Dementia in Europe

Is the dementia epidemic preventable?
Discussion with Professor Lutz Frölich in the European Parliament

Demystifying Dementia
A closer look at media reporting on Alzheimer's disease

Fighting dementia together
Françoise Grossetête explains how dementia is finally being made a European priority.

“The goal has been set ... discover or validate a diagnosis or treatment within 5 years.”
Florence Lustman talks about the French Alzheimer Plan
ACT NOW

Remember those who cannot
6.1 million people have dementia in Europe

THE TIME TO ACT IS NOW
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A warm welcome to Alzheimer Europe’s very first issue of The Dementia in Europe magazine. With predictions that the numbers of people with dementia will be increasing two-fold by 2040, we are launching the magazine at a pivotal time: Policy makers of today have a rare opportunity to change the course of the predicted epidemic of tomorrow. I believe this magazine to be a unique and informative tool for policy makers in that it is the first European magazine entirely dedicated to European policy on dementia.

By creating The Dementia in Europe magazine, we at Alzheimer Europe aim to raise and maintain both awareness and interest in dementia issues, as well as providing up-to-date and thorough information. To this end, this edition brings the most recent findings regarding factors which may increase and/or decrease our risk of getting dementia, which were presented during our third lunch debate at the European Parliament by Prof. Lutz Frölich earlier on this year.

Practical ways of how we (politicians, organisations and individuals) can help ensure that dementia becomes a European priority are given in “A new vision for dementia” and the impact that can be achieved when Members of the European Parliament unite is illustrated when Françoise Grossetête, the Chair of the European Alzheimer’s Alliance, talks about the achievements and hopes for the Alliance.

I am convinced that in 2008, we are witnessing the powerful effects political will can have. With the far-reaching and ambitious French Alzheimer’s Plan being implemented and the English Dementia Strategy being developed, we consider the detail of each plan and challenges that lie ahead.

We were encouraged by the political interest in our 18th Alzheimer Europe Conference “Breaking Barriers” in Oslo. In our coverage, we report on the contribution of Florence Lustman, the co-ordinator of the French Plan and the visit of nine Belgian MPs who attended our conference on a fact-finding mission. They, along with some 620 delegates, were told of the barriers people with dementia and their carers face and the impact barriers can have. This message was poignantly brought home to the delegates by Jan Henry Olsen, the Norwegian ex-Minister for Fisheries, who was diagnosed with dementia, and, his wife, Laila Lanes, both of whom gave exceptionally direct, brave and memorable speeches.

A false representation of dementia itself and of research results in the media can cause unnecessary hardship for people with dementia and for their carers. Jean Georges, Alzheimer Europe’s Executive Director, takes a critical look at the way dementia is portrayed in the press. Alexander Kurz of the Technical University in Munich and Miia Kivipelto of the Karolinska Institute in Stockholm compare the headlines of two newspaper articles with the reality behind these stories.

Conversely, in our Dementia in the News section, we are reminded of the power the media can have in helping people to understand the impact that this disease has in films such as Away from Her and Paul Watson’s documentary, “Malcolm and Barbara: Love’s Farewell”.

We trust that you will enjoy this publication. Together, we can ensure that all the people who live and deal with the effects of dementia receive the best support possible. However, with an epidemic looming, the time to act is NOW.

Maurice O’Connell, Chairperson
PRIORITISING DEMENTIA

A new vision for dementia
Prioritising the needs for people with dementia and their carers

Fighting Dementia Together
Françoise Grossetête talks about how the European Alzheimer's Alliance is making dementia a European priority

The European Alzheimer's Alliance in Action
Members of the European Parliament unite for the dementia cause

Can the dementia epidemic be prevented?
Lutz Frölich addresses this important question at the Alzheimer Europe lunch debate in the European Parliament

Breaking Barriers
Report on the annual Alzheimer Europe conference from Oslo

Françoise Grossetête
"It is clear we need to make Alzheimer's disease a European public health priority."

Breaking Barriers
Jan Henry Olsen, ex Fisheries Minister for Norway at the Oslo Conference
Prioritising Dementia

A NEW VISION FOR DEMENTIA

The political priorities of the European Alzheimer movement

Alzheimer Europe and its 31 member organisations adopted the Paris Declaration in 2006 in order to identify the action required by all stakeholders in the fight against dementia. To date, 70 members of the European Parliament have pledged to support the organisation’s campaign to make dementia a European priority.

The scale of the problem and some issues the Declaration seeks to address are that:

- 6.1 million people currently live with a form of dementia in the European Union
- Every year, 1.4 million people develop dementia in Europe
- Every 24 seconds, a new case of dementia arises in the European Union
- A diagnosis of Alzheimer’s disease can take up to 20 months in Europe
- Only 17% of carers are satisfied with the level of dementia care in their country
- 1 in 5 carers receives no information at diagnosis.

Identifying the priorities regarding dementia within four main areas (public health, research and medical, care and social support, and legal and ethical), the Declaration calls upon the European Union, the World Health Organisation, the Council of Europe and national governments to recognise fully the challenge that dementia presents us with and to take immediate action. Action plans on European, international and national levels are urgently needed to develop comprehensive strategies and solutions to address the different needs of people with dementia and their carers.

Much can be done in the fight against dementia in the areas of research and medicine. We need to address the wide variations in the length of time it takes to diagnose someone with dementia, which, in Europe, ranges from 10 months in Germany to 32 months in the United Kingdom. Dementia needs to be a compulsory part of medical training in order that the medical profession is aware of all aspects of the disease.

In addition, awareness campaigns are required targeted at the general public. Treatment of the disease needs to be both available and accessible under the state reimbursement system. Perhaps, most importantly of all, research needs to be shared with better collaboration on a pan-European level: This requires greater funding for Alzheimer’s research and active support for research centres.

Unfortunately, recent figures show us that only 41% of carers receive information on Alzheimer associations and only 18% on services available to them. Indeed, the majority of carers were unaware of existing services or felt they were unavailable to them. It is crucial that the medical profession ensures that newly diagnosed patients and their carers are given full support information. It is also pertinent for national governments

Facts about Dementia

Types: There are over 100 different types of dementia, with over half being attributed to Alzheimer’s disease. Vascular dementia and dementia with Lewy bodies are often considered to be other common forms.

Who it affects: Currently over 6.1 million Europeans have dementia. The risk of getting dementia increases with age but age alone does not result in dementia, nor is it exclusively an elderly condition.

Symptoms of dementia: The loss of brain cells associated with dementia results in a gradual and progressive deterioration of the person’s ability to function, mentally and behaviourally, eventually leading to death.
to recognise the significant burden carers of people with dementia carry and supply the necessary support in the development of adequate respite services.

The disclosure of the diagnosis to people with dementia varies greatly between European countries ranging from only 23% in Spain up to 80% of people in Scotland. People need to be informed so they are able to take an active part in decisions which affect their lives. Medical codes of practice regarding the disclosure of diagnosis need to be reinforced so that people are empowered to take control of their lives whilst they can.

Alzheimer Europe’s Lawnet projects revealed a wide variation of national laws regarding guardianship systems. The Council of Europe and national governments need to exchange best practices with regard to guardianship systems to allow people with dementia to nominate guardians or legal representatives who can support and represent them in their financial and healthcare management.

Advance directives can help families, carers and the medical profession to respect the person with dementia’s wishes. Governments need to provide a clear statutory basis for effective advance directives so that a person with dementia’s best interests can be protected.

National Alzheimer Associations play a crucial role by offering support, training, helplines and care for both people with dementia and also their carers. National governments need to recognise their invaluable contribution and provide a range of financial support such as VAT exemptions and tax deductibility of donations.

Much needs to be done if we are to meet the challenges of dementia head on, but together we can make a difference. With the number of cases of dementia in Western Europe expected to double, and in Eastern Europe to treble by 2040, “the time to act is NOW”.

**THE NUMBER OF PEOPLE WITH DEMENTIA IN EUROPE IN 2005**

<table>
<thead>
<tr>
<th>Country</th>
<th>Age group</th>
<th>Number of people with dementia (EURODEM)</th>
<th>As % of total population</th>
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<tr>
<td>Austria</td>
<td>30-94</td>
<td>305,511</td>
<td>1.27</td>
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<td>Belgium</td>
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<td>129,916</td>
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**EU27 – TOTAL**

6,126,842 1.25

**Iceland**

30-99 2,845 0.97

**Norway**

30-99 61,077 1.33

**Switzerland**

30-94 97,068 1.31

**Turkey**

30-74 129,715 0.18

**Other countries**

296,705

**GRAND TOTAL**

6,411,547

The length of time it takes to diagnose someone with dementia ranges from 10 months in Germany to 32 months in the United Kingdom.
In this article, Alzheimer Europe interviews Françoise Grossetête, Member of the European Parliament and Chairperson of the European Alzheimer’s Alliance about the activities of the Alliance, the commitment of the French government to the fight against Alzheimer’s disease and the possibilities for European collaboration on dementia.

Françoise Grossetête: Recent research has shown that 6.1 million Europeans have Alzheimer’s disease or another form of dementia. This is only the tip of the iceberg, since the disease does not only affect patients, but the family and carers of the patient are equally affected. At the same time, these numbers will continue to grow with the ageing of the European populations and it is expected that by 2050, the number of people with dementia will have grown to 15 million. Add to that the fact that Alzheimer’s disease is already the first cause of dependency and it is clear that we need to make this a European public health priority.

