Alzheimer’s associations throughout Europe celebrate World Alzheimer’s Day

Katalin Levai, MEP, highlights the importance of the European Alzheimer’s Alliance

Jan Tadeusz Masiel, MEP, talks about the situation in Poland for people with dementia

“The fight of all Europeans against Alzheimer’s disease is a priority”
Nicolas Sarkozy
ACT NOW

Remember those who cannot
6.1 million people have dementia in Europe

THE TIME TO ACT IS NOW
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I am delighted to be welcoming you to Alzheimer Europe’s second edition of The Dementia in Europe magazine. It has been wonderful to receive feedback that our Magazine has been used so widely to help raise awareness of the issues which surround this dreadful disease, and a heartfelt thank you goes out to all those who have contributed, helping to ensure the magazine is both relevant and informative.

European policy on dementia has been pushed to the forefront of agendas these last few months as our coverage of the high profile French Presidency Conference “The fight against Alzheimer’s disease and related disorders” illustrates. I am delighted that Alzheimer Europe’s agenda has been endorsed by no less than the President of France and national ministers from around Europe. That momentum should be growing at a time when we face economic uncertainty only adds to our commitment that we must persevere. Without exception, speakers at the Conference called for collaboration, cooperation and a pooling of resources in order that we continue to progress.

Current examples of collaborative work are given in the interview with Katalin Levai, MEP, who talks of the work of the European Alzheimer’s Alliance, in our report on the recently completed European Collaboration on Dementia project and in the article “Learning from each other: A European Ethics network”. Unfortunately, stark differences between the European countries are also revealed and perhaps most evident in our snapshot of national dementia specific plans. Further, in “The view from Poland”, Jan Tadeusz Masiel, MEP, talks of the lack of services for people with dementia and we also take a look at the differences in approach to dementia treatment and care at an individual level, as Roger Newman illustrates in his wonderful article “Gods for today!”

In this issue, we include evidence of the commitment and success of Alzheimer associations around Europe raising awareness during their World Alzheimer’s Day celebrations. Such events are crucial to remove the stigma described by Jan Henry T. Olsen and his wife, Laila Lanes, who courageously spoke out at the French Conference about the impact dementia has on their lives and called for people to be more open about this disease. This sentiment is echoed by Jean Georges, Executive Director of Alzheimer Europe in his article “Moving dementia out of the shadows”, which considers the negative reaction to the announcement that Britain’s former Prime Minister, Baroness Thatcher, has dementia. One way in which openness about the disease can be achieved is illustrated in the article on the German Alzheimer’s Association’s recent Youth Competition, which encouraged young people to be actively involved with people with dementia and their carers.

Up-to-date research on current treatment options of Alzheimer’s disease, which were presented during Alzheimer Europe’s fourth lunch debate at the European Parliament by Prof. Alexander Kurz in September, are also reported on.

Finally, we give details of the European Parliament’s Written Declaration n° 80/2008 on the priorities against Alzheimer’s disease. Members of the European Parliament have, for a short while, a golden opportunity to pledge their commitment to helping people with dementia and their carers by signing this Declaration and I take this opportunity myself of asking all MEPs, to please sign this Declaration without hesitation. Remember, the time to act is NOW.

Maurice O’Connell, Chairperson
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Professor Alexander Kurz
“The vision is to prevent dementia altogether”
WORKING TOGETHER TOWARDS A BETTER UNDERSTANDING OF DEMENTIA

As the European Commission’s three-year project to create a network of all players active in the field of dementia comes to a close, Alzheimer Europe reflects on the aims of the project and talks with work package leader Dianne Gove about the recommendations for social care.

The European Collaboration on Dementia (EuroCoDe) project was set up in order to develop a European network of all the players active in the area of dementia. The network brought together a number of established pan-European organisations, European projects and informal collaborations, such as the Cochrane Dementia and Cognitive Improvement Group, the European Alzheimer’s Disease Consortium, the European Association of Geriatric Psychiatry, the dementia panel of the European Federation of Neurological Societies, the INTERDEM (Early detection and timely intervention in dementia) group, the International Association of Gerontology (European region) and the North Sea Dementia Research Group.

The network of 36 researchers from 20 different countries, developed consensual indicators and an ongoing dialogue. In turn, the indicators and dialogue helped to identify ways of developing synergies and closer European collaboration. The EuroCoDe project was funded by the European Commission under its Public Health Programme and looked at (i) consensual prevalence rates, (ii) guidelines on diagnosis and treatment, (iii) guidelines on non-pharmacological interventions, (iv) recommendations on risk factors as well as risk reduction and prevention, (v) the socio-economic cost of Alzheimer’s disease and (vi) the level of social support to people with dementia and carers in Europe.

The specific aims of the project were:

1. Consensual Prevalence rates
   By gathering existing epidemiological studies and analysing the respective merits and shortcomings of individual studies, the working group, led by Emma Reynish of the European Alzheimer’s

“My biggest hope is that the recommendations can serve as a kind of tool which member associations can use in their campaigns and negotiations for better social support for people with dementia and their carers at national level.”
Dianne Gove

Alzheimer Europe (AE): Which recommendation(s) do you feel could be most useful for people with dementia and their carers?

Dianne Gove (DG): It is difficult to highlight any one particular recommendation as they are all valuable in their own right and many are interdependent on each other. However if I were to highlight any of the recommendations, it would be that:

- Governments should set up national action plans for dementia care and set aside the necessary funds to implement them. This is because in a lot of countries people with dementia do not get the appropriate services because they do not fall into...
Disease Consortium, were able to carry out a pooled-data-analysis of these studies and thus develop consensual European prevalence rates. The working group found a strong likelihood that current data under-estimates prevalence rates for dementia. This is due in part to the lack of insufficient reliable data for young people with dementia as well as the lack of data for the over 85s in some studies.

2. Guidelines on diagnosis and treatment
The aim of the project was to identify already existing guidelines and establish a comparative report on commonalities and differences. Rupert McShane of the Cochrane Collaboration/University of Oxford headed this working group, which developed consensual guidelines acceptable to the various networks and projects. 39 guidelines for diagnosis and treatment were found, many of which the group found consensus on. However, no agreement was found in relation to the cost effectiveness of certain diagnostic and treatment methods which were expensive and/or invasive.

3. Guidelines on non-pharmacological interventions
Myrra Vernooy-Dassen of the University Medical Centre St. Radbord, was the work package leader of this group which identified studies on the effects and usefulness of various interventions.

one of the existing categories, for example, support for the elderly and disability allowances may not cover a person with dementia who is relatively young. In addition, the prevalence of dementia is set to double by 2050 and to address this demands that dementia becomes a priority.
• The organisation and financing of healthcare and social support should be coordinated in such a way as to ensure a seamless provision of care, support and services to people with dementia and effective coordination between healthcare and social care systems and providers. This is because many people with dementia have both medical and social needs specific to dementia which may require different organisations’ support (such as social services as well as the health service). If the support is uncoordinated it leads to unnecessary complexities for people with dementia and their carers.
• A rehabilitative approach to social support for people with dementia should be developed and provided on a multidisciplinary basis in collaboration with people with dementia and carers. The working group felt that the rehabilitative approach was very important for people with dementia as it is a very individual approach. The emphasis is on encouraging people with dementia to use their cognitive, social and emotional resources to their full extent. This helps improve and maintain their functional capacity which in turn promotes autonomy.

AE: How do you see the recommendations being used?
DG: My biggest hope is that the recommendations can serve as a kind of tool which member associations can use in their campaigns and negotiations for better social support for people with dementia and their carers at national level. We will of course also be promoting these recommendations at European level.

Also, during our work, many interesting and inspiring local examples of good practice came to light and we included them in our report. It would be great if some of the examples of good practice could be adapted and used in other countries.
Prioritising Dementia

and presented them in a comparative report highlighting the strengths and weaknesses of the respective studies and the studied interventions. Based on the findings, the project aimed to elaborate consensual guidelines on non-pharmacological interventions. Guidelines were found to exist in only five countries.

4. Risk factors and risk reduction and prevention strategies
The issues of risk and prevention were considered by this work group, which was led by Lutz Frölich of the Central Institute for Mental Health. The group collected existing studies on risk factors for Alzheimer’s disease, and other forms of dementia, then presented them in a comparative report which highlighted some promising possibilities for the development of prevention strategies. The importance of addressing modifiable risk factors (such as cardiovascular) from an early age was noted, as was the need to keep socially, physically and mentally active throughout life.

5. Socio-economic cost of Alzheimer’s disease
Wimo Anders of the Karolinska Institute led the working group which focused on socio-economic costs. The project aimed at collecting existing studies and presented its findings in a comparative report. Furthermore, taking into account economic differences between the various Member States of the European Union, the project will result in the publication of a report on the socio-economic impact of dementia in Europe. 14 papers for cost models were found, with four care models emerging throughout the papers. This work group estimated the true cost of dementia in Europe (taking into account the cost of informal care) to be EUR 130 bn, or EUR 21,000 per person with dementia per year.

6. Inventory of social support systems
The project partners carried out a survey on the existing level of support available for people with dementia and their carers in the 27 Member States of the European Union. The project aimed at collecting existing studies and presented its findings in a comparative report. Furthermore, taking into account economic differences between the various Member States of the European Union, the project will result in the publication of a report on the socio-economic impact of dementia in Europe. The survey looked at the different treatment reimbursement systems, the level of carers’ allowances and benefits, care insurance systems, employment related benefits (such as carers’ leave, flexible working time, pension systems) and other benefits. This working group, led by Dianne Gove of Alzheimer Europe, combined their findings in a comparative report which served as a basis to make recommendations to improve social support as well as identify examples of good practices. Huge inequalities of access to diagnosis, services and treatment throughout Europe were found by this group.

At the end of 2008, Alzheimer Europe will publish the findings from the socio-economic, prevention, social support and non-pharmacological intervention work groups in the 2008 Dementia in Europe Yearbook. The findings from the diagnosis and treatment as well as the prevalence workgroups will be published in early 2009 and the research will be presented during Alzheimer Europe’s 2009 Conference in Brussels. It is essential that we build upon, and develop, the information and networks created during the EuroCoDe project. Alzheimer Europe hopes to be able to ensure the data gathered does not become outdated to include newly published data, as well as continue to develop an Observatory whereby research could be carried out and results disseminated on a European level.

Jean Georges, Executive Director of Alzheimer Europe, sums up the hope that the completion of the three-year project is seen “not as an ending, but a beginning of EU collaboration on dementia.”
Alzheimer Europe speaks with Katalin Levai, Member of Parliament for Hungary, about her recent election to Vice-Chairperson of the European Alzheimer’s Alliance, the Written Declaration on the fight against Alzheimer’s disease and the French Presidency

Alzheimer Europe (AE): Ms. Levai, many thanks for having accepted the position of Vice-Chairperson of the European Alzheimer’s Alliance. What is your motivation in supporting this cause?

Katalin Levai (KL): Alzheimer’s disease affects more than 6 million people in Europe causing them and their relatives long and oppressive suffering, and imposes enormous costs on society (more than EUR 55 billion per annum). These families should be helped! I believe that due to my position as Vice-Chairwoman of the European Alzheimer’s Alliance I could provide more support for patients and the medical profession than before.

