Dementia in Europe
The Alzheimer Europe Magazine

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Dagmar Roth-Behrendt hosted a lunch debate on dementia in the European Parliament.

Magda Aelvoet talks about the Belgian EU Presidency.

Irene Oldfather, MSP discusses the Scottish National Dementia Strategy.

EU Commissioner, John Dalli explains how we can ensure dementia is a European health priority.
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Discover the new area dedicated to national dementia plans and interviews with MEPs
04 Welcome
By Maurice O’Connell,
Chairperson of Alzheimer Europe

Prioritising dementia

06 Debating dementia in the European Parliament
A summary of the lunch debate dedicated to the national approaches adopted by France and England to dementia, which was hosted by Dagmar Roth-Behrendt, MEP (Germany).

10 The role Alzheimer associations play in Europe
Alzheimer Europe takes a look at the vast array of services which national Alzheimer associations provide across Europe.

14 A snapshot of Members’ work
Some of the activities carried out by national Alzheimer associations.

18 Towards a better protection of adults in Switzerland
Marianne Wolfensberger, Legal Affairs and Advocacy Manager from the Swiss Alzheimer Association, reports on legal developments in relation to guardianship in Switzerland.

Policy Watch

22 EU Presidency Watch: Belgium and Spain
In 2010 the rotating EU Presidency has been held by Spain and Belgium. In the first article, Magda Aelvoet, Minister of State for Belgium, talks about the work which Belgium will carry out to in order to keep dementia on the political agenda. The second article reports on the Spanish Conference on “Mental Health and Well-Being in Older People” which was held in June this year.

27 Dementia as a European Health Priority
John Dalli, the European Union Commissioner for Health and Consumer Policy, talks with Alzheimer Europe about how to ensure dementia is a European health priority.

30 The View From Luxembourg
Astrid Lulling, MEP (Luxembourg), highlights the situation for people with dementia and their carers in Luxembourg.

32 National Dementia Plan: Scotland
Irene Oldfather, MSP, Chair of the Scottish Parliamentary Cross-Party Group on Alzheimer’s disease and Jan Killeen, Director of Policy, Alzheimer Scotland, talk about the newly launched National Dementia Strategy.

36 Policy news round up
A brief look at some of the policy updates.

Dementia in the News

40 Members’ News
A roundup of Alzheimer Europe’s members’ recent news.

43 Dementia in Society
A look at how dementia is reported and portrayed in literature, the arts and society.

44 Living with dementia
James McKillop, who has dementia, talks about the impact that the decision to stop driving has had on his life.

46 Putting a face to commitment
An update on recent appointments by national Alzheimer associations.
I would like to extend a very big welcome indeed to everyone reading the 6th issue of our Dementia in Europe magazine. In it you will find the latest developments regarding European policy on dementia, interviews with various European and national policy makers, information on national Alzheimer associations’ services as well as a contribution offering a moving account of how everyday events are impacted by the disease. Alzheimer Europe is celebrating its 20th anniversary this year and I hope that you enjoy the enclosed supplement dedicated to this. I am so proud of how the organisation has evolved and humbled that I have been able to be a part of it. The founding members provided a sound base, but also a vision on which future members could build. The organisation has gone from strength to strength despite some financially precarious times. The achievements of the organisation are quite simply remarkable and evidence of the deep commitment of so many people.

This issue also carries our regular features and I am extremely grateful to all who have contributed as I believe these make the magazine vibrant, insightful and real. One such contribution, from the EU Commissioner for Health and Consumer Policy, John Dalli, explains how dementia can be made, and kept, a European health priority. He is clear that collaboration and investment are key.

Magda Aelvoet, the Minister of State for Belgium, talks about the forthcoming Belgian EU Presidency Conference on the stigmatisation and social exclusion of people with dementia and we also report on the recent Spanish EU Presidency conference which focused on the mental health and well-being of older people. Both of these illustrate the role which EU Presidencies can play in highlighting dementia. You will find a summary of a debate on the national approaches taken against Alzheimer’s disease which was held at the European Parliament. Members of the European Alzheimer’s Alliance were passionately engaged during this debate and I am delighted and grateful for their continued support for our cause. Work at national level is absolutely crucial in the fight against dementia and it is with great interest that I read about issues affecting people with dementia in Switzerland (Towards a better protection of adults in Switzerland) and Luxembourg (The view from Luxembourg). We also bring news from Scotland where their first National Dementia Strategy was recently launched.

For me, the work carried out at national level by the Alzheimer associations is awe-inspiring. In the article “the role Alzheimer associations play in Europe” you can find out about the very practical and invaluable services which national Alzheimer associations provide and will see that they somehow manage to grow and try to address the new challenges which people with dementia and their carers face.

Reading James McKillop’s article I was struck by how his life with dementia forced him to confront so many emotions. From the moment James found himself trying to find coping strategies for his unusual driving, one could imagine his journey of confusion, frustration, anger and final acceptance as he lost his independence and freedom to drive. I thank James for sharing this with us.

Finally, after six years, I step down this month as Chairperson of Alzheimer Europe. I leave with so many happy and wonderful memories and look forward to offering my support to the newly elected Chairperson.
Debating dementia in the European Parliament
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The latest lunch debate, which Alzheimer Europe organised in the European Parliament, was dedicated to the discussion of the French and English national approaches to dementia.

On 22 June 2010, Dagmar Roth-Behrendt (MEP, Germany) and Vice-chair of the European Alzheimer’s Alliance, hosted Alzheimer Europe’s 8th lunch debate held in the European Parliament, which was entitled “Alzheimer’s disease and dementia as a national priority: contrasting approaches by France and the UK”. Dagmar Roth-Behrendt welcomed all 36 participants (including seven MEPs or their representatives) to the debate.

**Introduction**

Ms Roth-Behrendt explained that dementia became a personal issue to her, as her mother lived with the disease until recently. She believes that despite Alzheimer’s disease presenting the EU with an enormous challenge and everyone saying that age-related diseases should be a priority, the reality is that Alzheimer’s disease is not given the same high priority as other diseases within EU health programmes. She also reflected on the need for greater awareness within the EU about the disease and on the lack of information at the time of diagnosis. In her case, she was grateful she could resort to Alzheimer Europe to find information and help. Ms Roth-Behrendt acknowledged the role Alzheimer Europe plays, saying “I have to thank Alzheimer Europe for the huge amount of work you do, it is very appreciated. Without you a lot of us would be lost.”

Ms Roth-Behrendt highlighted the issue of diagnosis and asked how a faster and better diagnosis could be achieved and, if that can be obtained, how can we ensure that the best treatments and practices are known throughout the EU. She also asked how we can help families get information about the disease and support. She then invited the speakers to first introduce their respective national plans.

**The French and English National Plans**

Presenting the French Plan Ms Lustman, Co-ordinator of the French Alzheimer Plan, said that the first step France had taken was to establish that Alzheimer’s disease was indeed a public policy issue. Ms Lustman emphasised that the French plan was a global one and that this, 3rd French plan, focused more than ever on the person with dementia and their carer. The first objective of the 3rd plan, she said, is that of knowing the disease and finding a medical treatment or cure. Therefore, research has been given a high priority within this plan. This differs to the previous Alzheimer plans and Ms Lustman was proud that in the last two years progress had been made. The second objective of the French plan is to take care (from both a medical and social point of view) of people with dementia and their carers by looking after them and improv-
ing their quality of life. The third objective is that of respect and Ms Lustman said that it was vital to guarantee the dignity of the person with Alzheimer’s and that an ethical approach was employed.

Mr Ketteringham, Director of external affairs, Alzheimer Society, then took the floor and reflected on the fact that the English strategy was a dementia strategy, not only an Alzheimer’s disease strategy, and how the term dementia and Alzheimer’s disease had connotations associated with them and that language usage played a part in the stigma associated with them. Removal of such stigma, he said, was a key element of the English strategy.

He explained that the English strategy had come into being as a result of two events: an Alzheimer Society report on dementia which highlighted the impact dementia had on the nation and the public dissatisfaction with the inaccessibility of dementia drugs. These two elements put the disease onto the political agenda.

Commenting on the strategy itself, Mr Ketteringham said that the English strategy has three key elements: raising awareness, providing information and giving support, all of which aim to put people with dementia in control of their own lives, with the message that one can live well with dementia. The Society put in place a powerful campaign of which the message was “I have dementia but I also have a life” and the English strategy entitled “Living well with dementia” was born.

Dementia Research

Ms Roth-Behrendt then asked for clarification regarding investment in dementia research and whether collaboration between Member States could be achieved.

Florence Lustman said that the 3rd plan identified a number of weaknesses in dementia research. A particular problem highlighted was that there were too few high quality researchers and, specifically, not enough young researchers working on dementia. In addition, a lack of collaboration and structure on a global level was identified as a weakness. As none of these issues could be overcome quickly, the Alzheimer Plan included the setting up of the Alzheimer Plan Foundation and EUR 200 million was committed to dementia research over a five-year period. Ms Lustman was proud to acknowledge that, after just two years’ work, the Foundation had been recognised at highest national level in a report on the identification by the Foundation of two new genes as being one of the 10 major scientific discoveries throughout all disciplines (2009 “Nature Genetics”).

In addition, she stated that France had put a lot of energy into encouraging the European Parliament and the European Commission to take action, and into the development of the joint programming of research initiative, which now has participation of 24 Member States.

With regard to the English strategy, Andrew Ketteringham said that following pressure from the Society the government accepted that research should be included. However, he said that dementia research remains a “poor relation” to other research areas, such as cancer. Acknowledging the problems faced within the current economic climate, Mr Ketteringham posed the question whether we can really afford not to invest in research, especially in light of the fact that it is often said that if you can delay the onset of Alzheimer’s disease by five years, the number of people with dementia can be reduced by 50%.
question whether we can really afford not to invest in research, especially in light of the fact that it is often said that if you can delay the onset of Alzheimer’s disease by five years, the number of people with dementia can be reduced by 50%.

Despite the current financial situation, Mr Ketteringham believes the financial argument to be strong, the political will evident and, a desire for action from the public will ensure that awareness will be maintained. In addition events such as the International Conference on Alzheimer’s Disease (ICAD) which will command considerable media attention.

