Charles Scerri and Heike von Lützau-Hohlbein
New survey indicates the importance of early diagnosis

Nicolas Sarkozy
Highlights of President Sarkozy’s address on the global crisis of dementia

Nicola Sturgeon
Deputy First Minister for Scotland, discusses the Scottish National Dementia Strategy

EU Commissioner Geoghegan-Quinn discusses active and healthy ageing in Europe
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New section dedicated to the “Value of Knowing” survey now on the website
Welcome
By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

Prioritising Dementia

Debating Dementia in the European Parliament
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Public Perceptions of Early Diagnosis
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The Polish Alzheimer’s Association – Looking Forward to the Future?
Alicja Sadowska, Chairperson of the association, reflects on the 20 years of work carried out by the association and the challenges ahead.

Policy Watch

Active and Healthy Ageing
Alzheimer Europe focuses on the European Commission’s European Innovation Partnership on Active an Healthy Ageing with interviews from the European Commissioner for Research and Innovation, Máire Geoghegan-Quinn, the Director General of DG Health and Consumers, Paola Testori Coggi and the Director General of DG Information, Society and Media, Robert Madelin of the European Commission.

The global Crisis of Alzheimer’s Disease
Highlights from President Sarkozy’s address to the 2011 Alzheimer’s Association International Conference in Paris, France.

National Dementia Strategies
Scotland’s Deputy First Minister, Nicola Sturgeon, talks about the progress and developments of the first year since the Scottish dementia strategy was launched. Alzheimer Europe provides a summary of the current status of national dementia strategies around Europe.

Policy Developments
A brief look at some recent developments at European and national level which may impact people with dementia and their carers.

Dementia in the News

Members’ News
A snapshot of the recent activities carried out by some of Alzheimer Europe’s member organisations.

Science Watch Round up
Highlights from recent scientific developments in the areas of prevention, diagnosis and treatment of dementia.

Putting a Face to Commitment
Alzheimer Europe reports on recent awards given to people for their work in the field of dementia and on personnel updates in national Alzheimer associations.

Dementia in Society
A look at how dementia is portrayed in the general media.
Issue 9 of the Dementia in Europe magazine is being launched at the 21st Alzheimer Europe conference, entitled “European Solidarity Without Borders” in Warsaw, Poland. As dementia is a disease which crosses all borders it is important we address it together in a collaborative way with international cooperation. The French President, Nicolas Sarkozy, emphasised this very point in his speech at this year’s Alzheimer’s Association International Conference (AAIC) in July in Paris, France. You will find the main points of his speech in this issue.

To mark our 21st Conference, there is a special “Spotlight on Poland” section dedicated to the issues which face people with dementia, carers, policy makers and the national Alzheimer association in Poland. This includes an article by Marusz Kazanczuk, who cares for his mother, Zenona. All of us who have been carers will be able to relate to this touching account of his life with his mother.

Diagnosis is a key component in being able to offer support to people with dementia and their carers. This year, Alzheimer Europe, together with the Harvard School of Public Health, carried out the “Value of Knowing” survey. We publish the results which show the importance of an early diagnosis and also the need for better public understanding of the disease.

There are currently 54 Members of the European Parliament who have joined the European Alzheimer’s Alliance. Their continued effort and support ensures that dementia is kept high on the EU political agenda. As well as reporting on the recent European Parliament lunch debate on the European Commission’s “ALCOVE” project, which had taken place at the end of June, this edition of the magazine has an update on the valuable support given at national level by several Alliance members.

A priority of the EU is now healthy ageing. I am pleased that we can include interviews on this topic with the European Commissioner for Research and Innovation, Máire Geoghegan-Quinn, the Director General of DG Health and Consumers, Paola Testori Coggi and also with the Director General of DG Information, Society and Media, Robert Madelin of the European Commission.

It is encouraging, that despite the financial crisis, that national dementia plans are increasingly being discussed at political level. Several national plans are now in place in EU countries. However, in some countries this is not the case. We provide an update of the current status of national dementia strategies around Europe. In addition, the Deputy First Minister of Scotland, Nicola Sturgeon, provides us with an insight of the first year of implementation of the Scottish dementia strategy.

I hope you find this issue of the Dementia in Europe magazine informative and useful.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe
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The Ethical Issues of Dementia Research
An update on the work being carried out by the working group on the ethics of research in dementia as part of the European Ethics Dementia Network.
On 28 June 2011, Alzheimer Europe organised its 10th lunch debate which was dedicated to a presentation on the European Joint Action on Dementia, namely “the Alzheimer Cooperative Valuation in Europe” project by the project’s leader, Dr Armelle Leperre-Desplanques. It was hosted by the Finnish MEP and European Alzheimer’s Alliance member, Sirpa Pietikäinen.

Dr Leperre-Desplanques remarked that before the process of data dissemination takes place, it is clear that better coordination with Alzheimer associations needs to be achieved.

Ms Pietikäinen gave a brief overview of how European action to address dementia has increased in recent years, citing the Alzheimer Europe 2006 Paris Declaration (which lists the political priorities of the European Alzheimer movement), the 2008 French European Presidency conference (on the fight against Alzheimer’s disease), subsequent Council health recommendations, the 2009 European Parliament Written Declaration (on priorities in the fight against Alzheimer’s disease) and the call by the European Parliament for European action on dementia. ALCOVE is an example of one such action.

The ALCOVE project leader, Dr Leperre-Desplanques, explained that the presentation was developed by herself, Nathalie Riolacci-Dhoyen and Maggie Galbraith. Dr Leperre-Desplanques said that ALCOVE is a Joint Action which is co-financed by the European Commission and it combines a wide spectrum of expertise by including input from physicians, researchers, clinicians, policy makers and legal experts. Having established dementia as a public health priority, she said, it was necessary to share experiences to develop a health policy. The project has the aim of capitalising on the work conducted during previous European studies [including Alzheimer Europe’s European Collaboration on Dementia (EuroCoDe) project].

The French Ministry of Health appointed Haute Autorité de Santé (HAS) in France as the main partner of the project. A willingness to participate and work collaboratively in this voluntary joint action has been shown by 30 partners from 19 countries (Belgium, Cyprus, Czech Republic, Finland, France, Greece, Hungary, Italy, Latvia,
Lithuania, Luxembourg, Malta, Netherlands, Norway, Portugal, Slovakia, Spain, Sweden and the UK) all of which have agreed to work in a collaborative manner at European level. Seven countries are leaders of seven work packages and the work package leaders will identify key stakeholders, including national Alzheimer associations, to involve in carrying out their work. The Executive Board is composed of the seven work package leaders. Essentially, four core questions are to be addressed:

• How to improve data for better knowledge about dementia prevalence? This workpackage (WP4) is led by Italy (Istitute Superiore di Sanita) and the aim is “to assess available epidemiological studies on dementia and to define best criteria for them in order to improve epidemiological data collection”. New studies will not be conducted, rather the group will consider existing information systems in all countries.

• How to improve access to dementia diagnosis as early as possible? The UK (Department of Health) will lead this workpackage (WP5) and will “address diagnosis through the assessment of (i) national recommendations, (ii) health care systems for early diagnosis of dementia and (iii) the implementation of such recommendations and systems”. Dr Leperre-Desplanques emphasised the importance of not only identifying systems for early diagnosis, but also of assessing how to implement them in different countries.

• How to improve care for people living with dementia and particularly those with behavioural disorders? Dr Leperre-Desplanques reflected that this is perhaps the most challenging of the workpackages and currently the analyses are completed but now consideration is being given to how the different health care systems can provide best practice guidelines. Finland (National Institute for Health and Welfare) are the leaders of this workpackage (WP6) which will “assess existing practices in home and institutionalised care and in training provided to carers and health professionals”.

• How to improve the rights of people with dementia, particularly with respect to advance declarations of will? This workpackage (WP7) will be led by Belgium (King Baudoin Foundation) and this group will “examine the issue of autonomy and dignity of people with dementia from an ethical and legal perspective”.

There are three transversal workpackages: coordination (WP1) led by France (HAS), dissemination (WP2) led by Spain (Instituto de Salud Carlos III) and evaluation (WP3) led Slovakia (Neuro Immunology Institute).

Work began on the project this year in Luxembourg with the Executive Board and Steering Committee deciding on the method to be employed. Over a period of 2 years, existing information will be collected, analysed, needs and priorities identified and finally recommendations made and information disseminated at the ALCOVE seminar planned in March 2013. Dr Leperre-Desplanques assured the national Alzheimer associations in the audience that they would be exposed to the outcome of the workpackages before they were published.

Three main outcomes are anticipated:

• The establishment of sustainable European network for the exchange of experiences and knowledge at the level of health care institu-
Prioritising Dementia

• To inform and advise decision-makers, healthcare professionals, caregivers and citizens in general through convergent recommendations in terms of health policy

• A reduction in the risks associated with psychotropic drugs, with a common focus on the use of psychotropic drugs, in particular antipsychotics.

Dr Leperre-Desplanques focused on the issue of antipsychotics and highlighted that the knowledge we have now (that antipsychotics can be non-effective, have side effects and can have a negative impact on the quality of life) was not available five years ago. This leads to different solutions being proposed such as an increase in care and an increase in the quality of life.

Sirpa Pietikäinen affirmed this by explaining that she had had the privilege of caring for her mother, who had dementia and that it proved highly beneficial to her mother to walk 3-4 km each day. The issue regarding antipsychotics is, said Ms Pietikäinen, that the use of antipsychotics is an abuse of human rights and not ethically right.

Frieda Brepoels, MEP (Belgium), wanted to know why certain Member States had not committed to this project such as Germany and Poland, the latter having the incoming Presidency of the EU. Dr Leperre-Desplanques said that reasons could be that the project has a limited budget, limited resources, is maybe perceived as not as important as other projects and is very short-term: all of these factors can make the project one which can be challenging to commit to. The project was also set up in a short time which may have resulted in less responsiveness. On the other hand, Dr Leperre-Desplanques reminded the audience that it was not too late to become a partner of the project and that the work groups are open to cooperation. She explained that it is the work-package leaders who are in charge of the coordination of the project and that Germany had been invited to participate but chose not to.

Clarification was sought by Ms Brepoels regarding the competence of partners required at national level and Dr Leperre-Desplanques said that the project is voluntary and that partners cannot be forced to work on it. It is the choice of each national government to propose a partner for the project and therefore the issue of competence is addressed at national level.

Whilst applauding the tight deadline within which the project is to be completed, Jeremy Hughes, Chief Executive of the Alzheimer’s Society, UK, stressed the importance of collecting data in a standardised way, which is challenging when some countries do not have data. Ms Leperre-Desplanques explained that the work-package leaders agreed with this concern and want to propose a common set of standards which would be implemented in all countries.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, asked how the results of the recommendations can be measured to ensure that they are implemented? Dr Leperre-Desplanques said that this will be difficult as ALCOVE is such a short project. Work is on-going on quality indicators but at this point in time she is not able to give concrete outcomes, although because the work on antipsychotics is so advanced it would be possible to propose a concrete programme about their use.

The issue of dissemination and involvement by civil society was raised by several participants. Charles Scerri, General Secretary of the Malta Dementia Society, asked if patient organisations would be involved in the dissemination part of the ALCOVE project. Dr Leperre-Desplanques said that it is early days yet and national Alzheimer as-
associations will be invited along with all participants of ALCOVE but that it was up to the workpackage leaders to identify who to include. Dr Leperre-Desplanques also remarked that before the process of data dissemination takes place, it is clear that better coordination with Alzheimer associations needs to be achieved before publication.

Mary Van Dievel, Mental Health Europe, reinforced the importance of including civil society and asked not only how civil society will be involved in future projects (especially in the forthcoming joint action on mental health) but also whether partners in the joint actions are urged to involve civil society. Ms Van Dievel highlighted the importance of such involvement, especially as it is at Member State level that results will be seen.

Jean Georges, Executive Director of Alzheimer Europe, said it would be very helpful to have some way of continually monitoring policy by way of a Dementia European observatory. Replying, Dr Leperre-Desplanques said that the ALCOVE network is not a specialist body of European policy, rather it is a network of experts on policy in each country and therefore does not have the necessary expertise for European level. However, she believed that it is possible to work together to bring the expertise to European level.

Mr Georges also reflected that the cost of joint action on Alzheimer’s disease is quite moderate. Recognising that dementia is one of the most costly diseases (e.g. it costs more than cancer and cardiovascular disease combined), Mr Georges asked what other joint action has been financed and to what level. Dr Leperre-Desplanques said that this joint action had been strongly supported by France. She gave an example of a currently discussed joint European action on patient safety, which had more than 40 partners, with a time frame of 3-4 years and a budget of EUR 6 m. Manuel Romaris, DG Research, explained that since 2007, EUR 300 m had been invested on brain neurodegenerative research in Europe. He highlighted the joint programming initiative which has a small budget of EUR 2 m, but that the idea is for Member States to pool their own resources and that the Commission’s role is to support the initiative by coordinating the project to facilitate Member States working together. Jean Georges remarked that it would be nice to see the same investment in DG Sanco (public health) as in DG research.

