Françoise Grossetête, MEP (France) discusses the new public health programme, “Health for Growth”.

Commissioner John Dalli talks about how the EU continues to address Alzheimer’s disease.

Debating dementia in the European Parliament
Alzheimer Europe dedicates its 12th lunch debate to the PharmaCog project.

Laying the foundations for the European Working Group for People with Dementia
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

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By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

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Of all the developments in the field of dementia over the last few months, I am particularly happy to bring to you information about the very first European Working Group for People with Dementia (EWGPD). This was a significant meeting. The coverage by Jean Georges, Executive Director of Alzheimer Europe, is uplifting and full of hope. I am grateful to all participants with dementia for their enormous contribution, ensuring the meeting was a great success.

We report on Alzheimer Europe’s 12th lunch debate in the European Parliament. Dedicated to the European project, PharmaCog, this meeting showed how Europe wants to speed up drug discovery for Alzheimer’s disease and was strongly supported by members of the European Alzheimer’s Alliance.

John Dalli, EU Commissioner for Health and Consumer Policy, illustrates how the EU continues in its fight to address Alzheimer’s disease. An in-depth look at how the new Public Health Programme “Health for Growth” can help people with dementia and their carers is provided by Françoise Grossetête, MEP (France), Rapporteur for the Environment, Public Health and Food Safety Committee in the European Parliament, together with the Shadow Rapporteurs, Milan Cabrnoch, MEP (Czech Republic) and Glenis Willmott, MEP (UK) and Rapporteurs for Opinion, Maria Badia i Cutchet, MEP (Spain), and Angelika Werthmann, MEP (Austria).

The continued need to raise awareness and immediate action is highlighted by the World Health Organisation/Alzheimer Disease International report “Dementia: A Health Priority”. Yutario Setoya and Tarun Dua, World Health Organisation, present the key findings.

In the UK, the launch of “The Prime Minister’s Challenge on Dementia” marks David Cameron’s personal commitment to provide world class care and research. Edwin Poots, Minister for Health, Northern Ireland, discusses the Northern Ireland dementia strategy with Alzheimer Europe. I am very encouraged by Scotland’s action to ensure that people who receive a diagnosis of dementia are to be offered one year of post-diagnostic support. Henry Simmons, Alzheimer Scotland’s Chief Executive, offers a frank insight into how this should be achieved.

Oana Antonescu, MEP (Romania) discusses the changes needed for people with dementia and Cătălina Tudose, President of the Romanian Alzheimer Society, laments the fact that dementia is still not a political priority in Romania. Alzheimer Portugal talks about its concerns regarding the impact austerity measures may have on plans to prioritise dementia.

Finally, I invite you to read the very personal account of Maria do Rosario Zincke dos Reis, who cared for her mother until she passed away in February after living with dementia for many years. This account will strike a chord with anyone who has cared for a loved one and help people to understand a little more about how this disease impacts not only those who have the disease, but also their carers.

Heike von Lützau-Hohlbein, Chairperson, Alzheimer Europe
PRIORITISING DEMENTIA

Marina Yannakoudakis, MEP (UK), Alexandra Aufrret (PharmaCog), Heike von Lützau-Hohlein (German Alzheimer Association), Jill Richardson (PharmaCog) and Elisabetta Vaudano (IMI) discuss the PharmaCog project during Alzheimer Europe’s lunch debate in the European Parliament.

06 Giving a voice to people with dementia
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Giving a Voice to People with Dementia

Jean Georges reports on the exciting meeting Alzheimer Europe organised in Glasgow that brought together people with dementia and delegates from national Alzheimer associations to discuss plans for a “European Working Group for People with Dementia”.

The meeting took place from 15 to 17 April and was organised together with the Scottish Dementia Working Group and Alzheimer Scotland. It was aimed at exchanging best practices between countries on how best to involve people with dementia and providing guidance to Alzheimer Europe for the setting up of its European Working Group for People with Dementia.