Taking action

Some Member States, said Ms Roth-Behrendt, believe that health is a national issue and not one that the EU should have competence to deal with. This being so, what can the EU do to help? Ms Roth-Behrendt said that action can be taken which doesn’t cost anything, such as just being open and talking about dementia. However, if the EU were to assist, Ms Roth-Behrendt thinks that national competence needs to be given up and she questioned whether the Member States were really ready take this action.

Nessa Childers (MEP, Ireland) explained to the participants that she had initially wanted to help in this area for personal reasons (her mother died on 9 May this year). She felt that MEPs can help, even if it’s by just speaking about dementia. Ms Childers said that it simply is not acceptable for health care professionals to say they don’t know what people with dementia and/or carers should do and that national associations can be of great help. She highlighted the fact that in Ireland there is no Strategy and that there is a serious situation.

Magda Aelvoet, Minister of State, Belgium, confirmed that policy makers in Belgium would be keeping dementia on the political agenda when they take on the EU Presidency. The Belgian government has decided to organise a high level meeting entitled “how to improve the quality of life for people with dementia” to which people from the Member States would be invited. Within this context, Ms Aelvoet is supervising a report on a survey which the Belgian authorities sent to both health authorities and associations within the Member States. The report will be shared at the high level meeting and Ms Aelvoet said that already the message is being heard that when one talks about quality of life, the carer should receive a lot of attention. Ms Aelvoet said, “it is important to see there are good practices which should be common knowledge.”

Sirpa Pietikäinen (MEP, Finland) said that she had her own personal experience of dementia as her mother has it. She highlighted three ways in which the EU could work in the area of dementia. Firstly, by extending the principle found in the Århus Convention, whereby an NGO is appointed to represent the interests of “those who cannot speak” more widely. Ms Pietikäinen mooted whether Alzheimer associations could provide this for people with dementia. Secondly, Ms Pietikäinen said that she believed it important that Member States have national programmes for dementia and then have a system of open co-ordination. Lastly, Ms Pietikäinen said the rights laid down in the Lisbon Treaty could be used more fully.

Economic burden

Newly-elected MEP, Keith Taylor (UK) said that he had found the debate to be interesting but sought clarification that research has economic benefits. Mr Ketteringham replied that in the UK less than GBP 40 million of public funds is put into dementia research each year, which, he said, is tiny compared to that of other diseases. Mr Ketteringham also said that if the onset of the
Dementia can indeed be delayed by five years, then some figures can be reduced including the numbers of people but also the financial burden.

Elisabeth Morin-Chartier (MEP, France) also highlighted the fact that in the UK people often pay for their own care, incurring enormous costs which could be deferred and even excluded if the onset of Alzheimer’s disease could be delayed. She concluded that we simply cannot keep talking in economic terms but keep in mind the human aspect of the disease.

Florence Lustman said that the economic cost is not the most important aspect of the plan and that she feels uncomfortable when discussions become limited to public funding. She reiterated the need for a diagnosis. In France, there is a relatively short waiting time (around 50 days) to receive a diagnosis and yet only one out of every two cases of dementia is diagnosed. Ms Lustman believes that doctors hold the key to why rates are so low. When she had meetings with them she was told that they were hesitant to give a diagnosis of dementia as some of them believed nothing could be done – a fact which Ms Lustman vehemently disagrees with. She would like to see that the message is received throughout Europe that there is help and intervention programmes which can improve the quality of life for people with dementia and their carers. Jean Georges said there is a huge growing sector in which more people are being employed to take care of people with dementia. This has benefits in terms of employment and taxation which can be seen as an investment.

Ms Morin-Chartier concurred and said that the EU needs to introduce flexible hours in the field of employment to enable people to have time to care and that the workforce need training programmes to help them detect symptoms and care in the best possible way.

**Stigmatisation**

Magda Aelvoet called for the image of dementia to be changed within society. She felt that we should all prepare our own societies, making them aware that although dementia is indeed a difficult disease to live with, you can live with it and live with it well.

Andrew Ketteringham agreed that Member States need to address the stigma of the disease but he said he preferred to use the term “understanding” rather than “awareness” as he believed understanding is twofold: of the disease itself and of how to respond.

**Conclusions**

Mr Ketteringham thanked the EU Parliament for calling for an action plan and applauded the EU Presidencies for placing and keeping dementia on the political agenda, but called for the EU to do more. He called on the Parliament to take the leadership in this issue. Florence Lustman thanked Ms Roth-Behrendt for organising the lunch debate and said that whilst recognising the tremendous steps taken, France wants more action from the European Commission.

Closing the debate, Mr O’Connell, Chairperson of Alzheimer Europe, said that as Vice-Chair of the Alliance he knows that Ms Roth-Behrendt will continue to make dementia a priority. He noted that, yet again, Ms Lustman’s enthusiasm for the French plan and her commitment was something every participant could take away from the meeting with great fondness and, he thanked Andrew Ketteringham for his deep insight into the issues which need to be addressed.

The next debate in the European Parliament will be held on 7 December 2010.
THE ROLE ALZHEIMER ASSOCIATIONS PLAY IN EUROPE

This, the first of two articles by Alzheimer Europe on the roles, structure and financial support national European Alzheimer associations have, looks at the services the associations currently provide.

The roles, range and quantity of services which national Alzheimer associations provide around Europe is nothing short of incredible. Whilst all of the national associations share the common goal of providing support, information and raising awareness and a greater understanding of the disease, you can see on table 1, that they achieve this by offering a comprehensive, varied and wide spectrum of services for people with dementia and their carers, in addition to holding events which raise awareness of the disease and the issues which surround it.

Not surprisingly, all of the associations provide some level of support and/or information on Alzheimer’s disease for people with dementia and their carers. Some associations also provide additional information on other forms of dementia including Pick’s disease, Creutzfeldt-Jakob Disease (CJD), vascular dementia, fronto-temporal dementia and Lewy body dementia to name but a few. Thousands of Europeans have benefited from this support, which is often provided by carers of people with dementia themselves.

Support groups play a key role in most of the associations’ work. In particular, support groups for carers are common throughout nearly all respondents’ countries (save for BG) with some countries just having one group (AT, CR and CZ) and others up to some 450 groups (DE). Many countries also have support groups for people with dementia themselves (AT, BE, CR, CY, CZ, FR, DE, GR, IE, MT, NO, PT, SL, ES, SE, CH and UK) ranging from just one such support group [AT, CR and CZ up to 44 (UK-England)]. Support groups for people with dementia are increasingly important as early diagnosis of the disease results in people with dementia being able to take an active role in decisions which will affect their lives.

National telephone lines can be nothing short of a lifeline for people facing dementia. Nearly all respondents said they offer a helpline (save for AT) and of those that do, many keep a record regarding the type of caller. On an annual basis, the number of calls received by the associations ranged from 85 (BG) to a staggering 28,068 (UK-England). Without exception, the highest proportion of calls were received from carers of people with dementia (from 30% (NO) to 100% (LU) of callers). Several countries also reported a considerable number of calls from health professionals [BE Flanders (23%), CR (15%), DE (14%), GR (11%), IE (10%) and CH (29%)]. Whilst countries did report that people with dementia used the helpline these calls were at a significantly lower quantity than other types of callers.

The Alzheimer associations also provide training programmes, often for carers of people with dementia [AT, BE, CR, FI, FR, DE, GR, IE, IT, LU, MT, NL, NO, PL, PT, SL, ES, SE, CH, UK (England and Scotland)] but some of the associations indicated they also offer training for professional carers too (such as BE, PL and UK). Some respondents said they offer some kind of home help [CY, CZ, DE, FI, GR, IE, IT, PL, PT, ES, CH and the UK (England and Scotland)].
Providing literature on the disease is also a crucial part of the associations’ role and 95% operate a website (except CY), providing information fact sheets [BE, CR, CZ, FI, FR, DE, GR, IE, IT, LU, MT, NL, NO, PL, PT, SL, ES, SE, CH, TK, UK (England and Scotland)] and publishing a regular newsletter and/or magazine. On average, the newsletters are published quarterly, although some do publish monthly newsletters [DE and UK (England)] and some countries provide both a newsletter and a magazine (DE and NL). Circulation of the newsletter ranged from 1,000 per issue (AT, MT and TK) up to 50,000 (NL). Interestingly, a few associations provide some of their literature in more than one language [BE, CY, FI, GR, LU, MT, CH and UK (England)] including sign language [UK (Scotland)]. Educational videos are also produced by some Alzheimer associations (BE, FR, DE, NO, SE, CH and UK).

In addition to the traditional support and information provided by associations, more associations are recognising the vulnerability of particular groups of people who live with dementia, such as people with dementia who are also young, and/or from an ethnic minority and/or gay. Younger people (under 65 years of age) who have dementia may find themselves being offered services which are geared to a much older generation and therefore fail to address the issues which may confront them including issues such as employment, mortgages, parenting and/or being a carer themselves. However, a considerable number of associations [AT, BE, CR, CY, CZ, FI, FR, GR, IE, LU, NL, NO, PT, SL, SE, CH and the UK (England and Scotland)] do manage to provide support and/or information for this group.

The growing cultural diversity societies now enjoy also brings added challenges and these extend to caring for people from other ethnic backgrounds who have dementia. It may be that the services offered are not compatible with peoples’ cultural preferences. Furthermore, a difference in language may present a barrier to the receipt of an otherwise good level of care. There is a stigma associated with dementia which may result in a reluctance by people with dementia to seek help. Services need to be adapted and accessible to this vulnerable group. Several national associations do provide information and/or services for people with dementia from ethnic minorities [BE, FI, LU, NL, NO, PT, SL, CH and UK (England and Scotland)]. Indeed, the UK (England) offers information to a considerably wide ethnic population (including Arabic, Chinese, Gujarati, Punjabi, Somali, Tamil, Urdu, Bangladeshi, Bengali, French and Polish).

In issue 2 (December 2008) of this magazine, Michael Cashman, MEP, spoke about the discrimination gay and lesbian carers experience and Roger Newman, who cared for his partner who had dementia, spoke about steps required to achieve inclusion and diversity, reminding us that “gay or straight, dementia does not discriminate”. People who live with dementia and are gay, may find a lack of tolerance from others, resulting in exclusion from discussions about the care of a loved one. In addition, sexuality is often a private matter but in order to be accepted it becomes necessary to expose your sexuality in a public arena. Currently, only 22% of the associations [BE, LU, PT, SL, UK (England and Scotland)] provide specific information and/or support for people with dementia and their carers who are gay and this reflects the situation when the survey was last carried out in 2003.

