60, pregnant women and women who have given birth in the last 12 months as well as people and their partners receiving income support.

Nevertheless, since primary care trusts have budgetary control over health care expenditure in their area, this entitles them to make decisions on which medicines will be available to patients free of charge in their area. It is therefore not always possible to provide general information as to which medicines are free of charge to patients throughout the United Kingdom. For some treatments, the National Institute for Health and Clinical Excellence may provide guidance documents which are widely followed by primary care trusts throughout the United Kingdom.

Under the devolved government arrangements for Scotland, NHS Quality Improvement Scotland does not reassess the evidence used in NICE guidance documents, but only seeks to identify contextual differences between England/Wales and Scotland. Hence NICE recommendations if approved for England and Wales are often also implemented in Scotland.

4.31.2.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in the United Kingdom and individual health care trusts may make them available to patients free of charge.

In its guidance of January 2001, the National Institute for Health and Clinical Excellence (NICE) made recommendations for the use of donepezil, rivastigmine and galantamine and recommended that they be made available under the National Health System under certain conditions:

- A diagnosis of Alzheimer's disease should be done in specialist centres and NICE provides a list of examinations that should be carried out,
- Treatment initiation should be recommended by specialist doctors only and treatment continuation decisions should only be done by general practitioners under shared care protocols,
- NICE does not recommend the use of acetylcholinesterase inhibitors for people with an MMSE score inferior to 12.

As for memantine, the Scottish Medicines Consortium rejected the wider use of memantine through the NHS in Scotland. The NICE recommendations were published before memantine became available in the United Kingdom and the recommendations do therefore not cover this product.

The review of these guidelines was still in process as this publication went to press.⁶⁵

⁶⁵ Please refer to the position of Alzheimer Europe on the availability of anti-dementia drugs in this publication for further information on this review process.

United Kingdom ⁶⁶	Donepezil	Rivastigmine	Galantamine	Memantine
NICE reimbursement recommendation	Yes	Yes	Yes	No
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Not applicable
Continuing treatment decision	Specialists or GPs under shared care protocols	Specialists or GPs under shared care protocols	Specialists or GPs under shared care protocols	Not applicable
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Not applicable
MMSE limits	Over 12	Over 12	Over 12	Not applicable
People living alone	No restrictions	No restrictions	No restrictions	Not applicable
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.31.3 Organisation of Home care in England and Wales

4.31.3.1 Legislation relating to the provision of home care services

In November 1989, the Government published the White Paper “Caring for People”, which laid out a framework for community care changes. Community care was defined in the White Paper as “providing the right level of intervention and support to enable people to achieve maximum independence and control over their own lives” (Focus on Disability, 2005)

The actual objectives of the White Paper were:

- To promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible.
- To ensure that service providers make practical support for carers a high priority.
- To make proper assessment of need and good case management the cornerstone of high quality care.
- To promote the development of a flourishing independent sector, along with high quality public services. (Social services would now be ‘enabling’ agencies - it would now be their responsibility to make maximum use of the private and voluntary sectors.)
- To clarify the responsibility of agencies and to make it easier to hold them to account for their performance.
- To ensure better value for taxpayers’ money by introducing a new funding structure for social care.

⁶⁶ The information contained in this table is based on the guidance document of the National Institute for Health and Clinical Excellence. Individual primary care trusts may have different rules in place to the ones in this table.

The National Health Service and Community Care Act 1990, which came into force in 1993, made the necessary legal changes to implement the objectives set out in “Caring for People”. This act, as modified by the Health and Social Care Act of 2001, provides the framework for assessment of social care needs (Nolan et al., 2004). If, whilst being assessed, it becomes clear that a person is disabled, the local authority is obliged under the Community Care Act to assess that person under the Disabled Person’s Act 1986. Under the latter act, a person may be entitled to practical assistance in the home amongst other services.

4.31.3.2 Organisation and financing of home care services

Healthcare is free at the point of delivery and funded by taxes not insurance. However, most social care is provided by local authorities who demand a modest means-tested contribution from patients. Although charges for home care services are at the discretion of local authorities, they are subject to the Fairer Charging Guidance issued to the Social Services Departments (SSD) under section 7 of the Local Authority Social Services Act 1970 (LASSA) (Nolan et al., 2004).

The NHS and Community Care Act 1990 gave local governments the opportunity to concentrate their efforts on community needs rather than on medicalised homes. Responsibility for care fees was transferred from the Department of Social Security to local authorities. They could decide which part of their budget should be allocated to community services and which part should be dedicated to residential care.

The aim of the act is to enable people to stay in their homes for as long as possible. It gives local authorities the responsibility to assess people’s needs. Local authorities differ in the kind of services they offer and the way that they are delivered. There is no obligation to actually provide services, just an obligation to assess needs.

The Community Care Act has resulted in a growing number of different services designed to support people in their own homes. However, the range and level of services vary a great deal from area to area. Financial constraints sometimes mean that it is not possible for someone to be supported at home. Local authorities are not legally obliged to provide community care for individuals if this would cost more than moving them to a residential or nursing home, although they sometimes will (Cayton, Graham and Warner, 1997).

On 27 March 2001, the UK government published the National Service Framework (NSF) for Older People. This document, which applies just to England, sets national standards for the care of older people who are being cared for at home, in a residential setting or in a hospital.

Carers may, if they wish, receive direct payments to purchase the services they need (i.e. for their own personally assessed needs, not those of the person with dementia), rather than receiving services. People with dementia may be entitled to vouchers to purchase additional support when the carer needs a break. These vouchers

are issued on behalf of the person with dementia but the recipient can ask to have them issued in the name of the carer so that the carer can redeem the vouchers (Nolan et al., 2004).

4.31.3.3 Kinds of home care services available

Services for people at home typically include the following:

- Domiciliary services e.g. home help, home care etc.
- Daytime services outside of the home e.g. day centres, lunch clubs or day hospitals
- Meals-on-wheels
- Respite care which allows carers and people with dementia to have a short break from each other
- Night sitting services
- Nursing home care
- Provision of equipment to help with daily tasks

4.31.3.4 Consultation with people with dementia and carers

The Government White Paper (November 1989), *Caring for People*, states that:

“... assessments should take into account the wishes of the individual and his or her carer, and of the carer’s ability to continue to provide care ... efforts should be made to offer flexible services which enable individuals and carers to make choices.”

The method of assessment should follow steps specified in a document called “the Practice Guidance”. This Guidance is used by local authorities when carrying out each part of the community care assessment. The Practice Guidance states that “... people being assessed should feel that the process is aimed at meeting their wishes.” Nevertheless, the person carrying out the assessment will obviously be responsible for defining the needs to be met. Furthermore it should be noted that two kinds of guidance are provided by the Department of Health. Policy guidance places a duty on councils to act in a certain way, whereas practice guidance is something which professionals working for the council should take into account when making decisions (Counsel and Care, 2004).

The Guidance also states that carers’ views should be taken into consideration and it should be remembered that the views of disabled people and carers are not always the same. Carers should be told that they may have an assessment of their own if they wish.

4.31.3.5 Sources:

Anonymous (2002), UK response to the EPC/SPC questionnaire on health and long-term care for the elderly, European Commission:

(http://europa.eu.int/comm/employment_social/social_protection/docs/uk_healthreply_en.pdf)

Cayton, H., Graham, N. and Warner, J. (1997), *Alzheimer's at your fingertips*, Class Publishing, London

Counsel and Care (2004), *Community care – Understanding the system*, Counsel and Care: (<http://www.counselandcare.org.uk/pdf/1understandingthesystem.pdf>)

Focus on Disability Website (anonymous), last updated 21/2/2005:

(<http://www.crossd17.freemove.co.uk/community%20care%201.htm>).

Nolan, M., Barber, L. Edis, Anne, Brown, J. and McKee, K. (2004), *National Background Report for the United Kingdom*, EUROFAMCARE,

http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/nabare_uk_rc1_a4.pdf

Roberts Clark IFS Limited (2005), *What will the state provide?* <http://www.nursingfees.co.uk/print.php/page/324>

The Multiple Sclerosis Society (2001), *The Community Care Act explained and the Community care, assessment of need:* (<http://www.infosci.org/MS-UK-MSSoc/ccassess.html>)

4.31.4 Organisation of home care in Scotland

4.31.4.1 Background information about dementia and home care services

According to Alzheimer Scotland, community care is a major priority of the Scottish Parliament. It aims to provide support and services for people with physical and/or mental health problems who are living at home or in a care home.

4.31.4.2 Legislation relating to the provision of home care services

The relevant legislation in Scotland governing the provision of home care services is “The Community Care and Health (Scotland) Act 2002”. This Act extended the range of duties placed on local authorities and assigned new powers to local authorities and NHS Scotland. The act ensured:

- free nursing and personal care for people over the age of 65
- more local collaboration between local authorities and NHS Scotland
- increased access to direct payments for home care services
- that the right to assessment was extended to informal carers, including young carers, and that they are made aware of that right
- that the contribution and views of carers, as well as the person they care for, are taken into account by local authorities before deciding which services to provide.

The Chronically Sick and Disabled Persons Act 1970 requires local authorities to make arrangements for the provision of certain services to individual chronically sick and disabled people resident in their area (Alzheimer Scotland, 2005). People with dementia may sometimes be eligible for services under this act. The services provided are:

- provision of practical assistance within the home
- provision of disability aids and equipment
- assistance with adaptations to the home
- provision of meals at home or elsewhere
- provision of, or assistance in, getting a telephone or any special equipment needed to use a telephone
- provision of holidays
- provision of, or assistance with taking advantage of, education or recreational facilities both inside and outside the home. This includes provision of, or assistance with, transport to and from such facilities.

4.31.4.3 Organisation and financing of home care services

In the past, local authorities or councils had main responsibility for assessing local need and for providing and co-ordinating services through their social work departments. However, services can now be provided by a variety of organisations e.g. housing associations, health authorities, voluntary sector agencies such as Alzheimer Scotland and private service providers.

On 1 July 2002, people over 65 years of age were granted free personal as well as nursing care. This was implemented under the Community Care and Health (Scotland) Act 2002. This is not dependent on financial status, capital assets, marital status or the amount of care provided by an unpaid carer. Personal care covers both personal care and personal support (as defined in the Regulation of Care (Scotland) Act 2001).

4.31.4.4 Kinds of home care services available

Home care services may include:

- personal care⁶⁷
- help at home with housework, shopping
- short breaks/respice care
- home adaptations; including disabled aids and equipment
- meals
- alarm systems to get help
- information about local services

⁶⁷ E.g. personal hygiene, continence management, problems of immobility linked to personal care needs, simple treatments and assistance with eating (not with the preparation or provision of food)

- day care
- transport to and from day care
- advocacy services
- befriending services
- holidays

4.31.4.5 Consultation with people with dementia and carers

§8 of the Community Care and Health (Scotland) Act 2002 states that both the views of the person whose needs are being assessed and the views of the carer should be taken into account in so far as it is reasonable and practicable to do so.

Under this act, the carer may also request a local authority to make an assessment of their ability to provide or to continue to provide care.

National and local policies recognise the importance of involving service users and carers in planning services in both health and social care. The NHS in Scotland has a policy of Patient Focus and Public Involvement [PFPI]. In 'Delivering for Health' (SEHD Nov 2005), the Scottish Executive committed itself to continuing to give patients an influential voice in the future of the health service and in their own individual care. Through initiatives such as Alzheimer Scotland's local involvement officers and the Scottish Dementia Working Group, people with dementia and carers are now involved at a number of levels in influencing public policy and local service provision (Fearnley, 2006).

4.31.4.6 Sources:

Alzheimer Scotland (2005), Community care and assessments: (<http://www.alzscot.org/info/commcare.html>)

Anonymous (2002), UK response to the EPC/SPC questionnaire on health and long-term care for the elderly, European Commission:

http://europa.eu.int/comm/employment_social/social_protection/docs/uk_healthreply_en.pdf

Information provided by Kate Fearnley (2006)

Scottish Executive (2003), Free personal and nursing care in Scotland:

(<http://www.scotland.gov.uk/Resource/Doc/1095/0001747.pdf>)

4.31.5 EuroCoDe network organisations

Alzheimer Scotland - Action on Dementia

Drumsheugh Gardens 22

EH3 7RN Edinburgh

Tel: +44 -131- 243 14 53

Fax: +44 -131- 243 14 50

alzheimerscot@alzscot.org

www.alzscot.org

Alzheimer’s Society

Gordon House, 10 Greencoat Place
SW1P 1PH London
Tel: +44 -20- 73 06 06 06
Fax: +44 -20- 73 06 08 08
enquiries@alzheimers.org.uk
www.alzheimers.org.uk

Association of British Neurologists

Ormond House, 4th Floor
27 Boswell Street,
London WC1N 3JZ
Tel: +44 -207- 405 40 60
Fax: +44 -207- 405 40 70
info@theabn.org
www.theabn.org

British Geriatrics Society

Marjory Warren House
31 St John’s Square
London EC1M 4DN
Tel: + 44 -20- 76 08 13 69
Fax: + 44 -20- 76 08 10 41
general.information@bgs.org.uk
www.bgs.org.uk

British Society for Research on Ageing

P.O.Box 2316
Cardiff CF23 5YY
debs@bsra.org.uk
www.bsra.org.uk

British Society of Gerontology

Department of Applied Social Science
University of Stirling
Stirling FK9 4LA
Tel:+44 -1- 786 46 77 01
susan.tester@stir.ac.uk
www.soc.surrey.ac.uk/bsg

Cochrane Dementia & Cognitive Improvement Group

Department of Clinical Geratology
Radcliffe Infirmary
Oxford OX2 6HE
Tel:+44 -1865- 22 48 63
Fax:+44 -1865- 22 41 08
colcig@geratol.ox.ac.uk
www.jr2.ox.ac.uk/cdcig

European Health Economics

St. James’s Square
London SW1Y 4J5
Tel: +44 -20- 76 61 93 79
Fax: +44 -20- 76 61 94 00
contact@ehe-uk.com
www.ehe-uk.com

Institute for Ageing and Health

Wolfson Research Centre
Newcastle General Hospital
Westgate road
NE4 6BE Newcastle Upon Tyne
Tel: +44 -191- 256 30 18
Fax: +44 -191- 219 50 91
i.g.mckeith@ncl.ac.uk
i.g.mckeith@newcastle.ac.uk