The inspirational meeting was attended by nine people with dementia from the Czech Republic, England, Germany, Ireland, the Netherlands and Scotland who shared both their personal experiences of being diagnosed with Alzheimer’s disease or another form of dementia, as well as their involvement in the work of national Alzheimer associations. In addition, 20 representatives from Austria, Bulgaria, Norway, Slovenia and Spain participated in the meeting to learn from the organisations that already involve people with dementia.

Setting the scene

Henry Simmons, Chief Executive of Alzheimer Scotland, was proud to welcome the participants to his home city. He stressed that the significant achievements of the organisation – securing the government’s recognition of dementia as a national priority and the development of the Scottish Dementia Strategy – would have been impossible without the active contribution of people with dementia through the Scottish Dementia Working Group.

In my own introduction, I highlighted that the involvement of people with dementia was not a new priority for Alzheimer Europe (AE). In fact, AE can look back on exactly ten years of activity in this field: during our 2002 Conference in Maastricht, Peter Ashley (a person with Lewy Body Dementia) made an impassioned call for the need of Alzheimer associations to give a voice to people with dementia. Since then, AE has provided a platform to people with dementia at successive conferences. They have been involved and consulted in working groups for projects and in policy work, on such important issues as advance directives, assistive technologies and the ethics of dementia research. AE now seeks to improve this involvement policy by setting up a European Working Group for People with Dementia. This will be a permanent group that will advise the organisation and will nominate a representative to sit on the AE Board.

The example of the Scottish Dementia Working Group

Although the idea of having a working group for people with dementia on a European level is new, national local groups for people with dementia exist in a number of European countries. A partic-
ularly successful example is the Scottish Dementia Working Group (SDWG) which was invited to talk about its work and its activities over the past ten years. In line with the team spirit of the group, the presentation was shared between the Chair Agnes Houston, the Vice-Chair David Batchelor, the group's co-founder James McKillop and a new committee member Archie Latta.

The group is run for and by people with dementia. Amongst the group’s important achievements, the speakers highlighted the group’s involvement with the Dementia Strategy, the drafting of a Bill of Rights and the Government’s “Skills and Knowledge framework”. It has also made a DVD and has recently published a popular joke book for Comic Relief. According to Agnes, the members of the SDWG have developed a reputation for being enthusiastic and fearless campaigners and have even been involved in less traditional activities such as training occupational therapists and university students. Membership of the group has increased from a few active members to over one hundred. Whilst this growth is positive, James highlighted that one of the key challenges for the group was how to cope with this larger membership without losing intimacy and informality. He stressed the importance of people with dementia maintaining ownership of the group so that it can act independently.

David underlined that the key to success was to keep objectives clear, simple and measurable. By acting on feedback, the group was able to respond and identify priorities as they arose. However, the members also stressed other factors such as good fortune, good timing (as policy makers now wanted to listen), the fact that there is now a Scottish government and last, but in no ways least, the funding and support provided by Alzheimer Scotland. The speakers agreed that the group could best be described as focused, disciplined, professional, respectful of others and delivering what it promises.

**Successful initiatives on a national level**

Participants heard of other groups for people with dementia in Europe, each having slightly different ways of working. Rob Groot Zwaaftink and Mieke and Victor Meijers described the group in the Netherlands known as the “Kerngroep Dementia” which was set up two years ago and has seven members. After permission by the participants, the group’s discussions are posted on the website so that others may read them. They have found this to be extremely popular, having around 3,400 hits each month.

A similar small group exists in the Czech Republic and Nina Balačkova highlighted how the contacts with other people with dementia had given her greater self confidence in speaking out in public and in raising awareness.

Helga Rohra and Helga Schneider-Schelte spoke of peer support groups in Germany. On a local level, some people with dementia are involved in the Boards of the regional member organisations of the German Alzheimer Association.

Helga Rohra emphasised the importance of portraying a balanced picture of dementia.
Learning from mistakes

Rob Samuelsen spoke of the reference group of people with dementia which has been set up in Norway and which the Norwegian association consults on a regular basis. Whilst this proved successful, the involvement of a person with dementia on the national Board was not satisfactory as the expected contributions from the person in question were not clearly defined at the outset.