Sirpa Pietikäinen concluded the debate by stressing the need to engage everyone at all levels and that national Alzheimer associations be included in this process.

Heike von Lützau-Hohlbein closed the debate by thanking Dr Leperre-Desplanques for such a clear and interesting presentation and the audience for their active participation. She identified three elements which she would take away from the meeting:

- Collaboration: Better ways needed to be found to collaborate with patient organisations and that we all need to consider how to reach countries which are not yet involved.
- Dissemination: That Alzheimer associations can play an important role in this process.
- Monitoring implementation: Whilst Ms von Lützau-Hohlbein was very positive that this work was being done, she said it is a weakness if the results are not measured.

Ms von Lützau-Hohlbein concluded by saying “We must be willing to measure the results of our work because we are the ones who want to help people with dementia and their carers. This is why we are here.”
A snapshot of Alzheimer Europe’s 10th lunch debate
PUBLIC PERCEPTIONS OF EARLY DIAGNOSIS

In this article we take a look at the findings of Alzheimer Europe’s international “Value of Knowing” survey which examined public perceptions and awareness of Alzheimer’s disease and public views on the value of diagnosis.

The “Value of Knowing” survey of 2,678 people was designed and analysed by the Harvard School of Public Health and Alzheimer Europe. Fieldwork was conducted via telephone (landline and cell phone) with nationally representative random samples of adults age 18 and older in five countries by TNS, an independent research company based in London. Countries surveyed were Germany, France, Spain, Poland and the U.S.

Jean Georges, Executive Director of Alzheimer Europe explained “The reason for the survey is related to the importance of promoting early Alzheimer’s diagnosis, and the fact that early diagnosis is included in national dementia plans in France, England, Norway and Scotland. In Europe, we are still encountering resistance from some in the medical profession due to their nihilistic views regarding the value of an early diagnosis and the benefits of current treatments. We were hoping that a public opinion survey would show a willingness to gain a diagnosis and the value of confronting the disease.”

Results of the survey reveal that over 85% of respondents in the five countries surveyed say that if they were exhibiting confusion and memory loss, they would want to see a doctor to determine if the cause of the symptoms was Alzheimer’s disease (see table 1). Over 94% would want the same if a family member were exhibiting the symptoms.

In four of the five countries, Alzheimer’s disease was the second biggest health fear after cancer (see table 2). The public were asked to choose which disease they were most afraid of getting from a list of seven diseases including cancer, heart disease and stroke. Around a quarter of adults in four of the five countries say they most fear getting Alzheimer’s disease.

Fear of Alzheimer’s gets worse with age, but even young adults are concerned, with approximately one in seven 18 to 34-year-olds reporting Alzheimer’s as the disease they are most afraid of getting from the list provided.

The survey found a large proportion of the public has had some experience with Alzheimer’s disease. Majorities in all five countries say that they know or have known someone with Alzhe-
imer’s disease (see table 3). In addition, about three in ten have personal experience with a family member with Alzheimer’s disease (see table 4).

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe and former carer, said: “The results demonstrate the importance of being honest with patients when diagnosing Alzheimer’s disease. As a former carer myself, I recognise how valuable it is for people to have first-of-all a name for all the uncertainties of their condition and then have the time to get their affairs in order. It will always be difficult to receive such a diagnosis but doctors need to empower patients and their loved ones to take the appropriate steps. The findings also show there is high awareness of Alzheimer’s disease, which is a testament to the success of the many awareness campaigns coordinated by Alzheimer societies.”

The high level of contact with Alzheimer’s disease shown in the survey is likely to have contributed to the wide recognition of common symptoms such as confusion and getting lost, which were recognised by at least 86% and 88%, respectively.

However, few people recognised the severity of Alzheimer’s disease with approximately 40% knowing that it is a fatal condition (see table 5). In fact, Alzheimer’s is the seventh-leading cause of death in high income countries and the only cause of death among the top 10 that cannot be prevented or cured.

Numerous respondents believe there is now an effective medical or pharmaceutical treatment to slow the progression of Alzheimer’s disease and make the symptoms less severe. Also, nearly half believe there is a reliable medical test to determine if a person suffering from confusion and memory loss is in the early stages of Alzheimer’s disease.

“Many of the public have high expectations about the possibilities of treatment alternatives and medical testing”, said Dr Robert Blendon, Professor of Health Policy and Political Analysis from the Harvard School of Public Health. He continued: “It is important for doctors to talk to patients about what treatment and testing options are or are not available.”
The survey also found public interest in predictive testing. Approximately two thirds of respondents said that, they would get a medical test which would tell them whether they would get Alzheimer’s disease before they had symptoms.

The results have been warmly received and Mr Georges highlighted what future action needs to be addressed, saying “The willingness to get a diagnosis that was expressed by the survey respondents is encouraging, however better public education is needed. We need to address potentially unrealistic expectations about the availability of a definitive early test and effective treatment for the disease, while providing positive reasons for seeking a diagnosis in the absence of disease modifying treatments.”

This conclusion was supported by Florence Lustman, the Coordinator of the French Alzheimer Plan, who said “Alzheimer’s is a fatal condition that affects most people’s lives at some time. One of the key priorities of the French Alzheimer’s Plan is early diagnosis, and the survey results support this focus. The findings demonstrate overwhelming public support for receiving diagnosis.”

The survey was supported by a grant to Alzheimer Europe from Bayer AG. Bayer was not involved in the design of the survey or the analysis of the findings. The results of the survey were presented during the Alzheimer’s Association International Conference in Paris, France in July.

*Results of the Value of Knowing survey can be found on www.alzheimer-europe.org*
Value of knowing

The news coverage generated by the publication of this survey was vast. Below are some examples of how it was reported in the media.
THE EUROPEAN ALZHEIMER’S ALLIANCE MEMBERS IN ACTION

Currently there are 54 MEPs who have joined the European Alzheimer’s Alliance (EAA). Members of the Alliance support people with dementia in various ways. In this article we highlight how they help raise awareness and understanding of the disease at a national level.

Elena Oana Antonescu, MEP (Romania)

Ms Antonescu supported the seminar entitled “Alzheimer’s – the disease that does not forget you”, which was held on 29-30 April 2011, at the National Institute of Statistics Bucharest, Romania and organised by the Romanian Alzheimer Society and Gerontological Association. During the press conference, Elena Oana Antonescu, sent a video message in which she stressed the importance of considering dementia a national priority.

“In 2020, the number of people with Alzheimer’s is set to dramatically increase, however the disease still sometimes goes unrecognised in the EU. Therefore, it is important that people be informed that the disease could be prevented through a healthy lifestyle” said the Romanian MEP.

Ms Antonescu continued: “I want to emphasise the importance of early intervention and preventive diagnosis in early cases of the disease and I think this is the key to progress in the fight against Alzheimer’s disease. The importance of a multidisciplinary approach to research in this area is vital. Science must provide benefits for the patient rapidly. Another priority is to promote the concept of “healthy lifestyle for a healthy mind”, as a healthy lifestyle may delay or prevent Alzheimer’s disease and other forms of dementia.”

Nessa Childers, MEP (Ireland)

Nessa Childers, organised a seminar entitled “Shared Priorities – Dementia and Alzheimer policy in Europe and Ireland” on 17 June 2011, in Dublin, Ireland. The seminar offered a platform for policy experts from Europe and Ireland to explore ways in which to help people with dementia and their families as well as ways in which to prevent the onset of dementia.

Ms Childers said: “Our health care system as it stands discriminates against older people, this may not be the intention but reflects a mind-set when it comes to spending policy. I’m calling for the end of the discrimination against illness of later life where there is a cap on medical care for older people that would not be tolerated in cancer care or care for children.”

Ms Childers focused on the EU Joint Action on Alzheimer’s disease, which was launched earlier in the year in an effort to step up cooperation and
support to improve prevention, diagnosis, treatment and care across the EU.

Ms Childers introduced the following amendments to the new EU Initiative:
• to focus on specific needs of women, who account for twice the amount of people living with dementia, or caring for a family member with dementia,
• to focus on a healthy diet as current research suggests that diet may be a significant causal factor in the development of Alzheimer’s,
• to examine the use of living wills.

Françoise Grossetête, MEP (France)

France is currently discussing adding a new branch to its social security system to cover “dependence”. As in other European countries, the ageing of the population calls for new measures.

In May 2011, Nicolas Sarkozy, President of the French Republic, gave Senator André Trillard the mission to present a report on the prevention of dependence in elderly people. The mission’s aim was to better understand elderly people’s views on dependence and make some suggestions on what the public authorities could do to preserve the health capital of individuals and prevent the risks of dependence while taking into account informal carers of dependent persons.

As Chair of the European Alzheimer’s Alliance, Françoise Grossetête was invited by Senator Trillard to discuss the topic and provide input to the report. The report was handed to President Sarkozy on 13 July 2011.

Marisa Matias, MEP (Portugal)

As Rapporteur of the European Parliament report on the European Commission Green Paper on the future of EU research (“From Challenges to Opportunities: Towards a Common Strategic Framework for EU Research and Innovation Funding”), Marisa Matias, organised a meeting in May 2011 in the European Parliament to discuss the future of research in Europe. She had invited a wide range of stakeholders to share their views and give her some input for the report.

The report is awaiting the European Parliament first reading.

Antonyia Parvanova, MEP (Bulgaria)

In April 2011, Antonyia Parvanova attended a round table meeting in Bulgaria on the socio-economics rights of people with dementia and their carers. The event had been organised by Alzheimer Bulgaria together with Compassion Alzheimer Foundation.

Dr Parvanova made a presentation on European policy on Alzheimer’s disease and also participated in discussions on the problems of families of people with Alzheimer’s disease, the lack of reimbursement for medication, the lack of support for families by social services and the lack of a national plan on the political level for addressing the problem.
THE ETHICAL ISSUES OF DEMENTIA RESEARCH

The focus of the European Dementia Ethics Network for 2011 is the ethical issues linked to dementia research. This article is an update on the working group’s progress so far.

In June 2011, the newly-formed working group on the ethics of dementia research met in Luxembourg. Chaired by Dianne Gove, Information Officer, Alzheimer Europe, the working group of 12 experts from 8 European countries consists of experts in the medical, pharmaceutical, bioethics and research domains, representatives from patient organisations as well as a person with dementia and two carers. Discussions at the meeting focused on the ethical issues related to:

• Involving people with dementia
• Protecting the wellbeing of participants with dementia
• Participation in clinical trials
• Research linked to prodromal or pre-symptomatic diagnosis
• Psychosocial and social sciences dementia research
• Selecting, monitoring and disseminating research
• End-of-life research
• Research on the brain and other tissue.

Following this first meeting, an extensive literature review was carried out and a draft document was written, highlighting the main ethical issues linked to the above-mentioned topics, amongst others, and containing a few preliminary recommendations. The members of the working group met again in Brussels on 23 and 24 August in order to discuss the draft document and further develop the recommendations. They were joined by two members of the Steering Committee of the European Dementia Ethics Network, namely Prof. Iva Holmerova (CZ) and Sabine Jansen (DE).

Several ethical issues were discussed at length such as proxy decision making for research (covering the basis on which proxy decisions are made and the extent to which they correspond to the wishes of the person with dementia on whose behalf they are being made). The group also discussed the ethical issues linked to various means of recognition and acknowledgement offered to people with dementia for their valuable participation in research. Another key issue of interest to the group was the involvement of people with dementia in the older age group in research.

The members of the working group contributed their professional and personal expertise, including their experience of conducting or participating in research, to the development of the working document which will eventually be the second report to be published by Alzheimer Europe on a specific ethical issue of importance to people with dementia and will be available at the beginning of 2012.

Working group: Dianne Gove, Information Officer of Alzheimer Europe is the Chair of the working group which consists of representatives from Austria – Dr Thomas Frühwald, Chief Doctor of the Department of Acute Geriatri of the Hietzing Hospital, Vienna; Belgium – Prof. Dr Liebe Van den Block, senior founding member of the End-of-life care Research Group of the Ghent University and Vrije Universiteit Brussel, and professor of communication and education in Family Medicine at the Vrije Universiteit Brussel, Belgium; France – Dr Fabrice Gzil, Head of Social Studies Department, Fondation Médéric Alzheimer in Paris; Italy – Dr Carlo Petrini, Head of the Bioethics Unit of National Institute, Rome and Prof. Sandro Sorbi, Professor of Neurology, Department of Neurological Science and Psychiatry at the University of Florence; Lithuania – Dr Rasa Ruseckiene, Consultant in adult and old age psychiatry and therapist; Sweden – Dr Peter Annas, Senior Research Scientist, PhD, and AstraZeneca’s representative in the PharmaCog project; UK (England) Angela Clayton-Turner, volunteer, carer, member of the Alzheimer Society and lay member of her local Research Ethics Committee and UK (Scotland) James McKillop (MBE), who lives with dementia and is a founding member of the Scottish Working Group on Dementia, and his wife, Maureen McKillop, carer.
The proliferation of counterfeit medicines poses a real and growing threat to patients around the world.

Over a two month period in 2008 customs from the EU Member States seized more than 34 million* illegal medicines.