Françoise Grossetête: There are different ways in which MEPs can become active. In some of the more recent political discussions in the European Parliament, I have ensured that the specific needs of people with Alzheimer’s disease are not forgotten. This was the case for a recent discussion on the participation by the Community in a research and development programme aimed at enhancing the quality of life of older people through the use of new Information and Communication Technologies (ICT). The European Union will contribute EUR 150 million to the programme.

I welcomed the adoption of the report and highlighted the need for the European Union to address the challenge of the ageing of European populations, in particular with regard to the growing use of technologies to enhance the quality of life of older people by alleviating and supporting people with memory, visual, auditive and mobility deficiencies.

Also, at the hearings of Ms Androulla Vassiliou, the new Health Commissioner, I asked what she intended to do in the field of Alzheimer’s disease, the third cause of mortality in the world and I was encouraged to hear that she gives primary importance to mental health and she feels that if we do not take action now, we will face many problems in the future.

But, we do not only work in an individual capacity, but work alongside policy makers from the same country or from the same political group. And I am personally encouraged by the great interest that different MEPs have shown to the European
Alzheimer’s Alliance which I have the honour of chairing.

AE: Could you describe the remit of the European Alzheimer’s Alliance?

FG: The European Alzheimer’s Alliance is a non-exclusive, multinational and cross-party group of Members of the European Parliament. We currently count 44 members from all political groups in the European Parliament and from 17 different European countries.

Our Alliance’s mission is to:
• Give the political signal that immediate and concerted action is needed at European and national level in the field of prevention, diagnosis and treatment of Alzheimer’s disease, research and social policies,
• Influence the European political agenda,
• Foster a favourable environment at European and national level where adequate resources are devoted to address the public health issue raised by Alzheimer’s disease,
• Promote actions that will give dementia and Alzheimer’s disease the priority it deserves at European and national level,
• Exchange information and work closely with European networks active in the field of Alzheimer’s disease.

AE: What are the activities of the Alliance?

FG: For a recently created group of Members of the European Parliament, the Alliance has already carried out an impressive list of activities. Alzheimer Europe launched its “Dementia in Europe Yearbook” comparing the social support systems of different European countries in the European Parliament in November of last year and we were delighted that Social Affairs Commissioner Vladimir Spidla participated. He gave a very clear commitment to including the social aspects of Alzheimer’s disease in European Union activities and also highlighted the need for concerted action in order to prevent elder abuse.

Astrid Lulling, one of my colleagues from Luxembourg and also a member of the Alliance, hosted a week long exhibition in the European Parliament to coincide with World Alzheimer’s Day on 21 September. The exhibition was entitled “Remember those who cannot” and provided a real call for action for us policy makers. I was really delighted to see so many of my colleagues participating at the launch of the exhibition.

In April of this year, the Alliance organised a lunch debate on the possible prevention of Alzheimer’s disease. Professor Lutz Frölich from Mannheim provided us with an exhaustive overview of the current scientific knowledge.

In April, I also worked on a Written Declaration on Alzheimer’s disease which I will deposit together with my colleagues from the Alliance, Jan Masiel from Poland, Brian Crowley from Ireland, John Bovis from the United Kingdom and Joseph Muscat from Malta.

AE: Could you please explain to us what a written declaration is and what the declaration is about?

FG: A written declaration can be deposited by

“For a recently created group of Members of the European Parliament, the Alliance has already carried out an impressive list of activities.”
Françoise Grossetête
“I am indeed proud of the very strong commitment that President Sarkozy has given to the fight against Alzheimer’s disease.”
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up to five Members of the European Parliament and is open for signature for a period of two months. If after this time, more than half of the Members of the European Parliament have signed the Written Declaration, it becomes an official document of the European Parliament. If that is not the case, the document unfortunately lapses.

In our Written Declaration, we call on the European Commission and the Council to recognise Alzheimer’s disease as a European public health priority and develop a European action plan to:
• foster pan-European research into the causes, prevention and treatment of Alzheimer’s disease,
• improve early diagnosis,
• simplify procedures for patients and carers and improve their quality of life,
• promote the role of Alzheimer associations and provide them with regular financial support.

AE: France already seems to be very active in the fight against Alzheimer’s disease. Could France be a model for the rest of Europe?

FG: I am indeed proud of the very strong commitment that President Sarkozy has given to the fight against Alzheimer’s disease. He pledged EUR 1.6 billion for the implementation of the Alzheimer Plan which runs from 2008 to 2012 and the plan will not focus solely on increasing our understanding of the disease, but is a truly comprehensive strategy covering the medical, care, ethical and legal aspects of the disease. I am of course also aware that other countries, such as Germany and the United Kingdom are also discussing new ways of prioritising dementia in the development of their own research and public health activities.

In the second half of this year, the French Presidency of the European Union will dedicate a European conference to Alzheimer’s disease and I hope that this conference will give a clear signal from all Health Ministers for increased collaboration between European countries in medical research, but equally in the exchange of best practices in the field of the care and support of people with Alzheimer’s disease.

AE: Ms Grossetête, Thank you very much for your time and your continued support to our campaign.

OVER 40 MEPS ARE MEMBERS OF THE EUROPEAN ALZHEIMER’S ALLIANCE, PLEASE SUPPORT US BY JOINING NOW

☐ As an MEP, I hereby confirm that I want to join the European Alzheimer’s Alliance.

First name ______________________ Last name ______________________

Town __________________________ Country __________________________

Your signature __________________________

Thank you for returning the completed form to Alzheimer Europe by mail to 145 route de Thionville – L-2611 Luxembourg or faxing it to +352-29 79 72
1 Two Dutch MEPs (Corien Wortmann-Kool and Dorette Corbey) in discussion at the AE exhibition in the European Parliament
2 British MEP John Bowis signs Paris Declaration while AE EU Public Affairs Officer Annette Dumas looks on
3 Greek MEP Marie Panayotopoulos shows her commitment to Alzheimer Europe’s campaign at a meeting organised by Athens association
4 Eva Himmer, chair of Hungarian Alzheimer’s association exchanges views with Katalin Levae, MEP during press conference for World Alzheimer’s Day
5 Mairéad McGuinness, MEP finds out more about situation in Ireland from AE Chairperson and Chief Executive of the Irish Alzheimer’s Society Maurice O’Connell
6 Astrid Lulling, MEP from Luxembourg, hosted week-long AE exhibition in the European Parliament
7 Françoise Grossetête, MEP (France), European Alzheimer’s Alliance Chairperson with Astrid Lulling, MEP (Luxembourg) and AE Executive Director Jean Georges
8 Joseph Muscat, MEP (Malta) takes part in Memory Walk of Maltese Dementia Society on World Alzheimer’s Day
9 Françoise Grossetête hosted AE lunch debate in November attended by Social Affairs Commissioner Vladimir Spidla
10 Polish MEP Jan Tadeusz Masiel (second from left) attends the opening of a new Alzheimer Café of the Ligue Alzheimer in Brussels
Prioritising Dementia

Lutz Frölich addresses this important question at a lunch debate organised by Alzheimer Europe in the European Parliament on 1 April 2008.

“Risk and protective factors in Alzheimer’s Disease and Dementia – Can the epidemic be prevented?” was the title of the third lunch debate which Alzheimer Europe organised in the European Parliament on 1 April. This event was hosted by Françoise Grossetête, the Chair of the European Alzheimer’s Alliance in response to Members of the European Parliament expressing their desire in previous Alzheimer Europe meetings to be updated on research in the field of dementia. Great interest was shown as some 12 Members of the European Parliament, representatives of several Permanent Representations of Member States in Brussels, pharmaceutical companies and Alzheimer organisations were present.

The main message of Professor Lutz Frölich, the keynote speaker during the lunch debate, was that whilst the dementia epidemic cannot be prevented, measures may be taken to delay the onset and/or lower the risk of developing dementia. He stressed in particular, that if the onset of the disease could be delayed by five years, then the prevalence of Alzheimer’s disease would be reduced by almost 50%.

Dementia risk factors identified were an increase in age, genetic variations, genetic mutations, cardiovascular and lifestyle choices, with the last two being in our capacity to alter. We can, ourselves, control our blood pressure, cholesterol levels and weight (cardiovascular factors), our intake of vitamins/antioxidants, fat, fish and alcohol and our smoking habits (environmental/nutritional factors) as well as regulate physical activity, cognitive and psychosocial activity and treat depression.

The strength of the research regarding preventative measures varies. There is evidence for an increased risk of dementia in later life for people who have high blood pressure and cholesterol during midlife. Similarly, clear evidence exists for measures that reduce the risk of dementia (such as antihypertensive medications, eating fish 2-3 times a week, a Mediterranean diet, an active and socially integrated lifestyle and a moderate alcohol intake). However, uncertainty remains regarding the role of blood pressure and cholesterol after midlife, in the role of statins in the prevention of dementia, the role of dietary fats in Alzheimer’s disease, and the effectiveness of the use of omega-3 fatty acids in dementia control.

