Antoni Montserrat presents the work of the European Commission on dementia.

Princess Mathilde of Belgium attends Alzheimer Europe’s 19th Annual Conference.

Alzheimer Associations throughout Europe celebrate World Alzheimer’s Day.

“The work to fight Alzheimer’s disease is key to reaching my goal during the Swedish Presidency.”

Maria Larsson, Swedish Minister for Elderly Care and Public Health.
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www.alzheimer-europe.org
Welcome
By Maurice O’Connell,
Chairperson of Alzheimer Europe

Prioritising dementia
Continuing our fight against dementia together
Annette Dumas, Alzheimer Europe’s Public Affairs Officer, reflects on the role which the European Alzheimer’s Alliance has played, and can continue to play, in the fight against dementia.

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The legal protection of people with dementia and their carers in the Czech Republic
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Debating dementia in the European Parliament
A report on the recent lunch debate entitled “European action on Alzheimer’s disease” held in the European Parliament and hosted by Frieda Brepoels, MEP (Belgium).

A common reflection on dementia ethics
Alzheimer Europe looks at the development of one of its new projects, the European Dementia Ethics Network which is supported by the German Ministry of Health.

Policy Watch
Promoting dignity across Europe
Jean Georges, Executive Director of Alzheimer Europe, reports on the Swedish Presidency Conference “Healthy and dignified ageing” and Maria Larsson, the Swedish Minister for Elderly Care and Public Health, talks with Alzheimer Europe about the role which the Swedish European Presidency can play for people with dementia and their carers.

National Dementia Plans: The Netherlands
Julie Meerveld and Marco Blom of Alzheimer Nederland talk about the new Dutch Dementia Care Plan.

A view from Ireland
Brian Crowley, MEP (Ireland), talks of the situation for people with dementia and their carers in Ireland.

Exchanging best practices on dealing with behavioural symptoms at home
Alzheimer Europe reports on the recent peer review held in Paris to examine the issue of coping with behavioural disorders associated with Alzheimer’s and other related diseases in the patient’s home.

Dementia in the News
World Alzheimer’s Day 2009
A snapshot of Alzheimer Europe’s member associations’ activities to celebrate 2009 World Alzheimer’s Day.

Spotlight on ... Malta, Croatia, Germany and the UK
Four of Alzheimer Europe’s members celebrate anniversaries this year. We take a look at their achievements and hopes for the future.

Faces behind commitment
Information on the two new directors appointed in Finland and Luxembourg as well as details of the Cross of Merit award which was given to Heike von Lützau-Hohlbein (Chair of the German Alzheimer Association) for her services to dementia.

Living with dementia
A moving account of how Hasse Hansson, who was diagnosed with dementia in 2006, and his wife Birgitta Ekmanner Hansson, live with dementia in Sweden.
In March of this year Alzheimer Europe hosted a lunch debate in the European Parliament calling for European action on dementia. Little did we realise then that our next lunch debate in September would be a summary of the (very fast) response by the European Commission to the European Parliament’s call for action to be taken on dementia. We report on the debate, which took place in September, and reflect on just how much can be achieved when all stakeholders (the Council, European Parliament, Commission and NGOs) are working in the same direction.

As the new European Parliament takes office, Annette Dumas reports on the achievements of those Members of the last European Parliament who came together to form the European Alzheimer’s Alliance. Their work was crucial in ensuring our call for European action was heard and we now call on the newly elected Members of the European Parliament to join the Alliance in order that people with dementia and their carers are heard at a European level.

In May Alzheimer Europe held its 19th Annual Conference, “Stars for Help”, in Brussels, Belgium. We report on the conference which included the findings from Alzheimer Europe’s recently completed European Collaboration on Dementia project. I am delighted that feedback on the conference was very positive and hope you enjoy our summary.

This issue also brings a wealth of information on various initiatives from around Europe. We have an update from Martina Mátlová, the Vice-President of the Czech Alzheimer Society, on the current laws in the Czech Republic for people with dementia. The national dementia plan in the Netherlands is looked at by Julie Meerveld and Marco Blom of Alzheimer Nederland. Brian Crowley (MEP, Ireland) considers the situation for people with dementia in Ireland and Alzheimer Europe reports on the well-received examples of best practice for people with dementia from France. Finally we have a very personal account of life with dementia in Sweden by Birgitta and Hasse Hansson in our “living with dementia” article.

The European Presidency is now held by Sweden and Jean Georges, Executive Director of Alzheimer Europe reports on the recent Swedish Presidential conference on dignified ageing. In addition, we speak with the Swedish Minister for Elderly Care and Public Health, Maria Larsson about how the Presidency can help people with dementia and their carers.

It brings me great pleasure to include snapshots of our member organisations’ events for this year’s World Alzheimer’s Day celebrations, held on 21 September. You will see that all across Europe Alzheimer associations worked hard to raise awareness and ensure that the debate on the issues which surround dementia are brought into the open.

Four of our members are celebrating anniversaries: Malta (5), Croatia (10), Germany (20) and the UK (30 years). It is fascinating to me to read about how each organisation has grown as well as how the scope of the work has developed.

I trust you will enjoy reading our fourth issue of the Dementia in Europe magazine and take this opportunity to, once again, call on all new MEPs to support us by becoming members of the European Alzheimer’s Alliance.

Maurice O’Connell, Chairperson
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CONTINUING OUR FIGHT AGAINST DEMENTIA TOGETHER

Annette Dumas, Alzheimer Europe’s Public Affairs Officer, reflects on the challenges which Member States face in relation to dementia, the achievements and role that the European Alzheimer’s Alliance has played in making dementia a European health priority and highlights how, by working together, we can continue the fight against dementia.

The work of Alzheimer Europe and the European Alzheimer’s Alliance in the European Parliament (EP) has led to a major shift in awareness about Alzheimer’s disease and a series of promising national or European initiatives.

Alzheimer’s disease: a daunting challenge for the Member States

According to Alzheimer Europe’s European Collaboration on Dementia project (EuroCoDe) (2005-2008) funded by DG Sanco – it is estimated that today some 7.3 million Europeans live with Alzheimer’s disease or another form of dementia.

Alzheimer’s disease, the most common form of dementia, is a neurodegenerative disease that slowly impairs memory, thinking, judgment and autonomy. It is the first cause of dependency in Europe.

The disease does not only affect the person with the condition: it is estimated that on average three persons in every family directly bear the burden. Consequently, 19 million Europeans are directly affected by the disease. The elderly and women are most affected. With the increase in life expectancy, the incidence of dementia will soar. The current forecasts project a doubling of the number of people affected by dementia every 20 years. This is a major challenge for health and social services as well as for the EU workforce.

Alzheimer’s disease is a costly disease: EuroCoDe estimated the total direct and informal care cost of Alzheimer’s disease and dementia to be EUR 21,000 per patient/year across the 27 Member States (56% for informal care).

Recent EU developments

- Launch of the European Alzheimer’s Alliance (2007)
- European Commission’s Communication on ageing well in the information society (2007)
- European Pact for Mental Health (2008)
- Council conclusions recommending a European Initiative on Alzheimer’s disease and a joint action in research (2008)
- European Parliament Written Declaration on the priorities in the fight against Alzheimer’s disease (2009)

To date, no cure has been found to halt or cure Alzheimer’s disease, only treatments that delay progression and improve the quality of life of the people with the disease and their carers.
Making dementia a European public health priority

The challenges of dementia had already been highlighted in EP Resolutions of 1996 and 1998. Unfortunately, these Resolutions remained without effect.

In 2006, Alzheimer Europe decided it was urgent to make Alzheimer’s disease a European public health priority. The organisation therefore launched its Paris Declaration which calls on European and national policy makers to make dementia a public health priority and focuses on four priorities: public health, medical and research, care and social support, legal and ethical issues. The Declaration immediately received the support of many European and national policy makers, health professionals and individuals.

“The challenges of Alzheimer’s disease became quickly clear to me. I had no hesitation in supporting Alzheimer Europe’s Paris Declaration”, said Astrid Lulling, Member of the European Parliament (MEP, Luxembourg) and founder of the European Alliance.

In 2007, she hosted an exhibition in the EP to raise awareness among her colleagues and EU policy makers about the challenges of Alzheimer’s disease and present the Paris Declaration. Many MEPs understood the importance of the initiative and expressed their support.

The same year, the European Commission EU health strategy ‘Together for Health’ identified the need to better understand neurodegenerative diseases such as Alzheimer’s disease within the context of an ageing population.

The European Alzheimer’s Alliance

In 2007, Alzheimer Europe secured the support of a handful of MEPs who agreed to set up the European Alzheimer’s Alliance. It is a non-exclusive, multinational and cross-party group of MEPs committed to support Alzheimer Europe and its members in making dementia a European public health priority and shaping the European health, social and research agenda.

“When Alzheimer Europe approached me to chair the Alliance, I immediately agreed. It was obvious to me that the European Parliament had to be a prime partner in making dementia a European Public health priority,” said Françoise Grossetête, MEP, Chair of the Alliance.

The European Alzheimer’s Alliance main mission is:

• to give the political signal that immediate and concerted action is needed at European and national level in the field of prevention, diagnosis and treatment of Alzheimer’s disease, research and social policies,
• to influence the European political agenda.
Alliance members actively raised awareness among their colleagues and the EU institutions, hosting focused lunch-debates or participating in interviews for Alzheimer Europe’s policy publications distributed to European and national policy makers.

They also contributed to national awareness, engaging in political initiatives or events organised by Alzheimer Europe’s associations. For example, Françoise Grossetête was invited to contribute to the French Alzheimer Plan. Others were invited to speak at meetings on dementia, took part in memory walks on World Alzheimer’s Day or had interviews featured in Alzheimer associations’ newsletters.

The Alliance’s major achievement was the adoption of EP Written Declaration 80/2008 on the priorities in the fight against Alzheimer’s disease in 2009. It was launched by five Alliance members and called on the European Commission and Member States to develop a European Alzheimer’s disease action plan with a view to promote pan-European research on the causes, prevention and treatment of Alzheimer’s disease and to improve early diagnosis.