Institute of Neurology

Dementia Research Group
Queen Square
London WC1 3BG
m.rossor@dementia.ion.ucl.ac.uk
www.dementia.ion.ucl.ac.uk

Institute of Psychiatry

Departments of Old Age Psychiatry and Neuroscience
De Crespigny Park
London SE5 8AF
Tel: + 44 -20- 78 48 02 39 / 05 50
Fax: +44 -20- 78 48 06 32
s.lovestone@iop.kcl.ac.uk
www.iop.kcl.ac.uk

Kingshill Research Centre

Victoria Hospital
Department of Old Age Psychiatry
Okus Road
Swindon SN1 4HZ
Tel : +44 -1793- 43 75 01
Fax : +44 -1793- 43 75 21
roger.bullock@kingshill-research.org

London School of Economics and Political Science

Houghton St. Aldwych
London WC2A 2AE
Tel : +44 -20- 79 55 71 00
Fax : +44 -20- 79 55 74 27

Memory Assessment and Research Centre

MARC
Moorgreen Hospital
Southampton SO30 3JB
Tel : +44 -23- 80 47 52 16
Fax : +44 -23- 80 46 30 22
David.Wilkinson@wht.nhs.uk
www.marc.soton.ac.uk

Mental Health Foundation

Sea Containers House
20 Upper Ground
SE1 9QB London
srichardson@mhf.org.uk

Research Institute for the Care of the Elderly

St Martins Hospital
Bath BA2 5RP
Tel: +44 -1225- 83 58 66
Fax: +44 -1225- 84 03 95
r.w.jones@bath.ac.uk
www.rice.org.uk

School of Psychiatry & Behavioural Sciences

2nd Floor, Education and Research Centre
Wythenshawe Hospital
Southmoor Road, Wythenshawe
Manchester M23 9LT
Tel: + 44 -161- 291 58 87
Fax: +44 -161- 291 58 82
a_burns@man.ac.uk

University College London

London Centre for Dementia Care
Department of Mental Health Sciences
Wolfson Building
48 Riding House Street
W1W 7EY London
margot.lindsay@ucl.ac.uk

University of Bristol

Dept of Care of the Elderly
Frenchay Hospital
Tel: +44 -117- 975 39 48
Fax: +44 -117- 957 39 55
Gordon.Wilcock@bristol.ac.uk
gordon.wilcock@bris.ac.uk

University of Hull / Hull & East Riding Community NHS Trust

Department of Clinical Psychology
Hertford Building, Cottingham Road
HU6 7RX Hull

University of Oxford

University Department of Pharmacology
Mansfield Road
Oxford OX1 3QT
Tel: +44 -1865- 27 18 83
Fax: +44 -1865- 27 18 82
david.smith@pharmacology.oxford.ac.uk
www.pharm.ox.ac.uk/optima.htm

University of Stirling

Dementia Services Development
Stirling FK9 4LA
Tel: +44 -1786- 46 77 40
Fax: +44 -1786- 46 68 46
dementia@stir.ac.uk
www.dementia.stir.ac.uk

University of Wales Bangor (UWB)

Institute of Medical & Social Care Research
Neuadd Ardudwy
Normal Site
Holyhead Road
Bangor
LL57 2PX Wales

University of Warwick

Centre for Health Services Studies
Section of Geriatric Medicine and Gerontology
Warwick Business School
Coventry CV4 7AL
Tel: + 44 -24- 76 52 82 03
Fax: +44 -24- 76 52 49 63
alan.sinclair@wbs.ac.uk





***Alzheimer Europe
Annual Report 2005***

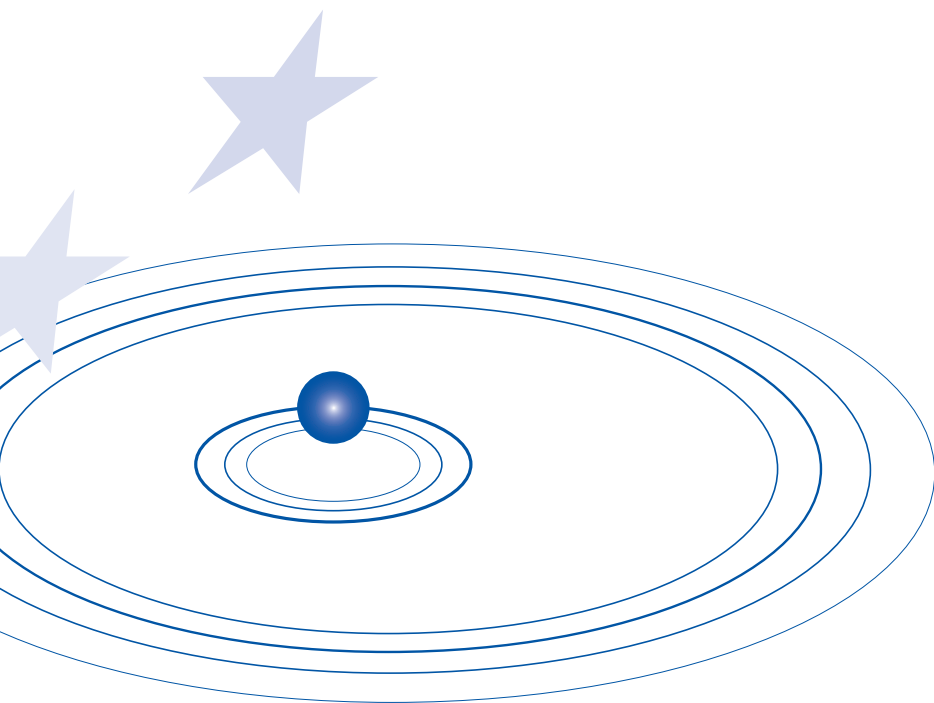
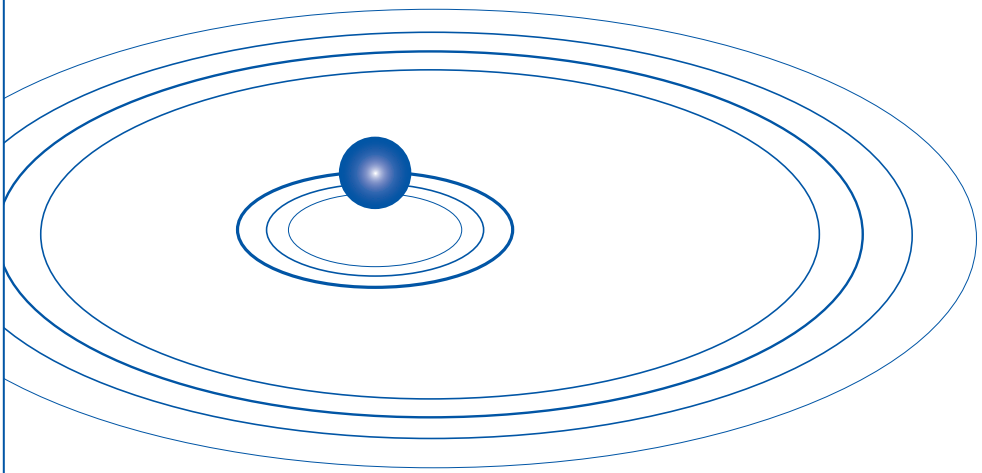




Table of contents

1. Annual Report 2005	236
1.1. <i>Preface</i>	237
1.2. <i>Executive Summary</i>	240
1.3. <i>Our core objectives</i>	242
1.4. <i>The business plan programmes</i>	251
1.5. <i>Other activities</i>	254
2. Financial Report	256
2.1. <i>Report of the independent auditor</i>	257
2.2. <i>Balance sheet as of 31 December 2005</i>	258
2.3. <i>Profit and loss account – Year ended December 31, 2005</i>	259
2.4. <i>Acknowledgements</i>	260
3. Position paper on advance directives	262
3.1. <i>Executive summary</i>	263
3.2. <i>Introduction</i>	265
3.3. <i>Clarification on the use of advance directives in the case of dementia</i>	267
3.4. <i>Guiding principles</i>	269
3.5. <i>The scope of advance directives</i>	271
3.6. <i>Practical issues linked to the writing and interpretation of advance directives</i>	275
3.7. <i>Legal issues</i>	282
3.8. <i>End-of-life issues and the availability of palliative care</i>	284
4. Position paper on anti-dementia drugs	286
4.1. <i>Executive Summary</i>	287
4.2. <i>Introduction</i>	289
4.3. <i>Alzheimer Europe position on anti-dementia drugs</i>	290
4.4. <i>Conclusions</i>	294



Annual Report 2005

1.1. Preface



I am pleased to report that my second year as Chairperson of Alzheimer Europe was another year of growth and expansion for the organisation.

As in the previous year, our business plan constituted the main focus for Alzheimer Europe and we were able to progress considerably on its four main programmes.

The survey of our member organisations, concerning the diagnosis of people with dementia and the importance of referring them to Alzheimer associations at the time of diagnosis was completed in 2005 and published together with our 2004 annual report.

Our programme on the autonomy of people with dementia and the importance of advance directives was concluded when our member organisations overwhelmingly endorsed the position paper on advance directives at our Annual General Meeting in Killarney. I consider this to be a great success that despite the cultural and legal differences between our European countries, we were able to come together as Alzheimer associations and reach consensus on a difficult issue. I can only congratulate Dianne Gove as the project manager, Alan Jacques as the chairperson of our working group and the other members of the working group (Peter Ashley, Holger Baumgartner, Dorthe Buss, Elaine Gadd, Nicole Kerschen, Anna Mäki-Petäjä and Anna Rovira) who made this difficult task seem effortless. I am sure the report and position which resulted from their work will prove a useful lobbying tool for both Alzheimer Europe and its member organisations for years to come.

Similarly, the guide for the time after diagnosis developed in the framework of our third business plan programme is a thoughtful document that answers the main questions that people with dementia and their carers will have when receiving the difficult diagnosis of Alzheimer's disease or another form of dementia. Again, Dianne Gove and the working group (Patrice Allard, Antonia Croy, Pierluigi de Bastiani, Sabine Jansen, Mireille Elsen, Alicja Sadowska and Micheline Selmes) managed to deliver a useful document and combined the information needs of both people with dementia and their carers, making this one of the first manuals that does so. I can only hope that member organisations will be able to translate and publish it in a number of languages and add to the growing list of Alzheimer Europe publications in direct use by tens of thousands of Europeans.

I am also encouraged by the fact that the communication strategy which we adopted in 2004 is now bearing fruit. Our quarterly newsletter provides a wealth of information on our various activities, as well as scientific breakthroughs and European developments. The visitors to our website have more than doubled, a positive trend which has continued in this year. In 2005, close to a quarter of a million people consulted our website to find much needed information on the care and treatment of Alzheimer's disease and other forms of dementia, a number I am justly proud of.

Alzheimer Europe has also become an established and trusted organisation in European circles. Clear evidence for this is that our organisation has been called upon by the European Commission to become a full member of a number of its advisory working groups, such as those on major and chronic diseases and on morbidity and mortality. Similarly, the involvement of Alzheimer Europe in the revision process of the diagnostic and management guidelines of the European Federation of Neurological Societies shows the importance that professional and medical organisations give to user and association input in general and to Alzheimer Europe in particular. Also, the nomination of Jean Georges, the Executive Director of our organisation to represent the wider patient community at the Management Board of the European Medicines Agency is undoubtedly another sign of the growing recognition of our organisation.

We were not only able to develop closer ties with the European Commission and the European Medicines Agency, but we also brought together a number of important and renowned European organisations and networks (Cochrane Collaboration, European Alzheimer's Disease Consortium, European Association of Geriatric Psychiatry, European Federation of Neurological Societies, International Association of Gerontology – European region, the Interdem and North Sea Dementia Research networks) to explore a closer collaboration in the future.

The success of this meeting and the interest of the participating organisations in this sort of closer collaboration led us to submit a project proposal to the European Commission entitled "European Collaboration on Dementia" and I am absolutely delighted that our bid was one of the 55 projects which the Commission decided to fund out of a total of 242 submitted project proposals. That Alzheimer Europe can be successful in such a competitive environment clearly shows the quality of our work and our plans for the future.

I am therefore confident that Alzheimer Europe will continue to grow from strength to strength and I would like to thank our small, but highly dedicated team consisting of Executive Director, Jean Georges, Information Officer, Dianne Gove and Communication Officer, Sandrine Lavallé for making this possible.

In particular, I would also like to thank the Luxembourg Alzheimer association for their continued support via the secondment of the Executive Director of our organisation and the provision of rent free offices.

Finally, our heartfelt thanks also go to Janssen-Cilag, Lundbeck and Pfizer which continued to support our different activities.

Maurice O'Connell

Chairperson

1.2. *Executive Summary*

In 2005, Alzheimer Europe:

- Organised a meeting bringing together representatives of pan-European organisations of professional or scientists to explore a closer collaboration between organisations active in the field of dementia,
- Was informed by the European Commission of the success of its project application “European Collaboration on Dementia” which aims to develop a European network to jointly develop consensual indicators and in particular,
 - o Consensual prevalence rates,
 - o Guidelines on diagnosis and treatment,
 - o Guidelines on psycho-social interventions,
 - o A report on risk factors and risk reduction and prevention strategies,
 - o A report on the socio-economic costs of dementia in Europe and
 - o An Inventory of social support systems in the European Union,
- Formalised its relationship with Alzheimer’s Disease International through the adoption of a partnership agreement between the two organisations,
- Continued its collaboration as an active member of the European Patients’ Forum,
- Collaborated in the Task Force of the European Federation of Neurological Societies for the revision of the organisation’s guidelines on the “Diagnosis and management of Alzheimer’s disease and other forms of dementia”,
- Continued its involvement with the European Alzheimer’s Disease Consortium and hosted and updated the website of this research network,
- Participated in a high-level round-table organised by the European Federation of Pharmaceutical Industries and Associations on the future of medicines research in Europe,
- Doubled the number of visitors to its website,
- Organised a successful annual conference in Killarney, Ireland, bringing together some 400 delegates from more than 30 different countries,
- Developed a consensual position on anti-dementia drugs in response to the preliminary recommendations of the National Institute of Clinical Excellence which was backed by over 100 European organisations and individual researchers,
- Participated in the conference of the Luxembourg Presidency of the European Union on long-term care,
- Was appointed as a full member to the Task Force on Major and Chronic Diseases and the Working Party on Morbidity and Mortality of the European Commission,

- Saw its Executive Director nominated by the European Parliament and Council of Ministers as one of two patient representatives on the Management Board of the European Medicines Agency,
- Continued its involvement in the working group with patient organisations of the European Medicines Agency,
- Participated in the quarterly meetings of the NGOs affiliated to the Council of Europe and presented its position on advance directives at the 8th European Conference of National Ethics Committees,
- Published the results of its survey of Alzheimer associations,
- Adopted a position on advance directives in which the organisation urges governments to provide a clear statutory basis for effective advance directives,
- Produced a guide for carers and people with dementia to address issues of concern in the time following diagnosis,
- Worked on an information organiser to support Alzheimer associations for the support and counselling of people with dementia and their carers,
- Carried out an extensive literature search on home care and produced national reports on the provision of home care for a number of European countries,
- Partnered with Lundbeck to carry out a survey of carers' experiences and needs in France, Germany, Poland, Scotland and Spain,
- Published new versions of its French and German Care Manuals and its French children's book,
- Developed a new strategic plan for the organisation focused on improving the access by people with dementia carers to treatment options and care services.