The role of the associations has also grown from the provision of information and/or support to the running of day care centres. Several associations...
Table 1: Services offered by national Alzheimer associations in Europe

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<th>Country</th>
<th>General Information Support</th>
<th>Support group for people with dementia</th>
<th>Support group for carers</th>
<th>Training courses for carers</th>
<th>Meals on wheels</th>
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The value of the work which national Alzheimer associations around Europe have already provided cannot be underestimated. Indeed, Spain now provides over 100 day care centres throughout the country. For most of the associations, their role does not extend to the provision of long-term care centres, although these were reported in five countries (FI, IE, LU, PL and TK). The type of services offered by associations continues to grow with Alzheimer cafes (BE, NL, TK, UK), counselling (IT and UK), holiday programmes (NL, CH), respite units (ES) and legal advice programmes (PL) being highlighted in the surveys.

Events to raise awareness and exchange information are commonly organised by Alzheimer associations. Nearly all associations reported that they hold regular information meetings (save for BG and FI) as well as hosting a national conference [BE, CR, CY, CZ, FI, FR, DE, GR, IE, NL, NO, PT, ES, SE, CH, UK (England and Scotland)]. Associations also highlight their campaigns during World Alzheimer’s Day on 21 September each year and, in addition, some hold additional events throughout the year [BE, CR, CZ, DE, FI, NL, UK (England and Scotland)]. The range and quantity of campaigns Alzheimer associations organise is inspiring with press conferences, memory walks, memory clinics, information days, competitions and concerts to name just a few. Just through the conferences alone, the combined number of people who have attended national Alzheimer conferences in the last year amounts to 7,535. Each conference draws anything from around 100 people (IE, NO) right up to 1,300 (SE). In addition to these events, members attend events to gather support from politicians, such as the lunch debates on dementia held in the European Parliament.

Table 2: List of country contributors

<table>
<thead>
<tr>
<th>Country</th>
<th>Association Name</th>
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<tbody>
<tr>
<td>Austria AT</td>
<td>Alzheimer Angehörige Austria</td>
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<tr>
<td>Belgium BE</td>
<td>Ligue Alzheimer ASBL &amp; Vlaamse Alzheimer Liga vzw</td>
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<td>Bulgaria BG</td>
<td>Alzheimer Bulgaria</td>
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<td>Croatia CR</td>
<td>Alzheimer’s Disease Societies Croatia</td>
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<td>Cyprus CY</td>
<td>Pancrepian Alzheimer Association</td>
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<td>Czech Republic CZ</td>
<td>Ceská alzheimerovská spolecnost</td>
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<tr>
<td>France FR</td>
<td>Alzheimer Alzheimer</td>
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<td>Finland FI</td>
<td>Muistilitto</td>
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<td>Greek Association of Alzheimer’s disease and related disorders</td>
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<td>Ireland IE</td>
<td>Alzheimer Society of Ireland</td>
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<td>Italy IT</td>
<td>Federazione Alzheimer Italia</td>
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<td>Lux LU</td>
<td>Association Luxembourg Alzheimer</td>
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<td>Malta MT</td>
<td>Malta Dementia Society</td>
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<td>Alzheimer Nederland</td>
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<td>Nasjonalforsenngen Demensforbundet</td>
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<td>Poland PL</td>
<td>Polish Alzheimer’s Association</td>
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<td>Slovenia SL</td>
<td>Association Forget-me-not</td>
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<tr>
<td>Sweden SE</td>
<td>de Alzheimer y otras demencias</td>
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<td>Switzerland CH</td>
<td>Alzheimerföreningen i Sverige</td>
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<td>England UK</td>
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<td>UK</td>
<td>Alzheimer Scotland</td>
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A SNAPSHOT OF MEMBERS’ WORK

Some of the activities carried out by national Alzheimer associations

Belgium: dance sessions

Croatia: information stand

Poland: press conference

Cyprus: day care center

Bulgaria: Press conference

Czech Republic: children’s book
Malta: memory walk

Finland: art therapy

Slovenia: pet therapy

Norway: awards

Germany: memory cards

Spain: memory bus

Ireland: day care centre

Italy: awareness-raising
ALZHEIMER EUROPE PUBLICATIONS

Dementia in Europe Yearbooks EUR 10 (plus handling and postage fees)

Our Yearbooks present the findings from various Alzheimer Europe projects, each year focusing on different issues linked to dementia. The annual accounts are contained at the back of each Yearbook. The Yearbook for:

• 2009 is dedicated to a comparison of national laws in Europe with regard to healthcare decision making by people with dementia.

• 2008 contains the outcome from four of the workgroups on the European Collaboration on Dementia (EuroCoDe) project.

• 2007 highlights the findings of a survey on social support systems amongst Alzheimer Europe’s member organisations.

• 2006 provides a European overview of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care.

Alzheimer Europe Reports EUR 5 (plus handling and postage fees)

The Alzheimer Europe Reports focus on specific aspects of dementia. Topics covered include end-of-life care, advance directives and the State of dementia care in Europe. Each Alzheimer Europe Report focuses on specific aspects of dementia.

• “End-of-life care for people with dementia” (2008): This practical guide is for all those involved in this delicate and demanding stage of dementia and is available in English and German.

• “The use of advance directives by people with dementia” (2006): This includes Alzheimer Europe’s position on advance directives as well as giving background information (legal, ethical, medical, personal and practical issues) in the case of dementia.

• Alzheimer Europe Survey “Who cares? The State of dementia care in Europe” (2006): This presents the results of a survey carried out by Alzheimer Europe which revealed a shocking picture of the level of commitment by carers, a significant lack of information for carers at the time of diagnosis, a lack of basic support services as well as the need of carers to contribute financially to existing services.

Care Manual Please see website for details of costs, supplier and language versions.

Written for carers, the Care Manual provides general information on Alzheimer’s disease, as well as specific information on symptoms and how to cope. It is published in several languages.
Children’s book Please see website for details of costs, supplier and language versions.

Written as a story through the eyes of a child, this book aims to help child gain awareness of Alzheimer’s disease and is available in several language versions.

Dementia in Europe Magazine EUR 2.50 (plus handling and postage fees)

The Dementia in Europe magazine is dedicated to covering dementia policy. Developments at both the European and national level are reported on as well as well as interviews with key policy makers.

• Issue 5 (April 2010): Aside from our regular features, highlights of this issue include interviews with the Executive members of the European Alzheimer’s Alliance, a review of the 2009 Dementia in Europe Yearbook, updates on the development of national plans in Europe and an interview with Professor Philippe Amouyel, the Chair of the Management Board of the Joint Programming Initiative of Neurodegenerative diseases.

• Issue 4 (December 2009): Highlights include the European Parliamentary lunch debate on European action on dementia, the 19th Annual Alzheimer Europe Conference in Belgium, the Dutch national dementia plan, the exchange of best practices on dealing with behaviour symptoms at home, the Swedish Presidency on dignified ageing and snapshots of the 2009 World Alzheimer’s Day.

• Issue 3 (May 2009): This issue carries interviews the European Health Commissioner, Androulla Vassiliou, the Czech Health Minister, Daniela Filipová and MEP for Greece, Maria Eleni Koppa. There is also a special section dedicated to several MEPs who evaluated the achievements of the 2004-2009 European Parliament in regard to helping people with dementia and their carers. The English Dementia Strategy is reported on and the legal rights for people with dementia in Norway are considered.

• Issue 2 (December 2008): The French Presidency Conference on Alzheimer’s disease is covered, as is the EuroCoDe project, the European Ethics network. Jan Tadeusz Masiel, MEP (Poland) discusses the situation for people with dementia in Poland and current treatment options for dementia are reported on.

• Issue 1 (June 2008): out of print – can be downloaded from our website.
Since 1912, for nearly a century, guardianship legislation (which is part of the Swiss Civil Code) has not been modified, apart from new regulations concerning forced internment, introduced in 1981. It became evident that this legislation no longer corresponded to modern circumstances and attitudes. In addition, the principles of proportionality were not respected to a sufficient degree.

Consequently, the Federal Council decided to amend the Swiss Civil Code. Due to the Swiss legislative process it took several years until Parliament adopted the new legislation in December 2008. Further, the new law will not come into force before 2013 as a lot of organisational adaptations are necessary in the Cantons (regions).

The main principle of the reformed law is to support the subject’s right to choose as well as relieve the administrative and financial burden on the State. As long as a person has legal capacity they can appoint a health care/welfare proxy who will represent them legally in the event of incapacity (Vorsorgeauftrag), thereby settling matters privately rather than through the authorities. A person can also issue advance health care directives that state how they wish to be cared for and which medical treatment they consent to (or not); a person can also nominate another person to take decisions on their behalf. These measures are new on federal level but already exist in most of the cantonal laws. This is because in Switzerland the health sector is mainly a cantonal responsibility.

Alzheimer’s disease and other forms of dementia are not legally defined as a disability and people with dementia are not generally considered as legally incompetent by the law. In the early phase of the disease they have normal legal capacity and should be encouraged to manage their own affairs, including the appointment of a proxy and issuing an advance directive. In the later stages of dementia (or any other disease which affects mental capacity) this is no longer possible. But even in this situation, it is not absolutely necessary to institute administrative measures. The new law grants spouses and civil partners the right to open mail, to ensure that income and assets are properly managed and to take necessary action to ensure living expenses are met. This strengthens family solidarity and avoids the authorities systematically having to invoke the official assistance system.

In this article Marianne Wolfensberger, Legal Affairs and Advocacy Manager from the Swiss Alzheimer Association, brings us up to date with the latest legal developments regarding guardianship in Switzerland.

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In this article Marianne Wolfensberger, Legal Affairs and Advocacy Manager from the Swiss Alzheimer Association, brings us up to date with the latest legal developments regarding guardianship in Switzerland.
But it is not always possible to avoid an administrative measure. If a person is no longer able to handle their own affairs as a result of mental disability, psychiatric disorder or similar mental disorder and the support provided by family members, private volunteers or public services is insufficient, the authorities will have to tailor a support package for that person. The new law therefore institutes a standard instrument – the concept of “official assistance” (Beistandschaft) – in place of standardised measures. The authorities must determine the tasks and roles to be fulfilled by the official assistant (Beistand) in accordance with the needs of the person concerned, so that the care provided by the State is limited to what is really needed.