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

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The medicine her doctor prescribes should be the medicine she receives.
The View from Poland
Elżbieta Katarzyna Łukacijewska, MEP (Poland) talks about the situation in Poland for people with dementia and their carers.

Living with Dementia
A moving account by carer Mariusz Kazanczuk about his mother, Zenona, who has dementia.

The Polish EU Presidency and Dementia
Lilianna Michalik, First Secretary (Health and Pharmaceuticals), Permanent Representation of the Republic of Poland to the EU speaks with Alzheimer Europe.

The Polish Alzheimer’s Association – Looking Forward to the Future?
Alicja Sadowska, Chairperson of the association, reflects on the 20 years of work carried out by the association and the challenges ahead.
Ms Elżbieta Katarzyna Lukacijewska, MEP (Poland) speaks about the situation for people with dementia and their carers in Poland.

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

Ms Elżbieta Katarzyna Lukacijewska (EKL): It is estimated that Alzheimer’s disease affects more than 250,000 people in Poland. The impact today is massive, and will accelerate in years to come. We must prepare now for the social and economic disruptions that this disease may cause. There are several challenges that people with dementia and their carers face in Poland, and we must take measures to ease their troubles.

The development of new institutions of specialist care, greater access to professional, legal, and financial assistance, as well as access to medical information are only some of the aims we need to target.

Moreover, there is still a considerable stigma attached to dementia and a widespread erroneous belief that people suffering from this condition cannot be active participants in society and lead normal lives. I do hope that in the future, we will be able to address the needs of this substantial and growing group of people.

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?

EKL: Unfortunately, I have to admit that we are not doing enough to address all the needs of people suffering from dementia in Poland. Nevertheless, we are becoming more and more conscious of the fact that the population is ageing and sooner or later we will have to take more courageous and decisive action. I am deeply convinced that the 6 month Polish presidency will provide us with the opportunity to engage in an advanced and fruitful debate on how to improve the lives of people suffering from dementia. We will surely attempt to become the initiators of such discussions. In addition, one of our main objectives will consist of implementing and supporting programmes on national levels.

AE: Do you believe that Poland will follow the example of France, Norway, the Netherlands, Scotland, Wales and England and create a National Alzheimer’s Plan?
EKL: Indeed, it would be my greatest wish that Poland follow in the footsteps of those countries. As we are dealing with the problem of an ageing society, it is essential to implement programmes such as a National Alzheimer’s Plan. We need to raise awareness about the disease and realise various action plans in order to improve the situation of people with dementia. Poland, as a fairly young democracy, does not possess the type of financial resources available in other countries and is therefore unable to finance a larger scale, national programme. Nevertheless, there exists a great will in the Polish society to meet the challenges posed by dementia and Alzheimer’s.

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

EKL: Having to face life with a chronic debilitating cognitive disease is difficult for both the patient and their caregiver. It is necessary that we meet the physical and emotional needs of people with Alzheimer’s while supporting their carers, which, in Poland, as in many other countries, are often the patient’s family members. One undertaking could include the development of permanent care homes as well as temporary or day care centres which will allow families to return to work knowing that their loved ones are receiving the support they need.

We also need to ensure that people living with dementia have access to proper guidance and support. The promotion of medical and scientific research is a key method by which we can achieve such a goal. By making advancements in this field, we can ensure earlier diagnosis and intervention.

Overall, I would like to see us strive towards improved awareness of the disease and a higher quality of care. I am sure that the Polish presidency will make advancements in these areas which will improve the situation of those living with dementia in Poland, as well as all of Europe.

AE: A last question on the need to 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 collaboration be?

EKL: The problems associated with an ageing population are becoming relevant in many European countries. Dementia is not an issue we can ignore, and I would welcome a plan which would work to aid the people affected by this condition. It is important that we strive to collaborate on a European level to ensure a brighter future for our elderly by providing them with the support necessary to live a dignified life. We need to work on the improvement of health care services and promote active and healthy ageing through transnational actions. We will do our utmost to find new funding opportunities, organise conferences on Alzheimer’s and consultations on advanced therapies. Finally, we will attempt to develop an on-going dialogue between the people affected by dementia and member states’ authorities.
We are climbing marble stairs inside the Warsaw Opera House. My mum is not holding on to the banister. She doesn’t have to. It’s funny to watch her try to avoid stepping on the red carpet. She probably thinks she does not deserve it. Oh, mum! We are just going to enter a beautifully lit hall and sit in the fifth row of the stalls. Mum is going to open her bag and take out a handkerchief, then a small mirror, and finally look at the programme. She still has enough time to read the title "Swan Lake", before the lights are turned off.

If someone spotted the elderly lady from the fifth row, which they might indeed do because of her big, antique brooch pinned to her black dress, they wouldn’t suspect she had such a serious condition. A hypothetical observer would probably be quite surprised to learn that she didn’t even know which year it was. She has no idea who our president is. When we were getting ready to go to the theatre, she wasn’t able to put on the dress herself. And it was not her who decided what to wear for such an occasion and whether to pin the brooch or not. I can remember that day very well, a happy day despite everything, when mum was playing the role of a healthy person. It was exactly 3 years ago. A lot has changed since then. She, who could then walk up and down the stairs quite easily, doesn’t go out any longer and moves around her flat with difficulty and only with my help. The usual route, which is now always the same: from the sleeping room to the bathroom, from the bathroom to the living room, towards the sofa, the table or the armchair, has unexpectedly become as risky as a path over a precipice.

Still being quite fit, she puts her feet down, although with fear, and walking beside her, I am also afraid she’s going to trip and fall down. Her hands seem also fine and she can still use them to make strange gestures which resemble a pantomime, but it is with my hands that she washes herself, combs her hair, dresses up, fetches a spoon or a fork. Oh, gosh, how difficult it is to help you eat, mum!

In 2008 I didn’t need to give her a bib. We could even eat out in a restaurant together. One day when my friend Mark dropped in, she made some sandwiches, a bit clumsily, but she made them herself. On the first day of spring of 2009 she was dancing in the middle of the living room, turning round and swirling and laughing... When I compare what I can see today to what it was like then, I am filled with sadness. It makes me so sad when I see her mind sink deeper and deeper. It’s like watching a sinking ship which nobody can rescue. But whatever my mum’s existence, I can still touch her, embrace her, stroke her grey hair. As long as she is alive, our common past is alive too, because our history which began 50 years ago is still happening. I am not a professional carer, but her son. When I look at her I can see not only an elderly, helpless woman, but also her previous incarnations: a beautiful girl, a young mummy,...

Those tender scenes from the past when she was leaning down, holding me, helping me button up my shirt, are still alive in a few old photographs.

"Not all about my mother", by Mariusz Kazanczuk
It’s not true that the past does not exist. It is still present. In the flat where I once lived with her, I have found my lost childhood time.

In her old flat, among objects connecting the old days with today I can recall the past which helps me go on living. It reminds me also of my mum’s childhood and her youth. Since her memory started getting worse and now when she cannot tell me any of her stories, her recollections have found a harbour in my own memory. I am reconstructing and telling her those stories: a story about an expedition to find some bread during the Warsaw Uprising, a story about dancing parties, or about uncle Lilek who bought her a balloon once but her cousin Julius made a hole in it with a pin and said: “I’ll buy you another, a nicer one”.

Some people express their sympathy when they see us. I smile then and explain that I do not need sympathy – my mum is still alive! I often hear that by devoting so much to her, I have given up on my own life. But this is just my life: very difficult but interesting. I am not fighting with my fate. The time of freedom and carelessness is over now as I have become my mum’s carer. It may seem strange but in my present life I can experience even more joy than before, although this joy is mixed with melancholy because for the last few years I have been living among the events which I realise are happening for the last time.

In August 2009 we went on a 10-day trip to Janowiec. I knew quite well then that it could have been our last trip together. We visited Kazimierz Dolny, a historic town, full of lovely Renaissance buildings on the Vistula river. We went on a boat trip. It was there where I understood that we would never go to France together. I always wanted so much to take her there, to the country of her childhood. Janowiec was then a substitute which had to replace Corbeil-Essonnes, a place in which she had spent together with her parents the first six years of her life. Kazimierz Dolny was compensation for her absence in Paris, often present in her stories before she was diagnosed. As a child she used to visit Paris accompanied by Madame Chevalier who was spoiling the small Polish girl in any possible way. The Vistula river pretended to be the Seine, and our Versailles were the ruins of the Firlejs’ castle. I managed somehow to get her there and she walked along the yard triumphantly, wearing a royal gown, which I had borrowed, and a crown made of cardboard paper. A day before we were leaving, I decided to see the castle again. Looking up my mum said: “What a lovely house”. Yes, mum – I thought – it is lovely, indeed. Once some noble family lived in it but their time is gone now and yours is not. Not yet! She comes up and smiles. “Well, what would you like to tell me, mum” – I ask. Three years ago, when I decided to move in and live with her, I often asked the same question and she would always answer: “That I love you”. I wanted to hear her say this again and again. But she no longer could say it, because she simply forgot her part. It happens to actors sometimes during a play and then a prompter reminds them the lines. I also would prompt her: “that I..., that I...” and she would finish “love you!” with confidence. If it was on stage, people would say she was playing the role of a mother very well. Today she doesn’t say anything anymore – she is silent. I know she would never say those words again. But I believe she still loves me. She is just not able to tell me that. The words “I love you” are stuck deep in her soul.

June 10th, 2008 is her 70th birthday. We are in the Krasinski Park where, despite the evening hours, it is still bright and lovely. We are sitting in front of some old trees, standing stock still. This is one of the moments when everything holds up
and the time seems to have stopped. Suddenly my mum interrupts the silence. She makes a remark, in a rather clever way, about the beauty of the old trees, with a sentence which evokes my admiration: “There is a lot of space in these trees”.

I’ve written a poem including such poetic statements expressed by my mother at that time. The “People Write Poems” Forum has published it:

*Zenona Kazanczuk: Memory*

I cannot remember what I remember,  
I cannot remember who I remember,  
I cannot remember.  
I can remember what the wind has said:  
There is a lot of space in these trees.

The presence of poetic structures in mum’s speech was connected with a gradual process of disappearance of common phrases, collocations, or lexical structures from her memory, which are necessary for everyday communication. As she could no longer refer to them, she was trying to describe the world using her own language. This was accompanied by a strange phenomenon: some of the words she used lost their meaning and became linked with other ones. The process of forgetting the language was happening rather quickly. In 2009 she could still say: “It is probably this” but making sentences became more and more difficult, and even short, simple statements were left unfinished or they ended with some unarticulated sounds, resembling baby speech. And finally she could only utter single words. Were these “free words”? Or maybe they were, as a linguist has called them, “orphaned words”, wandering in her conscience. Maria Brzezinska from Radio Lublin has used another term: “departing words”, which seems quite right, as my mum, after uttering a word several times, would never use it again. It was gone for ever! Her vocabulary was shrinking fast dramatically.

But I can also recall some days which were full of words. And what was interesting was that they almost never referred to the current situation and the reality, but they came from within, and perhaps were the reflection of her inner world. When leaving the bathroom she would repeat: “Ghosts, ghosts”, and going to bed: “Little horses, little horses”. Why? I never wanted to admit they were nonsense. Perhaps they were meaningful, but neither I nor anyone else could understand them. Once, quite a long time ago, she said something strange which sounded like a magic word: “kar-tarana”. What does it mean? - I asked her. She did not respond. “But do you know what it means?” - I asked again. And she said: ” “Yes”. Today the only words she can say are: “How?”, “But how?”, and “I had”. Nothing more!

June, the 6th 2011. I call Alicja Sadowska from the Polish Alzheimer’s Association: “My mother has been taken to hospital! I’m so scared she will never be able to walk again”. Alicja is listening patiently and offers support and comfort.

We first met at the beginning of 2009. When Alicja learned I was a Polish philologist, she suggested I should write something in the association’s newsletter. I sent a story about my life as a carer for which she praised me a lot and encouraged me to write more. Two stories were published this year.

June the 7th 2011. I am told by hospital staff, that mum gazes at the door all the time, as if she was expecting to see me.

June the 8th 2011. I’m standing at my mum’s hospital bed. A young woman, a medical student, currently doing her hospital practice, is approaching us. Mum is saying something very quietly and not clearly. But I seem to make out what she’s trying to say. This is impossible! “Did you hear what I heard?” - I ask the student. My mum said: “Want home”!

“Yes. That’s right. She said ‘want home’!”

*Those tender scenes from the past when she was leaning down, holding me, helping me button up my shirt, are still alive in a few old photographs.*
Alzheimer Europe speaks about prioritising dementia with Lilianna Michalik, First Secretary (Health and Pharmaceuticals), Permanent Representation of the Republic of Poland to the EU

Alzheimer Europe (AE): A number of EU presidencies have helped put dementia high on the European agenda: For example, the French presidency dedicated a High Level Conference to Alzheimer’s disease that led to far-reaching Council recommendations and the Swedish Presidency raised awareness about healthy and dignified ageing. Will the Polish EU Presidency also pay specific attention to the challenges of dementia?

Lilianna Michalik (LM): The covered topics of our conference will be closely related to one of the health priorities that Poland chose during its presidency: Brain research, Ageing, Stroke and Alzheimer’s Disease. Giving priority to studies on brain diseases will enable focusing on their importance, both in Poland and in the whole of Europe.