1.3. Our core objectives

As set out in its business plan, Alzheimer Europe is an interface between national member organisations and European structures in order to represent the interests of people with dementia and their carers, to promote information exchange and to develop policy.

1.3.1. Representing views

In 2005, Alzheimer Europe continued its networking with a number of European institutions, agencies and organisations in order to ensure that the views of people with dementia and their carers were adequately represented.

1.3.1.1. European Collaboration on Dementia

To strengthen its strategic partnerships, Alzheimer Europe organised a meeting on 8 April 2005 with representatives of a number of pan-European organisations of professionals or scientists active in the field of dementia in order to explore ways of collaborating more closely together in the future.

At the meeting, representatives of Alzheimer's Disease International, the Cochrane Collaboration, the European Alzheimer's Disease Consortium, the European Association of Geriatric Psychiatry, the European Federation of Neurological Societies, the International Association of Gerontology – European region and the Interdem network took part and welcomed the prospects of a closer collaboration between the different groups. Furthermore, the group agreed to jointly submit a project to the European Commission under its Public Health Programme.

On 30 August 2005, the European Commission informed Alzheimer Europe that the Commission services had decided to accept the organisation's project application "EuroCoDe - European Collaboration on Dementia" for co-financing.

The aim of the project is to develop a European network of all the players active in the field of dementia to jointly develop consensual indicators and to develop an ongoing dialogue between these actors to identify ways of developing synergies and a closer collaboration on a European level.

More specifically, the project will develop:

1. *Consensual Prevalence rates*

The project will gather existing epidemiological studies and analyse the respective merits and shortcomings of the individual studies. Based on the report on these studies, consensual European prevalence rates will be developed that will be acceptable to all partners and used as a "golden standard" within the respective organisations. Particular attention will be paid to providing a breakdown between

various forms of dementia (Alzheimer's disease, vascular dementia, Lewy-body dementia, fronto-temporal dementias and other rarer forms of dementia), as well as between the different stages of the disease (mild, moderate and severe stages).

2. Guidelines on diagnosis and treatment

The aim of the project is to identify existing guidelines and establish a comparative report on the similarities and differences between them. This report will then be used to develop consensual guidelines acceptable to the various network and project partners.

3. Guidelines on non-pharmacological interventions

The project will identify studies on the effects and usefulness of various interventions and present them in a comparative report highlighting the strengths and weaknesses of the respective studies and the interventions studied. Based on the findings, the project will aim to elaborate consensual guidelines on non-pharmacological interventions.

4. Risk factors and risk reduction and prevention strategies

As part of the project, existing studies on risk factors for Alzheimer's disease and other forms of dementia will be collected and presented in a comparative report highlighting promising venues for the development of prevention strategies. Particular attention will be given to developing recommendations for national Alzheimer associations to use in conjunction with campaigns promoting a "healthy brain lifestyle".

5. Socio-economic cost of Alzheimer's disease

The project will aim to collect existing studies. Since European healthcare systems are very different, it would be impossible to produce overall European data and the project will present its findings in a comparative report and aim to elaborate recommendations for the methodology of future socio-economic studies in the field.

6. Inventory of social support systems

The project partners will carry out a survey on the existing level of support available for people with dementia and their carers in the 25 Member States of the European Union and the accession countries. Such a survey will look at the different treatment reimbursement systems, the level of carers allowances and benefits, care insurance systems, employment related benefits (such as carers' leave, flexible working time, pension systems) and other benefits. The findings will be presented in a comparative report and discussed with the other network and project partners in order to identify best practices.

1.3.1.2. Alzheimer's Disease International

Alzheimer Europe continued its discussions with Alzheimer's Disease International in order to strengthen the collaboration between the two organisations. The partnership agreement drawn up in 2004 was approved by the Boards of both associations in 2005 and will provide a framework for an improved collaboration and exchange of information.

Also, representatives of the Alzheimer Europe Board attended the Annual Conference "Bridge at the Crossroads" which Alzheimer's Disease International organised together with its Turkish member in Istanbul from 28 September to 1 October 2006.

1.3.1.3. European Patients' Forum

Alzheimer Europe also continued its collaboration with the European Patients' Forum (EPF), an umbrella organisation of pan-European patient organisations which Alzheimer Europe helped to co-found in 2003.

Jean Georges, the Executive Director of Alzheimer Europe participated in the various meetings of the EPF Executive of which he has been a member since the beginning of the organisation. The Executive developed a clear business plan for the organisation, as well as a code of conduct for its collaboration with the pharmaceutical industry.

In collaboration with Pfizer Europe and the European Federation of Pharmaceutical Industries and Associations (EFPIA), EPF organised two successful conferences focused on European policy developments and capacity building for patient organisations ("Driving better health – The value of health education and compliance" on 22 and 23 June 2005 and "Strengthening Patient Groups in the EU: Exchange of Best Practice Between Patient Groups" on 10 and 11 October 2005).

Both events were attended by representatives of various member organisations of Alzheimer Europe.

1.3.1.4. European Federation of Neurological Societies

Apart from the contacts established in the framework of its "European Collaboration on Dementia" project, Alzheimer Europe further intensified its collaboration with the European Federation of Neurological Societies.

Thus, Alzheimer Europe was represented with a stand at the Annual EFNS Conference in Athens (17-20 September 2005) and Jean Georges, its Executive Director, took part in a symposium organised by Lundbeck ("Alzheimer's disease: Treatment benefits of memantine with a different focus") at which he presented various findings from different surveys with regard to inequalities of access of people with dementia and their carers to treatment options and care services.

Also, Jean Georges continued his involvement in the EFNS Task Force for the revision of the organisation's guidelines on the "Diagnosis and management of Alzheimer's disease and other forms of dementia". In line with the EFNS policy for the development of such guidelines, Alzheimer Europe was specifically asked to represent the views of people with dementia and their carers on this panel which was chaired by Gunhild Waldemar (Denmark) with contributions from Bruno Dubois (France), Murat Emre (Turkey), Philip Scheltens (Netherlands), Peter Tariska (Hungary) and Martin Rossor (United Kingdom). A draft of the guidelines was presented at the Lisbon conference and the publication of the final document is scheduled for 2006.

1.3.1.5. European Alzheimer's Disease Consortium

As in previous years, Alzheimer Europe continued its involvement with the European Alzheimer's Disease Consortium (EADC) alongside a number of highly respected research centres active in the dementia field.

In particular, Alzheimer Europe hosted and updated the website of the network and was involved in two EADC projects to represent the views of people with dementia and their carers:

- ICTUS: The impact of treatment with anticholinesterase inhibitors on Europeans with Alzheimer's disease, which is a prospective two year observational study which coordinates the centralisation of patient data available within the study's individual centres. Its primary objective is to determine whether treatment changes the pattern of institutionalisation.
- DESCRIPA: Development of screening guidelines and diagnostic criteria for pre-dementia Alzheimer's disease. The primary goal of the project is to reach an evidence-based European consensus on the identification of subjects with Alzheimer's disease in the pre-dementia stage.

1.3.1.6. European Federation of Pharmaceutical Industries and Associations

On 1 June 2005, the European Federation of Pharmaceutical Industries and Associations organised a round-table discussion on the subject "Medicines Research – Driving Europe's Health". The forum brought together representatives of the European Institutions (Günther Verheugen, Commission Vice-President and Dagmar Roth-Behrendt, Vice-President of the European Parliament), the regulatory authorities (Thomas Lönngren, CEO of the European Medicines Agency), the pharmaceutical industry (Franz Humer, CEO of Roche and Tom McKillop, CEO of AstraZeneca) and patient organisations (Jean Georges, Executive Director of Alzheimer Europe).

After listening to the Commission priorities with regard to the new regulatory framework for the pharmaceutical industry, patient safety and patient involvement, the different participants highlighted a number of concerns and preoccupations.

As a patient representative, Jean Georges stressed the importance of involving patient organisations in all relevant policy discussions such as patient safety, but also more controversial issues such as stem cell or animal research. In order for these organisations to have a more active role, he called on the European institutions to consider providing core-funding to relevant European organisations such as the European Patients' Forum.

He also questioned the economic assessments of the cost of diseases of most Member States of the European Union, which seem to focus on narrow cost-effectiveness models of existing treatment options without taking due consideration of the quality of life of patients or the global cost of diseases to society as a whole.

As in previous years, Alzheimer Europe actively participated in the quarterly meetings of the EFPIA think tank which brings together representatives of European patient organisations and the pharmaceutical industry to discuss European issues of interest to both stakeholders.

1.3.2. Information exchange

In 2005, Alzheimer Europe continued with the implementation of the communication strategy which the organisation had adopted in 2004. Its quarterly e-mail newsletter, the website and the annual conference remained the key tools for the association in this area.

1.3.2.1. Alzheimer Europe Website

The Alzheimer Europe website continues to be a useful source of information for people interested in finding out more about Alzheimer Europe and the care and treatment of people with dementia. Between 2004 and 2005, the number of visitors doubled with close to 20,000 persons visiting the Alzheimer Europe website every month.

Month	Visitors
January	13,208
February	15,681
March	17,391
April	15,835
May	13,540
June	16,543
July	21,357
August	15,469
September	22,298
October	27,095
November	31,623
December	29,221
Average	19,938

Alzheimer Europe regularly updated its website with information on its latest activities, the projects of its member organisations, research findings and the latest European developments.

1.3.2.2. 15th Annual Conference in Killarney, Ireland

'People with dementia have the right to self determination and must be allowed to play a more pivotal role in determining policy and practice in dementia care' was the main message from the 15th Alzheimer Europe Conference which was hosted by the Alzheimer Society of Ireland in the Great Southern Hotel, Killarney from 9-12 June 2005.

The 3 day conference, entitled 'Dementia Matters', highlighted key issues within the world of dementia in a stimulating and challenging way. Speaking at the opening ceremony Dr Niall Tierney, Chairperson of the Alzheimer Society of Ireland, said: "We are on the cusp of something new, with the opportunity to embrace a different perspective on dementia and the provision of dementia care. People with dementia have the right to play a more pivotal role in how we as policy makers, healthcare providers, advocates, carers and members of society plan and develop responses in dementia care and we are delighted to have several people living with dementia addressing us during this conference and giving us their perspective."

The Alzheimer Europe conference brought together approximately 400 delegates from more than 30 countries worldwide and focused on the issues of promoting a rights-based approach to dementia care, the person-centred philosophy in dementia care, the challenges that lie ahead and how they should be addressed.

1.3.3. Developing policy

In 2005, Alzheimer Europe continued to develop its policy making strategy. For that purpose, the association organised a meeting in Brussels on 24 February 2005 bringing together representatives of its member organisations involved in government affairs, campaigning or lobbying. Representatives of the Belgian, English, Finnish, French, German, Irish and Scottish member organisations discussed ways on how to improve the information flow between Alzheimer Europe and its member organisations and how to speed up the development of policies and positions in response to European developments.

1.3.3.1. Position on anti-dementia drugs

On 22 March 2005, Alzheimer Europe responded to the preliminary NICE recommendations on the prescription of anti-dementia drugs in which it strongly disagreed with the recommendations which would disbar tens of thousands of people from the only available treatment for their condition.

This position was approved unanimously by the 20 national member associations which responded to the organisation's consultation and received the endorsements

of other respected European organisations, such as the European Brain Council and the European Union Geriatric Medicine Society, as well as a high number of renowned dementia experts from all over Europe.

Carers and scientists alike were deeply concerned about the review proposed by NICE and demanded continued access for people with Alzheimer's disease to existing drugs, since:

- Enough clinical evidence exists to support the use of anti-dementia drugs and clinical trials have shown them to be effective not only in improving memory, but also for beneficial effects on behaviour and activities of daily living.
- This clinical data on the effectiveness of anti-dementia drugs is supported by testimonies of great numbers of people with dementia and their carers.
- Cost-effectiveness models used by the National Institute of Clinical Excellence fail to duly take into account effects on quality of life of carers of people with Alzheimer's disease.
- The existence of anti-dementia drugs has contributed to the development of dementia care through an expansion of memory clinics and other specialised services offering early diagnosis, advice and support for people with dementia and their carers.
- The discontinued prescription of anti-dementia drugs would take away one of the main reasons for people coming forward for an early diagnosis of their condition who would therefore no longer benefit from other significant advantages of an early diagnosis.
- The NICE recommendations would discriminate against a significant proportion of the population who already suffers from stigma and ageist prejudices.
- European citizens should have equal rights to protection and access to health care regardless of their country of residence. The NICE recommendations would disbar British people with Alzheimer's disease from access to treatment options available and reimbursed in other Member States of the European Union.

1.3.3.2. Presidency of the European Union

The Luxembourg Presidency of the European Union organised a conference on long-term care in Luxembourg from 12 to 13 May 2005 which was attended by national representatives from social and health ministries.

At the meeting, a report by Ms Nicole Kerschen, former advisor of the Alzheimer Europe Lawnet project, and her colleagues, was presented and discussed. This report highlighted the needs of dependant people, including those of people with dementia and presented an overview of the different national systems for the responsibility of the state and the individual in the countries covered.

