



ANNUAL
REPORT
2004

Alzheimer Europe gratefully acknowledges the financial support of Janssen-Cilag, Lundbeck and Pfizer which has made the publication of this Annual Report possible.



Also, Alzheimer Europe gratefully acknowledges a grant of the Pfizer Foundation which allowed the organisation to carry out a survey of the structure and services of its member organisations and to publish the results in this Annual Report.

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PREFACE

Taking on the task of Chairperson of a pan-European voluntary organisation would seem a daunting task to many. Yet, when I was elected as Chairperson of Alzheimer Europe, I was able to rely on a sound basis established by my predecessors and the continued support of the dedicated Alzheimer Europe staff.



The Alzheimer Europe business plan gave clear directions for the various activities of the organisation. It provides the organisation with a core philosophy, the promotion of the dignity, respect and the self-determination of the person with dementia and his/her carer throughout the course of the disease and a mission statement.

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. Furthermore, it sets out four main objectives for the organisation:

- ▶ Ensuring people with dementia and their carers are referred to Alzheimer associations,
- ▶ Promoting the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives,
- ▶ Improving the support and counselling of carers of people with dementia at the onset of the disease and
- ▶ Promoting quality of care at home.

In 2004, we were able to progress significantly in all four of these programmes. A survey of Alzheimer Europe's member organisations was carried out, the regional organisations of our members are now available on our web site and a draft position of Alzheimer Europe on advance directives was produced, as well as the first version of our manual for people with dementia and their carers for the time after diagnosis.

In this work, we were able to rely on the representatives of our members, as well as outside experts and I would like to take this opportunity to thank each one of them for their contributions. I am convinced that the results of all these programmes will prove useful for the work of our member organisations.

Without the support of Janssen-Cilag, Lundbeck and Pfizer, we would not have been able to carry out these ambitious tasks and I would like to thank them for their continued support and interest in our activities. Similarly, Fondation Médéric Alzheimer supported the literature search and legal update necessary for our work on advance directives for which I would also like to thank them.

Our growing recognition on a European level through our collaboration with a number of European networks constituted another important development for our organisation. Alzheimer Europe has become a respected member of the European Patients' Forum and the European Federation of Neurological Associations and some of our activities and principles have become a reference for other patient organisations.

This annual report therefore provides not only a progress report on our business plan, but an overview of our networking activities and our various contributions to the European institutions. This is an area where our organisation needs to grow further in the coming years and the Board of Alzheimer Europe has taken the first steps towards the establishment of a new public affairs strategy for the organisation.

With the adoption of a new communication strategy, Alzheimer Europe also set itself the ambitious task of becoming one of the main providers of information on Alzheimer's disease in Europe. Our quarterly newsletter and our web site provide a great wealth of up-to-date information on all our activities and those of our member organisations, on research findings and relevant European developments.

A recent report by the European Commission on health information on neuro-degenerative diseases complimented Alzheimer Europe on the quality of the information it provides and concluded that nothing similar existed for other neuro-degenerative diseases. This is high praise indeed and will encourage us to seek further ways of improving our information.

I am glad that in all of these tasks, we are supported by a small, but highly dedicated staff and I would like to express my heartfelt thanks to Jean Georges, Dianne Gove, Sandrine Lavallé and Claire Haigh for their contributions which ensured that 2004 was another year of continued growth for the organisation.

A handwritten signature in blue ink that reads "Maurice O'Connell". The signature is fluid and cursive.

Maurice O'Connell
Chairperson



EXECUTIVE SUMMARY

In 2004, Alzheimer Europe:

- ▶ *Improved its collaboration with International and European patient organisations and in particular Alzheimer's Disease International, the European Patient's Forum and the European Federation of Neurological Association,*
- ▶ *Strengthened its contacts with the scientific community through collaboration with the European Federation of Neurological Societies (EFNS), the European Alzheimer's Disease Consortium and the "Early Detection and Timely Intervention in Dementia" network,*
- ▶ *Represented the views of people with dementia and their carers in the EFNS task force for the revision of its guidelines on the diagnosis and management of Alzheimer's disease and other dementias,*
- ▶ *Adopted a new communication strategy to improve the information exchange between Alzheimer Europe, national associations and other organisations,*
- ▶ *Organised its 14th Annual Conference in Prague which brought together 300 participants from all over Europe,*
- ▶ *Received the support of 196 MEPs who signed a written declaration on the fight against Alzheimer's disease,*
- ▶ *Contributed to the Commission reflection document on the future development of a European health policy,*
- ▶ *Participated actively in the working group with patient organisations set up by the European Medicines Evaluations Agency,*
 - ▶ *Continued its collaboration with other NGOs which enjoy consultative status with the Council of Europe,*
 - ▶ *Presented the findings of its members' survey and included regional organisations of its members on its web site,*
 - ▶ *Carried out an extensive literature search and a comparison of the legal status of advance directives and prepared a first draft position on the subject,*
 - ▶ *Produced a first version of a manual for people with dementia and their carers for the time after diagnosis,*
 - ▶ *Set up a working group on home care and surveyed member organisations on the provision of home care in their respective countries.*



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.

Representing views

In 2004, 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.

Further steps were undertaken to develop the relationship between Alzheimer Europe and Alzheimer's Disease International. The organisation also played an active role as a member of pan-European patient organisations such as the European Patients' Forum and the European Federation of Neurological Associations and it continued to improve its links to professional organisations and networks of researchers, such as the European Federation of Neurological Societies, the European Alzheimer's Disease Consortium or INTERDEM.