AE: The ageing of the population and the rise in the number of people with dementia are a growing and long-term concern for European and national policy makers as well as for the population in general. How will Poland work with the next EU Presidencies to ensure continuity in tackling these issues?

LM: In more global perspective, implementing these measures supports the EU in the delivery of objectives of both health and social policies, and it should contribute to the delivery of the objectives stipulated in the Europe 2020 Strategy by supporting the employed in staying on the labour market, stimulating funds allocated to research and development, and measures addressing the inequalities in health. The Polish conference will become the first European Day of the Brain to be celebrated annually in different EU Member States. Conference conclusions will be prepared and will give a list of very concrete suggestions regarding measures that will be aligned with conference goals such as suggesting year 2014 to be made the European Year of the Brain.

AE: The European Innovation Partnership on Active and Healthy will be a key Commission initiative for the coming years. How do you see this initiative providing practical solutions for people living with dementia in the different Member States?

LM: Implementing this priority supports the EU in the delivery of objectives of both health and social policies, and it should contribute to the delivery of the objectives stipulated in the Europe 2020 Strategy by supporting the employed in staying on the labour market, stimulating funds allocated to research and development, and measures addressing the inequalities in health.

AE: What measures will the Polish presidency put in place to support 2012 as the European Year of Active and Healthy Ageing?

Giving priority to brain diseases should also result in an improved understanding and greater public awareness of brain diseases, and consequently in decreased stigmatisation, marginalisation and social exclusion.
Alzheimer NGOs in Poland have been active for almost 20 years. They were established after the radical social and economic changes brought about by the political transformation of 1989 in this part of Europe. The inspiration to found them came mostly from professionals but after a few years, carers and/or former carers took over and began to chair the associations’ boards while medical doctors were mostly supporting them by offering advice, experience and medical expertise.

The Polish Alzheimer’s Association (PAA) which dates back to 1992 marks the beginning of the Alzheimer’s movement in the whole country. We inspired and supported our colleagues in other Polish towns in the creation and growth of new organisations.

Today there are 34 of them all over Poland, mostly in big cities or towns, and although each one is independent, we are united by the National Agreement of Alzheimer’s NGOs which the organisations have signed. Such a solution gives each organisation more freedom and flexibility in its activities but also makes the whole movement more credible and powerful when it comes to raising awareness, especially during World Alzheimer’s Day or in lobbying the government. It also means that the Polish Alzheimer’s Association is responsible for coordinating the work of other organisations and represents the interests of people with dementia and their carers on an international level.

Every year the organisations meet at an Annual Conference where we present our achievements, failures or problems, discuss solutions and work out our priorities or common projects. In addition, the PAA runs a national help-line and distributes, free of charge, its educational publications to other associations and main libraries around Poland. The PAA has been an Alzheimer Europe member since 1992 and became an ADI member in 1997.

Among our numerous goals and tasks, the most significant has always been the support provided to individuals in need. It is the support which we have offered to thousands of people for 19 years that is the source of our greatest satisfaction and motivation. Often, after getting in touch with us, helpless, desperate or lost carers begin to believe that they will manage to cope, like others whom they can meet at the association’s support groups. This is a result of the carer being able to have an open exchange with an experienced carer or a psychologist (either of whom are full of empathy and understanding). During such individual sessions, we work out, together with the carer and sometimes the person with dementia, the best strategy for the present and for the future when the disease progresses and new symptoms appear. We make carers aware of the importance and need of including other family members in care and we suggest and inform them about ways of coping with negative emotions which might have to be overcome.
We also inform them about the disease, everyday care and nursing. We often stress that it is not enough to have intuition and to experiment, but that knowledge is important if one does not want to be surprised by new symptoms. We tell them that in order to avoid mistakes, which might otherwise lead to worsening the mood of the person with dementia or affect their well-being and sense of dignity, one has to know a lot, to read about the disease and listen to others as well as to share problems openly.

Without a positive attitude and readiness to know as much as possible, it is not only the person who needs our help who will pay for mistakes, but the whole family. As part of psychological counseling and support, carers may participate in individual or family therapies. Apart from that, on the first Saturday of every month we organise open educational meetings, not only for our members, but for anybody who wants to broaden their knowledge about Alzheimer’s disease. Among participants there are often professional carers, students, nurses and friends of families, interested in the problems of care and willing to help.

We understand very well that a carer cannot always be with us at such meetings. It is not easy to do that when you cannot leave the person you look after, alone at home. For such carers we have manuals, leaflets, or our quarterly newsletter “Bliżej Alzheimera” (Closer to Alzheimer’s”). They may also call us, write to us and receive advice and support through the internet. No one is left without help if they need it. Our association also provides a lot of practical information about other sources of support, about legal problems and regulations which is so important to people with dementia and their carers. Besides, we offer help in finding the right nursing home in Poland. There are more and more such homes, especially private ones, however they are often inadequate to the needs of people with dementia. We have created a data base of such institutions as our two volunteers have been visiting them, doing some field work and research and talking to the homes’ owners.

Most of our members are carers who are already retired and as their income is quite low we have decided to look for donors, encourage them to give us donations which are spent on buying basic care products, such as sanitary towels, pads, washing powder, bed linen, blankets, which make carers’ lives easier and lower the costs of care.

For three years, we also managed to offer nursing care at home to the association’s members. Our nurses taught carers practical nursing skills, necessary when one looks after someone in the final stage of the disease. They showed carers how to feed a person who had difficulty with swallowing, or how to change bed linen if someone cannot move, or how to wash a person who cannot be taken to the bathroom. There is of course always the need to continue this kind of support, but unfortunately with no money to pay the nurses, the project had to stop.

There were also financial reasons behind the decision to stop organising holidays for people with dementia and their carers. Between 1994 and 2006 a lot of our members had a chance to travel to a specially designed holiday resort. Today, because of the changes in financing this form of respite, it is no longer possible to offer such holidays.

Inspired by the success of Alzheimer Cafes in other countries which we heard about at conferences, we decided to try this form of support in

“After the campaign was over we felt the number of people visiting us or calling the association increased significantly.”
2009: Since December 2009 we have run Alzheimer Cafes in one of the cafeterias in Warsaw on the third Tuesday of every month between 6 p.m. and 9 p.m. Anybody who is interested in Alzheimer’s disease may come to talk with our volunteers, drink coffee and ask questions. A lot of people find this forum attractive.

Although helping people with dementia and their carers gives us the greatest satisfaction, when asked about our biggest success, we usually answer: it is raising awareness about dementia which we are most proud of. Already in 1993 we organised the first Alzheimer’s awareness week. The theme, which at that time was almost unknown to the general public and the media, was met with a lot of interest. At our first press conference there were more than 70 journalists from the press, radio and TV. Our publications – leaflets and posters – were distributed within minutes. Since then we have organized World Alzheimer’s Day every year and our stand in the Old Town draws people’s attention. It seems the awareness of the disease has increased greatly thanks to such educational campaigns. Most people know the name of the disease and its consequences. They are also aware that they can count on the support of NGOs, like ours.

Every year we also run media campaigns. A short film consisting of 7 episodes, each with a special message and information about typical symptoms, has always accompanied such campaigns. In 1998 we encouraged a producer of a very popular contemporary Polish soap opera “The Clan” to include a character with Alzheimer’s disease. The series enjoyed great popularity with 6 to 8 million viewers watching each episode, who could learn, among other things, what it means to have dementia.

Our members – carers and board members – have been invited many times to speak about Alzheimer’s disease in various TV programmes shown on public and commercial television. Several times a moving documentary about the life of a woman and her husband, our member, who was looking after her, was shown on public TV. Together with other NGOs, signatories of the National Agreement, we have been campaigning for the improvement of the quality of life of people with dementia in Poland. We focused on access to treatment and reimbursement of drugs. Before we started the campaign the cost of drugs was almost as high as a monthly pension of an average pensioner, making it very difficult to pay for treatment. Now in Poland, because of the availability of generic drugs, some Alzheimer disease drugs are not expensive.

However, reimbursement of the drug memantine is still needed. One of the campaigns on access to treatment and reimbursement was especially spectacular: the event was happening simultaneously in 6 towns where members of our associations were collecting signatures of ordinary people under a petition to the Minister of Health in which we urged for access to reimbursed drugs. In return for the signature, a person would get a handkerchief which they would then tie to make a knot, a symbol of remembering. The handkerchiefs were then collected and large baskets full of handkerchiefs were transported to the Ministry of Health together with the petition with people’s signatures. The action turned out to be a great success, supported by the media. Today they still remember it at the ministry as an example of a peaceful and effective campaign.

We also try to focus on general practitioners (GPs) in our educational campaigns, as we believe a lot depends on their attitude and knowledge. They are usually the first professionals whom carers or patients turn to for help. In one of our campaigns we sent leaflets informing about the importance of early diagnosis to 4,000 GPs from Warsaw and nearby towns and villages. Apart from a leaflet there was also a message in which we were asking doctors to let their patients know about our association’s help line and the support we provide. After the campaign was over, the number of people visiting us or calling the association increased significantly. Among our activities we are also trying to influence social policy to change and improve the situation of people
with dementia and their carers. In 2003, around World Alzheimer’s Day, we managed to organise a meeting of the Health and Social Policy Commission of the Polish Parliament. We presented the need to formulate a National Alzheimer’s Programme. The MPs who were participating in the meeting expressed their interest and respect for our work, however the outcome of the meeting remains rather poor. There is no such Programme yet, despite our continuous efforts to promote the idea whenever possible.

In August this year, an Alzheimer’s Coalition formed in Poland with 11 founding members (5 professors of neurology and/or psychiatry from the Polish Alzheimer’s Society, and 6 representatives of the Polish Alzheimer Organisation’s Forum). The Coalition’s first task is to organise a public debate on the development of a national Alzheimer’s plan for Poland.

When we look back and try to evaluate those 19 years of work for people with dementia and their carers, we can see how much we have done but also how much there is still to be done. It is not easy and with time it is getting even more difficult. For the third year our association is dealing with financial problems. Our costs have been cut to a minimum, we employ one person only and much of our work is done on a voluntary basis. In the 20th year of our existence we are facing a real threat of having to close our activities. Neither our members, nor the people who we are working for, can imagine that such a threat exists in a big country like Poland, where the capital city has 2 million citizens and where more than 400,000 people have dementia. It seems inconceivable that these people would be deprived of the help an association like ours can offer. What would people with dementia do? Where would they go to get information and comprehensive support?

The answer depends on finding out soon who really cares. Despite everything, we still do!

Poland – Facts and figures
In 2006, Alzheimer Europe carried out a survey of carers in France, Germany, Poland, Spain and the United Kingdom (Scotland). 201 Polish carers participated in the survey and the following are some of the key findings:
- 97% of patients were living at home with only 3% of patients being cared for in a nursing home.
- Over 50% of carers reported spending at least 10 hours a day caring for the patient regardless of disease severity.
- 87% of carers were caring for a person with Alzheimer’s disease and 10% for a person with vascular dementia.
- 65% of carers reported that the person with dementia had been informed about the diagnosis, whereas 35% had not.
- Only 33% of carers had been informed about the existence of the national Alzheimer’s association at the time of diagnosis.
- While 79% of carers knew of the existence of carer support groups, other services were less known, with 61% knowing about residential care, 53% about day care and 41% about respite care.
- Only 6% of carers felt that the level of care for the elderly was good in Poland and only 3% agreed that the cost of healthcare was reasonable.
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

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You can make a difference. Join the European Alzheimer’s Alliance today.
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ACTIVE AND HEALTHY AGEING

Alzheimer Europe spoke with the EU Research, Innovation and Science Commissioner, Máire Geoghegan-Quinn, the Director General of DG Health and Consumers, Paola Testori Coggi and also with the Director General of DG Information, Society and Media, Robert Madelin of the European Commission, about the EIP AHA and the impact it may have on people with dementia and their carers.

In 2010, the European Commission launched the Innovation Union to boost the European competitiveness while tackling societal challenges. The European Innovation Partnership on Active and Healthy Ageing (EIP AHA) is the first pilot Partnership of the Innovation Union. The backbone of this Partnership is that innovation can help the Member States tackle one current critical societal challenge common to all European countries: the ageing of the population.

Máire Geoghegan-Quinn, EU Commissioner for Research, Innovation and Science

Alzheimer Europe: Commissioner Geoghegan-Quinn, could you explain the Innovation Union and the European Innovation Partnership concepts?

Commissioner Geoghegan-Quinn (CG-Q): The Innovation Union action plan is at the core of Europe 2020, the EU’s overall economic strategy. It sets out a strategic approach to innovation focusing Europe’s efforts on key societal challenges like health and our ageing population, as well as climate change, energy and food security and resource efficiency.

The Innovation Union contains over thirty action points including ground-breaking proposals like the European Innovation Partnerships. These will mobilise stakeholders at EU, national and regional levels to tackle well-defined goals in areas that also hold potential for Europe to become a world leader in commercialising new technologies and methods.