Sabine Henry, Vice-Chairperson of Alzheimer Europe, took part in a round table discussion on the needs of patients and disabled people and provided an overview of the prevalence of dementia in Europe with the Alzheimer Europe estimates of the numbers of people with dementia in the Member States of the European Union.

She also presented some key findings of the Alzheimer Europe EPOCH project (Equality in the provision of care at home) on the status of carers in a number of European countries.

The conference sent a strong signal to the Commission and the Council of Ministers about the importance of including the question of long-term care into the open method of coordination in order to compare the different systems and to provide examples of best practice in this important field.

1.3.3.3. European Commission

Alzheimer Europe continued to develop its working relations with the European Commission. Thanks to the success of its project application "European Collaboration on Dementia", Alzheimer Europe was invited to participate as a full member in the Task Force of the European Commission on Major and Chronic Diseases, as well as the Working Party on Morbidity and Mortality.

These working groups met on 12 and 13 December 2005 and discussed the Commission work plan for 2006, as well as health information developments in oral health, in autistic spectrum disorders, in musculoskeletal diseases and also in neurological and non-psychiatric brain diseases.

Also, the European Commission published the Alzheimer Europe report on rare forms of dementia in 2005. This project which was completed in 2004 and resulted in a detailed report with information on over 30 rare forms of dementia which included a description of the disorder along with its symptoms and causes, the epidemiological data available and treatment, information on clinical trials and diagnostic procedures and finally a list of sources of further information.

1.3.3.4. European Medicines Evaluations Agency

2005 also constituted a highlight of the organisation's collaboration with the European Medicines Agency (EMA). Thus, Jean Georges, the Executive Director of Alzheimer Europe, was appointed as one of the two patient representatives on the EMA Management Board by the Council of Ministers of the European Union at its meeting of 29 July 2005.

As in previous years, Alzheimer Europe also participated in the quarterly meetings of the EMA working group with patient organisation which addressed patient-specific issues within the European regulatory system, such as:

- Pharmacovigilance and reporting of adverse drug reactions,
- Accessibility and readability of patient information leaflets,
- Transparency and dissemination of information on prescription medicines to patients.

The working group recommendations for the criteria that patient organisations need to fulfil in order to become involved in EMEA activities were adopted by the EMEA Management Board in 2005.

1.3.3.5. Council of Europe

Besides the institutions of the European Union, Alzheimer Europe also continued its collaboration with the Council of Europe. As an organisation with consultative status, Alzheimer Europe took part in the quarterly meetings of NGOs affiliated to the Council of Europe and participated in the meetings of organisations with an interest in health.

From 25 to 26 April, Jean Georges also participated in the 8th European Conference of National Ethics committees (COMETH) in Dubrovnik, Croatia at which he presented the work that the Alzheimer Europe working group on advance directives had developed.

Approximately 100 participants from 42 countries took part in this conference to discuss the ethical implications of an ageing society and the Convention on Human Rights and Biomedicine.

1.4. The business plan programmes

Apart from clearly setting out the core objectives of Alzheimer Europe, the business plan also provides a number of priority programmes which the association should collaborate on with its national member organisations, as well as with other interested third parties.

1.4.1. BP 1 – Alzheimer associations

The objective of the first business plan programme is to ensure that people with dementia are referred to their Alzheimer association at the time of diagnosis.

Alzheimer Europe had carried out an extensive survey of its member organisations to highlight the great number of services provided by Alzheimer associations. These results were collected in a report on the Alzheimer movement in Europe which was published in 2005 together with the 2004 Annual Report.

The results of the survey were also presented at a number of conferences of medical professionals such as the Conference of the European Federation of Neurological Societies in Athens (18-21 September 2005) or a symposium on “Communicating Treatment Benefits” organised by Pfizer in Rome (11 November 2005).

Similarly, the importance of Alzheimer associations was discussed with specialists in the framework of the EFNS task force for the review of their guidelines on the diagnosis and management of dementia.

Finally, a survey conducted in a number of European countries in collaboration with Lundbeck aimed at identifying the degree of satisfaction of diagnosed persons with the diagnostic process and the information provided by specialists.

1.4.2. BP 2 – Advance directives

The second business plan objective was the promotion of the autonomy of people with dementia through the recognition of advance directives.

An extensive literature search on the subject of advance directives had been carried out by Dianne Gove thanks to additional financial support from the Fondation Médéric Alzheimer. In her work, she was supported by a working group chaired by Alan Jacques (United Kingdom) and consisting of Peter Ashley (United Kingdom), Holger Baumgartner (Austria), Dorthe Buss (Denmark), Elaine Gadd (United Kingdom), Nicole Kerschen (Luxembourg), Anna Mäki-Petäjä (Finland) and Anna Rovira (Spain).

In 2005, the working group finalised a position paper on advance directives which was adopted at the Annual General Meeting of Alzheimer Europe with only two abstentions. In its position paper, the organisation made the following main points:

- Alzheimer Europe would like to promote the use of advance directives for decisions covering a wide range of health related issues e.g. treatment, care, welfare, research, the appointment of health care proxies etc.
- Alzheimer Europe supports the concept of health care proxies and encourages governments to legally recognise their role and also to develop the relevant safeguards for their involvement in the decision-making process.
- Alzheimer Europe would like to emphasise the importance of involving doctors and other qualified health care professionals when considering whether/how to draw up an advance directive within the context of advance care planning.
- Due to difficulties in obtaining an appropriate level of precision (which is neither too vague nor too specific to be of practical use), Alzheimer Europe encourages people to write statements of values.
- Alzheimer Europe expects governments to set up appropriate systems for the registration, use and review of advance directives.
- Alzheimer Europe is of the opinion that for an advance directive to be valid, certain generally accepted criteria should be fulfilled, e.g. that the person has the necessary and relevant capacity, is free from undue pressure, has not made a more recent version and has stated wishes that are applicable to the current situation/proposed treatment.
- With regard to debates surrounding the issue of current versus formerly expressed wishes, Alzheimer Europe insists on the importance of always trying to ascertain the wishes of patients even if they have written an advance directive. If the person is fully competent, doctors should not follow instructions/wishes expressed in the advance directive. If the person is not fully competent and there appears to be a conflict between current and former wishes, the person's current wishes and feelings should be considered alongside those expressed in the advance directive as they represent the person's current mental and emotional state and attitudes.
- Decisions not to comply with valid advance directives should be documented in the patients' medical files and an explanation should be given to significant others, relevant supervisory bodies and health care proxies.
- In order to guarantee equity in the provision of health care and to ensure that people have a real choice, Alzheimer Europe emphasises the need to increase the availability and improve the quality of palliative care services/facilities.
- Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

- A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.

1.4.3. BP 3 – Counselling and support

The third business plan programme focuses on improving the support and counselling of carers of people with dementia at the onset of the disease.

With the support of a working group consisting of Patrice Allard (France), Antonia Croy (Austria), Pierluigi de Bastiani (Italy), Sabine Jansen (Germany), Mireille Elsen (Luxembourg), Alicja Sadowska (Poland) and Micheline Selmes (Spain), Dianne Gove produced a manual for informal carers and people with dementia which responds to their specific needs in the period of time following a diagnosis. Member organisations, as well as people with dementia, were consulted on various drafts to ensure that the language used was appropriate and met their expectations. A final draft was approved by the Board of Alzheimer Europe in its meeting of 8 and 9 October 2005. The translation and dissemination of the manual will be done in 2006.

In 2005, the above-mentioned working group also started work on the development of a guide for Alzheimer Associations. This will take the form of an information organiser covering the main issues that staff in the associations may be asked about by informal carers and people with dementia. It will contain general information about the various topics and guidelines on the kind of support that could be provided. Associations will be expected to add their own information and/or references indicating where such information is located, as well as relevant contact details. The guide is intended to be used as a loose-leaf file in order to ensure that it can be easily updated and adapted to the needs of each organisation.

1.4.4. BP 4 – Care at home

With its fourth business plan programme, Alzheimer Europe aims at promoting quality of care at home. As with the other programmes, a working group with representatives of national organisations was set up to advise Alzheimer Europe on the work it carries out in this field. The group is comprised of Sirkkaliissa Heimonen (Finland), Sabine Henry (Belgium), Noni Cobban (United Kingdom), Majken Ploby (Sweden) and Eugen Stefanut (Romania).

In 2005, an extensive literature search was carried out on home care provisions and Dianne Gove produced a series of national reports describing the provision of home care and the legal framework for home care for a series of European countries. These reports will be finalised in 2006 together with an overall report outlining the results of the literature search.

1.5. Other activities

1.5.1. European Carers' Survey

In 2005, Alzheimer Europe partnered with Lundbeck to develop “The dementia carers’ survey” which aimed at identifying the challenges that Alzheimer’s disease presents to carers in the participating countries. These include coping with symptoms and care, as well as national differences with regard to diagnosis and the availability and access to treatment and care services. Member organisations of Alzheimer Europe in France, Germany, Poland, Scotland and Spain conducted this survey in November and December 2005 in their respective countries and each association was able to achieve or surpass the set minimum of 200 respondents.

The results of the survey will be analysed and presented in 2006.

1.5.2. Alzheimer Europe Publications

Alzheimer Europe was also able to continue with the dissemination of its previous Commission-financed projects. In 2005, Alzheimer Europe was thus able to produce a 2nd edition of the French version of its Children’s book and to thoroughly revise both the German and French versions of its Care Manual which were published in 2005 in their 2nd and 3rd editions, respectively.

1.5.3. New Strategic Plan

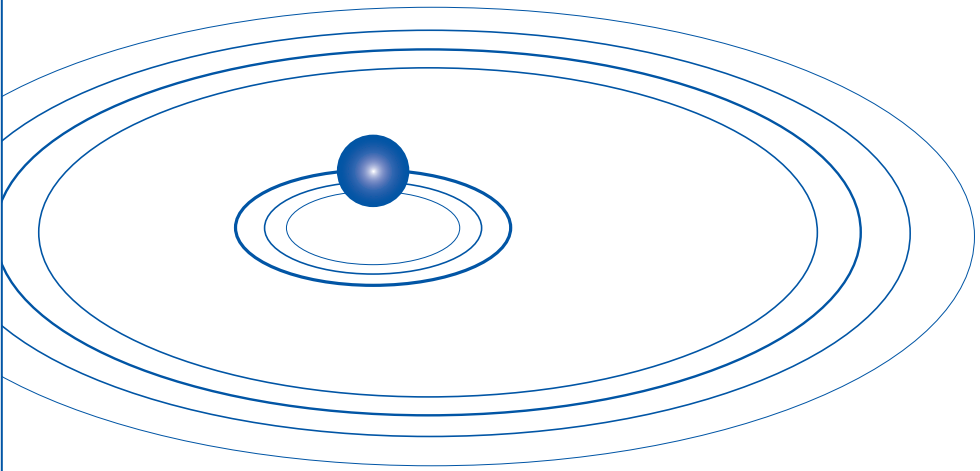
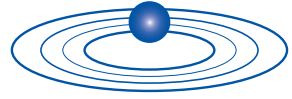
Conscious that the business plan of the organisation would come to an end in 2006, Alzheimer Europe started discussions on the implementation of a new strategic plan for the organisation.

After some discussion, the Alzheimer Europe Board decided to opt for a more general strategic plan that would be supplemented by more detailed annual work plans highlighting the priorities of the organisation for the year.

The strategic plan, which will be submitted for ratification at the Annual General Meeting of the organisation in 2006, summarises Alzheimer Europe’s mission as consisting of changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services .

Furthermore, the strategic plan stresses that to achieve its mission and its objectives, Alzheimer Europe will represent the interests of people with dementia and their carers, involve and support its national member organisations, promote information exchange between national Alzheimer associations and other stakeholders, carry out transnational comparative surveys, develop policies and network with other relevant European organisations.





Financial Report

2.1. Report of the independent auditor

 M A Z A R S

To the Board of Directors
ALZHEIMER EUROPE A.s.b.l.

LUXEMBOURG

REPORT OF THE INDEPENDENT AUDITOR

We have audited the accompanying balance sheet and profit and loss account of **ALZHEIMER EUROPE A.s.b.l.**, association internationale sans but lucratif, for the year ended December 31, 2005. These balance sheet and profit and loss account are the responsibility of the Board of Directors. Our responsibility is to express an opinion on these accounts based on our audit.

We conducted our audit in accordance with International Standards on Auditing. Those Standards require that we plan and perform the audit to obtain reasonable assurance about whether the balance sheet and profit and loss account are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the accounts. An audit also includes assessing the accounting principles used and significant estimates made by the Board of Directors, as well as evaluating the overall accounts presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the attached balance sheet and profit and loss account give, in conformity with the Luxembourg legal and regulatory requirements, a true and fair view of the financial position of **ALZHEIMER EUROPE A.s.b.l.** as of December 31, 2005 and of the results of its operations for the year then ended.

Luxembourg, June 26, 2006

For MAZARS, Réviseurs d'entreprises


Philippe GLENDZAK
Partner


Joseph HOBSCHIED
Audit Manager

Enclosed : Balance sheet as of December 31, 2005
Profit and loss account as of December 31, 2005

MAZARS - RÉVISEURS D'ENTREPRISES & EXPERTS COMPTABLES
10A, RUE HENRI M. SCHNADT, L-2530 LUXEMBOURG - TÉL : (352) 29 94 94-1 - FAX : (352) 29 92 20 - e-mail : info.mgl@mazars.lu
SOCIÉTÉ ANONYME - RC LUXEMBOURG B 56248 - TVA INTRACOMMUNAUTAIRE LU 16893816

2.2. Balance sheet as of 31 December 2005

ALZHEIMER EUROPE A.s.b.l.