Daphne Wallace explained that the UK group had lost momentum when one of the key instigators left. In addition, the group had faced financial difficulties. She was therefore delighted that the Alzheimer’s Society had recently appointed Gaynor Smith as User Involvement Manager. Gaynor explained that she is currently focused on developing a consistent involvement policy and guidelines for staff, as well as ensuring that volunteers are confident working with people with dementia.

Eleanor Edmond from the Alzheimer Society of Ireland explained how difficult it had been to find people with dementia who are willing to be open about it, due to the stigma attached to the disease. The Society found that it was essential for people to feel valued and listened to before they were prepared to talk openly. Eleanor was therefore delighted that Dermod Slevin was prepared to do so as a person with dementia from Ireland. Dermod underlined how he had found that being part of a group had given him the confidence to speak out.

These presentations showed that involving people with dementia is not without its difficulties. For that reason, participants of the meeting stressed the need to monitor and assess involvement policies and to learn from past mistakes.

Learning from each other

The meeting was also a great opportunity for member organisations interested in setting up working groups for people with dementia or in improving their involvement strategies to learn from the existing initiatives. Luis Garcia Sanchez from the Spanish Alzheimer Foundation had expressly come to Glasgow to present the plans of his organisation and to get advice and guidance from the participants. According to Štefanija Lukič Zlobec (Slovenia), the meeting was a true eye opener as it made her aware that setting up a group for people with dementia should be one of the key priorities for her organisation.

Barriers to involvement

It was evident during the meeting that there are barriers which need addressing to facilitate people with dementia being able to join a group. Perhaps most obviously, people with dementia need to know that such a group exists. In Scotland, this issue is addressed by Alzheimer Scotland’s Dementia Advisers: part of their job description is to offer information about the SWDG.

Antonia Croy, Alzheimer Austria, highlighted that sometimes over-protectiveness by carers
could become a barrier and that it was necessary to help carers to understand the advantages of specific groups for people with dementia.

**Getting our message to policy makers**

Access to politicians by people with dementia varied considerably. Agnes reflected that ten years ago it was rare for people with dementia to speak out, whereas nowadays the SDWG is routinely heard at the highest policy level. Irina Vasileva Ilieva and Vasilka Krumova Dimitrova spoke of the round table discussions in Bulgaria between policy makers, Alzheimer associations, people with dementia and carers. Whilst eight events in eight locations had been carried out, it was difficult to maintain discussions as there had been four changes of ministers in just one year.

In the Netherlands, the Kerngroep Dementia was still very small and the Dutch delegates felt that they had not yet reached the point where they could confidently approach the government.

James McKillop was impressed by the number of local support groups for people with dementia in Germany – but also wondered whether the lack of a central spokesperson was an issue when trying to communicate with the government. In Scotland, he said, it helped to be able to speak with a collective voice.

**Involving people with dementia**

The meeting served as a forum on what is needed to involve people with dementia and to help them achieve their goals. It identified the following areas in which people with dementia should be involved:

- the production of guidelines on how to influence government at local and national level
- information written for, and by, people with dementia
- guidance on speaking out in the media
- guidance on good practice involving people with dementia
- gathering “soft” information (individual, ad hoc accounts from people with dementia on a range of issues) to help inform government and others
- networking.

Helga Rohra emphasised the importance of portraying a balanced picture of dementia, rather than focusing solely on the end stage, saying “after all, we all die”.

All participants agreed on the importance of early diagnosis and the absolute right of people with dementia to be told their diagnosis as prerequisites for involving people with dementia. In addition, post diagnostic support, including access to peer support, were identified as priorities for all countries.

**Mixing business and pleasure**

The highly productive meeting took place in a relaxed and friendly atmosphere. This was helped by the arrival of participants on Sunday, as they were treated to a traditional “High Tea” followed by a small welcome reception and a joint dinner. This informal get-together made sure that people felt well acquainted by the official start of the meeting on Monday morning. Anyone seeing the participants in action would have thought it was a reunion of old friends.