Lively debate ensued with important issues on prevention being raised such as early screening for the ApoE 4 gene, brain scans and the significance of the biological signs of the disease. Concluding that the dementia epidemic can be delayed, rather than avoided, he likened it to our own death, which is a disease, we spend a lifetime trying to delay!
Having long limbs may be an indication of a reduced risk of developing dementia. Having a larger hippocampus may protect against the symptoms of dementia. Insulin problems may increase the risk of Alzheimer’s disease. Dutch studies suggest that depression may be a risk factor for Alzheimer’s disease. Animal research suggests that drinking coffee may protect the brain from damage. Limited benefits but also increased risk of stroke have been found for elderly people taking ginkgo biloba extract. Incidence dementia may be associated with changes in folate, vitamin B12 and homocysteine concentrations. Having a large waist increases the risk of Alzheimer’s disease irrespective of overall weight. Researchers examine links between oestrogen levels and verbal memory impairment. Study examines the risk of Alzheimer’s disease in children who have two parents with the disease. Study suggests lack of exercise to increase vulnerability to disease as well as ageing process. Study questions role of statins in preventing Alzheimer’s disease.

Treatment

Diagnosis
US company hopes to launch blood test to distinguish between AD and two other diseases. Computers may support Alzheimer’s diagnosis by examining MRI scans. Study concludes that clinical predictors of Alzheimer disease are better than volumetric magnetic resonance imaging (MRI).

RECENT RESEARCH DEVELOPMENTS
This year we have covered a number of research stories, details of which may be found on our internet site (www.alzheimer-europe.org). Areas covered include:

Prevention
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Research development

Diagnosis
US company hopes to launch blood test to distinguish between AD and two other diseases. Computers may support Alzheimer’s diagnosis by examining MRI scans. Study concludes that clinical predictors of Alzheimer disease are better than volumetric magnetic resonance imaging (MRI).
At the 18th Alzheimer Europe Conference, entitled "Breaking Barriers" in Oslo, Norway, some 620 delegates were confronted with the barriers people with dementia face and how necessary, and indeed possible, it is to break them down by exposing the myths and taboos that surround this disease. Encouragingly, amongst these delegates was the coordinator of the French Alzheimer’s Plan, Florence Lustman, the Norwegian State Secretary for the Department of Health and Care Services, Kari Henriksen, as well as nine Belgian MPs on a fact-finding mission, which may be evidence that efforts to get policy makers to face the dementia epidemic seriously are paying off.

At the opening session of the Conference, the first boundary to be challenged was that of how we address the issue of dementia. Professor Mary Marshall from the University of Stirling, Scotland invited us to widen our perspective to ensure that dementia and age ing be considered within a global context, rather than in isolation. Mary emphasised that both ageing and dementia “become more of a challenge when we look at the connections between them and other global issues”. Over 60% of the world’s oldest citizens live in the “developing” world and Mary drove home the impact that food and water shortages, wars and conflict have on people with dementia and the need to address global challenges at national, European and international levels. Half of the world population now lives in cities, and, added to this, is the fact that out of every 35 people, one person is now a migrant (of which nearly half are women), and the consequences for people with dementia are that they can suffer by being either left behind without support, by joining their families but then having to adjust to their new lives but also by being left to be cared for by people from other countries who may, or may not understand the culture they work in. It was clear that dementia cannot be addressed in isolation and this notion was to be heard repeatedly throughout the conference.

Whether it is possible to lead a good life with dementia was considered in the first plenary session. Enlightening and delighting his audience, Carlo Chiesa, an Italian priest who has dementia, told us that despite being frustrated with his inability to recall names of people he has known for many years, he believes
that he is now in the happiest and freest time of his life.

However, it became apparent that opportunities to enhance the lives of people with dementia are being missed. Anyone who heard the Norwegian, ex-Minister for Fisheries, Jan Henry Olsen and his wife, Laila Lanes, talk at the Alzheimer Europe Conference in Oslo, could not have failed to be deeply moved by their brave and open explanation of how living with dementia has not only had an impact on their lives, but has also revealed the barriers that exist for people with dementia. Mr Olsen explained to the Conference how, somewhat unexpectedly, he encountered a barrier as early as when his diagnosis was given. Confused by a well-meaning, but misguided health professional, who wished to “keep it (the diagnosis) quiet” has resulted in Mr Olsen being motivated to challenge such stigmatisation. Christine Swane, Director of the EGV in Denmark, said that “stigmatisation goes to the core of what it means to be a human-being”, yet it is “in this area that there is a huge potential to improve life for people with dementia”. She cited Tom Kitwood’s approach to move the focus away from talking about a person with DEMENTIA to instead focus on a PERSON with dementia as a way to achieve destigmatisation.

“Life for a person with dementia is a life with boundaries” stated Beata Terzis of the Södra Stockholms Geriatric Clinic, Sweden, and she advocated that changing people’s attitudes toward this disease is only part of helping people to live with it. Amongst other measures, Beata talked of the unique benefits early diagnosis of dementia can give in that “unlike many others that receive information concerning a fatal disease, we have – if nothing else occurs- time to prepare ourselves and our loved ones as well. We have time to make the most out of important things in our lives”.

An understanding of the disease itself, the risk factors associated with it, its genetic basis, its clinical features and its development as well as understanding how we might prevent or delay the onset of dementia is crucial if we are to remove barriers to good practice. The plenary session, “Knowledge today, perspectives for tomorrow” was dedicated to just this. Peter Wetterberg of the Department of Geriatrics, Ullevål University Hospital, Oslo, gave an absolutely fascinating presentation regarding memory loss and how being forgetful is distinguished from that of having a disease.

Illustrations of hereditary dementia as well as the consequences of DNA testing were given by Jørgen E Nielsen of the Memory Disorders Research Unit of Copenhagen University Hospital,
Prioritising Dementia

Rigshospitalet who concluded by quoting Erik Pontoppidan who said “You cannot be too cautious in making your choice of parents!”

Describing the measures we can take to reduce our risk of dementia, Miia Kivipelto of the Karolinska Institute, Stockholm, emphasised the need for a combined private and public role to address dementia, reminding us of our own personal responsibility in that “nobody can take better care of your health than yourself”. She also referred to the Ottawa Declaration which states there is a public responsibility to “make the healthy choices the easy ones” reinforcing the multi-disciplinary action required to address this disease.

Fundamentally, any approaches taken to help people with dementia will be bound to fail if they do not recognise, support and value the immeasurable contribution carers make. This was recognised in the title of the final plenary presentations calling carers and volunteers an “irreplaceable resource”. Appropriate support for people with dementia and their carers was, we heard from Florence Lustman, at the heart of the French national plan on Alzheimer’s, but, the importance of collaboration on an international level is necessary to ascertain the nature of the best support to offer.

A range of tailored interventions for carers were recommended by Bob Woods from the University of Wales, UK, after he raised the issues of depression and strain amongst carers. He also illustrated how carers can feel unheard when he quoted a carer saying “It was as if the five years of my looking after him didn’t really count... but it was as if “Oh, we’re the professionals, we know what we’re doing”.

After each plenary session delegates were able to select from a wide range of parallel sessions, which supported the morning’s presentations. Included in the parallel sessions were topics such as end of life issues, sexuality, younger people, legal and ethical issues, art and culture, and technical aids, to name but a few. In addition, the delegates were given insights into the world of people with dementia and their carers by their diary extracts being beautifully read to us by actors Godfrey Jackman and Pam Lyne.

Over the four days a common thread emerged. For people with dementia and their carers barriers do indeed exist which are possible to break, but it cannot be done in an isolated fashion, it requires that all actors collaborate, share information and work together. Only by this tailored, multi-disciplinary approach will we be able to deconstruct barriers.
The Conference ended with a strong and personal message from Heike von Lützau-Hohlbein, of the Deutsche Alzheimer Gesellschaft, whose mother and mother-in-law had both lived with dementia. Heike summarised the challenges that lie ahead for Alzheimer societies, with perhaps the most important being that we should “allow our loved ones to live in dignity with self-determination, hope and humour”. Closing the conference, Heike focused our minds by reminding us of Peter Ashley, who has dementia and who emphasises in his public speeches that “I am living with dementia, not dying from it”.

Alzheimer Europe: Ms Bertouille, a delegation of 9 Members of the Walloon Parliament took part in the Alzheimer Europe conference in Oslo. What led to this visit?

Chantal Bertouille: I recently submitted a draft resolution for “a better management and support of Alzheimer’s disease in the Walloon region”. This led the health Committee of the Walloon Parliament to organise a series of hearings to get an overview of the situation in our region as regards prevention, research and the support of people with dementia and their carers.

In this context, the Walloon Parliament decided to send a Parliamentary Delegation on a further fact finding mission to the 18th Alzheimer Europe Conference in Oslo.

Alzheimer Europe: What impressions did you take home from the conference?

Chantal Bertouille: The conference was a great opportunity to hear about the experiences of other countries and to learn more about some initiatives adopted in other countries to provide responses to the problems caused by Alzheimer’s disease. The knowledge we gained from the conference will undoubtedly enrich our own discussions.

“I am living with dementia, not dying from it”
Heike von Lützau-Hohlbein, quoting Peter Ashley
Overcoming everyday challenges in Alzheimer’s disease

At Lundbeck we are dedicated to overcome the challenges of Alzheimer’s disease. It is our goal to improve the quality of life for people living with the disease and for those who care for them.

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POLICY WATCH

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Neil Hunt
“The real challenge will be getting the leadership, commitment and money in place to make the Strategy happen.”

Florence Lustman highlights her priorities for implementing the French Alzheimer Plan
FRANCE PLEDGES EUR 1.6 BILLION TO FIGHT ALZHEIMER’S DISEASE

French President unveils ambitious Alzheimer Plan to address a “real national drama”

The French President, Nicolas Sarkozy, announced the far-reaching “French Alzheimer Plan” on 1 February this year, pledging EUR 1.6 billion to the five-year programme. The Plan aims to fight dementia and is concerned with three main areas, firstly, to improve the quality of life for people with dementia and their carers, secondly, to develop our understanding of the disease for future action and, thirdly, to mobilise society for the fight against dementia. In total, the Plan lists 11 objectives and over 40 comprehensive measures to achieve these objectives.

