Anders Wimo, MD, PhD presents findings on the cost of dementia.

Daniela Filipová, Czech Health Minister, talks about dementia and the European Czech Presidency.

Maria Eleni Koppa, MEP highlights the situation for people with dementia in Greece.

“It is the responsibility of all of us to ensure that people can age with dignity, in good health and with their rights respected.”

Androulla Vassiliou, European Commissioner for Health.
20th Alzheimer Europe Conference
Facing Dementia together
Luxembourg / 30 September-2 October 2010
Mark the dates!

www.alzheimer-europe.org/conferences
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By Maurice O’Connell, Chairperson of Alzheimer Europe

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I am thrilled that, at least on a European level, dementia has been thrust into the political limelight at a startling pace these past few months. To this end, we report on the far reaching conclusions on Alzheimer’s disease which were adopted by the Council of European Health Ministers as well as Members of the European Parliament showing their support by adopting Written Declaration 80/2008 on the priorities in the fight against Alzheimer’s disease. We speak with Françoise Grossetête about her passion for launching this campaign, as well as hearing from national Alzheimer associations around Europe who tell us how much this action has meant to their work.

As part of the “troika” presidencies (French, Czech and Swedish) who had pledged their commitment to addressing Alzheimer’s disease, we talk about the role of the current European Czech presidency with the Czech Health Minister, Daniela Filipová.

Androulla Vassiliou, the European Health Commissioner, explains what the Commission has already done to combat Alzheimer’s disease as well as the Commission’s future plans. I particularly welcome the recognition by Ms Vassiliou of the work to be done as it offers reassurance that the Commission is addressing the challenge of dementia head on.

The European Parliament has its elections in June and in our “Election Special”, we hear from several MEPs who reflect on the Parliament’s achievements with regard to dementia and who share their vision for helping people with dementia and their carers.

This issue we hear from Maria Eleni Koppa, MEP, who highlights the need for a national dementia action plan in Greece and we consider the legal rights for people with dementia and carers in Norway. We take a look at the detail of the recently-launched English Dementia Strategy and hear how it may help Heather Roberts and Daphne Wallace, who have dementia, as well as Angela Clayton-Turner, a carer. Whilst there is a great enthusiasm that the Strategy has been launched, I am mindful that implementation will be the real test of its effectiveness.

Similarly, I am heartened that our call to make dementia a priority seems to have been heard but much work remains. Indeed, we report on the findings from the European Collaboration on Dementia (EuroCoDe) project which suggest that the scope of the problem in terms of prevalence and the socio-economic cost of Alzheimer’s disease is much bigger than anticipated.

Reading Stuart Cooper’s article about living with dementia in Luxembourg, reminds us that as more and more Europeans choose to live outside their country of birth, the challenge to provide accessible care is raised.

Our work could not be possible without our member organisations and I particularly enjoyed reading Jean Georges’ article on just this, entitled “The power of solidarity”. Such achievements seem even more incredible when we are reminded of the discrepancies which exist between Alzheimer associations in respect of the financial assistance received from the State in “Essential work needs support”. This simply cannot continue if we are serious in our quest to address Alzheimer’s disease.

I would like to thank all those who work in this field for making sure dementia is kept in the political spotlight. By doing this, you offer hope to people with dementia and their carers and remind policymakers that the time to act is NOW.

Maurice O’Connell, Chairperson
PRIORITISING DEMENTIA

Françoise Grossetête
“We need to keep the momentum and capitalise on the achievement right from the beginning of the next mandate.”

Berit Holmlimo
of the Norwegian Alzheimer Association considers the legal situation for people with dementia in Norway

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A report on two recent lunch debates on dementia which were held in the European Parliament. The first considers the rising cost of dementia and the second debate looks at developing a European Action plan on dementia.
Françoise Grossetête, MEP (France) highlights the role that the European Alzheimer’s Alliance has played at European level in order to make Alzheimer’s disease a public health priority and Alzheimer member organisations comment on what this means to them.

Alzheimer Europe (AE): Ms Grossetête, your mandate as Member of the European Parliament is ending with some remarkable achievements in raising awareness that dementia, and in particular Alzheimer’s disease, are a public health priority. Could you briefly remind us of these achievements?

Françoise Grossetête (FG): It is true that within a record period of time, the urgency to tackle Alzheimer’s disease, both in terms of public health and research, has been echoed by the Member States.

I am proud that France has been a driver in this campaign: first, the very comprehensive French Alzheimer plan launched by President Nicolas Sarkozy at the beginning of 2008 caught the attention of a number of European policy makers. Then, the decision to make Alzheimer’s disease a priority of the French presidency of the EU led two Councils of Ministers to produce recommendations. The first recommendation, from the Competitiveness Council, encourages the Member States to engage together in the fight against neurodegenerative diseases, and mentions specifically Alzheimer’s disease. The second recommendation, from the Health and Social Affairs Council, calls on the European Commission to adopt an initiative in 2009 that will reinforce European collaboration in research and exchange of good practices in the areas of prevention, early diagnosis, treatment, social support and rehabilitation. Ethical issues and the protection of patients’ rights are also featured in the recommendations.

AE: In the European Parliament, the European Alzheimer’s Alliance, of which you are President, has also given a strong signal that it was urgent to act. What has been the role of the Alliance and what are your views on this group?

FG: The Alliance has been a driver in raising awareness at European level and it is with great pleasure that I have engaged in its work. The support I have received from four of my fellow MEPs to produce a European Parliament Written Declaration on the priorities in the fight against Alzheimer’s disease, as well as the support of a large majority of my colleagues in the European Parliament, clearly evidence the importance of the topic. This Written Declaration also calls for a European action plan in the field of research, diagnosis, simplification of procedures for patients and their carers and improvement of their quality of life.

The priorities of Alzheimer Europe’s Paris Declaration, that inspire the work of the Alliance, have received an overwhelming response within the European Parliament. It is really remarkable that MEPs from the 27 European Member States...
and 5 European political groups have supported the Paris Declaration and/or joined the Alliance.

I hereby wish to congratulate Alzheimer Europe who has managed to create the synergies favourable to such a European political wave.

**AE:** The European Commission has also given a strong signal. Could you tell us a bit more?

**FG:** It is comforting and encouraging that the European Commission, the third major EU institution, has heard the recommendations of the Council and European Parliament. At the opening of the EU Open Health Forum, the Health Commissioner, Androulla Vassiliou, announced a European Commission initiative on Alzheimer’s disease within the course of 2009.

Some preparatory work is currently taking place with various partners in order to shape the initiative’s modalities.

**AE:** You will be running in the next European elections. If you are re-elected, what will your priorities be to safeguard the interests of the people with dementia and their carers?

**FG:** I am determined to continue my engagement. Of course, I will follow the Commission’s initiative and the proposals that will be made with great attention. It will also be imperative to remain vigilant and ensure that the Council recommendations of 2008 are followed by concrete actions. The European Alzheimer’s Alliance must be perpetuated during the next mandate and be granted a clear recognition from the European Parliament. We need to keep the momentum and capitalise on the achievements right from the beginning of the next mandate.

**AE:** Ms Grossetête, thank you very much for your support. Alzheimer Europe wishes you all the best for the next elections we look forward to continuing working with you in the future.

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**Written Declaration**

A written declaration is a short text which is presented to the European Parliament to launch (or re-launch) a debate on any subject that falls within the EU’s remit.

Launched by a maximum of five MEPs and governed by rule 116 of the Rules of Procedure, MEPs show their support by signing the declaration at the entrance to the Chambers (or a designated room) in Strasbourg and Brussels. For information purposes only, the declaration is posted on the European Parliament’s website.

A declaration will be adopted if the majority of MEPs sign it. So far, the current Parliamentary session (2004-2009) has considered some 400 declarations. Of these, the majority have lapsed due to lack of support after the prescribed three month period (377) and less than 10% (35) have succeeded in being adopted. Successful declarations cover a wide spectrum of interest including the protection of children, health, finance, empowerment, subtitles on TV to name but a few. During the last five years some written declarations in the sphere of health (eg. fibromyalgia, Alzheimer’s disease, rheumatic diseases, cancer, hepatitis C, diabetes, rheumatic diseases and deaf-blind people) which have been adopted. Written Declaration 80/2008 on priorities in the fight against Alzheimer’s disease managed to secure 465 signatures, illustrating the high level of support from MEPs with only three other declarations securing a higher number of signatures than this.

Once adopted, the declaration, together with a list of signatories, is forwarded to the institutions named in the text. In Declaration 80/2008, these were named as the Council, Commission and governments of the Member States. Although there is no legal obligation to take action, the adopted Declaration is a strong signal to the recipient(s) that the European Parliament wants them to take action.

“We need to keep the momentum and capitalise on the achievements right from the beginning of the next mandate.”
Françoise Grossetête
REATIONS TO WRITTEN DECLARATION 80/2008 FROM ALZHEIMER ASSOCIATIONS

Alzheimer associations across Europe give their reactions to the adoption by the European Parliament of Written Declaration 80/2008, talking about how they can use the Declaration in their work as well as the contact they had with, and support from, their MEPs.

**Bulgaria: 16 out of 18 MEPs signed (88.89%)**
The Compassion Alzheimer Bulgaria team: “The adoption of the Written Declaration was very important for our organisation, and now we hope that the Bulgarian authorities will change their attitude towards people suffering from Alzheimer’s disease. We are truly delighted that our campaign has resulted in this great success.”

**Cyprus: 6 out of 6 MEPs signed (100%)**
Antigoni Diakou, President of the Cyprus Alzheimer Association: “We managed to contact all 6 of our Cypriot Euro MPs and this gave us a unique opportunity to let them know of our existence and the purpose of our Alzheimer Association in Cyprus. We were also able to explain to them the importance of signing the Written Declaration. Personal contact proved to be an invaluable exchange as it builds bridges of mutual understanding between the European MPs and our NGO. We succeeded in persuading all 6 MEPs to sign basically because we set it as our goal and perservered through co-ordinated action to achieve this. We are already emphasising the full support we received in order to ensure Alzheimer disease is recognised as a priority in our health system.”

**Czech Republic: 16 out of 24 MEPs signed (66.67%)**
Martina Rokosova, Executive Vice-President of Czech Alzheimer Society:

Contacting Members of European Parliament was quite an interesting experience. Some of the Czech MEPs were really happy to help and reacted very quickly and positively but some of them did not reply at all. We find our MEP Milan Cabrnoch very supportive. He contacted his colleagues and asked them to sign the declaration two days before the deadline. We feel that support for the declaration means a lot for the Alzheimer movement at both a European and national level. Hopefully, the Declaration will motivate people to improve the quality of life of people with dementia and their relatives.

**Denmark: 10 out of 14 MEPs signed (71.43%)**
Nis Peter Nissen, Director of Alzheimerföreningen: “Contacting the Danish MEPs was a very positive experience and has given us some useful network connections. The response rate from the Danish MEPs was positive and quite high – especially from the prominent MEPs as the former Danish Prime Minister Poul Nyrup Rasmussen. We have mainly used the responses from the Danish MEPs on a national arena as a way to place the idea of a national dementia strategy in the Danish Parliament. It has also given us some contacts to relevant Danish MPs.”

**Germany: 21 out of 99 MEPs signed (21.21%)**
Heike von Lützau-Hohlbein, Chairperson of the Deutsche Alzheimer Gesellschaft: “This is an important acknowledgment of our
work. However we are somewhat disappointed that only 21 of the 99 deputies of the German Members of the European Parliament supported the European Alzheimer’s initiative.”

Greece: 24 out of 24 MEPs signed (100%)

Anastasia Apostolidou of the Greek Association of Alzheimer’s Disease and Related Disorders:
“We contacted our Members of the European Parliament and almost everyone responded positively, willing to sign the declaration as they realised early on the importance of the declaration. From Greece 24 out of 24 Members of the European Parliament signed the declaration and therefore this filled us with happiness and satisfaction. We feel very proud of our Members in the European Parliament and their response to this movement and it signals the importance of recognising dementia as a national priority and the importance of unifying all efforts to achieve this. We can use this as guidance in our work and to raise awareness by distributing it widely throughout Greece.”

Malta: 4 out of 5 MEPs signed (80%)

Charles Scerri, General Secretary of the Malta Dementia Society:
“I contacted our MEPs by email and they were very helpful. All they needed was a little bit of reminding, but in the end, the majority of them signed the Declaration. Four out of 5 MEPs signed the Declaration. That gives us an 80% response rate which is quite a good percentage. Maltese MEPs coming from the two major political blocks in the European Parliament signed the Declaration. It will be used as part of our media strategy in raising awareness. It was also communicated to the Parliamentary Secretary responsible for Elderly Care who was very pleased with the response rate. It will surely add to the political will to launch National Dementia Strategy in Malta.”

Ireland: 11 out of 13 MEPs signed (84.62%)

Maurice O’Connell, Chief Executive of the Alzheimer Society of Ireland:
“I think what we have achieved on a political level has been tremendous for us and on a European level it has indicated that our role is a significant one for the future planning of policy and practice within Europe. It will have an impact on those we serve: Both people with dementia and their family carers. It will give encouragement to the national countries, who, like us, have still some persuasion to do with our local governments. I have had the privilege of attending the meetings in the Parliament and I was very happy at the attendance of our Irish MEPs. This does influence the politicians at home especially in a small country. All in all the collaboration on national and European levels has been a great success. A big thank you to the staff of Alzheimer Europe for their continuous hard work.”

Portugal: 20 out of 24 MEPs signed (83.33%)

António Oliveira Costa, Executive Director of Alzheimer Portugal:
“It was quite exciting to participate in (hopefully) history making. When you see a window of opportunity to change the world you live in, even in a small way, it becomes a call. This was only possible due to the work of the Alzheimer Europe team, who created a favourable agenda and timing. We were trying to get 100% of Portuguese MEPs to sign and even the four MEPs who were unable to sign, had promised to. Anyway, it was a huge success. We will use the Declaration to raise awareness for the need to create and develop a specific plan for dementia.

“We now have a document for all of us in the EU to work with.”

Kristina Westerlund of Alzheimer-föreningen i Sverige
Spain: 36 out of 54 MEPs signed (66.67%)

Jesus Rodrigo, Executive Director of CEAFA:
“we sent a letter from our Chairman explaining the importance of the Written Declaration to all Spanish Members of the European Parliament, asking for their collaboration. We followed this by telephoning various MEPs and holding personal interviews with some of them. We are really satisfied with the MEPs because 66.67% of Spanish MEPs signed the Written Declaration, 36 out of 54. The fact that the MEPs were of different parties is very important, because it means that unity is possible independent of political background when fighting against Alzheimer’s disease. We have disseminated this success through all channels at our disposal. In the short term, we’ll use the Declaration in all our meetings with National policy makers, so we hope it will become a strategic tool to inspire more action from the national (and regional) authorities against Alzheimer’s disease.