On Monday evening, we had the great honour of being invited by the Mayor of Glasgow to a civic reception in the prestigious and sumptuous...
Prioritising dementia

Glasgow City Hall where we were joined by other members of the Scottish Dementia Working Group, as well as key representatives of the City of Glasgow and Alzheimer Scotland. The guided tour of the City Hall which rounded off the evening was another great experience for all participants. The welcome provided by Glasgow City was clear testimony for the recognition of dementia as a priority on a local level.

Looking back on two days

Over the two days, there may have been tears when participants shared particularly difficult moments, but my main memory of the meeting will be of the many laughs that we shared. The enthusiasm of all participants, their willingness to share their own experiences and the openness to learn from one another were truly inspiring. It seems clear to me that Alzheimer Europe was right in deciding to continue to improve the way in which we involve people with dementia. Our goal of developing a European Working Group of People with Dementia was welcomed and supported by everyone at the meeting.

I am confident that this first meeting with nine people with dementia will only be the first of many and that we will be able to build on this success. The seeds we planted in Glasgow will hopefully result in new successful initiatives on a national level and a dynamic and productive collaboration of people with dementia on a European level. The next meeting is already planned, at our Annual Conference in Vienna later this year.

My thanks go to Jan Killeen, Policy Consultant of Alzheimer Scotland who expertly moderated the two day meeting and ensured that all participants had sufficient time and were able to actively contribute to the discussions. Above all, Alzheimer Europe is indebted to the people with dementia who freely shared their experiences and provided us with invaluable advice and guidance on how to continue our work.

“The seeds we planted in Glasgow will hopefully result in new successful initiatives on a national level and a dynamic and productive collaboration of people with dementia on a European level.”

Jean Georges
A snapshot of the first-ever European Working Group for People with Dementia
Participants with dementia reflect on the first-ever meeting for the EWGPD

**Nina Balackova (Czech Republic)**

It was very useful for me and I hope that even for the Czech Alzheimer Society too. I was a tired, but happy there! It was interesting to hear about other countries, how it works in their Alzheimer society and how people with dementia live there. We were surprised to visit the Scottish Parliament. We had a wonderful afternoon there. For me, personally, it was useful as I have been a little sad since February. I see that Mr Alzheimer starts to a little win over me. But, I was very happy in Glasgow and with my carer and friend together we had a lot of fun. And I saw many people with dementia how hard-working they are. I admire them! I have new energy to fight with my health.

**David Batchelor (Scotland)**

I am not sure when it happened but I suddenly realized we were seeing the birth of something big, like opening a window through which you could see a tremendous prospect.

**Agnes Houston (Scotland)**

I found it inspiring to meet others who actively campaign just like we do in the SDWG. It’s nice to be not alone and to know our brother and sister in Europe are the same as us. Dementia does not respect boundaries or country differences. I felt at home and others confirmed the reasons why we need to continue and join together to share our knowledge and the old adage “Knowledge is power” and “that there is strength in numbers”. In saying all of this, it was done with laughter and joy. I felt energised and encouraged and enabled that I too could continue to live with a diagnosis of Dementia. I felt it was like a think tank of Dementia – a meeting of minds with the purpose of helping others to attain to be all they can be.

**James McKillop (Scotland)**

What I hadn’t anticipated was how quickly people would gel together, and an onlooker would have imagined we were all old friends. The meetings were conducted at a pace to suit all, and everyone had a chance to contribute in their own way. Some countries, new to the game, did not think they had achieved much, but in fact, they had done what others took years to do. So I imagine people took heart from being on the right track. Did I enjoy it? Yes! It is nice to know you are not alone in the dementia world and you can always learn from listening to others. People were just so nice and helpful. I like to think all the delegates made a difference in some way and inspired others. As I sat there and looked around, I felt overwhelmed. There was a sense of history in the making. Years ago we would never have met. Now we meet as citizens, who are working to improve the lot of people with dementia and their carers throughout every hamlet in Europe. I could tell from the charged atmosphere, that people were motivated to go back to their respective countries and try even harder. Some who shared similar cultures and languages, seemed to want to keep in touch.
A really historic moment - for the first time there was a meeting of a European working group for people with dementia. A real highlight in my life, as a dementia activist for the last few years in Germany I was keen on exchanging ideas with my friends in Europe. I learned a lot how we could get involved in programs. A good example to be followed is the Scottish Dementia Working group – politicians there understand the dementia as being a phenomenon more than a problem. I wish we could speak up in the same way in Germany. I wish we had the same chance like in the Netherlands, to have a “carer/assistant” for a lifetime, the moment we get diagnosed. I wish we get many enthusiastic young people to work in Alzheimer associations, to promote our cause – like in Spain. But I am also grateful that my country gives us so many opportunities to foster our still existing abilities – compared to the Czech Republic or Slovenia. Those days together gave us affected by dementia a strong feeling of solidarity. Europe – dementia can overcome boundaries. I am grateful to AE for this unique opportunity, and many should follow – you all living you new life with dementia believe in your abilities and join us in our working group.