The authorities can appoint a family member (or several) as “official assistant”. In this case the family members will be granted certain privileges. For example, they will not have to produce inventories or submit periodic reports, as is the case with institutional assistants.

The new law also stipulates which persons (and in which order) have the right to take decisions in medical matters for a person without legal capacity. If designated, it is the person appointed in an advance directive, or the person designated by the authority as “official assistant”, otherwise it is the spouse or any other person who lives with the incapacitated person and cares for them. Finally, the children or parents qualify if they care regularly for the person.

In addition, the revised legislation will also provide better protection to people without legal capacity who live in residential and/or nursing homes. A written care agreement must be concluded for these individuals in order to assure transparency about exactly what services are being provided and what extra costs are paid for. It must also be stipulated under which conditions freedom of movement may be restricted. Finally, the cantons will be obliged by law to monitor such residential and nursing institutions.

The revised legislation also provides for the protection of dignity and extends the legal protection assured to people living in care homes.

At present, the Swiss system of guardianship is a mixture of different rules and regulations at different levels. In the future, when the new law comes into force, the rules and principles of procedure will be applied uniformly throughout Switzerland.

**THERE WERE 110,654 PEOPLE WITH DEMENTIA IN SWITZERLAND IN 2006.**

![Number of people](chart.png)

**Number of people**

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<tr>
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<td>18,000</td>
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NB. Prevalence figures for 30-59 age group from EURO DEM (Hofman et al) and for 60+ age group from EuroCoDe (Reynish et al).

“The new law … strengthens family solidarity and avoids the authorities systematically having to invoke the official assistance system.”
Restoring the Tradition of European Medical Innovation

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

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

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

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

www.pfizer.com
European Health Commissioner John Dalli explains how we can ensure dementia is a European health priority.

Magda Aelvoet, Minister of State (Belgium) talks about the Belgian EU Presidency.

EU Presidency Watch: Belgium and Spain
Magda Aelvoet, Minister of State for Belgium, talks about the work which Belgium will carry out in order to keep dementia on the political agenda and Alzheimer Europe reports on the Spanish Conference on “Mental Health and Well-Being in Older People”.

Dementia as a European Health Priority
John Dalli, the European Union Commissioner for Health and Consumer Policy, talks with Alzheimer Europe about how to ensure dementia is a European health priority.

The View From Luxembourg
Astrid Lulling, MEP (Luxembourg), highlights the situation for people with dementia and their carers in Luxembourg.

National Dementia Plan: Scotland
Irene Oldfather, MSP, Chair of the Scottish Parliamentary Cross-Party Group on Alzheimer’s disease and Jan Killeen, Director of Policy, Alzheimer Scotland, talk about the newly launched National Dementia Strategy.

Policy news round up
A brief update on recent policy developments.
EU PRESIDENCY WATCH: BELGIUM AND SPAIN

Belgium took over the EU Presidency in July this year. Alzheimer Europe interviews Magda Aelvoet, Minister of State for Belgium, about EU collaboration on dementia and the forthcoming high level Belgian conference on the stigmatisation and social exclusion of people with dementia.

“Some legal decisions are real bombshells for people with dementia and deprive them of certain rights from one day to the next”

Alzheimer Europe (AE): Last year, the European Commission issued a Communication on Alzheimer’s disease and neurodegenerative diseases that called for a Joint Action on Alzheimer’s disease. Belgium is one of the countries which has agreed to participate in this Joint Action. What are the priorities for Belgium in this type of collaboration?

Magda Aelvoet (MA): Let us say a few words first about the Joint Action on Alzheimer’s disease. A Joint Action between Commission and Member States is at this moment in time still in the making as the formal approval could be given at the earliest in autumn.

The Joint Action between the Commission and Member States pursues the following objectives:

• To incorporate the “dementia dimension” into the European Union’s ongoing and future actions on health prevention, especially those related to cardiovascular health and physical activity.

• To produce a citizen’s summary of dementia prevention measures under a “Healthy brain lifestyle” set of recommendations.

• To use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive deficiencies.

• To map the existing and emerging good practices related to treatment and care for persons suffering from Alzheimer’s disease and other forms of dementia and to improve the dissemination and application of such practices (using, when possible, Structural Funds).

• To improve epidemiological data on Alzheimer’s disease and other dementias (implementing the conclusions of the EuroCoDe Project).

• To establish, using the facilities provided by the Health Programme, a European Network for the rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable adults and tackling patient abuse.

Seven different work packages of the Joint Action will cover the objectives set out.

Belgium will take the lead of the work package dealing with the issue of rights, autonomy and dignity of people with dementia from an ethical and legal perspective. A more balanced view of dementia and respect of each person’s autonomy
could go a long way towards making a significant improvement to the quality of life of people with dementia and those around them.

Belgium will focus on two crucial issues: advance declarations of will and competence assessment of people with dementia.

Advance declarations of will (ADW) have been developed in different Member States either by public authorities or by private organisations (such as patient organisations or ethical bodies). Advance declarations of will can be particularly useful for people with dementia in the early stages, so that they can keep the direction of their life decisions at most in their own hands.

It is Belgium’s intention to create an overview of existing advance declarations of will in the EU (and in some non-EU countries) and to analyse their content and their legal framework. Detailed information will be collected on how the practice and use of the document is assessed by the people concerned.

To this end, a balanced multidisciplinary working group of different Member States will be set up with the task to formulate recommendations with respect to the legal framework, the content of the ADW and the promotion of its use.

This work package is likely to increase the knowledge and awareness of the possibilities and limitations of advance declarations of will within Member States. The expected outcome is to improve and increase the use of advance declarations of will throughout the EU with the benefit of respecting the wishes of patients in the last stages of their life.

**Competence assessment of people with dementia**

Although their aim is to protect people with dementia rather than penalising them or limiting their freedom, some legal decisions are real bombshells for people with dementia and deprive them of certain rights from one day to the next. People with dementia do not simply lose all of their capabilities (e.g. driving, controlling their own assets) at once.

People with dementia can be subject to discrimination as a result of ill-suited legal provisions or the lack of dialogue and cooperation between the judiciary and the medical sector.

In order to overcome the negative impact of inadequate protection measures Belgium intends to make an inventory of good practices that correctly assess the competence of elderly people with cognitive impairments.

A multi-disciplinary competence assessment working group with legal, and medical experts from different Member States will be set up with the task of producing a multi-disciplinary analysis and leading to the formulation of practical recommendations.

This group will work further on the European Dementia Consensus Group (EDCON) consensus on competence assessment of dementia and on obtaining an increased knowledge on best practices on competence assessments and dissemination among Member States.

The outcome of both issues will not only be communicated to the Commission and the Member States but will specifically be reported to the Dementia Ethics Network and to Alzheimer Europe so as to share the results with the largest possible group of organisations and people concerned.

**AE: The focus on dementia will remain during the Belgian Presidency of the European Union. This time, a conference focusing on the social impact and stigma of dementia will be organised in November 2010. Could you tell us a bit more about this conference and what outcomes you expect?**

“How dementia is dealt with is a challenge for society as a whole”
MA: How dementia is dealt with is a challenge for society as a whole. The aim of this high-level conference is to highlight the societal aspects of dementia and to provide a forum for the exchange of good practices. Just as there are countless ways of living with dementia, there are also various prospects for improving the quality of life of people with dementia and their families. By identifying and facilitating the exchange of good practices between Member States, this event and the preparation leading up to it will create and strengthen networks and these will, in turn, extend the basis for broad recognition of dementia and the promotion of a positive societal response to the condition. Several important initiatives have already been taken at the European level by the European Council, the European Commission, a number of members of the European Parliament and by the French EU presidency in 2008.

Dementia is now a part of the agenda of the Belgian Presidency of the EU, with the objective of communicating a clear message on the basis of a Policy Report which is currently being drafted, drawing inter alia on findings of a survey to which a large number of Member States and Alzheimer Associations contributed.

This European conference is a crucial step in achieving this objective. The Belgian Presidency will bring together experts and practitioners to discuss and identify best/good practice care models and promising strategies to reach out to people with dementia and their carers. The conference also aims to set down a significant milestone in improving dementia policy strategies within the EU. The conference report will highlight the opinions of conference participants on the priorities for objectives and action, as well as best practices in the European Union in view of the EPSCO Council meeting in December.

AE: Ms Aelvoet, thank you very much.

FOCUS ON CARERS UNDER THE SPANISH EU PRESIDENCY

Alzheimer Europe reports on the EU Presidency Conference “Mental Health and Well-Being in Older People” which took place in Madrid on 28 and 29 June 2010

Spain followed in the footsteps of previous EU Presidencies and took up the subject of dementia in one of its Presidency Conferences. The Madrid Conference “Mental Health and Well-Being in Older People – Making it Happen” was the third thematic conference organised in the framework of the European Pact for Mental Health and addressed different key subjects, such as mental health promotion in old age, older people in vulnerable situations, the prevention of mental disorders, care and treatment systems and informal carers.

The conference recognised that informal carers carry a large share of the provision of care and that older women provide an increasingly large share of that care. Therefore, the conference recommended the following actions to support carers:
• Provide official recognition, financial support and social security benefits to informal carers,

• Provide mental health protections measures for informal carers such as respite, flexible and part-time work, psychosocial support and training,

• Provide professional home visits and communication between professionals and informal carers,

• Use the experience of informal carers in the training of professional carers.

It was hardly surprising that Alzheimer’s disease and dementia were also amongst the issues which were included in the conference programme and conclusions. In the first plenary session, Professor Antonio Lobo from the University of Zaragoza provided an overview of our current understanding of the prevalence as well as the risk factors of dementia and depression. He concluded that these two diseases constituted the most serious threats to mental health in old age.

From the European Parliament, Antonyia Parvanova, MEP (Bulgaria) and Nessa Childers, MEP (Ireland), two very active members of the European Alzheimer’s Alliance, took part in the opening and closing sessions of the conference. Ms Parvanova highlighted the fact that mental health issues are a challenge for the entire society and that solidarity was therefore key. For that reason, the topic of mental health should be a common European responsibility. Ms Childers equally confirmed her commitment to raising the profile of mental health in the overall public health field and in political discussions, as she was aware that stigma continued to exist in this field and she conceded that policy makers did not pay enough attention to mental health.