Alzheimer's Disease International (ADI)

Alzheimer Europe and ADI continued their discussions to develop a closer relationship between the two organisations and a draft partnership agreement was prepared to highlight some areas to improve the exchange of information between the two organisations and coordinate possible joint actions.

Furthermore, representatives of Alzheimer Europe participated in the Annual Conference which ADI organised in Kyoto (Japan) from 14 to 16 October 2004, as well as the Facing Dementia Forum which Pfizer organised in collaboration with ADI in Rome on 19 and 20 June 2004.

European Patients' Forum (EPF)

Alzheimer Europe is a founding member of the EPF and has been represented by its Executive Director, Jean Georges on the EPF Board since its inaugural meeting. In 2004, the European Patients' Forum was formally launched in the European Parliament on 22 March 2004, an event which was hosted by Uma Aaltonen, MEP.

Speaking at the event, Fernand Sauer (Director for Public Health at the Directorate General for Health and Consumer Affairs) welcomed the creation of the Forum a "platform that can speak on behalf of patients and facilitate dialogue with the European institutions".

Alzheimer Europe actively contributed to the development of the Forum and represented the Forum at a number of meetings organised by the European Commission or other institutions. The European Patients' Forum also organised two workshops for patient representatives from Central and Eastern Europe to provide them with an overview of the European institutions. Both events were attended by representatives of national Alzheimer associations from the new Member States of the European Union and the accession countries.

European Federation of Neurological Associations (EFNA)

Alzheimer Europe also collaborated with other organisations of people living with brain disorders in the framework of the EFNA. Through his collaboration on the EFNA Board and as the organisation's Secretary General in 2004, Jean Georges was also appointed to the patient advisory group of the British Medical Journal and the working group with patient organisations of the European Medicines Evaluations Agency (EMA).

European Federation of Neurological Societies (EFNS)

Conscious of the need to also develop closer ties with professional and scientific organisations, Alzheimer Europe took a more active role within the Paris conferences organised by the EFNS from 4 to 7 September 2004. Alzheimer Europe was represented at the meeting with a stand which attracted a lot of attention from the participating neurologists and participated in a symposium of the EFNS Neuroethics Panel on end-of-life decisions in dementia.

Furthermore, Alzheimer Europe was asked to nominate a representative to 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).

European Alzheimer's Disease Consortium (EADC)

As in previous years, Alzheimer Europe continued its involvement with the 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.

Early detection & timely INTERvention in DEMentia (INTERDEM)

In 2003, Alzheimer Europe established initial contacts with the INTERDEM network, a group of researchers on the psychosocial dimension of dementia and further developed this relationship in 2004. Thus, Alzheimer Europe hosted and updated their website and provided a full opportunity to the network to present its various European projects to a wider audience during two special symposia at the Alzheimer Europe conference in Prague.

Information exchange

In 2004, Alzheimer Europe adopted a new communication strategy in order to improve the information exchange between

the organisation, its national member associations and its growing network of professionals and politicians with an interest in dementia. A quarterly e-mail newsletter, the website and the annual conference are the key tools for the organisation in this field.

Alzheimer Europe Website

The Alzheimer Europe website plays an important role in the dissemination of the results of the various projects undertaken by Alzheimer Europe and in 2004, it had on average in excess of 10,000 visitors a month.

The website is regularly updated and news covered in the e-mail newsletter is automatically included. Alzheimer Europe would like to encourage visitors to return to the website by providing a wealth of information on scientific developments in the field of Alzheimer's disease and related disorders, but also on the activities of Alzheimer Europe, its national associations and other European organisations.

14th Annual Conference in Prague

From 21 to 23 May 2004, Alzheimer Europe organised its 14th Annual Conference in Prague. The meeting was attended by over 300 participants from all over Europe and brought together people with dementia and their carers, volunteers and staff members of Alzheimer associations, as well as professional carers and researchers in the field of dementia care.

The meeting served to give an update on Alzheimer Europe projects on advance directives and home care and allowed the invited experts to address such varied subjects as the treatment of dementia, rarer forms of dementia, the role of Alzheimer associations and palliative care, to name but a few of the issues that were covered.

At the same time, Alzheimer Europe continued its policy of actively involving people with dementia in the conference programme as Peter Ashley from the United Kingdom shared his experience of obtaining a diagnosis of Lewy Body Dementia and the impact of this diagnosis on his life, while Lynn Jackson from Canada presented her views on how advance directives helped her take an active part in decisions affecting her life.

In the framework of the conference, Alzheimer Europe also presented its second award for outstanding services for people with dementia. After H.M. Queen Silvia of Sweden in 2001, the award was presented to Harry Cayton, the former Chief Executive of the Alzheimer's Society (UK) for his contributions to our understanding of dementia and the model work of his organisation in changing how people with dementia are viewed.

Finally, the Annual General Meeting was also organised in Prague and resulted in the election of a new Board to lead the organisation for the next two years.

Developing policy

As in previous years, Alzheimer Europe worked closely together with other organisations in monitoring European developments of relevance to patients and carers. The association continued to develop its relationship with the European Parliament and the European Commission, as well as the European Medicines Evaluations Agency. As an organisation with consultative status with the Council of Europe, Alzheimer Europe also used 2004 to further develop its collaboration with this European institution.