Balance sheet as of December 31, 2005

	2005	2004
	<u>EUR</u>	<u>EUR</u>
ASSETS		
Current assets		
Other debtors	40.141	26.477
Cash at bank and on deposit	100.616	109.102
	<u>140.757</u>	<u>135.579</u>
Accruals	120	455
	<u>140.877</u>	<u>136.034</u>
Total Assets	<u>140.877</u>	<u>136.034</u>
LIABILITIES		
Capital and reserves		
Results brought forward	83.745	77.479
Result of the year	-10.300	6.266
	<u>73.445</u>	<u>83.745</u>
Creditors		
Payments received on account	30.000	31.416
Trade creditors	20.172	5.859
Other liabilities	17.260	15.014
	<u>67.432</u>	<u>52.289</u>
Total Liabilities	<u>140.877</u>	<u>136.034</u>

2.3. Profit and loss account – Year ended December 31, 2005

ALZHEIMER EUROPE A.s.b.l

Profit and loss account Year ended December 31, 2005

	<u>2005</u> <u>EUR</u>	<u>2004</u> <u>EUR</u>
Other operating income		
Sponsorship	165.415	197.456
Sponsorship received on account	-	-31.416
Co-financing in kind	114.885	103.277
Membership fees	40.000	40.000
Donations	1.500	7.500
Publication sales and royalties	12.012	56.041
Internet services	5.925	-
Project participation	6.391	5.274
Other operating income	4.834	18.539
Alzheimer Europe Conference	10.000	8.100
External charges		
External experts	-119.591	-106.908
Publication and information material	-19.859	-40.220
Travel expenses	-28.773	-36.572
Communication costs	-17.828	-17.494
Accommodation expenses	-31.397	-31.884
Office rent and associated costs	-22.887	-20.833
Office stationary and related costs	-1.810	-4.874
Leasing	-13.248	-18.219
Membership fees	-700	-700
Other costs	-574	-1.881
Irrecoverable debt	-937	-2.681
Staff costs		
Wages and salaries	-88.670	-90.912
Social security costs	-24.322	-24.788
Interest receivable and similar income	581	605
Interest payable and similar charges	-1.247	-1.144
	<u>-10.300</u>	<u>6.266</u>

2.4. Acknowledgements

2.4.1. Platinum donors and sponsors (Donations and sponsorship from € 50,000)

Alzheimer Europe is grateful to **Association Luxembourg Alzheimer** and the **Luxembourg Ministry for Family** for the secondment of the Executive Director of Alzheimer Europe and the office space they make available to the organisation free of charge.

2.4.2. Gold donors and sponsors (Donations and sponsorship between € 20,000 and € 49,999)

Alzheimer Europe is grateful to Janssen-Cilag, Lundbeck and Pfizer which generously agreed to support the activities Alzheimer Europe carried out in the framework of its business plan in 2005.

Furthermore, Alzheimer gratefully acknowledges the support it has received from Lundbeck for the organisation of a carers' survey in France, Germany, Poland, Scotland and Spain and to Pfizer and Eisai for their financial support for the development of the Alzheimer Europe website.

2.4.3. Silver donors and sponsors (Donations and sponsorship between € 5,000 and € 19,999)

Alzheimer Europe is grateful to Harry Cayton for his donation to support carers and staff members from Alzheimer associations in Central and Eastern Europe to attend the AE conference in Killarney, Ireland.

2.4.4. Bronze donors and sponsors (Donations and sponsorship between € 1,000 and € 4,999)

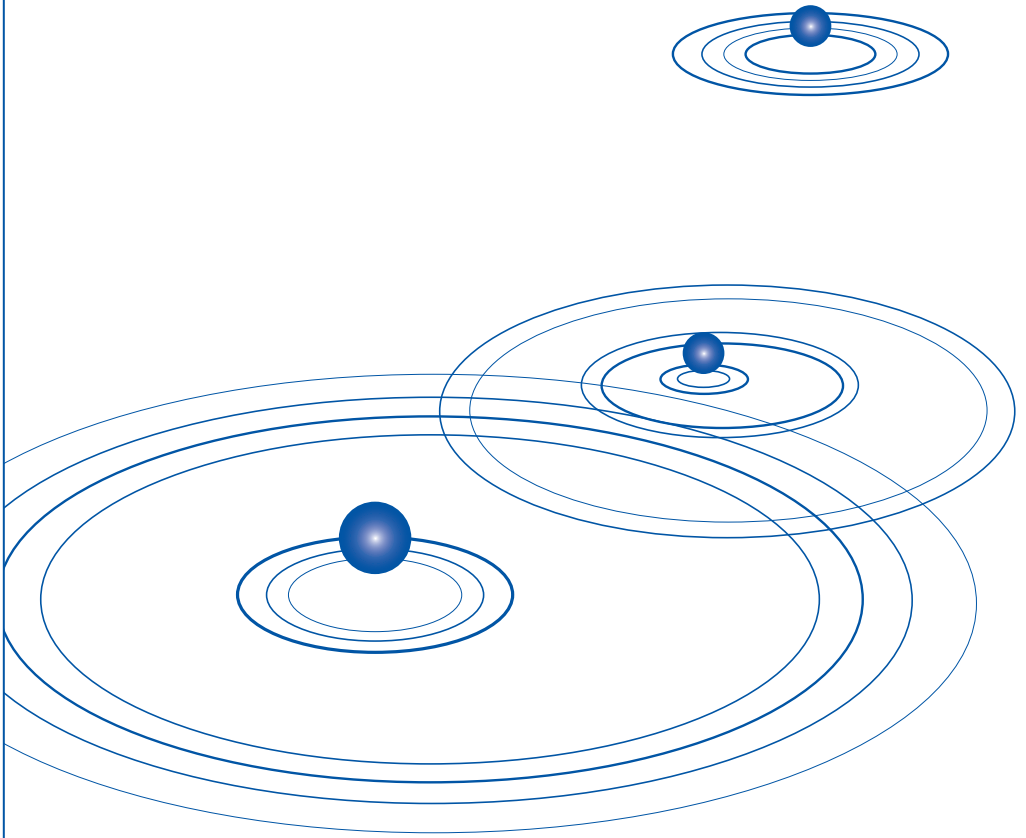
Alzheimer Europe is grateful to **Mazars** for having carried out the audit of the 2005 financial accounts of the organisation free of charge.

Alzheimer Europe gratefully acknowledges a generous donation of the **European Investment Bank**.

2.4.5. Support from the pharmaceutical industry

In line with the new criteria for transparency established by the European Medicines Agency, Alzheimer Europe has slightly changed the presentation of the support it receives from pharmaceutical companies. The following table lists sponsorship and donations received by companies, as well as other payments, such as speakers fees, honoraria and travel costs. Also, the global support received from individual companies is presented in terms of percentages of the overall income of the organisation.

Company	Sponsorship and donations	Other payments	TOTAL	% of AE income
Lundbeck	€ 46,872	€ 4,811	€ 51,683	14.29%
Janssen-Cilag	€ 40,000		€ 40,000	11.06%
Pfizer	€ 37,724	€ 1,506	€ 39,230	10.85%
Roche	€ 990		€ 990	0.27%
GlaxoSmithKline		€ 684	€ 684	0.19%
EFPIA		€ 674	€ 674	0.19%
Drug Information Association		€ 598	€ 598	0.16%
Total	€ 125,586	€ 8,273	€ 133,859	37.02%



*Position paper
on advance directives*

3.1. Executive summary

The present paper constitutes the input of Alzheimer Europe and its member organisations to the ongoing discussions within Europe about advance directives (in the context of Alzheimer's disease and other forms of dementia). It is the result of discussions carried out in a multidisciplinary group, comprising experts in the field of psychiatry, neurology, pharmacology, psychology, law and ethics, in collaboration with the Board of Alzheimer Europe and its member associations.

Alzheimer Europe's position on advance directives was guided by several general principles and was influenced by principles contained in pre-existing European or international documents.

On the basis of these principles and of a review of current literature concerning issues linked to the use of advance directives, Alzheimer Europe has developed the following position with regard to advance directives.

- Alzheimer Europe would like to promote the use of advance directives for decisions covering a wide range of health related issues e.g. treatment, care, welfare, research, the appointment of health care proxies etc.
- Alzheimer Europe supports the concept of health care proxies and encourages governments to legally recognise their role and also to develop the relevant safeguards for their involvement in the decision-making process.
- Alzheimer Europe would like to emphasise the importance of involving doctors and other qualified health care professionals when considering whether/how to draw up an advance directive within the context of advance care planning.
- Due to difficulties in obtaining an appropriate level of precision (which is neither too vague nor too specific to be of practical use), Alzheimer Europe encourages people to write statements of values.
- Alzheimer Europe expects governments to set up appropriate systems for the registration, use and review of advance directives.
- Alzheimer Europe is of the opinion that for an advance directive to be valid, certain generally accepted criteria should be fulfilled, e.g. that the person has the necessary and relevant capacity, is free from undue pressure, has not made a more recent version and has stated wishes that are applicable to the current situation/proposed treatment.
- With regard to debates surrounding the issue of current versus formerly expressed wishes, Alzheimer Europe insists on the importance of always trying to ascertain the wishes of patients even if they have written an advance directive. If the person is fully competent, doctors should not follow instructions/wishes expressed in the advance directive. If the person is not fully competent and there appears to be a conflict between current and former wishes, the person's current wishes and feelings should be considered alongside those expressed in the

advance directive as they represent the person's current mental and emotional state and attitudes.

- Decisions not to comply with valid advance directives should be documented in the patients' medical files and an explanation should be given to significant others, relevant supervisory bodies and health care proxies.
- In order to guarantee equity in the provision of health care and to ensure that people have a real choice, Alzheimer Europe emphasises the need to increase the availability and improve the quality of palliative care services/facilities.
- Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.

3.2. Introduction

Decision-making in the early stages of the disease. Most forms of dementia involve the gradual and irreversible deterioration of cognitive abilities (e.g. memory, language and thinking etc.). An early diagnosis of Alzheimer's disease may enable the person concerned to benefit from medication which treats global symptoms and is most effective in the early to mid stages of the disease. In the early stages, it is still possible for the person with dementia to make decisions concerning their finances, personal welfare, medical treatment and possible participation in research.

Respect for autonomy and human dignity. Alzheimer Europe therefore feels that it is important that people with dementia are given the opportunity to exercise their right to self-determination and is of the opinion that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity.

Use of terms:

- **Advance statement** is a **general term** covering any statement a person may wish to make about future decision-making. This may be a statement of principles, a statement of preferences or dislikes, or refer to a specific decision (e.g. regarding a specific nursing home or doctor). It can be positive, negative or neutral. The term encompasses advance directives.
- **Advance directive** is a **more specific** term relating to particular decisions or types of decisions, particularly regarding medical treatment and health care that may have to be made in the future. Although usually a negative advance directive (also termed an advance refusal), it can also be positive. In some countries, the term is used to refer to a document consisting of two parts:
 - o **instructions/requests** concerning medical treatment and/or health care;
 - o a **proxy form** (sometimes referred to as a **medical power of attorney** or **health care proxy**), which lets a person name someone to make decisions about their medical treatment or health care on their behalf. However, the two possibilities need to be thought about separately. It is possible but not necessary to complete both parts of the document.
- **Living wills.** Advance directives are sometimes referred to as *living wills*.

For the purposes of this document, we will use the term **advance directive** or **advance statement** depending on the context.

Early diagnosis and disclosure. People with dementia have a real opportunity to exercise their right to self-determination in this way with regard to the management of their condition only, if they are aware of that condition at a sufficiently early stage. This underlines the importance of an early diagnosis and disclosure of

the diagnosis to the person with dementia. In addition, people should be provided with information about the implications of the diagnosis and the prognosis. Face-to-face discussions should be backed up by written material.

It is important to inform people about advance directives whilst they still have the necessary capacity to write one, should they eventually decide to do so. Later on in the illness forward planning becomes impossible because of the progressive impairment which is central to dementia. Alzheimer Europe and its member organisations wish to emphasise the importance of this issue.

Legal recognition of advance directives. For an advance directive to serve the purpose for which it was intended, it needs to be legally recognised, readily available when needed and legally effective. Although some governments have recognised the need to clarify the legal status of advance directives and have legislated in this domain, others are lagging well behind.

Alzheimer Europe therefore urges governments and their legislators:

- to legally recognise advance directives,
- to provide guidance on their use and
- to set up a registration system.

Alzheimer Europe and its member organisations also recognise their own role in raising awareness of advance directives.

Advance care planning. Alzheimer Europe would like to put the writing of advance directives in the context of advance care planning in general. For people with dementia, this can be seen as a global approach to future health care and welfare involving reflection, discussion and communication of treatment and care preferences throughout the course of the disease and also at the end of life. Advance care planning may or may not lead to the writing of an advance directive. We would like to stress that no one should be forced or put under any pressure to write an advance directive. If somebody does not want to address such issues and prefers to let others decide on their behalf, their choice should be respected.

Points to consider and guiding principles. Before discussing the scope of advance directives and certain practical and legal issues, we would like to clarify a few points concerning the use of advance directives specifically for people with dementia. Furthermore, we would like to stress the absolute necessity to improve the provision of palliative care. Finally, an outline of some of the guiding principles behind this position paper will be provided.

3.3. Clarification on the use of advance directives in the case of dementia

Advance directives and end-of-life decisions. Advance directives are usually associated with life-threatening illnesses such as cancer or heart disease. They also cover emergency situations where patients have lost consciousness or refer to prolonged states of unconsciousness e.g. persistent vegetative state. In such cases, the provisions contained in the advance directive usually concern end-of-life decisions. Indeed, the concept of the advance directive, which was pioneered by Luis Kutner and others in the late 1960s¹, was to give people the opportunity to express the sentiment that when death is near and unavoidable, dignity and comfort should take precedence over efforts to prolong life and postpone death which are considered unlikely to enhance quality of life in the last moments of a person's life.

Issues concerning advance directives in the case of dementia. The situation is somewhat different in the case of dementia. Depending on the stage at which a person is diagnosed, they may live with the disease from that point on for anything from about 5 to 20 years. During this time, the mental capacity of people with Alzheimer's disease and some other forms of dementia will gradually and progressively deteriorate and this will affect their ability to make decisions. In the early stages, people with dementia can still make some decisions but not others. As the disease progresses, the ability to make decisions will deteriorate although people may still be able to participate in the decision-making process to some extent. Eventually, there may come a time when they will no longer be able to make any decisions. At various times during the illness, situations will most probably arise when health-care decisions must be made. It should therefore be possible for advance directives to cover a long period of time when the person has partial capacity and not be limited to end-of-life decisions. For these reasons, Alzheimer Europe supports the development of advance directives specifically for people with dementia.