For example the pilot Innovation Partnership on Active and Healthy Ageing, which was launched in early 2011, aims to extend by two years the proportion of our lives in which we enjoy good health. As well as having enormous benefits for older people and their families, this would also help to relieve the strain on public finances and boost the EU’s competitiveness in new and growing markets. The European Innovation Partnerships will serve as a framework to step up research and development, coordinate investment, speed up standard-setting and mobilise demand, for example through targeted public procurement.

Other challenges identified that could in future be addressed through European Partnerships include energy, “smart” cities and mobility, water efficiency, non-energy raw materials and sustainable and productive agriculture.
AE: The ageing of the EU population and the competitive decline of Europe are among the challenges and call for urgent action. How do you see the European Innovation Partnership on Active and Healthy Ageing concretely addressing these challenges?

CG-Q: The US experience shows that when politicians, industry and science sit down together and agree a clear strategic direction, this boosts public and private investment and makes things happen.

The pilot European Innovation Partnership on Active and Healthy Ageing will pursue a “triple win” for Europe:

- Enabling EU citizens to lead healthy, active and independent lives while ageing;
- Improving the sustainability and efficiency of social and health care systems;
- Creating new opportunities for businesses.

Work will focus on very concrete issues like standard-setting, coordinated public procurement of innovative products and services and advising the Commission, other funding bodies and also the private sector on R&D investment strategies.

AE: What policy and financial instruments will support the Innovation Union?

CG-Q: Legal instruments include EU legislation where necessary, to remove barriers to good ideas getting to market. One of the first examples is the proposal for a unitary EU patent, on which we are making real progress. The Commission has also made proposals on standards and freeing up venture capital. National policy instruments will be equally important and will involve everything from tax breaks for innovation to increasing investment in science education.

Financial instruments will support research at regional, national and European levels, and are already being tailored to fit the Innovation Union strategy.

One example is the current Joint Programming Initiative (JPI) on neurodegenerative diseases, which pools national research activities in this field, and should make an important contribution to the implementation of the Partnership on Active and Healthy Ageing, the aims of which it complements very well.

AE: The Member States are called upon to considerably increase their percentage of GDP dedicated to research by 2020. Will there be an assessment of how the Member States will be complying?

CG-Q: Because research is key to our economic future, Member States decided at the European Council of June 2010, to accept the Commission’s proposal to include the objective of “improving the conditions for research and development, in particular with the aim of raising combined public and private investment levels in this sector to 3% of GDP” amongst the Europe 2020 targets.

The European Commission’s 2011 Innovation Union Competitiveness Report shows that the EU is slowly advancing towards this target, investing 2.01% of GDP in research and development in 2009. The report also showed that seventeen Member States maintained or increased their R&D budgets in 2009 and sixteen did so in 2010. Early indications are that a similar result is likely in 2011. The 3% R&D intensity target is a shared target at EU level, not a “one size fits all” target applicable to every Member State.

This is why the European Council asked Member States to set national targets, taking account of their relative starting positions and national circumstances. Most Member States set R&D intensity national targets in their National Reform Programmes in April 2011. Progress will be monitored both by the Commission – as part of its Annual Growth Survey published every January – and by the European Council (heads of state and government) each year in Spring.

“It (the Horizon 2020 programme) will help to address the EU’s biggest societal challenges in a comprehensive way.”
AE: How will the next EU Research Framework Programme support the Innovation Union? In particular, how will the fragmentation of research and red-tape barriers be overcome to ensure that more EU stakeholders engage in research and benefit from EU research funding?

CG-Q: From 2014, the new Horizon 2020 programme will cover all research and innovation funding currently provided through the Framework Programme for Research, the Competitiveness and Innovation Framework Programme (CIP) and the European Institute of Innovation and Technology (EIT).

This streamlined framework will help to address the EU’s biggest societal challenges in a comprehensive way, covering all dimensions of the innovation process, from the production of new ideas to the transformation of knowledge into new products and services.

Horizon 2020 will also make it simpler to apply for and manage funding, so that researchers spend more time in the lab and less in the office, and taxpayers get the best value for every euro invested.

AE: EU funding of research into age-related diseases like Alzheimer’s disease and other forms of dementia is still lagging behind when compared to other diseases. Will DG Research ensure that dementia is a priority in the next Research Framework Programme?

CG-Q: I have to say that I do not agree that EU support for research into age-related diseases like Alzheimer’s disease is “lagging behind”. The EU has been strongly supportive of research into neurodegenerative diseases in the Seventh Framework Programme for Research and development (FP7).

About 319 million euro has been allocated to support research on neurodegenerative diseases between 2007 and 2011.

A substantial additional amount is expected to be allocated to projects resulting from the 2011 FP7 calls, where three out of four topics in the area of “brain research” address neurodegenerative diseases.

In addition, several other sections of the health calls are relevant to research on neurodegenerative diseases (such as diagnostics, medical technologies, innovative therapeutic approaches and personalised medicines).

The EU is also committed to supporting Member States’ initiatives, such as the “Neuron” network, whose activities have included linking up national programmes on neurodegenerative diseases.

Since 2010 we have also financed the JUMPAHEAD project, which provides coordination and support for the Joint Programming Initiative on Neurodegenerative Diseases (see above).

It is too early to determine in detail the precise content of the Horizon 2020 programme, however health and the ageing of our population will definitely be at its core – since my first day in this job I have identified tackling these issues as key among the societal challenges which EU-funded research and innovation must prioritise.
Paola Testori Coggi, Director General of DG Health and Consumers, European Commission

Alzheimer Europe (AE): Ms Testori Coggi, the ageing of the population has been identified as a major societal, economic and public health challenge. How will European Innovation Partnership on Active and Healthy Ageing tackle this issue?

Ms Testori Coggi (PTC): The ageing of the EU population is indeed one of the EU’s greatest challenges for the future. By the end of this decade, over 20% of the EU population will be 65 years or older. At the same time, the number of sufferers of conditions such as dementia is set to rise.

This is why we need to explore innovative ways to improve the health and quality of life of older people so that they can lead active, independent and longer lives. The European Innovation Partnership on Active and Healthy Ageing seeks to achieve exactly that. It looks beyond purely technical innovation, embracing a broad understanding of innovation from technology based and ICT enabled products and devices, to business models and social innovation.

Its goal is to raise the average healthy lifespan of Europeans by two years by 2020 by streamlining existing initiatives so that we can identify and remove current barriers to innovation. By working together across the research and innovation chain with all levels of government, with many sectors and a wide range of public and private partners, we will look at how to best translate innovative ideas into tangible products and services that really respond to the needs of Europeans.

At the same time, it addresses societal, economic and public health challenges as it would offer a better health and quality of life, particularly for older Europeans; create more efficient and sustainable health and care systems; and boost EU competitiveness and growth.

AE: Innovation is a major strand of this Partnership and has a large scope. From DG Sanco perspective, how can innovation improve the health and quality of life of older people and enable them to live active and independent lives? How can it contribute to the sustainability and efficiency of health and social care systems?

PTC: New health technologies have the potential to make health systems more efficient. At the same time, they can improve access to safe and good quality healthcare and deliver more patient-centred care. eHealth is a prime example as it can give patients access to the best medical expertise in the comfort of their own home, while health professionals can monitor their condition from a distance. This would make life easier particularly for older people.

By moving routine checks from hospital to home, telemonitoring can reduce hospital admissions and thus free up health professionals’ time and resources; and, at the same time, improve patient’s comfort and control over their own health. This is particularly significant considering that there will be a shortfall of around 1 million healthcare workers by 2020.

“We need to explore innovative ways to improve the health and quality of life of older people so that they can lead active, independent and longer lives.”
Furthermore, integrated care to better manage chronic diseases would be impossible without supportive eHealth technologies.

I believe better coordinated health and social care services for older people and new products which are developed to meet their needs, can certainly contribute to the accessibility, quality, sustainability and efficiency of health care systems in the long run. This is an approach strongly supported by the Partnership. If older people can live more actively and independently, the need for hospital care will be reduced, which will, in turn, help alleviate the pressure on public health and social budgets.

**AE:** How do you see people with dementia benefit from the Partnership? How are the carers of dependent elderly people included in this initiative?

**PTC:** The idea behind the Partnership is to use European public and private funds spent on research and innovation more efficiently, and to scale up and hasten the uptake of life improving and life-saving technologies. In addition, the Partnership encourages action on early diagnosis, clinical guidelines and integrated care solutions, which could benefit both carers and those suffering from dementia.

Carers of dependent older people are also included in the Partnership’s steering group, and I hope that they will be very active as their contribution is essential for the success of the Partnership.

**AE:** The respondents to the Commission’s open consultation see the Partnership’s role in 1) funding, 2) providing evidence and 3) identifying regulation and framework conditions as well as 4) building capacity and skills. How will DG Health and Consumers and DG Research and DG Information Society coordinate their work and involve interested partners to identify the very specific needs of an ageing population and engage these partners in working towards tangible outcomes?

**PTC:** A high level steering group has been created to guide the Partnership’s strategy towards achieving the partnership’s overall objectives. The steering group is made up of a wide range of backgrounds and communities who have an important role to play in delivering on the partnership’s promises.

In order to involve other interested partners, the steering group has also set up workshops to gather valuable input from a broader range of stakeholders to work on specific aspects of the partnership, such as the prevention, diagnosis and treatment of ageing-related chronic diseases. They also focus on integrated care systems, including home care provision, self-care, training for health and social care workers and support services for informal carers and social innovation.

Achieving the objectives of the Partnership requires a sustained effort from all partners to help turn this Partnership into innovative solutions that bring tangible benefits to Europeans.
Alzheimer Europe (AE): The ageing of the population has been identified as a major societal, economic and public health challenge. How will European Innovation Partnership on Active and Healthy Ageing tackle this issue?

Robert Madelin (RM): The ageing of our population is indeed a major challenge and opportunity. Over the next 20 years, the number of Europeans aged over 65 is expected to rise by 45% from 85 million in 2008 to 123 million in 2030 and the number of over 80+ will almost double in the same period. This continued increase in life expectancy is a major achievement, which at the same time risks putting an additional strain on the economy, society and the sustainability of public finances.

Public and private healthcare spending in the EU already accounts for 8.3% of GDP (2008), and, by 2030, due to ageing, total public age-related expenditure is expected to increase by 2.7% of GDP. This increasing economic burden is compounded by a shrinking and often insufficiently skilled workforce in the care sector. On the opportunity side, there is a large untapped potential of the ageing population to remain active and contribute to society for longer and to become consumers of new products and services targeting ageing consumers as a major new market opportunity in Europe. There are many research and innovation projects across Europe demonstrating the high potential of innovation to address these challenges so why do most of these remain isolated, local experiments or pilot projects and generally fail to scale up and become mainstream practice?

The results from the recent public consultation, organised to gather input from stakeholders on the European Innovation Partnership on Active and Healthy Ageing, broadly confirm there are major barriers to overcome. In particular involvement of demand side stakeholders in the innovation development process, policies to promote innovation within public authorities are lacking, current efforts and funding are fragmented across Europe and legal frameworks around care are complex, unclear or and often unpredictable. In addition common guidelines for innovative care are missing as well as harmonisation of regulatory requirements and reimbursement schemes within the single market and targeted standards for interoperability of devices and services.

Many stakeholders, including Member States, agree that finding effective solutions and producing more tangible impacts in active and healthy ageing, first and foremost, requires new ways of working together in a collaborative way across borders, across disciplines, across sectors and across institutions, setting common strategic directions and improving the coherence between different research, innovation and financing mechanisms. In response to this situation, the European Innovation Partnership on Active and Healthy Ageing aims to bring together major stakeholders from the demand and supply side of innovation in active and healthy ageing in order to overcome obstacles slowing down innovation from research to market. It will build on active engagement and commitment of these stakeholders to work together in defining common strate-
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gic priorities for innovation in active and healthy ageing, identify key barriers to be overcome and launch related actions to overcome these in order to accelerate and scale up innovation. The Partnership’s headline target is to increase Healthy Life Years (HLYs) by 2 additional years by 2020, and in achieving this pursue a triple win, i.e. improving health status and quality of life of the elderly, improving the sustainability and efficiency of health and social care systems, and developing and deploying innovative products, devices and services for ageing well, thus fostering competitiveness and growth of EU markets and businesses.

The Partnership is not meant to be a new funding instrument; it will be funded through optimising the use of existing EU instruments (e.g. FP7, EIB, structural funds, CIP), and by leveraging additional private and public funding. It will build on fostering synergies and mobilising expertise and resources across Europe by integrating all initiatives and tools into a coherent and coordinated framework, and complement with new actions where necessary.

AE: How can innovation improve the health and quality of life of people with dementia and enable them to live active and independent lives? How can it contribute to the sustainability and efficiency of health and social care systems?

RM: Dementia is an example of an age related impairment which has major negative consequences not only for the patient itself, but also for society (in terms of costs), for carers (in terms of stressful working conditions) and for relatives. We have unfortunately not yet a cure for dementia, but innovation has the potential to play a major role in earlier detection, preventive measures, prolonging independent living and assisting the formal and informal carers.