European Parliament

With regard to the European Parliament, the organisation was particularly pleased that 196 MEPs signed a written declaration on the fight against Alzheimer's disease and brain diseases tabled by Jacqueline Rousseaux, John Bowis and Miguel Angel Martínez Martínez. In this written declaration, the MEPs called upon the Commission "to allocate a significant proportion of funding for research in life sciences to the brain and brain diseases and, in particular, neuro-degenerative disease and Alzheimer's". Furthermore, they asked for a system of social protection providing practical and financial help to be put into place and suggested the setting up of a European monitoring centre for brain diseases.

European Commission

Commissioner Byrne's reflections on the future development of a European health policy, as well as the discussions on patient mobility, animal research and equitable access to healthcare were of particular interest to Alzheimer Europe.

The organisation endorsed a position developed within the framework of the European Patients' Forum (EPF) on the Commission's reflection document. In its reply, EPF supported the Commissioner's views of a Europe where high-quality health care is equal, accessible and affordable and where there is reliable information on health, illness and treatment options. In addition, EPF reminded the Commission of the need to involve all health stakeholders and in particular patients in shaping the policies and initiatives that influence their health and treatment options and stressed the importance of making accessible health education a priority.

European Medicines Evaluations Agency (EMA)

Alzheimer Europe was actively involved in the working group with patient organisations set up by the EMA and represented the European Federation of Neurological Associations at these meetings.

The EMA group addressed patient-specific questions 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.

In all three areas, as well as on the question of criteria for patient organisations to become involved in the EMA decision making process, the group developed recommendations to improve the access of patients to relevant information on their treatments which were submitted to the EMA management board for their adoption in 2005.

Council of Europe

As in previous years, Alzheimer Europe was represented at the quarterly meetings of organisations with consultative status at the Council of Europe. In particular, the organisation collaborated with other NGOs on health questions.

Furthermore, the organisation included Elaine Gadd as a representative of the Council of Europe in the working group of its business plan priority on advance directives and was able to involve some of the national legal experts in a survey on the legal situation of advance directives and their use in a number of European countries.

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.

BP 1 – Alzheimer associations

The objective set by the first business plan priority is to ensure that people with dementia are referred to their Alzheimer association at the time of diagnosis.

To show the extensive list of services and support provided by Alzheimer associations, Alzheimer Europe carried out a survey of its member organisations in 2003, as well as an inventory of the regional organisations its members.

In 2004, the findings of the survey were presented on a number of occasions and the regional organisations were included in a database on the Alzheimer Europe website.

Furthermore, through its collaboration with the European Federation of Neurological Societies, Alzheimer Europe worked towards including the role of Alzheimer associations into diagnostic guidelines and encouraging professionals to refer people diagnosed to the support available from these organisations.

BP 2 – Advance directives

The second business plan priority is dedicated to the promotion of the autonomy of people with dementia through the right to an early diagnosis and the recognition of advance directives.

With the support of Fondation Médéric Alzheimer, Alzheimer Europe was able to carry out an extensive literature search on the subject, as well as a comparative overview of the legal status of advance directives in various European countries. On the basis of these findings, Dianne Gove, the project manager was able to draft a position of the organisation which will be presented for adoption at the Annual General Meeting in June 2005. 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).

A background document on the literature search and the legal update are available on the Alzheimer Europe website and the initial findings were presented at the Neuroethics meeting of the European Federation of Neurological Societies and a conference of Fondation Médéric Alzheimer. Also, articles on the findings were submitted to and accepted by a number of specialised journals.

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 and aims at developing a manual for informal carers of people with dementia which will respond to the specific needs in the period of time just after diagnosis.

With the support of the 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 first draft of the manual which was sent out for consultation to all member organisations, as well as to people with dementia to ensure that the language used is appropriate and meets their expectations.

As initially planned, the manual will be finalised in 2005 and work will start on the development of a training manual for Alzheimer associations on counselling and support of carers following diagnosis.

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), Angela Keegan (Ireland), Mary Marshall (United Kingdom), Majken Ploby (Sweden) and Eugen Stefanut (Romania).

A first meeting of the group took place in 2004, but progress on this priority was less than for the other programmes due to limited staff resources. Nevertheless, an extensive literature search was carried out by Dianne Gove and member organisations were contacted for descriptions of the organisation of home care in their respective countries.

FINANCIAL REPORT

Report of the independent auditor



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, 2004. 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, 2004 and of the results of its operations for the year then ended.

Luxembourg, May 18, 2005

For MAZARS, Réviseurs d'entreprises

Philippe SLENDZAK
Partner

Joseph HOBSCHEID
Audit Manager

Enclosed : Balance sheet as of December 31, 2004
Profit and loss account as of December 31, 2004

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Balance sheet as of 31 December 2003



ALZHEIMER EUROPE A.s.b.l.

Balance sheet as of December 31, 2004

	<u>2004</u>	<u>2003</u>
	EUR	EUR
ASSETS		
Current assets		
Subsidies due (EC)	-	24.948
Other debtors	26.477	20.107
Cash at bank and on deposit	<u>109.102</u>	<u>106.044</u>
	135.579	151.099
Accruals	455	5.184
	<u> </u>	<u> </u>
Total Assets	<u><u>136.034</u></u>	<u><u>156.283</u></u>
LIABILITIES		
Capital and reserves		
Results brought forward	77.479	72.783
Result of the year	<u>6.266</u>	<u>4.696</u>
	83.745	77.479
Creditors		
Payments received on account	31.416	70.221
Trade creditors	5.859	7.352
Other liabilities	<u>15.014</u>	<u>1.231</u>
	52.289	78.804
	<u> </u>	<u> </u>
Total Liabilities	<u><u>136.034</u></u>	<u><u>156.283</u></u>

Profit and loss account - Year ended December 31, 2004



ALZHEIMER EUROPE A.s.b.l.