This initiative forms a European framework for cooperation in public health and research. The idea is to share knowledge, capacities and resources for the benefit of people with dementia and their families and to date, 20 countries have demonstrated their willingness to participate in this initiative.

The Commission’s initiative on Alzheimer’s disease

In July 2009, the priorities of the Paris Declaration and EP Written Declaration received due attention: building on two Council recommendations of 2008, the European Commission presented its Communication on a European initiative on Alzheimer’s disease and other dementia and a proposal for a Council recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer’s, through joint programming of research activities.

“I am glad to hear the Alliance will continue during this mandate. I urge all MEPs to join us in keeping dementia on the European political agenda. It is our duty to tackle the challenges of the next generations right now”, said Maurice O’Connell, Chairperson, Alzheimer Europe.

Already, a good number of MEPs have renewed their commitment and we look forward to further increasing this level of support: the more members, the stronger the Alliance will be in defending people with Alzheimer’s disease, their carers, the medical community and the researchers’ priorities.
The Alliance work plan 2009/2014 will include the continued provision of well-documented information about dementia to national and European policy makers. Alliance members will host lunch-debates in the EP, the first was held on 29 September and presented the European Commission’s Alzheimer’s initiative; the next lunch debate will present Alzheimer Europe’s comparative overview of legislation relating to consent in healthcare decisions, advance directives and patient rights issues concerning the right to information and diagnosis.

The Alliance will work closely with EP Inter-groups who share some of Alzheimer Europe’s concerns, such as family, ageing and discrimination issues. Alliance members will also be invited to push the agenda at national level and participate in initiatives organised by our national associations, public events, interviews for a newsletter or articles in local papers.

Alzheimer Europe will work with the Rapporteurs to improve the Council proposal and all stakeholders to ensure the Commission’s initiative delivers concrete results.

The support of the European Alzheimer’s Alliance has been invaluable. “As a founder of the Alliance and one of its first Vice-Chairs, I have been impressed by the involvement of my colleagues and the success in raising awareness and shaping the political agenda. The Alliance has shown its potential as a key partner to Alzheimer Europe, its members and the EU institutions. Let’s continue our fight against dementia together”, encouraged Brian Crowley, MEP, Vice-Chair & founding member of the European Alzheimer’s Alliance.

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

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

First name __________________________ Last name ________________________________

Party __________________________ Country _______________________________________

Signature __________________________

Thank you for returning the completed form to Alzheimer Europe by mail to: 145, route de Thionville. L-2611 Luxembourg or faxing it to (+352) 29 79 72
Prioritising Dementia

Prioritising Dementia

The Conference motto “Stars for Help” sought to highlight the European Union’s (EU) significant advances in making Alzheimer’s disease and other forms of dementia a public health priority. Some 300 delegates (including, amongst others, people with dementia, carers, local, national and European policy makers and health care professionals) from over 20 countries participated. Opening the conference, Maurice O’Connell, Chairperson of Alzheimer Europe, highlighted important European developments, such as the EU French Presidency Conference dedicated to Alzheimer’s disease as well as the Council of Ministers’ recommendations at the end of 2008 which called upon the European Commission to promote European research into dementia and propose an EU initiative on Alzheimer’s disease. Mr O’Connell also reminded the audience that despite the current economic crisis, people with dementia still have needs which must be met and urged Member States to make dementia a public health priority and develop national dementia plans. This sentiment was echoed by Jeannot Krecké, Minister of the Economy, Luxembourg (and former Chairperson of Alzheimer Europe) who highlighted the plight certain groups face, such as patient groups, in the current economic climate and called on finance, health and social ministers to not forget such people.

STARS FOR HELP: WORKING TOGETHER TO MAKE DEMENTIA A EUROPEAN HEALTH PRIORITY

Alzheimer Europe’s 19th Annual Conference took place in Brussels, Belgium, on 28-30 May 2009. Supported by the attendance of Her Royal Highness Princess Mathilde of Belgium, the Conference was hosted by the Belgian Alzheimer Association (Ligue Nationale Alzheimer Liga) together with Alzheimer Europe. We take a look at some of the highlights.

The Conference motto “Stars for Help” sought to highlight the European Union’s (EU) significant advances in making Alzheimer’s disease and other forms of dementia a public health priority. Some 300 delegates (including, amongst others, people with dementia, carers, local, national and European policy makers and health care professionals) from over 20 countries participated. Opening the conference, Maurice O’Connell, Chairperson of Alzheimer Europe, highlighted important European developments, such as the EU French Presidency Conference dedicated to Alzheimer’s disease as well as the Council of Ministers’ recommendations at the end of 2008 which called upon the European Commission to promote European research into dementia and propose an EU initiative on Alzheimer’s disease. Mr O’Connell also reminded the audience that despite the current economic crisis, people with dementia still have needs which must be met and urged Member States to make dementia a public health priority and develop national dementia plans. This sentiment was echoed by Jeannot Krecké, Minister of the Economy, Luxembourg (and former Chairperson of Alzheimer Europe) who highlighted the plight certain groups face, such as patient groups, in the current economic climate and called on finance, health and social ministers to not forget such people.

Belgian policy makers also participated in the opening ceremony, calling for intensive collaboration (Pascale Pensis, representing Emir Kir, Minister for Social Policy and Family Affairs for Brussels), a national dementia action plan (Isabelle Paul, representing Didier Donfut, Minister for Social Affairs, Health and Equal opportunities for Wallonia) and further raising of public awareness (Laurette Onkelinx, Deputy Prime Minister and Minister for Social Affairs and Public Health (Belgium)). Laurette Onkelinx also updated the audience on the progress of the recently launched Belgian action programme on chronic diseases, which aims at improving the care and quality of life of patients and carers. This programme includes the creation of memory clinics and the introduction of specific training of GPs on diagnosis as well as carers’ training.

Prime Minister and Minister for Social Affairs and Public Health, Belgium). Laurette Onkelinx also updated the audience on the progress of the recently launched Belgian action programme on chronic diseases, which aims at improving the care and quality of life of patients and carers. This programme includes the creation of memory clinics and the introduction of specific training of GPs on diagnosis as well as carers’ training.
The focus of the first day’s plenary session was on how to improve the lives of people with dementia and their carers. Excerpts from the DVD “Een steen in je hand” (a stone in the hand), which was produced by a support group of people with dementia in Belgium, proved to be a powerful introduction to the Conference. This was followed by the writer and poet, Marleen Declercq, who has dementia, and Marina Thijssens, whose husband has Alzheimer’s disease, offering thought-provoking and memorable insights into their experiences living with dementia.

Dr Sigurd Sparr of the Norwegian Dementia Association (and Honorary Secretary of Alzheimer Europe) presented Alzheimer Europe’s recommendations for quality care at the end of life, explaining that the principles of the report are the autonomy and the dignity of the person and stressing the use of advance directives. He summarised the recommendations that favour good end-of-life care as i) access to palliative care, ii) the avoidance of hospitalisation and iii) the adjustment of certain environmental measures (such as light, furniture and noise). Dr Sparr explained that “palliative care” does not necessarily refer to the prolongation of life, rather the improvement of the quality of life of the person with dementia.

The term “quality of life” can be controversial and Michel Ylieff, Liège University, Belgium, explained some ways in which it has been assessed and ways which are used in an attempt to define it. “Good life”, “well-being”, “life satisfaction” and “happiness” are all ways in which quality of life has been described and in the search for a precise definition, various indicators (such as education level, physical and mental health) have been developed. Subjective and objective indicators fluctuate over time and in the particular case of dementia there are two obstacles: Firstly, the ability to answer questions about the quality of life by the person with dementia will diminish over time. Secondly, if a proxy assessment of the quality of life is made, for example by a carer, this can be highly subjective according to the disposition of the person exercising the proxy. Indeed, studies have shown that if a carer is depressed they may evaluate the person with dementia’s quality of life to be poor. Researchers have developed three considerations to establish a person’s quality of life: (a) the global level of the quality of life, (b) other factors that influence the quality of life and (c) the influence of the disease on the quality of life. Based on these considerations they have found that quality of life does not diminish homogeneously and is better when a person stays at home.

The second day’s plenary session was dedicated to the findings of Alzheimer Europe’s three-year project. Perhaps the most dramatic message was that a five-year delay in the onset of Alzheimer’s disease would decrease the prevalence by 50% and therefore any interventions that modulate the risk of Alzheimer’s disease can have a truly major impact on public health.
Prioritising Dementia project, the European Collaboration on Dementia (EuroCoDe). This European Commission funded project brought together a network of 36 researchers from over 20 different countries to develop consensual indicators on a number of important issues: Prevalence, prevention, diagnosis and treatment, non-pharmacological interventions, socio-economic cost and social support systems for dementia.

The findings from the working group on the prevalence of dementia in Europe was presented by Emma Reynish, European Alzheimer’s Disease Consortium, France. The key findings were that prevalence had not changed significantly over the last few decades but that there may have been an underestimation in the oldest age group and that prevalence is higher in the oldest old females. The group also found that with the increasing ageing of the population, the absolute numbers of individuals with dementia will continue to rise.

Lutz Frölich, University of Heidelberg, Germany, presented the results of the working group on the risk and prevention of dementia. Perhaps the most dramatic message was that a five-year delay in the onset of Alzheimer’s disease would decrease prevalence by 50% and therefore any interventions that modulate the risk of Alzheimer’s disease can have a truly major impact on public health. Factors identified include genetics, age, gender, cardiovascular factors and lifestyle. Whilst it is not clear whether a change in lifestyle in later life can influence the onset of the disease, high blood pressure and cholesterol were found to be risk factors. Protective measures were found to be unsaturated fatty acids, moderate alcohol intake and an active and social lifestyle. Dr Frölich said it was too simplistic to say that we can prevent dementia but better to say that we can modulate the risk though an active and healthy lifestyle.