From Spain we only can say thank you to all of you who have been involved in this project, the benefits of which will be for all the millions of people with Alzheimer’s disease.”

Sweden: 7 out of 19 MEPs signed (36.84%)

Kristina Westerlund of Alzheimerföreningen I Sverige:
“Our MEPs were, in most cases, easy to reach and they listened carefully to what we had to say to them. They didn’t believe us when we told them that in Sweden only 3 out of 10 get diagnosed and treated. Whilst delighted seven of our MEPs supported the declaration, we were very disappointed with the overall support from our MEPs. The reason they told us that they would not sign was “In principle I don’t sign things like this”! We can use the Declaration as a way to make people aware of the lack of commitment shown by certain Swedish MEPs. We are happy that so many politicians signed the declaration and that we now have a document for all of us in the EU to work with.”

United Kingdom: 49 out of 78 MEPs signed (62.82%)

Vicki Combe, Public Affairs Manager of the Alzheimer’s Society:
“The Alzheimer’s Society was delighted that the European Parliament passed a Written Declaration on the need to make Alzheimer’s disease a European health priority. We were pleased that almost two thirds of MEPs in the UK signed the Declaration and this can largely be attributed to so many of our supporters getting behind the campaign and contacting their MEPs about the issue. This June will see elections for the European Parliament. It is vital we lobby all those people standing for election to ensure they understand that dementia is the biggest health and social care challenge Europe faces and that they commit to taking action on dementia through delivering a European Action Plan on Alzheimer’s disease.”

United Kingdom (Scotland): 6 out of 7 MEPs signed (86%)

Jan Kileen, Director of Policy, Alzheimer Scotland:
“We had 6/7 success rate - following our letter to stimulate interest. The one MEP that did not sign was a member of the Scottish Government SNP party which is a surprise as the Scottish Government has made dementia a clinical priority and has put £1,000,000 into the establishment of a Dementia Research Network as well as funding pilot projects on early diagnosis and support, amongst other measures. However we do not know the personal circumstances of the person who did not sign so we cannot criticise. Alzheimer Scotland is impressed by the high level of response across Europe. The Declaration requires not only sign up by governments but by researchers and practitioners - it’s crucial that these two groups work together to ensure that research is relevant - looking at social supports as well as scientific research - and that together they influence policy development both nationally and internationally.”
Thank you to the following MEPs for supporting Written Declaration 80/2008

Individual signatories by country

**Austria**
Berger Maria, Ettl Harald, Karas Othmar, Pirker Hubert, Prets Christa, Researtis Karin, Rübig Paul, Schierhuber Agnes, Swoboda Hannes

**Belgium**
Belen Ivo, Berpools Frieda, Busquin Philippe, Claeyx Philip, Corda Giovanna, Dehaene Jean-Luc, Deprez Gérard, De Vits Mia, El Khadraoui Said, Grosch Mathieu, Langendries Raymond, Neys-Uyttebroeck Annemie, Ries Frédérique, Staes Bart, Sterckx Dirk, Thyssen Marianne, Van Lancker Anne

**Bulgaria**

**Cyprus**
Adamou Adams, Demetriou Panayiotis, Kasoulides Ioannis, Matsakis Mario, Matsi Yiannaki, Triantaphyllides Kyriacos

**Czech Republic**

**Denmark**
Auen Margrete, Busk Niels, Camre Mogens, Christensen Ole, Jensen Anne E., Lebech Johannes, Rasmussen Poul Nyrop, Riis-Jorgensen Karin, Soregaard Soren Bo, Thomsen Britta

**Estonia**
Mikka Marianne, Ovior Sirri

**Finland**
Itala Ville, Lax Henrik, Myller Riitta, Passilainen Reino, Pietikainen Sirpa, Seppanen Esko, Tikkula Hannu

**France**

**Germany**

**Greece**

**Hungary**

**Ireland**
Aylward Liam, Burke Colm, Crowley Brian, de Rossa Proinsias, Doyle Avril, Harron Marian, McGuinness Maitre, Mitchell Gay, O Neachtain Seán, Ryan Eoin, Sinnott Kathy

**Italy**

**Latvia**
Andrejevs Georgs, Krasts Gunturs, Kristovskis Girts Valdis, Piks Rihradis, Zdanoka Tatiana

**Lithuania**
Andrikiene Laima, Budreikaité Danutė, Dūkūtė Jolanta, Maldeikis Eugenijus, Paleckis Justas, Sakalas Aloyzas

**Luxembourg**
Goebls Robert, Hennicot-Schoepges Erna, Lulling Astrid, Spautz Jean, Ternes Claude
Prioritising Dementia

Malta
Attard-Montalto John, Bedingfield Glen, Busuttil Simon, Casa David

Netherlands
Belder Bastiaan, Blokland Johannes, Bozkurt Emine, Buitenweg Kathalijne Maria, Cotterbe Dorette, Cremers Jan, Doorn Bert, Hennis-Plasschaert Jeanine, Jacobs Lily, de Lange Esther, Loattrd Kartika Tamara, Manders Toine, Martens Maria, van Nistelrooij Lambert, Oomen-Ruijten Ria, Wortmann-Kool Corien

Poland

Portugal
Capoulas Santos Luis Manuel, Casaca Paulo, Coelho Carlos, Esteves Maria da Assuncao, Estrela Edite, Fernandes Emanuel Jardim, Ferreira Elisa, Figueiredo Ilda, Freitas Duarte, Gomes Ana Maria, Ribeiro e Castro José, Santos Manuel António dos, Silva Peneda José Albino

Poland

Portugal
Capoulas Santos Luis Manuel, Casaca Paulo, Coelho Carlos, Esteves Maria da Assuncao, Estrela Edite, Fernandes Emanuel Jardim, Ferreira Elisa, Figueiredo Ilda, Freitas Duarte, Gomes Ana Maria, Ribeiro e Castro José, Santos Manuel António dos, Silva Peneda José Albino

OVERVIEW OF SIGNATORIES

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A NEW LOOK AT THE PREVALENCE OF DEMENTIA IN EUROPE

Alzheimer Europe reports on the findings of the working group on prevalence of the European Commission financed “EuroCoDe – European Collaboration on Dementia” project

One of the work packages of Alzheimer Europe’s EuroCoDe project aimed at gathering existing epidemiological studies in the field of dementia and producing new consensual guidelines. The project also hoped to achieve a better understanding of the breakdown between various forms of dementia (Alzheimer’s disease, vascular dementia, Lewy-body dementia, fronto-temporal demetias) and other rarer forms of dementia, and the different stages of dementia (mild, moderate and severe).

The rationale for this work was clear. The prevalence figures most in use in Europe and consistently used by Alzheimer Europe till now date back to 1991, when the EURODEM network published an excellent collaborative study of 11 population based cohorts from 8 countries looking at the prevalence of dementia. Although the article remains highly relevant today, it was recognised that the work was based on cohorts commenced in the 1980’s and did not include data from Eastern Europe.

The EuroCoDe project lead by Emma Reynish from the European Alzheimer’s Disease Consortium (See Table 1 for members of the EuroCoDe working group) therefore carried out an extensive literature search using Cochrane review methodologies and compiled a database of all European epidemiological studies in this field up to the present date. 194 articles were identified in this search and the EuroCoDe working group developed quality criteria for those studies that would be included in the collaborative analysis. In particular, studies needed to be community based (including people in institutions), have a minimum sample size of 300 with a response proportion of over 50%, use standardised diagnostic criteria and have a study date of 1990 or later. Furthermore, the study authors were contacted to submit the raw prevalence data to be included in a meta-analysis of all studies that fulfilled these strict criteria.

A total of 17 post 1990 studies were included in the final meta-analysis and the key findings of the working group confirmed that the prevalence of dementia had not changed significantly for men (See Table 2) or for women up to the age of 85 and age remains as the single most important risk factor for dementia. Nevertheless, due to the lack of data in previous prevalence studies, the prevalence of dementia in women over the age of 85 had been underreported (See Table 3). Also, prevalence is higher than in men of the same age.

The review of epidemiological studies in the dementia field also highlighted areas which require further investigation, in particular the prevalence of dementia in younger people under the age of 60, as well as the prevalence of different types of dementia.
dementia, rather than the overall impact of dementia, and so the European Commission proposal to improve the collaboration between epidemiological researchers through the possible creation of a European network is most welcome. As a consequence of this work, Alzheimer Europe will also need to reassess its estimation of the numbers of Europeans living with a form of dementia. Rather than estimating the number of people with dementia in the European Union to 6.1 million people, Alzheimer Europe will use the more accurate figure of 7.3 million people (See Table 4 for details).

The Prevalence of Dementia in Europe

Alzheimer Europe calculated the numbers of people with dementia by combining the UN population statistics and the EuroCoDe and EURODEM prevalence figures:

<table>
<thead>
<tr>
<th>Country</th>
<th>UN figures</th>
<th>EuroCoDe</th>
<th>EURODEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>2006</td>
<td>123,296</td>
<td>111,294</td>
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<tr>
<td>Belgium</td>
<td>2006</td>
<td>163,511</td>
<td>144,594</td>
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<td>Bulgaria</td>
<td>2006</td>
<td>99,291</td>
<td>90,584</td>
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<td>Cyprus</td>
<td>2006</td>
<td>8,024</td>
<td>7,285</td>
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<tr>
<td>Czech Republic</td>
<td>2006</td>
<td>123,194</td>
<td>111,141</td>
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<tr>
<td>Denmark</td>
<td>2006</td>
<td>78,744</td>
<td>70,108</td>
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<tr>
<td>Estonia</td>
<td>2006</td>
<td>17,825</td>
<td>15,831</td>
</tr>
<tr>
<td>Finland</td>
<td>2006</td>
<td>77,516</td>
<td>68,738</td>
</tr>
<tr>
<td>France</td>
<td>2005</td>
<td>974,391</td>
<td>854,219</td>
</tr>
<tr>
<td>Germany</td>
<td>2006</td>
<td>1,368,330</td>
<td>1,214,085</td>
</tr>
<tr>
<td>Greece</td>
<td>2006</td>
<td>159,275</td>
<td>144,745</td>
</tr>
<tr>
<td>Hungary</td>
<td>2006</td>
<td>131,995</td>
<td>118,169</td>
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<tr>
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<td>37,417</td>
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<tr>
<td>Italy</td>
<td>2004</td>
<td>1,012,819</td>
<td>896,688</td>
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<td>Latvia</td>
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<tr>
<td>Lithuania</td>
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<td>36,423</td>
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<td>Luxembourg</td>
<td>2006</td>
<td>5,814</td>
<td>5,178</td>
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<td>2006</td>
<td>4,524</td>
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<td>Netherlands</td>
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<td>210,666</td>
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<td>Spain</td>
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<td>690,992</td>
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<td>3,319</td>
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<td>Norway</td>
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<td>71,447</td>
<td>62,679</td>
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<td>Switzerland</td>
<td>2006</td>
<td>125,614</td>
<td>110,654</td>
</tr>
<tr>
<td>Turkey</td>
<td>2000</td>
<td>253,367</td>
<td>242,771</td>
</tr>
</tbody>
</table>

7,299,318 6,486,560
7,753,065 6,905,631
THE LEGAL PROTECTION AND RIGHTS OF PEOPLE WITH DEMENTIA IN NORWAY

Focusing on Norway, Dianne Gove, Information Officer, Alzheimer Europe, takes a look at the ongoing “Lawnet” project.

THE LAWNET PROJECTS AND REPORTS

People with dementia and carers are regularly faced with situations in which they have to make decisions about their daily lives and which may have consequences for their future wellbeing (such as obtaining a diagnosis, consenting to treatment, making a will, managing their finances and civil responsibility). In some situations, they may find that their rights are not respected (e.g. deprivation of liberty, the use of coercion, consent to treatment and disclosure of the diagnosis etc.). However, they are not always aware of their rights and do not necessarily have easy access to the information they need. Therefore, Alzheimer Europe decided to carry out an extensive inventory of legislation relating to the rights and protection of people with dementia in Europe.

There were two initial aims: 1. to make this information available to Alzheimer Europe’s member associations so that they could disseminate it at national level; 2. to compare legislation in different countries in order to contribute towards the development of recommendations for policy makers to improve the legal rights and protection of people with dementia in Europe.

In 1998, thanks to the financial support of the European Commission, Alzheimer Europe and a team of legal experts were able to carry out this inventory and to draft a series of reports, which contained summaries of legal provisions written in everyday terms. In addition, recommendations were written and a discussion paper on the use of coercion was drafted. This necessitated the translation into English of numerous laws.

Three broad areas were addressed: 1. restriction of liberty (including involuntary internment, other deprivation of liberty and the use of coercive measures), 2. legal capacity (covering guardianship arrangements and various issues linked to incapacity such as marriage, voting, making a will, carrying out transaction, civil and criminal liability) and 3. healthcare and decision making (covering informed consent, access to information, confidentiality and end-of-life care issues).

In the ten years following the Lawnet project, there have been several new laws and amendments, some of which reflect a growing awareness of the rights of people with dementia and an attempt to respect and promote their autonomy. Alzheimer Europe therefore felt it necessary to update these reports and to draft reports for the countries which had joined the European Union since 1998, as well as for Norway, Switzerland and Iceland. In this article, I would like to present some of the legislation from the report on Norway which has recently been drafted thanks to the assistance of Berit Holmlimo from the Norwegian Alzheimer Society.

LEGAL RIGHTS AND PROTECTION IN NORWAY

Norway has a mixture of legislation, of relevance to people with dementia, dating back to the early 20th century (e.g. in the case of guardianship and contractual capacity) combined with more recent provisions such as the 1999 Act relating to Patients Rights, the 2003 Act relating to Biobanks and an Act on Health Research which has yet to be implemented. Norway is one of the few countries in Europe with laws containing specific references to dementia, such as in the...
One of the concerns in deciding how to help people remain in their own homes, is the use of technology. Technology can contribute to independence being maintained for a longer period, and people with dementia should have the opportunity to use it if they want to. It can also be a help to carers for people with early dementia living at home.

Indeed, technology for tracing a person who is lost is already available. On the one hand, this type of technology offers a less radical solution than the locking of doors, but on the other hand, tracking systems may be considered more radical than, say, an alarm system, as the tracking device traces a person continually. Supervision often has a negative connotation within welfare services, but this has to be balanced with the fact that alarms and technology can offer positive solutions for people with dementia.