Perhaps the most significant measure is under the ambit of developing our understanding of the disease where one objective is to “produce an unprecedented effort for research”. No less than 13 recommendations are listed under this objective.

One objective is to “produce an unprecedented effort for research.”
President Sarkozy

Q: Ms Lustman, you have been appointed by President Sarkozy to coordinate the implementation of the ambitious French Alzheimer’s Plan, a plan that covers 44 important recommendations. Can you highlight the three priorities which you would consider to be the most urgent or important?

With resources of EUR 1.6 billion over 5 years, the Alzheimer’s Plan aims to integrate research, medical care and social care to fulfil the needs of patients and their carers.

The first priority of the plan is to know better Alzheimer’s disease in order to defeat it. A scientific cooperation foundation will be set up with

THE NUMBER OF PEOPLE WITH DEMENTIA IN FRANCE 2005

<table>
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<tr>
<th>Age group</th>
<th>Women</th>
<th>Men</th>
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<td>30-59</td>
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to make France one of the leading countries for dementia research. It is also proposed to establish a new foundation for Alzheimer’s research which should coordinate all efforts of doctors, scientists and researchers in addressing dementia.

The first measure to have been implemented is the “Alzheimer’s disease health and emergency care card” which has been issued to secure better and more appropriate treatment in the case of emergencies for people with dementia. The card opens to display the person’s details, including contact information as well as “golden rules” for handling the disease.

This initiative is one of the first direct results of the report by Joël Ménard, which made a number of recommendations for better solutions for helping both public and private funding. It will coordinate nationally a stronger “translational” research and international cooperation. The goal has been set by President Sarkozy: “to discover or validate a diagnosis or a treatment within 5 years”.

The second priority is to improve the quality of life for patients and their carers. First, the plan will help patients and their families cope with the shock of discovering the disease by giving them a better access to a coached diagnosis. Secondly, the plan will increase the quality and integration of health and social care; it will give every patient access to a one stop-shop, the MAIA, where a specifically dedicated case-manager will design an integrated plan of health and social care suitable for the patient. Home-based support will be developed with new respite structures and adaptation of housing to cognitive handicaps. In rest homes, Alzheimer units will be set up. In all cases, health and social staff will be specifically trained in Alzheimer’s and related diseases.

The third priority is ethical: to change the way people look at Alzheimer’s disease and to set up a new status of the patient.

Q: Alzheimer Europe was delighted to see that the French Alzheimer’s Plan also mentions the importance of making Alzheimer’s disease a European priority. Which actions should we expect to be taken under the French Presidency of the European Union in the second half of 2008.

My mission specifically involves an international perspective: I am developing all useful relations on an international and European basis. The Alzheimer’s plan includes the organization of a pan-European conference on Alzheimer’s disease under the French Presidency of the European Union. This conference will take place in Paris on 30-31 October 2008. It should focus on three main topics including an ethical perspective on each one: developing the coordination of the European research, presumably on strategies of prevention of the disease and the subsequent loss of autonomy; sharing good practices or standards in the management of health and social care on a European level; identifying common objectives on specific skills and training of medical and social staff related to Alzheimer’s disease. We look forward to cooperating within Europe on all these subjects.
Policy Watch

people with dementia and which formed the basis of many of the Plan’s priorities.

The Plan also aims to help families deal with the stress involved with caring for the people with Alzheimer’s and foresees some key initiatives, such as the development of respite care, carer training programmes, domiciliary care services as well as the setting up of a network of nursing homes.

To help meet the EUR 1.6 billion cost of this comprehensive plan and, recognising that the cost of caring for people with Alzheimer’s disease in France is around EUR 10 billion per year, the President believes that everyone should help fight the disease. President Sarkozy therefore proposed that patients contribute a token amount towards their prescriptions and any paramedical aid or medical transport. He also recognises that “this is a lasting commitment on behalf of the state in the fight against this disease. This is a personal commitment”.

The plans have been well-received by all stakeholders, including the French Alzheimer Association.

Although the President called Alzheimer’s disease a “real national drama”, recognition is given to the scope of the disease with the President planning to use the French Presidency to organise a pan-European conference on Alzheimer’s disease. Summarising the path ahead, President Sarkozy said “To fight this illness is a challenge. It has nothing to do with left or right-wing politics. All governments over the next 30 years will be confronted by it.”

“The French Alzheimer plan

- Improve the quality of life of people with dementia and carers
- Develop our understanding of the disease for future action
- Mobilise society for the fight against dementia

1. Improve support and respite for carers
2. Reinforce the coordination between all key actors
3. Make home care a real option for people with dementia and their carers
4. Improve access to diagnosis and ensure a continuous chain of care
5. Improve residential care
6. Develop skill sets and vocational training for all care professionals
7. Make an unprecedented research effort
8. Set up epidemiological monitoring
9. Provide information and increase awareness amongst the general public
10. Promote an ethical debate and approach
11. Make Alzheimer’s disease a European priority

“It has nothing to do with left or right-wing politics. All governments over the next 30 years will be confronted by it.”

President Sarkozy
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Where patients come first
ENGLISH DEMENTIA STRATEGY ABOUT TO BECOME A REALITY

England is on the brink of launching a National Dementia Strategy. Here Neil Hunt explains how it happened, what he wants to see in the Strategy and the challenge that lies ahead.

People in the dementia community have been campaigning for decades to get dementia on the public and political agenda. Sometimes after going to meet politicians or talking on the radio you ask yourself, “Are we getting our message through?” Last year, after developing evidence about the impact of dementia, lobbying and public campaigning in England, we found that all the effort had indeed paid off.

In August last year following discussions with the Alzheimer’s Society, our Government Minister with responsibility for dementia, Mr Ivan Lewis, committed to developing a National Dementia Strategy for England. He said he wanted to see a transformation plan for dementia services that would tackle public and professional awareness, early diagnosis and intervention and improving quality of care. We were delighted and have been working with the Government since then to make it a reality.

How did this happen?

A number of factors were key, but central to achieving the political commitment were a.) getting the evidence to put our case intelligently, and b.) an assertive campaign of public and political work to raise the profile of dementia and the need for a national plan:

1. We gathered the evidence about the scale of dementia, the numbers of people affected and the financial cost. This was put to the politicians and wider public.
2. We worked with other bodies and most influentially the National Audit Office (which is a body that monitors Government expenditure) and politicians on an influential parliamentary committee to make the case and ask the Government for action.
3. We galvanised our local and national network of volunteers to continue challenging public and political audiences to do more. In particular we took the UK medicine body which decides whether people can have publicly funded medication to Court to challenge their decision to restrict access to drug treatments.

All of these factors were key in driving dementia up the political agenda AND when the time came, we had a politician who was willing to act and show leadership on our cause.

What happened after the announcement?

The Government Health Minister Ivan Lewis put Professor Sube Banerjee, a specialist in old age psychiatry and Jenny Owen a Director of adult social services in charge of writing a strategy. In addition he asked me as Chief Executive of the Alzheimer’s Society to put together an external reference group of people with dementia, carers, and organisations who all have an interest in improving life for people affected by dementia to set out the priorities for action.

The external reference group was an invigorating group of people passionate about dementia. All discussions included people with dementia and carers, including people who many of you will have come across like Barbara Pointon and Peter Ashley who are quoted here separately.
What I expect from the Dementia Strategy
Peter Ashley has been living with dementia for eight years and is an internationally recognised advocate for people with dementia.

- People with dementia will be treated with respect throughout their lives and not regarded as second rate citizens; always consulted and included in any debate about them or the subject of dementia.
- People with dementia retain their personhood and individuality no matter how severe their condition. Their voices rank equally with any others whilst in a position to express themselves.
- People with dementia have an absolute right to delegate their wellbeing to any third party whilst in position to do so under a Lasting Power of Attorney (Mental Capacity Act 2005). They can also create an Advanced Directive which must be followed without exception under the law.
- People with dementia expect to receive the best possible care from their nominated care partners and other carers, including the State, throughout their lives, in line with their wishes.
- As people with dementia approach the end of their lives, their rights and wishes should be respected in so far as the law permits. Palliative care will be provided in line with these principles.

The group reported our findings back to the Department of Health and we asked for a radical but achievable plan of action which would significantly change quality of life for people with dementia and their carers. Specifically:

1. A programme of activity to improve public and professional understanding about the symptoms of dementia, the importance of getting a diagnosis and what help is available. We also said that public campaigns about stigma need to reduce the fear and stigma that people feel.
2. Getting services in place to diagnose dementia early and accurately and then having information and help available to help people through their journey.
3. Making sure that people who work with people with dementia have the attitudes, knowledge and skills to be in a position to provide high quality care. This needs to happen whether someone is in their own home, or in a hospital, or in a care home.

What happens next?

In June the Government will publish a draft strategy and the Society will respond. In doing so we will draw on the views and experience of people with dementia and their families. We are very conscious that opportunities like this one do not come often and we need to make the most of it.

What will the challenges be?

The real challenge will be getting the leadership, commitment and money in place to make the Strategy happen and lead to real changes for people with dementia. It is no good having a great plan if no one does anything about it.