An examination of existing guidelines on the diagnosis and treatment of dementia was carried out by Rupert McShane’s (Cochrane Dementia Group UK) working group. They found that the majority of the guidelines lack emphasis on the value of new diagnostic techniques and that there exists controversy on the use of cholinesterase inhibitors, the use of memantine and the use of antipsychotics and antidepressants. The group recommended the creation and use of European guidelines as these would help smaller countries and be less prone to any national bias.

Myrra Vernooij-Dassen, University of Nijmegen, the Netherlands and her working group looked at how to develop a set of quality indicators on psychosocial interventions in order to improve the professional practice of psychosocial care in dementia in Europe. They found that psychosocial interventions resulted in improvements of daily functioning, of the family carer’s sense of competence, and in the quality of life of persons with dementia and their family carers. Furthermore, they were shown to be cost effective. 15 quality indicators were discussed and validated via a pan-European pilot investigation.
The cost of dementia across the 27 Member States was estimated by the socio-economic working group, led by Anders Wimo, Karolinska Institute, Sweden. The group also found an urgent need to have better figures for informal care, which represents the highest proportion of any cost estimate.

The last presentation on EuroCode was given by Dianne Gove, Alzheimer Europe. Her working group had produced recommendations regarding the social support systems, which together with the socio-economic, psychosocial intervention and risk and prevention workgroups’ findings, have been published in Alzheimer Europe’s 2008 Yearbook. The social support group was led by Dianne Gove, Alzheimer Europe, Luxembourg and the recommendations include the call upon governments to set up national Alzheimer plans for dementia care, to respect the rights and dignity of people with dementia, to fund and organise social support and to ensure equal access to social support.

On the final day, presentations were made to illustrate how Member States have acted to improve the situation for people with dementia and their carers. Professor Joël Ménard, author of the French Alzheimer Plan, explained that the five-year plan evolved around a desire for better organisation of the services, more training, more research and more coordination. As there is a direct reporting line to the highest level (i.e. the French President, Nicolas Sarkozy), the French Plan is unique.

Mike Splaine, Alzheimer’s Association, USA, explained how dementia is being addressed in the US, which now has dementia state plans underway in 27 states. Mr Splaine talked of both the opportunity (such as jobs) but also threat (such as rising health care costs) that the baby boom generation has resulted in. He highlighted that people with dementia require between 30% to 300% more funding than people with other conditions, largely due to hospitalisation. To better address the issue, the focus within the public health sector is now surveillance, epidemiology and the prevention of chronic diseases. The English Dementia Strategy was launched earlier this year and Peter Ashley, who has dementia, presented the Strategy with pride, explaining the role that people with dementia had in its development.

Throughout the two days delegates had a wide range of parallel sessions from which to choose. A particularly popular session was the dementia policies session which illustrated various political developments as well as presenting how civil society could be instrumental in raising awareness among policy makers about the challenges of dementia.

Jeannot Krecké, Minister of the Economy, Luxembourg (and former Chairperson of Alzheimer Europe) highlighted the plight certain groups face, such as patient groups, in the current economic climate and called on finance, health and social ministers to not forget such people.
People with dementia require between 30% to 300% more funding than people with other conditions, largely due to hospitalisation.

Maija Juva, Norwegian Alzheimer Association, Norway, explained how her organisation was moving from a national dementia plan to a local reality. One initiative is their “from powerlessness to power” campaign which encourages sustained lobbying to ensure compliance with the National Plan. Ursula Naue, Department of Political Science, University of Vienna, Austria, highlighted the prejudice associated with dementia and called for collaboration between disability and dementia organisations. Whilst recognising their different political objectives, she emphasised their shared need to address stigma together. Paul-Ariel Kenigsberg, Fondation Médéric Alzheimer, France, gave a quick overview of the French Plan, acknowledging that in a rapidly changing environment, there was some uncertainty as to how the measures will be implemented. In addition, he aired concern about the sustainability of the 100% health coverage system.

Thanking all participants for such a diverse, inspiring and interesting conference, Sabine Henry (Ligue Alzheimer/Alzheimer Liga) wished all well in their lives and/or work with dementia. Maurice O’Connell closed the conference, reflecting on the tremendous value the two days had brought by sharing our experiences and learning about new ways in which to help people with dementia and their carers. He invited people to make a note in their diaries for the 2010 conference, which will take place in Luxembourg.

Feedback on the two days was positive. For the first time ever, Alzheimer Europe was delighted to be able to offer some complimentary tickets to people with dementia. One of the recipients, Stewart Cooper, who has dementia, said of the conference that he “was amazed at the number of people attending, representing so many institutions throughout Europe, including the UK”, finding “the depth of research by all these dedicated people (to be) amazing.” Other delegates said that they had found the programme to offer informative, interesting and comprehensive presentations. Indeed, some found that they were spoilt for choice with the parallel sessions as they said they would have liked to have been able to attend all of them! The bar for next year’s conference in Luxembourg is set!
In November 2009 the Czech Republic will celebrate the 20th anniversary of the Velvet Revolution. The democratic development which followed the Revolution has influenced all parts of our lives and, of course, legal regulations as well. A lot has been done in the field of legal issues in the Czech Republic during the last two decades, but there is still much to do. A case in point is the use of the instruments regarding incapacitation and guardianship for people with mental illnesses.

According to the European Collaboration on Dementia (EuroCoDe) prevalence data from 2009, there are more than 120,000 people suffering from dementia in the Czech Republic. Data from 2008 shows that in 2007 more than 24,000 people in the Czech Republic were deemed to be incapacitated and more than 4,000 Czech citizens had their legal capacity limited by the court. Although the detailed statistics of people who were deprived of their legal capacity are not available, the numbers do correlate with the feeling that family caregivers of people with dementia are rarely ready to commence court proceedings to deprive a person of such capacity.

The procedure itself is an important instrument that should protect the rights of people affected by mental illness (people with dementia are included in the category). Why is it that there are not so many people who undergo the legal procedure of incapacitation, and yet, according to the prevalence figures on dementia in the Czech Republic there are many people who could benefit from the protection this legal procedure affords? There might be different explanations for it. There is probably some psychological reason for choosing not to deprive an individual of their legal capacity, as taboo and stigma continue to be associated with mental illness and dementia. There is even a possibility that people do not have enough information about the procedure itself and/or might be afraid of dealing with courts. Another explanation might be that family caregivers do not consider such a process as necessary, being able to live their normal lives without the procedure. For example, caregivers can act for people with dementia in their financial matters quite easily by managing their finances in banks (via internet banking or by withdrawing cash from banking machines), etc. It seems that this situation improves the lives of caregivers and makes their care giving easier, but there is no proof that every family caregiver is able and willing to act in the best interests of the person with dementia. It is for this reason that we believe that the legal procedure of incapacitation should be used more widely.

Taboo and stigma continue to be associated with mental illness and dementia.
Some human rights experts argue that the concept of legal capacity and its deprivation has many problems that should be solved in order to protect the rights of people who are mentally ill and that it is even used too broadly in the Czech Republic. Some procedures that legal guardians are obliged to do (like annual accounting reports to courts) are, according to the experts, applied rather rigidly. The other problem, the experts claim, is the number of guardians; it seems as though, at the municipalities, there is a lack of guardians and this lack, coupled with the quantity of people for whom they must act, must have an impact on the guardians’ performance. Another issue is that of the control of the guardians; Czech courts are permanently overloaded and therefore their ability to fulfil their “control role” is quite debatable.

Another questionable issue is the possibility of starting the procedure of incapacitation without informing the individual whose capacity is in question. This procedure is possible in the Czech Republic. Although the official explanation for not informing the individual is not to harm him/her, it leaves the individual in question in a highly vulnerable position.

An opportunity exists for radical improvements to be made to the legal situation for people with dementia and their carers in the Czech Republic. This opportunity lies in the fact that the Civil Code, which covers the areas of legal capacity and guardianship, is due to be amended quite dramatically in the near future. Indeed there are signs that the issue of legal incapacity in particular is going to be comprehensively addressed and there is even going to be an instrument developed on the issue of advance directives and the appointment of guardians. We therefore have some slight optimism that the future development of Czech law will go some way towards helping people with dementia and their carers.

**THERE WERE 123,194 PEOPLE WITH DEMENTIA IN THE CZECH REPUBLIC IN 2006**

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NB. Prevalence figures for 30-59 age group from EURODEM (Hofman et al) and for 60+ age group from EuroCoDe (Reynish et al).
At European level, the calls to address the challenges posed by dementia have been answered at a phenomenal rate. On 29 September 2009, Frieda Brepoels, MEP (Belgium) hosted the lunch debate in the European Parliament on Alzheimer’s disease.

Frieda Brepoels, MEP (Belgium) hosted Alzheimer Europe’s seventh lunch debate in the European Parliament which was entitled “European Action on Alzheimer’s Disease”. She welcomed her fellow MEPs, their assistants, representatives from national Alzheimer associations and pharmaceutical companies, who were among the audience of nearly 60 participants. She spoke of her delight that calls for action by policy makers and Alzheimer Europe had been heard and had resulted in proposals aiming at concrete results for the 7.3 million people with dementia in Europe. The European Alzheimer’s Alliance, said Ms Brepoels, had been a prime partner in triggering initiatives.

Although Article 152 of the EC Treaty lays down a requirement for action to improve “public health, prevent human illness and disease”, it is the Member States which have the competence for health within their own countries. The Treaty does, however, offer some power to the Commission. Mr Montserrat also highlighted the second health programme but noted that the fourth pillar, regarding diseases, was not adopted and left the Commission feeling as though, in terms of dementia, that there was an “enormous mountain to climb.” However, a strong signal came from the French Presidency which resulted in two Council recommendations. This, together with the message from the European Parliament (in the form of Written Declaration 80/2008), resulted in action from the Commission even though action was not scheduled within the health programme.