Such issues raise a series of ethical questions which have not yet been addressed by the authorities. Nevertheless, our concern lies with the people with dementia and affording them some independence. There have been several new cases in the media concerning people with dementia who got lost. A tracking device could have been a great help in some of these cases. However, a main concern for our organisation

Guardianship Act of 22 April 1927 and the Patients’ Rights Act. Norway also has a national dementia-specific plan, Demensplanen “Den gode dagen”.

The Patients’ Rights Act of 1999 seeks to involve people who lack capacity in decisions relating to their care and treatment. For example, adults who are considered clearly incapable of safeguarding their own interests due to a physical or mental disorder (including “senile dementia”) must nevertheless be provided with information about their health condition and possible health care. Competence to give consent to treatment may be partly or wholly withdrawn if the person is clearly incapable of understanding what consent involves. However, it is stated in the Patients’ Rights Act that even a person who has been declared legally incapacitated (in accordance with the 1928 Act on Incapacity) should, to the greatest extent possible, personally consent to treatment. These provisions reflect an understanding of capacity which takes into account varying degrees of capacity in different domains, and a move towards a better recognition of the right to self-determination of people with dementia.

A novel feature of the Patients’ Rights Act is the recent addition of §4a which covers compulsory health care for adults who are incapable of con-
sent and are refusing to accept care. This paragraph can only be applied if not having the treatment or care would constitute a danger to the person concerned and provided that acceptable voluntary solutions have been tried prior to resorting to compulsory measures. This measure is an improvement on the situation in many countries, where involuntary internment is only possible for the treatment of the actual mental disorder and where people with dementia are unlawfully deprived of their liberty in closed care homes.

So far, reports from 14 countries have been either updated or newly written, and reports from a further 6 reports are in the pipeline. The member associations of Alzheimer Europe have played a key role in finding legal experts who were willing to work on these reports and to whom Alzheimer Europe is most grateful. However, several countries remain for which no legal expert has been found (mainly for countries in the Eastern part of Europe). This is indeed a challenge as we cannot hope to improve the legal protection and rights of people with dementia if the current legal status cannot first be identified and brought to the attention of policy makers. Moreover, such information is essential for people with dementia and their carers who, like any other members of society, are entitled to protection and respect of their rights.

“At present, we lack sufficient laws regulating the use of technology within welfare services for old people and people with dementia.”
Berit Antonie Holmlimo
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.

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Pfizer European Public Affairs and Policy
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ESSENTIAL WORK NEEDS SUPPORT

A snapshot of state financial support given to help Alzheimer associations carry out their work across Europe

Alzheimer associations are a central component in how we assist people with dementia and their carers. Originally they were created for three reasons: (a) to provide much needed information on Alzheimer's disease (b) to provide support for carers and to provide them with the possibility to exchange information and experiences and (c) to raise awareness in order to ensure that people are diagnosed properly. Over time, the associations have grown considerably, both in the size of each organisation themselves, but also in terms of the number of national associations which now exist. The first European national association was in the UK, which was set up in 1979. 30 years on, and there are now over 30 national associations within Europe. As the organisations grew, so did their work mandate which extended to include campaigns for particular issues as well as policy work.

Such essential work cannot be done if there is insufficient funding. The Paris Declaration of 2006, which lists Alzheimer Europe's political priorities, calls upon "national governments to recognise the important contributions provided by Alzheimer associations and to provide financial support to these organisations in order to help them to improve the services they give to people with dementia and their carers." Alzheimer Europe carried out a survey regarding the current financial support of its member organisations which reveal a huge discrepancy between levels of support around Europe, with some organisations receiving 85% of their income from some form of State support and others nothing.

Of those which received support, the conditions varied. Some organisations were free to allocate how they used the financial support received, such as in Scotland and Spain. Others were obliged to allocate the support to certain projects, but were also left with some money to use as they saw fit. For example, in Switzerland, part of the state funding they received had to be allocated to holidays for people with dementia and their carers as well as a national helpline. There are also organisations which must allocate all state received funding to specified projects. This was the case in Malta, who received 6.9% of their total income from the State, given as co-sponsorship which enabled a visit to Alzheimer Netherlands. Most disturbing are those countries, Bulgaria, Greece, Italy and Turkey, which do not receive any financial support at all from the State on either a national, regional or local level. Although in Greece the State does provide funding for five day care centres, no funding is allocated to the work of the Alzheimer association.

If Alzheimer associations are to really help people with dementia and their carers, then funding for their core activities is crucial. The German association were able to do just this, with money received being used for their helpline, information brochures, an awareness campaign as well as the support of local structures and a conference.

With the dementia epidemic looming, national governments need to act now.

If Alzheimer associations are to really help people with dementia and their carers, then funding for their core activities is crucial.

<table>
<thead>
<tr>
<th>Alzheimer Association</th>
<th>% of income from the State for the organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vlaamse Alzheimer Liga vzw, Belgium</td>
<td>8.27</td>
</tr>
<tr>
<td>Alzheimer Bulgaria</td>
<td>0.00</td>
</tr>
<tr>
<td>Czech Alzheimer Society, Czech Republic</td>
<td>63.00</td>
</tr>
<tr>
<td>France Alzheimer</td>
<td>3.00</td>
</tr>
<tr>
<td>Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz, Germany</td>
<td>37.00</td>
</tr>
<tr>
<td>Greek Association of Alzheimer Disease and Related Disorders, Greece</td>
<td>0.00</td>
</tr>
<tr>
<td>The Alzheimer Society of Ireland</td>
<td>60.5</td>
</tr>
<tr>
<td>Federazione Alzheimer Italy</td>
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</tr>
<tr>
<td>Malta Dementia Society</td>
<td>6.90</td>
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<tr>
<td>Alzheimer Nederland, Netherlands</td>
<td>6.22</td>
</tr>
<tr>
<td>The Norwegian Alzheimer Association, Norway</td>
<td>26.00</td>
</tr>
<tr>
<td>Alzheimer Scotland</td>
<td>3.00</td>
</tr>
<tr>
<td>Confederación Española de Familiares de Enfermos de Alzheimer y Otras Demencias (CEAFA), Spain</td>
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<td>Demensförbundet, Sweden</td>
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<tr>
<td>Association Alzheimer Swiss, Switzerland</td>
<td>11.00</td>
</tr>
<tr>
<td>Alzheimer Society of Turkey</td>
<td>0.00</td>
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</tbody>
</table>
DEBATING DEMENTIA IN THE EUROPEAN PARLIAMENT

A summary of two lunch debates on dementia which were held in the European Parliament.

In December 2008, the first debate, on the findings of the European Collaboration on Dementia project’s working group on the socio-economic cost of Alzheimer’s disease, was presented by Anders Wimo, MD, PhD.

Jan Tadeusz Masiel (MEP, Poland) hosted Alzheimer Europe’s fourth lunch debate in the European Parliament and began the proceedings by explaining that the lunch debates had become something of a tradition between Alzheimer Europe and the European Alzheimer’s Alliance, enabling a platform for discussion about Alzheimer’s disease within the European Parliament. Great interest was shown by some 45 participants, including 13 MEPs and/or their assistants attending as well as national Alzheimer Associations, representatives of permanent representations and pharmaceutical companies.

Commenting on the launch of the third Dementia in Europe Yearbook which focuses on social support, socio-economic cost, psycho-social interventions and prevention, Mr Masiel reflected that each of the three Alzheimer Europe Yearbooks had been launched at European Parliament lunch debates. The launch of the first Yearbook, which presented the number of people suffering from dementia in Europe, access to treatment and reimbursement for treatment for Alzheimer’s disease, was hosted in 2006 by Astrid Lulling, (MEP, Luxembourg). In 2007 the second Yearbook was launched at a lunch debate hosted by Françoise Grossetête (MEP, France). The publication presented the first part of the European Collaboration on Dementia (EuroCoDe) project results on support systems to patients and their caregivers.

Highlighting additional ways in which MEPs have the opportunity to be kept informed about Alzheimer’s disease, Mr Masiel spoke of the 80 MEPs who had already pledged their support to fight Alzheimer’s disease by signing the Paris Declaration, which lists Alzheimer Europe’s political priorities, or/and becoming a member of the European Alzheimer’s Alliance.

Jean Georges, Executive Director of Alzheimer Europe, thanked Mr Masiel for hosting the meeting and talked about the work of Alzheimer Europe, highlighting the EuroCoDe project and also explained how MEPs can help people with dementia. Launching the second issue of the Dementia in Europe magazine, Mr Georges stressed that the magazine focuses on European policy on dementia and that a large proportion of this issue has been dedicated to coverage of the recent French Conference, saying that he found it both truly inspiring and humbling to receive the unequivocal backing of a European plan from no less than the President of France as well as Ministers from various European countries.
Finally, Mr Georges spoke of Alzheimer Europe’s recently completed EuroCoDe project, which had been funded by the European Commission under their Health Programme and introduced Anders Wimo, who was the leader of the socio-economic cost of Alzheimer’s disease work package within EuroCoDe.

Presenting the aims of the EuroCoDe work package 8 as being to firstly identify reports on the socio-economic cost of dementia and subsequently to produce a report on the cost of dementia within the European Union, Anders Wimo explained that their report on the cost of dementia had been calculated for three groups: (a) EU27 (b) EU27 plus the candidate countries (Croatia, Former Yugoslav Republic of Macedonia and Turkey) plus EEA (Norway, Iceland and Liechtenstein) plus Switzerland and (c) the whole of Europe (including amongst others Russia). The working group identified 14 papers for inclusion in their cost model, from which four different care patterns had emerged (a) Northern (Denmark, Ireland Scandinavia, Sweden and the UK), (b) Western (Belgium, France, Germany and the Netherlands), (c) Southern (Italy, Spain and Turkey) and (d) Eastern (Hungary). For countries where no cost of illness figures were available the working group used imputation.

Future cost calculations will be affected by the predicted increase in prevalence rates. The group found that prevalence forecasts for the whole of Europe have risen from just over 4 million people with dementia in 1970, to 8 million in 2005 with predictions of over 12 million people with dementia by 2030 and that prevalence is higher in women than men. This is because there are more women than men, but also because being female is a risk factor for dementia. They also found a similar rate of increase reflected worldwide with figures rising from 15 million in 1970 to 110 million by 2050, with a dramatic exponential increase being expected in the developing countries.

Defining what constitutes a cost is controversial but Mr Wimo said that his group looked at two types of cost (a) direct costs such as medical (e.g. hospital care, drugs) and non-medical costs (e.g. nursing, home care, home services) (b) indirect costs such as production losses of patients and of unpaid informal carers. Mr Wimo said that quantifying informal costs is a big issue and not easy to achieve. The group noted that the cost of illness figures are merely descriptive as they do not include anything about cost effectiveness.

The total cost of dementia in the whole of Europe in 2005 amounted to EUR 141 billion, or on an annual basis, the cost was found to be EUR 16,770 per person with dementia: In these cases, the majority of the cost is for informal care. However, when the costs are examined at a regional level the direct costs were found to be greater for the Northern and Western regions than the Eastern and Southern regions, with the cost of informal care being significantly greater than the direct costs in the Southern region. The figures, he said, illustrate the magnitude of the costs of informal care and he went on to give a personal example of informal care, showing a photograph of his great-grandmother with his great aunt Christine. Mr Wimo told participants that Christine had left Sweden and successfully set up a new life for herself in the US. However, when his great-grandmother wrote to her to ask her to come home, Christine did so and took care of her for 30 years and this was considered a natural thing to do then. He then posed the question that in our modern societies with so much migration, who will be there to care in future generations. Mr Wimo believes that this will be a key challenge facing people with Alzheimer’s disease.
Looking at the costs comparatively, Mr Wimo asked for caution as comparisons are not often so easy to make and he emphasised the importance of transparency, as it is essential to understand the basis of the calculations if you are going to compare them. The working group considered other cost estimates which had given a cost per person with dementia in Europe and these ranged from EUR 11,000 to EUR 28,000. In comparison to the rest of the world, the working group found that Europe has the highest cost of dementia, followed by Asia and North America but that the cost per person is highest in North America and Europe is placed third.

Comparisons were made with other illnesses. Dementia was the higher cost (EUR 141 billion) when compared to the cost of depression (EUR 121 billion). The cost of dementia in Europe is in second place both on a per case basis (after strokes) and on a cost of illness basis (after alcohol).

Looking at the difference between the more developed regions, less developed regions and least developed countries, the cost burden of the disease was also compared by using the measurement of “disability adjusted life years” (DALYs) which is a measure of the overall disease burden frequently used by the World Health Organisation (WHO). Diabetes was then compared to dementia by using the DALYs and Alzheimer’s disease and dementia were found to be a higher burden than diabetes in all three EU categories. The figures showed, said Mr Wimo, that dementia creates great disability throughout the world.”

Mr Wimo concluded that the group had found the societal costs of dementia in the EU to be enormous and if treatment remains the same then the cost will rise from EUR 130 billion to EUR 200 billion by 2030. He highlighted the need for much more data from Eastern Europe to help make the figures more meaningful. They also found informal care to be a substantial part of the total cost of dementia and that the quantification of informal cost is crucial for any cost estimates.

Jean Georges thanked Anders Wimo for his interesting presentation, as well as Mr Masiel and Agnieszka Szczesniak for their help in hosting and preparing this lunch debate.

Closing the lunch debate Jan Tadeusz Masiel offered his heartfelt appreciation to Mr Wimo for his excellent presentation, saying that the EuroCoDe project had managed to provide a clear picture on a subject often difficult to grasp: namely the socio-economic costs of Alzheimer’s disease and he went on to say that the results will be an essential basis for the work of political actors at both a national and European level. He shared Mr Wimo’s concern regarding future carers noting that in the next decades there will be less and less people in the labour force which will create a major challenge for the elderly. Mr Masiel stressed the importance of fully understanding all aspects of the disease and of working closely with the European Commission to find a solution to the problems faced by patients and caregivers. He also praised the role played by national Alzheimer associations calling their contributions “vital for us all”.

Mr Masiel stressed the importance of fully understanding all aspects of the disease and of working closely with the European Commission to find a solution to the problems faced by patients and caregivers.
The second debate, “Towards a European Action Plan on dementia” was held in March 2009. This debate was presented by Florence Lustman, the Coordinator of the French Alzheimer’s Plan, and Antoni Montserrat from the European Commission.

“Towards a European Action Plan on Alzheimer’s Disease” was the focus of Alzheimer Europe’s 6th lunch debate which was hosted by Françoise Grossetête (MEP, France) and presented by both Florence Lustman, the Coordinator of the French Alzheimer’s Plan together with Antoni Montserrat, the Policy Officer for rare diseases, neurological and neurodevelopmental disorders, Directorate of Public Health, European Commission.