Profit and loss account Year ended December 31, 2004

	<u>2004</u> <u>EUR</u>	<u>2003</u> <u>EUR</u>
Subsidies from the European Commission	-	62.844
Other operating income		
Sponsorship	197.456	152.172
Sponsorship received on account	-31.416	-70.221
Co-financing in kind	103.277	110.140
Membership fees	40.000	40.875
Donations	7.500	4.523
Publication sales and royalties	56.041	4.920
Internet services	-	3.480
Project participation	5.274	1.622
Other operating income	18.539	11.230
Alzheimer Europe Conference	8.100	10.303
External charges		
External experts	-106.908	-116.160
Publication and information material	-40.220	-7.816
Travel expenses	-36.572	-26.177
Communication costs	-17.494	-17.870
Accommodation expenses	-31.884	-23.775
Office rent and associated costs	-20.833	-20.317
Office stationary and related costs	-4.874	-4.637
Leasing	-18.219	-28.243
Membership fees	-700	-925
Other costs	-1.881	-2.916
Irrecoverable debt	-2.681	-
Staff costs		
Wages and salaries	-90.912	-61.756
Social security costs	-24.788	-16.838
Interest receivable and similar income	605	1.060
Interest payable and similar charges	-1.144	-822
	<u>6.266</u>	<u>4.696</u>

Acknowledgements

Alzheimer Europe would like to thank the following individuals, organisations and companies for their invaluable support in 2004.

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.



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 2004. Alzheimer Europe gratefully acknowledges the support of **Fondation Médéric Alzheimer** which generously agreed to support the organisation's programme on advance directives and in particular, the literature search and legal overview in this field.



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 2004 financial accounts of the organisation free of charge. Alzheimer Europe gratefully acknowledges a generous donation of the **ING Bank**.





**THE
ALZHEIMER
MOVEMENT
IN EUROPE**

INTRODUCTION

In the majority of European countries, civil society plays an important role and non-governmental organisations, charities or foundations have been created to represent the interests of people in a great number of subject areas.

Undoubtedly, trade unions are amongst the oldest interest organisations, since they were formed in the 19th century to defend the interests of workers. Some other issues, such as animal welfare, the protection of the environment or collaboration with developing countries have also given rise to well developed fourth sector organisations.

In the field of health, this development is more recent and a variety of organisations has been created, some defending more general public health issues such as health promotion, others dedicated to prevention or the fight against tobacco, alcohol or drug abuse. Finally, a great number of organisations have been founded to represent the interests of people living with chronic conditions, as well as the interests of their carers.

In order to give an overview of the current state of development of Alzheimer associations throughout Europe, Alzheimer Europe carried out a survey of its member organisations in 2002 and in 2004 with the hope of highlighting the important contributions these associations make to society.

Through this survey, Alzheimer Europe was able to collect information on 28 of its 29 member organisations, as well as three further Alzheimer associations from Croatia, Malta and Slovenia which are not currently members of Alzheimer Europe.

Before presenting the findings, some words of caution are necessary:

- ▶ The findings present the answers provided by the associations which are members of Alzheimer Europe and do not reflect the services of the public sector or other not-for-profit organisations in the countries in question.
- ▶ For most countries, the services and contributions of regional and local organisations may not be fairly represented in the findings, since some regional organisations act independently of the national headquarters of their organisations or may not provide this data to the national organisation.

▶ For the above reasons, the findings only provide a limited overview of all the contributions provided by the Alzheimer movement in the various European countries and all quoted figures are therefore an understatement of the real contributions of national and regional organisations which in most cases will surpass those quoted in this report.

Nevertheless, this report provides for the first time an estimation of some of the services provided by the Alzheimer movement in Europe and its contributions in favour of people with dementia and their carers.



HISTORY OF THE ALZHEIMER MOVEMENT

Alois Alzheimer, a German neuropathologist, was the first to describe in 1906 the symptoms and brain damage of what was to become known as Alzheimer's disease. His patient Auguste D. had presented extreme fits of jealousy towards her husband which were shortly followed by memory loss, depression and hallucinations. She died five years after her first visit to Dr. Alzheimer, aged 51. The brain autopsy carried out by Alzheimer revealed signs of general atrophy but he detected no tumors or evidence of a stroke. Then, examining her cerebral cortex, Dr. Alzheimer found lesions, extensive tissue distortion and cell damage — the hallmarks of what we now know as Alzheimer's disease.

While research continued into the causes of Alzheimer's disease, few services existed for people living with the disease or their carers and one had to wait until 1979, when the first European association was created in the United Kingdom to provide support and information to carers of people with Alzheimer's disease. In the United States, a similar organisation was set up in 1980.

In the ensuing years, Alzheimer associations were set up in other Western European countries and after the fall of the Berlin Wall, this trend continued also in Central and Eastern European countries, with the creation of Alzheimer associations in 1992 in both Poland and Romania.

Currently, Alzheimer associations are established in almost all the Member States of the European Union, as well as in the accession countries.

Date of creation	Country
1979	United Kingdom
1982	Ireland
1984	Sweden
1985	France, Italy
1986	Belgium
1987	Luxembourg
1988	Finland, Portugal, Switzerland
1989	Germany
1990	Austria, Spain
1991	Denmark
1992	Poland, Romania
1994	Norway
1995	Greece
1997	Czech Republic, Turkey, Slovenia
1998	Slovak Republic
1999	Croatia
2004	Malta

Table 1 Date of creation of Alzheimer associations
N.B.: for countries where there is more than one organisation, the date reflects the creation of the first Alzheimer association in this country.