The parallel session on informal carers also provided additional opportunities to highlight the impact of dementia on spouses, partners and families of people with dementia. The session which was co-chaired by Jean Georges, the Executive Director of Alzheimer Europe, included presentations by Robert Anderson, the President of Eurocarers, Ursula Brand, a Board member of EUFAMI, Matthias von Schwanenflügel from the German Ministry of Health and Jesús Norberto Fernández from the Spanish Ministry of Health and Social Affairs.

In the discussions, the conference recommendations were welcomed by all speakers who provided additional priorities for future action on a European and national level, such as:

• Increased research on carers through the European research programme,

• Recognition of the heterogeneous composition of carers and the need to differentiate the support provided to different groups of carers, such as carers of people with dementia or carers of children with mental health problems,

• Training and peer-support groups for informal carers,

• Provision of low threshold services such as support groups, circles of care and day care,

• Better collaboration between health and social care.

Closing the conference, Michael Hübel of the European Commission thanked all participants for their contributions and promised that the discussions and recommendations would be integrated into the European Pact for Mental Health. Other possibilities for European action were the launch of a European Year of Active Ageing and Intergenerational Solidarity, the inclusion of Mental Health in the Open Method of Coordination with Member States on Social Protection and Social Inclusion and the exchange of best practices in the field of mental health.
At Lundbeck we are dedicated to overcoming the challenges of Alzheimer’s disease. It is our goal to improve the quality of life for people living with the disease and for those who care for them.

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DEMENTIA AS A EUROPEAN HEALTH PRIORITY

The newly appointed European Union Commissioner for Health and Consumer Policy, John Dalli, speaks with Alzheimer Europe about European initiatives on dementia, the promotion of good health, cooperation with other Commissioners and the role EU Presidencies and Member States have in ensuring dementia is a health priority.

Alzheimer Europe (AE): Mr Commissioner, over the past couple of years, the EU has made significant progress in making dementia a European public health priority. Major EU initiatives, such as the European Commission’s Communication on Alzheimer’s disease and the Joint Programming of research activities for neurodegenerative diseases, are two of our political interests. Would you tell us how you plan to support both the Joint Action on Alzheimer's disease that is put forward in the Communication on Alzheimer’s disease and the Joint Programming Initiative?

Commissioner John Dalli: Addressing neurodegenerative diseases such as Alzheimer’s disease is important, in particular in the context of the ageing population. At the moment, the European Commission is working together with the Member States as part of a “Joint Action” on Alzheimer’s disease that is put forward in the Communication on Alzheimer’s disease and the Joint Programming Initiative.

I am pleased to say that this Joint Action, led by the Haute Autorité de Santé in France, is now up and running. Its main objectives are: (i) setting up a register of epidemiological data; (ii) a protocol defining criteria and practices for epidemiological data; (iii) assessing the effectiveness of existing preventive actions; (iv) a common definition of criteria for diagnosis and an assessment of diagnosis systems; and (v) improving practices that respect the rights of those who are cognitively impaired.

Furthermore, the European Commission launched a major research initiative this spring to tackle neurodegenerative diseases such as Alzheimer’s and Parkinson’s diseases. 24 European countries have decided to work together in an unprecedented collaborative research initiative to pool their scientific knowledge, medical expertise and social approaches.

The European Commission’s contribution does not end here. The Commission has also allocated EUR 136 million to 28 projects on neurodegenerative diseases as part of the 6th Research Framework Programme on 2002-2006. The Commission is currently supporting 34 projects worth EUR 159 million as part of the 7th Framework Programme.

Finally, I welcome the close cooperation between the European Commission and Alzheimer Europe. Together, we have made good progress for example through initiatives such as the "24 European countries have decided to work together in an unprecedented collaborative research initiative to pool their scientific knowledge, medical expertise and social approaches."
EuroCoDe (European Collaboration on Dementia) project, thanks to which we now have new data on the prevalence of dementia.

AE: The ageing of the population is a major and long-term challenge for the European health, social and research agenda. The health of elderly people and elderly care are closely bound together. How do you think your motto “Patients first, consumers first” will take up this challenge?

Commissioner John Dalli: "Patients first, consumers first" is indeed my guiding principle. I have a vision of Europeans living longer and healthier lives; and having a say in the policies that concern them.

I believe Europe needs to focus much more on the promotion of good health and prevention of diseases. This requires appropriate investment. I find it unacceptable that only 3% of health budgets are dedicated to prevention. Promoting good physical and mental health (such as encouraging education and learning throughout life) can help avoid cognitive decline leading to dementia.

High blood pressure, high cholesterol levels and smoking can also contribute to dementia. Given that half of all dementia cases have a vascular component, controlling vascular risks could help prevent dementia. More targeted research is therefore required to fully understand what a “healthy brain lifestyle” is.

This is an issue which will increase in importance alongside demographic ageing. I believe that identifying and promoting best practice in the early diagnosis of Alzheimer’s disease and other forms of dementia is necessary so that we can tackle the disease at the earliest possible stage.

AE: Will you enhance cooperation with other Commissioners to ensure all patients’ and carers’ perspectives are effectively taken into account, and to raise awareness about measures to prevent dementia, to better deal with the people affected and the training of the carers?

Commissioner John Dalli: Dealing with health issues such as Alzheimer’s disease requires joint efforts by a range of different policies in particular, social policy, research and also education. I therefore intend to foster synergies and work with other Commissioners in addressing important health issues such as Alzheimer’s disease.

With regard to carers, last December the Health Council specifically called for European action on healthy and dignified ageing, and highlighted the very important role of carers. In this context the European Commission could consider, for example, supporting training for carers.

AE: The quality of life of people with dementia and dignified ageing have been addressed by several EU presidencies. How do you plan to work with the next EU Presidencies to ensure healthy, active and dignified ageing is kept on the EU political agenda?

Commissioner John Dalli: I am delighted that EU Presidencies over the past couple of years have placed healthy ageing high on their political agendas. The French Presidency laid the foundations for this work with a conference on “The fight against Alzheimer’s disease and related disorders” and with Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and, in particular, Alzheimer’s disease. Ageing has remained a priority of subsequent Presidencies.
The Commission will play an active role in the conference on the societal impact of dementia which will be organised by the Belgian Presidency in Brussels this autumn. It will also host an Alzheimer Europe Conference in Luxembourg on 30 September this year.

AE: As you will have realised, the momentum around dementia has gathered speed. In May 2009, in your home country, the Malta Dementia Strategy Working Group presented recommendations for a national dementia strategy to the Parliamentary Secretary for the Elderly and Community Care. Would you consider stimulating the countries where no such strategy is considered? How would you enhance cooperation between European countries on dementia issues?

Commissioner John Dalli: Dementia is one of the emerging priorities of health programmes at national level. There are several ways in which Member States coordinate work at national level. Some countries have adopted national dementia plans. Others are focusing on research and public health cooperative schemes or on coordination with patients’ organisations.

In all cases, I am convinced that ongoing Joint Action on public health and Joint Programming on research will facilitate cooperation between Member States at European level.

AE: Commissioner, thank you very much for sharing with us how dementia will remain on the European health agenda. We look forward to supporting you in this endeavour for the benefit of the people we represent.

“Dementia is one of the emerging priorities of health programmes at national level.”
THE VIEW FROM LUXEMBOURG

Astrid Lulling, MEP, member of the European Alzheimer’s Alliance, talks with Alzheimer Europe about the challenges facing people with dementia in Luxembourg.

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

Astrid Lulling (AL): In my opinion, people with dementia and their carers face quite similar problems across Europe. Very often, the early symptoms of the disease are not recognised and the disease is therefore diagnosed quite late in the disease process. The impact of a diagnosis and the experience of dementia pose significant emotional and psychological challenges for the person with the disease and his/her immediate family and there is a continued need for adequate support, counselling, respite and services throughout the progression of the disease from diagnosis to end-of-life.

Where countries differ significantly though is in the type of support available to people with dementia and carers. And by support, I mean both the services that are available for people with dementia and the financial support for families caring for a person with dementia.

In both areas, I believe that Luxembourg has found some innovative approaches to ensure a better quality of life of people with dementia and their carers.

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?

AL: In Luxembourg, the demographic changes and the growing number of people were at the heart of the discussions at the time of the long-term care insurance. The government was fully aware of the need for a sustainable solution for the care and treatment of persons with long-term dependency needs.

These discussions continue of course today and all governments are currently discussing the impact of ageing populations on their economies. These discussions mostly take place in the context...
of the long-term sustainability of our pension and social security systems.

**AE:** Do you believe that Luxembourg will follow the example set by France, Norway, the Netherlands and England and implement a National Alzheimer’s Plan?

**AL:** The introduction of a “Plan démence” (dementia plan) is an element of the Coalition agreement which the government approved after the parliamentary elections in 2009. This dementia plan will be developed by the Ministry of Family in collaboration with the Ministry of Health.

I am therefore confident that Luxembourg will soon follow the example of these other countries.

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

**AL:** I believe that one of the key priorities in Luxembourg has to do with training and vocational training for all healthcare professionals to better equip them to care for people with dementia including professionals in acute and hospital care.

An area where Luxembourg is somewhat lagging behind is the area of guardianship systems. Our “tutelle” and “curatelle” systems are primarily geared towards protecting the person’s financial assets and I believe we can learn from other European countries where guardianship systems take a more comprehensive approach to promoting a person’s autonomy as much as possible.

Last but not least, I believe that our long-term care insurance needs to be continuously monitored to ensure that the system adequately protects and supports people with dementia at all stages.

**AE:** Finally, a last question on the need for a European response to the growing numbers 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?

**AL:** I have been a founding member of the European Alzheimer’s Alliance and I have been happy to support Alzheimer Europe’s Paris Declaration which calls for the establishment of a European Action Plan. I was also one of the first MEPs to sign Written Declaration 80/2008 which called upon the European Commission to become active in this field.

I am delighted that our pressure has already produced some concrete results. The Commission has now adopted a Joint Programming Initiative to promote European research in the field and a European Alzheimer’s initiative for cooperation on the public health aspects.

It seems clear to me that there should be great added value in European countries collaborating and pooling their resources in the field of research. Equally, there seems to be a self-evident justification for the exchange of good practices in the field of diagnosis, treatment, care and financing of social support between different European countries. We would all be able to benefit from a greater exchange rather than each country trying to find solutions in isolation.