Jean Georges, Executive Director of Alzheimer Europe, introduced the debate by paying tribute to the “champions” who had helped to put a European spotlight on Alzheimer’s disease: the French President who, during the European French Presidency had given his personal commitment to ensuring that Alzheimer’s disease be addressed, the politicians who have been active and supportive of the European Alzheimer’s Alliance. In particular, he thanked Françoise Grossetête for her unrelenting support of Alzheimer Europe’s work and her determination alongside MEPs John Bowis (UK), Katalin Levai (Hungary), Jan Tadeusz Masiel, (Poland) and Antonis Trakettellis (Greece) for initiating and seeing through adoption of the Written Declaration 80/2008 on the priorities in the fight against Alzheimer’s disease, and last, but by no means least - the people who make up the member associations of Alzheimer Europe. Mr Georges said that the support of the Declaration, like dementia itself, had cut across borders, party allegiances and nationalities.

Jean Georges explained that both the host of this lunch debate, Ms Grossetête, and the presenters, Ms Lustman and Mr Montserrat, had been hugely instrumental in helping to make dementia a European priority.

Ms Lustman took to the floor first and gave an overview of the comprehensive 3rd French Alzheimer’s Plan, which was launched last year. Unlike previous plans which focused on health issues at a national level, she highlighted that this 3rd Plan also took a global perspective and included research issues too. In addition, Ms Lustman explained that there is a direct report line to the President of France, Nicolas Sarkozy, and that this personal commitment ensures that the Plan is taken seriously at the highest level of State.

Although the long-term goal is to find a cure for the disease, there is no sign of a breakthrough within the next five years and therefore, said Ms Lustman, the real challenge is to improve the quality of life of patients and carers and that it is important to get a continuous chain of care which is lacking at present. She was pleased that their educational programme for carers had just been published.

Concluding her presentation, Ms Lustman reflected on the achievements in the field of Alzheimer’s disease which had been made during the recent six-month French Presidency, highlighting the conclusions regarding neurological degenerative diseases which were made by the Competitiveness Council as well as the conclusions by the Health Council which decided to combat age-related diseases and called on Member States for national initiatives. The Competitiveness Council’s conclusions have

Ms Grossetête reminded the audience that there is much more work to be done.
"Some Member States have agreed, on a voluntary basis, to meet, discuss and pool research in dementia in order to prevent duplication in research and maximise the investment". Florence Lustman

resulted in the launch of a European initiative this year: some Member States have agreed, on a voluntary basis, to meet, discuss and pool research in dementia in order to prevent duplication in research and maximise the investment. Ms Lustman was impressed that already nine countries had committed to this process. However, she reminded the audience that we still do not know for certain the number of people with disease at a European level as many countries have poor systems of diagnosis and this, she stressed, has to be addressed.

Françoise Grossetête then spoke of her delight that the European Parliament’s Written Declaration had been adopted and thanked Alzheimer Europe and its national associations for their hard work in drawing attention to this issue, enabling the European Alzheimer’s Alliance to take up its role. She stressed the fact that it is not possible to speak about the demographic problem without taking into account the consequences of an ageing population.

Ms Grossetête said that whilst many politicians were sympathetic to the problems associated with dementia, it was vital that this sympathy was turned into the positive action. She acknowledged the role that national associations had made by asking their MEPs directly to give their support and spoke of her pride in her Parliamentary colleagues, of which some 60% had signed the Written Declaration.

Whilst the first step has been made, Ms Grossetête reminded the audience that there is much more work to be done if we are to be sure that people with dementia and their carers receive the appropriate support and services. Recognising the work France has already begun, she highlighted the need for other countries to also address this disease and emphasised the importance of coherent research which can be put to a common use. She concluded that whilst a good start had been made that now it was time to “roll up our sleeves” and continue the work carried out by the Council and Commission.

Speaking on behalf of the European Commission, Antoni Montserrat, told participants that the Commission first took action on Alzheimer’s disease in 1996. More recently it had given its support to Alzheimer Europe’s European Collaboration on Dementia project (2006-2008) (EuroCoDe) which has resulted in three Yearbooks highlighting stark differences between the 27 Member States. He explained that the differences found are extremely useful as they as they make people listen, acting as a basis for further actions. Indeed, the results from EuroCoDe have changed the situation of the Commission’s Health Strategy.

Directly addressing the call for a European health action plan, Mr Montserrat explained that the Commission does not have a tradition for “disease specific” actions plans with the exception of cancer, communicable diseases and, just recently, rare diseases. He also said that the Commission does not have the means to adopt action plans for all different kinds of diseases. However, Mr Montserrat stated that the Commission is in a position to engage Member States in addressing a particular issue and monitor implementation of the recommendations. This is why the two recent Council’s recommendations, which call for action in the field of Alzheimer’s disease, together with the momentum built in the French Presidency, have stimulated the Commission to act and work on an Alzheimer’s initiative and Mr Montserrat proceeded to lay down the Commission’s plans to do so.

Firstly Mr Montserrat spoke of the joint programming initiative on research which is being developed, with the aim of avoiding the current
waste and duplication of research by inviting national Member States, on a voluntary basis, to pool ideas together. To date, nine countries have signed up and the Commission hopes that more will join before July this year. The Commission also hopes to build on information gained from EuroCoDe, which he said, was an excellent project achieved by good collaboration with Alzheimer Europe. To contribute to track early diagnosis of dementia across Europe, the Commission plans to carry out “The European Health Examination Survey” including a cognitive decline module for which people will be invited to go to a clinician and be examined. The Commission can also employ initiatives used by the Social Protection Committee in order to establish agreement and definition for standards of care.

However, in order for the Commission to be effective for people with dementia and their carers it is essential, said Mr Montserrat, that it works with a solid partner, such as Alzheimer Europe, as they need organised dialogue with access to EU patient organisations. He spoke of the importance of developing best practices guidelines and his hope that work done in the Yearbooks be extended.

Therefore, there are various initiatives which are open for consideration by the Commission when addressing Alzheimer’s disease. Indeed, one day it may be possible to conclude what actually constitutes a “healthy brain lifestyle.” Whilst the Commission’s approach is not extensive nor ambitious, it is possible to reuse existing initiatives in an imaginative way. Mr Montserrat concluded by saying that in an ageing society, (which the Swedish presidency has pledged to make a priority), perhaps the three most useful approaches for the Commission to employ are to be found within their public health, research and social protection activities.

Sirpa Pietikäinen (MEP, Finland) stated that there is a need to do something at an EU level in terms of patients’ rights and role of assessment and suggested the model of environmental impact assessment to speak on someone’s behalf be applied. However, Antoni Montserrat said that rather than say a particular model should be employed, it is preferable to say that any one model is one which may be considered.

Whilst thanking the European Parliament for their “fantastic support”, Alicja Sadowska of the Polish Alzheimer’s association, also highlighted the fact that there are differences between the Member States, with some governments not yet ready to face the problem or do anything about it. She asked that those MEPs who are elected in June support our work to ensure that the associations are not left powerless.

Again, recognition was given to the work Alzheimer associations are doing when Milan Cabrnoch, (MEP, Czech Republic) thanked the associations and said that, as politicians, they need the associations’ advice as without this they don’t know which problems exist.

Martin Banks, Editor, Parliament Magazine asked for examples of recognised public figures who have/have had this disease. Jean Georges cited a few examples such as Ronald Reagan, Margaret Thatcher, Terry Pratchett and Iris Murdoch but emphasised that different countries have different levels of openness about this disease.

Thanking the host and presenters for their commitment in so strongly supporting making dementia a European priority, Jean Georges made special mention again of the Written Declaration’s initiators. He closed the meeting by wishing all MEPs the best of luck with their forthcoming elections.
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Through our research and development efforts we hope to make a difference in the lives of patients and families affected by Alzheimer’s disease.
In the run up to the elections, Alzheimer Europe asked Members of the European Parliament the following questions:

1. As the mandate of this European Parliament draws to a close, we would be very interested in hearing which you consider to be the key accomplishments of this Parliament which had a direct impact on people with Alzheimer’s disease and their carers?

2. After the European Parliament elections in June, which are the main policy initiatives that will be important for people with dementia and their carers?

3. If re-elected, do you have any personal priorities that would be of particular interest to people with dementia and their carers?

Here's what they said …
The new Parliament will have to monitor carefully the outcomes of the Written Declaration

Frieda Brepoels, Belgium

The key accomplishment of the European Parliament is obviously the adoption of the Written Declaration 80/2008 on Alzheimer's disease, which was signed by an overwhelming majority of MEPs. The adoption confirms the recognition of Alzheimer's disease as a priority on the European health agenda. For me, the strength of the declaration lies in its comprehensive approach. It not only recognises the urgency to respond to the health challenges posed by Alzheimer's disease, but also highlights the important social challenges we are facing and calls for evidence-based action by underlining the importance of research.

Moreover, the adoption of the Resolution on Mental Health equally provides a hopeful signal. The resolution recognises mental health of older people as a priority and stresses the need to promote research into prevention and care with regard to neurodegenerative disorders and other age-related mental illnesses. Furthermore, it asks for any future Commission action or proposal to distinguish between Alzheimer's disease or similar neurodegenerative disorders and other forms of mental illness. Also, the horizontal priority of the Resolution, prevention of stigma and social exclusion, seems very relevant for Europeans confronted with Alzheimer's disease.

At the EU Health Forum in December 2008, Public Health Commissioner Vassiliou announced an initiative on Alzheimer's disease for 2009. It will be crucial for the new Parliament to follow these developments closely.

Furthermore, I think, as a first stage, the new Parliament will have to monitor carefully the outcomes of the Written Declaration. The elected MEPs will have to make sure that Member States and the Commission step up their actions and keep Alzheimer's disease high on the agenda. Finally, the implementation of the Mental Health Pact also deserves full attention.

We all know that Europe's ageing population will make more people - including people with Alzheimer's disease - dependent on care. Though people with Alzheimer's disease have different, individual needs, many want to stay at home as long as possible. In this regard, I would like to see more European initiatives related to homecare. I strongly believe the EU can have an added value by raising awareness and establishing indicators to collect information and data. We can learn a lot by exchanging best practices and experiences, for example on training of health professionals and carers. The EU can also (co-)fund and coordinate research on neurodegenerative diseases, and stimulate research into new medication, treatment (for example, programmes that stimulate cognitive functions and hence slow down the progression of dementia) and medical technologies to support patients, their families and carers. A lot remains to be done in this area.

Brian Cowley (Ireland)

I will continue to assist people with dementia and ensure their carers have the maximum amount of protection and services. As I was one of the founders of the European Alzheimer's Alliance, I will continue, if elected, to push the concerns of all carers and those suffering from dementia.

Astrid Lulling (Luxembourg)

The European Parliament (EP) has played a big role in raising awareness and moving the European policy agenda forward. After the two Council recommendations of September and December 2008, the EP Written Declaration on Alzheimer's disease that I have signed is another step forward in making dementia an EU priority. The European Commission is now called upon from all sides to have an initiative on Alzheimer's disease and encourage national Alzheimer plans. I was glad to hear that Commissioner Vassiliou had announced a Commission initiative on Alzheimer's disease in 2009.

The ageing of the population is a sensitive issue. The increase in the number of older people will be coupled with an increase in the number of people with dementia. In Luxembourg, it is estimated that some 4,500 persons suffer from dementia (over 1% of the population). These numbers are expected to double and even treble by 2050, having a huge impact on health and social services. It is therefore imperative to act now and answer the needs of
people with dementia and their carers and plan for the future.
I will ensure that the EP Written Declaration and French Presidency conclusions are followed by actions in the next EP and will follow with great interest the Commission’s Alzheimer initiative. I remain committed to supporting the work of Alzheimer Europe during the next mandate as well as continuing to support the European Alzheimer’s Alliance and ensuring it gets the European Parliament recognition it deserves.

Jan Tadeusz Masiel (Poland)
The European Parliament has played a significant role in raising awareness about Alzheimer’s disease and the impact this disease has on people themselves, their carers and society. The members of the European Alzheimer’s Alliance - of which I have been an active member since the very beginning have been instrumental in raising the profile of this disease not only at European level but also at national level. It is without any hesitation that I joined Françoise Grossetête and four fellow MEPs to launch the EP Written Declaration on the priorities in the fight against Alzheimer’s disease. This Declaration received an outstanding response from my colleagues. I am very proud that the European Parliament has added its voice to that of the Council and the European Commission who both recently put Alzheimer’s disease on the European agenda.

The next policy initiatives must focus on research. More research must be carried out in order to find the cause(s) of Alzheimer’s disease and then the treatment for people with Alzheimer’s disease. I hope that the European Alzheimer’s Alliance will continue during the next mandate and I pledge my continued and active support. My priorities will be to ensure that the decisions made by the European Parliament, the European Commission and the Council are followed by concrete action that will relieve the plight of people with dementia and carers, and take up the challenges of an ageing population. I will also do my very best to motivate Polish policy makers to ensure that Poland takes these European developments fully on board.

Linda McAvan (United Kingdom)
Over the course of its current 5-year mandate, the European Parliament has been the venue for various awareness-raising events, seminars, special interest groups and workshops. These are designed to bring together organisations, MEPs and EU policy-makers to discuss the treatment and research of Alzheimer’s disease in a European context. The Parliament also approved a wide-ranging research programme proposal - with a total budget of EUR 50 billion over 5 years - which includes a specific reference to brain and related diseases. This fund has ensured that research into Alzheimer’s disease has received vital financial support from the European Union. More recently, the European Parliament adopted a Written Declaration on Alzheimer’s disease, which calls on policy makers in the European Union and Member States to make the disease a European public health priority. It also includes specific reference to supporting sufferers, their carers and Alzheimer’s associations. As this Written Declaration is now the official position of the European Parliament, the European Commission will work towards ensuring that it is reflected in future policies, including funding programmes.

Europe’s population is ageing, and the policy initiatives of the European Union will be central to ensuring a coordinated effort to fight Alzheimer’s disease. A union-wide health monitoring system will play an important role in terms of collecting meaningful and comparable data about Alzheimer’s disease and associated issues, such as causal factors and preventative strategies. Continued funding for research, as well as increased support for Alzheimer’s associations, will help all Member States cope with the social and economic costs of Alzheimer’s and work towards better conditions for carers and better treatment for people with Alzheimer’s disease.

“The next policy initiatives must focus on research. More research must be carried out in order to find the cause(s) of Alzheimer’s disease and then the identification of treatments.”
Jan Tadeusz Masiel, Poland
Everybody knows somebody who has been affected by Alzheimer’s disease. I believe that every effort should be made to bring together the best professionals and researchers from across Europe to tackle this terrible disease. In the last Parliament, I and other MEPs formed a Special Interest Group in the European Parliament which focused specifically on brain disorders. I very much hope we will be able to continue this work in the next Parliament.