AE: You recently signed a Written Declaration together with your colleagues Françoise Grossetête, John Bowis, Antonios Trakatellis and Jan Tadeusz Masiel. What do you hope to achieve with this Declaration?

KL: I hope that by this action we will draw the attention of other European decision makers to the fact that European health policy is lacking as well as encourage the decision makers to recognise Alzheimer disease as a European priority.

AE: Apart from the Written Declaration, are there other ways in which a Member of the European Parliament can support measures to improve the quality of life of the 6.1 million people with dementia in the European Union?

KL: Indeed, it is our responsibility to keep the issue alive on the European and national levels. The Alzheimer’s associations should receive more regular support and permanent promotion on the pan-European research working in the field of the prevention and treatment of the disease.

AE: As a Member of the European Parliament from Hungary, how would you compare the situation of people with dementia in your country to that of patients in other European countries?

KL: 160,000 people suffer from Alzheimer’s disease in Hungary, unfortunately in difficult living and medical conditions. Thanks to the Hungarian Alzheimer Association and its director, Ms Eva Himmer, their lives are getting more comfortable day by day.

There is no country in the world which could cope with such a big disease. The social and health care systems of countries are not prepared to handle this crisis, which crosses over national borders. I see the solution lying in an inter-governmental cooperation and therefore I would like to emphasise the importance of the newly launched Global Alzheimer’s Disease Charter.

AE: Thank you for this interview.
LEARNING FROM EACH OTHER: A EUROPEAN ETHICS NETWORK

A summary of the European workshop on ethics which was held in Berlin on 1 September 2008

The creation of a European dementia ethics network came closer to being realised when the German Ministry of Health organised a European workshop with policy makers, carers, ethicists, Alzheimer organisations and researchers, who discussed the ethical issues surrounding dementia and the possibility of setting up such a network.

Presentations covered a wide spectrum of issues relating to dementia: Taboos, dignity, lying, cost considerations, religious beliefs, quality of life, decision making and inclusiveness were all discussed before concrete options were presented as to how the group might move forward.

Thanking self-help groups for fighting to remove the taboo that surrounds dementia, Klaus Theo Schröder, the German Secretary of State for Health, reminded the audience that there is much that still needs to be done. He went on to explain that ethical issues and the problems faced by people with dementia and their carers, such as the feelings of loss, isolation and stigma, are not issues limited by national borders.

The stigma surrounding dementia was also discussed by Prof. Dr Eric Schmitt from the Institute for Gerontology in Heidelberg, who said that there is a cultural denial of ageing which results in discrimination. He believed that contact with people with dementia often provokes unconscious existential fears in care staff which prevents them from making authentic contact with the person with dementia and emphasised the need for a change in societal models of dementia with a focus on dignity and individuality. In particular Prof. Schmitt recommended the need for training to deal with unconscious fears.

"With ethical issues it is seldom a matter of deciding what is right and what is wrong as it is never that simple. Rather, it is more a conflict between what is right/good for the person with dementia and what is right/good for carers.”

Harry Cayton.

Heike von Lützau-Hohlbein, of the German Alzheimer Association, reinforced Mr Schröder’s statement and went on to say that solutions, just as the problems, are not limited at a national level and will be found by a pooling of ideas. She also emphasised that it is not possible to separate ethical issues from dementia and also the importance of ensuring any recommendations be linked to everyday life. Whilst acknowledging that it may not always be possible, Ms von Lützau-Hohlbein felt that economic considerations should come second in a decision-making process.
Prof. Dr Sabine Bartholomeyczik from the University of Witten-Herdecke highlighted the difficulty of dealing with challenging behaviour putting the ethical dilemma into three categories:

- power versus violence,
- self-determination versus caring for the person with dementia and
- the same treatment versus different treatment.

Such decisions, she pointed out, would be approached in different ways depending on which ethical issue (e.g., self-determination or protection of life) takes precedence. Giving the specific example of force feeding, Prof. Bartholomeyczik believed it to be a form of violence. When faced with challenging behaviour and in order to help with the decision making process, Prof. Bartholomeyczik proposed that the response should be “Why is this person behaving like this” rather than “What can I do to stop this?”

The discussion then turned toward the ethical and moral issues of lying. Dr Klaus Peter Rippe from Zurich posed the question whether lying to people with dementia is acceptable and gave the example of a person with dementia who constantly asks when their son (who died some time ago) is coming to visit. If it is acceptable to lie, Dr Rippe asked in which circumstances. He explained that on the one hand people can struggle with lying whereas others justify it as a form of caring. This provoked considerable discussion and Matthias von Schwanenflügel, from the German Ministry of Health, suggested that maybe we could learn from the experience of dealing with people with psychoses. Following on from Dr Rippe’s example of the person with dementia asking for their son, Harry Cayton, of the Nuffield Council on Bioethics, said that the point of the question may not have been to know when her son was coming, but more of an expression of her wish that her family was around her. This interpretation would lead to a different solution and rather than lying. The answer could perhaps lie in putting photographs of her family around her or arranging for her family to visit etc.

The work of the Nuffield Council on Bioethics, including the ethical issues it has addressed, was presented by Harry Cayton. He claimed that with ethical issues it is seldom a matter of deciding what is right and what is wrong as it is never that simple. Rather, it is more a conflict between what is right/good for the person with dementia and what is right/good for carers. Mr Cayton emphasised the need to consider ethical issues per se and only to consider dementia when it affects that
issue, so that the basic human element was paramount rather than the dementia. For example, with regard to lying he said the question should be “is it ethical to lie?” rather than “is it ethical to lie to people with dementia?”

Florence Lustman, the coordinator of the French Alzheimer Plan presented the French plan which includes a number of measures in the ethical field, including the preservation of the autonomy of people with dementia and the need to keep them involved in actions affecting their lives. Similarly, the need to inform patients about their diagnosis with the development of adequate post-diagnosis support forms another of the plan’s priorities. Michael Schmieder, director of the Sonnweid Institution and the originator of the project idea, presented concrete examples of when a Dementia Ethics Network could provide support and advice to family or professional carers of people with dementia and described the platform as an “ethical reference book for our society.”

Jean Georges, Executive Director of Alzheimer Europe, then presented the fine detail of how to proceed with setting up such a network and ideas mooted included the network being both a discussion forum and reference library. The participants welcomed the project idea and agreed that partnerships and networks on ethical issues between interested centres would indeed be a valuable new initiative.

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**Alzheimer Europe talks with Ulla Schmidt, German Minister for Health about the ethical work shop**

Alzheimer Europe (AE): Ms Schmidt, the German Ministry for Health recently organised a European workshop on the ethical issues in the care of people with dementia. What led to this initiative?

Minister Schmidt: Dementia constitutes a constantly growing challenge for politics and society. What is important for ensuring the provision of care for persons suffering from dementia is the appropriate legal and financial framework conditions. Making humane care possible is an objective which is also especially dear to my heart. To this end, we need to conduct an open discussion about ethical problems and questions arising in daily situations of long-term and nursing care. For example, what is dignity? How do we deal with aggression? What is the relationship between the right to self-determination of the person in need of care and that of the person providing the care?

Since an exchange across borders is imperative in this area, we have proposed the launching of a European internet platform. When Michael Schmieder, Director of the ‘Sonnweid’ facility in Switzerland, put forward a concept with the name ‘Dementia Ethics Network’, we were immediately on board. This platform is to offer information about ethical conflict situations in care and long-term care, especially that of dementia patients.

A forum for exchange, discussion and the elaboration of new solutions is to be created. Background information on questions from care providers or members of the health professions is also to be published. I was delighted to see that both the German Alzheimer’s Association and Mr. Georges...
from Alzheimer Europe have been involved in the project right from the beginning.

During the workshop, we had open and critical discussions with European experts about the nursing science and ethical perspectives of supranational cooperation. The workshop provided a fillip to an European dialogue on ethical foundations and the problems of living together with persons suffering from dementia and how best to care for them. The aim was not only to achieve certainty about the path chosen but also to win the active support of the scientific community and of the relevant national and European institutions for the project.

**AE:** What would you expect from increased European collaboration on this issue?

**Minister Schmidt:** The increasing number of dementia patients presents a major task for all of Europe’s societies. Irrespective of the individual socio-political responses to this trend, a social and ethical debate is taking place in all states. Alzheimer’s presents a challenge which has to do with each and everyone of us. In Europe we have to join forces. We need common answers to how we can improve the situation of the sick and their families in the long term. An intensive exchange of experience and know-how can help to spread good practice and make use of European synergies.

I therefore consider it imperative that these discussions be conducted across the boundaries of individual states. The ‘Dementia Ethics Network’ endeavours to do just this through the medium of a European website.

At the Alzheimer’s Conference in Paris at the end of October 2008, there was a clear feeling that these questions are indeed on the European agenda. It was impressive to see that even the French president, in his capacity as President of the EU Council of Ministers, addressed these issues and supported the debate on ethical questions at this conference.

**AE:** Are there other areas in the dementia field where you believe there is a need for European cooperation?

**Minister Schmidt:** One thing is true for the entire population of Europe. There has been a massive improvement in medical progress, sanitary conditions and people’s nutritional status over the past hundred years. These are the reasons why people are becoming older and older.

Unfortunately, the older people become, the more likely they are to suffer from dementia. This is why, in the Europe of the future, more and more dementia patients will be dependent on medical and nursing care. At present, over six million people are suffering from Alzheimer’s or other forms of dementia in the EU’s Member States.

We in Europe must also cooperate more intensely in research on Alzheimer’s. It is incumbent on all of the Member States of the EU to guarantee, first and foremost, good care and long-term care for those affected because, while research holds out the possibility of an improvement in the future, good care is improvement in the present.

“Alzheimer’s presents a challenge which has to do with each and everyone of us. In Europe we have to join forces.”

Ulla Schmidt

Ulla Schmidt, German Minister for Health
Prioritising Dementia

A look at the “Alzheimer Europe position and recommendations on end-of-life care”, which is due to be published at the end of 2008.

In the last stage of dementia people often need constant care and may require specialised attention. However, a survey carried out by Alzheimer Europe, within the framework of the recent European Collaboration on Dementia (EuroCoDe) project, revealed that palliative care services which are adapted to the specific needs of people with dementia were found to be severely lacking. This lack of palliative care services for people with dementia within Europe, as well as a lack of support for carers of people with dementia in the final stage of life, led Alzheimer Europe to set up a working group to look at the practical issues linked to the good care of people dying with/from dementia (that is not just “end-stage” dementia but anyone with dementia who is near death/dying). The resulting paper: “Alzheimer Europe position and recommendations on end-of-life care” is a thorough, thought-provoking and practical guide for all those involved in this delicate and demanding stage of the disease, offering much needed insight into how to provide good end-of-life care.

Defining, even estimating, the end-of-life stage is difficult. However, the paper searches for the components of good end-of-life care, focusing on the days or weeks before the actual moment of death. These components are considered from the perspective of four groups (people with dementia, carers, healthcare professionals and policy makers/the State). The recommendations are naturally weighted with the nature of the role each actor takes: for people with dementia the practicalities of treatment and care are highlighted; for carers the need for their support; for healthcare professionals the need for consultation, training and treatment management and for policy makers Alzheimer Europe lists required measures which will enable good end-of-life care to be put in place.