Before Glasgow, I had never spoken with anybody else who openly had a diagnosis of dementia. I’ve always found this surprising given that so many people are supposed to have it! I felt at home as soon as I arrived in Glasgow, right from the welcome in the hotel lobby and the big hugs from Jan and Agnes. It was hard to figure out who had dementia and who didn’t! There was a lot to take in over the few days but the atmosphere was so warm and welcoming. I never felt ill at ease. A huge amount of work clearly went into organising the summit and making it so welcoming. I’d really like to thank everyone involved. I feel that there is huge benefit to be had from meeting people in similar situations. It has been a kick in the backside (in a nice way!) to stay active and be positive. As was mentioned several times in Glasgow, a diagnosis of dementia can lead to depression and withdrawal. Lack of good information or support at diagnosis is a big problem. I used to be involved in community organisation, I used to love travelling. Since my diagnosis I hadn’t travelled or been an activist in any way. Now I feel my confidence coming back. World domination beckons!

I did enjoy the meeting very much. It was so interesting to hear about the situation in other EU countries. Some of them are so far behind us with no money to really make much noise! I was disappointed that there were some countries unrepresented where I have friends. I hope that the Working Group continues to meet and goes from strength to strength. I would love to attend the next meeting if that is possible. We are in a situation of review about how we keep contact with people around the Country who have dementia and are able to participate in increasing understanding of the role of those with an early diagnosis to speak out and campaign and also to educate.
NILVAD: A EUROPEAN PROJECT TO TEST THE EFFICACY OF A NEW DRUG FOR ALZHEIMER’S DISEASE

Alex Teligadas, Communications Officer, Alzheimer Europe, presents the recently launched NILVAD project. Supported with EUR six million within the European Commission’s Seventh Framework Programme, this project will conduct trials of the drug “nilvadipine” for the treatment of Alzheimer’s disease.

Nilvadipine has been in use for many years to treat hypertension. In 2007, researchers at Archer Pharmaceuticals found that the drug also blocks production of the amyloid protein that is believed to be central to the Alzheimer’s disease process. Nilvadipine reduced the development of amyloid plaques in the brain, cleared amyloid from the brain and increased blood flow to the brain. These results came from laboratory tests on mouse models and convinced scientists that a human trial would be worthwhile. This Phase 2 trial took place successfully in 2010 and led directly to the current NILVAD project.

Dr. Brian Lawlor, Project Coordinator, explains “People with Alzheimer’s disease and their carers will benefit greatly if this trial is successful as it would represent a significant advance in the area of Alzheimer’s disease treatments. NILVAD will also strengthen Alzheimer research networks in Europe and help speed up developments to advance care for people with Alzheimer’s disease.”

NILVAD began on 1 January 2012 and is coordinated by Trinity College Dublin. The Phase 3 trial will perform a double-blind, placebo controlled study to test the efficacy and safety of nilvadipine in 500 subjects with mild to moderate Alzheimer’s disease over a treatment period of 18 months. Men and women aged between 50 and 90 in nine European countries will be included in the study. If the trial is successful, nilvadipine will be marketed for the treatment of Alzheimer’s disease in Europe.

The consortium consists of 17 partners based in ten EU member states and in the United States. The Project Coordinator is Dr. Brian Lawlor, Professor of Old Age Psychiatry at Trinity College Dublin. He will oversee the activities of more

**NILVAD project partners**

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than 40 team members working on the eight work packages (WP) that make up the project.