Alzheimer Europe has played a fundamental role too, said Mr Montserrat, as he explained that Alzheimer Europe’s European Collaboration on Dementia (EuroCoDe 2005-2008) project provided essential information at European level on different aspects of dementia.

He also talked of the potential usefulness of the Directive from the European Parliament and Council on the application of patients’ rights and cross-border health care, the adoption of the 2008
European Pact for Mental Health and finally, the best practices identified in the recent Peer Review on Alzheimer’s and other related diseases: “coping with behavioural disorders in the patient’s home”.


The Commission also adopted a proposal addressed to the Council entitled “Proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer’s, through joint programming of research activities” details of which would be given by the next speaker, Maria-José Vidal-Ragout.

Explaining that the Communication consists of practical measures to be taken, Mr Montserrat said that the Commission will:

a) Provide Alzheimer Europe with an Operational Grant in 2010
b) Commit to “joint action” with Member States, whereby each party engages to implement the Communication. This will be financed by the 2010 Health Programme
c) Lay the ground work for the Joint Action by organising a panel of experts on Alzheimer’s disease and other dementias in December 2009
d) Support and highlight the 20th Alzheimer Europe Conference in 2010.

Mr Montserrat detailed the objectives of the Joint Action which include:

a) Ensuring that existing policies incorporate the “dementia dimension” (i.e. to ensure that it is explicitly mentioned)
b) The production of a set of recommendations on prevention, improved epidemiological data on Alzheimer’s disease and other dementias
c) The use of the European Health Examination Survey to provide new data on prevalence of people with early cognitive deficiencies. This survey will be carried out on more than 200,000 people and the Commission will introduce a module instrument on “cognitive decline” to determine the long-term trend of decline
d) Mapping the existing and emerging good practices related to the treatment and care of people with Alzheimer’s disease and other forms of dementia
dementia and the improvement of the dissemination and application of such practices and
e) The establishment of a European Network of
eight and dignity of people with dementia.
Mr Montserrat explained that at present the difference in this area between Member States is
too great, for example access to medicines, care
and treatment varies from country to country.

The 3rd Health Programme (2014-2020) must
reintroduce the disease dimension if long-term
action is to be guaranteed by the Commission.
Mr Montserrat emphasised that “it is extremely
important that common issues, such as social,
health, ageing and dignity should converge and it
is something I think we can do.” Concluding his
presentation, Mr Montserrat again spoke of his
delight that the Commission could now continue
to work to help address the challenges dementia
creates and was grateful that momentum to act
had been built by the Council, European Parlia-
ment, Commission and NGOs all working in the
same direction.

The Recommendation invites Member States to establish:

• A common vision of how cooperation and coor-
dination at EU level can help us to understand,
detect, prevent and combat neurodegenerative
diseases, in particular Alzheimer’s disease
• A Strategic Research Agenda establishing medi-
um to long term research needs and objectives
in the area of neurodegenerative diseases
• A management structure to monitor the imple-
mentation of the Strategic Research Agenda.

Ms Vidal-Ragout then explained that neurode-
generative diseases are a major issue for public
health, with dementia being the most prevalent
and some 19 million European being directly
affected by it, constituting a formal and informal
cost bill of EUR 130 billion. The focus on these
diseases arises too from the fact that there is a
growing priority for research funding in Europe
as well as the EU Research Framework Programmes
giving growing attention to neurodegenerative
diseases. But perhaps the most encouraging
reason that focus falls on this area is the belief
that better coordination would greatly benefit
research efforts by pooling skills, knowledge and
resources.

Ms Vidal-Ragout proceeded to show how these
issues are to be addressed by the Commission by
the implementation of a pilot joint programming
initiative, whereby Member States engaged volun-
tarily to the extent and in which areas they wish
in order to develop a common vision on how to
address major societal challenges. To date, there
are some 20 countries participating. If this initia-
tive is successful, the pooling of information and
resources should enable the EU to make very practical advances, for example by developing:
1. An assessment regarding the effectiveness of various treatments and the development of new ones
2. Early diagnostic tests
3. Large cross-border population studies to address risk factors
4. Databases
5. Standardised diagnostic criteria and assessment tools throughout Member States
6. A way of sharing knowledge on health care systems.

Ms Vidal-Ragout ended her presentation by saying to the audience that the one main reason she had attended today was to help the audience realise “you are an important player – we are looking for your support”.

Ms Brepoels then opened the floor for discussion. Florence Lustman, MEP (France), Coordinator of the French Alzheimer Plan congratulated the Commission on their brilliant work and speed in reacting to the European Parliament’s proposal. She suggested that regular communication be made to Member States and citizens to ensure that they are also aware of the practical results for all Europeans which can be achieved in a very short period of time.

In answer to Ms Brepoels question regarding the term “early diagnosis”, Antoni Montserrat said that in the UK, it had been found that if diagnosis could be made earlier, that later costs could be reduced by up to 20%. He said that at present there is no magic tool to diagnose dementia. Maria-José Vidal-Ragout also added that dementia can be difficult to diagnose as the symptoms can be very different and even hidden by other factors such as depression.

Sigurd Sparr, Honorary Chair of Alzheimer Europe said he was impressed by the work of the Council, Parliament and Commission and asked what role Alzheimer Europe could play. Mr Montserrat said that all parties had recognised and were in no doubt that Alzheimer Europe is a privileged partner in that it has the competency, professionalism and capacity to carry out the work required and that the Commission needs the participation of Alzheimer Europe. Ms Vidal-Ragout added that Member States should take the lead in the joint programming initiative, but that there is a role for Alzheimer Europe to contribute to the creation of the management structure as well as to provide focus for the participating experts.

Florence Lustman spoke of the importance of people receiving a diagnosis of Alzheimer’s disease. She said that she believes that GPs need to be more informed about dementia as they are essential to
help diagnose people with dementia. Ms Lustman encouraged people who have the symptoms of dementia to obtain a diagnosis in order that they receive the wide support that is available.

Pekka Laine, member of the Alzheimer Europe Board, talked about the Finnish prevention programme entitled “Save your brain” which gives information to the public on ways in which to treat risk factors. This programme has received governmental support.

Dirk Sterckx, MEP (Belgium) asked Mr Montserrat and Ms Vidal-Ragout if there was a link between Alzheimer’s disease and other types of dementia. Mr Montserrat said that Alzheimer’s disease accounted for between 50 to 70% of dementia and that it was impossible for the Commission to have a different policy for every type of dementia, but that it was possible to find the similarities between the diseases.

Jean Georges, Executive Director of Alzheimer Europe, asked for clarification on how widely the Commission defines “Europe”. Ms Vidal-Ragout said that whilst it was not possible to be open to all countries, it was important to be open to collaboration and cited the advances made in the United States and Australia.

In answer to Frieda Brepoels question on funding, Maria-José Vidal-Ragout said that the funding levels vary widely and it is better to focus on the “the most efficient use of resources”, advocating the pooling of knowledge.

Jean Georges echoed Florence Lustman’s earlier comments regarding the speed at which action had been taken at a European level. In March Alzheimer Europe had held a lunch debate calling for a European action plan on dementia and now, just six months later we find that the European Parliament, Council of Ministers and the Commission had responded. He extended his gratitude to the European institutions for their swift action on behalf of the 7.3 million Europeans with dementia. Mr Georges warmly thanked the host, Ms Brepoels, her assistant and Mr Montserrat and Ms Vidal-Ragout for their highly informative presentations. Ms Brepoels closed the debate by saying that the Commission proposals have raised many expectations for people with dementia and that the European Parliament would be vigilant to ensure the work proceeds. She concluded by once again asking fellow MEPs for their support in joining the European Alzheimer’s Alliance as well as asking them to rally support from their extended colleagues.
A COMMON REFLECTION ON DEMENTIA ETHICS

Thanks to the support of the German Ministry of Health, Alzheimer Europe will be able to start with the development of a European Dementia Ethics Network.

At last year’s French Presidency Conference on Alzheimer’s disease, President Sarkozy highlighted the need for Member States of the European Union to have an exchange on some of the ethical challenges posed by dementia and advocated the creation of a European network for this purpose. This recognition of the importance of the ethical aspects of dementia was echoed in the European Commission’s Alzheimer’s initiative and a common reflection on dementia ethics is highlighted as one of the priority areas for European collaboration.

In parallel to these developments, the German Health Ministry and Alzheimer Europe held a number of meetings to explore the setting up of a European Dementia Ethics Network and in September 2009, Ulla Schmidt, German Minister for Health announced that the implementation and setting up costs of such a network would be supported financially with a grant of EUR 60,000.

The initiative dates back to 2008, when Michael Schmieder, the director of Sonnweid, a care facility in Switzerland, put forward the concept of such a network based on the need for family and professional carers to get support when faced with ethical dilemmas. At a workshop in September 2008, the concept was discussed in more detail with ethics experts from various European countries (see Issue 2 of the Dementia in Europe Magazine for more details) and was welcomed by all participants.

Thanks to the support of the German Ministry for Health, Alzheimer Europe has now set in motion the first steps towards the establishment of greater European collaboration on dementia ethics:

- Dianne Gove, the information officer of Alzheimer Europe has been appointed as coordinator of the European Dementia Ethics Network,
- a number of key ethics experts, such as François Blanchard from France, Andreas Kruse from Germany and Sigurd Sparv from Norway have agreed to take part in the Ethics Advisory Board set up to monitor the activities of the network,
- the first priorities of the network have been decided and the network will focus on the ethical implications of new technologies, as well as some of the ethical challenges (consent, placebo research, genetic testing) posed by dementia research,
- the new website of Alzheimer Europe will include a specific section dedicated to dementia ethics and information on some of the ethical approaches to dementia has already been included on the website.