**Claude Moraes (United Kingdom)**

I appreciate the chance to highlight the work the European Parliament has done to help people with Alzheimer’s disease as well as their carers.

However, I also recognise that Alzheimer’s disease must remain a key health priority in the European Union, and that much work still needs to be done to improve care and support for those affected by the disease.

I am pleased that the gravity of Alzheimer’s disease is now recognised throughout Europe and that research carried out into the disease has developed hugely over the last few years.

- The Community Public Health Programme, adopted by the Parliament and Council, supported and provided funds for the European Collaboration on Dementia to bring together Alzheimer’s organisations across Europe.
- Also, funding from the 5th, 6th and 7th framework programmes has helped drastically improve research into Alzheimer’s disease and the ERA-NET is helping to promote cooperation in research across national bodies responsible for research into Alzheimer’s disease in Member States.
- Furthermore, the 2008 conference held in Paris entitled “The fight against Alzheimer’s and related diseases” was yet another chance to discuss and bring focus to the issue.

MEPs continue to use their position in Parliament to question the Commission and Council on progress made in the field to ensure that the issue remains a priority.

Although research has improved greatly, action is now needed to bring into effect policy that improves the lives of sufferers and carers based on the recommendations of this continuing research. This is why the recent declaration from the European Parliament calling on the Council, Commission and Member States to develop a European action plan is crucial. Such an action plan will be vital to ensure improvements in care and support for sufferers and their carers throughout Europe.

Alzheimer’s disease was included as a priority initiative in the Commission’s Legislative and Work Programme for 2009 and we can therefore be hopeful that progress will continue to be made throughout 2009 and under the Czech and Swedish Presidencies.

If re-elected in June, I would hope to see rapid progress made on such an action plan in order to allow Alzheimer’s sufferers to age with dignity and be cared for to the highest standards. Furthermore, I would like to see more support for the carers whose jobs and employment rights are often affected by the time they spend caring for people with Alzheimer’s disease.

**Elisabeth Morin-Chartier (France)**

The European Alzheimer’s Alliance, of which I have been a member as a Member of the European Parliament, has been very instrumental in the European Parliament in raising awareness about the urgency for Europe and the Member States to make Alzheimer’s disease a public health priority.

The success of the Alliance’s work in the European Parliament was epitomised by the signing of the EP Written Declaration on Alzheimer’s disease by some 60% of the Members of the European Parliament, from all EU Member States and EP political groups.

Not only has the Alliance increased awareness, it has also motivated the Members of the European Parliament to take the issue to national level. I am particularly proud that French President, Nicolas Sarkozy, launched in 2008 a broad and comprehensive Alzheimer Plan. His decision to organise a conference dedicated to Alzheimer’s disease during the EU French Presidency has produced recommendations that were later on taken on board at two Council meetings.

Since then, I was equally happy to hear Androulla Vassiliou, Health Commissioner, announce that the European Commission will be launching an Alzheimer initiative in 2009.

It is quite remarkable that within a fairly short period of time, the three major EU institutions have converged towards the common goal of addressing Alzheimer’s disease comprehensively. This is a concrete example of what Europe can do to improve the quality of life of people with Alzheimer’s disease and their carers.

I welcome the French EU Presidency initiative to invite the Member States to form, on a voluntary
basis, a European network that will pool resources in the field of Alzheimer’s disease, thereby avoiding duplication and waste of resources. To date, some 10 EU countries have responded positively to this invitation and it would be comforting to see the remaining countries join the network. This initiative certainly needs to be further promoted to yield results that will benefit the research community, people with dementia and carers.

The discussions and decisions made within the context of the current economic crisis must never forget the people with dementia and their carers. The ageing of the population associated with age-related diseases and the foreseen reduction of the labour force will lead to an increase in the need for caring professions, respite care and tailor-made social services. The opinion I made on behalf of the Employment and Social Affairs Committee for the Committee on Economic and Monetary Affairs on a European recovery plan in particular calls on the Member States to invest in the social economy which can contribute towards growth since it has a considerable potential for creating high-quality jobs and strengthening social and territorial cohesion. It is important that all future EU policies take these parameters into account.

I also look forward to the recommendations that will be brought forward by the Czech Presidency conference on the care and social protection of seniors.

The new European Parliament will need to be vigilant and ensure that the recommendations of the Council and the Parliament are followed by concrete measures. I will of course follow with great interest the European Commission initiative on Alzheimer’s disease and offer my support.

The European Alzheimer’s Alliance must survive during the next term and pursue its excellent work. Considering the challenges of an ageing population and the foreseen increase in the number of people with dementia, it would be legitimate for the Alliance to be granted formal recognition by the European Parliament and thereby optimise its outreach. I hereby would like to congratulate Alzheimer Europe for its passionate work and recent achievements. I am happy to have been part of this adventure and pledge to continue in the future.

Sirpa Pietikäinen (Finland)

France’s high prioritising of Alzheimer’s disease during its EU Presidency in 2008 brought forward a general debate about Alzheimer’s disease in Europe and put a dynamic development programme in place in this area. The European Parliament has also been active in the field. The Written Declaration on the fight against Alzheimer’s disease adopted by the Parliament in February 2009 is an important step forward in making Alzheimer’s

Marie Panayotopoulos-Cassiotou (Greece)

In general, the majority of the decisions taken during the mandate 2004-2009 concerning the improvement of the living conditions and the care of people living within the EU without any discrimination benefited people with Alzheimer’s as well as their carers.

Moreover, more specific and focused actions have been taken, whereas research, prevention and treatment for the Alzheimer have been encouraged.

The French Presidency took significant steps and the dialogue between the European institutions was set up with the active inclusion of the national stakeholders.

My personal point of view is that future policy initiatives should include:

• special measures that will fill the gap between different generations so that each person with Alzheimer’s disease, or other incurable diseases, has access to a social infrastructure providing cohesion and support,
• the raising of awareness and a fight against stigma and an improvement in the quality of public services should function at a European level equally,
• organisation and cooperation with regard to research in all Member States, use of structural funds, especially the European Community Funds, to improve access to diagnosis and treatment,
• at national level, funding by national institutions so that they cover medical and social insurance,
• a proposal for increased dialogue between all stakeholders in order to encourage and authorise relatives to take care of people with dementia and improve the quality of life of both people with dementia and their carers.

If I am re-elected, my personal priorities which I believe would be of particular interest to people with dementia and their carers are a) the promotion of research for Alzheimer’s disease by making use of the EU Seventh Framework Programme, b) the enforcement of horizontal policies for the family which address factors linked to the generation gap and c) that all Member States provide services after retirement.
I feel that the key accomplishment of this Parliament was the creation of the Special Interest Group on Carers and Caring. As a full time carer for over three decades, I have experienced first hand the difficulties facing carers and the people they care for. In June 2007, I founded the European Parliament Interest Group on Carers with the aim of ensuring that policy development takes the issues of carers into account and to check policies for their impact on the situation of carers. The Interest Group on Carers vets legislation for the good of carers and aims at making MEPs more aware of their situation. The Carers Interest Group, of which I am organiser and co-chair, cooperates and interacts with Parliamentary Intergroups, such as the Intergroup for Disability, the Intergroup on Ageing and the Intergroup for Family, where the issue of carers is critical.

Two reports that I authored that I felt were relevant to people with dementia and their carers were the Employment and Social Affairs Committee report on the European Mental Health Strategy and the Environment, Public Health and Food Safety Committee report on Prevention of Injury and Promotion of Safety.

Finally, I brought two European Commission projects to Ireland on the Rescue of Person with Disabilities in Emergencies. The first project was general while the second focused on flooding. I am one of the first signatories of the “Verona Charter” which came out of these projects and emphasises the rights of people with disabilities to be treated equally in access to rescue services. I am currently a co-author of a Written Declaration in the Parliament which endorses the principles of the Verona Charter.

Carers are often under-valued and neglected in most European laws and policies. Carers are invisible in employment legislation, despite the EU’s competence in this area. We need to bring carers and their concerns into focus and support them. Carers are important in how we deal with an ageing Europe in terms of meeting the needs of our older citizens and stabilising our plunging birth rates.

One of the main pieces of legislation which I think will have a detrimental effect on people with dementia and their carers is the “on-call” provision in the Time at Work Directive. This Directive poses a serious threat to respite services for home carers. As the Directive is presently written, all hours for which a worker is at their place of employment, must be counted as time at work. Take the example of a family carer who cares for a person with dementia in their own home and is given weekend respite. Typically a family carer provides care 24/7 for that person within their own home. In order to have a weekend off, it is necessary for a care worker to come into the home and stay over, even though during the night hours they sleep. The person being cared for may not require intervention at night but under the present formation of the Working Time Directive, the time spent sleeping is considered as time spent working which means that a second care worker will be required to work the next morning.

The Time at Work Directive is a prime example of legislation which ignores the contribution of carers and fails to take them into account. The provision in this Directive for “on-call” working time will make providing respite to carers far more expensive and in many cases impossible. The fact that the needs of family carers were not included in this Directive once again highlights that informal care is not valued to the same extent as formal care.
A number of existing and current policy issues are relevant to the issue of carers and should be focused on in the next term. These include the Lisbon Agenda with its emphasis on favourable working conditions, the Mental Health Strategy, PROGRESS, the Public Health Programme, the Green and White Papers on Demography, the Green Paper on Modernising Labour Law and the Green Paper on the Workforce for Health.

If re-elected, one of my priorities would be to promote research into dementia and promote an appreciation of the value of every human person regardless of age or condition.

It is because of human dignity that, for me, caring is about a relationship, a very special type of intense relationship and this would only be improved if we can lift some of the worry from the shoulders of carers. However, one of the biggest challenges facing carers is the lack of appreciation of caring.

When I brought up the issue of carers during a Committee meeting in the European Parliament last year, I was told that carers, people caring for the elderly, people with dementia, people with disabilities and children, are people on career breaks. To call caring a career break is to show ignorance of what carers do and of the value of what they do. Governments and Europe need to take carers seriously in the future.

If I am re-elected, a particular goal of mine is to continue the work of the Interest Group on Carers and to get recognition for carers and for the essential service they perform.

Corien Wortmann-Kool (Netherlands)

We managed to get the European Parliament’s declaration on Alzheimer’s disease, initiated by Françoise Grossetête, adopted. Consequently, the European Commission has to undertake a communication on Alzheimer’s disease. That’s very important, because Alzheimer’s disease is a European and worldwide problem.

With regard to research into causes, treatment and medication for Alzheimer’s disease, Europe should encourage the exchange of good practices.

My husband is director of Alzheimer’s Disease International, which means that I am very sensitive to this huge problem and the urgent need for Europe to make more of an effort. Therefore, I will actively support initiatives in this domain, also in my new mandate in the European Parliament.

Anna Záborská (Slovakia)

In the European Parliament, it is possible to raise awareness of those engaged in taking a political or legislative decision. The problems of people with neurodegenerative diseases – and particularly with Alzheimer’s disease – as well as those of their carers must not be left out of the picture. Our Carers Interest Group in the European Parliament is a real medium for reflection and setting up of strategies. It enables the institutional decision makers to get acquainted with the very problems of the carers thanks to the contribution of NGOs such as Alzheimer Europe or the European Federation of Unpaid Parents and Carers at Home (FEFAF), as well as their national associations.

During my first mandate in the European Parliament, I wrote a report on women’s poverty in Europe and another one on inter-generational solidarity. Of course, I called on the policy makers to officially recognise the contribution of the women and the men who care for a dependant person. It is just a matter of equity and social justice.

Policies at all levels must reflect the carers’ predominant cross-cutting role for the sake of the people who are ill and for the common good of society. This is why I note with great pleasure that this was addressed not only within the Women’s Committee that I preside, but also within the Public Health Committee.

Do not forget that the European Parliament adopted Written Declaration 80/2008 on the need to recognise Alzheimer’s disease as a European public health priority and that this declaration is now an official European Parliament document! I invite all the people with Alzheimer’s disease as well as their carers to make good use of the work of the European Parliament.

The work continues! I am fully aware that various political issues will compete with each other. The work of the Carers Interest Group is vital for policy makers who work on carers’ issues. It must remain a high priority and survive.

Right from the beginning of the next mandate, we must fight to include a budgetary allocation for the financing of Alzheimer associations and carers associations.”

Anna Záborská, Slovakia
work on the opportunities offered by the political agenda. In addition to World Alzheimer’s Day (21 September), I also think of World Day of Social Justice (20 February), World Health Day (7 May), Mothers’ Day (10 May), International Day of the Family (15 May) and Fathers’ Day (in June), Old People’s Day (1 October), or still, International Human Solidarity Day (20 December). All these dates are public opportunities to remind us that people with Alzheimer’s disease are first and foremost cared for by a family member, and that these carers play a fundamental role for those who are sick, the other family members and the common good.

I would also suggest holding a European policy forum on Alzheimer’s disease and their carers. This cross-cutting event could be held in the European Economic and Social Committee.

Finally, if you allow me to dream, I would be delighted if DG Health in the European Commission could take forward the Council conclusions of 16 December 2008 that call for public health strategies to fight neurodegenerative diseases linked to age, and in particular Alzheimer’s disease. There again, this will be a major political initiative.

I am a Member of the European Parliament for Slovakia. In my country, we also face problems linked to neurodegenerative diseases, such as Alzheimer’s disease. We have marvellous people who we need to support in their endless fight. I thus will continue my involvement in favour of the persons with the disease, their families and their carers.

I promise to take forward the priorities of Written Declaration 80/2008 on the need to recognise Alzheimer’s disease as a European public health priority. We will thus need to promote pan-European research on the causes, prevention and treatment of Alzheimer’s disease, improve early diagnosis, simplify procedures for patients and carers and improve their quality of life, and, finally, give the Alzheimer associations regular support.

At the end of the mandate, we will be called upon to negotiate the 8th Framework Programme for European research. Neurodegenerative diseases, especially Alzheimer’s disease, will have to be included in the Programme. Regarding carers, we should make a better use of the European agencies to carry out a detailed analysis of the real work provided by the carers in order to better develop tools that will recognise the true value of their engagement.

Dushana Zdravkova (Bulgaria) The current European Parliament adopted a number of documents concerning Alzheimer’s disease, the most recent of which is the Written Declaration of February 2009 on the priorities in the fight against Alzheimer’s disease. Although the fight against the disease has always been on the Parliament’s agenda, the focus was on research and development of new medicines. With this Declaration, we stressed that the scope of our policies should be broadened and include also the improvement of quality of life and providing support for the associations working on this issue. However, in my opinion, the inclusion of carers in finding solutions is key. Being closest to the people affected by Alzheimer’s disease, they are central to successful implementation of any strategy or solution.