The Alzheimer’s Society in England will be looking at what we can do as a service provider to support the delivery of the Strategy for people with dementia. We will also continue to raise the political pressure and public awareness that are needed to keep dementia high on the agenda for the health service, social care, politicians and the public.

Conclusion

We need dementia to rise to the top of the public and political priority list. Dementia needs to be considered as important as cancer or heart disease.

The National Dementia Strategy for England will be a significant step forward in that journey. The challenge will be to ensure that a good plan delivers substantial change. I hope that the priority that dementia is being given in the UK to this work will help other nations to achieve the same level of commitment and progress.

“"It is no good having a great plan if no one does anything about it”
Neil Hunt

What I expect from the Dementia Strategy
Barbara Pointon, who cared for her husband Malcolm up until his death from Alzheimer’s disease last year, shares her priorities for the English Dementia Strategy.

- Dementia education for all medical and nursing staff, care-workers (wherever they work) and those who come into official contact with the elderly (e.g. police)
- Free respite/replacement care for carers in return for all the money they save the State.
- A fully integrated, holistic dementia service which recognises the full spectrum of needs – physical, mental, psychological, sensory and spiritual.
- Improving quality of life for the person with dementia and their carer – at every stage of the illness
The Hague Convention on the International Protection of Adults provides rules for the mutual recognition of guardianship measures, yet only the United Kingdom and Germany have ratified this important legal instrument with the former explicitly limiting the scope of the Convention to Scotland. This article explores the articles of the Convention in greater detail.

In a Europe where people are increasingly mobile, in particular, when retirement can equate with emigration, there is a pressing need to have clarity over applicable health rights and responsibilities. Take the following case: George, a retired Swedish labourer, decides to see out his days in Croatia. He keeps his car in Sweden, partly so he can get around when visiting relatives but also because the one passion in his life was motor cars and he is the proud owner of a classic Saab. He moves into his newly-purchased Croatian one-bedroomed apartment overlooking the sea. Unfortunately, George is diagnosed with Alzheimer’s disease, and as the disease progresses, he finds himself no longer able to deal with his personal finances and he is not in a position to pay for care as well as his living costs. Even though he is unable to drive his car, he is incapable of selling it. George’s brother, Martin, wants to make sure George has sufficient funds to be cared for so considers selling both George’s beloved car and his new apartment.

Now the legal questions start. Should Martin apply for a court order in Sweden or Croatia? If Martin is appointed as the legal representative of George in Croatia, can he also sell George’s car in Sweden? What about George’s bank account in Sweden? Can Martin use George’s money to pay for some of the living costs such as the electricity? Can Martin rent out, or indeed sell, George’s apartment to raise the money George will need for future care?

The Hague Convention on the International Protection of Adults was developed in 2000 to find solutions for just this type of practical problems faced by carers of people who become unable to represent themselves. Amongst the issues that the Convention wants to address are:

- Which country has jurisdiction? In George’s case, a Croatian court would have been in charge as George had his normal residence there and Martin could have asked the court to become George’s legal representative.

- Can legal representatives act outside their normal country? If both Sweden and Croatia had ratified the Convention, it would have been possible for Martin to act on his brother’s behalf in both countries. In order for the guardianship measure to be applicable, the Croatian courts would have issued a certificate to Martin outlining his authority as an attorney and/or guardian which would have been recognised in Sweden. Martin would then have been able to close George’s bank account in Sweden or even sell his car.

- Which law is applicable? According to the Convention, Croatian law would have been applicable, as the initial guardianship decision was made by a Croatian court. This would mean that George’s brother would have the same authority in Sweden as he would have in Croatia.

We need clear rules of international law to improve people’s protection if they become mentally incapable of looking after themselves or their affairs.
Alzheimer Europe recognised the usefulness of such a Convention for people with dementia and their carers and called on national governments to ratify the Convention, as three countries need to have done so, for it to enter into force. So far only two countries have ratified the Convention.

The United Kingdom ratified the Convention in November 2003, but limited its scope to Scotland. On the day of the ratification, Scottish Deputy Justice Minister Hugh Henry stressed that: “We need clear rules of international law to improve people's protection if they become mentally incapable of looking after themselves or their affairs. This protection can only be delivered by means of legal regulation and international co-operation. The Convention reflects and applies in a practical way the guiding principles of independence, inclusion, care, self-fulfilment and the dignity of the individual.”

Germany followed Scotland’s example and ratified the Convention in April 2007. The Federal Minister of Justice Brigitte Zypries summarised the role of the Convention as follows: “As Europe grows closer together, people have become increasingly mobile in both their professional and personal lives, and the number of citizens living outside their home countries continues to rise. At the same time, questions pertaining to protective measures for incapacitated adults are gaining in importance for increasing numbers of people. Persons living outside of their home countries also need to be able to get fast, citizen-friendly answers to legal questions involving protective measures for incapacitated adults. The Hague Convention on the International Protection of Adults is designed to fulfil this purpose. “

Q: Mr Peddie, the United Kingdom was the first country to ratify the Hague Convention on the International Protection of Adults in 2003, but did so by limiting its scope to Scotland alone. Why does Scotland consider this convention to be such an important legal instrument?

As populations age and societies become increasingly globalised, the need for a comprehensive worldwide instrument to protect vulnerable adults has never been greater. For instance, increasing numbers of people are choosing to retire to countries other than those in which they and their families reside. This means that action to protect vulnerable adults must be seamless and coordinated across borders. We in Scotland believe that the Convention answers that need by reflecting and applying in a practical way the guiding principles of independence, inclusion, care, self-fulfilment and the dignity of the individual. The Scottish Government is committed to those values in terms of its domestic policy, which is why we enacted appropriate domestic legislation (the Adults With Incapacity Act) in 2000 and were then the first jurisdiction to ratify the Convention. It is worth noting that Scotland also played a significant role in the development of the Convention: for instance Professor Eric Clive of Edinburgh University chaired the Diplomatic Special Commission in The Hague that completed the negotiations on the Convention.

Q: Germany is the second country to ratify the Convention in 2007, but the Convention needs at least three ratifications to enter into force. Can you explain the seeming reticence of countries to sign?

I understand that only 5 countries have signed the Convention so far, and only 2 have ratified. As I am sure you will appreciate, I cannot speak for other countries as to why they have not yet signed, or, where they have signed, ratified, the Convention. Naturally, a State will want to ensure that its domestic law meets the Convention’s requirements before it commits itself to complying with its terms. We went through that process for Scotland before our ratification took place, and other countries would have to do so too before ratifying although they may also have other policy and/or practical issues that we in Scotland are not aware of.
POLICY OVERVIEW

Taking research seriously – Germany commits EUR 50 million annually to Centre for Neurodegenerative Diseases

Plans for a new research centre for neurodegenerative diseases in Germany were unveiled in February 2008, with the Minister for Education and Research, Annette Schavan, dedicating a much-needed EUR 50 to 60 million per year to this project.

The Centre will have scientists and doctors working alongside each other to address the demands arising from a higher life expectancy and demographic development of the population.

Alzheimer’s disease will be among those diseases studied. Annette Schavan said “We want to give people a better life through research into the causes of the diseases, new possibilities for prevention and early recognition, development of effective therapies and the best form of care”.

Causing particular excitement is the new level of collaboration that the project demands between all participants, doctors, scientists and institutions, throughout Germany. The “Helmholtz-Zentrum Bonn – Deutsches Zentrum für neurodegenerative Erkrankungen” as it will be called, will be based in Bonn, and collaborate with four institutions, the University Clinic of Bonn, the Research Centre CESAR, the Max-Planck Institute for Research into the Elderly in Cologne and the Neuroscience Research Centre of Helmholtz Jülich.

Attached to the main Centre will be six partners (in Göttingen, Munich, Tübingen, Madgeburg, Witten and Rostock/Greifswald) and Dresden will become a partner institute.

Raising awareness and giving support: Scotland announces new three-year package for people with dementia and their carers

The Scottish Public Health Minister, Shona Robinson, announced in April that the Scottish government would, over three years, be investing more than £630,000 to support people with dementia and their carers.

Highlighting the problems that follow diagnosis she said “A diagnosis of dementia can and does have a traumatic effect on all concerned. Everything that can be done to minimise that trauma through immediate help and advice should be done.” Recognising the need for post-diagnosis support and advice for patients and their families, the Scottish government has asked for proposals for practical solutions from Alzheimer Scotland and the Dementia Services Development Centre.

Funding has also been dedicated to an innovative arts-in-health programme to support people with dementia who are in hospital and hospice care.

The Scottish government has committed itself to issuing regular updates on their key actions on dementia care as part of their public awareness and information campaign.

English Court asks NICE to be more transparent in their assessment of anti-dementia drugs.

The manufacturers of anti-dementia drugs, Eisai, Pfizer and Shire, were successful in their appeal against the National Institute for Health and Clinical Excellence (NICE)’s method for calculating the cost-effectiveness of anti-dementia drugs. The drug companies had claimed that NICE had not been transparent in carrying out these calculations.
and the Court of Appeal agreed. This may have far-reaching effects for other NICE decisions which have been based on the same economic model.

The Court of Appeal ruled that NICE must now make available to the drug companies a “fully executable” version of the economic model they used in their calculations. Eisai and Pfizer may then make new representations from which NICE may reappraise their recommendation.