Dianne Gove, the coordinator of the network summarised the main objectives as follows: “The aim of the network is to foster European dialogue around the ethical issues in dementia and promote a better understanding of different ethical approaches, create a European reference library of existing ethical positions, draft reports on specific ethical issues such as the use of new technologies and highlight areas where a consensus or differences exist.”
Promoting dignity across Europe
Jean Georges, Executive Director of Alzheimer Europe, reports on the Swedish Presidency Conference “Healthy and dignified ageing” and Maria Larsson, the Swedish Minister for Elderly Care and Public Health, talks with Alzheimer Europe about the role which the Swedish European Presidency can play for people with dementia and their carers.

National Dementia Plans: The Netherlands
Julie Meerveld and Marco Blom of Alzheimer Nederland talk about the new Dutch Dementia Care Plan.

A view from Ireland
Brian Crowley, MEP (Ireland), talks of the situation for people with dementia and their carers in Ireland.

Exchanging best practices on dealing with behavioural symptoms at home
Alzheimer Europe reports on the recent peer review held in Paris to examine the issue of coping with behavioural disorders associated with Alzheimer’s and other related diseases in the patient’s home.
The Swedish Presidency Conference on healthy and dignified ageing took place in Stockholm from 15 to 16 September 2009 and brought together representatives of ministries and civil society from 27 European countries. Jean Georges, Executive Director of Alzheimer Europe, reports on the two-day Conference.

A key goal of the Swedish Presidency of the European Union was to promote the dignity and quality of life of elderly persons in Europe and a conference was dedicated to this subject in order to explore how to enhance the cooperation and coordination between the health and social sectors at EU, national and regional level.

Maria Larsson, Swedish Minister for Elderly Care and Public Health, opened the conference by stressing how our perceptions of age had undergone profound changes over time and that the ageing of European populations would lead to an increased demand for social care. All European healthcare systems, said Ms Larsson, are therefore faced with the challenges of how best to promote health, whilst at the same time providing high quality services respecting the dignity and individual wishes of people in poor health. She stressed that “Europe can deal with the challenges of an ageing population”.

Jérôme Vignon, Director, DG Employment, Social Affairs and Equal Opportunities, European Commission, welcomed the Presidency initiative to dedicate a conference to healthy and dignified ageing and reminded the audience of previous EU Presidencies which had highlighted similar themes, such as the Luxembourg Presidency’s focus on the economic, social and ethical aspects of long-term care, the Slovenian Presidency Conference on intergenerational solidarity or the French Presidency initiatives in the field of Alzheimer’s disease and related disorders.

Who cares?

Having been commissioned by the Swedish Presidency to prepare a discussion paper for the conference, Mr Bernd Marin, the Executive Director of the European Centre for Social Welfare Policy and Research presented the key findings of the “Who cares?” report. His first observation was that elderly care and long-term care are relatively new areas of interest that are only now emerging. It has unclear boundaries and a high degree of fragmentation between the health sector and social care. There are also huge differences between Member States as to the scope and quality of services.

Within the EU, only 3.3 percent of elderly persons live in residential housing, whereas the US has a much higher percentage of people in institutions. Europe also has a very high degree invested in home help and home health care. The coverage of institutional care is not increasing in any European country. At the same time, the 3.3 percent of persons living in residential care take up more...
than half of available resources and Bernd Marin questioned the sustainability of this allocation of resources in the long term.

Another topic that he dealt with in his presentation was about carers, both formal and informal. To an increasing extent there is a shortage of skilled care workers. Without the important work that family members and friends are doing, he stressed that systems could break down. He also highlighted the growing black market in social care, with hundreds of thousands of migratory workers travelling from the eastern regions of Europe working in families as carers and this in many cases without a working permit, regulated working hours or pension rights.

Despite these disparities between European countries, he concluded that “it is obvious that countries could learn a lot from each other – and also from other parts of the world. Even comparatively poor countries may devote a lot of resources and have innovative ideas for the elderly care sector.”

**Focus on dementia**

Quoting the recently released prevalence figures of the “European Collaboration on Dementia – EuroCoDe” project, Prof. Bengt Winblad, Director of the Alzheimer’s Disease Research Center of the Karolinska Institutet highlighted the need to include the 7.3 million Europeans living with a form of dementia in our discussions on dignified ageing.

In particular, he felt that the recently adopted national guideline for good dementia care in Sweden provided some important pointers on how to develop a “caring philosophy” which is person-centred and where staff competencies and staff conditions are key to promoting diagnostic and prognostic thinking in order to avoid future complications. Presenting some of the latest research with regard to prevention and treatment of Alzheimer’s disease and other dementias, he concluded by calling for more European investments in dementia research and the need to reduce the gap and time between research and clinical practice.

A number of parallel workshops were organised during the conference with one focusing specifically on Alzheimer’s disease. This workshop was chaired by Florence Lustman, the coordinator of the French Alzheimer’s Plan who reminded the audience that the true number of people affected by dementia in the European Union was 19 million if the carers and family members of people with dementia were included.

During the workshop, Nick Fahy, Head of Unit for Health Information at the European Commission, presented the four pillars of future European action on dementia which will focus on prevention and early diagnosis, better coordination of European research, exchange of good and best practices in the field of care and collaboration on ethics and fundamental rights of people with dementia.

“Europe can deal with the challenges of an ageing population.”

Maria Larsson
Sylvie Legrain, Professor of Geriatrics at Hôpital Bretonneau, provided a report on the peer-review organised by the European Commission and hosted by France on the subject of how best to deal with behavioural problems at home. The key recommendations resulting from this exchange between Member States concerned the role of general practitioners and the need for better training of health care professionals, better information to informal carers and campaigns to address the stigma perceived by society. A fuller presentation of the peer review process can be found on page 35 of this magazine.

I outlined some of the findings of Alzheimer Europe's Lawnet and EuroCoDe projects which had highlighted differences between European countries in social support systems or the legal protection of people with dementia and had identified some existing best practices in this field. To improve the autonomy and self-determination of people with dementia, I highlighted the clear need for closer collaboration between Member States on care approaches and social support systems, as well as on the legal and ethical aspects of dementia. Thanks to the support of the German Ministry of Health, Alzheimer Europe was able to start with the development of a European Ethics Network which is presented in more detail on page 22 of this magazine.

**Dementia knows no borders**

The second day of the conference was opened by a highly personal testimony of H.M. Queen Silvia of Sweden who recounted how her mother,
diagnosed with Alzheimer’s disease, turned to her complaining “I forgot my life”. She stressed that at the time of diagnosis 15 years ago, little training was provided for professional carers which gave her the vision of creating “Silvia-hemmet”, a foundation which provides training programmes for nurses and assistant nurses in dementia care. The guiding philosophy of any care, she said, should be the best quality of life for the person with dementia and the family throughout the whole disease. According to H.M Queen Silvia, dignity is not just about treatment, but about attitudes and she concluded that “informal carers also require recognition and support for their own health and quality of life, which I appreciate from my own experience”.

During the high-level round-table discussion at the close of the conference, Maria Larsson thanked the Queen for sharing her personal experience and convictions. With elderly care already representing over 50% of healthcare budgets, all European societies are faced with the challenge of how to expand this sector whilst improving the quality of care at the same time. The Swedish

AE: During the EU Presidency Conference on healthy and dignified ageing, you mentioned that Sweden had adopted a new guideline for dementia care. Could you highlight the key recommendations of this guideline for our readers?

ML: The national guidelines for dementia care gives recommendations on how municipalities, county councils and private care providers together can satisfy the care needs of people with dementia and the support to their close family and friends. The guidelines are the basis for decision making and for regional and local work with developments in the field of action as well as a support to professionals. The most important recommendations are about person-centered care, multi-professional work, long-term education efforts, how to make early diagnoses, pharmaceuticals to be used in connection to Alzheimer’s disease, follow-up to the disease, special day care and special housing for persons with dementia and support for informal care givers. Other important areas are care of, pharmaceuticals for and investigation of behavioral and psychological symptoms connected to dementia.

AE: One of the strong points of the conference was the clear call for greater European collaboration on ageing and dementia. Which are the areas where you would expect the greatest results for people with dementia and their carers?

ML: One of the outcomes of the conference was, as you mentioned, that it showed the need for enhanced EU-cooperation in the field of healthy and dignified ageing. It is evident that we have a lot to learn from each other and a lot to gain from greater cooperation. This is very clear in the field of dementia and I believe a few points were particularly stressed. The need for education and support for formal and informal carers, the need for a more patient centered care for persons with dementia and the need for cross-professional and cross-sectoral cooperation among people working with persons with dementia including the need for the health and social sectors to work closely with civil society. Hopefully, we will reach council conclusions on healthy and dignified ageing in the coming EPSCO-council that will oblige both EU Member States and the EU Commission to cooperate more closely on these matters.
“Informal carers also require recognition and support for their own health and quality of life, which I appreciate from my own experience.”

H.M. Queen Silvia

Minister underlined that this would only be possible by adopting a preventive approach aimed at promoting health, by enhancing the collaboration between the health and social sectors and through a stronger focus on the individual by increasing free choice and finding ways for older people to influence their own lives. Her aspiration was to “put elderly issues permanently on the EU agenda”.

Further challenges and opportunities were identified by the other participants in the round table. Mr Marian Hösek, Deputy Minister of Labour and Social Affairs of the Czech Republic, focused on the growth of the labour market in the social care field with an increasing demand for skilled staff and the need to review existing education systems to promote possibilities for requalifications and life-long learning. He believed that particular attention should also be paid to the use of new technologies as an important part of comprehensive solutions for care of the elderly.

Ms Melinda Medgyaszai, Hungarian Secretary of State for Health, emphasised the lack of communication between health and social sectors and called for social care knowledge to be included in medical education, to find ways of better valuing social care professions and a better recognition of geriatrics as an important medical speciality.

Reiterating the fact that an ageing society represents an economic opportunity, Ms Lenia Samuel, Deputy Director-General of DG Employment, Social Affairs and Equal Opportunities of the European Commission, described the care sector as an important growth factor for employment with 82% of new jobs in this sector having been taken by women and jobs being less dependent on the fluctuations of the economy. At the same time, she recognised that access for all to high quality care, with a preference for home care or care in the community, remains problematic.