The next European Parliament will have to tackle many challenges with the final ratification of the Lisbon Treaty by all Member States on top. Some may say that there are more pressing issues than fighting Alzheimer’s disease, but the most democratic European Institution cannot leave more than 6 million Europeans on their own.”

Dushana Zdravkova, Bulgaria
POLICY WATCH

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Androulla Vassiliou
“It is the responsibility of all of us to ensure that people can age with dignity, in good health and with their rights respected.”

Daniela Filipová
The Czech Health Minister talks about the Czech European Presidency

Maria Eleni Koppa
MEP Maria Eleni Koppa highlights the issues facing people with dementia and their carers in Greece
THE COUNCIL OF EUROPEAN HEALTH MINISTERS CALLS TO MAKE DEMENTIA A EUROPEAN PRIORITY

A look at the “Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease” which the Council of European Health Ministers adopted in December 2008

At the end of the French Presidency, the Council of European Health Ministers gave a clear signal that policy-makers at the highest level were heeding the call that dementia is a major public health issue by adopting “Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease” at the 2916th Employment, Social Policy, Health and Consumer Affairs Council meeting.

The Council identifies their reasons for taking this step, including (a) a recognition of the challenges faced with a doubling ageing population, (b) the fact that increased longevity should be accompanied by a certain quality of life, and that (c) prevalence of neurodegenerative diseases, in particular Alzheimer’s disease, rises with age.

Citing existing European tools and initiatives which draws attention to the Council were the principles of Chapter 1 (on dignity) of the EU Charter of Fundamental Rights that patients can grow old with dignity, the Commission’s White Paper “Together for Health: a Strategic Approach for the EU 2008-2013” in which the primary strategic objective is to promote good health throughout a person’s life cycle and the commitment made in 1996 by the European Parliament to support European action to combat Alzheimer’s disease. The Council also acknowledged the work already carried out to make Alzheimer’s disease a public health priority at EU level, and noted the work carried out by associations.

The Conclusions are not legally binding, but they call for action to be taken by the Member States, Commission as well as the Social Protection Committee. Both the Member States and the Commission have been called on to (1) recognise dementia as a priority for action (2) take account of the potential consequences of the increase of the diseases and (3) reflect together on existing quality criteria. Member States are asked to establish national strategies, improve the distribution of information, promote coordination and collaboration between all parties, evaluate administrative procedures and to improve the skills of professionals to ensure a high quality of care.

The Commission was asked to adopt an initiative which should have four mains themes: research, exchange of best practices on all aspects of the disease, the improvement of the quality of epidemiological information and the exchange of best practices on the issues of protection and patients’ rights. In addition, the Commission is called upon to take initiatives which develop methodologies and capabilities at EU level, to use existing Community programmes and activities including the ongoing work of the Commission on health care and long-term care and, lastly, to use the possible connections between actions developed on these diseases and those developed to address mental health issues in the ageing population.

The Council also asks the Social Protection Committee to continue to promote the sharing of experiences and the exchange of best practice in specified areas, as well as to continue its activities on quality in long-term care.
RISING TO THE CHALLENGE:
THE ROLE OF THE EUROPEAN COMMISSION

European Health Commissioner, Androulla Vassiliou, talks with Alzheimer Europe about the work of the European Commission in the field of Alzheimer’s disease

Alzheimer Europe (AE): Madam Commissioner, the Council of Ministers has adopted far-reaching conclusions on the importance of European action in the field of Alzheimer’s disease and Members of the European Parliament have overwhelmingly supported Written Declaration 80/2008 which calls for the development of a European Action Plan on Alzheimer’s disease. How does the European Commission intend to respond to these initiatives?

Androulla Vassiliou (AV): I welcome these initiatives as they draw attention to the plight of the many individuals and their families coping with Alzheimer’s disease and other dementias. We need to recognise that this issue is linked very closely to a wider challenge for Europe: the ageing population. The White Paper “Together for Health: A Strategic Approach for the EU 2008-2013” that we adopted in 2007, identifies the better understanding of neurodegenerative diseases such as Alzheimer’s disease as important in the context of demographic ageing. It is the responsibility of all of us to ensure that people can age with dignity, in good health and with their rights respected. Alzheimer’s disease and dementias are, unfortunately, a part of this ageing process for a lot of European citizens.

We are currently preparing our own initiative on Alzheimer’s and other dementias, which takes into account and builds upon the important work carried out in the past few years. Of course, the principal responsibility for all health issues lies with the Member States. However, discussions under the French Presidency in 2008 identified several areas where Europe could add value in tackling Alzheimer’s disease. Three dimensions for action were identified: The public health dimension, covering the prevention and early intervention aspects, including a better understanding of the risk factors of dementia, the social protection dimension, addressing the quality and the long-term sustainability of dementia care in health systems, and finally, the research dimension, improving and ensuring better coordination between national and European resources on dementia and avoiding potential duplication of efforts.

AE: The European Commission has of course not waited for the Council of Ministers or the European Parliament to become active in the Alzheimer’s field. Could you highlight some of the key initiatives that the Commission has supported over the past years?

AV: The importance of these conditions has long been recognised by the European Commission. Within the programme of Community action in the field of public health (2003-2008) the European Commission financed a project called “European Collaboration on Dementia (EuroCoDe)”. This project cost EUR 1,423,190 (with EUR 843,000 funded by the Commission through the Health Programme), and was coordinated by Alzheimer Europe. EuroCoDe involved extensive surveys of its members to highlight inequalities within the European Union with regard to the access of people with Alzheimer’s disease to existing...
treatments and support systems. The results were published in the ‘Dementia in Europe Yearbooks’.

Additional funding has come from the Framework Programmes for Research where EUR 20 million was invested in FP5, and increased to EUR 65 million in FP6 for research on Alzheimer’s disease and other dementias. Efforts in this area have been reinforced in the current FP7 within the ‘Health theme’ in the areas on brain research and a new activity on ‘Optimising the delivery of health care to European citizens’. EUR 29 million has already been committed to the subject of dementia and Alzheimer’s disease as a result of the first two calls for proposals in the brain research area. In addition, the Framework Programme has allowed for the coordination of national research activities in this area through various projects.

Strengthening the use of incentives at national or European level to strengthen research into dementias and development of medicinal products is being encouraged. An example of this action is the Innovative Medicines Initiative that aims to support the faster discovery and development of better medicines for patients and enhance Europe’s competitiveness by ensuring that its biopharmaceutical sector remains a dynamic high-technology sector. The IMI platform was launched under the 6th Framework Programme for Research as a gathering of stakeholders, led by the pharmaceutical industry. It is estimated that the total public funding in the Member States allocated to dementia research in Europe amounted to EUR 57 million in 2005. In addition to funding research on Alzheimer’s disease, several Member States are building infrastructures to better tackle the dementia problem.

Apart from funding of research projects, I would also like to mention the Open Method of Coordination in the social field. This provides a framework for the EU Member States to reform their social protection systems on the basis of policy exchanges and mutual learning. Following the 2008 National Strategic Reports and the 2009 Joint Report on Social Protection, a specific peer review will be held in France in May 2009 on: “Alzheimer’s disease and other related diseases: how to cope with crisis situations occurring in the patient’s home?” (focusing on non-medical treatment). This will be followed by a conference in September 2009, under the Swedish Presidency of the Council, on Healthy and Dignified Ageing, which will include a workshop on the coordination of care for persons suffering from Alzheimer’s disease and other dementias.

AE: One of the key achievements of the European Commission in 2008 has been the adoption of the Mental Health Pact. Are there any aspects of the Pact which would be of particular impor-

“It is the responsibility of all of us to ensure that people can age with dignity, in good health and with their rights respected.”

Androulla Vassiliou
Psychological aspects play an important role in Alzheimer’s disease and other dementias. Some studies suggest that depression increases the risk of developing dementia. We know that depression is a common experience for people with Alzheimer’s disease or other dementias, with co-morbidity rates of up to 50%. Family carers of those suffering with dementias also show a significantly increased risk of mental disorders. The European Pact for Mental Health and Well-being established by the EU high level conference “Together for Mental Health and Well-being” of 13 June 2008 takes into account this dimension of the disease and can raise awareness activities and the exchange of good practices in addressing Alzheimer challenges. A key event for addressing these issues will be the thematic conference on mental health in older people under the Pact, which the Commission and the Spanish Presidency will co-organise during the first half of 2010.

Alzheimer’s disease is not only a medical question and people with dementia and their carers often face social isolation due to the stigma attached to the disease. Also, there are specific legal and ethical issues that are different from those of patients living with other long-term conditions. Is there scope for collaboration with other Commission departments to promote the exchange of information on these issues between European countries?

The image of Alzheimer’s disease and other dementias in European society is often a negative one, associated with fear and helplessness. We need to focus on the respect of the rights and the dignity of people with dementia. Unfortunately, cognitive abilities steadily decline and there generally comes a time when the person with dementia can no longer manage entirely alone and where he/she will need help in making decisions of varying importance, such as financial management or medical decisions. Assistance could be provided by a guardian or lawful representative, but national laws differ widely as discovered by Alzheimer Europe when it carried out its Lawnet projects.

I have already illustrated above how we work to ensure that this important subject is addressed in a coordinated and a coherent manner at EU level.

The European Commission can provide political leadership in recognising the rights and the contribution of older adults. We are exploring how to address this concern and possibly to establish a European Network for rights of people with dementia. This network could formulate and feed into recommendations on dignity, autonomy and social inclusion. The gradual loss of capacity makes it difficult for people with dementia to maintain their place and active participation in society. Carers may also experience social exclusion based on the effects of dementia on their loved ones. The disclosure of the diagnosis to people with dementia is of significant importance. We do not help people if we attempt to protect them by not telling them about their condition. On the contrary, being told as early as possible is a crucial step for people with dementia to take an active part in decisions affecting their lives.

Madam Commissioner, thank you very much indeed for sharing with Alzheimer Europe ways in which the Commission has, and will continue to employ initiatives aimed at helping people with dementia and their carers enjoy a better quality of life.
Alzheimer Europe (AE): Minister Filipová, the ageing of European populations has been recognised as a priority by a number of EU Presidencies. The French Presidency organised a key conference on Alzheimer’s disease and two Council conclusions were dedicated to the importance of greater European collaboration on Alzheimer’s disease. Does the Czech Presidency plan any specific follow-up initiatives in this field?

Daniela Filipová (DF): The Czech Republic is committed to the shared priority of troika (The European Presidencies of France, Czech Republic and Sweden) that is to promote healthy, active and dignified ageing. Of course, in the context of demographic ageing and rising numbers of frail seniors, Alzheimer’s disease and other forms of dementia are one of the key challenges for the near future, in terms of ensuring quality treatment and care, protecting dignity and rights of people with dementia and their carers and promoting social inclusion.

Demographic ageing requires a change in the health strategy. The rising number of frail, older people necessitates adapting health services and ensuring the availability of geriatric care, long-term and palliative care. The challenge ahead is to transform the success and progress of our ageing societies into future development and to promote healthy and secure lives and to strengthen cohesion in our families, communities, and societies. Adopting, implementing and developing policies that promote inclusive age-friendly society are thus strategic long-term priorities.

The Czech Government is aware of those challenges at both EU and national levels. The Czech Government in January 2008 adopted a broad strategy called “Quality of Life in Old Age”. Its primary goal is to mainstream ageing into health, education, housing and other relevant policies so that they reflect and adapt to the needs of ageing populations. The programme has set forth priorities for the period 2008–2012 (1. active ageing, 2. age friendly environment and community, 3. improving health and health care in old age, 4. supporting family and carers and supporting participation of older persons in society and protection human rights). The promotion of “ageing-in-place” and protecting human rights are the overreaching priorities of the programme.

AE: Are there other Presidency priorities in the health or social fields, which would be of interest to people with Alzheimer’s disease and their carers?

DF: The Czech Presidency inter alia organises the European conference “Social Services – A Tool for Mobilising Workforce and Strengthening Social Cohesion”, which will take place in Prague on 22nd and 23rd April 2009. The conference will focus on growing employment opportunities in social services in the context of population ageing, support for informal carers, the role of social services in reconciliation of employment and care, the balance between professional and family care, and active social inclusion. The conference will contribute to the exchange of best practice in those areas.
The Czech Republic is prepared to address the issue of the creation of a voluntary and legally non-binding European framework for the methodology of standards of quality of social services, which will significantly contribute to the debate on possibilities of cross-border provision of social services, and to specifically address the question of standards of quality of social services within public procurement procedures.

AE: The Czech Presidency will organise a conference on dignity and the elderly in May 2009. Do you intend to raise the specific problems faced by people with dementia and their carers at that conference?

DF: The Czech Presidency is organising “the European Conference on Dignity and Hazard in the Elderly”, which will take place in Prague on 25th and 26th of May 2009. The conference is of strategic importance for formulating responses to challenges and opportunities of our ageing populations at the EU as well as national, regional and local levels. The conference will focus on active and healthy ageing, community and long-term care, the needs and preferences of older persons in ageing society, the role of municipalities in provision of integrated care services, geriatric frailty, prevention of abuse and neglect, ageism etc. The problems faced by people with dementia and their carers are, of course, among the issues, which will be addressed from different perspectives and in different contexts during the conference.

AE: As you know, the European Commission is in the process of developing a European initiative on Alzheimer’s disease. Which areas do you consider to be most appropriate for increased European collaboration?

DF: Undoubtedly, the most efficient way to tackle a common challenge is to streamline our efforts to prevent and minimise incidence of dementia and/or its consequences. Supporting research and an effective research strategy are a key way to address this challenge. Improving the situation and dignity of carers and people with dementia by ensuring quality staff and availability of specialised health and social services is a key task and challenge.

AE: Ms Filipová, thank you for giving Alzheimer Europe this interview.

“Alzheimer’s disease and other forms of dementia are one of the key challenges for the near future, in terms of ensuring quality treatment and care, protecting dignity and rights of people with dementia and their carers and promoting social inclusion.”

Daniela Filipová
Prioritising Dementia

Alzheimer Europe (AE): Ms Koppa, what are the key challenges that people with dementia and their carers face in Greece?

Maria Eleni Koppa (MEK): Currently there are 150,000 dementia patients in Greece. First of all, there is lack of a national action plan against dementia. There is lack of day-care services and total care of long-stay institutions. Home-based care also has to be developed. Another problem is that there are no allowances for people with dementia and carers. There are only 6 day-care centres in the country (all run by Alzheimer’s Associations under the 3rd European Support Framework) and no rest homes especially made for Alzheimer’s patients.

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?