May I add that the best recipe to avoid Alzheimer is to be active after 60, 70, 80 and 90 years. I think I am a good example to prove this is the case.
In this article, Jan Killeen, Director of Policy, Alzheimer Scotland, talks with Alzheimer Europe about the newly launched National Dementia Strategy in Scotland.

Alzheimer Europe (AE): Scotland’s first National Dementia Strategy was launched in June this year. How has Alzheimer Scotland raised awareness of the need for a strategic plan against Alzheimer’s disease in Scotland?

Jan Killeen (JK): Alzheimer Scotland has campaigned relentlessly over many years for successive governments to give high priority to dementia care. The impact of our work is at last bearing fruit. We believe our success is based on a strategic approach to creating change. We have targeted our energies and efforts to build up the pressure necessary to influence the hearts and minds of politicians. We have written and published well researched policy reports, we have established a strong voice nationally and locally, using the power of personal experience; and through always seeking a positive collaborative approach to all the stakeholder groups which we believe have a responsibility towards meeting the complex health and social care needs of people with dementia and assisting their families and communities to care for their loved ones at home for as long as possible.

We have very clear messages about our priorities which are based on what people with dementia and their families tell us is needed. We have gathered examples of best and worst practice. We take every opportunity to promote the value of specialist dementia care services. We have used all of this to brief politicians and raise awareness through the media.

The ability to demonstrate strong local support is an important factor in the minds of politicians, especially given the population profile of the voting public. We have increased our membership and engaged the support of individuals and branches to lobby local politicians. Last year we devoted resources to consulting on our Dementia Manifesto and Charter of Rights for People with Dementia and their Carers in Scotland, through a series of local events and a web-based questionnaire. We gathered the views of over 600 people. As a result of this success, the Scottish Government worked in partnership with us to carry out further local consultations on priorities for the strategy. The Scottish Dementia Working Group, a campaigning group run for and by people with dementia as part of Alzheimer Scotland has had an immense impact on the views of professionals and politicians about how services need to change if they are to meet the needs of individuals and their families.

But to take a step back for a moment – to before the last Scottish General Election. At that time, in 2006, we met the leaders of each of the main political parties and briefed them about why it is crucial to the well being of individuals, families and communities that they commit to improving dementia care in their party manifestos. The Scottish National Party (SNP) was the only party to do so.
In power the SNP has been as good as its word. In 2007 dementia care was given high priority, a National Dementia Forum was set up, chaired by the Minister for Health, and several initiatives were funded. Representation on the forum included our Chief Executive and a member of the Scottish Dementia Working Group.

In May 2009 the Minister, Shona Robison, announced that there would be a National Dementia Strategy for Scotland. Over the past year we have worked in partnership with the Scottish Government to shape the strategy through representation on each of the five strategy workstreams. The Strategy identifies 8 “Action Areas” of which top priority has been given to:

- the development of post-diagnostic support services;
- improved general hospital care.

Other key areas for action include:

- training – to improve staff skills and knowledge in both health and social care settings;
- the development and implementation of dementia specific care standards;
- targets for the reduction in the inappropriate use of antipsychotic drugs;
- integration of health and social care for people with dementia at a local level;
- improved data collection and information management for planning purposes;
- action to support dementia research.

We pressed successfully for the Strategy to be underpinned by the Charter of Rights for People with Dementia and their Families.

AE: What role can Alzheimer Scotland play now that the Strategy has been launched?

JK: The Scottish Government has established an Implementation and Monitoring group in which Alzheimer Scotland has representation through Henry Simmons, our Chief Executive. Henry is also chairing the group taking forward work on the training strand of the strategy; we also have representation on the group developing dementia specific standards. Alzheimer Scotland provides support to people with dementia and carers who are represented on these national implementation groups.

At a local level we are establishing Alzheimer Scotland – Dementia Action Teams which include people with dementia, carers, members and our staff. These teams aim to influence the development of Local Dementia Strategies and act as “watch-dogs”. This will enable us to report back to the National Implementation and Monitoring Group on progress from the perspective of people with dementia and their carers.

We are also supporting the implementation of improved dementia care through our work to empower people with dementia and their families. This includes producing a “human rights” handbook which will set out, in simple language, what rights and entitlements people with dementia and their families have within services e.g. from the doctor, from the social worker, in a care home or hospital.

A major problem is that the Dementia Strategy comes at the worst time for the economy and there is little new money to fund developments. We believe that the current social care system has many failings and leads to a waste of precious resources. The largest part of the health and social care budget for dementia goes to paying for expensive care in hospitals and care homes. We believe that the provision of low level, ongoing support

“A major problem is that the Dementia Strategy comes at the worst time for the economy and there is little new money to fund developments.”

Jan Killeen
after diagnosis, tailored to the needs of individuals, can delay the need for complex care packages or admission to long-term care by two years. We will be working with the health and local authorities to find more effective and efficient ways of supporting people in their own homes through demonstration projects. Some of these are currently being resourced through fundraised income for example, our community based Dementia Advisors and specialist Dementia Nurses based in general hospitals.

The Scottish Government is committed to producing an Annual Report on the Dementia Strategy and intends to commission a review of the strategy which will take account of progress and learning. The revised strategy is to be in place by 2013 for a further three years.

Despite the dismal economic climate, Alzheimer Scotland will continue to press for much needed additional funding to meet the growing demands arising from our ageing population. Dementia is not a normal part of ageing, it is an illness, and we will stick by our Dementia Manifesto – we have a Scottish Parliamentary General Election on the horizon in May 2011 and have much work to ensure dementia continues to receive top priority from whichever party comes to power!

“We will be working with the health and local authorities to find more effective and efficient ways of supporting people in their own homes through demonstration projects.” Jan Killeen

Irene Oldfather, MSP, Chair of the Scottish Parliamentary Cross-Party Group on Alzheimer’s, talks about the need for a national approach to tackle dementia and how patient groups can support the National Dementia Strategy.
Alzheimer Europe (AE): Why was there a need for a National Dementia Strategy in Scotland?

Irene Oldfather (IO): In recent years there has been a plethora of reports from organisations such as Alzheimer Scotland, the Mental Welfare Commission, and the Care Commission, which have highlighted poor practice, and inadequate staff training with regard to the care of elderly people with dementia. It has been apparent for some time that a national approach to tackling this issue was required.

AE: What would be the key issues to be addressed in the national plan from your perspective?

IO: First and foremost, raising standards of care in care homes, hospital wards and in the community is vital if we are to improve the quality of life of people with dementia.

Secondly, people with dementia and their carers do not all fit into the same box, and therefore it has to be recognised that they have differing and personalised care needs.

Thirdly, the Cross-Party Group on Alzheimer’s disease in the Scottish Parliament believes that changing attitudes and practices that deny people with dementia their rights is a key challenge facing the health and social care sectors. With this in mind, the Cross-Party Group launched a Charter of Rights for People with Dementia and their Carers, which now forms part of the National Dementia Strategy and should serve both as an instrument for enabling much needed culture change, and as a tool to empower people with dementia.

AE: What role can patient groups and non-governmental associations play in ensuring the Strategy is a success?

IO: If the Strategy is to be a success then it needs to be properly resourced and supported. Patient groups and non-governmental associations can play their part through lobbying to ensure that the aims of the Strategy are fulfilled. We have a responsibility to send out a message that we are with people who have dementia, that we will support them, defend them, give them a voice and ensure that they have the dignity and respect in old age that they deserve.

“We have a responsibility to send out a message that we are with people who have dementia, that we will support them, defend them, give them a voice and ensure that they have the dignity and respect in old age that they deserve.”

Irene Oldfather, MSP
European Parliament to write report on the European initiative on Alzheimer’s disease

In July 2009, the European Commission presented a Communication on a European initiative on Alzheimer’s disease and other dementias (COM(2009) 380 final). The Communication addresses four issues on which the Community action could help:

1. **public health**: prevention, early diagnosis and treatment of dementia,
2. **research**: understand the disease; enhance coordination in research and need for sufficient epidemiological data,
3. **social affairs**: share good practice regarding diagnosis, treatment and financing of therapies,
4. **legal**: patients rights, autonomy and stigma.

In June 2010, the European Parliament announced that it is now going to write an own initiative report in which suggestions could be made to improve the Communication. The Rapporteur is Marisa Matias (Portugal, GUE/NGL group), Industry Committee. The Shadow Rapporteurs are Elena Oana Antonescu (Romania, EPP), Nessa Childers (Ireland, S&D), Frédérique Ries (Belgium, ALDE) and Marina Yannakoudakis (UK, ECR), Environment and Health Committee.

The provisional timeline has been set as:

- The Rapporteur will work on her report in July.
- The draft report will be considered in the Environment and Health Committee on 27 October.
- The deadline for amendments will be 8 November at 12h00.
- The vote in the Environment and Health Committee is scheduled during the week 29 November-1 December.
- The vote in Plenary will take place in January 2011.

UK Government body launches quality standards on dementia

On 30 June 2010, the National Institute for Health and Clinical Excellence (NICE) presented its advice on quality standards on the care and treatment of people who have had a stroke, have dementia and/or have had venous thromboembolism (VTE).

The standards have been produced in collaboration with the National Health Service (NHS) and social care with the following audiences in mind:

- Patients and the public
- Clinicians
- Public health practitioners
- Commissioners and
- Health and social care professionals

The quality standards on stroke, dementia and VTE prevention make a number of key recommendations, including:

- Patients who have suffered a stroke should be offered a minimum of 45 minutes’ appropriate active therapy for at least five days a week for as long as they continue to benefit from it.
- All patients who have suffered a stroke are screened within six weeks of diagnosis, to identify mood disturbance and cognitive impairment.
- People with dementia receive care from health and social care staff that have been adequately trained in dementia care.
- Carers of those with dementia receive an offer of needs assessment to ensure they have the support they require.
• Patients/carers receive verbal and written information and advice on VTE prevention at the time of admission and discharge.

**UK announces review into the funding of palliative care**

The UK Secretary of State for Health, Andrew Lansley, announced, on 9 July 2010, a review into the funding of palliative care. The review will “look at how Government can make sure that the money intended to help look after people who are approaching the end of life is spent in the right way.”

The review, which will be chaired by Tom Hughes-Hallett, Chief Executive of Marie Curie Cancer Care, will make recommendations for a funding system that will cover care provided by the NHS, a hospice or any appropriate provider:

- which encourages more community-based care, so a patient can remain in their own home and,
- that will be fair and transparent to all organisations involved in palliative care.