Speaking on behalf of the forthcoming Spanish EU Presidency, Ms Pilar Rodríguez, Director General of the Institute for the Elderly and Social Services (IMSERSO), promised a continuation of the focus on elderly issues at a European level during the next year. She highlighted some of the recent initiatives of the Spanish government to promote the dignity of elderly in her country, such as the introduction of a law on personal autonomy and a long-term care dependency system, a campaign to break social isolation of the elderly and an outreach programme for rural areas. She informed us of a White Paper on the elderly which is currently under preparation and will be presented during the Spanish Presidency Conference.

Mr Fabrice Heyriès, Director General at the French Ministry of Health, presented some of the key innovations introduced through the French Alzheimer’s Plan and highlighted the development of a common European research agenda on Alzheimer’s and the use of the open method of coordination and peer reviews as key elements for the definition of a common European basis for standards and principles in the field of elderly and dementia care.

Thanking her colleagues, Maria Larsson expressed her great satisfaction with the fruitful discussions of the previous two days and concluded the conference with the statement that “there is a need for strengthened collaboration on ageing”.

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NATIONAL DEMENTIA PLANS: THE NETHERLANDS

Julie Meerveld and Marco Blom of Alzheimer Nederland talk about their organisation’s involvement with the National Dementia Programme (2004-2008) and, together with Alzheimer Europe, take a look at the new Dutch Dementia Care Plan.

In 2008 the four-year Dutch National Dementia Programme (LDP) came to an end and the evaluation of this, together with the call for improvements to the care provided to people with dementia (presented as the “Dementia Delta Plan” to the Dutch Lower House by the Member of Parliament, Agnes Wolbert), highlighted how better provision of care for people with dementia and their carers may be achieved. As a result, and in order to build on earlier progress made within the context of the LDP, Dr J Bussemaker, the State Secretary of Health, Welfare and Sports, announced the “Dementia Care Plan” (DCP).

The National Dementia Programme (2004-2008)

“Alzheimer Nederland” both initiated and participated in the National Dementia Programme. Alongside the Ministry of Public Health, Welfare and Sport and the Netherlands Institute for Care and Welfare (Vilans), Alzheimer Nederland coordinated a programme for regional providers of care, welfare and treatment of dementia to improve dementia care from a client’s perspective. The results were impressive: 90% of the country participated with 206 improvement projects fitting the needs of patients and families and 50 “beauties” were selected for their good results from a client’s perspective. Providers of care, welfare and treatment worked together with volunteers of Alzheimer Nederland. The wishes and demands of families of patients in 160 focus groups were compiled by Alzheimer Nederland using the “LDP-questionnaire” (N=900). Nevertheless, more incentives were necessary to integrate help for people with dementia and their families from the beginning until the end of the dementia.

The Dementia Care Plan

In response to the outcome of the earlier LDP, as well as the calls for improvement from Alzheimer Nederland to care providers for people with dementia, the Dutch Dementia Care Plan (DCP) began to be developed in 2008. The overall aim of the DCP is to “improve the quality of life of people with dementia and their carers and the provision of the right tools to professionals, enabling them to deliver good quality dementia care”. This will be achieved by realising three objectives (1) the creation of a coordinated range of care options that meet the client’s needs and wishes; (2) the provision of sufficient guidance and support for people with dementia and their carers and (3) the monitoring of the quality of dementia care annually.

Objective 1: The creation of a coordinated range of care options throughout the Netherlands that meet the client’s needs and wishes

To successfully meet the client’s needs and wishes there needs first to be a true understanding of what those needs are, an awareness of the care options available as well as their cost and, lastly, examples of best practice from which to draw upon. Alzheimer Nederland carried out two polls
Prioritising Dementia Policy Watch (in 2007 and 2008) to investigate the needs and wishes of informal carers. The other elements are being developed and should soon be available in the DCP.

Recent improvements to the assessment process in the Netherlands will hopefully result in quicker and more accurate assessments being made which should ensure the client’s needs and wishes are identified. A guide for the purchase of coordinated care is being developed to ensure that care providers are aware of the care options and their cost, which are available to them. This development is being carried out by the representative body of the providers of care insurance in the Netherlands, Zorgverzekeraars Nederland, the Ministry of Public Health, Welfare and Sports, together with Alzheimer Nederland. Pilots of the guide will be carried out, enabling final adjustments to be made, but the aim is to have the range of coordinated dementia care options and their purchase options available and in practice throughout all regions by 2011. A set of best practices containing concrete examples should be available soon in the Netherlands as they will be part of the final evaluation of the previous dementia strategy (LDP) and this is due for publication soon.

Objective 2: People with dementia and their carers have sufficient access to guidance and support

A lack of information can delay a diagnosis of dementia and hence also delay any support and treatment that could benefit a person with dementia and their carers. As Dr Bussemaker said, “This subject is undeservedly taboo, so people will often keep it to themselves. And yet the more people who are aware that a person has dementia, the more we are able to support that person and their family. The importance of supporting people with dementia and their families must not be underestimated.” Whilst recognising the key role which Alzheimer Nederland plays in the dissemination of information, Dr Bussemaker also called on the municipalities to play their role, indeed legal obligation (under the Social Support Act “Wet maatschappelijke ondersteuning”), of supporting informal carers.

Another way in which people with dementia and their carers can be assured the appropriate support they need is by operating a case management system. Many benefits have been shown across the board when such systems are operational. Examples include increased satisfaction from the client and carer with the care and support they receive, greater ability to cope by the informal carer, reduced burden on the informal carer and GP, fewer admissions into residential care and/or crisis admissions and also that resources are used more effectively.

Case management is already being used across the Netherlands, with the application enjoying a degree of flexibility, to allow for regional differences and solutions. Indeed the role of case manager is taken on by different people (from district nurses to a specialist in case management for people with dementia) according to the local situation. This same flexible approach was also used in the LDP which adhered to the principle “Let 100 flowers boom” allowing for each region to search for its own solutions and resulted in many innovative approaches being employed. Whilst flexibility is a key element, Dr Bussemaker has stipulated some basic requirements which must be fulfilled when operating a case management system: case managers must be independent and have knowledge of dementia and the system must be available for the client in their home setting, being offered as a natural point of contact.
Another issue which needs to be addressed is the fact that although many innovative approaches have been created, many of them remain unknown outside of their own regions.

**Objective 3: Measuring the quality of dementia care annually**

Thirty-five indicators, divided into ten themes (care, communication and information, physical well-being, care-related safety, living and life circumstances, participation, mental well-being, safety at home and in residential care, sufficient and skilled staff and, lastly, coordinated care) are being developed to measure dementia care this. These measures hope to ensure that transparent information is available, enabling “clients to make choices, support insurers in their contracting activities, support the IGZ (inspection of public health) in its supervisory role and encourage internal quality improvements” says Dr Bussemaker.

Funding for the DCP, according to Dr Bussemaker, already exists and can be found within the National Elderly Care Programme (2008-2011), the rules on building and small-scale living (2009-2011), the budget for development of outcome indicators for dementia care (2008) and the care innovation fund (2009) and therefore there are no additional monies being allocated. Alzheimer Nederland doesn’t agree with this statement of the Secretary about funding. The 100 flowers of the LDP are known as ‘beauties’ and have been positively reviewed by patients and informal carers. But these improvements are only available to a restricted number of patients and carers. Also, more than half of all people with dementia are not known by professionals and care providers. They cope with the disease alone until a crisis occurs. Also, care providers complain they don’t find budgets to provide the necessary care as described in the guide for the purchase of integrated dementia care in the DCP. Consequently, Alzheimer Nederland is lobbying those politicians running for next year’s elections to obtain a more solid financial basis for the purchase of integrated care for all people with dementia.

“By implementing this plan I am taking a major step towards achieving client-orientated, coordinated dementia care which can impact the entire care sector” said Dr Bussemaker. For people with dementia and their carers, we hope the Dutch Dementia Care Plan will soon be fully realised.

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**THE NETHERLANDS’ DEMENTIA CARE PLAN**

**AIMS**

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“The importance of supporting people with dementia and their families must not be underestimated.”

Dr Bussemaker, State Secretary of Health, Welfare and Sports, the Netherlands
Prioritising Dementia Policy Watch

Alzheimer Europe (AE): Mr Crowley, what are the key challenges that people with dementia and their carers face in Ireland?

Brian Crowley (BC): Alzheimer’s disease and other dementias affect 44,000 people in Ireland, and impact on 50,000 carers and hundreds and thousands of family members. Dementia has a life changing physical, emotional and mental impact on all those affected and day-to-day living can become incredibly challenging. Even so, families cope, providing wonderful care to their loved one and making a massive contribution to the baseline cost of dementia care.

The experience of living with dementia and its challenges, vary from family to family. The current economic crisis means that the Irish government will have to make difficult decisions regarding public spending in the coming months and it is important that the decisions that are made protect the most vulnerable.

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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?

BC: Even though the Irish population is somewhat younger in profile than other countries in Europe, there is a growing focus on the issue of demographic ageing is in line with current population trends. Funding for community services for older people, including people with dementia and their families, has increased over the last decade, but we must do our best to maintain these services despite the current economic crisis if we are to sustain people in living at home for as long as is possible and practicable. The establishment of the Health Information and Quality Authority, means that there is now an independent body responsible for the registration and inspection of all residential care services for older people which will result in better standards of care.

In recent years, the Irish government has established an Office of Older People within the Department of Health and appointed a cross-departmental Minister for Older People and Health Promotion. We have just commenced a consultation process for developing a National...
Positive Ageing Strategy that ensures that Ireland will be the place to grow older in and this will really open up the public debate on ageing and age-related issues. However it is fair to say that demographics are important but they are not our destiny.

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

BC: I believe that Ireland will follow the example set by our European partners and create a national Alzheimer’s plan or strategy and in the near future. Dementia is a complex condition which impacts on the lives of the person, their family and the wider community; so a coordinated multifaceted response is needed in order to maximise the quality of life of those living with dementia.