The Court of Appeal’s decision has been welcomed by Alzheimer associations. Jim Jackson, Chief Executive of Alzheimer Scotland, said, “We will all now be able to examine how they reached their perverse recommendation not to prescribe these treatments at the beginning of the illness, when they are most likely to be of benefit”, and, Neil Hunt, the Chief Executive of the Alzheimer’s Society, said the decision was a damning indictment of the “fundamentally flawed process” used by NICE and called on NICE to reconsider its decision in order to make the drugs available.

**Consultation and risk assessment required for the EU Directive on electromagnetic fields**

The European Parliament has approved the Commission’s request for a four-year postponement of EU Directive 2004/40/EC. The delay will enable time for a comprehensive risk assessment of the Directive and a stakeholder consultation, after which amendments to the Directive can be made.

The Directive lays down the minimum health and safety requirements at work where workers are exposed to risks from electronic fields. However, the current published Directive has the effect of denying those people who may require assistance (for example, the elderly) during MRI (magnetic resonance imaging), as it prescribes that healthcare staff may not help patients during the MRI imaging process itself. MRI is an essential tool for the diagnosis of certain forms of dementia, as well as for treatment and research programmes in the field of dementia.

The postponement is a direct result of the lobbying by the Alliance for MRI, of which Alzheimer Europe was an active member. “It is essential that this major advance in healthcare technology is not threatened by burdensome legislation when concerns can be addressed through responsible guidance to medical and service personnel” stated the Alliance for MRI.

**EU Directive on cross-border health care delayed**

At a meeting on patients’ rights organised by the Ludwig van Mises Institute in the European Parliament, Philippe Brunet, Head of Cabinet of the EU Health Commissioner, announced that the directive on cross-border healthcare initially planned for April 2008 would be delayed.

**Ms Androulla Vassiliou the new Public Health, Food Safety, Animal and Welfare Commissioner, promises high health standards for Europeans.**

The new Public Health, Food Safety, Animal Health and Welfare Commissioner, Ms Androulla Vassiliou, has replaced Mr Markos Kyprainou, who left to become the Cypriot’s foreign minister.

Ms Vassiliou, who said, “Health is wealth and I am determined to work hard towards ensuring high standards for our citizens, be they in Romania, Sweden, the UK or Cyprus” Androulla Vassiliou
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DEMENTIA IN THE NEWS

Demystifying Dementia
A critical look at media reporting of dementia research by Jean Georges, Alexander Kurz and Miia Kivipelto

Dementia in Society
Our understanding of dementia is helped by films such as “Away from Her”, moving documentaries by Paul Watson and reports of Terry Pratchett’s diagnosis of Alzheimer’s disease and of Charlton Heston’s death.

Spotlight on... Switzerland
Looking back on twenty years of achievements of the Swiss Alzheimer’s association

Putting a face to commitment
The people behind Alzheimer Europe

“Breakthroughs” in dementia
“Is research accurately represented by the press?”

Alexander Kurz
“Misinterpretation is driven by sensation-seeking and is accomplished by overstatement and simplification.”
Jean Georges, Executive Director of Alzheimer Europe, takes a critical look at some of the research findings reported in the media.

Of Mice and Men

Hardly a day goes by without some new research into the diagnosis, prevention or treatment of Alzheimer’s disease or other forms of dementia being reported in the media. This is testimony to the increased research effort being undertaken and should be reason for hope that new and more effective treatments will one day be available.

People living with dementia today, and their carers, are justifiably impatient for such news and are desperate for a breakthrough sooner rather than later. We therefore owe it to them to report research news in a responsible fashion, without raising false hopes or causing concerns.

Getting past the headline

Let us have a look at some of the recent headlines appearing in the media. “Discovery of the decade?” asked the Belfast Telegraph on 16 April. “Alzheimer’s helmet therapy hope” could be seen on the BBC website on 25 January and the Daily Express already promised a “Breakthrough on Alzheimer’s” on 17 December 2007. Google the two words “Alzheimer’s” and “breakthrough” and you will get over a million results, 1,060,000 to be exact. “Alzheimer’s” and “hope” will still get you a very respectable 470,000 hits. Yet, are we truly closer to a cure or new treatment for people with Alzheimer’s disease?

Reading the article after the headline often makes for more sobering reading. The “discovery of the decade” was in fact a case study showing promising results of a drug in a single patient, the “therapy hope” referred to research on mice that has not yet been reproduced in humans and the “breakthrough on Alzheimer’s” had not shown any conclusive results with people who actually have dementia, but only that a camera could help healthy individuals with memory recall.

It is understandable that when reporting on terminal illnesses, such as Alzheimer’s disease, there is a real desire to deliver good news. However, embellishing or summarising stories may instead result in false hopes and ultimately disappointments for those most affected by the disease.

Comparing the headline “Animal research suggests that drinking coffee may protect the brain from damage” with “A daily cuppa beats dementia” illustrates the different slant the same news may be given. The former is somewhat less dramatic, yet I am convinced that it is more informative and closer to the scientific facts. In short, the first headline is of far more real use to the people who read it.

Making sense of research stories

Reading scientific news often requires some real understanding of the organisation of research or of the development process of new medicines. Unfortunately, it is not possible to always include the full details of the drug development process when reporting on research “breakthroughs” on new treatments for Alzheimer’s disease and other forms of dementia, but it may be useful to highlight the key stages. Any reader needs to have information placed in context and, in respect of drug development, it is essential that the reader
understands the timescales involved in the drug
development and production.

- During the preclinical development, laboratory
tests document the effect of an investigational
drug on cells in the test tube and in animals to
assess their safety.

- Phase I clinical trials are normally conducted
on health volunteers to assess the short-term
tolerability and safety of a new compound.

- In phase II clinical trials, the efficacy and safety
of a product is tested on several hundred pa-
tients treated for usually several weeks or a few
months.

- These results are refined and confirmed in phase
III clinical trials which involve larger patient
numbers, as well as long-term treatment.

- The results of the clinical trials are submitted for
regulatory approval (for Alzheimer’s treatments
to the European Medicines Agency) who will
give their opinion on whether the products
meets all the safety and efficacy requirements
and whether it should be approved. In case of a
positive opinion, the drug can be marketed and
be made available to patients.

With these figures in mind, it is worthwhile
revisiting some of the research stories that made
the news. Some of the reported breakthroughs
were the results of research carried out on mice
into new treatments, diagnostic tools or preven-
tion methods. Research on animals is carried out
at the earliest stage of drug development and any
results will need to be confirmed and fine-tuned
in humans. As mentioned above, that process is
long and the failure rate is high, so any such
research story of results in mice should always
be accompanied with the necessary caveats and
cautions. Similarly, results of case studies or a
small number of patients will similarly need to be
confirmed in bigger and longer clinical trials.

Two important points need to be made here
which should underpin any interpretation
of research news about new treatments or cures
for Alzheimer’s disease. Drug development is a
lengthy process and it can take ten to thirteen
years from the identification of a new molecule
to its reaching individual patients. Also, the
attrition rate in the development process is very
high and, according to the Innovative Medicines
Initiative, only 1 in 10,000 drug candidates
reaches patients.

We owe it to people living with dementia, as well
as their carers, to provide them with realistic and tangible
information. Publishing individual break-
through stories which are at best premature and
at worst may raise false hopes can only add to the
heavy burden of those people who are already
trying to cope with this devastating condition.

The media are absolutely essential in passing on
otherwise unattainable research news, but to do
so without reflecting on the consequences of their
reporting style can lead to misunderstandings
and dashed hopes. Breakthroughs can be made at
any stage of the drug development process but to
hail them as such without giving the breakthrough
a context is misleading.

With the growing commitment to research in
different European countries, together with the
improved collaboration between research centres,
we can all hope that the real medical break-
through that helps people with dementia is com-
ing. Let us get the facts straight and the meaning
clear, after all, mice are not men.

“We owe it to people living with
dementia, as well
as their carers, to
provide them with
realistic and tangible
information.”
Jean Georges
A miracle cure for Alzheimer's disease?

Prof. Dr. Alexander Kurz considers the newspaper claim that Alzheimer's symptoms can be reversed in minutes.

A headline in the Daily Mail on 10th January 2008 has created a wave of public interest, confusion and alarm. It reads: Drug' can reverse Alzheimer's symptoms in minutes. The media report goes on to state that "A drug used for arthritis can reverse the symptoms of Alzheimer's in minutes. It appears to tackle one of the main features of the disease: inflammation in the brain".

The newspaper report refers to an article in the Journal of Neuroinflammation published online on 9th January 2008. In that article, Edward Tobinick and Hyman Gross describe a rapid treatment effect of Etanercept observed in a 71-year-old patient with moderate dementia with Alzheimer's disease (AD).

The authors state that ten minutes after dosing the patient was calmer, less frustrated and more attentive. His responses to questioning seemed less effortful and more rapid. Two hours after drug administration an improvement was observed on several simple cognitive tests compared to testing before treatment. After seven weeks further improvement was noted on these tests.

In 2006, the authors of the case report had used Etanercept for the treatment of 15 patients with mild to severe AD in an open-label study. After 6 months of weekly injections a significant improvement in three dementia tests was observed as well as rapid clinical improvement within minutes.

What does the case report show?

Ten minutes after the injection of the drug minor changes in the patient's behaviour were observed, and two hours later his performance on simple tests were somewhat better. The observation of a temporal association between a change in behaviour or performance and application of a drug does not demonstrate a causal relationship as the changes could be due to a number of factors including a placebo effect, the dramatic treatment procedure, spontaneous fluctuation in the patient's condition, or responses of the patient to his environment. The same limitations apply to the pilot study. Without a group of patients randomly assigned to placebo it cannot be excluded that improvements on tests were due to the placebo effect, repeated administration of the same tests, or spontaneous fluctuations of the patients' cognitive abilities. Case reports and open-label studies may provide first cues to the possible effects of drugs which must be rigorously tested in randomised controlled trials on sufficiently large patient populations.