Although the needs and obligations of each group revealed differences, there were some common issues throughout such as respect, training, consultation and support. Underlying the whole discussion paper is the importance of respecting the dignity of the person with dementia and trying to provide the best care possible. Acknowledging that opinions as to what is considered “dignified” or not may be different, the working group identified some common measures which might enhance dignity but also which are relatively simple to implement. Encouraging independence, getting to know the person with dementia and respecting their individuality, showing kindness, maintaining dialogue and regularly reviewing decisions were all proposed as ways to enhance dignity.

Dignity is the first and central consideration for people with dementia and Alzheimer Europe recommends that this be maintained by ensuring that the wishes of the person with dementia and carer are heard when deciding where care should be provided and also by keeping the person with dementia and carer consulted and informed in all issues of treatment and care. The purpose of treatment and care, should, Alzheimer Europe states, be the attainment of a certain quality of life and level of comfort for the person with dementia. Further, treatment should be avoided if it does not offer an improvement in the quality of life.

The issue of support features prominently in Alzheimer Europe’s recommendations for carers. The nature of the support required is wider than
just practical support, such as receiving specific dementia training, with emotional, spiritual and psychological support also being highlighted as necessary. To best meet carers’ requirements an assessment of needs should be carried out so that a care plan may be developed which can later be reviewed in order that changes in those needs can be allowed for. As in the case of people with dementia, the importance of consultation between the carer and health care professionals, throughout the care of the person with dementia, was also highlighted.

A natural overlap exists in some of the recommendations for healthcare professionals and carers. For example, both require specialised support, both require training and there is a need for consultation between the two groups. Alzheimer Europe reminds us of the importance and value that the consultation process can have for healthcare professionals by consulting with the carer, stating “as most carers have in-depth knowledge of the person with dementia, are aware of his/her preferences and are experienced in communicating with him/her in a meaningful way”. Training features prominently in the recommendations for healthcare professionals with every type of healthcare worker, from doctors to volunteers, being highlighted as requiring dementia training. For doctors, the recommendations advocate the inclusion of specific dementia training as a part of their undergraduate studies and professional development studies.

Dignity is the first and central consideration for people with dementia.

An essential component of offering good end-of-life care is that of continuity of personnel. To this end, the working group recommends the appointment to every resident with dementia in a nursing home/resident care institution of an assigned care worker on the one hand and, on the other hand, recognition by the healthcare professionals of a key contact person from amongst the carers, relatives and close friends, to act as the main communication partner for the person with dementia. Not only will this assist with the continuity of care, but it will also facilitate consultation between the parties.

The management of pain will largely fall upon healthcare professionals and much has been written in recent months about this topic. Alzheimer Europe recommends that healthcare professionals be trained in the management of pain for people with dementia and experienced in the use of relevant pain assessment tools ensuring their ability to distinguish between pain and discomfort or distress and therefore avoid unnecessary sedation and/or invasive treatment.

Policy makers need to put into place the required framework for good of end-of-life care to be possible. On behalf of people with dementia and their carers, Alzheimer Europe calls upon the policy makers to:

- Recognise end-stage dementia, when appropriate, as a terminal condition, requiring palliative care
- Provide and guarantee access to palliative care/geriatric services for people with dementia
- Provide free information on the availability of services for people with end-stage dementia
- Ensure anti-dementia drugs are accessible and reimbursed
- Support carers by giving free respite care, promote flexible working hours and/or paid leave and protect carers’ pension rights
- Train sufficient numbers of healthcare professionals in dementia care
- Reflect the value of the specialised nature of healthcare professionals who work in palliative care by sufficient financial remuneration and attractive working conditions
- Promote research into palliative care for people with dementia.
CURRENT AND FUTURE TREATMENT OPTIONS FOR ALZHEIMER’S DISEASE


“The treatment of Alzheimer’s Disease: current options and future perspectives” was the focus of Alzheimer’s Europe’s 4th lunch debate. Hosted by Katalin Levai, MEP (Hungary), the Vice Chairperson of the European Alzheimer’s Alliance, the lunch debate seems to have been the most successful to date with 50 attendees which included some 20 MEPs and/or their assistants, representatives of pharmaceutical companies and Alzheimer organisations attending.

Opening his presentation, Professor Kurz explained that the incidence of Alzheimer’s will double by 2050 and that the disease is a proteinopathy (a malfunction of protein): In Alzheimer’s disease there is an accumulation of two proteins (a) amyloid, which forms plaques and/or (b) tau protein which clots and builds tangles. However, the sequence of events which results in Alzheimer’s disease is a complex cascade which entails many more steps than just the overproduction of protein.

This cascade of events lasts approximately 20 years, with physiological changes in the brain starting in the entorhinal cortex and progressing to the hippocampus. It is not until these physiological changes reach the temporal, parietal and frontal cortex that symptoms (loss of memory and cognitive function) associated with dementia become evident. Therefore, dementia occurs in the later stage of the complex disease process and Professor Kurz explained that current treatments are only targeting these last few years.

From a medical point of view, the “threshold of dementia” is said to be crossed when the ability to perform everyday activities by people with dementia is significantly reduced. It should be noted that the perspective of patients remained positive regarding their quality of life if they were able to function in everyday life, maintain social bonds, feel accepted and supported by others, participate in life and have a role in which they felt significant to others.

Although Professor Kurz believes the current drugs (donepezil, rivastigmine, galantamine, memantine) are the best available, their impact on the disease is unfortunately limited both in terms of their magnitude and duration due to the fact they target the disease at a very late stage in the overall
Professor Kurz' own view is that treatment should be targeted earlier on those people who are at risk in an attempt to prevent the transition to dementia, with the vision being to prevent dementia altogether by patients never reaching the dementia threshold.

New approaches to medical treatment have indeed targeted earlier stages in the cycle of Alzheimer's disease, but results so far have been mixed. Some were disappointing as the larger trials failed to confirm the excitement generated from the earlier trials (for example, non-steroidal anti-inflammatory agents, secretase inhibitors, lipid lowering agents, the removal of metal ions and amyloid immunisation trials). Some appear to be encouraging, for example a) those drugs which target amyloid, such as bapineuzumab, b) the dye methylmethionium chloride which attempts to redress aggregation of the tau protein, c) a nutritional compound using a combination of vitamins and fatty acids and d) an antihistamine known as dimebon, but all require further research.

Professor Kurz finished his presentation by saying that there will be no fast track results within the next five years. More effective treatment is required but it is also necessary to take into consideration the ethical, economic issues as well as patient suffering and caregiver burden.

In the debate that followed, Sirpa Pietikäinen (MEP, Finland) asked what impact dietary treatments have had. Professor Kurz highlighted that significant amounts of fatty acids were good for the brain and the beneficial effects that adhering to a Mediterranean diet can have.

Charles Scerri (Alzheimer Europe Board Member, Malta) believed that Alzheimer's disease to be a disease of middle age as physiological changes occur many years before symptoms appear. Professor Kurz concurred, saying that the youngest known patient was 19, the youngest patient he himself had known was 37.

Managing patient expectations in the light of media “miracle breakthroughs” was an issue raised by Jean Georges (Executive Director, Alzheimer Europe). Alexander Kurz explained that whilst he does believe there will be better treatments in the future, he puts the “miracle breakthroughs” into context by sharing current information with people with dementia and also explaining that the press have a need to be sensationalistic so that they can increase sales.
Jennifer Johnson (Assistant to MEP Peter Stastny, Slovak Republic) sought clarification on whether Alzheimer’s disease can be identified in a living patient with accuracy. Professor Kurz said he believed that a 95% accurate diagnosis is possible in specialised centres, with a clinical examination, laboratory tests and brain imaging all aiding diagnosis.

Dr Sigurd Sparr (Alzheimer Europe Board member, Norway) asked for Professor Kurz’s opinion on postponing the start time of dementia by the identification of risk factors. Professor Kurz acknowledged that aside from hyperthyroidism, depression and head trauma, no new risk factor had been identified and that many risk factors have proved insignificant. Further they do not explain the 40% incidence rate of dementia at the age of 103. However, Professor Kurz said that if he were to select the single most important risk factor to focus on, it would be the prevention and/or management of vascular disorders as they are often left unrecognised.

Ms Levai thanked Professor Kurz for his informative presentation and for the strong support shown by the high numbers of attendees. Jean Georges closed the meeting, thanking both Professor Kurz and Ms Levai and reminded participants that the next Alzheimer Europe lunch debate in the European Parliament will be on 9 December.
THE EUROPEAN ALZHEIMER’S ALLIANCE IN ACTION

Members of the European Alzheimer Alliance have been busy raising awareness and ensuring that Alzheimer’s disease is at the very top of policy makers’ agendas.

Currently, Alliance members are focusing their efforts on gathering as much support as possible for the European Parliament’s Written Declaration 80/2008 on priorities in the fight against Alzheimer’s disease. Five Alliance members, Françoise Grossetête, John Bowis, Katalin Levai, Jan Tadeusz Masiel and Antonios Trakatellis launched this Declaration in October.

In a show of support for their national Alzheimer associations, Alliance members attended celebrations of the World Alzheimer’s Day. For example, in Greece, Maria Matsouka attended the celebrations which had been organised by the Athens Alzheimer’s Association and in Italy Pier Antonio Panzeri joined Federazione Alzheimer Italia at a gala concert to celebrate World Alzheimer’s Day.

At the end of September, Jean-Pierre Audy (France) took the opportunity to highlight the need for concerted action for Alzheimer’s disease on a European level when he gave a speech at a European home care conference in Chamalières, France.

The recently elected Vice-Chairperson of the Alliance, Katalin Levai (Hungary) hosted Alzheimer Europe’s 4th lunch debate in the European Parliament in September and this event was well-supported by the Alliance: Among some 50 attendees Alliance members Elisabeth Morin (France), Marie Panayotopoulou-Cassiotou (Greece), Sirpa Pietikainen (Finland) and Jean Spautz (Luxembourg) attended, and Alliance members were also represented by the Assistants to Maria da Assunção Esteves (Portugal), John Bowis (UK), Bernadette Bourzai (France) and Jan Tadeusz Masiel (Poland).

Speaking at the French Conference “The fight against Alzheimer’s disease and related disorders” at the end of October, Françoise Grossetête (Chair of the European Alliance) said that the time had come for a European action plan against Alzheimer’s disease and called upon Member States to follow in the footsteps of the French and adopt a national plan.

Alzheimer Europe would like to take this opportunity to wish Alliance member Bernadette Bourzai every success in her new role in the French Senate and also offer our heartfelt thanks for the support she has given to the various initiatives of Alzheimer Europe in the European Parliament.
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Europe unites against Alzheimer’s disease
Report on the French Presidency Conference on the fight against Alzheimer’s disease

Making dementia a European priority
Members of the European Parliament call for the development of a European Action Plan on Alzheimer’s disease

National dementia strategies
A snapshot of the status of national dementia strategies within Europe

The view from Poland
Jan Tadeusz Masiel, MEP, talks of the challenges faced by people with dementia and their carers

Confronting double discrimination
Roger Newman and Bill Cashman talk about discrimination, inclusion and diversity in the context of people with dementia and their carers

Policy overview
A roundup of policy developments in the EU

Developing the European Pact of Mental Health
John Bowis, MEP, talks to Alzheimer Europe
A major step forward to achieve European collaboration on Alzheimer’s disease was made at the conference “The fight against Alzheimer’s disease and related disorders” organised by the French Health Minister, Roselyne Bachelot. The conference drew unprecedented attention to the plight of the 6.1 million people with dementia in Europe, as well as their carers, by having the support of not only national ministers, but of the French President himself.