A report is due in the summer of 2011.

**US Bill introduced on Alzheimer’s disease**

On 30 July 2010, new legislation was proposed in the US which aims to, inter-alia:

- increase the detection and diagnosis of Alzheimer’s disease and other dementias,
- provide access, information and support for newly diagnosed people with dementia and their families,
- provide health cover for people with Alzheimer’s disease and other dementias.

The proposals have been endorsed by the Alzheimer’s Association.

The Bill, entitled “Health Outcomes, Planning and Education Act, HR 5926” (The HOPE Act), was introduced to the House of Representatives by Congressman Markey (of Massachusetts) and will need to go through the US Parliamentary procedures (go to Committee, be voted on by the House, go to the Senate, if necessary go through a reconciliation process between House and Senate, then to the President) in order to become law.

**The State of California develops an Alzheimer’s Plan**

In May, the Alzheimer’s Association (US) and the State Alzheimer’s Advisory Committee led the development of a State Alzheimer Plan, which was the first time that policy and practices regarding Alzheimer’s disease had been addressed since 1987. It is being drafted by the Alzheimer’s State Plan Task Force, which is composed of representatives from the health care and provider community, researchers, academics, family caregivers, local and state governments, law experts for the elderly and Alzheimer’s association staff and volunteers. The Plan will be completed at the end of 2010 and will address:

- Care and Services for people with Alzheimer’s disease and related dementias
- Support for family caregivers
- Public awareness and education
- Creation of a dementia capable workforce
- End-of-life care

African-Americans are at higher risk for Alzheimer’s disease, but less likely than whites to have a diagnosis and this can result in a delay of treatment. To address this, a special consultation meeting (at the Town Hall) was arranged and online feedback was also possible.
The proliferation of counterfeit medicines poses a real and growing threat to patients around the world. Over a two month period in 2008 customs from the EU Member States seized more than 34 million* illegal medicines.

* Brussels, 16 December 2008 IP/08/1980 Customs: Millions of illegal medicines stopped by “MEDI-FAKE” action

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DEMENTIA IN THE NEWS

**Members' News**
A roundup of Alzheimer Europe’s members’ recent news.

**Dementia in Society**
A look at how dementia is reported and portrayed in literature, the arts and society.

**Living with dementia**
James McKillop, who has dementia, talks about the impact that the decision to stop driving has had on his life.

**Putting a face to commitment**
An update on recent appointments by national Alzheimer associations.
MEMBERS’ NEWS

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

**Greece: Workshops organised for the carers of people with dementia**

The Athens Association of Alzheimer’s Disease and Related Disorders organised educational workshops for relatives and caregivers of people with dementia in April. More than 250 caregivers attended and had the opportunity to talk with health care professionals about the problems and difficulties experienced trying to meet patients’ needs. Brochures and booklets were distributed to 1,500 people while 150 new members enrolled with the Athens Alzheimer’s Association.

The Association also participated in the “Students Week”, held at Aristotle University of Thessaloniki in May. The Association organised a workshop entitled “Supporting the caregivers – An updated view on coping with dementia”. The event was open to all members of the academic community but also to the general public and was attended by almost 220 people. The event proved to be a unique opportunity, both for students who were able to make presentations and learn more about dementia, but also for caregivers, who were given up-to-date information in order to deal with their strenuous role.

**Finland: The Finnish Alzheimer Society poster awarded the title of the “Best Health Promotion Material of the Year”**

The Finnish Centre for Health Promotion has a tradition of electing the Best Health Promotion Material of the Year. This year’s title was awarded to a poster by the Alzheimer Society of Finland. The message of the poster is built on a play of words: The Finnish word MUISTA meaning both the imperative form of the verb “to remember” and also the word “others”. All in all, the message is to encourage people to care for others, to get inspired about others, to worry about others – and to remember it all. The poster was designed by a small Finnish Advertising Agency called Maustamo.

**Portugal: Project launched to help children understand dementia and the Portuguese Alzheimer association campaigns to highlight the need for a national Alzheimer’s plan**

The Northern Branch of Alzheimer Portugal have embraced a new project, aimed to raise awareness in children regarding the importance of support for their grandparents in helping them to overcome memory problems and some daily life difficulties.

Based on the book “Memo, the baby elephant”, which was edited by Alzheimer Portugal, “The Storyteller – Kelembra has forgotten” is intended for children aged 6 to 10 years and is presented in a very creative and captivating way. Also involved are an Occupational Therapist and a Clinical Psychologist, from the Association, who answer the questions, which arise from the story, regarding Kelembra the grandmother and the attitudes of Memo comparing them with real life situations of children. These sessions aim to stimulate children’s social interaction, patience, affection, and provide a better understanding of the relations with grandparents.

In August, Alzheimer Portugal started a campaign to raise awareness of the need for a national Alzheimer’s plan. A spokesperson for Alzheimer Portugal explained that: “We may say that due to the economical and social crises we are now expe-
Dementia in Europe

The storyteller in Portugal

Experiencing, it is not a good moment to talk about it. But, firstly, the number of people with dementia will increase irrespective of such crises. Secondly, we can see dementia as an opportunity – an opportunity to create new jobs – for carers. This will mean reducing unemployment through the development of new skills and new training programmes, as well as the recognition of specialised care for people with dementia. Also, the setting up of care facilities, as with respite care, day care centres and home care, will create jobs. Additionally, these new jobs would reduce the financial burden of carers. We know that informal carers receive a much lower pension and may be prone to neglect their own health and find themselves in a worse financial position because of the fact they provide care. Alzheimer Portugal said: “there is no time to lose and there is no excuse for not acting now!”

Ireland: Calls made for the development of a national dementia strategy

In May, the Alzheimer Society of Ireland called for action to be taken to develop a national dementia strategy, streamline dementia care and increase funds. The Society launched an online campaign for public support calling on the government to:

- recognise Dementia as a National Health Priority and expedite its plans to develop a Dementia Strategy and implementation plan so that there can be better planning of services and policy as soon as possible. The Society has reaffirmed its commitment to working with all the relevant stakeholders to achieve this objective;
- take immediate action to streamline dementia care so that current spending on vital services can be more effective for families;
- increase the commitment of funding for community based services – such as those provided by the charity – in order to enable families to continue caring for their loved ones at home, with dignity, for longer.

Spain: Spanish Alzheimer association receives recognition for its quality management system

The national Spanish Alzheimer association, Confederacion Española De Familiares de Enfermos de Alzheimer y Otras Demencias (CEAFA), received accreditation for its quality management system, having successfully fulfilled the requirements laid down in the Ad Qualitatem certification process for Quality Management Systems and Social Responsibility in Patient Organisations (GCRP-25). A spokesperson from CEAFA explained: “The GCRP-25 certification is the recognition to a job well-done and recognition of the Association’s openness and orientation to the members and their objectives.”

The accreditation was received by CEAFA’s President, Emilio Marmaneu, and Executive Director, Jesús Mo Rodrigo on 8 July 2010.

Switzerland: Swiss Alzheimer association launched a series of information leaflets on dementia for different professions

To help specific professions understand dementia more, the Swiss Alzheimer association have launched a series of information leaflets. The first leaflet has been developed and is targeted at hair-
UK: Campaign launched to raise awareness of dementia and of the survey results on diagnosis

In May, the Alzheimer Society campaigned to raise awareness of dementia and highlighted the findings from a YouGov survey on dementia which found that after diagnosis:

- 31% of people would not know how to get information and support if they received a diagnosis of dementia.
- 14% of people would want support but would have no one to turn to.
- 74% of people would be frightened, 55% would feel depressed and 35% angry.
- Over one in four (26%) would feel lonely and one in 10 (10%) would feel ashamed.
- More than four out of five (82%) people would turn to a professional for support.

Other findings included:

- 37% of all respondents think people with dementia lose their personality. However, the Society said that evidence suggests that people with dementia can still have likes and dislikes, just the same as everyone else but it is often their dementia which prevents them from expressing themselves the way they used to.
- More than seven out of 10 (73%) people say they would turn to family or friends for support if they were diagnosed with dementia. However, the charity hears countless stories of people with dementia losing friends following a diagnosis. Research by the Department of Health earlier this year found many people fear and misunderstand dementia causing them to avoid people with the condition or treat them differently.

Ruth Sutherland, Acting Chief Executive of the Alzheimer’s Society, said: “Friends and family have a strong role to play in helping people with dementia. We must tackle the stigma surrounding the condition if we are to ensure people with dementia are treated with the dignity and respect they deserve.”

The findings were highlighted during the Alzheimer Society’s campaign, entitled “remember the person” which called on people to look beyond someone’s diagnosis of dementia and engage with them.

UK (Scotland): Report launched on social care for dementia

Alzheimer Scotland’s report, “Let’s Get Personal – Personalisation and dementia”, was launched at the end of April and received significant Scottish media coverage. The report demonstrated what can be achieved when people with dementia and their carers are given control over their own social care support.

The Chief Executive of Alzheimer Scotland, Henry Simmons, said: “This research shows that, when empowered to direct their own support, families effectively combine State resources around their own natural supports – creating truly personalised support. Our findings add weight to the Scottish Government’s drive towards self-directed support and point to a new way forward for dementia services.”
DEMENTIA IN SOCIETY

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

Play performed about Rita Hayworth’s life and struggle with Alzheimer’s disease

“Me, myself and Rita” is a one-actress play depicting the life of 1940s film star, Rita Hayworth which has been performed in many countries, the latest of which has been performed in Malta in May. Written and acted by Almog Pail, the play presents the contrast of Ms Hayworth’s glamorous stage life with that of her real life, in which she lived with early onset Alzheimer’s disease.

In an interview in the Malta Independent, Ms Pail described the impact Alzheimer’s disease had on Rita Hayworth saying, “Alzheimer’s disease struck Rita in her early forties, progressively ruining her life. She could barely memorise text, and it became impossible to work with her. The real tragedy was the lack of awareness of the disease at the time, leading people to confuse her condition with alcoholism and foolishness. She was thrown out of Hollywood, dying as a recluse in her New York apartment after a 20-year struggle. The power of this destructive disease and its symptoms played a big role in my decision to write the play. I have personally experienced it through a close family member, and it is not easy to grasp the deterioration of a person with so much knowledge and vividness. It is one of the most absurd phenomena of human nature.”