We know that our population is ageing and that the incidence of Alzheimer’s disease and dementia is likely to increase in the decades to come. Without a dementia-specific plan in place, opportunities may be missed to address the specific issues that arise with dementia in a coordinated way, reducing effectiveness and efficiencies.

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

BC: There are three policy priorities for policy makers in Ireland:

a. To firmly place the person with dementia, supported by their family carer(s), at the heart of all policy and planning; recognising the rights of the person with dementia and the rights of their carer. Consultation with both carers and people with dementia should become the cornerstone of policy conception, development and delivery – evidence shows us that this approach works best.

b. To ensure that quality community services are available, to maximise quality of life of the person with dementia and their carer, promote earlier diagnosis and facilitate continued living at home for as long as possible. That is what families want.

c. To look to and learn from the European drive to look strategically at the issue of dementia in terms of policy, planning, services and research so that ultimately those affected by the devastating condition are best served.

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?

BC: I am delighted that the European Commission has heeded the call of the European Parliament and that shortly after the adoption of Written Declaration 80/2008 on the priorities in the fight against Alzheimer’s disease, the Commission launched a European Alzheimer’s initiative in July this year. This initiative will bring European countries together to find better ways of how to prevent and diagnose dementia, pool research capacities, exchange best practices on care approaches and organise collaboration on the ethical issues posed by dementia. I will support this initiative in the discussions within the European Parliament, as I am convinced that there is huge potential to improve the lives of people with dementia and their carers through this type of cooperation between European countries.

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EXCHANGING BEST PRACTICES ON DEALING WITH BEHAVIOURAL SYMPTOMS AT HOME

Representatives from nine European countries met on 5 and 6 May 2009 in Paris for an exchange on how best to cope with behavioural symptoms of people with dementia at home. This report provides an overview of the key findings.

Peer Reviews are a key instrument of the Social ‘Open Method of Coordination’ (OMC). They enable an open discussion on social protection and social inclusion policies in the different EU Member States and facilitate the mutual learning process among them. On the initiative of the French Ministries for Labour, Labour Relations, Family, Solidarity and Urban Affairs, for Housing and for Health and Sports, such a peer review was convened in Paris to examine the issue of coping with behavioural disorders relating to Alzheimer’s and other related diseases in the patient’s home. Government representatives and experts from the Czech Republic, Finland, Germany, Luxembourg, the Netherlands, Poland, Slovenia and the United Kingdom participated in the meeting which also saw a representation from the European Commission and from Alzheimer Europe and its member organisations from the Czech Republic, France, Luxembourg and the Netherlands.

The lively discussions between the different experts highlighted a number of key conclusions and recommendations, in particular:

- Dementia should be diagnosed as early as possible.
- Any assessment of behaviour should include an assessment of the context in which the behaviour occurs.
- Various behaviour assessment tools, including the Neuropsychiatric Inventory (NPI), the Cohen-Mansfield Agitation Inventory (CMAI) or the BEHAVE-AD are used to different degrees in the participating countries.
- Approaches to diagnosis and assessment should be multidimensional and multidisciplinary involving general practitioners, specialists, nurses, health care workers and family carers.
- Proper planning of care is essential and should take into account the types of care available in the country.
- Continual assessment throughout the course of the disease is needed and it was suggested to have case managers for people with dementia.
- Health and social care services should be linked up together and better coordinated.
- The focus should be on prevention rather than management and meaningful activities for people with dementia and effective information and training for carers are essential in that respect.
- More public education to remove the stigma of dementia is needed.

Murna Downs summed up the day’s discussions and the impact on carers of people with dementia by stressing: “Loving somebody with dementia is not bad for your health, but doing so without support is.”

Murna Downs, Professor of Dementia Care, University of Bradford

“Loving somebody with dementia is not bad for your health, but doing so without support is.”

Murna Downs, Professor of Dementia Care, University of Bradford
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* Brussels, 16 December 2008 IP/08/1980 Customs: Millions of illegal medicines stopped by “MEDI-FAKE” action
Dementia in Europe

World Alzheimer’s Day 2009
A snapshot of Alzheimer Europe’s member associations’ activities to celebrate 2009 World Alzheimer’s Day.

Spotlight on …
Malta, Croatia, Germany and the UK
Four of Alzheimer Europe’s members celebrate anniversaries this year. We take a look at their achievements and hopes for the future.

Faces behind commitment
Information on the two new directors appointed in Finland and Luxembourg as well as details of the Cross of Merit award which was given to Heike von Lützau-Hohlbein (Chair of the German Alzheimer Association) for her services to dementia.

Living with dementia
A moving account of how Hasse Hansson, who was diagnosed with dementia in 2006, and his wife Birgitta Ekmanner Hansson, live with dementia in Sweden.
WORLD ALZHEIMER’S DAY 2009

On 21 September each year, people with dementia, their carers and Alzheimer associations from nearly 80 countries come together to raise awareness about the realities and effects of dementia on individuals, families and societies. Below are snapshots of World Alzheimer’s Day activities from the various European Alzheimer Associations.
Four national Alzheimer associations are celebrating their anniversaries this year: the Malta Dementia Society (5th), Alzheimer Disease Society Croatia (10th), Deutsche Alzheimer Gesellschaft e.V. (20th) and the Alzheimer’s Society (UK) (30th). We take a look at some of their key achievements over the years and their hopes for the future.

**MALTA**

The Malta Dementia Society celebrates its 5th anniversary, having been established September 2004. Charles Scerri, General Secretary, looks back at the organisation’s achievements:

“Our greatest achievement is definitely ensuring that dementia is a disease that everybody talks about without feeling shame.” Charles Scerri, General Secretary, Malta Dementia Society

Dementia is not considered to be a taboo subject anymore and stigmatisation has been considerably reduced in recent years. Another achievement would be that of making the Health Authorities aware of the problem to an extent that they want to do something about it. Now our focus is to continue working towards the completion of a Dementia Strategy that, on implementation, would provide better care for individuals with dementia and their caregivers. We hope to make Malta a dementia-friendly place in which high-quality care is available to all those who need it.

**CROATIA**

Ninoslav Mimica, MD, President of ADSC and Mihovil Mladinov, MD, ADSC Board Member talk about the work of Alzheimer Disease Societies Croatia over the last ten years:

Alzheimer Disease Societies Croatia (ADSC) was founded in 1999 with the main goal to raise the awareness and improve the care and treatment of people with Alzheimer’s disease and other types of dementia. We are very proud to say that the idea of organising a society that will help people with dementia was initiated by their families and caregivers. That was best evidence that people with dementia and their caregivers needed urgent support.

Because of the well known spectrum of cognitive and behavioural symptoms, as well as the lack of efficient drug treatment and insufficient care for the elderly in general, with no institutional support for people with dementia and their families, it is difficult and challenging to provide specific care for people with dementia in Croatia. Through its history, ADSC has been carrying out many different activities. The most important are counselling families on a weekly basis and the organisation of self-help groups. Furthermore, we organised various projects – last year it was “institutional care for people with Alzheimer’s disease”, with the aim to provide training and education for caregivers in Croatia. Other means by which ADSC educates caregivers, nurses, physicians and social workers are public lectures, discussions and workshops. Every two years a national congress on Alzheimer’s disease, with
international participants, is organised and takes part in different Croatian cities. We regularly raise awareness of Alzheimer’s disease in cooperation with the media and each year we celebrate World Alzheimer’s Day.

The most important initiatives launched in the last few years by ADSC have been: (1) the building of a nursing home that will meet the specific needs of people with dementia in Zagreb; (2) the change of the law in order to obligate nursing homes to provide at least 10 beds for people with dementia; and (3) to ensure that national medical insurance covers expensive medications for Alzheimer’s disease. Unfortunately, as these projects need a significant amount of funding and political cooperation, we still have yet to fully realise these changes.

It is hard to believe that all the above mentioned activities in the last 10 years were run with no office and place to work. In the first years, the University Hospital Centre “Zagreb” provided us with a room, and later we had an office at the Croatian Institute for Brain Research. Finally, in April this year, on the 10th anniversary of ADSC, the city government gave us an adequate place in the city centre. This was, undoubtedly, one of the greatest achievements of ADSC, because we now have a place where all our activities can be performed and brought together. It was also an acknowledgment by the city of Zagreb of our efforts to improve the quality of life of elder people in the local society.

In summary, we can say it has taken almost ten years of intensive work to be recognised by the public and local community. Now that we have built a “home” for our Society, we expect to raise the number of active volunteers and perform our work in an easier and more efficient manner, which will all lead to a better care for people with dementia and their families in Croatia.

GERMANY

This year, the Deutsche Alzheimer Gesellschaft e.V. celebrates its 20th anniversary. Sabine Jansen, Executive Director, and Hans-Jürgen Freter, Information Officer talk about their organisation’s work:

Perhaps one of our greatest achievements over the last twenty years is that we are able to offer our support to a wider audience. We have been able to do this by the creation of a helpline which was set up in 2002 and now receives more than 6,000 calls per year, and also by our organisation expanding. We now have a total of 119 independent regional Alzheimer Associations offering help and support to people with dementia and their carers. We are proud that we have organised five national conferences, one Alzheimer Europe conference (in Munich, 2000) and an Alzheimer’s Disease International conference (in Berlin, 2006). Increasingly, our organisation has been able to assert a growing influence on legislative changes in Germany, for example the Long-Term Care Insurance. Raising awareness of dementia and the challenges which people face is central to our organisation’s work and we have successfully raised awareness through several campaigns and by events we hold each year on World Alzheimer’s Day.

In addition to the normal daily work of the organisation, the German association’s current focus is on: (a) people with dementia who live alone, (b) education (including information to staff of the police service, fire service and financial

“The by working together, the support groups are united and strong in their work to help people with dementia and their carers.” Sabine Jansen and Hans-Jürgen Freter, Deutsche Alzheimer Gesellschaft e.V.
institutions, as well as the community at large), (c) encouraging collaboration between generations (for example, our “Alzheimer and You” project) and (d) raising awareness of other forms of dementia (such as Pick’s disease).