Withdrawal or non-application of life-saving or life-sustaining treatment. Although an advance directive may contain wishes linked to the withdrawal or non-application of life-saving or life-sustaining treatment, Alzheimer Europe would like to emphasise that the use of advance directives to request assisted suicide or active voluntary euthanasia raises important ethical issues that are beyond the scope of this document and which may be particularly complicated in the case of dementia. A major difference between active euthanasia and the withdrawal of life-sustaining treatment is that the aim of the former is to cause death whereas the aim of the latter is to stop a treatment which no longer has any chance of being of benefit to the patient's condition and/or may be causing undesirable side effects or risks to the patient. Furthermore, it should be noted that in the vast majority of countries, a request in an advance directive for active euthanasia would not be considered valid.

¹ Maude, B. et al. (2004), Advance Medical Directives (living will, power of attorney and health care proxy) (Internet article: retrieved 31/3/2005 –

Statements concerning the refusal of treatment and the prolongation of life.

Whereas some people are concerned about the overuse of medical treatment (i.e. when there is no hope of improvement or recovery), others fear that they will *not* be given the treatment they need at a time when they are unable to speak for themselves. Alzheimer Europe would like to ensure that advance directives in the case of dementia are not focused only on refusal of treatment. A person must be equally supported and encouraged to express a wish to receive whatever form of appropriate medical treatment and/or care is available to prolong their life.

3.4. Guiding principles

Recommendations on the legal rights and protection of adults with incapacity.

At its Annual General Meeting in Munich on 15 October 2000, Alzheimer Europe adopted recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia. This included a section on bioethical issues. These recommendations obviously need to guide any response of the organisation regarding advance directives.

- Every person diagnosed with dementia should have the right to be informed of the diagnosis as soon as possible. (§6)
- The autonomy of the person with dementia should be respected at all times. As long as s/he maintains the ability to make decisions concerning his/her life, such decisions should be sought, respected and given priority over any proxy decision maker. Indeed, irrespective of the level of capacity of the person with dementia, his/her interests must always come first. There should always be an assumption in favour of capacity and of involvement and choice. (§7)
- People with dementia should be informed about the advantages of writing an advance directive and appointing a guardian/lawful representative (preferably, but not necessarily together). The necessary structures or facilities should be put into place by governments to ensure that this is possible. (§8)
- Alzheimer Europe has written an advance directive which is available in all the official languages of the European Union ². We recommend, however, that people seek guidance from a doctor in order to ensure that the advance directive is clear and in line with modern practice. It is also necessary to ensure that the person writing the advance directive is aware of the consequences of his/her choices and that s/he has sufficient capacity to write such a document. In order to ensure that advance directives are respected, we recommend that legal representatives and medical professionals be obliged to take into consideration wishes expressed in such documents. Failure to do so should require valid justification. Furthermore, we recommend the setting up of a national register of advance directives, the creation of cooperation between countries and the inclusion of details about the advance directive in existing computerised medical files (subject to respect for national laws on data protection). (§9)
- It is important to ensure that at all stages, as well as when the person with dementia approaches the end of his/her life, his/her rights are respected and his/her dignity maintained. Certain decisions which need to be taken at the end of a person's life cannot be easily taken by someone else e.g. concerning resuscitation, life-prolonging treatment, the use of certain forms of harsh or invasive treatment or painkillers and the provision of palliative care. Such decisions should therefore ideally be noted in an advance directive. This should be clearly recorded in the person's medical file. (§19)

² The advance directive is available in the official languages of the European Union before enlargement i.e. Danish, Dutch, English, Finnish, French, German, Greek, Italian, Portuguese, Spanish and Swedish.

General principles. The following general principles should also be borne in mind:

- A person with dementia remains a full person regardless of the severity of the disease or the degree of cognitive decline. Alzheimer Europe does not adhere to any theory which denies people with dementia “personhood”, i.e. which implies or states that a person lacking capacity is in some way not a person. The person with dementia should always be treated with respect and consideration.
- The autonomy of the person with dementia should be respected at all times, although other principles such as beneficence, justice and non-maleficence should also be borne in mind and balanced with respect for the person’s right to self-determination.
- Capacity is not an all-or-none phenomenon. We believe that it should always be considered and assessed in relation to specific decisions or categories of decision (the person is deemed capable or incapable of decision A or decision B, etc.). In addition, capacity can be partial. In dementia a person does not usually suddenly lose the capacity to decide about something, but gradually loses it. In many forms of dementia, furthermore, a person’s capacity to make certain decisions may fluctuate with time. For all these reasons, capacity should be assessed on a case-by-case basis, in relation to specific areas of decision-making, and taking into account the overall condition of the person.
- It must be recognised that many legal provisions on proxy decision-making, whether by guardians, courts or other means, have traditionally depended on an all-or-none view of capacity, though new laws in a number of countries are attempting to provide a more flexible and graduated approach to incapacity.
- Alzheimer Europe recognises the need to include people with dementia in the early to late stages of the disease in research, albeit with the necessary prior and current consent, and the existence of adequate safeguards. It is important to find the right balance between the protection of people with dementia and their right to decide whether to participate in such research (please see paragraphs 31 to 33 for more information).

Other principles from pre-existing European or international documents. In drafting this position paper on advance directives, the above principles as well as the Declaration on the Promotion of Patients’ Rights in Europe (WHO, 1994), the Council of Europe’s Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo, 4.IV.1997) and the Council of Europe’s Recommendation no. R (99) 4 of the Committee of Ministers to Member States on principles concerning the legal protection of incapable adults have been taken into account.

3.5. *The scope of advance directives*

3.5.1. **What should not be covered in an advance directive**

Examples of areas covered by an advance directive. Alzheimer Europe is in favour of advance directives being used to cover consent to treatment, refusal of treatment, resuscitation, palliative care, end-of-life care, requests concerning general care, decisions relating to residential and other types of care, financial decisions linked to the provision of care and statements about preferences (including psychological, spiritual and religious needs, relationships and lifestyle).

Although advance directives are usually not applicable to interventions on the body after death, making an advance directive is a good opportunity for a person to consider issues such as possible donation of organs and/or tissue for transplantation and/or research after death and to set out their views in writing.

Terminology. The terms “treatment”, “care” and “health care” should be understood as referring to every aspect of treatment and care, not merely the medical aspects and not merely end-of-life treatment or care. For example, a person might wish to attend a day-care centre, to have a bath instead of a shower, not to have breakfast, to go for a walk once a day etc. These kinds of wishes can also be included in an advance directive.

Other uses for an advance directive. We are also in favour of people using advance directives to indicate their wishes concerning the appointment of a health care proxy as well as their participation in research (please refer to the following two sections on health care proxies and research).

Advance directives and place of treatment or care. Advance directives should not be restricted to hospital care but should cover medical treatment irrespective of where it is provided, e.g. at home, in nursing homes, in hospices, etc.

Proposed restrictions for the use of advance directives. Alzheimer Europe is opposed to the use of advance directives for requests for clinically inappropriate health care or treatment, the refusal of basic care (washing and mouth care), the refusal of appropriate pain relief and the refusal of the offer of food and drink by mouth. It should, nevertheless, be possible to refuse artificial feeding, including gastrostomy, intravenous feeding and hydration and tube feeding, and to refuse over-sedation, or to tolerate some discomfort in order to be able to maintain awareness and/or retain some contact with family and friends.

3.5.2. Health care proxies

Appointment of health care proxies. As stated above, it should be possible to use an advance directive to appoint a health care proxy with the power to make decisions on behalf of the person with dementia when the latter is no longer able to do so. Health care proxies are of two main types. Here we are referring to proxies appointed by the person with dementia while still mentally capable of doing so. Other terms in use include health care attorney and welfare attorney. Health care proxies may also be formal or court appointees, appointed when the person is no longer able to make competent decisions about his or her own health care, or appoint a proxy. Other terms include health care guardian or welfare guardian. In different legislations, there are various relationships between these proxy powers and others, such as those relating to financial affairs and property.

Difference between health care proxy and legal guardian. Health care proxies usually differ from legal guardians appointed to make financial or general decisions on behalf of a person as their powers are limited to health care decisions. In some countries, it is possible for a person to appoint a welfare attorney or guardian, who can also make health care decisions among others, or it may be possible to have a court appointed health care guardian.

With or without written statement of wishes. Alzheimer Europe supports the concept of health care proxies, either without any specific written guidance on the person's wishes or in combination with a written statement covering certain health care decisions.

Advantage of having a health care proxy in addition to an advance directive. We would encourage people making advance directives to consider the option of also appointing a proxy. Advance directives are often limited to specific circumstances or kinds of treatment. It can therefore be beneficial to have a health care proxy who has the power to make some or all decisions related to health care, particularly in situations not covered by the advance directive or in cases where the wishes contained in the advance directive are ambiguous or difficult to interpret, e.g. due to recent medical advances or unforeseen health complications.

Importance of discussing wishes with health care proxy. A health care proxy should be aware of the preferences, values, beliefs and wishes of the person they are representing. For this reason, Alzheimer Europe, as well as being in favour of proxy measures in general, recognises the specific value of health care proxies in enhancing the autonomy of people with dementia in the domain of health care. We encourage people writing advance directives to discuss health care issues with the proxy decision maker and if appropriate to provide them with a statement of values (please see paragraphs 41 to 43 for details).

Formalities linked to the appointment of health care proxy. Details of the chosen health care proxy should be included in the advance directive e.g. name, address, phone number, email address etc. The health care proxy should have agreed to act as proxy and should sign the advance directive to show that they are in agreement and have read the content. They should also receive a copy of it. The extent of the powers granted to the health care proxy should be recorded in the advance directive.

Need for safeguards in legislation. The concern that health care proxies might make decisions based on their own views, wishes or prejudices, as opposed to the prior wishes of the patient, should be covered by safeguards in legislation, e.g. a complaints procedure or requirement to record decisions.

3.5.3. Research

Advance directives covering participation in research. Alzheimer Europe encourages the use of advance directives to cover wishes to participate in research (or not participate as the case may be). We feel that allowing consent in this way respects people's right to self-determination and their possible desire to do something constructive which may eventually benefit others with a similar medical condition.

Safeguards for the use of advance directives for participation in research. Whilst Alzheimer Europe accepts the provisions of the Convention on Human Rights and Biomedicine³ concerning therapeutic and non-therapeutic research in cases where a person with incapacity has not consented, we feel that consent to research in an advance directive should be accepted as a valid expression of a person's wish to participate in such research provided that:

- the person had the capacity to make such a decision (which may involve greater capacity than for other health care decisions);
- the person was willing to accept the kind of risks and/or burden involved. An indication should be given in the advance directive of the level of risk/burden that would be acceptable as the actual nature of the future research is unlikely to be known when consent is given in the advance directive;
- the person does not show any sign of unwillingness to participate at the start of the research, e.g. refusing to take medication when offered, obvious distress when interviewed, etc.;
- the person is withdrawn from the research if they display signs of unwillingness to continue participating and/or experience distress as a result of the research;
- the research has been approved by an ethics committee with sufficient expertise in dementia issues. Alzheimer Europe strongly recommends that patient advocacy groups be consulted in this matter;

³ The Committee of Ministers adopted an Additional Protocol to the Convention on Human Rights and Biomedicine on Biomedical Research. It was opened for signature on 25 January 2005. Details of the Additional Protocol can be found at: www.coe.int/bioethics

- the wellbeing of the research participants is appropriately monitored by an independent controller or control system;
- the health care proxy (if one has been appointed) is involved in determining whether the research that is eventually proposed is in line with the wishes expressed in the advance directive.

Caution using “research advance directives” in residential/semi-residential settings. Extreme caution should be exercised by researchers, ethics committees and external controllers in the case of people with dementia who consented in advance to participate in research and are currently living in an institutionalised or semi-institutionalised setting as they are in a situation of additional dependency on others (perhaps including those responsible for the research) which may affect their genuine willingness to participate. They may, for example, fear reprisals or want to avoid letting people down.

3.6. *Practical issues linked to the writing and interpretation of advance directives*

3.6.1. **The importance of involving doctors and other qualified health care professionals**

The role of doctors and other health care professionals. Doctors and other health care professionals have an important role to play in informing patients about the possibility of making an advance directive and in explaining the nature and possible consequences of various treatment options. They can also serve as witnesses that the person producing the document has the necessary capacity to do so. However, some feel uneasy about approaching patients about advance directives, fearing that this might give a message that the patient's condition is hopeless or that the doctor is giving up on them. Doctors and qualified health care professionals should therefore be provided with guidance on how to deal with this issue.

The use of vague or specific terminology. When making an advance directive, it is important to pay attention to how it is worded, as this will effect its future interpretation. Whereas detailed and specific advance directives should leave medical staff in no doubt as to what a patient wants, such documents may actually be so specific that they are unlikely ever to fully correspond to a particular situation. On the other hand, documents containing vague terminology such as "heroic measures", "artificial means" or "terminal illness" may be difficult for doctors to interpret and could lead to a different interpretation to that intended. For these reasons, Alzheimer Europe feels that it is very important to discuss the content and terminology used in the advance directive with healthcare professionals.

The necessity for and cost of consultation. Adequate opportunity for discussion between patients and healthcare professionals may have to be built into the health care budget and doctors and qualified health care professionals should consequently be able to charge for this time. This cost should be borne by health insurances or whatever governmental funding arrangement pertains, and not directly by patients. Alzheimer Europe believes that writing an advance directive should be straightforward and a procedure which is free for patients.

3.6.2. **The form and style of the advance directive**

Writing an advance directive adapted to one's own needs. Alzheimer Europe recognises that people have different reasons for making advance directives and that they come from different backgrounds (e.g. cultural, religious, educational etc.). Consequently, we are in favour of a flexible system which allows people to make advance directives that correspond to their particular needs and wishes. People should be permitted to draft their own advance directive, as available forms do not suit everybody's needs. Different examples exist on the Internet and are available

from various organisations. However, as stated above, it would be wise to consult a doctor or other qualified health care professional when drafting an advance directive.

Specific reference to dementia in the advance directive. Alzheimer Europe favours the use of a form which specifically refers to dementia, as decisions concerning future care in the case of dementia are likely to differ from those made by people with other conditions. As dementia may exist alongside other medical conditions, it may be useful to choose a form which allows for treatment choices in relation to different scenarios e.g. dementia, dementia with terminal illness, dementia and coma etc.