Charles Scerri, General Secretary of the Malta Dementia Society, who attended the play said: “I found the performance very refreshing and I believe it can be used as an educational tool in raising awareness. It was different and highly entertaining.”

British newscaster talks about his experience of his wife having dementia

British newscaster, John Suchet, spoke about his experiences since announcing that his wife, Bonnie, had dementia. After some encouragement by specialist nurse, Ian Weatherhead, he kept a journal about this journey, which he has decided to publish, calling it “My Bonnie: How Dementia Stole The Love Of My Life”. Originally Mr Suchet thought not many people would take notice of his announcing his wife’s dementia, but he explained his surprise as he “received hundreds of thousand of e-mails and letters from all across the world, all from carers saying that’s what we’re going through. Thank you for talking about it.”

Since the announcement made last year of Bonnie Suchet’s dementia, Mr Suchet has had to place her in a home. He said: “Bon went into full-time care last September and to say it was the most difficult decision I’ve ever had to take is a pathetic understatement.” He also described the day he took her into care and the fact he had to buy her a one way train ticket, saying: “It’s the little things that break you up.” Mr Suchet talked of his own struggle, having to adapt to his new life without his wife and said: “I’m starting a new life. Am I happy? Of course not. Am I excited? God, no. It was never supposed to be like this.”
James McKillop describes the impact dementia has had on his ability to drive.

Once you have passed your driving test, the law assumes you are able to drive unless you are disqualified for some traffic offences, or are judged no longer able to drive safely, due to certain illnesses, dementia being one. In my case I did have driving problems such as attempting to drive down the wrong side of a dual carriageway several times. I was positioned to turn right, indicating, ready to proceed, and it was only due to oncoming drivers flashing their headlights at me, that I was prevented from making that potentially fatal manoeuvre.

When the average person hits problems, they devise ways to get round them. I was no different. When I approached roundabouts I used to circle several times, feeling more and more dizzy and take the wrong exit in panic. I took a road and if it was not the correct one, I would do a U turn and return to the roundabout and repeat the process until I reached the exit I wanted. My wife Maureen refused to sit in the car with me, if I was driving. She stopped me taking my young son out with me in the car. She remarked that I kept weaving from one side of the lane to the other side then back again. I couldn’t seem to hold a straight line. This of course I strenuously denied. I was a perfect driver. I also started stalling the car. My clutch control was haywire. I blamed the clutch and had it replaced, then grumbled that the garage had done a poor job. I hit kerbs when turning corners, and I just couldn’t fathom out what on earth was going on. I did report my driving problems to my doctor, who advised me to stick to roads I knew very well.

It all became clear when I was diagnosed with dementia. My psychiatrist advised me to stop driving. But after coming to terms with my illness and receiving medication, I felt capable of driving, now I knew what was wrong. So I persisted with applying to continue to drive. I passed a test arranged by the DVLA. I was given a licence to drive for three years and continued to drive. I had no further problems. I no longer undertook long journeys as I, like many people with dementia, lose concentration when weary, or as the day goes on.

When I applied to renew my licence I fully expected to sit another test. I heard nothing for six months and on a Christmas Eve, I received a letter from the DVLA saying they were withdrawing my licence. What a Christmas spoiler! They did tell me I could appeal. My wife was in charge of the finances and refused to give me money for an appeal. I felt this was against my human rights and I should at least have been given another test. I later found out it was my GP who had provided the report which barred me. Yet the ironic thing is that after diagnosis by a Consultant, my GP had never mentioned the word dementia to me. She had no idea that I had been driving safely, and was unaware of my capabilities.

It is a bitter blow losing your licence. Your mobility is turned upside down. Your freedom to get up and go at a moment’s notice is gone. You lose your independence. You may have to rely on others to get about. You feel a nuisance if you ask and are reluctant to bother busy people. You may
feel infantilised, taken about like a toddler. It can be humiliating and demoralising. If lucky, you go in their chosen time but you are at their mercy. After all these years it still rankles to be a passenger. When I sit in a car, I still “drive”. I am a terrible front seat passenger and get tired on a journey, as I watch the road like a hawk. My feet get sore with driving. Why both feet? The imaginary clutch and brake! I can anticipate other driver’s manoeuvres and know when they are going to turn, when not indicating. I feel I can still drive, just give me a chance.

In conclusion, the medical person who comments on a person’s ability to drive, should be the person who sees and treats the person with dementia, if someone is not diagnosed until well on into the illness, they may clearly be unfit to drive and may realise it themselves. All others should be allowed to sit a test. If someone has their licence withdrawn without a test and they respond to treatment and medication, they should be allowed to sit a test, and abide by the result. I also strongly feel that in appropriate cases there should be a restricted licence available. For example, you could be restricted to say, daylight only, A or B roads, not motorways, your local town, X miles from your home, or so many hours a day.

Finally, do not expect someone to surrender their car keys without a fierce fight. If they do hand them over, feel lucky. Any suggestion to stop driving can be like a death knell. There may be bitter recriminations, making you feel guilty. How could you be so cruel and unfeeling? But remember, you have a duty of care towards them. It is heartbreaking making the right decision. You are tearing out their heart and demoralising them, but you will have them for longer, without the added worry of what grief/havoc they could cause in someone else’s life. Plenty of TLC (tender loving care) comes in handy. Understand their anguish. You are surgically removing a great part of their life. It will be a knock to their self-esteem. There can be an overwhelming sense of loss. What have I done to deserve this!

It is better to persuade them to cease driving out of love and concern for them and others, rather than have some official body wrenching your licence from you. After seven years, I am still resentful! I would love to drive again even if it was on a race track while not in use, field, forest road or a (deserted) sand/shingle beach. Research what is available to carry on life as before. Family, neighbours, friends and members of clubs may be able to offer lifts. Is there any other alternative to driving?

If someone is having driving problems and has not been diagnosed with dementia, remember other illnesses can mimic dementia. Get a proper assessment as soon as possible.

James McKillop highlights some problems one may experience when driving, including:

• Hitting the gate post when entering a drive. Hitting the kerb (curb).
• Being involved in “near misses”. Someone’s quick reactions prevented a bump.
• Being involved in low speed crashes, or worse, high speed collisions.
• Other drivers blasting their horns at you for some traffic violation, or gesticulating at you.
• Minor bumps and scrapes on the car body and/or the tyres, alloy wheels or wheel trims/hubcaps.
• Getting lost while driving and having to stop to work out where you are.
• Forgetting where they parked the car, or going home forgetting they came by car.
• Not slowing for pedestrians, who may have to jump for it.
• Going the wrong way down, a one way street (dual carriageway/roundabout already mentioned).
• Being unaware of running red lights/pedestrian crossings.
• Trouble trying to fit within parking lines/bays.
• Problems with driving in the dark, exacerbated when it is raining/

snowing. Note, a sight test may show the eyes are in order, but there may be a problem between what the eyes see and what the brain processes.
• Passengers squirming, sweating, dismayed, telling you to be more careful as you have just done something dangerous and were lucky to avoid a collision with someone or something.
• Passengers expressing disquiet at your driving, etc. People refusing to sit with you, when you are driving.
• Road rage at other drivers (who may be innocent, it was who/what caused the problem) from a normally placid person.
• Muttering how bad other drivers seem to be these days.
• Inside the car. Forgetting to look in the mirror, signal, dip headlights, monitor the fuel gauge and watch the speed, according to the local regulations.
• Outside the car. Forgetting to check the engine oil, tyre pressure, washer bottle, weekly check on car lights and fuel gauge. Do they run out of fuel at times or put in diesel instead of petrol and vice versa?
Alzheimer Society appoints new Chief Executive, Jeremy Hughes

Jeremy Hughes, currently Chief Executive of Breakthrough Breast Cancer, was appointed on 16 June 2010, as the new Chief Executive of Alzheimer’s Society, it was announced today. He takes up his appointment in November.

Making the announcement this morning, Alastair Balls, Chairperson of Alzheimer’s Society said: “This is a critical time for the Society as we implement government sponsored dementia strategies. Jeremy will provide the insight, leadership, campaigning skills, commitment and energy to drive this forward successfully.”

Jeremy Hughes has been at Breakthrough Breast Cancer for over five years, during which time it has become a recognised world leader in breast cancer research as well as a powerful influence on the NHS, ensuring better treatment for women regardless of where they live. This experience was particularly attractive to the board of Alzheimer’s Society as it continues to grow in both size and influence.

Jeremy Hughes said: “I look forward to working closely with all involved with Alzheimer’s Society to meet the challenges of the new decade. Everyone must play their part, to ensure that people living with dementia have better prospects in 2020 than today.

“I will be sad to leave Breakthrough, where it has been a privilege to steward the energy, enthusiasm, expertise and commitment of scientists, advocates supporters and staff. Our vision of a future free from the fear of breast cancer could have been seen as wishful thinking six years ago. Today that is no longer the case: It is now very achievable.”

Jeremy has also been instrumental in establishing National Voices, the umbrella body for over 200 health and social care charities, and currently is its Chair.

Paying tribute to Jeremy for his work at Breakthrough, chair of trustees Stephanie Monk said: “Everyone involved with Breakthrough will want to pay tribute to Jeremy, an excellent ambassador and enthusiastic promoter of our cause. His strategic stewardship and energetic commitment, brought real progress in realising the vision of a future free from the fear of breast cancer. We wish him well and confidently look forward to the next exciting chapter in Breakthrough’s unique contribution for people affected by breast cancer.”

New Chairperson, Marie Odile Desana, of Alzheimer France appointed

On 23 July 2010, Marie Odile Desana succeeded Arlette Meyrieux as the new Chairperson of France Alzheimer. In compliance with the statutes of the association, Ms Meyrieux stepped down as Chairperson in June. Ms Meyrieux and Ms Desana, as Vice President delegate since 2008, have worked closely together with “great trust and loyalty.”

Ms Desana became a carer herself when her mother was diagnosed with dementia in 1990 and became motivated to create an association of family caregivers in 2003 (Aix-en-Provence) and has been President of the association France Bouches-du-Rhône since 2004. She has identified the challenges ahead as taking care of people with Alzheimer’s disease by giving them a good quality of life, supporting the carer and protecting them from exhaustion as well as generating support for research and hope for families.

“This is a critical time for the Society as we implement government sponsored dementia strategies. Jeremy will provide the insight, leadership, campaigning skills, commitment and energy to drive this forward successfully.”

Alastair Balls,
Chairperson of Alzheimer’s Society
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