We sincerely hope that our work will help to ensure better care for people with dementia as well as better support for their caregivers, a willingness of society to take responsibility and help people with dementia (especially those people with dementia who live alone) and also that, by working together, the support groups are united and strong in their work to help people with dementia and their carers.

ALZHEIMER’S SOCIETY, UK

Alastair Balls CB, Chair, and Neil Hunt, Chief Executive reflect on the achievements and hopes of the Alzheimer’s Society:

30 years ago two remarkable women decided to see how their shared experiences of caring for loved ones with dementia could be put to use providing emotional and practical support to other people in the same situation. From this connection – started around a kitchen table, the organisation we now know as Alzheimer’s Society was born.

In the last three decades, our world has changed beyond recognition. In 232 communities, people with dementia and carers now access services provided by the Society, as opposed to struggling in isolation.”

Alastair Balls CB, Chair, and Neil Hunt, Chief Executive, Alzheimer’s Society

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In the last three decades, our world has changed beyond recognition. In 232 communities, people with dementia and carers now access services provided by the Society, as opposed to struggling in isolation. As awareness has grown, so too has the level of support for our work – the Society now ranks amongst the top 100 charities in the UK. The launch of the National Dementia Strategy for England, and equivalent developments in Wales and Northern Ireland, signal a growing recognition on the part of policy makers that dementia is one of the biggest issues facing us today. Undeniably, progress has been made but we must not underestimate the scale of the challenge that lies ahead. There are 700,000 people living with dementia in the UK – and this number is due to increase to over 1 million by 2025. The need for the work of the Society – our services, information, campaigning voice and research funding – has never been more compelling.

Our vision of the future is one in which people with dementia, in every corner of England, Wales and Northern Ireland, enjoy real quality of life. This involves having access to high quality services and information, living their lives free from stigma and receiving the support they need to participate in their communities. Over the course of the next 30 years the Society – with the help of our supporters, funders and partners – will continue our work to make this vision a reality.

### Milestones of the Alzheimer’s Society

- **1979** - Alzheimer’s Society set up
- **1981** - First newsletter produced
- **1987** - Staff employed
- **1994** - 20,000 membership
- **1996** - First time income exceeds GBP 10 million
- **1998** - Website launched
- **1999** - Quality Research in Dementia (QRD) launched. This consumer network programme enables people who live with dementia to be involved in the decision-making process in identifying what research takes place.
- **2000** - First national awareness campaign takes place (focus on stigma)
- **2001** - 10% yearly increased to income of GBP 20 million
- **2002** - “Talking point” launched (an on-line discussion forum)
- **2006** - Dementia Catalogue – on line reference database for day care and research
- **2007** - Dementia UK report launched
- **2009** - National Dementia Strategy launched. Last figures show we helped to give practical support to over 86,000 people last year
NEW DIRECTOR APPOINTED AT THE ASSOCIATION LUXEMBOURG ALZHEIMER

Romain Schmit began work on 21 July 2009 in his role as Director of the Association Luxembourg Alzheimer (ALA). Mr Schmit has studied Economics at the University of Toulouse, France. Prior to his appointment, he held senior positions within the financial sector, latterly as a Member of the Board of Ephidos Holdings S.A.

In Luxembourg Mr Schmit is an Official IFBL (Institut de Formation Bancaire Luxembourg) Senior Expert, Member of IFBL Private Banking Quality Circle and a Member of the Jury of Certified Private Bankers.

HEIKE VON LÜTZAU-HOHLENBEIN AWARDED THE CROSS OF MERIT ON RIBBON OF THE ORDER OF MERIT OF THE FEDERAL REPUBLIC OF GERMANY

Heike von Lützau-Hohlbein, chair of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft) was presented with the Cross of Merit by Social Minister of Bavaria, Christine Haderthauer in Munich on 29 April 2009. The Minister stated, “With over 20 years of service to people with dementia, you have certainly earned it. For your outstanding performance the Federal President has awarded you the Cross of Merit on ribbon.”

Heike von Lützau-Hohlbein has been on the Board of the Deutsche Alzheimer Gesellschaft since 1990, was a founder of the German Alzheimer Foundation, was Treasurer of the Deutsche Alzheimer Gesellschaft for many years and is currently Honorary Treasurer of Alzheimer Europe. On presentation of the award, Ms von Lützau-Hohlbein declared that she was very pleased to receive this honour and that she accepted on behalf of the many volunteers who through self-help groups and Alzheimer societies help improve the situation of more than a million people with dementia and their relatives. She pointed out that 20 years ago there was practically no support for people with dementia and their carers, that much has been done but that there is still a lot to do. She concluded by saying that the award gave her the strength to carry on.

ALZHEIMER SOCIETY OF FINLAND WELCOMES SUSANN MÖRCK AS NEW EXECUTIVE DIRECTOR

Susann Mörck (Master of Economics) started her work as the Executive Director of the Alzheimer Society of Finland (Muistiliitto ry) on 7 September 2009 and replaced the outgoing Executive Director, Varpu Kettunen.

Prior to her current position, Susann worked as the Executive Director of the Neurological Foundation from 2002 to 2007. She has also been the initiator of the Brain Foundation in Finland and worked as a Financial and Development Consultant.
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LIVING WITH DEMENTIA

Hasse Hansson, 68, who was diagnosed with Alzheimer’s disease in 2003, and his wife, Birgitta Ekmanner Hansson, 64, have lived together for nearly 30 years. In this interview they talk with Alzheimer Sweden about living with the disease.

The news that Hasse has Alzheimer’s disease came as a terrible shock! Although Birgitta had realised that Hasse was sick, when it turned out to be Alzheimer’s disease it first seemed like a disaster. Being aware of the fact that his memory is declining, Hasse prefers that Birgitta tells their story. And so she does.

“Our daily lives have been affected by the disease. Hasse’s memory has gradually deteriorated. Take for instance all the bills which Hasse cleverly took care of before and which I have now taken over. Although Hasse understands his illness, it offends him when he cannot do what he has done before. Today he can get lost in the city, especially places he has not been to very often. Simple things like going shopping nearby sometimes result in Hasse coming home with the wrong products. While realising that this can be the case, he always finds a humorous way to sort it out and save his honour. This highlights how vital humour is to us. We are actually in the middle of the grief which surrounds this incurable disease, and it is important for us to be able to laugh at the misery.

“We have both worked as teachers. I’m now retiring. During Hasse’s working life he has been a lecturer, rector of Konstfack (Art School) in Stockholm as well as having written pedagogical books of art. I have got a son, and Hasse a daughter and a son from earlier marriages. Together we have five grandchildren.

“The disease came on slowly. It began with Hasse getting very tired. In the autumn of 2002 he had been unusually busy at Konstfack with teaching and lectures. In addition, he had several book projects which should have been completed. He had not managed to get much sleep and he had felt a tremendous amount of stress. Added to this, at Christmas, there were many people and many obligations to fulfil.

“It was then that Hasse broke down. ‘What’s happening to me?’ he said with anxiety. Whereas Hasse would normally be very well-organised and calm, Christmas proved to be too much for him. It was obvious that something was wrong and I told him to go and see the doctor.

“We all thought that Hasse was burnt-out, but the doctor started investigations which continued for a long time. I knew nothing. I thought the samples were taken for a medical investigation. We were finally told that the test answers were clear and that we would see a doctor at Huddinge hospital. It was a Friday. I got a shock when it turned out that we were going to the Memory Clinic.

“The doctor entered and looked Hasse straight in his eyes and said: ‘You have got Alzheimer’s disease.”
Prioritising Dementia

Dementia in The News

I felt like falling headlong into an abyssmal darkness. I had never had any thought of Alzheimer’s disease.

“Now I saw Hasse disappearing in front of me and we both started crying. Finally we calmed down and then something very strange happened. Hasse had relaxed and was relieved to finally understand what had been wrong.

We stopped talking and thinking about this dramatic information and instead we took romantic long walks and went to different events going on around us.

“However, this feeling did not last. We woke up the following Monday morning and landed straight back in reality. What would happen now? We had to grope our way along. Much seemed to revolve around different types of medication. For a long time Hasse had many problems with medication. Finally he got the medication that worked for him.

“Hasse wished that everything would carry on as usual, for as long as possible. It took a very long time before we told anyone about the disease. Our own fear and ignorance made it difficult, but we realised that it must be done. First we told close friends and some of Hasse’s colleagues at Konstfack. At last we got the courage to tell the family. We told our grown up children when we all were gathered and we were nervous of their reaction, but despite anger and strong emotions, they all took it well.

Hasse continued stubbornly to work even though he began experiencing severe concentration problems. Retirement came earlier than expected.

“I felt very bad and became increasingly concerned. What happens to Hasse later? How will I be able to handle this?

I began searching for more information on this disease and found the Alzheimer’s Association. When I talked to a woman at the association’s office, she asked: “How are you Birgitta in all this?” This had never been an issue in the past. Normally, the question would be to enquire after Hasse. When she instead asked how I felt, I started crying and said: ‘We were going to grow old together, and now this!’ I will never forget that conversation. It was the first time I met real understanding. She knew exactly how I felt. Coming into contact with the Association was like getting a life-line.

“During that time, 2006, the Alzheimer’s Association had launched an Alzheimer Café in Stockholm for young people diagnosed with early onset Alzheimer disease.

It felt absolutely fantastic to meet and talk with others in the same situation. Often the Café provides lectures from researchers, health professionals and entertainers. We have got new friends there.

“We are forced to adapt ourselves to new situations as time goes by, which is especially difficult for me as carer and I don’t know how I could cope with this disease or my grief without support from other people in the same situation!

“We have our ‘twilight’ days and sometimes everything feels hard. But then we try to go out to see an exhibition or go to theatre or cinema. It’s important to find stimulating things to do together.”
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