All of these solutions can also contribute to increased sustainability of the care systems, because if we can delay institutionalisation, make care work less stressful and help relatives to remain active on the labour market, while caring for relatives, this could have a major socio-economic impact. As an example the Commission has funded a set of pilot projects testing ICT solutions for prolonged independent living of people with milder cognitive impairments based on regional cooperation across Europe. These projects are developing sound socio-economic evidence on impacts on quality of life for the elderly and their carers as well as measuring efficiency gains of care. We need to get away from the common misconception that ICT is just expensive gadgets and solid socio-economic evidence of return of investment is one of the key ingredients to do this. In the context of the Active and Healthy Innovation Partnership we can then accelerate the further uptake as part of mainstream solutions across Europe, e.g. by mobilising investments by regions and industry.

AE: Information and Communication Technology (ICT), Assistive Technologies or Ambient Assisted Living are an intrinsic part of the Digital Agenda. How do you see people with dementia benefitting from these initiatives? How are the carers of people with dementia included in these initiatives?

RM: There are numerous examples on how ICT can be used in connection with dementia. For example, the EU is funding research to explore new ICT solutions to help to detect the disease earlier by unobtrusive long-term observation of changes in behavioural patterns. This is becoming realistic because due to the increased attention to the need for energy efficiency, we will soon have a host of different sensors in normal homes, all of
which could be used also for independent living and medical applications. ICT can also help to keep elderly people mentally and physically active through brain training and serious gaming, increase quality of life by extended independent living through safe and assistive environments providing reminders, remote assistance, safety monitoring and mobility tracking, thereby also facilitating the lives of formal and informal carers.

One of the mandatory success criteria for research and innovation in this field is to involve user representatives through all stages of the projects. Only in this way is it possible to assess the potential usefulness of the proposed solution and get a realistic measure of the possible impact. In this context it is also necessary to take care of design and usability of solutions in order to ensure that they genuinely will work and be acceptable, by developing and testing under realistic conditions. There are obviously important ethical aspects to be considered, which we do take very serious in all EU funded projects to ensure compliance with ethical rules for user involvement in research and innovation activities.

AE: The respondents to the Commission’s open consultation see the Partnership’s role as being linked to 1) funding, 2) providing evidence and 3) identifying regulation and framework conditions as well as 4) building capacity and skills. How will DG Health and Consumer Policy, DG Research and DG Information Society and Media coordinate their work and involve interested partners in identifying the very specific needs of an ageing population and engage these partners in working towards tangible outcomes?

RM: A great innovation of the Active and Healthy Ageing Innovation Partnership is indeed that it is a joint effort between DG INFSO, DG SANCO and DG RTD. By bringing together the Research, Innovation, Information Society and Health policies in the European Commission sends a strong signal to Member States and other stakeholders that this is a new approach with a strong policy backing within the Commission. This also means that we can build on a broad range of policy and funding instruments to help underpin the priorities for innovation from research to deployment. This cooperation is reflected by the direct cooperation between the involved Commissioners as well as the joint operation of the secretariat of the partnership. In addition we also involve other DGs in the Commission such as DG Employment, DG ECFIN and DG REGIO.

The steering group of the partnership ensures a broad involvement of representatives of key stakeholders, such as the Member States, regions, industry, service providers, health and social care professionals and elderly user organisations. This group has ownership of the development of priorities in the form of a strategic implementation plan which will set out the key areas for action and associated barriers to be addressed. This partnership is all about action, it is not just a talking shop. I am very encouraged about the interest and commitment which has materialised so far through more than 500 contributions to the public consultation and major interest in numerous workshops and events related to the development of the partnership priorities and commitment towards emerging actions.

I hope that beginning of next year you will start to see the first concrete actions emerging in response to the priorities set out by the partnership and that this will show how innovation can bring a substantial contribution to improving quality of life for people suffering from dementia as well as helping the dedicated formal and informal carers around them.

“The steering group of the partnership ensures a broad involvement of representatives of key stakeholders.”
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THE GLOBAL CRISIS OF ALZHEIMER’S DISEASE

Alzheimer Europe reports on the speech given by the French President, Nicolas Sarkozy, during the 2011 Alzheimer’s Association International Conference (AAIC) in July in Paris, France.

President Sarkozy, was introduced to delegates by Harry Johns, CEO of the Alzheimer’s Association, who expressed his gratitude for the President’s leadership of the Alzheimer’s movement and his leadership on the creation of what is a model plan for Alzheimer’s in the world.

Addressing the researchers within the audience, the President’s opening statement gave recognition to their work in the fight against Alzheimer’s disease when he said, “You represent the excellence of science in the world and you embody the hope of millions of patients who suffer and their relatives who are with them through this ordeal.”

President Sarkozy emphasised that the issues which surround Alzheimer’s disease go far beyond support and treatment, asking that consideration be given to wider issues such as what the proper position of the elderly and their families is within society. He said, “The humanity of our society is at stake through the place we give to our most vulnerable people and our ability to protect those who cannot take care of themselves.”

Since his election in 2007, the President has ensured that Alzheimer’s disease is a priority in France by his personal involvement in monitoring the implementation and progress of the national Alzheimer Plan. It is also possible, he explained, for every French person to follow the progress by visiting the plan’s website which provides regular progress reports on the internet.

For people with the disease there have been many improvements since the Plan was put in place. People with dementia are now able to be given guidance and offered the best options for their personal situation by the creation of the Medical Centres for Autonomy and Integration (MAIA). There are expected to be more than 100 such centres by the end of 2012. Better care facilities and home support should be available now as medical and paramedical personnel have received targetted training.

“The humanity of our society is at stake through the place we give to our most vulnerable people and our ability to protect those who cannot take care of themselves.”
The President also spoke also of France’s “unprecedented research support programme,” which has included more than 600 doctors being trained in clinical research on Alzheimer’s disease since 2008. Over 100 research projects are currently being funded in France which represent a wide range of research areas, including basic, clinical, social science, management of the disease, early detection and research into improving the quality of life of people with dementia. The planned overall spending on research over the five years of the Alzheimer’s plan was for EUR 200 million of which EUR 70 million have already being allocated.

Other advances are being made. France has provided researchers with the ability to study the natural history of the disease by creating the “Memento” cohort which consists of some 2,500 people with Alzheimer’s disease. Universities have been given autonomy enabling them to build partnerships, attract the best researchers and best teachers. Since 2007 state investment in higher education and research has increased by EUR one billion each year, despite the economic crisis.

In addition, EUR 200 billion will be dedicated to higher education and research with EUR 2.5 billion being earmarked in the field of health and biotechnology. The President confirmed the status afforded to Alzheimer’s disease research when he said, “As you can see, research on Alzheimer’s disease has a particularly favourable environment in France since our country has an attractive tax policy and tools for researchers to give their best performance.”

The global crisis of Alzheimer’s disease, he said, demands international collaboration. Obstacles to this collaboration, such as personal interests and national conflicts, need to be removed if we are to alleviate the suffering of people with dementia and their families. The President spoke with pride of France’s support for such collaboration in the Presidency of the European Council as well as the current European collaborative research programme (Joint Programming) whereby 23 countries are working together to fight Alzheimer’s disease. He also highlighted the fact that, due to international collaboration, within the last two years alone, more than 10 new genes have been identified. He said to the conference delegates, “you represent the largest research teams in the world. You know that nothing great is done alone. The international dimension is crucial to serve science and medicine in the area of advanced technology and global health challenges.”

Raising the issue of addressing Alzheimer’s disease within the context of the global economic crisis, the President said “The question is not about debt, but getting in debt for what. If it’s getting in debt for economic progress, or for innovation, then I think it is a source of future profit. This is a major choice that France has made.” With respect to the investment made to the national Alzheimer’s plan, he said “We have committed EUR 1.6 billion. This is considerable – but I tell you, this is less expensive – giving means to researchers and doctors, than waiting for the development of the disease.”

To the applause of the audience, the President closed by reaffirming France’s commitment to the fight against Alzheimer’s disease by saying “I want to assure you of the utter commitment of my Government. You can count on France for help.”
Nicola Sturgeon, the Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy in Scotland, talks with Alzheimer Europe about the priorities and challenges of the Scottish Dementia Strategy.

Alzheimer Europe (AE): What are the key priorities of the Scottish Dementia Strategy?

Nicola Sturgeon (NS): We published Scotland’s first national dementia strategy in June 2010, determined to make a real and measurable improvement to the quality of dementia services, and people’s experience of them, over an initial 3-year period. As we’ve moved into this second term, I’ve made improving dementia services for people at all ages, and care for all older people, personal priorities.

Prior to publication of the strategy, we had made some significant progress – particularly in increasing the number of people diagnosed with dementia. We wanted to build on that, in recognition that people are often not receiving the level of care to which they are entitled; but also to lay the groundwork for the long-term transformation of dementia services across all sectors to accommodate the increasing number of people with the illness.

The strategy is focussed on two main improvement areas – support after diagnosis and treatment in acute general hospitals. We need to improve the former so that people with dementia, and their families and carers, are enabled to get the full range of support needed after diagnosis, and as the illness develops. Often there is a long period between an initial diagnosis and a next contact with services during a crisis, and we need to prevent that happening unnecessarily.

On acute general hospitals, we know that care is often not good enough for people with dementia and can, sometimes, go very wrong. It’s vital that we improve this situation and I’ve asked my Chief Nursing Officer to use our new dementia standards to give assurance that acute settings are capable of providing safe, effective and compassionate care.

AE: At the Alzheimer Scotland conference in June this year, you launched two key documents (Standards of Care for Dementia and Promoting Excellence, a skills framework for health and social services staff). How do you see these helping people with dementia and their carers in Scotland?

NS: Implementation of the standards and Promoting Excellence in tandem is key to driving change in dementia services.

The standards describe what good quality services should look like across all settings and were produced in large part in recognition that, as the illness develops, people with dementia often have difficulty in getting the care to which they have a right. The standards empower people and their families to get the care they are entitled to, and they will also, of course, inform the auditing, commissioning and scrutiny of services.

“The strategy’s value is that it was developed with the close and committed involvement of the voluntary and independent sector in Scotland, and people with dementia and their families.”
Promoting Excellence is designed to help services and their workforces meet those standards by taking a comprehensive approach to developing and enhancing the skills and knowledge of all of those in health and social care settings who have contact with people with dementia. This approach, of course, includes all staff in general hospital settings, where changes in practice will be so important.

AE: What role can patient organisations and the non-governmental sector play to ensure that the Strategy is implemented successfully?

NS: The strategy’s value is that it was developed with the close and committed involvement of the voluntary and independent sector in Scotland, and people with dementia and their families. It was important to us that Alzheimer Scotland and The Scottish Dementia Working Group (who are a campaigning group of and for people with dementia within Alzheimer Scotland) endorsed our approach, and they and others are significantly involved not only in implementing the strategy at a national level but also in terms of delivering and supporting local services.

AE: The Strategy was launched during a time of global economic crisis. Do you believe the aims of the strategy will be fully realised within the three year (2010-2013) time frame?

NS: When publishing the dementia strategy we were upfront about the significant challenges facing the public sector in Scotland as elsewhere, and that we have to work within those constraints while delivering and sustaining dementia services for a steadily growing number of people. However, our approach is not reliant on strategic or new investment in services – it’s about changing the way the existing workforce responds to people with dementia and supporting and enabling that change.

AE: How will the longer-term objectives of the Strategy be addressed after 2013?

NS: We will refresh the strategy after 2013 and progress made by then will inform that refresh. Our approach is to take initiatives, like publishing standards, where we can be confident they will effect change, while in the process learning more about how we lever further change – and feeding that learning into our approach after 2013.

So, as part of the strategy, we’re supporting 3 local partnerships to demonstrate the benefits of more integrated, cost-effective local dementia care systems, moving from a traditional emphasis from high-cost long term care settings to more community-based services where the involvement of people with dementia and their families and carers is a central part.

The bigger picture, of course, is the future configuration of all services for our expanding older population and we’ve been taking forward a parallel strategy to tackle that broader and longer-term issue, including providing a £70 million Change Fund for this year alone to enable local health and local authority partnerships to take innovative, whole-system approaches to restructuring and reprioritising local care systems.

On a final note, thank you for inviting me to talk to your readership about Scotland’s approach to dementia. I know Scotland will be represented at your Warsaw Conference, where there will be further opportunities to share the Scottish experience and for us to learn from the approaches of other administrations.

For further information on the National Dementia Strategy in Scotland please write to david.berry@scotland.gsi.gov.uk
Europe national dementia strategies

In this article, Alzheimer Europe gives an overview of the current status of national dementia strategies around Europe.

Alzheimer Europe identified the need for countries to have a national dementia strategy in its political priorities listed in the Paris Declaration of 2006. At that time there was a national plan in place in France and in the Netherlands. In 2008, dementia was given unprecedented exposure during the French European Presidency and since that time the development of national plans throughout Europe has been gaining momentum. Currently there are ten national strategies in place within Europe (see map) and a further eight countries have commitment at governmental level to develop a national dementia strategy.

Austria: There is no national dementia plan in Austria at present. At the beginning of 2010 a national report on dementia was completed which included contributions from the national Alzheimer association, Alzheimer Angehörige Austria.