THE CHANGING FACE AND ROLE OF ALZHEIMER ASSOCIATIONS

The main driving reasons for setting up Alzheimer associations were threefold:

- ▶ Alzheimer associations were to provide much needed information on Alzheimer's disease, a disease of which very little was known in the early days of the Alzheimer movement.
- ▶ In the absence of existing treatment and often even of services for people with Alzheimer's disease, Alzheimer associations were set up to provide support for carers of people with Alzheimer's disease and to provide them with the possibility to exchange information and experiences.
- ▶ Finally, one of the primary roles of Alzheimer associations was to raise the awareness of the general public about Alzheimer's disease in order to ensure that people are diagnosed properly.

While it is true that Alzheimer associations still keep to these core objectives, a number of developments should be noted that have diversified the role of Alzheimer associations.

Regionalisation of Alzheimer associations

Since their creation, Alzheimer associations have grown considerably. Most national associations have set up regional branches, which provide services and support on a local level which the national office would be unable to provide. In total, the 31 national associations, which replied to the survey, represent 1,141 regional organisations.

This development is to a large extent linked to the age of organisations and more recent organisations have only started the process of developing regional branches. This is particularly true for Eastern European organisations in Croatia, the Czech and Slovak Republics, Poland and Romania, but is also the case for Greece and Portugal.

On the other hand, this development has been particularly pronounced in the Nordic countries. Thus the Norwegian organisation has 125 regional associations, in Sweden there are 127 regional organisations, whereas the Finnish organisation has 46 regional branches. Although these countries have relatively small

Country	Branches
Austria	30
Belgium	44
Croatia	3
Cyprus	4
Czech Republic	29
Denmark	16
Finland	46
France	98
Germany	88
Greece	1
Ireland	29
Italy	69
Luxembourg	1
Netherlands	42
Malta	1
Norway	125
Poland	1
Portugal	5
Romania	5
Slovak Republic	1
Slovenia	2
Spain	44
Sweden	120
Switzerland	18
Turkey	6
United Kingdom	310
TOTAL	1141

Table 2 Branches of national Alzheimer associations

Country	Members	People with dementia	Percentage
Austria	2,000	97,137	2.05
Belgium	3,013	129,389	2.33
Cyprus	500	2,705	18.48
Denmark	4,000	65,959	6.06
Finland	9,200	58,797	15.65
France	13,553	758,229	1.78
Greece	1,297	131,283	0.99
Ireland	2,500	31,702	7.89
Italy	5,000	791,205	0.63
Luxembourg	634	4,665	13.59
Norway	3,600	57,758	6.23
Poland	400	311,879	0.13
Portugal	3,800	103,690	3.66
Romania	900	139,787	0.64
Slovak Rep.	60	42,197	0.14
Spain	15,130	488,956	3.09
Sweden	9,837	131,643	7.47
Switzerland	6,300	88,304	7.13
U. K.	28,745	741,042	3.88

Table 3 Membership of Alzheimer associations

Thanks to the work of the European Community Concerted Action on the Epidemiology and Prevention of Dementia group (EURODEM for short), it is possible to estimate how many people in a given country are likely to have dementia provided that accurate population statistics are available. 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 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. 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.

populations, the populations are spread over large territories and the Nordic organisations were successful in developing their regional associations in the rural areas.

Outreach of Alzheimer associations

Despite the survey carried out by Alzheimer Europe, it remains difficult to give an exact figure of the members of Alzheimer associations, since the definition of member may vary from one organisation to another:

- ▶ The vast majority of national Alzheimer associations have individual members which make up the organisation.
- ▶ A number of associations are federations of regional organisations and individuals become members of the regional organisations, rather than of the national organisation. While the French and Swiss organisations require their regional organisations to indicate the number of members they have and can therefore provide the numbers of members nationwide, this is not the case for the German, Italian and Spanish organisations.
- ▶ The organisations in Greece and Poland have formed loose networks and alliances with other Alzheimer associations in the country, yet the membership figures they provide are those of the local associations in Thessalonica or Warsaw and do not include the members of other associations on the network.
- ▶ Finally, the Dutch association has chosen the legal form of a foundation, which does not have members, and the numbers they have reported when answering the survey are those of its donors. Since they have a very successful fundraising campaign, the organisation can count on the support of over 200,000 donors, but this figure was not included in the results reproduced hereafter.

Bearing in mind these reservations, one can nevertheless estimate that the 31 associations that replied to the survey represent over **114,000 members** throughout Europe.

This number remains relatively low when one compares it to the number of people with dementia in the countries (See table 3) and organisations rarely manage to represent as much as 5% of their target population, except for Cyprus (18.48%), Denmark (6.06%), Finland (15.65%), Ireland (7.89%), Luxembourg

(13.59%), Norway (6.23%), Sweden (7.47%) and Switzerland (7.13%).

While these figures may be disappointing, it is worthwhile remembering that:

- ▶ The prevalence figures quoted indicate the total number of people with dementia in a country, whereas a number of these remain undiagnosed or are diagnosed at a very late stage,
- ▶ The prevalence of Alzheimer's disease and most other forms of dementia increases with age and therefore people with dementia and their carers are predominantly elderly people who may be more reluctant to join Alzheimer associations,
- ▶ The care of people with dementia is a highly time consuming occupation and carers may not necessarily have the time and/or energy to become active members of an Alzheimer's association,
- ▶ Alzheimer associations provide information and support to a much wider audience than their immediate membership and no Alzheimer association has made membership a requirement for access to the services they provide.