Describing Alzheimer’s disease as the disease where a “rich person becomes poor” Didier Houssin, Director-General for Health at the French Ministry of Health, Youth and Sport, welcomed delegates who included people with dementia, carers, national and European policy makers, Alzheimer associations, experts and professionals.

The first section of the Conference was dedicated to explaining why this disease should be considered a European priority. Henry Brodaty, Professor of Old Age Mental Health, University of New South Wales, Australia, opened by telling us that research in dementia is crucial for Europe. Calling neurodegenerative diseases “diseases of the 21st century”, he presented some sobering statistics: Every seven seconds, a person in the world gets dementia; 25 million people live with dementia in the world in 2008, but this will rise to 80 million by 2040; in Europe the figure will rise to 10 million by 2040 and whilst 1% of most European countries’ GDP is spent on dementia, this is set to triple.

Research, said Prof. Brodaty, is an essential component of facing the challenge of dementia as it informs us of the best method for diagnosis, treatment as well as the best way to help carers. If we are able to find a way to delay the onset of dementia (by 2 or 5 years) then prevalence rates drop dramatically (by 20% to 50% respectively). New approaches to treatment are vital if we wish to stop the progression of the disease or prevent the disease developing, rather than current treatments which can only delay progression. Research into carers has also enabled us to offer appropriate services, but more needs to be done. Summing up, Prof. Brodaty left us with the thought that “research is expensive, but ignorance costs more”.

Challenging the stigma which is often associated with Alzheimer’s disease, Jan Henry Olsen (ex-Minister for Fisheries of Norway) and his wife, Laila Lanes gave courageous and moving speeches. Talking of their decision to be open about Mr Olsen’s diagnosis, Ms Lanes described the unexpected level of interest shown and the stigma they have found associated with this disease saying “so many people say they don’t want to talk about it. Sometimes you have the feeling it’s close to a criminal act (…) but by being open you are able to get a foothold from which you can move forward instead of being left in a wilderness.” She hoped that “every conference, every newspaper that writes about us will help people to accept dementia”.

Having accepted that Mr Olsen’s dementia is an illness, they have decided to make the best out of it and continue to enjoy going to pubs, football, the cinema and socialising. Instead of focusing on what Jan Henry cannot do, they focus on what he can do.
At a European level much can be done, such as stimulating research and development, creating centres of excellence in every country, acknowledging and financially supporting Alzheimer’s associations, facilitating NGOs with more fiscal instruments, as well as taking the lead in collaboration with the World Health Organisation (WHO) said Marc Wortmann, Executive Director of Alzheimer’s Disease International.

The second session, opened by Maurice O’Connell, Chairman of Alzheimer Europe, as dedicated to current issues in Alzheimer’s disease. Mr O’Connell said Alzheimer’s disease was “one of the greatest challenges that we face across Europe.” He talked of Alzheimer Europe’s priorities, listed in the Paris Declaration, which include the need for national plans, early diagnosis, awareness campaigns, social support, dementia specific services, carers’ support, treatment, ethical and legal debate as well as recognition of the role that Alzheimer’s associations play. Mr O’Connell spoke movingly of his own family’s fear and denial of the diagnosis of dementia saying “it’s a very lonely place to know your loved one potentially has dementia” and reminded everyone that Alzheimer’s associations have been the voice of people with dementia “when no one wanted to talk or understand the devastation that was happening”. He also emphasised that in time of economic downturn we must be on our work, not regress.

The highly regarded French plan which began being implemented earlier this year, was presented by its author, Prof. Joël Menard. The core objectives of the plan are to address patients’ needs and family support. Detailing action already taken on the plan, such as the setting up a Scientific Research Foundation, or the introduction of an Alzheimer’s card for people who have been diagnosed, Prof. Menard explained that the implementation included strong monitoring with a direct reporting line to the French President every six months, as well as monthly meetings of the steering committee and the patients committee meeting every three months.

An example of current EU collaboration was given by Jean Georges, Executive Director of Alzheimer Europe who presented the European Collaboration on Dementia (EuroCoDe) project. This project, financed under the EU Public Health Framework Programme, was carried out by Alzheimer Europe in collaboration with 36 researchers from 20 different countries. Highlighting that the working groups have had some interesting results, such as current prevalence figures being underestimated and the cost of dementia in Europe amounting to EUR 130 bn, Mr Georges concluded by emphasising the need to keep the project ongoing and build upon it. This belief was supported by Antoni Montserrat of the Health Information Unit, DG Health, European Commission, who recognised that EuroCoDe had delivered its intended goal of providing good indicators and created an exchange of expertise in Europe. He said that the findings of EuroCoDe detailed the differences between European countries with regard to access to diagnosis, treatment and services and stressed that it is necessary to see what instruments were available to help address these inconsistencies.

Summarising the day’s presentations and parallel sessions, Florence Lustman, General Inspector for Finance and coordinator of the Alzheimer Plan, said it was evident that we had for far too
long totally underestimated the abilities of people with dementia. She was particularly impressed by the tangible examples given, such as people with dementia becoming engaged and open when visiting a museum. “Believe me” she said, “this is a very positive image and full of hope”. Ms Lustman was convinced that such initiatives, which gave people back their self-esteem, albeit briefly, should be supported and encouraged. She spoke of the presentation given by Nick Fahy, Head of the Information Unit on Health, DG SANCO, European Commission, who had talked of the EuroCoDe project illustrating the Commission’s three pillars of comparison, partnership and pooling. Comparison, she said, is needed to trigger mechanisms for change, partnership and collaboration will facilitate exchange of information and good practice, whilst pooling can lead to consensus, codification and guidelines.

Françoise Grossetête, Member of the European Parliament and Chair of the European Alzheimer’s Alliance spoke of the urgent need to help people with dementia and asked Members of the European Parliament to sign the Written Declaration which she and four colleagues had instigated asking for the development of European action on Alzheimer’s disease. Encouraged by the fact that the Declaration had already received the support of over 100 Members of the European Parliament, she nonetheless called upon Alzheimer associations to write to their MEPs to sign the Declaration. Speaking about the role of Alzheimer Europe she said that it needs to become a centre of coordination and information for Alzheimer associations and all other organisations involved in the field.

Ms Grossetête also appealed to national and European policy makers to ensure that Alzheimer’s disease is recognised as a neurodegenerative disease per se and not hidden under mental health issues generally. Finally, Ms Grossetête talked about the European reference networks mentioned in the current draft legislative proposal on cross border healthcare, saying that these centres will enable better European cooperation, better management of new healthcare technologies, better pooling of data and impact assessment.

Confirming the need for coordinated efforts, Valérie Pécresse, the French Minister for Higher Education and Research, reminded delegates that the French Alzheimer Plan aimed to better finance and coordinate research. She disclosed that only 15% of their research efforts are coordinated with EU projects which can lead to unnecessary duplication of research efforts and wasted resources. She was therefore encouraged by the recent decision of the Council of Ministers to further increase European collaboration on research into Alzheimer’s disease. Valérie Létard, the French Secretary of State for Social Solidarity reiterated that each Member State can both learn from and teach its neighbours and expressed her hope that a closer collaboration between European countries would not only build on research, but also lead to an exchange of best practices on care approaches and care systems.

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The European Health Commissioner for Health, Androulla Vassiliou, said that the 19 million people in Europe who experience the devastating consequences of Alzheimer’s disease, have a right to expect answers. The Commission, she said, has acted for more than a decade on this problem and continues to do so under their 2008-2013 White Paper for Health. In particular, the Commissioner mentioned that the EU health strategy will include a better understanding of the neurodegenerative diseases such as Alzheimer’s disease. Whilst expressing her wish that the Commission

“The Conference should be a stepping stone to a European Plan, which we have all been waiting for.” Françoise Grossetête

“The people in Europe who experience the devastating consequences of Alzheimer’s disease, have a right to expect answers.” Androulla Vassiliou
continue to have good cooperation with Alzheimer groups in the future, she said that we should respect that people should age with dignity and receive the same rights as any other age group. She went on to thank Alzheimer Europe for carrying out its project “European Collaboration on Dementia” which could form a basis for future European action in the field.

Delegates were assured that the building momentum would not be lost when the European presidency is taken over by the Czech Republic and then by Sweden next year. Maria Larsson, the Swedish Minister for Senior Citizens and Public Health, said that healthy ageing is on her agenda and called for it to be put permanently on the agenda.

There has been a strong commitment to addressing dementia in Germany, with EUR 50 million being pledged annually to research. Marion Caspers-Merk, the Parliamentary Secretary of State in the Federal German Health Ministry believes that we face three consequences of our ageing populations a) we have opportunity to have a long quality of life, b) we have the challenges associated with old age (such as healthcare, demographics etc.) and c) we have the risk that we cannot meet that challenge. The Health Secretary looked to Europe for cooperation, collaboration and coordination and said that she is happy that Alzheimer Europe is supportive of the German initiative to set up a European ethics network and hoped that the Commission would also support this initiative.

Sofija Mazej Kukovic, the Health Minister of Slovenia emphasised how useful information for carers is just as important as research. She reminded delegates that the Mental Health Pact calls for action to combat stigma and social exclusion of the elderly and emphasised the importance of well-known personalities with dementia being open to help address this.

Participants throughout the Conference had thanked Jan Heny Olsen and Laila Lanes for sharing their experience. Mr Mario Galea, Parliamentary Secretary for the Elderly and Community Care from Malta, spoke of the Olsens’ courage and strong message they had conveyed and he reiterated the fact that unfortunately stigma with the disease is still a reality. He felt that this issue needed the support of not just NGOs but also of the EU Institutions if we are to be successful in eradicating it. For his part, he said “being a politician, I will try to keep my promise! It is the duty of us politicians to ensure and safeguard peoples’ rights and dignity”.

Nicolas Sarkozy, President of the French Republic, closed the conference with a passionate speech, laying out concrete ways in which he sees Europe addressing the “scourge” of Alzheimer’s. He said that he wanted to commit himself personally because of the numbers of people who have Alzheimer’s disease, because almost all families are affected and because he believes that he, along with the Ministers, have a duty not to take a fatalistic approach but be active in this fight.

Speaking of the French plan, he said that it was the first which developed a comprehensive approach which integrates research, care and support with the goal being to intensify efforts in each area but also to develop synergies which improve the quality of life for patients and their relatives.

However, the French President does not see this fight confined to a national level and said that it is essential to take the fight against Alzheimer’s to the whole of Europe, for which the creation of a
European Plan is essential. He wishes that the European Council adopt, before the end of the French EU Presidency, recommendations inviting each Member State to develop national Alzheimer plans by 2010. These recommendations would serve as a kind of toolbox, from which each Member State will extract ideas, whilst recognising their individual specificities and respecting the principle of subsidiarity. While each plan will be different, the priorities will be common. A global scientific, medical and social approach needs to be shared by all.

In our fight against dementia, Europeans, no matter which Member State they are from, face common issues and therefore Mr Sarkozy proposed three ways in which Europe can work together:

- **Research:** Whilst acknowledging the recognition given by the Competitiveness Council to build a European Research Area earlier this year, Mr Sarkozy also lamented the low investment into research for Alzheimer’s disease. Rather than working in isolation or duplicating other work, money could be assigned to joint research programming. In addition, he said that Europe should promote the mobility of researchers and he talked of offering Alzheimer scholarships to young researchers who would work in other European countries. By 2010, Member States should be invited to develop a coordinated plan for research.