Belgium: In Belgium, the regions (Flanders and Wallonia) each have a dementia plan. In Flanders the “Dementia Plan 2010-2014” is complemented by a Flemish governmental campaign to establish a different view of dementia and to put the person with dementia in the spotlight.

Bulgaria: There is no national plan at present. The national association, Alzheimer Bulgaria, has called for the development of a plan. In April 2011, Antonyia Parvanova, MEP (Bulgaria) participated in a round table discussion in Bulgaria at which the lack of a national plan on the political level was discussed.

Cyprus: Work commenced on a draft plan in January 2010 which is now complete. In September 2011, the draft is due to be discussed with the multidisciplinary committee at the Ministry of Health.

Czech Republic: In September 2010, the government of the Czech Republic invited various stakeholders to collaborate and prepare a “Plan Alzheimer”. The draft Plan should have been published in June 2011, but will now be delayed until the autumn of 2011.

Denmark: In 2010 the four-year Action Plan for Dementia (National Handlingsplan for demensindsatsen) was launched and EUR 4 million was allocated to implement the plan over a four-year period. This figure represents a significantly lower amount than is allocated for other action plans regarding other diseases in Denmark excluding cancer and according to Alzheimerforeningen does not match the challenges of the growing number of people with dementia in the next 10-30 years.

Finland: The Finnish Ministry of Health announced plans for the development of a Finnish Alzheimer’s Plan in October 2010. The working group is due to report back at the end of 2011.

France: The French President, Nicolas Sarkozy, announced the 3rd “French Alzheimer Plan” on 1 February 2008, pledging 1.6 billion euro to the five-year programme. In February 2011 the 3-year review of the plan took place with the President,
government ministers and experts taking part. All participants agreed that the 3rd plan should be followed by another, which should be just as ambitious in order to maintain the momentum and capitalise on advances made.

**Germany:** Germany does not have a national dementia plan. However, the issue of dementia is addressed by various Ministries (Health, Family, Seniors, Research, Work and Social Affairs).

**Greece:** There is no approved national dementia plan in Greece. A plan has been developed and submitted to the Greek parliament by the Greek Federation of Alzheimer’s Disease and Related Disorders. The Federation also presented a petition with the signatures of more than 15,000 people who supported its campaign for a national dementia plan to the Mayor of Athens and representatives from the Ministry of Health in September 2010.

**Ireland:** The newly-elected government’s programme in Ireland contains a commitment to the development of a National Dementia Strategy by 2013. Preparatory research and scoping work commenced this year, led by dementia academics with the Alzheimer Society of Ireland being an active member of the expert working group.

**Luxembourg:** After the 2009 elections, the development of a “plan démence” (Dementia Plan) became an integral part of the coalition agreement. Work has started in 2011 with the setting up of four working groups to make concrete recommendations by the end of 2011.

**Malta:** There is a draft National Dementia Strategy in Malta and it is hoped that the implementation will commence in 2012 and continue to 2020. This draft is based on previous work done by the Dementia Strategy Group (DSG) which was launched in May 2009 by the Parliamentary Secretary for the Elderly and Community Care. It
is a comprehensive strategy, which provides direction in the various areas of dementia care from increasing awareness, to improving early diagnosis, to increasing support to dementia patients and their families and providing end of life and palliative care.

**Netherlands**: The three-year Dutch “Dementia Care Plan” was announced by the State Secretary for Health, Welfare and Sports, Dr J Bussemaker, in 2008. This followed the evaluation of the earlier Dutch National Dementia Programme (2004-2008).

**Norway**: The Norwegian Ministry of Health and Care Services launched a 7-year national dementia plan, “Demensplan 2015: den gode dagen” (Dementia Plan: making the most of good days) in 2007. Demensplan 2015 forms part of the national care plan for the coming years.

**Poland**: In Poland there is not a national strategy for Alzheimer’s disease. At the end of August 2011, an Alzheimer’s Coalition was formed in Poland which will campaign for a national Alzheimer’s plan.

**Portugal**: In October 2010, the Portuguese Parliament approved two resolutions proposing the recognition of dementia as a national priority and called for a national dementia plan to be drafted.

**Romania**: The Romanian Alzheimer Society, Societatea Română Alzheimer, sent letters asking for the development of a national plan to government departments in January and June this year. No replies have been received yet.

**Spain**: Spain does not have a national dementia strategy. Led by the Spanish Alzheimer Federation, CEAFA, the “Alzheimer’s Alliance” (which includes a cross-section of national organisations such as Spanish Societies of Neurology, Geriatry, Primary Attention and the Foundation Pasqual Maragall) aims to ensure a National Alzheimer Strategy is implemented. The Alliance is due to have a formal meeting with the Health Ministry to discuss a national plan, but the meeting has been delayed due to the forthcoming national elections in November 2011.

**Sweden**: The national dementia strategy in Sweden came into force in May 2010. Entitled “National guidelines for people with dementia diseases”, the strategy was set up by Socialstyrelsen and the government.

**Switzerland**: In Switzerland, two motions on the need for a dementia plan were unanimously accepted earlier this year by the Conseil National. The next stage is for the second chamber (Conseil des Etats) to vote on the motions in the autumn. Should they be accepted, the government will have to develop a national Alzheimer’s plan.

**Turkey**: There is no state-developed or state-confirmed national strategy. In 2010 the Turkish Alzheimer Society developed a national strategy. The main pillars are: a) to enhance efforts for increasing awareness at all levels of society, b) to support development of respite care, day care centres and nursing homes in terms of care, c) better training of primary care physicians, in particular of newly established family physicians in terms of diagnosis, d) to increase cooperation with legislators in order to improve legislation in support of people with Alzheimer’s disease and their families.

**UK (England)**: In February 2009 the “National Dementia Strategy for England: Living well with dementia” was launched. The five-year plan was supported by an extra investment of GBP 150 million to support local services to deliver the strategy. A revised implementation programme
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was published in 2010 when the newly-formed coalition government pledged to continue to implement the strategy. A Dementia Action Alliance of over 50 organisations has been formed to ensure the plan happens.

**UK (Northern Ireland):** The consultation period for Northern Ireland’s first dementia strategy ended in September 2010. The Alzheimer’s Society participated in the consultation. In November 2010 a summary of responses to the consultation were published by the Department of Health Social Services and Public Safety entitled “Improving Dementia Services” but the strategy, which was due to be published before May 2011 (when the Assembly elections took place) has not yet been published.

**UK (Scotland):** The Scottish government published its national dementia strategy on 1 June 2010. It has a timeframe of 3 years. Two further documents were launched in June 2011: “The care standards for dementia” and “A framework for staff working with people with dementia”.

**UK (Wales):** The Welsh Assembly voted unanimously for a Dementia Plan in July 2008 and the plan “A dementia vision for Wales” was launched in February 2011. The Welsh Government announced additional funding of £1.5 million each year to support and implement the action plans. There has also been an additional £400,000 one-off funding to improve training and information on dementia.
POLICY DEVELOPMENTS

Recent European and national developments are reported on which may impact people with dementia and their carers.

Three workshops organised on the European Innovation Partnership on Active and Healthy Ageing (EIP AHA)

In June, the European Commission organised three workshops in June to discuss the leading themes identified by the EIP AHA Steering Group after the Commission public consultation. The workshops were: (i) assisted living of older people, social inclusion of older people and ageing at work; (ii) prevention, screening and early diagnosis and (iii) integrated care, management of chronic conditions, evidence, cost-effectiveness and cost-efficiency.

Council agreement on 2012 as European Year of healthy ageing and solidarity between generations

At its meeting in June 2011, the Council agreed in principle on 2012 to be the European Year of healthy ageing and intergenerational solidarity. The objectives are to raise awareness about the value of active ageing and highlight the contribution that older people can make to society and to the economy, facilitate exchange of ideas and good practice on how best to promote active ageing policies, offer a framework for action to support the development of policies and specific activities that will encourage active ageing and solidarity between generations.

Trio Presidencies work programme discussed

The General Affairs Council discussed the Trio Presidencies (Poland, Denmark and Cyprus) draft work programme (July 2011 – December 2012) at its meeting in June 2011. The strategic framework of the programme is set within a wide context with long-term objectives running into the subsequent three Presidencies (Ireland, Lithuania and Greece have thus been consulted). The overreaching theme will be the recovery from the economic crisis and foundations for future growth.

Report published on cost effective dementia services

In the UK, the report “The £ 20 billion question – an inquiry into improving lives through cost effective dementia services” was published in July 2011. The report is a summary of the findings of an inquiry carried out by the All-Party Parliamentary Group on Dementia (APPG). The inquiry highlighted the need to focus on early intervention and prevention to reduce early entry to residential care and reduce unnecessary hospital admissions. It also calls on the health and social care system to work closely to improve the efficiency and quality of dementia services.

UK invests GBP 18 million in dementia research

In August the UK the government has announced a total investment of GBP 800 million in health research, GBP 18 million of which is allocated to dementia research. The GBP 18 million will be divided between four new biomedical research units (at the University of Cambridge, Newcastle University, Kings College London and University College London) which specialise in dementia research.
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National Dementia Summit takes place in Ireland.

Edward McLaughlin (above) and James McKillop (below) are each awarded an MBE.

Members’ News
A snapshot of the recent activities carried out by some of Alzheimer Europe’s member organisations.

Science Watch Round up
Highlights from recent scientific developments in the areas of prevention, diagnosis and treatment of dementia.

Dementia in Society
A look at how dementia is portrayed in the general media.

Putting a Face to Commitment
Alzheimer Europe reports on recent awards given to people for their work in the field of dementia and on personnel updates in national Alzheimer associations.
MEMBERS’ NEWS

In this article we provide an overview of some of the National Alzheimer associations’ recent activities

**Germany:** The May edition of the German Alzheimer Association’s journal, Alzheimer Info, was dedicated to what constitutes a good nursing home for people with dementia. The report highlights the fact that care home managers need also to be trained and qualified to manage care homes for people with dementia. There are also articles concerning the selection of a suitable home (including a checklist and useful references websites), the rights of nursing homes residents and an article on problems which may arise from nursing notes.

**Greece:** Magda Tsolaki, the President of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders, was invited by Leonidas Grigorakos, the Chair of the Special Driving Committee of the Greek Parliament, to make a presentation on the issue of driving and dementia on 23 June 2011. Professor Tsolaki’s presentation, entitled “Dementia – giving up driving: A painful but necessary condition” highlighted various issues surrounding dementia and presented facts of many studies that have been conducted regarding the driving behaviour of elderly people suffering from dementia, the accidents that derive from this condition and the Greek law framework in comparison to the European laws. A proposal made by Professor Tsolaki (whereby people with dementia could be examined by means of a Mini Mental State Examination to help determine driving capability and responsibility) has been put on the agenda of the Special Driving Committee.

**Iceland:** The Nordic Alzheimer associations (from Norway, Finland, Sweden, Faroe Islands, Iceland and Denmark) met for three days at the end of June in Iceland with the aim of “inspiring each other and discussing common challenges and solutions in their work”.

A fundamental problem for the associations was identified as the need for more financial resources. Participants shared suggestions for better funding, such as applying to the Nordic Council, the EU and public foundations, “going out with the collection box” and sending letters to relatives of deceased dementia sufferers. Several solutions were suggested for raising awareness of dementia including better information on the possibilities a person can have when living with dementia, on factual information and by asking well-known personalities to be spokespeople for the associations. In addition, prior to general elections, participants agreed that a campaign should be launched whereby postcards would be sent to all politicians, calling on them to include issues on dementia in their political campaigns. To improve the quality of life for people with dementia and their carers suggestions included the provision of more information and better support measures, more day care centres and by offering special interest activities (such as high school courses, visits to museums and swimming lessons).
Ireland: In June 2011, the Alzheimer Society of Ireland hosted a National Dementia Summit at Buswell’s Hotel, Dublin and Dail Eireann (House of Parliament) to mark the 2011 Carer’s Week. The aim of the Summit was to secure a mandate from carers and people living with dementia on what is needed in Ireland to live well with dementia. A spokesperson from the Society said that “The Summit was a phenomenal success involving 21 family carers and people living with dementia from all over the country”.

Following focus groups sessions in the morning, CEO Maurice O’Connell led the group across to Dail Eireann, under the invitation of Minister for Disability, Older People, Equality & Mental Health, Kathleen Lynch T.D., where there was an opportunity for some of the politicians to hear more about the issues raised. During lunch, people had an opportunity to speak to high profile politicians including the Minister for Health, James Reilly T.D. and Minister for Environment, Community and Local Government, Phil Hogan T.D.

In the longer term the Alzheimer Society of Ireland will be producing a report based on the group’s feedback and what they feel is necessary to live well with dementia in Ireland.

UK (England and Wales): The Alzheimer’s Society organised its 2011 Dementia Awareness Week campaign, entitled “Remember the Person” in June. A spokesman explained “the idea of ‘Remember the Person’ is encouraging people to be a friend to someone with dementia. It is trying to take the fear out of dementia and make people realise that people living with dementia are just people. It gives them ten simple things they can do to help a family living with dementia that will hopefully get people to support families living with dementia more.”