It seems clear nevertheless that programmes to boost the membership of national Alzheimer associations could prove useful in the vast majority of countries.

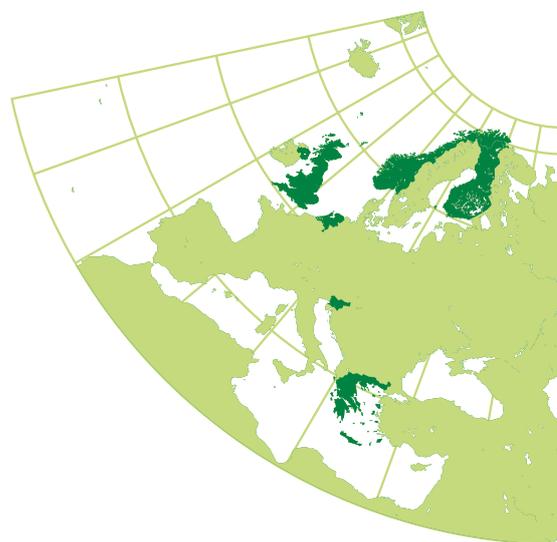
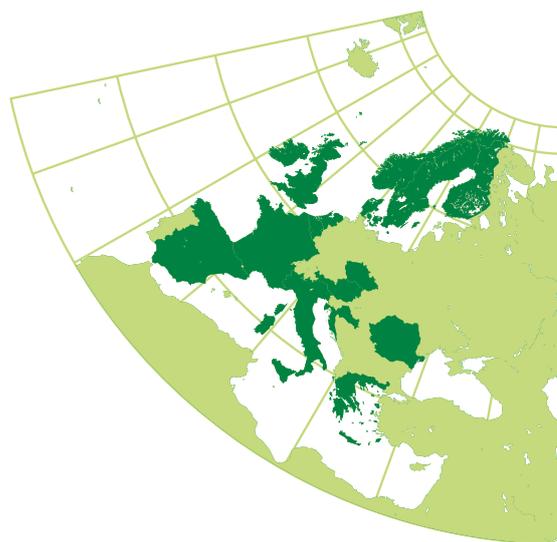
In its survey of Alzheimer associations, Alzheimer Europe therefore also wanted to see whether its member organisations had developed outreach programmes for certain minority groups, such as younger people with dementia, people with dementia from ethnic minorities or gay people with dementia.

Of the 31 associations that replied to the survey, 19 (61.29%) had specific programmes or services for younger people with dementia, 8 (25.80%) provided information and support for people with dementia from ethnic minorities and 5 (16.13%) had developed specific services for gay people with dementia.

Younger people with dementia and their carers

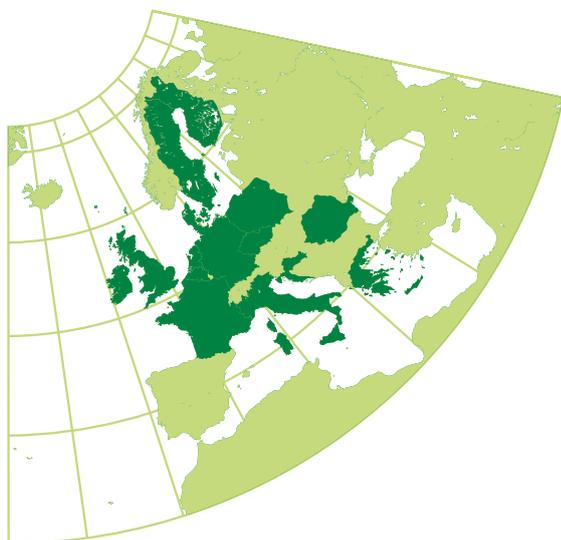
Early onset dementia affects people under 65. Younger people with dementia are normally between 40 and 65 years old, with a majority of them in their 50s and early 60s. Due to their lower age, they have a number of different needs, since they may still be in paid employment at the time of diagnosis or have younger children.

Map 1 Countries providing specialised services for younger people with dementia and their carers: Austria, Belgium, Czech Republic, Denmark, Finland, France, Greece, Ireland, Italy, Netherlands, Norway, Romania, Spain, Sweden, Switzerland, United Kingdom and Croatia.



Map 2 Countries providing specialised services for people with dementia and their carers from ethnic and cultural minorities: Finland, Greece, Netherlands, Norway, United Kingdom and Slovenia.

Map 3 Countries providing specialised services for gay people with dementia and their carers: Belgium, Ireland, Italy and United Kingdom.



Map 4 Countries providing information and services for people with other forms of dementia: Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Netherlands, Poland, Romania, Sweden, United Kingdom and Croatia.

The situation of younger people with dementia is often characterised by a lack of adequate services. Care needs to be planned in another way and services must take into account the fact that the younger person with dementia, as well as the carer, may still have family and professional responsibilities.

A growing number of organisations have recognised this and provide specific counselling and other services for younger people with dementia. 19 of the 31 national associations do so, yet access to these services unfortunately often remains highly dependent on the location of younger people with dementia, since these specialised services are not normally available in the whole country (Map 1).

People with dementia from ethnic minorities and their carers

Most European countries have societies with variably sized minorities of citizens from other countries and cultures. Members of these ethnic and cultural minorities grow older and some of them will develop dementia and require information on the disease and access to services. In such cases, information may not always be available in a language understandable to members of these ethnic minorities and services may not be adequate for their differing cultural needs.