- **Care and support:** By sharing best practices in care and support, Member States can develop a common set of recommendations. Again, he highlighted the need to collaborate to avoid isolation and duplication and cited the EuroCoDe project as providing a rich source of information on various aspects of Alzheimer’s disease and called for more initiatives like EuroCoDe.

- **Ethics:** Whichever country we live in, questions, such as how to obtain the consent of someone entering a home or how to act with a person who has lost their usual method of communication, are common to all Europeans dealing with this disease. Advocating ethical reflection and the exchange of good practices, the President believed that Europe should support the creation of such a network.

Finally Mr Sarkozy explained why he feels he should continue to speak of the fight against Alzheimer’s disease when, at the same time, we face an economic crisis: “If we were dealing with people’s health only when there is global growth it would be unacceptable… I want to say that whatever the context we are in, the fight of all Europeans against Alzheimer’s disease is a priority.”

A Ministers’ press conference followed. For all those who have long fought for action against Alzheimer’s disease, the Minister’s round table and support of the French President was a welcome sight. The coverage and visibility which the French Presidency has given to Alzheimer’s disease by organising such a Conference cannot be underestimated. Delegates left the auditorium with a renewed and real hope that maybe, at last, concrete measures will be decided and implemented and, that the conference would, as Françoise Grossetête hoped “be a stepping stone to a European Plan, which we have all been waiting for.”
Françoise Grossetête (France), John Bowis (United Kingdom), Katalin Levai (Hungary), Jan Tadeusz Masiel (Poland) and Antonios Trakatellis (Greece) joined forces to issue a call to the European Commission and the Council of Ministers to recognise Alzheimer’s disease as a European public health priority and to develop a European Action Plan on Alzheimer’s disease.

In their Written Declaration (80/2008), the Members of the European Parliament from five different European countries and three different political groups call in particular for increased European collaboration on research into the causes, prevention and treatment of Alzheimer’s disease, as well as earlier diagnosis, improved support for people with dementia and their carers and better recognition of the role of Alzheimer associations.

Françoise Grossetête, Chairperson of the European Alzheimer’s Alliance stressed: “As Members of the European Parliament, we cannot remain indifferent to the 6.1 million European citizens who live with Alzheimer’s disease or a different form of dementia today. We give our full support to the French Presidency initiative to improve the collaboration between Member States on dementia research, but this call goes even further. We fully support the proposal to develop a comprehensive European action plan on Alzheimer’s disease and other forms of dementia which will also focus on the exchange of best practices in the areas of care and social support of people with dementia and their carers. We hope that Members of the European Parliament will overwhelmingly support this call of their colleagues.”

Jean Georges, Executive Director of Alzheimer Europe, welcomed the European Parliament initiative: “I am delighted that five Members of the European Parliament have given such clear support to our campaign to make dementia a European priority. The Written Declaration follows closely on the decision of the Council of Ministers to improve the collaboration between Member States on dementia research, but this call goes even further. We fully support the proposal to develop a comprehensive European action plan on Alzheimer’s disease and other forms of dementia which will also focus on the exchange of best practices in the areas of care and social support of people with dementia and their carers. We hope that Members of the European Parliament will overwhelmingly support this call of their colleagues.”

The Declaration, which is open for signatures until 22 January 2009, will become official provided that more than half of the Members of the European Parliament sign it.

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Jean Georges, Executive Director of Alzheimer Europe
NATIONAL DEMENTIA STRATEGIES

A snapshot of the status of National Dementia Strategies in Europe

The first item on the Paris Declaration, which lists the political priorities of the European Alzheimer movement, is the call for national governments to “recognise Alzheimer’s disease as a major public health challenge and develop (...) national action programmes.” This is further supported by Alzheimer Europe’s recommendations on the provision of social support to people with dementia and carers, which also calls upon governments to “set up national action plans for dementia care and set aside the necessary funds to implement them.”

In order to get an idea of the current status of national dementia plans within Europe, Alzheimer Europe carried out a small survey: The findings make uncomfortable reading. Although France (who commenced their third national plan this year), Norway, Scotland and England have national plans, the large majority of Alzheimer Europe members who responded do not have a plan in place. Moreover, many do not have any indications that there are future plans to develop national dementia strategies.

However, in some countries, there are clear indications that dementia is on the way to becoming a national priority. For example, the Welsh Assembly voted unanimously for a Dementia Plan in July of this year and in Malta the Department for the Elderly, together with the Malta Dementia Society, has started work on an overall local strategy for dementia care.

Alzheimer associations are also hopeful that the importance of national plans can be placed on national governments’ agendas. The Swiss organisation has managed to generate some 9,000 signatures to their manifesto since August 2008 and will use this to highlight the plight people with dementia and their carers face. The Danish Association has now made it their strategic priority to put a national dementia strategy on the political agenda and we also eagerly await the outcome of the Northern Ireland Executive’s recently finished consultation process for the reformation of services for people with mental health conditions. In Ireland, the establishment of a working group on dementia brings hope as does the announcement by the Belgian Health Minister that there will be a development of new measures for people suffering from chronic diseases, including Alzheimer’s disease. The appointment of Katalin Levai, MEP, (Hungary) as Vice-Chair of the European Alzheimer Alliance has brought great encouragement to the Hungarian association that debate will now be provoked at a national level and the Cyprus Alzheimer’s Association also finds encouragement by the fact that two Cypriot MEPs have given their support to the European Parliament’s Written Declaration 80/2008 on priorities in the fight against Alzheimer’s disease.

Some of the Alzheimer associations and/or local government bodies are either in the process of drafting, or have written, Alzheimer plans (eg. Belgium, Romania and Spain) but these are not operational at governmental level as yet. In Portugal there are local dementia strategies, but they are not homogeneous throughout the country, nor are they in every region.

Whilst there may not be a national plan in place, some countries are giving recognition to the needs of people with dementia and their carers within
their existing frameworks. For example, in Germany dementia is prioritised by different governmental bodies as the Ministries for Health, for the Elderly and for Research all have initiatives for people with dementia and their carers. Similarly in Luxembourg, whilst dementia featured prominently in the review of their long-term health care plans, there is not a specific dementia plan per se. In May 2008, there was a proposal in Italy for a law for the prevention and care of Alzheimer’s disease, but no progress has yet been made. Some of the Italian local authorities include dementia within their health care plans, but not all and there is nothing at the national level. Spain also has health and social plans developed with their Autonomous Communities, some of which include provision to deal with mental diseases, but there are no dementia-specific plans.

Without establishing a national dementia-specific plan, opportunities may be missed to address the specific issues which arise with dementia in a coordinated, integrated way and this will result in a lack of effectiveness and of efficiency. With the predicted numbers of people with dementia set to double by 2050, governments need to address the specific needs people with dementia and their carers face: Remember, the time to act is now.

Results of survey carried out by Alzheimer Europe (10 / 2008)

Is there a national dementia-specific plan currently operational in your country?

Yes: England, France, Norway, Scotland

No: Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Malta, Northern Ireland, Poland, Portugal, Romania, Slovenia, Spain, Switzerland, Turkey, Wales

CORRECTION

We would like to apologise for an error which occurred in the first edition of our Dementia in Europe Magazine. Unfortunately, the numbers of people with dementia in Austria and Belgium were incorrect in the table included on page 7. Below we publish the corrected numbers:

THE NUMBER OF PEOPLE WITH DEMENTIA IN EUROPE IN 2005

<table>
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<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>
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<td>68,430</td>
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Jan Tadeusz Masiel, MEP, talks to Alzheimer Europe about the challenges people with dementia and their carers currently face in Poland.

Alzheimer Europe (AE): Mr. Masiel, you have been an active member of the European Alzheimer’s Alliance since its creation last year. What are the key challenges that people with dementia and their carers face in Poland?

Jan Tadeusz Masiel (JTM): First of all, there is a lack of a national action plan for people who suffer from dementia in Poland. Government involvement in care for the sick as well as the prospects for a solution to the problem of care in the future are missing in my country. The growing number of older people potentially threatened by Alzheimer’s disease and other kinds of dementia requires that a national plan of assistance be put in place for this group of people.

In 2003 the Polish Association for the Care of People with Alzheimer’s disease gave an overview of the situation of people with dementia in the Polish Senate and proposed the creation of a National Program to combat Alzheimer’s disease, but no action followed this meeting.

Another problem is that the sick do not have any privileges. Medicines are reimbursed by the government at 70% but only for the first stage of the disease. For the second and late stage of the disease in Poland, as in the rest of the world, the drug memantine is used but it is not refunded in our country. The monthly cost of treatment is estimated as PLZ 500 (about EUR 130). Patients can get a care allowance regardless of their age, if they have a decision on full disability (First invalidity group), the care allowance is the same as that given to anyone in Poland who is over 75.

Moreover, there is a lack of day care homes. There are only about 15 of them in the country and a limited number of specialist home carers. Day care homes are created and run by Alzheimer’s organisations with the cooperation of local governments. In Warsaw, there is one such house for 12 patients.

The problems listed above are the biggest challenge for patients and their families but also for the government when it comes to daily life problems; when the carer (adult child) is going to work. In a nutshell there is a lack of institutionalised care for the sick in Poland.

Finally, we can see in Poland a lack of support for patients staying all the time at home. There are no reimbursements, no financial support and not enough social workers going to the house of the patient. Care is expensive and the sick cannot afford it. The sick can buy per month on prescription (50% payment) 60 incontinence pads and that is everything.

AE: Governments across Europe are starting to pay more attention to the demographic changes in our societies and the resulting increase in the number of people with dementia in the future. Are there similar discussions in your country on a governmental or parliamentary level?

JTM: As far as I know, the Polish government does not pay that much attention to this problem at the moment, which of course might have very bad consequences in the future.
AE: Do you believe that Poland will follow the example of France and create a National Alzheimer’s Plan?

JTM: I would like my country to follow the example of France in creating a National Alzheimer’s Plan but looking at the current situation in Poland it is unlikely that this will happen.

AE: What do you believe should the three policy priorities be for Polish policy makers to improve the lives of people with dementia and their carers in your country?

JTM: In my opinion, it is necessary to call for the unification of standards of treatment and care in EU countries, the creation of a strategy to help states lagging behind those standards and to encourage them to devote specific measures for financing care for a person with dementia residing in the house. The government in Poland always indicates other important priorities. Unfortunately, the old and the sick are not getting enough attention in my country.

AE: Finally, a last question on the need of a European response to the growing number of people with dementia. Would you support the development of a European Action Plan in this field and, if so, what should the priorities for such a European collaboration be?

JTM: I would certainly support the development of a European Action Plan in this field and the Written Declaration which I have submitted in the European Parliament with my colleagues Françoise Grossetête, Katalin Levai, John Bowis and Antonis Trakatellis calls for more coordinated European research and an exchange of best practices in the field of care approaches.
People with dementia and their carers often face discrimination, which can be even worse for people from minority groups. Roger Newman explains how real inclusion and diversity can be achieved.

GODS FOR TODAY!