What is etanercept?

Etanercept is a drug used for the treatment of rheumatoid arthritis and psoriasis. It acts by blocking a natural protein which induces inflammation: tumor necrosis factor alpha (TNF alpha), which is is a pro-inflammatory protein synthesised by a variety of cell types.

What is the role of inflammation and anti-inflammatory drugs in Alzheimer's disease?

An inflammatory response does occur in AD, particularly in the vicinity of the deposits of beta amyloid. However, AD is not an inflammatory disease, and it is not clear whether the inflammatory response is a cause or a consequence of other pathological events.
What is wrong with the newspaper article?

Neither the case report nor the pilot study claimed a reversal of symptoms. There were only minor changes in behaviour and performance on simple tests. The media article grossly overstates these observations. The article also exaggerates the role of inflammation in Alzheimer’s disease.

Finally, it grossly simplifies the role of TNF alpha accusing it of damaging the brain, which is not supported by science. In summary, the article in the Daily Mail is an awkward example for the misinterpretation of scientific findings. These results themselves raise a number of doubts, but this is another issue. The misinterpretation is driven by sensation-seeking and is accomplished by overstatement and simplification.

**Dementia: preventing facts from becoming fiction**

Mia Kivipelto, MD, PhD, highlights why news coverage of Alzheimer’s should not be over-simplified.

This optimism attracts much media interest, with the positive effect of increasing awareness of cognitive problems. However, the media forgets sometimes that Alzheimer’s disease is a complex disease, involving interactions between many genetic and environmental factors. Lifestyle factors are interrelated, so it is often impossible to separate their effects and pinpoint a single factor as most important. This can be illustrated by newspaper headlines such as: ‘A daily cup of coffee may halt Alzheimer’s or ‘Cabernet Sauvignon red wine reduces the risk of AD’ or ‘Eating broccoli may reduce dementia risk’. Constantly assaulting the public with oversimplified (even contradictory) ‘prevention advice’ can only create confusion, false hope and unnecessary anxiety. Such headlines are often based on a single and sometimes methodologically limited epidemiological or experimental study.

Things should be made as simple as possible, but not over-simplified. Reducing dementia risk requires **integrative action**. The Cardiovascular Risk Factors, Aging and Dementia (CAIDE) research group in Finland and Sweden has recently created the Dementia Risk Score which is the first tool to estimate dementia risk based on risk profiles (age, gender, education, midlife blood pressure, cholesterol, body mass index, physical activity) instead of single factors. This Score is meant to identify people who could benefit most from preventative interventions.

However, pieces are still missing from the Alzheimer risk factor puzzle and more studies are needed to formulate adequate integrative lifestyle interventions and to clarify to what extent they can delay cognitive impairment/dementia. Synchronization and critical reviewing of available data should also be highlighted and is urgently needed for health education and community planning.
DEMENTIA IN THE NEWS

DEMENTIA IN SOCIETY

A roundup of how dementia is reported and portrayed in literature and the arts

CHARLTON HESTON DIES WITH ALZHEIMER’S DISEASE

Charlton Heston died at his home in Beverly Hills on 6 April at the age of 84. In 2002, he announced he had the early stages of Alzheimer’s disease. One of his last public appearances was at the White House in 2003 when he received the Presidential Medal of Freedom.

Heston’s screen breakthrough was in “The Greatest Show on Earth” and he went on to enjoy a career spanning over sixty years in films such as “The Ten Commandments”, “Ben Hur” (for which he won an Oscar), “The Agony and the Ecstasy”, “El Cid”, “55 Days at Peking”, “Touch of Evil”, “The Planet of the Apes”, “The Omega Man”, “Earthquake” and “Airport”. He also served as president of the Screen Actors Guild and was chairman of the American Film Institute.

The actor was also a political activist, having marched alongside Martin Luther King, he was later to become a strong supporter of the National Rifle Association (NRA) and was president of the NRA from 1998 until 2003 when he retired due to ill-health.

Charlton Heston will be remembered for his larger than life roles. He said of himself, “I have played three presidents, three saints and two geniuses (...) If that doesn’t create an ego problem, nothing does (...) I have lived such a wonderful life. I’ve lived enough for two people.”

AWAY FROM HER

Away from her, starring Julie Christie and Gordon Pinsent, brilliantly reflects the effect Alzheimer’s disease can have on both a person with Alzheimer’s but also those we hold dearest. Based on “The Bear Came Over the Mountain” by Alice Munro, Away from Her tells the story of Grant and Fiona, who, after fifty years together and deeply still in love, have to face the realities that Alzheimer’s disease brings after Fiona’s diagnosis. As her memory deteriorates it becomes necessary to move Fiona into a retirement home. Not unnaturally, Fiona makes new attachments in the home but when she starts to fall in love with one of the residents Grant is left to cope with a void that is becoming apparent between them.

It is a wonderful exploration of the impact love and loyalty have when our memory fails us, as well as the feelings of guilt carers face. Julie Christie won a Golden Globe for “Best Actress” and the film was Oscar nominated for “Best Adapted Screenplay” and ”Best Actress”.

Directed by Sarah Polley, the film sensitively, and sometimes humorously, shows the audience the emotional roller-coaster that people with dementia and their nearest and dearest often face.
Recognising Paul Watson’s unique work, the British Academy of Film and Television (Bafta) gave him their award for “outstanding contribution to television”. Paying tribute to Paul’s 300 films over a 35-year career, John Willis, Chairman of the Bafta committee, said, “Paul Watson is one of the giants of documentary film-making. Over several decades he has created a string of memorable and often controversial documentaries, always striving for innovation in both form and content.”

Paul is particularly well known in the world of dementia for his 2007, 90 minute documentary “Malcolm and Barbara: Love’s Farewell” which was the study of Malcolm’s journey with Alzheimer’s disease and its effect on those around him.

Speaking at the award’s ceremony, Paul said, “I hope we will carry on putting ordinary people on the screen because they provide the information about what is going on in this country”.

Terry Pratchett, 59, is the best-selling author of the Discworld fantasy and children’s books. He entitled his recent diagnosis of early-onset Alzheimer’s disease as an Embuggerance on a friend’s website. He voiced his anger at the unavailability of state-funded medication, and at the lack of a local specialist, at the Annual Network Conference of the Alzheimer’s Research Trust, when he explained, “the NHS kindly allows me to buy my own Aricept because I’m too young to have Alzheimer’s free, a situation I’m OK with in a want-to-kick-a-politician-in-the-teeth kind of way.”

He also expressed his shock that, “there’s nearly as many of us as there are cancer sufferers, and it look as if the number of people with dementia will double within a generation” yet “it is a shock to find out that funding for Alzheimer’s research is just three per cent of that to find cancer cures”. Subsequently he pledged £500,000 to the UK Alzheimer’s Research Trust.
SPOTLIGHT ON... SWITZERLAND

“Association Alzheimer Suisse” celebrates its 20th anniversary this year. Alzheimer Europe looks at some key achievements of the organisation

8 June 1988 Association Alzheimer Suisse is founded by among others Jean Wertheimer, geriatrician from Lausanne
1988 First sections chapters are created in Basel, Berne, Geneva, Tessin, Vaud and Zug
1989 Start of the “Alzheimer INFO”, bulletin for association members 3 issues/year
1992 Number of members reaches 1,000
1992-1996 Development of new services holidays for people with dementia and their carerstraining seminars for carers awards for research participation in World Alzheimer’s Day activities
1997 Inclusion of anti-dementia medicines in reimbursement system
1998 8th Alzheimer Europe Conference in Lucerne with over 800 participants
1998 5,000 members and budget of CHF 2 million
1999 Independent audit of the organisation’s activities
1999 Member of Federal Commission for guardianship reform
1999-2002 Development of new services Alzheimer Telephone Enlarged Website
2002 Information and fundraising campaigns start
2002 Report on “Basic support for people with dementia”
2003 Report on “Indicators for the future”
2004 6,200 members, 100,000 donors and budget of CHF 5.7 million
2006 450,000 information brochures distributed
2007 Conferences on “Living at home with Alzheimer’s disease” together with home care organisations
2008 7,100 members, 130,000 donors and 21 sections

Association Alzheimer Suisse / Schweizerische Alzheimervereinigung / Associazione Alzheimer Svizzera
8E, rue des Pécheurs, 1400 Yverdon-les-Bains, Switzerland
Tel.: +41-24-426 20 00, fax: +41-24-426 21 67
info@alz.ch, www.alz.ch

21 regional organisations
Aargau, Bern, Basel, Fribourg, Genève, Glarus, Graubünden, Jura, Luzern, Neuchâtel, Obwalden-Nidwalden, St. Gallen/Appenzell, Schaffhausen, Solothurn, Thurgau, Ticino, Uri-Schwyz, Vaud, Valais, Zug and Zürich

Chairperson: Welti Myrtha
Board members: Hagmann Hermann-Michel
Jenni Giovanna
Kohler Stephan
Meyer-Kaelin Thérèse
Meyer Urspeter
Sticher-Levi Miriam
Studer Andreas

Executive Director: Martensson Birgitta
Assistant: Favre Robert
Executive Directors: Gleche Helke
PUTTING A FACE TO COMMITMENT

April 2008 – Portugal
António Oliveira Costa has joined Alzheimer Portugal to act as its first Executive Director. Before joining Alzheimer Portugal, António worked for 13 years as Institutional Director for a Portuguese NGO in the field of drugs addiction, and 5 years for the Council of Europe (North South Centre), as External Relations Responsible, based in Lisbon. In both cases, his portfolio included fund and awareness raising, media and public relations, and relations with Portuguese Government and local authorities. António has a degree in Political Science and is finishing his MA in Cultural and Political History.