Only 8 national associations have recognised this cultural diversity and developed outreach programmes for ethnic and cultural minorities by providing information sheets in a number of different languages, as well as adapting services to these specific needs (Map 2).

Gay people with dementia and their carers

Gay and lesbian people with dementia and their carers often face specific problems or discrimination due to their sexual orientation. Care workers may not be prepared to discuss health and care questions with the partners of gay people with dementia and support groups may not welcome the participation of gay people with dementia and their partners.

The Alzheimer's Society in the United Kingdom was the first national organisation to recognise the added discrimination faced by gay people with dementia and their carers and started a specific support network for this group. Other organisations, such as

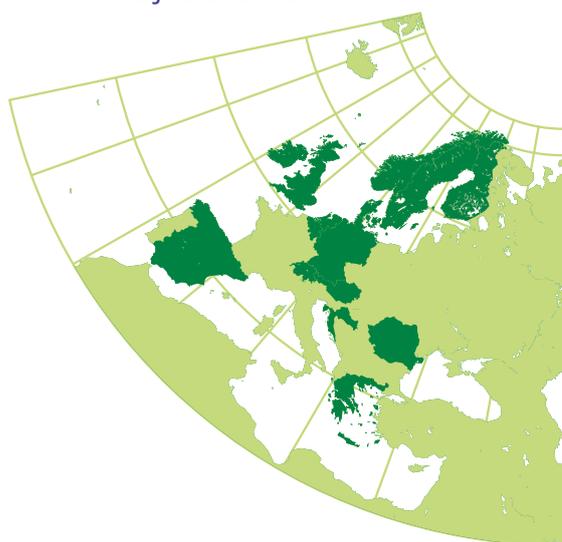
Alzheimer Scotland – Action on Dementia have followed suit and now provide specific support programmes for gay people with dementia. Nevertheless, only 5 national organisations of the 31 organisations who replied to the survey provide such specialised support (Map 3).

Alzheimer’s disease and dementia

While Alzheimer’s disease is by far the most common form of dementia, there exist other forms of dementia, such as vascular dementia, fronto-temporal dementias and Lewy Body dementia, as well as a wide range of other rarer forms of dementia.

Initially, Alzheimer associations were created to provide information and support for carers of people with Alzheimer’s disease, but over the course of the years, most organisations started to develop information on other forms of dementia. Thus, in the survey carried out by Alzheimer Europe, 20 of the 31 organisations replied that they also provided information, support and services for people suffering from other forms of dementia (Map 4).

Map 5 Countries providing support groups for people with dementia: Austria, Belgium, Denmark, Finland, Germany, Greece, Ireland, Netherlands, Norway, Romania, Spain, Sweden, Switzerland, United Kingdom and Croatia.



The names of some of the member organisations (Demensförbundet in Sweden or Alzheimer Scotland–Action on Dementia in the United Kingdom) reflect this wider focus on dementia in general. The Alzheimer’s Society in the United Kingdom accompanies their logo with the mission statement “Dementia care and research” to show their commitment to people living with any kind of dementia.

Inclusion of people with dementia

Early diagnosis had led to people with dementia being diagnosed at a stage when they are able to understand the diagnosis and take an active role in decisions affecting their lives. For that reason, organisations can no longer merely focus on the needs of carers of people with dementia without also providing support and services directly to people with dementia.

As a result, 18 of the 31 associations now provide support groups for people with dementia, either as peer support groups or together with their partners/carers (Map 5).

Of the 31 associations, only Alzheimer Scotland – Action on Dementia had a person with dementia represented in their national Board of Directors.

Alzheimer associations as service organisations

With the expansion of their core objectives beyond awareness raising and provision of information on Alzheimer’s disease, Alzheimer associations started to diversify the services that they provide for people with dementia and their carers. Also, in a number of countries, Alzheimer associations stepped in to provide those services not or no longer provided by the public sector.

As a result, a number of associations are now successful service providers. Alongside the more traditional services, such as support groups (29 associations), training programmes for carers (25 associations) and helplines (26 organisations), associations run such essential services as day care centres (15 organisations) or home care services (13 organisations).

In the Czech Republic, Finland and Turkey, the organisations even provide long-term care in an institution entirely run by the organisation with a number of further associations currently studying similar projects.

Country	Support groups	Training programmes	Helplines	Day care	Home Care	Long-term care
Austria	✓	✓				
Belgium	✓	✓	✓			
Croatia	✓		✓			
Cyprus			✓		✓	
Czech Republic	✓		✓	✓	✓	✓
Denmark	✓	✓	✓	✓		
Finland	✓	✓	✓	✓	✓	✓
France	✓	✓	✓	✓	✓	
Germany	✓	✓	✓	✓	✓	
Greece	✓	✓	✓	✓		
Ireland	✓	✓	✓	✓	✓	
Italy	✓	✓	✓			
Luxembourg	✓	✓	✓	✓		
Netherlands	✓	✓	✓			
Malta		✓				
Norway	✓	✓	✓			
Poland	✓	✓	✓		✓	
Portugal	✓	✓	✓	✓	✓	
Romania	✓	✓	✓	✓		
Slovak Republic	✓	✓	✓	✓		
Slovenia	✓	✓	✓			
Spain	✓	✓	✓	✓	✓	
Sweden	✓	✓	✓			
Switzerland	✓	✓	✓		✓	
Turkey	✓	✓		✓		✓
United Kingdom	✓	✓	✓	✓	✓	

Table 4 Services provided by Alzheimer Associations

THE ECONOMIC CONTRIBUTIONS OF ALZHEIMER ASSOCIATIONS

As organisations started to provide more and more services, the number of people working for Alzheimer associations as paid members of staff or as volunteers has grown considerably. Similarly, from small organisations with limited budgets, some associations have developed into flourishing third sector service providers with substantial budgets.