I live in a world where the words ‘inclusion’ and ‘diversity’ are sometimes even gods! They reflect an understanding of modern society which for some might be exasperating but for me as a gay man, and therefore a member of a minority group, they can be a salvation.

As a founder member of the Lesbian, Gay, Bisexual and Transgender (LGBT) Support Group of the Alzheimer’s Society I have been glad that it has more than just paid lip service to such principles, indeed at its Annual Conference in September it gave the Group a prestigious award for volunteering with a citation which read ‘they are brave and dedicated people and we are proud to honour them’.

Surely all European Alzheimer’s Groups would subscribe to the belief that inclusion and diversity are fundamental to their work of supporting carers and those with dementia, but I have long since realised that it is one thing to have a principle and another to commit yourself thoroughly to achieving it.

I want to suggest these steps to achieving real inclusion and diversity:

- There must be a proactive acceptance that dementia is more than a white, middle class, heterosexual, Christian condition. We have two compelling posters: One has two men clearly devoted to each other and the other has two women similarly so, which state ‘Gay or straight, dementia does not discriminate’. Such statements can easily be replicated for any minority and I believe that it is essential to proclaim such truths because we are too frequently tempted to take the easier option of concentrating on our ‘own kind’.
- There must be a positive affirmation of minorities by our societies. It is too easy to sign up to equal opportunities projects and then hide behind statements like ‘it doesn’t matter who you are – we treat everyone the same’ because the result is surely just a low threshold of common care. Instead the affirmation should reflect the belief that minorities belong because they are black, gay, muslim etc; and then by asking questions, however searching, it will become clearer how dementia affects them and what their distinctive needs are. The consequence will be real insight and will ensure that the resulting inclusion is truly focused, informed and positive.
- There must be clear and active means of achieving ‘inclusion’ and ‘diversity’. Certainly policies will be necessary, but publications will also need to reflect this. Yes, show caring families and devoted partners but also at times show carers and those with the condition who are black, same sex, concerned friends and so on. In our Society’s magazine ‘Living with Dementia’ there is an active approach to publishing articles reflecting the diverse nature of our population. There may also be the need to establish specific groups like the LGBT group because sometimes minorities feel happier that way and there may need to be positive discrimination in employment too.
- Finally there must be training for all service providers and volunteers so that inclusion becomes fundamental to the way they undertake their work. Nothing short of that can ensure that dementia care meets the needs of the whole person.

The end result? Well surely nothing more nor less than skilled, successful, fulfilled, accepted people, professionals, carers and those with the condition alike, who know that in this world of dementia the very best has been offered and received, because dementia does not discriminate.
Michael Cashman, MEP, talks with Alzheimer Europe about some of the key problems faced by gay and lesbian carers, as well the draft directive on the protection from discrimination on the basis of sexual orientation.

Alzheimer Europe (AE): Mr. Cashman, as President of the European Parliament’s Intergroup on Gay and Lesbian Rights, what do you consider to be the key problems that gay and lesbian carers experience?

Michael Cashman (MC): The key problems faced are that some countries and some service providers fail to take our families seriously. We have achieved equality in some countries but by no means all. Equality is our goal and that is where visibility is the key. When people see the role that we play in society and how common it is to the role played by others in similar situations so the case for prejudice begins to fail. I have always said that we are ordinary women and men made extraordinary by society’s preoccupation with what they think our sex lives are. They air brush our lives and seek to define us solely by sexual activity. Lesbian and gay carers demonstrate so heroically how we face the same problems but the problems are aggravated by mind numbing discrimination.

AE: What can gay and lesbian carers expect from the draft Commission directive providing protection from discrimination on the basis of sexual orientation?

MC: The directive before the EP, which I led the battle for - and it was battle to get it from the Commission, but it was another battle that with single minded determination we won - will substantially improve the lives for gay and lesbian carers. In the supply of goods and services no longer will countries be allowed to discriminate on the grounds of sexual orientation (as well as age, religion or belief, disability or a combination of these). Some countries will still be better than others but there should be minimum standards which will be legally enforceable. There is a big BUT. We have to get this agreed by the 27 Member States of the EU and currently some are proving problematic, like Germany, Ireland and the Czech republic.

AE: Are there marked differences between European countries as to the situation of gay and lesbian carers?

MC: As stated above there are marked differences, especially where the role of religion is dominant in politics. But that will not stop me and the Inter-group of the European Parliament from pursuing our achievable aim of equality, dignity, respect. These are Universal values and certainly values upheld by the Treaties of the European Union. It is incredible that one can suffer discriminatory care merely because of where one lives in the EU.
Pricing and reimbursement of anti-dementia drugs

Access by European citizens to existing anti-dementia drugs is a key concern of Alzheimer associations throughout Europe. Further, a core objective of Alzheimer Europe’s is “changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services”.

Recent policy developments may offer some hope that concerns regarding accessibility are being heard. In the UK, research was commissioned in August 2008 by the National Institute for Health and Clinical Excellence (NICE) to establish the threshold at which drugs are considered to be “cost effective.” The threshold was set nine years ago and is considered outdated. Commenting on the methods used by NICE to determine whether drugs should be made available, Professor John Harris, Professor of Bioethics at Manchester University said that “tossing a coin” would be fairer. The outdated threshold, together with the expected NHS surplus of £1.75 bn has given rise to considerable criticism that the threshold is set too low. People with early-stage dementia have been denied access to cholinesterase inhibitors as they were considered not to be cost-effective; a decision that was received with dismay from people with Alzheimer’s disease, their carers and patient organisations. Speaking on this subject, the best selling-author, Terry Pratchett, explained that he feels “particularly angry on behalf of early onset patients because it feels like an insult and the younger you are the more insulting it is.” He went on to say “It’s probably easier to get drugs off Fat Charlie round the back of the bus station than it is to get medicines – but there we are.”

The results of the cost effectiveness research are expected in January 2009.

It is also encouraging that in October, when concluding their three-year review, the High Level Pharmaceutical Forum (HLPF) set up by the European Commission published its findings which included recommendations that:

“7.1 Member State authorities and stakeholders of the Pharmaceutical Forum should strengthen their efforts in ensuring timely access to valuable innovations and in ensuring access to medicines for all citizens.

7.2 Member State authorities and stakeholders of the Pharmaceutical Forum should strengthen their efforts in ensuring sustainable availability and delivery of medicines to all EU Member States, in particular to small national markets.”

The Forum called for a review of the progress of their recommendations within 2 years.

Patients’ rights in cross-border healthcare discussed by the European Parliament

The European Commission adopted a proposal for a directive on the rights of patients accessing cross-border healthcare on 2 July. This directive was further discussed by the Members of the European Parliament (MEPs) on 25 September when they considered the health aspects of the social package.

The importance of this proposal was highlighted by both Roselyne Bachelot, French Minister for Health, who confirmed that the proposal will “remain a priority during the next 18 months, as this is included in the common agenda of the French, Czech and Swedish Presidencies” and by Androulla Vassiliou, the European Commissioner for Health, who said that the proposal “was without doubt the most important initiative on health of the present Commission”. Ms Vassiliou explained that the proposal has three objectives:
1. to clarify the conditions under which patients are entitled to seek healthcare abroad
2. to guarantee safe and high quality cross-border healthcare across the EU and
3. to reinforce cooperation between the different healthcare systems
and she called for a new framework for Europe where “cooperation is key and where knowledge and skills are particularly important.”

MEPs then discussed the Commission’s proposal highlighting the following issues:
• To put patients at the centre of the issue
• Legal certainty
• Prior authorisation for care
• Reimbursement and cost
• Continuity of care
• Quality and safety of care
• Compatibility and interoperability of health information systems.

Political groups failed to find agreement on a joint motion for a resolution on the overall social package during the debate. The report for the first reading is being prepared by John Bowis (United Kingdom) so that it can be put before the European Parliament in December.

A number of recent initiatives have recognised the importance of dementia research

The importance research has in addressing dementia is slowly being reflected at both the national and European level. In Germany, the work of the new Degenerative Dementias Competence Network commenced on 1 July and it will focus on the origin of dementia, animal models and early diagnosis, the course of dementia and therapy and costs. In August, the Scottish Government announced an additional £1 million funding for research into dementia to be allocated to fund a new Dementia Clinical Research Network in Scotland. Further, the National Institute for Health Research in England has benefitted from a pledge of £18 million to fund work which will “conduct research and improve care in conditions including dementia.”

On a European level the European Commission presented their communication “Towards joint programming in research: Working together to tackle common challenges more effectively” at the end of September. This communication proposes the method of “Joint Programming” in order to make better use of public funds by asking Member States (on a voluntary basis) to identify key challenges on which to focus, agree on a common vision and develop and implement a Strategic Research Agenda for each area. This was debated by the Council and conclusions are being drafted, ready for possible adoption by the Competitiveness Council in December.

At the same meeting, the Commission presented the Draft Regulation on the Community legal framework for a European Research Infrastructure (ERI) which will facilitate the setting up of European Research Infrastructures (for example, observatories for environmental sciences, data banks in genomics or state of the art large super computers).

In addition, the Competitiveness Council adopted at its 26 November meeting conclusions on a common commitment by the Member States to combat neurodegenerative diseases, particularly Alzheimer’s disease. The conclusions include: a) support research to better understand, detect, prevent and combat the basic mechanisms which trigger neurodegenerative diseases, particularly Alzheimer’s, b) significantly strengthen cooperation and coordination of research efforts, the level of financial investment and degree of mobility of researchers, and c) prepare research activities that can be implemented rapidly.

“The proposal on cross-border healthcare was without doubt the most important initiative on health of the European Commission.”
Androulla Vassiliou
DEVELOPING THE EUROPEAN PACT FOR MENTAL HEALTH

John Bowis, Member of the European Parliament for the UK, talks to Alzheimer Europe about the European Pact for Mental Health and Well-being.

Alzheimer Europe (AE): Mr Bowis, you have closely followed the European discussions on the development of a European Pact for Mental Health and Well-being. Which of the proposed actions do you think are of particular interest to people with dementia and their carers?

John Bowis (JB): The most important achievement is to have a European Policy - or Pact - for Mental Health. It is on the EU health agenda, where some of us have been pressing for years it should be. The fact that the five specific areas of mental health to be taken forward are children and young people, stigma, suicide, people at work and older people means dementia is up there on the front page. It ties in with the work already underway in the EU research programme on neurodegenerative diseases.

Europe, as we know, does not have the power to lay down standards of provision by national health services; we use our position to find and share good practice. However mental health at work is an EU competence and so we can, for example, call for reports on what employers are doing both for employees who start to contract dementia or who are carers for a dementia patient at home. Likewise, where our new policy on Cross Border Health is concerned, people are beginning to realize we need to share standards and measurements for quality and safety and a great deal of work is now tackling this.

The other side of the coin is of course that we are looking not just at how we can improve policy and practice for people who have dementia but we are looking for ways of encouraging mental well-being and the prevention - or at least the slowing - of the onset of such diseases.

AE: How will the recommendations of the Pact be put into practice?

JB: The next steps are that the five key areas will each have a “take forward” group to discuss, debate and progress ideas for each. This may or may not lead to legislation; it may be left to Member States to take forward.

AE: In your opinion, which other actions are necessary to make dementia a European public health priority?