Focussing on quality of life or treatment options. Alzheimer Europe accepts that some people might want to focus on outcomes (e.g. resulting quality of life, burden of the treatment, likelihood of a positive or negative prognosis) rather than on specific forms of treatment. This puts the onus on medical staff to decide which treatment corresponds best to the patient's wishes and to ensure that they have the necessary information, and have consulted with significant others⁴, to enable them to judge, if necessary, what constitutes quality of life for the person concerned. For this reason, we recommend that people who prefer to focus on outcomes consider the possible advantage of writing a "statement of values" (please see paragraphs 41 to 43 for details).

Possibility of including a trial option. Finally, we would like to draw attention to the possibility of including a trial option whereby a particular treatment is applied for a sufficient period of time to assess the benefit and burdens (or lack of them) of the treatment for the patient. This enables patients to benefit from potentially useful treatment without running the risk of the treatment being continued if it turns out to be futile, ineffective or unduly burdensome.

3.6.3. Statement of values

Advantage of writing a statement of values. In view of the fact that it is difficult to ensure that an advance directive is sufficiently precise yet not too precise that it cannot be accurately interpreted in a given context, Alzheimer Europe encourages the use of "statements of values". A statement of values is a document which contains information about what is important and meaningful in life for the person writing it. It consists of a series of statements or answers to questions. Statements of values may help prevent third parties from making assumptions about a person's quality of life based on their own beliefs and values.

How statements of values differ from advance directives. Unlike advance directives, statements of values are not phrased in legal terminology and are not limited to medical treatment or care options. Statements of values are generally fairly lengthy

⁴ For example relatives, a partner, a close friend, etc.

and require detailed information. They provide valuable information about a person's background, beliefs, preferences and values which may facilitate the interpretation of advance directives, particularly in cases where the wishes stated do not fully correspond to the current situation. However, as they do tend to be very detailed documents and as preferences may change over the course of the disease, it is important to make sure that they are regularly updated for as long as this is possible.

How statements of values can be used. A statement of values, although generally clear in its intent, is not directive in terms of particular actions. For this reason, it may be beneficial given the uncertainties that often surround clinical decisions. We therefore recommend the use of statements of values as a supplement to advance directives or on their own.

3.6.4. Registration, use and review

The need for a registration and retrieval system. Whilst it is important that governments grant legal recognition of advance directives, their efficacy may be limited if there is no effective registration process and system of retrieval at the appropriate time. We as an organisation expect governments to set up registration procedures which fit in with their national procedures. Such procedures should guarantee confidentiality and not be excessively bureaucratic or over-formal. The registration of advance directives would contribute towards legitimising their use.

Informing people about advance directives. Governments should look into the possibility of setting up a system to routinely inform patients of their right to make an advance directive and a system of registration and retrieval in order to ensure that doctors are aware of the existence of a person's advance directive and have access to it when needed. However, it is important to bear in mind that people have different levels of education and financial resources. They may also be seriously ill and have restricted mobility. Consequently, the registration system should be simple, straightforward and cost-free for the person writing the advance directive. In some countries, it may be necessary to register the advance directive with a notary.

Computerised recording. The existence of an advance directive should be included in any computerised medical records (in accordance with the requirements of data protection laws). Alzheimer Europe would welcome cooperation between countries on this issue.

Keeping and distributing copies of the advance directive. Whether there is a registration procedure or not, a copy of the advance directive should be kept by the author for reference and stored in a place where it can be found when needed. A copy should also be given or made available to the doctor responsible for the person's care⁵ and to the specialist medical team if the person is receiving hospital care. The

⁵ By this term, we mean a doctor whom the patient would consult in the first instance for any medical problem. This doctor would then, if necessary, refer the patient to a specialist. Such doctors are called general practitioners in the United Kingdom. In certain other countries, they are called family doctors. In some countries, this concept does not exist as health care is organised differently.

health care proxy or representative, if one has been appointed, and other people likely to be involved in future care should have a copy of the directive. It might also be helpful for people to carry a card (similar to donor cards) indicating that they have made an advance directive.

Updating the advance directive. As long as the author has the necessary capacity, the advance directive should be regularly updated (at least every 5 years). If no or minimal changes are decided, the document can be newly signed and dated. If a new document is required, older versions should be destroyed or marked as void and updated copies given to the relevant people. It should be borne in mind that the validity of older documents may in some cases be questioned due to recent medical advances.

Withdrawal or amendment of the advance directive. It should of course be possible to withdraw or amend an advance directive at any time provided that the person with dementia has the necessary capacity to do so. If a person has incapacity in many/most areas but firmly and clearly expresses a wish to revoke or amend an advance directive, doctors should assess that person's capacity as it specifically relates to the current issue and consider revoking or amending the advance directive. The overall process should be witnessed by an independent person and recorded in the person's medical file.

Disposing of old copies of advance directives. If an advance directive is withdrawn or amended, all copies of the former advance directive should be destroyed or marked as void.

Witnesses and the certification of capacity. The document may need to be witnessed in accordance with the usual legal practices, but in addition, there may need to be certification of capacity (if that is not assumed in law), by the doctor or another relevant professional.

In countries where witnesses are not legally required, the use of witnesses may help to strengthen the directive against future challenges to its validity. This may be particularly useful if the person making the directive is aware that significant others are likely to disagree with the wishes expressed within it.

3.6.5. Criteria for validity and applicability

Validity criteria. Alzheimer Europe is of the opinion that for an advance directive to be valid, certain criteria should be fulfilled.

- The person writing the advance directive must have the necessary and relevant capacity to do so. This means that the person should be capable of understanding the nature, purpose and likely consequences of possible treatment options to

which they are consenting or refusing and the likely consequences of not receiving the treatment.

- When writing the advance directive, the author should be free from undue influence or pressure from other people. The author of the advance directive should also bear in mind the possible effects of pain, depression, drugs or medication when choosing treatment options as these may influence any decisions made.
- For an advance directive to be considered valid, it should be the most recent version made. Any wishes contained in an advance directive, which was made before the most recent version, should be considered invalid.

Wishes contained in an advance directive should be applicable to the circumstances and proposed treatment or care at the time the advance directive comes into force.

Validity of advance directives in hospital and prison settings. Advance directives, which fulfil the above criteria for validity, should be considered valid even if the author has been involuntarily placed in hospital or is serving a prison sentence. In the case of compulsory treatment orders, the advance directive should be advisory.

Advance directives which do not correspond exactly to the current situation. In the case of wishes which do not correspond exactly to the situation described in the advance directive, doctors should nevertheless act in the general spirit of the statement even though it may not be considered legally binding in the particular circumstances.

Duration of validity of advance directives. As dementia is a disease which can last for a number of years, during which time a person's mental capacity gradually declines, Alzheimer Europe is not in favour of setting a limit on the duration of validity of advance directives.

Using existing documents as guidance. A health care proxy must be guided by any currently valid advance directive or other advance statement in coming to the necessary treatment decisions.

Importance of always trying to assess current views. Doctors should only follow the instructions/wishes contained in an advance directive if the person who wrote it lacks the capacity to give or refuse consent to a particular treatment at the time the treatment is needed. The existence of an advance directive should not prevent doctors from trying to assess the current views of a person with dementia.

Procedure in case of difficulty interpreting the advance directive. Where advance directives are legally binding, doctors should be authorised to follow instructions or wishes contained in an advance directive without having to consult the health care proxy if there is no doubt about the meaning or validity of the document. In case of

doubt about how to interpret the advance directive, the health care proxy, relatives and significant others, as well as the multi-disciplinary team, should be consulted.

3.6.6. Issues linked to the interpretation of advance directives

Discussion with others and avoidance of conflict. When writing the advance directive, people should take their time and if possible discuss various issues with family/friends, and particularly those who are likely to be present when the advance directive is used. It would also be advisable to give a copy of the advance directive to family and close friends who could help ensure that it is kept up to date. This may reduce the likelihood of later conflict between family members/friends and/or medical staff. It would also be beneficial for doctors to receive training in conflict management skills, and for relevant conflict resolutions procedures to be available.

Discrepancy between past and present wishes. Sometimes, there may seem to be a discrepancy between past and present wishes. For example, a person who consented to a certain form of treatment in advance may refuse it when the time comes or someone who gave an advance refusal of antibiotics may risk dying from an untreated condition even though they are showing clear signs of enjoying life and wanting to live. There is currently an ethical debate about the extent to which a person in an advanced stage of dementia is the same person (i.e. has the same personal identity) as the one who originally wrote the advance directive. Please refer to Alzheimer Europe's accompanying report for further details and a fuller discussion about this issue.

Full personhood of people with dementia. Whilst Alzheimer Europe encourages people to make their own minds up about such issues, we strongly object to any theory which calls into question the full personhood of people with dementia at any stage of the disease.

Respecting current wishes. Alzheimer Europe believes that if advance directives are to be taken seriously, the wishes contained in such documents should generally be respected. There are, however, two exceptions:

- Current competently expressed wishes cannot be overridden, and
- Nobody should be subjected to medical treatment or suffer from a lack of medical treatment on the basis of a prior decision when it is obvious that they are currently displaying clear and unambiguous signs of wishes to the contrary.

In such cases, staff should be able to act humanely in accordance with current professional standards and taking into consideration the context and the doctor-patient relationship and on the basis of good communication between all concerned, including the person with dementia. The advance directive should be regarded as part of this communication.

Some may find the concepts of beneficence and non-maleficence of benefit or useful in this context.

Responding to current wishes. The degree to which any current ascertainable wishes and feelings should be respected will depend on a careful assessment of their competence and validity. Clearly, where they are judged to be fully competent and valid, any advance directive is not applicable. Even where they are relatively incoherent and deemed incompetent from a purely legal standpoint, they retain some validity as an expression of the person's current mental and emotional state and attitudes. In line with the principle of continuing personhood, these wishes and feelings should be considered alongside those expressed in the advance directive. The doctor in charge of treatment should consult with the health care proxy (if one has been appointed) and when necessary with significant others in order to determine the extent to which the current ascertained wishes and feelings of the person should modify or even override the treatment decisions which would have been made based solely on the advance directive. If there is disagreement between the doctor, the health care proxy and/or significant others as to whether the advance directive should be considered binding, or if the doctor and the significant others agree that the advance directive should be overridden, then the issue should be subject to some form of judicial or other independent review.

When requests seem to contradict “best interests”. A problem may arise when requests made in an advance directive seem to go against what the doctor feels is best for the patient, i.e. which would do them the most good and the least harm. Alzheimer Europe does not believe that doctors should ever be obliged or pressurised to act in a way that runs counter to their professional or personal beliefs and values.

When the values or beliefs of doctors differ from those of patients. On the other hand, the beliefs and values of individual doctors, e.g. concerning life-prolonging treatment and the sanctity of life, should not be imposed on patients with different values and beliefs, or for whom they have no meaning.

Training and counselling for doctors. Alzheimer Europe recommends that doctors should receive training or counselling in questions related to advance directives such as their legal status, the consequences of respect and of non-respect, and ethical or personal dilemmas.

3.7. *Legal issues*

Importance of advance directives recognised in Europe. Although advance directives are not legally recognised in all countries in Europe, there are a few documents on a European level which refer to patients' rights to make advance decisions about health care issues and which may have been influential in guiding national laws in this domain.

Governments urged to legally recognise advance directives.

Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.

Protection from criminal and civil liability when respecting advance directives. If advance directives are to become legally binding and include wishes to forego life-saving treatment, life-sustaining treatment and the relentless pursuit of treatment which does not benefit the patient, as well as the administration of powerful or large doses of drugs to alleviate pain which may have the double effect of hastening death, doctors who comply with such advance directives in good faith should be protected from criminal and civil liability.

Personal, moral or ethical reasons not to comply with an advance directive. In non-emergency situations, doctors should be liable in civil or criminal law for failing to comply with a valid advance directive. If, for personal, moral or ethical reasons, the doctor does not comply, he/she should be obliged to transfer the care of the patient concerned to another doctor who is willing to comply with the advance directive. If this is not possible, the doctor should be obliged to obey the law and comply with a valid binding advance directive.

Obligation to comply with advance directive in emergency situations. If doctors have been informed of a patient's wishes through a valid advance directive prior to emergency treatment, they should of course be obliged to comply during emergency treatment. If, for personal, moral or ethical reasons, a doctor does not wish to comply with an advance directive and cannot, due to the urgent need for a decision regarding treatment, refer the patient to a colleague, he/she should be obliged to comply with a valid advance directive.

Lack of awareness of the existence of an advance directive. Doctors should not be liable in civil or criminal law for failing to comply with a valid advance directive if they are unaware of its existence and have no reason to suspect that one exists or cannot obtain a copy in time (e.g. in the case of emergency treatment).

Procedure to follow in the case of non-respect of an advance directive. Failure to respect wishes contained in an advance directive (whether or not it is legally binding), for example because it is not considered to be valid or to apply to the current circumstances, should be documented in the patient's medical file along with an explanation for this failure. An explanation should also be provided to significant others and to any relevant supervisory body. Health care proxies should be informed of the reason so that they can challenge the decision, should they wish to do so.

Intentional concealment or destruction of valid advance directive. Anyone who intentionally conceals or destroys another person's currently valid advance directive (during that person's lifetime) should be guilty of an offence.

The need for a specific reference in legislation to cover people with dementia. Alzheimer Europe believes that existing legislation on advance directives which limits their validity to cases where a person is suffering from a terminal illness should be amended to specifically include people suffering from dementia who lack the capacity to make health care decisions, for example by including incurable and progressive conditions within the scope of the legislation.

Legal recognition of health care proxy's right to make decisions. We believe that decisions taken by a health care proxy, recognised by national law, should be respected, and that refusals of treatment by health care proxies should be legally binding except in exceptional circumstances. In such cases, the reason for failing to respect a proxy's decision should be documented and explained to the health care proxy and any relevant supervisory body.

3.8. End-of-life issues and the availability of palliative care

Possible inequalities concerning access to treatment and care. People do not all have the same level of access to medical treatment and palliative care e.g. due to insurance cover, marginalisation, availability of facilities/equipment or waiting lists. With regard to people with dementia and medical treatment/care, there is a risk that in the absence of formerly expressed wishes, their wellbeing may be further jeopardised by other considerations and factors.