Three of these packages are directly involved in recruiting people for the trials, conducting the trials, collecting the results and analysing the final data:

WP4, directed by Prof William Molloy, will review the ethical and legal issues regarding recruitment of cognitively impaired adults. Prof Molloy’s team will ensure that these issues are properly addressed in the project and will also establish an Ethics Advisory Board for the duration of the study.

WP5, led by Dr. Lawlor, is the platform that will conduct the clinical trials. This team will obtain ethical and regulatory approvals and will oversee the test sites. They will also examine any modifying effects of potential interventions such as frailty, nutritional status and social connection on treatment outcome.

WP6, headed by Prof Leslie Daly, will validate the trial design and procedures. The group will also develop the statistical analysis plan, perform the final data analysis and produce the statistical section of the clinical study report.

The other work packages provide essential support such as project management, setting up the study framework, training and scientific direction. Alzheimer Europe is a partner in WP7, which will manage the dissemination and communication of information relating to the project. In addition, Maurice O’Connell, Board Member of Alzheimer Europe, sits on the NILVAD Scientific Board.

As of June 2012, the project framework, training programme and legal/ethical review are all in development. Authorisation requests to the national authorities and ethics committees have been submitted. These authorisations are needed for each country that will host a test site and must be approved before recruitment begins in October. A project website (www.nilvad.eu) and a secure intranet have been launched while the first project newsletter is planned for June.

“People with Alzheimer’s disease and their carers will benefit greatly if this trial is successful as it would represent a significant advance in the area of Alzheimer’s disease treatments.”

Dr. Brian Lawlor

First meeting of the NILVAD project team, February 2012, Dublin
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DEBATING DEMENTIA IN THE EUROPEAN PARLIAMENT

On 28 February 2012, Alzheimer Europe organised its 12th lunch debate in the European Parliament. The debate focused on how to speed up drug discovery for Alzheimer’s disease within the framework of the Innovative Medicines Initiative and the PharmaCog project.

Elisabeth Morin-Chartier, MEP (France) opened the debate on behalf of host, Françoise Grossetête, MEP (France), by explaining that in Europe there are some 7.3 million people who live with dementia of which around 75% have Alzheimer’s disease. Ms Morin-Chartier highlighted the research programme and innovation partnerships as ways in which Europe can aim to improve the quality of life. Emphasising the need for Europe to face challenges together, Ms Morin-Chartier spoke of the Horizon 2020 programme (which has been assigned EUR 80 billion) and the need for world leaders to be driving the research agenda.

Dr. Elisabetta Vaudano, Principal Scientific Manager, Innovative Medicines Initiative (IMI), European Commission, presented the current challenges: (1) There are some 35.6 million people with dementia in the world and by 2050 this is expected to rise to 115.4 million; (2) the societal cost of Alzheimer’s disease in the world is calculated to currently be EUR 72 billion, but by 2040 it will be EUR 144 billion; (3) there is no cure for dementia. Despite vast amounts of work being carried out to develop new treatments, the reality is that the last drug approval was nearly a decade ago (memantine, 2003). Of the drugs which have been developed it is found that they work only in some of the people with the conditions and (4) there is need for greater collaboration and funding in dementia research. Dr. Vaudano illustrated the stark contrast between research for dementia and other areas of research such as nuclear fusion for example. At the moment, spending and coordination for research on dementia is low and fragmented, whereas research into nuclear fusion enjoys strong funding and collaboration and the research effort is not fragmented.

To overcome such barriers, Dr. Vaudano said that there is a real need for innovation, with new research models which involve all stakeholders. The idea behind the IMI was to do exactly this by having the public sector (represented by the European Commission and a budget of EUR 1 billion) and the private sector (represented by the pharmaceutical industry and matching a budget of EUR 1 billion) work together in a non-competitive environment in order to develop a new way forward. Dr. Vaudano said that we need to realise the aim of finding the “right drug, for the right patient, at the right time and with the right dose.”