UK (Scotland): In collaboration with the University of Edinburgh, Alzheimer Scotland announced the opening of a new Dementia Research Centre in September which aims to “provide a high quality environment for dementia research, commission and develop a balanced portfolio of scientific and clinical research, attract external dementia research funding, and develop and maintain a Dementia Brain Tissue Bank.” The Centre will be led by Professor John Star, Co-director of the Centre for Cognitive Ageing and Cognitive Epidemiology.
Below is a selection of the recent scientific developments in the prevention, diagnosis and treatment of dementia

**Prevention and risk factors**

**Certain health problems may be associated with risk of dementia**

A 10-year study on over 7,000 people over the age of 65 suggests that a person’s likelihood of developing dementia increased if they had certain health problems (including arthritis, poor eyesight, broken bones and skin or chest problems) and that the more problems a person had, the greater the risk of dementia. The study was conducted by scientists at Dalhousie University, Halifax, Nova Scotia, Canada and published in the journal Neurology (14 July 2011).

**Relationship between US veterans with traumatic brain injury and dementia examined**

Medical records of 281,540 US veterans aged 55 years and older were reviewed and the database for traumatic brain injury (TBI) and dementia diagnoses was searched. The risk of dementia was 15.3% in those with a TBI diagnosis compared with 6.8% in those without a TBI diagnosis, leading researcher Kristine Yaffee to conclude “The data suggest that TBI in older veterans may predispose them toward development of symptomatic dementia.” The study was conducted by Kristine Yaffee, Professor of Psychiatry, Neurology and Epidemiology, University of California, San Francisco (USCF), USA and colleagues and reported on during the Alzheimer’s Association International Conference on Alzheimer’s disease in France (18 July 2011).

**Study suggests ways in which to prevent 3 million cases of Alzheimer’s disease**

The findings from a study suggest that by reducing the prevalence of certain lifestyle-based, chronic disease risk factors by 25 per cent that, potentially, 3 million cases of Alzheimer’s disease worldwide could be prevented. Researchers used a mathematical model to calculate the percentage of Alzheimer’s disease cases that may be attributable to diabetes, mid-life hypertension, mid-life obesity, smoking, depression, low education attainment and physical inactivity. Large-scale studies have been called for. The study was carried out by Deborah Barnes, Associate Professor of Psychiatry at the University of California, San Francisco and mental health researcher at the San Francisco Veterans Affairs Medical Center and colleagues and presented at the Alzheimer’s Association International Conference in Paris, France (19 July 2011).

**Diagnosis**

**Some doctors struggle to identify people in the early stages of dementia**

A study suggests that general practitioners (GPs) are “struggling to correctly identify people in the early stages of dementia resulting in both missed cases (false negatives) and misidentifications (false positives).” The researchers examined 30 previous studies involving 15,277 people in primary care for cognitive disorders, including 7,109 assessed for dementia. GPs managed to identify
eight out of ten people with moderate to severe dementia. However, most with early dementia were not recognised. The research was conducted by the University of Leicester, UK, the National Collaborating Centre for Mental Health, UK and the Department of General Practice, Düsseldorf, Germany (20 June 2011).

Study examines the relationship between the retinal changes and Alzheimer’s disease

A small pilot study investigated whether characteristics of blood vessels in the retina might serve as possible biomarkers for Alzheimer’s disease. By examining retinal photographs of people with Alzheimer’s disease, mild cognitive impairment and healthy participants, researchers found that the width of certain blood vessels were different for people with Alzheimer’s disease. The study was carried out by Shaun Frost, CSIRO Australian e-Health Research Center, and colleagues and reported on during the Alzheimer’s Association 2011 International Conference on Alzheimer’s disease in Paris, France (17 July 2011).

Alzheimer’s disease symptoms may be less noticeable in people over 80

A study which measured cognitive function in people with and people without Alzheimer’s disease found that whilst both groups had similar levels of cognitive impairment that “the pattern of changes associated with Alzheimer’s disease appeared to be less noticeable in people over the age of 80 (very-old) compared to those between the ages of 69 and 75 (young-old).” Researchers concluded that the study illustrated the effect age can have on the profile of brain atrophy and cognitive changes in Alzheimer’s disease. The study author was Mark Bondi, PhD, University of California San Diego School of Medicine and VA San Diego Healthcare System, USA and the research was published in Neurology, the medical journal of the American Academy of Neurology (10 August 2011).

Treatment

Potential explored of cancer drug use for treatment of people with dementia

A mouse study using a cancer-treatment drug known as Suberoylanilide hydroxamic acid (SAHA) suggests that it may be useful to treat familial fronto-temporal dementia (FTD). The mouse study appeared to show that treatment with SAHA could overcome the chemical deficiency (an imbalance in the levels of the protein progranulin (GRN) associated with FTD. Further studies are required to see if SAHA can cross the blood-brain barrier. Joachim Herz, University of Texas Southwestern Medical Center, Dallas, USA and colleagues and published on line in the Journal of Biological Chemistry (1 June 2011).

The role of painkillers in treating agitation in people with dementia examined

A study on over 300 people with moderate or severe dementia has found that painkillers reduced agitation in some people with dementia. Researchers concluded that some agitation may arise from untreated pain and that if the pain was properly managed that doctors may be able to reduce the number of prescriptions for antipsychotic drugs. The British (Kings College, London) and Norwegian study was published on the British Medical Journal (BMJ) website (18 July 2011).

Symptoms of dementia may be helped by the use of music intervention

A study on 100 elderly people with dementia has found that agitated behaviour can be alleviated by group music intervention. The researchers concluded that group music intervention in routine activities could be incorporated into nursing facilities for elderly people with dementia in order to “enhance emotional relaxation, create interpersonal interactions and reduce future agitated behaviour”. The study was carried out by Yu Lin, from Taipei Medical University, Taiwan and colleagues. It was published in the journal of Geriatric Psychiatry (29 July 2011).
PUTTING A FACE TO COMMITMENT

Alzheimer Europe reports on recent awards in the field of dementia and new personal appointments.

**Scientists recognised for their work in the field of Alzheimer’s disease**

Four scientists have been recognised for their “extraordinary contributions to Alzheimer's disease research”. The honorees are:

- Kaj Blennow, MD, PhD, Department of Neuroscience and Physiology the Sahlgrenska University Hospital in Sweden, who received the 2011 Henry Wisniewski Lifetime Achievement Award for his “groundbreaking contribution to a greater understanding of cerebrospinal fluid (CSF) biomarkers for Alzheimer’s disease”.

- John Hardy, PhD, Department of Molecular Neuroscience and Reta Lila Western Laboratories, UCL Institute of Neurology United Kingdom, who received the 2011 Khalid Iqbal Lifetime Achievement Award. Geneticist, John Hardy, led the research group that found the first amyloid mutation related to Alzheimer’s disease and formulated the amyloid hypothesis.

- Margaret Pericak-Vance, PhD, John P. Hussman Institute for Human Genomics University of Miami, Miller School of Medicine who received the 2011 Bengt Winblad Lifetime Achievement Award. For more than two decades, she has played a major role in advancing the understanding of the genetics contributing to Alzheimer’s disease.

- Bruce Lamb, PhD, Department of Neurosciences, Lerner Research Institute of the Cleveland Clinic; Cleveland Clinic Lerner College of Medicine; Departments of Neurosciences and Genetics at Case Western Reserve University, who received the 2011 Zaven Khachaturian Award. Bruce Lamb spearheaded and chaired the Alzheimer’s Association’s Breakthrough Ride in 2010. In Washington, Lamb and his fellow riders and researchers delivered more than 110,000 petition signatures urging Congress to make Alzheimer’s disease a national priority.

The awards were announced during the Alzheimer Association International Conference (AAIC) 2011 in Paris.

**Two members of the Scottish Dementia Working Group receive recognition for their work**

Edward McLaughlin and James McKillop both ex-chairpersons of the Scottish Dementia Working Group (SDWG) have been awarded MBEs from the Queen.

Mr McLaughlin will receive the award at a ceremony in October. It will be given in recognition of his work in raising awareness of dementia as well as his demonstrating ways in which people can live well with the disease. The Chief Executive of Alzheimer Scotland, Henry Simmons, said “Alzheimer Scotland
are greatly pleased that Edward’s achievements and those of the Scottish Dementia Working Group have again been publicly recognised. Edward has never shied away from discussing his illness and helping others to improve their understanding of it.”

James McKillop, founding member of the Scottish Dementia Working Group, received an MBE from the Queen in July in recognition of his work to improve the rights of people with dementia and raising awareness of the disease. Henry Simmons, said “James is a true inspiration to us all: using his own experiences of dementia to make a huge difference to the lives of countless others who have the illness.” The SDWG have brought an important and much-needed new perspective of dementia to health & social care professionals, politicians and the media – their impact cannot be underestimated.

The SDWG is an independent group run by people with dementia, the purpose of which is to campaign to improve services for people with dementia and to improve attitudes towards people with dementia.

Alzheimer Europe appoints new Communications Officer

Alex Teligadas joined Alzheimer Europe as the new Communications Officer of Alzheimer Europe on 1 September 2011. Previously Alex worked for 14 years in marketing and communications with the satellite and communications company SES ASTRA. Alex will be in charge of the newsletter and the website and represent Alzheimer Europe on various projects. The previous Communications Officer, Julie Fraser, will continue to work with Alzheimer Europe as the Editor of the Dementia in Europe magazine.

Alicja Sadowska reelected as chairperson of the Polish Alzheimer Association

The Board of the Polish Alzheimer Association reelected Alicja Sadowska as the Chairperson of the Association for a term of three years from April 2011. Ms Sadowska is also a member of the board of Alzheimer Europe.

“James is a true inspiration to us all: using his own experiences of dementia to make a huge difference to the lives of countless others who have the illness.”

Henry Simmons
Dementia in Society

A brief look at news items on dementia within the media.

22 June 2011: Country music star diagnosed with Alzheimer’s disease

Grammy Award winner and US country music star, Glen Campbell, has been diagnosed with Alzheimer’s disease. He plans to retire this year with a series of farewell concerts. Famous hits include “Rhinestone Cowboy” and “Wichita Lineman”.

23 June 2011: Actor Peter Falk dies with Alzheimer’s disease

Actor Peter Falk, who played the character “Columbo”, has died with Alzheimer’s disease. Mr Falk’s 50-year career included work on Broadway (e.g. Don Juan, Diary of a Scoundrel), on TV and in films (e.g. Wind Across the Everglades, Murder Inc., Pocketful of Miracles, Husbands and A Woman under the Influence). He was nominated for Best Supporting Actor in 1961 for his role as Abe Reles in the film Murder Inc. He is perhaps best known as Lieutenant Columbo in the TV crime series “Columbo” for which he won four Emmy Awards and a Golden Globe. An accomplished artist, Mr Falk exhibited his artwork in 2006 at the Butler Institute of American Art. He also published his memoir, “Just one more thing”, in 2006.

10 August 2011: Actor Larry Hagman talks of his experience of living with his wife who has Alzheimer’s disease

Actor Larry Hagman, who starred in the TV series Dallas, has spoken about the effects of Alzheimer’s disease has had on his wife, Maj. He said “Alzheimer’s hasn’t robbed her of the knowledge of who I am, but I dread that day. She can remember things that happened 50 years ago but she can’t remember what she had for breakfast.” After caring for her, Mr Hagman eventually found it necessary to move her to a flat where she has constant care. He said “It is hers and she feels safe and she has 24-hour care. I still go and see her every day for lunch and more if I can.” He added “I miss her every day. We were a good team.”

10 August 2011: UK court allows Alzheimer’s disease case to be reported

As a legal first, Judge Mr Justice Ryder has allowed the reporting of Court of Protection case (which usually sits in private) whilst it is in progress. Journalists were allowed into the hearing of a case concerning a family’s wish to care for SJ, their 92-year old father who has dementia and whose family believes he has been unlawfully deprived of his liberty for nearly six months. In addition, the family claims that SJ has been denied contact with his son. The local authority disputes this, claiming that the father “lacks the mental capacity to make the decision over where he should live and has insisted he is better off in the care home.”
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Association Alzheimer Suisse

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Demensförbundet

SWEDEN – LUND
Alzheimerföreningen i Sverige

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Fundación Alzheimer España

SPAIN – PAMPLONA
C.E.A.F.A.

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Slovak Alzheimer Society

SLOVENIA – ŠENTJUR
Association “Forget-me-not”

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Czech Alzheimer Society

DENMARK – HELLELRUP
Alzheimerforeningen

ESTONIA – TARTU
Estonia Association of Alzheimer’s Disease

FINLAND – HELSINKI
Muistiliitto

FRANCE – PARIS
Association France Alzheimer

GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V.

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

IRELAND – DUBLIN
Alzheimer Society of Ireland

ITALY – ROME
Uniti Onlus

ITALY – MILAN
Federazione Alzheimer Italia

LUXEMBOURG – LUDEMBOURG
Association Luxembourg Alzheimer

MALTA – MSIDA
Malta Dementia Society

NORWAY – OSLO
Nasjonalforeningen Demensforbundet

NETHERLANDS – BUNNIK
Alzheimer Nederland

POLAND – WARSAW
Polish Alzheimer’s Association

CROATIA – ZAGREB
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