Limitations based on availability and appropriateness of treatment and care. However, it must also be emphasised that a request for certain treatment or care cannot oblige doctors to provide it as they are limited to providing what is available and considered appropriate for the patient's medical condition in the light of current medical knowledge and practice.

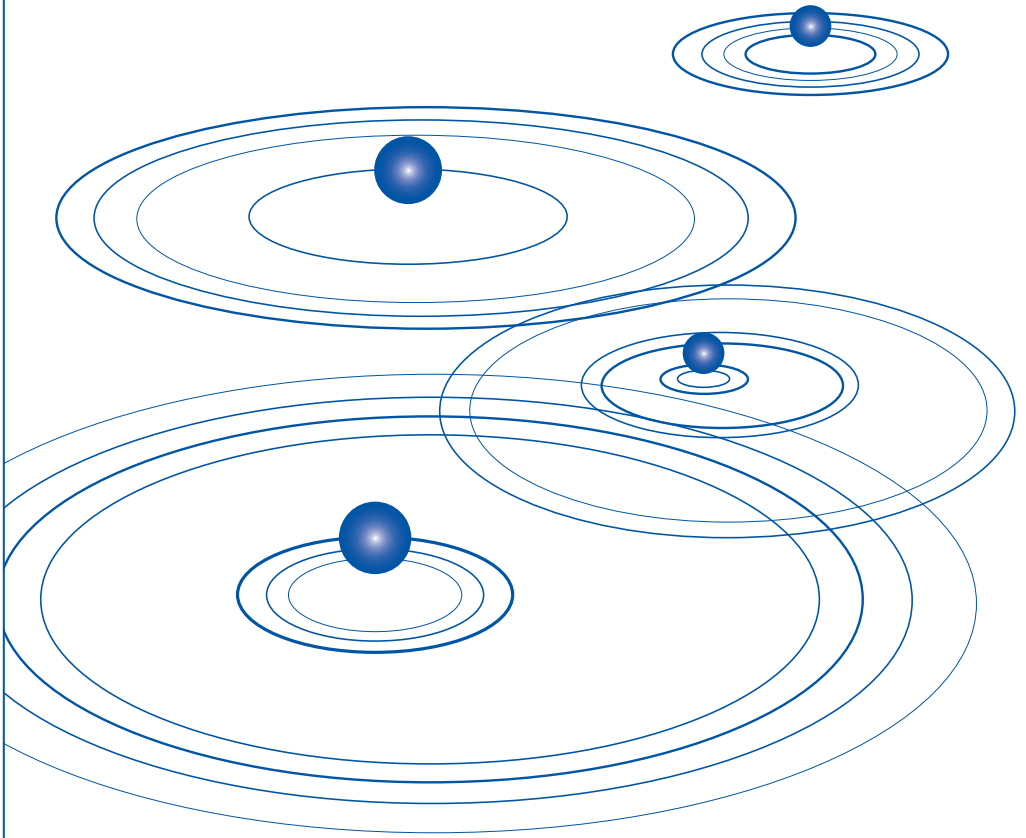
The risk of economic factors affecting end-of-life decisions. For economic reasons and due to the lack of available palliative care in certain areas, some people may see the refusal of life-saving or life-sustaining treatment as the only option available to them. Alzheimer Europe believes that good quality palliative care should always be an option for people in the terminal stages of dementia.

Ensuring that people with dementia are treated as valued and respected members of society. When combined with constant messages about problems linked to the ageing population (particularly with regard to fears about insufficient funds to cover health care), some people may see options in advance directives to refuse life-sustaining and life-saving treatment as a message from society that some lives are less worthy of being saved or prolonged than others. Consequently, they may feel that it would be selfish to ask for all possible measures to be taken to prolong or save their own lives. Alzheimer Europe recognises its role in increasing awareness of dementia as a disease, reducing stigma attached to it, protecting the dignity of people with dementia of all ages and presenting a positive image of people with dementia within the wider community.

Requests for palliative care may reveal inadequate provision. In some countries, an increase in the number of people making specific requests regarding end-of-life treatment is likely to reveal an inadequate provision of palliative care and consequently the necessity to improve the availability of such services and facilities.

Steps must be taken to ensure that people with dementia have a real choice. Alzheimer Europe urges governments to increase the availability and improve the quality of palliative care services/facilities in order to guarantee equity in the provision of health care and to ensure that people writing advance directives actually have a real choice.





*Position paper on
anti-dementia drugs*

4.1. Executive Summary

The present paper constitutes the response of Alzheimer Europe to the preliminary recommendations of the National Institute of Clinical Excellence which would in the future prevent the prescription of existing treatments for people diagnosed with Alzheimer's disease under the National Health Systems in the United Kingdom.

The following position and recommendations were adopted as a response to the NICE preliminary recommendations, but do equally apply to other attempts of regulators or governments to impose further barriers to the access to anti-dementia drugs.

Alzheimer Europe strongly disagrees with the NICE recommendations which would disbar tens of thousands of people from the only available treatment for their condition.

- As reiterated by the NICE appraisal, enough clinical evidence exists to support the use of anti-dementia drugs since clinical trials have shown them to be effective not only in improving memory, but also for beneficial effects on behaviour and activities of daily living.
- This clinical data on the effectiveness of anti-dementia drugs is supported by testimonies of great numbers of people with dementia and their carers.
- Cost-effectiveness models used by the National Institute of Clinical Excellence fail to duly take into account effects on quality of life of carers of people with Alzheimer's disease. Similarly, cost models for care used by the National Institute of Clinical Excellence do not take into account the optimum care that people should receive but are rather based on actual care provided which is often inadequate and of low quality.
- The existence of anti-dementia drugs has contributed to the development of dementia care through an expansion of memory clinics and other specialised services offering early diagnosis, advice and support for people with dementia and their carers.
- The discontinued prescription of anti-dementia drugs would take away one of the main reasons for people coming forward for an early diagnosis of their condition who would therefore no longer benefit from other significant advantages of an early diagnosis.
- The NICE recommendations would discriminate against a significant proportion of the population who already suffers from stigma and ageist prejudices.
- European citizens should have equal rights to protection and access to health care regardless of their country of residence. The NICE recommendations would disbar British people with Alzheimer's disease from access to treatment options available and reimbursed in the other Member States of the European Union.

Alzheimer Europe is therefore convinced that governments and regulators should not further restrict the access to anti-dementia drugs. Treatment should be offered as one part of a care package taking into account the various needs of people with dementia and their carers and anti-dementia drugs should be made available under national reimbursement systems for people with Alzheimer's disease in all Member States of the European Union. Doctors should be encouraged to discuss the likely benefits and side effects with people with Alzheimer's disease and their carers in a realistic way without raising false hopes.

4.2. Introduction

On 28 February, NICE, the National Institute of Clinical Excellence for England and Wales, published the following preliminary recommendations on the use of drugs in Alzheimer's disease:

- “1.1. Donepezil, rivastigmine and galantamine are not recommended for use in the treatment of mild to moderate Alzheimer's disease (AD).
- 1.2. Memantine is not recommended for the treatment of moderately severe to severe AD, except as part of ongoing or new clinical studies that are designed to generate robust and relevant data on long-term outcomes, disease progression, quality of life and costs.
- 1.3. People currently receiving donepezil, rivastigmine, galantamine and memantine, whether as routine therapy or as part of a clinical trial, may be continued on therapy (including at the conclusion of a clinical trial) until it is considered appropriate to stop.”

NICE welcomes contributions to its preliminary recommendations and the present position paper constitutes the response of Alzheimer Europe to the consultation process.

Furthermore, Alzheimer Europe asked other European organisations with an interest in dementia and members of its Expert Advisory Panel for their endorsement of the views outlined by the organisation.

4.3. *Alzheimer Europe position on anti-dementia drugs*

Below, Alzheimer Europe outlines its views on the existing treatment options for people with Alzheimer's disease which support their continued use.

4.3.1. The efficacy of anti-dementia drugs is supported by clinical evidence

There is a large body of published scientific data on the clinical effectiveness of the four drugs available for the treatment of Alzheimer's disease. These drugs have been shown to have significant, measurable and positive effects for people with dementia.

In particular, reviews carried out by the Cochrane collaboration confirm this efficacy:

- For donepezil (Aricept), the Cochrane review finds that "Clinical efficacy is confirmed"
- For galantamine (Reminyl), the Cochrane review "shows consistent positive effects for galantamine".
- For rivastigmine (Exelon), the Cochrane review states that it "appears to be beneficial for people with mild to moderate Alzheimer's disease".
- For memantine (Ebixa), the Cochrane review concludes that "there is a beneficial effect [...] for patients with [...] Alzheimer's disease".

Existing guidelines of some professional organisations, such as the American Academy of Neurology therefore recommend that "Cholinesterase inhibitors should be considered in patients with mild to moderate AD" as a standard in its practice guideline .

4.3.2. The efficacy of anti-dementia drugs is supported by consumer evidence

The effectiveness of anti-dementia drugs is supported by testimonies and reports by carers collected by a number of carers' associations.

In particular, two surveys carried out by the Alzheimer's Society showed that between 73% to 76% of respondents responded positively to the question: "When taking everything into consideration, do you feel that the drug treatment you have received worked?"

Asked in an open question about the benefits of treatment, the respondents cited amongst other things the following: Slowing or stabilisation of illness, Person with Alzheimer's disease is happier, brighter, more aware or more active, Improvement or help with memory loss, Less aggression, Increase in independence, Improved conversation, speech, Less confusion, Better quality of life, Increase in confidence.

4.3.3. Cost-effectiveness models are inadequate for neuro-degenerative diseases such as Alzheimer's disease

It is recognised that the cost of dementia is high in terms of both public and private resources, yet the real cost to society of neuro-degenerative diseases is more difficult to assess. A recent comparison of socio-economic studies of brain diseases thus found that "The cost of care for patients with dementia can be measured by collection of empirical data. The cost due to dementia, however, cannot be measured directly":

Similarly, the Alzheimer's Society warns against using traditional socio-economic evaluations, since "conventional pharmacoeconomic evaluations cannot be applied to drug therapies for dementia. [...] many of the benefits that a treatment may bring affect indirect costs through reduced carer burden and an increase in a person's quality of life. These are outcomes that are not easily amenable to cost-benefit analysis."

4.3.4. The effects of anti-dementia drugs on development of dementia care

The introduction of anti-dementia drugs has been accompanied by a number of other positive developments which could be negatively affected by the decision of regulators and governments to no longer prescribe anti-dementia drugs within national reimbursement schemes.

Jim Jackson, Chief Executive of Alzheimer Scotland – Action on Dementia states that 'These drug treatments have led to diagnostic services being improved and recognition that better services throughout the illness are required. The draft guidance would take us back to a time when people with dementia and their families were ignored and left to cope as best as they could.'

4.3.5. Benefits of early diagnosis

The availability of treatment is undoubtedly one of the reasons why people with Alzheimer's disease will seek a diagnosis when confronted with the early symptoms of dementia. Taking away this motivation may lead to great numbers of people with Alzheimer's disease no longer actively seeking a diagnosis.

Similarly, informing people about a diagnosis of Alzheimer's disease is a process considered to be difficult by medical professionals. If medical professionals are no longer able to prescribe treatment, they may be even more reluctant in sharing the diagnosis with people with dementia and their carers.

Alzheimer Europe and its member organisations campaign for the right of people with dementia to be informed about their diagnosis and fear that the NICE guidance would negatively impact the growing trend of informing people. Such disclosure does not only open the door to possible drug treatments, but also to a wealth of other information and support services.

Furthermore, an early diagnosis allows people with dementia to take a more active part in decisions affecting their future life through the appointment of health care proxies or the writing of advance directives.

4.3.6. Stigma and ageist prejudices

People with Alzheimer's disease and their carers report a high degree of stigma still attached to the disease, which may result in social exclusion and isolation. Although Alzheimer's disease does not only affect older people, age is the main risk factor for the disease.

Attitudes towards older people are often ageist and they are viewed as unproductive members of society. This is exacerbated by the fact that memory loss is still often considered as a normal result of ageing rather than as a symptom of a disease.

These ageist prejudices also seem to exist within the medical profession and there is anecdotal evidence that doctors are less inclined to start treatments for older persons than for younger persons with the same condition.

For these reasons, Alzheimer Europe wonders whether similar strict recommendations on stopping the use of anti-dementia drugs would have been applied, if the disease affected more younger members of society.

4.3.7. Equality of access to care and treatment

As a European umbrella organisation of national Alzheimer associations, Alzheimer Europe campaigns for equal access of European citizens to health care services and treatment options. The NICE recommendations would deprive British people with Alzheimer's disease treatment available under national reimbursement schemes in the other Member States of the European Union thus further enlarging the already existing gap with regard to access to diagnosis and treatment between the United Kingdom and other European countries.

A recent survey conducted in a number of European countries highlighted a number of areas where the situation of people with Alzheimer's disease in the United Kingdom lagged behind that of those from other European countries.

The time taken to a diagnosis of Alzheimer's disease after symptoms were first noticed was considerably longer in the United Kingdom (32 months) than in France (24), Poland (23), Spain (18), Italy (14) or Germany (10).

Fewer carers in the United Kingdom (51%) reported that physicians recommended treatment at the time of diagnosis than those of Germany (78%), France (83%), Italy (85%), Poland and Spain (86%).

The number of carers who believed that governments did not invest enough in Alzheimer's disease was higher in the UK (87%), than in Italy (65%), Germany (77%), France (80%) and Spain (82%), though lower than in Poland (88%).

Similarly, physicians had lower expectations from the available drug treatments (68% of respondents agreed or strongly agreed that early treatment can delay the progression of Alzheimer's disease) than their colleagues in Spain (86%), Germany (87%), Italy (91%), France (92%) and Poland (96%).

4.4. Conclusions

Based on the arguments described above, Alzheimer Europe is convinced that governments and regulators should not further restrict the access to anti-Alzheimer's drugs.

Rather, treatment with anti-Alzheimer's drugs should be recommended as a standard for people with Alzheimer's disease.

Treatment should be offered as one part of a care package taking into account the various needs of people with dementia and their carers and the existing anti-dementia drugs should be made available under national reimbursement systems for people with Alzheimer's disease.

Doctors should discuss the likely benefits and side effects with Alzheimer's disease and their carers in a realistic way without raising false hopes.