Staff employed by Alzheimer associations

Almost all national associations, with the exception of Austria, Croatia, Malta, Slovenia and the Slovak Republic have paid members of staff to run the office of the organisation, to fund-raise or to lobby national governments. Some organisations also employ paid members of staff for some of the services, such as helplines or support groups provided by the national office. Finally, some organisations with a well developed service structure throughout the country, such as the associations in Finland, Ireland, Luxembourg and the United Kingdom, employ considerable numbers of staff.

With a total of 3,453 people employed by the 31 national associations who took part in the Alzheimer Europe survey, it is clear that the contributions of the Alzheimer movement in supporting people with dementia and their carers are considerable. As with the members of associations, it has proved difficult to obtain global figures for some countries (France, Germany, Italy), as regional branches which are independent of the national headquarters may also employ staff members which are not included for these countries.

The budgets of Alzheimer associations

The growth of the budgets of Alzheimer associations went hand in hand with the development of services and the increase in staff. Nevertheless, this development is not uniform and a number of organisations continue to survive on an annual income below €100,000. This is mostly the case for organisations in Eastern Europe, such as Croatia, Poland, Romania and Slovenia, but even Austria finds itself in this category.

For a number of organisations, the figures provided by Alzheimer Europe do not adequately reflect the contributions of these associations for the support of people with dementia and their

Country	Central office	Global
Austria	0	0
Belgium	5	5
Croatia	0	0
Cyprus	1	6
Czech Republic	15	23
Denmark	4	4
Finland	17	117
France	12	12
Germany	12	12
Greece	2	7
Ireland	17	437
Italy	8	8
Luxembourg	72	72
Malta	0	0
Netherlands	48	48
Norway	7	17
Poland	1	1
Portugal	5	26
Romania	1	15
Slovenia	0	0
Slovak Republic	0	0
Spain	8	82
Sweden	6	6
Switzerland	7	17
Turkey	2	3
United Kingdom	333	2,530
TOTAL	587	3,453

Table 5 Staff employed by national Alzheimer associations

carers, since the expenditure and income of these associations does not take into account the fundraising and services of the regional organisations in the country.

Despite this, the amount spent by Alzheimer associations for the support of people with dementia and their carers is considerable and totals almost €78 million in 2003. When calculating how much national organisations spend per person with dementia in each country, Luxembourg arrives first (€412.75), followed by Ireland (€205.03) and the United Kingdom (€69.52).

SUMMARY

Country	Income	Expenditure	Expenditure per person with dementia
Austria	8,000	8,000	0.08
Belgium	353,000	273,000	2.11
Croatia	4,000	4,000	
Czech Rep.	200,000	195,000	1.98
Denmark	529,000	507,500	7.69
Finland	2,142,000	2,140,000	36.40
France	4,100,000	3,500,000	4.62
Germany	830,000	820,000	0.79
Greece	196,000	159,500	0.79
Ireland	6,800,000	6,500,000	205.03
Italy	430,500	327,000	0.41
Luxembourg	1,932,000	1,925,500	412.75
Netherlands	4,800,000	4,600,000	27.89
Norway	610,000	365,000	6.32
Poland	50,000	52,500	0.17
Portugal	387,500	400,000	3.86
Romania	30,000	28,500	0.20
Slovenia	8,000	8,000	
Spain	1,989,500	1,828,000	3.74
Sweden	817,000	780,000	6.00
Switzerland	1,950,000	1,948,000	22.06
Turkey	133,000	51,000	
U. K.	54,853,000	51,519,000	69.52
TOTAL	83,062,500	77,796,200	

Table 6 **Income and Expenditure of Alzheimer associations (In 2003 and in Euro)**

While the Alzheimer Europe survey does not provide an exhaustive overview of the services provided by Alzheimer associations and the contributions that they give to the support and care of people with dementia and their carers, the survey has allowed the organisation to give an estimation of the significant and manifold contributions of the European Alzheimer movement:

The 31 national associations, which replied to the survey:

- ▶ Regroup 1,141 regional branches
- ▶ Have 114,981 members
- ▶ Employ 3,452 staff members
- ▶ Run 753 support groups for carers of people with dementia, 120 support groups for people with dementia and 614 training programmes
- ▶ Operate 186 day care centres, 113 home care services and 25 long-term care services
- ▶ Contributed €77,936,500 for the support of people with dementia and their carers in 2003.

PRACTICAL INFORMATION



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THE EXPERT ADVISORY PANEL OF ALZHEIMER EUROPE

The organisation is regularly asked for its views on a variety of important issues for people with dementia and their carers, including scientific and related issues. Recent examples have included ethics of research, genetic testing, stem cell research and legal provisions for people with dementia who have reduced capacity.

In responding to these requests, the organisation of course contacts its member organisations for their advice and views. However, we have been conscious that, as an organisation, we lack in-house expertise to inform our consultations and responses. We therefore decided to set up a Scientific Advisory Panel, with experts in four main fields:

- ▶ Medical and Research Issues
- ▶ Care and Social Issues
- ▶ Ethical Issues
- ▶ Legal Issues

Legal issues

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Denmark

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