March 2008 – Poland
Alicja Sadowska, a Board member of Alzheimer Europe was re-elected as Chair of the Polish Alzheimer’s Association.

May 2008 – Alzheimer Europe
The new Alzheimer Europe Board was elected at the Annual General Meeting in Oslo.

January 2008 – Finland
Pekka Laine stepped down as Chairman of the Finnish Alzheimer Society. In recognition of his contribution to the Finnish Society Pekka was awarded the position of the first Honorary Chair. Riitta Korhonen has been appointed as the new Chair of the Finnish Alzheimer’s Society.

Alzheimer Europe Board
Left to right:
Pekka Laine (Finland)
Maria do Rosário Zincke dos Reis (Portugal)
Maurice O’Connell (Ireland)
Sabine Henry (Belgium)
Alicja Sadowska (Poland)
Sigurd Spar (Norway)
Iva Holmerová (Czech Republic)
Heike von Lützau-Holbien (Germany)
Charles Scerri (Malta)
Neil Hunt (UK)

Also elected but not in photo:
Marc Schaeter (Luxembourg)
Patrick Maugard (France)
ALZHEIMER EUROPE PUBLICATIONS

DEMENTIA IN EUROPE YEARBOOK 2007
Luxembourg (2007), 294 pages 20 € plus p&p

The 2007 Dementia in Europe Yearbook highlights the findings of a survey on social support systems amongst our national member organisations. The survey reveals the huge discrepancies that exist across Europe when it comes to the services and the support provided by governments for people with dementia and their carers. This publication also includes the 2006 Annual Report of Alzheimer Europe.

DEMENTIA IN EUROPE YEARBOOK 2006
Luxembourg (2006), 294 pages, 20 € plus p&p

The 2006 Dementia in Europe Yearbook provides a European overview of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care, as well as a detailed description of these findings for 31 European countries (27 Member States of the European Union and Iceland, Norway, Switzerland and Turkey). The Yearbook also provides useful contact addresses of associations and research centres active in the field of Alzheimer’s disease. The publication also includes the 2005 Annual Report of Alzheimer Europe.

ALZHEIMER EUROPE REPORTS: THE USE OF ADVANCE DIRECTIVES BY PEOPLE WITH DEMENTIA
Luxembourg (2006), 103 pages, 10 € plus p&p

This publication contains Alzheimer Europe’s position on advance directives and provides background information on the legal, ethical, medical and personal and practical issues surrounding the use of advance directives in the case of dementia. This is followed by a summary of the legal status of advance directives in 15 EU member states and in Switzerland and Norway.

AE SURVEY: WHO CARES? THE STATE OF DEMENTIA CARE IN EUROPE
Luxembourg (2006), 10 pages

This report presents the results of a survey carried out by Alzheimer Europe and its member organisations in France, Germany, Poland, Scotland and Spain and gives a voice to more than 1,000 people caring for a person with dementia who took part in the survey. This survey was conducted in collaboration with Lundbeck. The results paint a shocking picture of the level of commitment required from carers, since half of the carers surveyed cared for the person with dementia for more than 10 hours each day. The survey also revealed a significant lack of information provision to dementia carers at the time of diagnosis, a lack of basic support services and the need of carers to contribute financially to existing services.
ALZHEIMER EUROPE CARE MANUAL

Prices vary according to language edition

The Care Manuals are destined for family members and people taking care of a person with Alzheimer’s disease or another form of dementia. The manual provides general information on dementia and Alzheimer’s disease, as well as more specific information about symptoms and how to cope.

Each manual is divided into 5 sections:
1. Information on Alzheimer’s disease
2. The onset of the disease
4. Coping with caring
5. How to get support

Language editions available from Alzheimer Europe or member organisations: French, Italian, Portuguese, Danish, German, Greek and Turkish

CHILDREN’S BOOK: DEAR GRANDMA

10 € plus p&p.

The Children’s book relates a story of the daily life of a family in which the grandmother is suffering from Alzheimer’s disease. The story is portrayed through the eyes of one of the grandchildren.

It is targeted at children from 9 to 11 years of age.

Currently, the following language editions are available from Alzheimer Europe or member organisations: French, German, Italian, Danish, Dutch and Greek.

To order our publications online, please see:
http://www.alzheimer-europe.org/?content=eshop
FORTHCOMING EVENTS
AND CONFERENCES

12-16 July 2008  
Federation of European Neuroscience Societies  
*6th Forum of European Neuroscience*  
Geneva, Switzerland  
fens2008.neurosciences.asso.fr/

1-2 August 2008  
International Academy on Nutrition and Alzheimer  
*3rd IANA Meeting: Nutrition, Exercise & Alzheimer and Clinical Trials on Sarcopenia*  
Albuquerque, USA  
www.serdi-fr.com/ABQ.htm

6-8 August 2008  
II Conference of Alzheimer Iberoamerica:  
“Desde el diagnóstico precoz hacia la prevención”  
Buenos Aires, Argentina  

7-9 August 2008  
Mental Health Europe  
Diversity in mental health and well-being – An opportunity for intercultural dialogue  
Aalborg, Copenhagen  
www.mhe-aalborg.dk/

23-26 August 2008  
12th Congress of the European Federation of Neurological Societies  
Madrid, Spain  
efns2008.efns.org

3-5 September 2008  
FTD 2008 – 6th International Conference on Frontotemporal Dementias  
Rotterdam, Netherlands  
www.ftd2008.org

4-7 September 2008  
International Federation of Ageing  
*9th Global Conference on Ageing*  
Montreal, Canada  
www.ageingdesignmontreal.ca

16 September 2008  
Alzheimer Europe and European Alzheimer’s Alliance  
Current and future treatments of Alzheimer’s disease  
European Parliament, Brussels, Belgium  
www.dementia-in-europe.eu

17-19 September 2008  
Clinical Trials on Alzheimer’s disease  
Montpellier, France  
www.ctad.fr

16-19 October 2008  
6th International Congress on Mental Dysfunctions and other non-motor features in Parkinson’s disease  
Dresden, Germany  
www.kenes.com/pdment2008

23-26 October 2008  
2nd World Congress on Controversies in Neurology  
Athens, Greece  
comtecmed.com/cony/2008/

9 December 2008  
Alzheimer Europe and European Alzheimer’s Alliance  
European Collaboration on Dementia  
European Parliament, Brussels, Belgium  
www.dementia-in-europe.eu

11-15 March 2009  
AD/PD 2009  
Prague, Czech Republic  
www.kenes.com/adpd

25-28 March 2009  
Alzheimer’s Disease International  
*24th Conference of Alzheimer’s Disease International*  
Singapore, Singapore  
www.adi2009.org

28-30 May 2009  
Alzheimer Europe  
*19th Alzheimer Europe Conference*  
Brussels, Belgium  
www.alzheimer2009.eu
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 26 COUNTRIES

AUSTRIA – VIENNA
Alzheimer Angehörige

BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liége

BULGARIA – SOFIA
Alzheimer Bulgarija

BULGARIA – VARNA
Foundation Compassion Alzheimer Bulgaria

CYPRUS – LARNACA
PanCyprian Alzheimer Association

CZECH REPUBLIC – PRAGUE
Czech Alzheimer Society

DENMARK – HELLERUP
Alzheimerforeningen

FINLAND – HELSINKI
Alzheimer-keskusliitto

FRANCE – PARIS
Association France Alzheimer

GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V.

GREECE – THESSALONIKI
Greek Association of Alzheimer’s Disease and Related Disorders

ICELAND – REYKJAVIK
F.A.A.S.

IRELAND – DUBLIN
Alzheimer Society of Ireland

ITALY – MILAN
AIMA

ITALY – MILAN
Federazione Alzheimer Italia

LUXEMBOURG
Association Luxembourg Alzheimer

MALTA
Malta Dementia Society

THE NETHERLANDS – BLOKKENBERG
Alzheimer Nederland

NORWAY – OSLO
Nasjonalforeningen Demensforbundet

POLAND – WARSAW
Polish Alzheimer’s Association

PORTUGAL – LISBON
AFADA

ROMANIA – BUCHAREST
Societatea Alzheimer

SLOVAKIA – BRATISLAVA
Slovak Alzheimer Society

SPAIN – PAMPLONA
C.E.A.F.A.

SPAIN – MADRID
Fundación Alzheimer España

SWEDEN – LUND
Alzheimerforeningen i Sverige

SWEDEN – STOCKHOLM
Demensförbundet

SWITZERLAND – YVERDON-LES-BAINS
Association Alzheimer Suisse

TURKEY – ISTANBUL
Alzheimer Vakfı

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

UNITED KINGDOM – LONDON
Alzheimer’s Society
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

Alzheimer Europe gratefully acknowledges the support of the following MEPs, who have either become a member of the European Alzheimer's Alliance and/or signed the Paris Declaration.

You can make a difference. Sign the Paris Declaration and become a member of the European Alzheimer’s Alliance today.