MEK: Neither the Greek government nor the Greek Parliament pay much attention to the growing problem of dementia in Greece. For the time being, they have other priorities.

AE: Do you believe that Greece will follow the example of France and create a National Alzheimer’s Plan?

MEK: There is an urgent need to get dementia on the public and political agenda in Greece. First, evidence about the impact of dementia has to be estimated and both medical and social care has to be established to meet both the patients’ and the carers’ needs. I would very much like my country to follow their example but there is still a long way to go.

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

MEK: The three policy priorities should be (1) to raise awareness and fight stigma, (2) to improve access to diagnosis and treatment and (3) to improve the quality of life of both people with dementia and their carers.

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?

MEK: We would certainly support the development of an action plan against dementia on a pan-European level. Collaboration and exchange of practices between European countries is crucial. There are 21 Alzheimer’s Associations in 21 towns around Greece some of which are very active. Since February 2009, the Athens Association of Alzheimer’s Disease and Related Disorders has launched the Greek Alzheimer’s Initiative a signature collection campaign in order to make dementia a public health priority and highlight the plight patients and carers’ face.

“A VIEW FROM GREECE

Maria Eleni Koppa, MEP, and member of the European Alzheimer’s Alliance, talks to Alzheimer Europe about national and European Alzheimer plans as well as the challenges ahead for people with dementia and their carers in Greece

There is an urgent need to get Dementia on the public and political agenda in Greece.”
NATIONAL DEMENTIA PLANS: ENGLAND

Alzheimer Europe considers the vision, aims and implementation of the recently-launched English Dementia Strategy

The English Health Secretary, Alan Johnson and Care Services Minister, Phil Hope, launched “Living well with Dementia: A National Dementia Strategy” on 3 February this year. This five-year plan aims to ensure “that significant improvements are made to dementia services in England across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care”. Seventeen key objectives have been identified and the government has pledged a further GBP 150 million to fund implementation of the strategy. Having worked closely alongside the Government during its development, the Alzheimer’s Society believes that the strategy “will make an incredible difference to the lives of people with dementia and their carers”.

The “Vision”

The strategy’s authors give their vision for dementia services as “a system where all people with dementia have access to the care and support they need. It would be a system where the public and professionals alike are well informed; where the fear and stigma associated with dementia have been allayed; and where the false beliefs that dementia is a normal part of ageing and nothing can be done have been corrected. It would be a system where families affected by dementia know where to go for help, what services to expect, and where the quality of care is high and equal wherever they might live.”

Such aspirations, if realised, would make a huge difference for all those affected by dementia. However, Alan Johnson reminds us of the challenge when he says, “I don’t under-estimate the scale of the task ahead (…) It will require a great deal of work and commitment by those responsible for commissioning and providing services.”

The strategy reflects the thoughts of many, having encompassed a comprehensive consultation process during which over 4,000 people were heard at nearly 50 events and some 600 responses to the consultation document were considered. The authors of the strategy also had the benefit of the recommendations from the External Reference Group (chaired by Neil Hunt, Chief Executive of the Alzheimer’s Society) which were incorporated into the final document.

The Aims of the Strategy

First to be tackled is the lack of awareness and understanding about dementia itself and the issues which surround it, as they create a significant barrier to diagnosis and the receipt of good-quality care. As a person with dementia explains in the strategy document, “It’s as though that’s it, you are dribbling and nodding, and that’s Alzheimer’s. That’s the picture of Alzheimer’s. But we are all sitting here talking perfectly normally. We have got Alzheimer’s of some form, but we are not nodding and dribbling”. Misconceptions such as this contribute to why people have waited up to three years before reporting the symptoms of de-
mentia to their doctor. Further barriers to an early diagnosis were identified such as carers believing that the symptoms of dementia were “just a part of ageing”. Even if carers did suspect dementia, they would often prefer to be in denial. Add to these factors that only a third of English GPs questioned believed they had the necessary skills to diagnose and manage dementia, together with the fact that people over 65 are more worried about developing dementia than cancer, heart disease or stroke, it will come as little surprise that half of the public surveyed were found to believe that there is stigma attached to this disease. Removing such stigma is, as Alan Johnson explains, crucial, because “dementia is not a natural consequence of ageing and it is not true that nothing can be done for people with the condition. In reality, a great deal can be done to help people overcome the problems of dementia, to prevent crises and to improve the quality of life for all involved.”

Experiences highlighted in the English Strategy, such as “I’ve just been told you’ve got Alzheimer’s and they walk out; (it) is absolutely bloody disgusting”, will hopefully be avoided if the second aim of the strategy, early diagnosis and support, is realised. Various initiatives are proposed to achieve early diagnosis including the creation of memory services, which will be staffed by specialists who will “sensitively” communicate the diagnosis and provide good quality information and advice. Early support could be enhanced by a “dementia adviser”, peer support networks and a possibility to be actively involved in the creation of local services: All of these are envisaged within the Strategy.

The practical initiatives which can be employed throughout the community, hospitals, care homes and during end-of-life care are the focus of the strategy’s third aim of living well with dementia. Recognition of the huge contribution carers make by the implementation of a “New Deal for Carers” would see an assessment of carers’ needs being made and enable the provision of better support as well as the allocation of carers’ breaks. To facilitate independence for people with dementia, housing support and telecare initiatives are highlighted. The improvement of dementia care in care homes is envisaged by a senior member of staff taking the lead to ensure that there is a clear line of responsibility and accountability. However, there have been calls for other incentives to be offered to care home staff such as pay awards or the possibility of being awarded a nationally recognised dementia care qualification. Another issue addressed is the misuse of medication for people with dementia in various forms of institutionalised care, with the strategy listing ways in which the over-use of medication can be reduced.

**Delivering the Strategy**

To ensure successful implementation, the strategy has placed great emphasis on the need for training and workforce development as well as the establishment of local commissioning and planning mechanisms. Standards of health and care services will be monitored by the Care Quality Commission (CQC) which will inspect and assess for quality across health and social care services, and primary and secondary care.

Heeding the calls made during the consultation process to build up the research base in dementia for prevention, cause, cure and care, the strategy lists action already taken and states that a “clear picture of research evidence and needs” should be established. Amongst others, Rebecca Wood, Chief Executive of the Alzheimer’s Research Trust, believes that research has not been emphasised enough as “the Strategy has failed to include any new pledge on dementia research, which receives just 2.5% of the medical research budget”. Perhaps further attention will be drawn to this at the recently announced Parliamentary debate of the strategy.

Decisions will be taken at a local level regarding the funding of individual objectives and the pace...
of implementation will vary according to local circumstances. Nevertheless, it is clear from objectives 13 to 17 that all actors, whether at national, regional or local levels are expected to work together to ensure implementation. Indeed, whilst joint leads of the strategy, Sube Banerjee and Jenny Owen recognise that “we have a unique opportunity to make a true difference for those affected by dementia” they acknowledge that this will not be a simple process as “Success will require true joint planning and joint working between health and social care commissioners and providers, the third and independent sectors and people with dementia and their carers. It will require flexible and imaginative leadership at all levels along with constant vigilance and scrutiny if the delivery of the strategy is to be kept on track. It will require commitment over time and ambition in the face of the true scale of the challenge.”

The very fact that England now has a national dementia strategy has been warmly welcomed. Reflecting the thoughts of many, Maurice O’Connell, Chairperson of Alzheimer Europe, said, “I am delighted for the 570,000 people living with dementia in England, as well as their carers, that this long-awaited strategy will now be implemented and that England joins Norway, France and Scotland in giving dementia the priority it deserves. I hope that other national European policy-makers take heed and implement their own national dementia strategies.”

### THE ENGLISH DEMENTIA STRATEGY

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<td><strong>Objective 3:</strong> Good-quality information for those with diagnosed dementia and their carers</td>
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<td><strong>Objective 5:</strong> Development of structured peer support and learning networks</td>
<td><strong>Objective 10:</strong> Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers</td>
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Feedback on the English National Dementia Strategy

Daphne Wallace, a retired old-age psychiatrist and who has early vascular dementia talks about the National Dementia Strategy

I am pleased with much that is in the Strategy. The issues which most concerned me about dementia care have been addressed. In particular I am glad to see the objectives (2, 4 & 6) which refer to early diagnosis and support from the time of diagnosis.

I have very early vascular dementia. I am glad to see that the various types of dementia are explained. I am concerned that the information and training planned should ensure recognition of vascular dementia and its varying early presentations which may be ignored in people presenting with other vascular diseases. Support at the point of diagnosis and available throughout the journey through dementia is essential. The need for this support for those with dementia and their carers is indeed a significant part of the strategy but the more detailed suggestions for support may not be sufficient if generalised early diagnosis is achieved.

My diagnosis was very early. Psychologically, considerable adjustment is needed and support for the person with dementia and their family is not just beneficial, but essential to avoid later problems. I had no follow-up for three years until I asked to see someone appropriate to monitor my progress. This lack of support left me feeling abandoned. I did not need frequent consultations but just the knowledge that there was someone there when I needed them. Such support can ensure ‘Living well with dementia’. The ‘dementia care adviser’ is a suggested solution to this issue.

Heather Roberts, who lives with Alzheimer’s disease, shares her thoughts on the National Dementia Strategy for England

I’m Heather Roberts, I’m 54 years old and have Alzheimer’s disease. My diagnosis was a tortuous one beset by preconceptions of how someone with dementia should act. Frankly I didn’t fit the mould being young and still bright. I knew how I had changed and what I could no longer do but I wasn’t listened to. Like many others I was forced to take anti-depressants because the medics would not consider dementia. However, after 2 years of sophisticated memory testing they finally agreed with what I already knew.

The National Dementia Strategy for England describes a future which addresses the issues I face: poor levels of knowledge, convoluted diagnostic pathways and a care system not geared up to the needs of people with dementia and their carers. If fully implemented a simpler and earlier diagnosis will be less stressful. Early intervention and support will be welcomed and if this means access to drugs currently banned in England for people in the mild stages then this is great news. I am lucky as I take Aricept. This has made a massive difference to my quality of life. I believe it is wrong to deny others the opportunity to find out if these drugs work for them.

The key element of the strategy for me is improving the knowledge, capability and awareness amongst healthcare professionals in order to get them to listen more effectively to what their patients are saying about how their lives are being affected, to break down any preconceptions and to enable them to deliver a faster and more effective diagnosis. The Dementia Adviser role will help me get the best out of the system and provide focussed support when I need it. This is important for someone just after diagnosis when it can feel that your whole world is collapsing. I have concerns. Is the NHS prepared for the impact of full implementation? More effective and earlier diagnosis will increase numbers and will inevitably shift the balance towards younger people making current services focused primarily on the needs of older people less relevant. Younger people in many areas of England are simply not catered for.

Big changes will be necessary so the big question is will sufficient money and resources be made available?

Angela Clayton-Turner, whose husband, Ted, has dementia, talks about the benefits that the National Dementia Strategy offers.

We are now in the 14th year of our dementia journey and we have had good and bad experiences along the way. An early diagnosis gave us the opportunity to sort out legal matters and focus on enjoying life for as long as possible but there was no personal support available to help us come to terms with our situation. Our experience with the general hospital was poor and had a negative impact. Onset at a young age meant that local services were not age appropriate for Ted and that I searched in vain for local peer support from a couple in a similar situation. I had no advocate to support me when I had to deal with difficult and upsetting case conferences. Luckily through work I had experience of dementia, nevertheless much useful information was gained only accidentally. The strategy reflects and addresses these issues, with the exception of the needs of people with young onset dementia and their families.

Ted is now in the end stages of the disease and lives in a Care Home. For us now, the main benefits of the strategy are those areas relating to the quality of care in Care Homes and improving end of life care. However who knows whether or not my loved ones will develop this horrible disease in the future? For the sake of future generations and the public purse it is imperative that more money and effort is spent on research and I am reassured to see that this has been included.
Dementia in Europe

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When the member organisations of Alzheimer Europe unanimously approved the Paris Declaration of the political priorities of the European Alzheimer movement at our Annual meeting in Paris in 2006, no one could have foreseen the incredible progress we achieved in so little time.

Only last year, the French Presidency of the European Union organised the first Presidency conference dedicated to Alzheimer’s disease and two far reaching recommendations were adopted which call for the establishment of a European Alzheimer’s initiative and greater European collaboration on Alzheimer’s disease and other neurodegenerative diseases.

This was followed by the adoption of Written Declaration 80/2008 in March this year which was signed by close to 60% of all Members of the European Parliament and calls on the Member States of the European Union and the European Commission to recognise dementia as a political priority and to develop a European Action Plan on Alzheimer’s disease.

Since 2006, we have also seen greater awareness at a national level and a number of countries have implemented national dementia or Alzheimer’s strategies (Norway, France, Scotland and England) with other promising initiatives being launched in other European countries, such as the development of a dementia research network in Germany, the adoption of a resolution by the Walloon Parliament or the establishment of a dementia strategy group in Malta.

I am convinced that this recognition by policy makers is not only due to the increasing numbers of people with dementia due to the ageing of European populations, but it is also a true testament to the dedication and political advocacy of Alzheimer associations across Europe.

Our recent campaign to secure the necessary signatures for the European Parliament Written Declaration really brought home to me how much a united Alzheimer movement can achieve. Receiving the backing of 465 of 785 Members of the European Parliament would have been impossible if it had not been for the full involvement of our national member organisations and their solidarity with our campaign.

Of course, Alzheimer Europe repeatedly contacted all MEPs and provided regular updates of the signatories to our members, but it was the personal meetings, the telephone calls and intense follow-up of our national member organisations which truly made a difference. How else could you explain that 100% of all Cypriot, Greek and Slovenian MEPs endorsed this call for greater European action on dementia?

I was also delighted to see that the contacts established on a European level provided member organisations with new opportunities for interaction with policy makers on a national level and a number of Members of the European Parliament have supported activities of our members by attending World Alzheimer’s Day events and other meetings.
Looking back at the success of our campaign so far and the incredible level of support and solidarity by our national member organisations, I am confident that our goal of making dementia a national and European priority will become a reality.