JB: My hope is that we will have at the very least a Council recommendation and maybe a full blown directive setting out where we expect action and the sort of targets to aim at, but leaving the detail to the discretion of each Member State. Alongside this, I do believe we can and should require by EU legislation that firms above a certain size should annually report on their mental health at work company policy. At the very least, this would concentrate their minds and, maybe, prompt them to initiate some imaginative ideas.

I have no doubt at all however that some Member State governments would rather we did not do anything of any consequence in this area. If you believe, as I do, that this would not be acceptable, then we need individuals and organisations such as Alzheimer Europe to press their governments and Ministers to look positively on this excellent first step on the way to a better future in Europe for the very large number of our fellow citizens, who have to live with mental health problems and increasingly have to face the prospect of the frailty of mind, that comes with longevity for so many of us.
DEMENTIA IN THE NEWS

Moving dementia out of the shadows
Jean Georges, Executive Director of Alzheimer Europe, looks at the contribution that public figures can make to the fight against stigma

Dementia in Society
A look at how dementia is portrayed in literature and the arts

World Alzheimer’s Day
Alzheimer associations across Europe campaign for change

Spotlight on ... Finland, Italy and Portugal
A look back at the associations’ achievements as they celebrate their anniversaries

Members’ events
The German Youth competition

Putting a face to commitment
The people behind Alzheimer Europe
GSK’s goal is to improve the quality of human life - not just through our medicines and vaccines, but also through our work with communities around the world.

By partnering with non-profit organisations, we can improve the health and education of those who need it most. Targeted, sustainable programs benefiting future generations in both the developing and developed world-helping them to do more, feel better and live longer.

Caring for the world... one person at a time™

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MOVING DEMENTIA OUT OF THE SHADOWS

Jean Georges takes a look at the contribution public figures can make to the fight against stigma associated with Alzheimer’s disease and other forms of dementia

“I have recently been told that I am one of the millions of Americans who will be afflicted with Alzheimer’s disease. (…) I now begin the journey that will lead me into the sunset of my life”.

This was how former US President Ronald Reagan announced in 1994 that he had been diagnosed with Alzheimer’s disease. For many, the announcement came at a time, when Alzheimer’s disease was little known and little understood. Both Ronald and Nancy Reagan stated that they hoped that their openness in talking about Alzheimer’s disease would “promote greater awareness of this condition”. Without a doubt, they were successful in doing so.

Since, a number of well known figures and celebrities from the political, sports and arts world have joined Ronald Reagan in the long list of people who have openly talked about the experience of living with dementia. Actor Charlton Heston, former British Prime Minister Harold Wilson, writer Iris Murdoch or actress Rita Hayworth, to name but a few, are all now associated with Alzheimer’s disease and their family and friends have been powerful advocates to raise awareness and to combat the stigma still associated with this disease.

In most of Europe, there seems to be less willingness to be open about a diagnosis of dementia than in the United States. Fewer public figures have “come out” and the media coverage of such announcements has not always been positive.

Just recently, Carol Thatcher talked candidly about her mother’s struggle with Alzheimer’s disease. Particularly poignant was her retelling of the former British Prime Minister asking after her dead husband and being sad every time she was told that he had died. Yet the reaction in some papers was negative and Carol Thatcher was accused of betraying her mother’s legacy. Similarly, a documentary on French television about Annie Girardot’s life with Alzheimer’s disease was criticised as diminishing the life of a universally well liked French actress.

The reactions show the stigma that is still associated with a diagnosis of dementia. A recent report by the Alzheimer’s Society entitled “Out of the shadows” confirmed the isolation felt by people with dementia and their carers. A number of participants in a survey stated that their symptoms had been dismissed as merely part of the ageing process by their GP, while others had neighbours and friends ignoring them and even crossing the street to avoid them and avoid having to confront the disease.

So rather than condemning Carol Thatcher for somehow diminishing the stature of the former British Prime Minister, we should be applauding her for the candid description of her mother’s life with dementia. The more public figures speak openly about the impact of Alzheimer’s disease, the more we will be able to move the condition “out of the shadows” and combat the stigma faced by people with dementia and their carers.

Two carers participating in the survey of the Alzheimer’s Society summed it up really well, with one saying: “The more, as you say, it’s talked about, about well known people having it, the better it’s accepted as part of life” and another one stating: “A few more Terry Pratchetts could be useful.”
Dementia in Society

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

22 July 2008: “Golden Girls” actress, Estelle Getty, dies with Lewy body dementia

Estelle Getty, the actress famously latterly for her part in the American sitcom “The Golden Girls” (1985-92) died aged 84, with Lewy body dementia.

Starting her career as a stand-up comedian in summer resorts in the Catskill Mountains, Estelle Getty’s break came as in the role of a meddling mother in the Broadway play, Torch Song Trilogy. She went onto have parts in sitcoms (Empty Nest, Blossom, Nurses, Ladies Man and The Golden Palace) and in films (Stop! Or My Mom Will Shoot, Mask, Tootsie, Stuart Little and Copacabana). She was often cast as a mother-figure, which led her to reflect in her autobiography “I’ve played mothers to everyone but Attila the Hun!”

23 August 2008: Daughter reveals Baroness Thatcher’s struggle with dementia

Carol Thatcher, daughter of ex-British Prime Minister (1979-1990) Baroness Margaret Thatcher, has described how the signs of dementia emerged in her mother. In 2000, she first realized her mother’s memory was failing. Carol said “Whereas previously you would never have had to say anything to her twice, because she’d already filed it away in her formidable memory bank, Mum started asking the same questions over and over again, unaware she was doing so.” In addition, Carol explained how she had to repeatedly tell her mother that her (Margaret’s) husband, Denis, had died, Carol said “Every time it finally sank in that she had lost her husband of more than 50 years, she’d look at me sadly and say “Oh”, as I struggled to compose myself. “Were we all there?” she’d ask softly.”

20 September 2008: Controversial remarks by UK philosopher cause outcry

In an interview with the Church of Scotland’s magazine, Life and Work, former Government advisor, Lady Warnock, said “If you’re demented, you’re wasting people’s lives – your family’s lives – and you’re wasting the resources of the National Health Service.

Lady Warnock, 84, who has had a long career in academia, specializing in ethics also wrote an article for a Norwegian periodical entitled “A Duty to Die?” in which she suggests “that there’s nothing wrong with feeling you ought to do so for the sake of others as well as yourself.”

Neil Hunt, chief executive of the Alzheimer’s Society, said “I am shocked and amazed that Baroness Warnock could disregard the value of the lives of people with dementia so callously... With the right care, a person can have a good quality of
life very late into dementia. To suggest that people with dementia shouldn’t be entitled to that quality of life or that they should feel that they have some sort of duty to kill themselves is nothing short of barbaric.”

21 September 2008: Documentary of French actress, Annie Girardot, who lives with Alzheimer’s disease, shown on World Alzheimer’s Day

The French channel TF1 broadcast a documentary about Annie Girardot, the famous French actress, who lives with Alzheimer’s disease on 21 September, World Alzheimer’s Day.

Annie Girardot was diagnosed with Alzheimer’s disease in 1998. With her consent, her daily life was filmed by her close friend, Nicolas Beaulieu, during 2006 and 2007. She continued to act, but when she began to feel lost and alone Ms Girardot moved into a specialized home.

The documentary ends stating “Annie, despite her family’s efforts, forgot everything about Girardot.”

29 September 2008: Terry Pratchett calls on politicians to prevent the “tsunami” of dementia

Speaking at the Conservative Party conference, Terry Pratchett, the best-selling author and Patron of the Alzheimer’s Research Trust, likened the impending dementia epidemic to that of a “tsunami of dementia suffering” and asked the delegates “Is there going to be a government willing to put its money where its mouth is or will dementia remain the most feared disease for the over 55s? … What is unthinkable is to do nothing at all.”

He explained “the toll of this nasty disease is greater than you think. An appreciable number of people in this room will be affected by it. Dementia isn’t a disease of the bumbling elderly. People get it in their 50s and 60s.” He believes that people with dementia are stigmatized as “superfluous old farts”.

Mr Pratchett again highlighted the lack of funding for research for Alzheimer’s disease and related diseases. The delegates gave him a standing ovation.

“Is there going to be a government willing to put its money where its mouth is or will dementia remain the most feared disease for the over 55s? … What is unthinkable is to do nothing at all.” Terry Pratchett
WORLD ALZHEIMER’S DAY

On 21 September each year, people with dementia, their carers and Alzheimer associations from nearly 80 countries come together to raise awareness about the realities and effects of dementia on individuals, families and societies. Below are snapshots of World Alzheimer’s Day activities from the various European Alzheimer Associations.
Dementia in the News

Denmark

Hungary

Switzerland

UK

Portugal

Luxembourg

Malta

Spain

Greece

Scotland

Germany

France

Italy

Alzheimer Europe
Restoring the Tradition of European Medical Innovation

Over the past 200 years European scientists have been at the forefront of medical progress. Today, that proud tradition is under pressure from policies that devalue the role of innovation.

Innovation takes many forms: from the ground-breaking treatments and cures that emerge from our laboratories, to new solutions for today’s and tomorrow’s major health challenges. An ageing population, access to the best treatments and the availability of credible health information are issues of concern for both policy makers and society as a whole.

We believe that partnerships between governments, public institutions and the research-based pharmaceutical industry are essential to meet public demand for medical excellence, while revitalizing Europe’s spirit of innovation and competitive position in the global marketplace.

For more information:
Pfizer European Public Affairs and Policy
17, Blvd. de la Plaine, 1050 Brussels, Belgium
e-mail: europe.information@pfizer.com

www.pfizer.com
SPOTLIGHT ON … FINLAND

Celebrating their anniversaries this year are Alzheimer Europe Members, Alzheimer-keskusliitto (Finland) and Alzheimer Portugal, who both celebrate their 20th anniversary and Federazione Alzheimer Italia, who celebrate their 15th. We take a look at some of their key achievements.

ALZHEIMER-KESKUSLIITTO
(THE ALZHEIMER SOCIETY OF FINLAND)

1988 The Alzheimer Society of Finland was created. The magazine Muisti (Memory) started and a day care center for people with dementia opened
1989 “Leena’s Care Home” established. Member of Alzheimer’s Disease International
1991 Member of Alzheimer Europe
1996 New premises in Helsinki purchased with funds from new RAY project
1997 Hosted the joint 13th ADI and 7th Alzheimer Europe Conference in Helsinki with 1 500 participants from 51 countries
2000 Description of Good Dementia Care – project commenced, consequently sixteen different seminars were arranged both to the local organisations and to the social and healthcare workers all over Finland. The first Strategy for Alzheimer Society of Finland launched
2001 Organised the “Who can stay at home?” seminar in Rovaniemi
2002 Peer helpline for caregivers started and subsequently expanded to cover both the internet website and the chatroom on the internet.
2003 Organised the “Puzzle of Dementia Care” in Helsinki
2004 Second strategy launched. Three projects launched: “Maintain your brain” – project “Help in Time in Homecare” project (which promotes the legal rights of people with dementia and their caregivers and proves legal counseling) and “Pathways of Rehabilitation” project
2005 Formula for Advance directives for end-of-life care published
2006 “Expert and Support Centres network” project commenced and the “Model for the Rehabilitation of people with dementia” published. Educational development campaign commenced
2007 Life is Cool with a Fit Brain – health promotion campaign for teenagers launched. 2008 Third Strategy being drafted.