### KEY MILESTONES

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<th>Date</th>
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<td>4 February 2009</td>
<td>United Kingdom</td>
<td>English Health Secretary announces launch of Dementia Strategy</td>
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<tr>
<td>February 2009</td>
<td>Malta</td>
<td>Maltese Secretariat for the Elderly and Community Care appoints National Dementia Strategy Group to prepare long-term dementia strategy</td>
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<tr>
<td>22 December 2008</td>
<td>Belgium</td>
<td>Walloon Parliament adopts resolution on Alzheimer’s disease</td>
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<tr>
<td>17 December 2008</td>
<td>European Union</td>
<td>Council of Ministers calls for greater European collaboration on Alzheimer’s disease and asks European Commission to develop European Alzheimer’s initiative</td>
</tr>
<tr>
<td>12 December 2008</td>
<td>Portugal</td>
<td>Portuguese Parliament approves laws to improve social protection of people with Alzheimer’s disease</td>
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<tr>
<td>30-31 October 2008</td>
<td>European Union</td>
<td>French Presidency of the European Union organises two-day conference on the fight against Alzheimer’s disease</td>
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<tr>
<td>2 October 2008</td>
<td>United Kingdom</td>
<td>Medical Research Council announces £30 million research initiative</td>
</tr>
<tr>
<td>26 September 2008</td>
<td>European Union</td>
<td>Council of Ministers adopts conclusions on a “common commitment by the Member States to combat neurodegenerative diseases, particularly Alzheimer’s” calling for increased collaboration on research</td>
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<tr>
<td>1 July 2008</td>
<td>Germany</td>
<td>New public research network is launched bringing together researchers from 17 German towns</td>
</tr>
<tr>
<td>28 April 2008</td>
<td>United Kingdom</td>
<td>All Party Parliamentary Group on Dementia (APPG) urges British Government to stop the over-prescribing of anti-psychotic drugs to people with dementia</td>
</tr>
<tr>
<td>21 April 2008</td>
<td>United Kingdom</td>
<td>Scottish government announces three-year plan to help people with dementia and their carers (investment of £630,000)</td>
</tr>
<tr>
<td>14 March 2008</td>
<td>Germany</td>
<td>Reform of German long-term care insurance results in some improvements for people with dementia</td>
</tr>
<tr>
<td>1 February 2008</td>
<td>France</td>
<td>French President launches third Alzheimer’s Plan (five year plan with EUR 1.6 billion)</td>
</tr>
<tr>
<td>12 December 2007</td>
<td>United Kingdom</td>
<td>Scottish Government’s strategy makes dementia a national clinical priority</td>
</tr>
<tr>
<td>30 October 2007</td>
<td>Norway</td>
<td>Norway adopts its dementia plan “Making the most of the good days”</td>
</tr>
<tr>
<td>29 June 2006</td>
<td>European Union</td>
<td>Alzheimer Europe adopts Paris Declaration of the political priorities of the European Alzheimer movement</td>
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</table>

“Our goal of making dementia a national and European priority will become a reality.”
Jean Georges
MEMBERS NEWS

A brief roundup of Alzheimer Europe’s members’ recent news

ARLETTE MEYRIEUX, PRESIDENT OF FRANCE ALZHEIMER, RECEIVES THE LEGION OF HONOUR FOR SERVICES TO ALZHEIMER’S DISEASE

The French President, Nicolas Sarkozy, bestowed the highest decoration in France, the “Chevalier of the Legion of Honour” upon Arlette Meyrieux, the President of France Alzheimer at a ceremony held at the Elysée Palace, Paris on 18 December 2008. Accepting the award, Ms Meyrieux thanked the volunteers who work for the association for their dedication on a daily basis. Arlette Meyrieux started working with France Alzheimer in 1995 and was elected President of France Alzheimer Savoie in 1998. Becoming the first elected member of the Board of Directors of France Alzheimer in 2000, in 2003 she was elected as its Vice President and its President in 2005.

PHONE-IN RAISES MORE THAN EUR 50,000 FOR FEDERAZIONE ALZHEIMER ITALIA

Television appeals broadcast in January to help raise money to help people with dementia and their carers resulted in nearly 40,000 text and phone calls being made, raising more than EUR 50,000 for the Alzheimer Federation, Italy (Federazione Alzheimer Italia). Seventeen broadcasts were aired from 19-25 January. The Federation thanked all those who supported this initiative for their collaboration and sensitivity, including RAI Italy, TIM, Vodafone, Wind, 3 Italia and Telecom Italia as well as Pippo Baudo, Michele Mirabella, Marco Mazzocchi, Federica Sciarelli, Carlo Conti, Ada D’Eusanio, Fabio Fazio, Bruno Vespa and Andrea Vianello.

EASYJET SELECTS THE ALZHEIMER’S SOCIETY AS ITS CHARITY PARTNER

Following a vote of EasyJet’s 7,000 staff across Europe, the company announced that its charity partner for 2009 is the Alzheimer’s Society. The Society will benefit from donations from in-flight collections over the summer and be granted a percentage of the proceeds from the scratch cards sold on flights.

THE GERMAN ALZHEIMER SOCIETY LAUNCHES A NEW INTERNET SERVICE

The German Alzheimer Society offered new link on their website (http://www.deutsche-alzheimer.de/index.php?id=48&news=124) which facilitates the search for support and respite services for the relatives of dementia sufferers.
Users of the website can now search by type of service (advice centres, support groups, helper circles, clinics, short-term care, care services, residential care, day care and/or doctors) and have the possibility of narrowing the search by region. Users will be shown both a rating of services offered as well as details of the services themselves.

Heike von Lützau-Hohlbein, Chairperson of the German Alzheimer Society, explained why they had developed this service “More and more people want to inform themselves, but also obtain personal advice. With the new internet service account this is what we hope to provide.”

**THE ALZHEIMER SOCIETY OF FINLAND LAUNCHES NEW WEBSITE**

In March, the Alzheimer Society of Finland launched its new website (www.muistiliitto.fi) new logo (above) and new name “Muistiliitto ry”.

**“COMMitted TO ELlExCElLENCE” AWARD GIVEN TO ALZHEIMER SCOTLAND**

Alzheimer Scotland has been awarded a “Committed to Excellence” award from Quality Scotland for their work including their Staff and Volunteer Recognition Scheme, improvements made on their intranet with space allocated for the sharing of ideas and for “creating a culture of continuous improvement”. The award, which is valid for two years, is part of the European Foundation of Quality Management (EFQM) Levels of Excellence Scheme.

**NEW ALZHEIMER CAFES OPEN IN BELGIUM**

In addition to the existing 13 Alzheimer cafes in Belgium, two additional Alzheimer cafes (in towns of la Louvière and in Enghien) were opened by La Ligue Alzheimer in April. Alzheimer cafes were set up to offer a place where people with dementia, and their carers can meet up on an information basis and also benefit from a presentation on a particular aspect of dementia.

**IT IS WITH GREAT SADNESS THAT WE HEARD OF THE DEATH OF TWO GREATLY VALUED COLLEAGUES.**

**ISTVÁN DEGRELL** passed away on 14 February 2009. He was a professor of the Department of Psychiatry at the University of Debrecen. He was a well known researcher in the field of Alzheimer’s disease with an impressive publishing record. From 2006 to 2009, he was actively involved in Alzheimer Europe’s EuroCoDe (European Collaboration on Dementia) project and contributed to the work package on the prevention of dementia.

**NAJA SKOVGAARD** died on 13 March 2009 after a short illness. She was an active member of Alzheimerforeningen, our Danish member organisation of which she was a Board member and which she represented at international and European meetings. She was elected to the Alzheimer Europe Board at the Annual General Meeting in Maastricht in 2002 and was an active member of the AE Board until 2006. She participated in a number of Alzheimer Europe projects, including the EPOCH (Equality in the provision of care at home) project and the work package on psycho-social interventions of the EuroCoDe project. Anne Arndal, chairperson of Alzheimerforeningen remembers her by saying: “Naja was always very committed to the work for better conditions for persons with dementia. She will be missed in Denmark and 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.
**LIVING WITH DEMENTIA**

Stewart Cooper, 73, who is British, describes his life with Alzheimer’s disease in his adopted country of Luxembourg

I arrived in Belgium in 1992 and my wife, Siobhan and two children joined me six months later. Our initial five year plan turned into 17 years! I came to work on as a Project Electrical Engineer on an industrial plant. For the first five years, we lived very happily in a converted farmhouse near Arlon, Belgium, and then we bought some land and built a house in Hagen, Luxembourg, where we have spent the last 12 years living. My wife returned to work and I became a house-husband.

Things started to go wrong for me in May 2007 and this led to my visiting a doctor and having a series of tests, after which I was diagnosed with “mild cognitive impairment” and given treatment. On my next visit to the doctor I was told I had Alzheimer’s disease. My wife and I have been devastated by this diagnosis.

I do not wear this malady on my sleeve. We talk naturally about it. Friends accept it and make allowances for my forgetfulness. I try to lead a useful life. I love classical music and I still teach piano. The worst problem for me is not being able to concentrate. I find it difficult to work on the computer. I have had one book published and I have been trying to finish my new book, “Tome” “A history of Christianity” for the last two years, but it just sticks at 900 pages. This article has taken me six attempts and I find this very frustrating. Mental tasks seem to be harder for me now, rather than physical.

I understand that in the UK people with dementia cannot always afford the medication, especially if they are in the early stages. Here the medication is subsidised within the health care system and for me the cost of my treatment works out at about EUR 12 for six weeks instead of EUR 168. I have found the medical care to be outstanding. Even though the official languages in Luxembourg are Luxembourgish, French and German, all the staff I have come into contact with have spoken English. I have every respect for them. One doctor I see manages to give me plenty of time, so I am able to really talk.

Some things are difficult to establish though, such as what support services are available to me and my wife, as well as our rights. It would be nice to have someone who can explain this to us. I would dearly like to know if there are any other English speaking people here with dementia. I can speak French, but now it seems to take me all my time to speak in English. There are Alzheimer cafes and I will try to see if there is one near me. Siobhan has been fantastically supportive and I would like it if someone can also give her support as I think it must be incredibly frustrating, if not a little frightening, when I forget things. I know it is for me.

In May, I will attend the Alzheimer Europe conference in Belgium and hope to get a greater understanding of dementia. At the moment, with the medical care I receive, my family and friends around me, and the quality of life I have, I feel truly blessed to live in Luxembourg.
Dementia in society

A look at how dementia is reported in literature and arts

British personalities raise awareness and call for action on dementia

The Prince of Wales, British broadcaster, John Suchet, author Terry Pratchett and actors, Jim Broadbent and Kevin Whately, have all spoken out about dementia.

At the Alzheimer’s Research Trust’s 10th annual conference, a statement from His Royal Highness the Prince of Wales was read out in which he congratulated the Trust for their work “to lift the shroud of mystery that has long surrounded dementia” and recognised that the “emotional, social and economic burden we will all face if (dementia) is left unchecked will be catastrophic”.

Also at the Alzheimer’s Research Trust annual conference, actor, Jim Broadbent, (who won an Oscar for his portrayal of the husband of Iris Murdoch who suffered from dementia) spoke about his own experience with dementia, having lost his mother to the disease. He said that ministers “have an opportunity to think about how they fund research into dementia, which has long been marginalised… Once we conquered the stigma attached to cancer… This must happen now for dementia… The government must seize the moment and help to give hope that one day we will live in a world free of the curse of dementia.”

During a BBC breakfast show, Mr Suchet, whose wife, Bonnie, has Alzheimer’s disease, explained that whilst he had been determined to be supportive and understanding after his wife’s diagnosis that “every now and then you just explode… It was a culmination of little things – dinner plates going straight back onto the shelf instead of going into the dishwasher or being wiped dry whilst they were still dirty. It just built up and up and I exploded. I felt so guilty afterwards.” Mr Suchet has help from an Admiral Nurse (who is a specialist nurse working with people with dementia and their carers) said: “It is so important for people to get help, as the very nature of dementia means that the full burden falls on the shoulders of the carers.”

Ambassador for the Alzheimer’s Society, actor Kevin Whately, whose mother has Alzheimer’s disease, took part in a documentary on dementia. The programme highlighted the fact that vast differences exist in the diagnosis, nursing home care and treatment of dementia.

Having spoken out about dementia several times this last year, author Terry Pratchett, who is living with dementia, has continued to raise awareness of the disease by allowing a film crew to film his first year with the disease which was aired by the BBC and entitled “Living with dementia”.

Play about dementia debuts in London’s West End and donates its profits to the Alzheimer’s Society

The new play, “For Once I Was", which opened in London’s West End in April, is about the impact of early onset Alzheimer’s disease on a father and daughter’s relationship. Initiated by Becca Stevenson whose father, John, was diagnosed with early onset Alzheimer’s disease nine years ago, all profits are being donated to the Alzheimer’s Society.

The “emotional, social and economic burden we will all face if (dementia) is left unchecked will be catastrophic”

HRH Prince of Wales
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 26 COUNTRIES

- Austria – Vienna: Alzheimer Angehörige
- Belgium – Brussels: Ligue Nationale Alzheimer
- Bulgaria – Sofia: Alzheimer Bulgaria
- Bulgaria – Varna: Foundation Compassion Alzheimer Bulgaria
- Cyprus – Larnaca: Pancyprian Alzheimer Association
- Czech Republic – Prague: Czech Alzheimer Society
- Denmark – Hellerup: Alzheimerforeningen
- Finland – Helsinki: Alzheimer-keskusliitto
- France – Paris: Association France Alzheimer
- Germany – Berlin: Deutsche Alzheimer Gesellschaft e.V.
- Greece – Thessaloniki-Hellas: Greek Association of Alzheimer’s Disease and Related Disorders
- Iceland – Reykjavik: F.A.A.S.
- Ireland – Dublin: Alzheimer Society of Ireland
- Italy – Milan: AIMA
- Italy – Milan: Federazione Alzheimer Italia
- Luxembourg: Alzheimer Association Luxembourg
- Malta: Alzheimer Society of Malta
- Norway – Oslo: Nasjonalforeningen Demensforbundet
- Poland – Warsaw: Polish Alzheimer’s Association
- Portugal – Lisbon: APADA
- The Netherlands – Bunnik: Alzheimer Nederland
- United Kingdom – London: Alzheimer’s Society
- United Kingdom – Edinburgh: Alzheimer Scotland
- Turkey – Istanbul: Alzheimer Vakfı
- Sweden – Stockholm: Demensförbundet
- Sweden – Lund: Alzheimerföreningen i Sverige
- Spain – Madrid: Fundación Alzheimer España
- Spain – Pamplona: C.E.A.F.A.
- Slovakia – Bratislava: Slovak Alzheimer Society
- Romania – Bucharest: Societatea Alzheimer
- Portugal – Lisbon: APADA
- Norway – Oslo: Nasjonalforeningen Demensforbundet
- The Netherlands – Bunnik: Alzheimer Nederland
- Malta: Malta Dementia Society
- Luxembourg: Association Luxembourg Alzheimer

ACT NOW

Remember those who cannot

6.1 million people have dementia in Europe
WE WHOLE-HEARTEDLY THANK ALL MEPS

who supported
Written Declaration nº 80/2008
on the priorities in the fight against Alzheimer’s disease

YOU have helped 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

The Declaration was officially adopted by the European Parliament on 5 February 2009