Alzheimer-keskusliitto
Luotsikatu 2 E
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Web: http://www.alzheimer.fi

Chairperson
First Vice-Chairperson
Second Vice Chairperson
Board members and their personal deputies:
member
deputy
Hiltunen Rakel
Loi Pehr
Mäkipalo-Ropponen Merja
Rollas Heikki
Suokonen Jaana
Tikanmäki Jukka
Urvas Maire
Korhonen Riitta
Perho Maija
Autio Risto

Chairperson of the Central Council: Rehula Juha
Vice-Chairperson of the Central Council: Pletikäinen Sirpa

Leena’s Care Home in Helsinki
SPOTLIGHT ON ... ITALY

FEDERAZIONE ALZHEIMER ITALIA

30 June 1993 Federazione Alzheimer Italia founded. Launched the first Italian help line.
1995 Organised the 5th Alzheimer Europe Conference in Milan. “E sull’Alzheimer” project launched
1996 Launched website. Collaboratively launched “Pronto”, the Alzheimer telephone helpline
1997 Collaborated on “Transnational analysis of the socio-economic impact of Alzheimer’s disease in the EU”
1998 Collaboratively started pilot carer project. Collaborated on “Predict - Transnational study on institutional care”
1999 Published the Italian edition of Alzheimer Europe Care Manual. Member of the Council of Volunteers in Health at the Ministry of Health
2000 Member of the National Commission for Neurosciences at the Ministry of Higher Education and Scientific Research
2001 Disseminated the Italian translation of the book “Dear Grandma”
2002 Second carer project and published two books: “Partial vision – A diary of Alzheimer’s” and “Music therapy for patients with Alzheimer’s disease”
2004 Volunteer Health Project between patients and associations of citizens and community medical science
2006 Collected 2000 signatures in support of the “Paris Declaration”. Organised the first fund and awareness raising concert at the Teatro alla Scala in Milan
2007 Project “Census and evaluation of services and facilities for care and assistance in Lombardy” Second concert at the Teatro alla Scala in Milan
2008 The third concert at the Teatro alla Scala in Milan. Inaugurated the first “Alzheimer House” in Imola.

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Info@alzheimer.it, www.alzheimer.it

45 Full Member Associations and Associated Member Associations:
Ancona, Asti, Bari, Bologna, Borgomanero (Novara), Carpi (Modena), Camposampiero (Padova), Como, Faenza (Ravenna), Foggia, Genova, Imola (Bologna), Lamezia Terme (Catanzaro), La Spezia, Lecce, Lecco, Milano, Milazzo, Modena, Monfalcone (Gorizia), Paternò (Catania), Perugia, Piacenza, Pieve di Sacco (Padova), Pizzo Calabro (Vibo Valenza), Potenza, Ravenna, Rorna, San Remo (Imperia), Sassari, Taranto, Torino, Trento, Trieste, Udine, Verona, Venezia, Verbania, Vignola (Modena), Vicenza, Alzheimer Canton Ticino (Svizzera)
In Milano there are 4 associations and in Venice two associations

Chairperson: Gabriella Salvini Porro
Vice-Chairperson: Gerardo Langone
Treasurer: Lucia Valtancoli
Members: Maurizio Carrara, Giampaolo Cassinari, Andrea Gelati, Paola Pennecechi, Katia Pinto, Gilberto Salmoni
**SPOTLIGHT ON ... PORTUGAL**

**ALZHEIMER PORTUGAL – 20TH ANNIVERSARY**

1988 Alzheimer Portugal is founded by Professor Carlos Garcia, a neurologist
1993 Start of the newsletter
1994 The Help Line is launched and Alzheimer Portugal organises the first seminar about Alzheimer’s disease. The first Christmas sale also takes place. Alzheimer Portugal becomes a member of Alzheimer Europe
1996 A group of volunteers organises the 1st support group.
2002 1st Edition in Portuguese of “Querida Avozinha” (Dear Grandma)
2003 The “Professor Carlos Garcia Day Care Center and Home Service” opens in Lisbon – it is the first of its kind in Portugal
2004 Website launched which now has 60,000 visitors per year
2006 Became a full member of Alzheimer’s Disease International
2007 Host the 17th Alzheimer Europe Conference “The Sound of Silence”
2008 20th Celebratory Conference (“Alzheimers and other forms of dementia – watching the future”) in Lisbon. Also launched an exhibition at the National Parliament to encourage national legislators to make dementia a national priority and raise awareness.

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Tel.: 00 351 21 3610460/8  Fax: 00 351 21 3610469
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www.alzheimerportugal.org

Head office – Lisbon

**Chairperson:** Maria do Rosário Zincke dos Reis
**Vice-Chairperson:** Maria de Lurdes Quaresma
**Board Members:**
Noémia Losna
Maria Francisca Távora
Ana Isabel Gameiro
António Oliveira Costa

*Carlos García Day Care Centre*
FOCUS ON MEMBERS’ EVENTS: THE GERMAN YOUTH COMPETITION

Highlights from the German Alzheimer's Association's Youth Competition

In order to explore ways in which young people can support people with dementia, and to raise their awareness of the disease, the German Alzheimer’s Association (Deutsche Alzheimer Gesellschaft) launched their national youth competition, “Alzheimer and You” on World Alzheimer’s Day 2007. The aim of the competition was to help the “grandchild generation” (aged between 14 and 21) to a) become more aware of the disease and b) learn how to help support people with dementia.

Individuals, classes and teams were invited to participate in the competition in which they had to demonstrate their commitment to the project by making contact with someone with dementia (for example, going for a walk or going through a photo album with them and then documenting their activities by means of texts, pictures, illustrations or films).

Subsequently, some 600 young people took part in the competition submitting 110 creative contributions. The winners were announced on 10 September 2008 under three categories:

1. Individuals: Painting by Lisa Maassen (aged 17) from Hamburg. During her internship in a nursing home, Lisa was moved by watching an old lady, who absent-mindedly filled her shoes with water whilst her husband anxiously looked on. Lisa explained “There was an old man who looked very frightened and could not believe that his wife was so confused. I tried to paint that. You see a woman with a watering can, who, without any awareness, pours water onto their shoes, not noticing the worried look on her husband’s face.” It was this scene she portrayed in her painting.

2. Schools: Project by St Xavier aus Bad Driburg High School. The religious class submitted interviews, recordings of music lessons in a nursing home and their thoughts about dementia. The judges had been particularly impressed with a ballad which the school had composed. Yvonne Brüggemeier, the head of the course explained that “the confrontation with the topic of dementia was a particular challenge for the students. Some students from the group had already experienced dementia with relatives or acquaintances, for most however, it was their first encounter with dementia. This initially resulted in fear, but during the course of the project this significantly decreased.”

3. Training college: Concept for pet therapy by nursing school, Goslar. The judges selected this concept due to its relevance to practice. Student, Anja Schröter (21) said “We have the experience that animals have a very positive impact on sick people. My wish would be that our project will be practically implemented.”

The prizes were presented by the Parliamentary State Secretary, Dr. Hermann Kues and Heike von Lützau-Hohlbein, Chair of the German Alzheimer’s Society. Heike said “The competition entries demonstrate that the young generation shows a willingness to help and to respect people with dementia. This is of great importance to our society.”
31 July 2008: The Danish Alzheimer Association appoints its new Chief Executive Director

Nis Peter Nissen has joined the Danish Alzheimer Association (Alzheimerforeningen) as its Executive Director. Prior to his appointment, Nis Peter Nissen MA (History), MPA, was responsible for the Department of Web and Development in one of the five Administrative Regions in Denmark. He was central to the creation of Denmark’s first information centre for environment and health issues and has worked with the Danish Red Cross and the M.S. Danish Association for International Cooperation.

6 August 2008: Liane Kadusch-Roth succeeds Paul Diederich as chairperson of Luxembourg Alzheimer Association

At the General Assembly of “Association Luxembourg Alzheimer”, Liane Kadusch-Roth was appointed as the new chairperson. She replaces Paul Diederich who was a founding member of the Association which celebrates its 20th anniversary this year.

11 August 2008: Henry Simmons succeeds Jim Jackson as the Chief Executive of Alzheimer Scotland

Following the retirement of Jim Jackson, Alzheimer Scotland has welcomed Henry Simmons as its new Chief Executive. Acknowledging the achievements of Alzheimer Scotland, Henry said “You only need to look at the level of priority being placed on the needs of people with dementia by the new Scottish Government to understand how effective the organisation has been. This is a real credit to the work of Jim Jackson and all the staff, members and volunteers involved in Alzheimer Scotland.” He went on to say “I aim to build on that work and to make sure that we use this platform to take the organisation forward and maximise every opportunity we have to improve the lives, services, support and recognition of people with dementia and their carers.” Henry has an MBA and is a qualified social worker with over 20 years of experience working on behalf of people with learning disabilities and mental health problems. Prior to his appointment with Alzheimer Scotland he was the Chief Executive of ENABLE Scotland (a national voluntary organisation dedicated to learning disability issues).

9 October 2008: Dr Sigurd Sparr, Honorary Treasurer of Alzheimer Europe, receives “The Kings Gold medal” for his work with dementia

Dr Sigurd Sparr, Honorary Secretary of Alzheimer Europe and Chair of the Norwegian Dementia Association (Nasjonalforeningen Demensforbundet), has been officially recognised for his work in the field of dementia. He was awarded the Norwegian Order of Merit (the King’s Gold Medal) which was presented at the University Hospital of Northern Norway, Tromsø.

The Order of Merit was founded by King Haakon in 1908 and is granted for a nationwide lifelong contribution in the arts, science or business. Dr Sparr received the highest medal, namely the Order of Merit in gold, for his extraordinary work on behalf of people with dementia and their carers. In addition to working as head of the Geriatrics department at the University Hospital in northern Norway, he has been travelling around the country on behalf of the Norwegian Alzheimer Association making dementia a political and public priority. Alzheimer Europe and the Norwegian Dementia Association would like to congratulate Sigurd and are very proud that his important work for our cause has been acknowledged at the highest level.
## FORTHCOMING EVENTS AND CONFERENCES

<table>
<thead>
<tr>
<th>Event Date</th>
<th>Organizing Body</th>
<th>Event Title</th>
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<tr>
<td>11-13 June 2009</td>
<td>Kuopio University</td>
<td>5th Kuopio Alzheimer Symposium</td>
<td>Kuopio, Finland</td>
<td><a href="http://www.uku.fi/alz2009">www.uku.fi/alz2009</a></td>
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**OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 26 COUNTRIES**

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<tr>
<th>Country</th>
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CALL ON ALL MEPS TO SIGN THE EUROPEAN PARLIAMENT’S WRITTEN DECLARATION Nº 80/2008 ON PRIORITIES IN THE FIGHT AGAINST ALZHEIMER’S DISEASE

“As members of the European Parliament, we cannot remain indifferent to the 6.1 million European citizens who live with Alzheimer’s disease or a different form of dementia” (Françoise Grossetête).

Help to ensure that Alzheimer’s disease is given recognition as a European health priority and to develop a European action plan with a view to:

• Promoting pan-European research on the causes, prevention and treatment of Alzheimer’s disease
• Improving early diagnosis
• Simplifying procedures for patients and carers and improving their quality of life
• Promoting the role of Alzheimer’s associations and giving them regular support.

Please sign the Written Declaration before 22 January 2009
Thank you.