“We need to realise the aim of finding the “right drug, for the right patient, at the right time and with the right dose.”
Elisabetta Vaudano
Currently, IMI is financing 30 projects of which the “Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development” (PharmaCog) project is one. Alzheimer’s disease is still high in the agenda for future IMI initiatives and there will be the launch in 2013 of a new project (EMIF-AD) part of the EMIF (European Medical Information Framework). At this stage, said Dr. Vaudano, the opportunity to use the information received has not yet been fully realised as each country records data differently and has varying standards. However, an opportunity for future research could arise once the harmonisation process of data has taken place.

The PharmaCog project was presented by Dr. Jill Richardson, GSK R&D China, EFPIA coordinator together with Dr. Alexandra Auffret, PharmaCog Academic Coordinator, Marseilles University, France. Dr. Richardson said that the main issue, despite years of research, is that we still do not really understand how neurodegenerative diseases manifest themselves and we don’t know which are the best targets to pursue. Therefore, there is an urgent need for good tools which provide objective measures to enable diagnosis of patient populations, classification of disease severity, prediction of treatment outcome and drug response.

Dr. Richardson explained that PharmaCog aims to take a very broad approach to drug development and, in so doing, addresses some of the reasons why late stage trials for Alzheimer’s disease had not been successful. These included an over-focusing on the lowering of amyloid, a lack of

harmonisation of protocols and data, a failure to identify relevant and accepted endpoints and a lack of clarity on how biomarkers translate into clinical benefit. In addition drugs had been targeted at a late stage in the disease, leading to poor results. It is now thought that amyloid lowering agents should be given much earlier. The cost of trials may also hinder progress of drug development. Long trials are required for dementia drugs (two years or more) and the cost for this is around EUR 20 million.

Dr. Auffret presented how the PharmaCog project works in practice. Launched in 2010, this five-year project has five objectives:

- to develop and validate pre-clinical and clinical models with greater predictive capacity to increase the effectiveness of the drug discovery process in Alzheimer’s disease
- develop and validate translatable pharmacodynamics markers to support dose selection
- identify and validate markers of disease progression and patient stratification
- gain industry and regulatory acceptance of models and markers
- develop a pan European network of experts in technologies fully translatable from animal to human, experts in translational medicine, drug discovery and mathematical modelling.

To carry out these objectives, there are 32 partners across Europe providing expertise: academic institutions (advice on science and technology), EFPIA companies (Alzheimer’s disease drug discovery, archived data, pharmacology expertise, harmonisation and statistics), SMEs (innovative biomarkers and clinical trial authorisation procedures), the European Medicines Agency (advice and information on clinical trials) and Alzheimer Europe (communication of results and work on ethical issues). Dr. Auffret said that whilst the project is indeed a massive challenge, it is also an opportunity to share a vast amount of expertise and avoid duplication. Innovation, translation and harmonisation are, said Dr. Auffret, key words of this project.
Teams collaborate on the ten work packages and research is ongoing covering topics such as induced cognitive deficit, intensity of cognitive deficit, prediction and dose effect, touchscreen technology and identification of best markers. All studies are designed to improve the ability to identify successful new medicines and to stop the development of those medicines destined to fail as early as possible.

Ms Brepoels, MEP (Belgium) asked what we could learn from the investment levels on dementia research in the US. Ms Vaudano explained that whilst investment in the US appeared higher, the scope of work is often wider in Europe. She said that in some areas the US was actually learning from how Europe works and had been surprised that in Europe people from different disciplines can work together in a collaborative way.

Elisabeth Morin-Chartier mentioned the role of technology in Alzheimer’s disease treatment and referred to the European discussions on the use of MRI and the exemption of MRI from the limit values of the revised Directive on Electromagnetic Fields. She insisted that it was our responsibility to strive towards a European legislation that will allow MRI to be performed in the same way across all Members States to avoid inequalities and ensure people with dementia can be diagnosed properly. Dr. Auffret added that in France there is a lack of federal facilities for research and that access to MRI is a challenge.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, reflected that Alzheimer Europe had highlighted the importance and need for increased funding for research and greater research collaboration in the 2006 Paris Declaration. She said that she was delighted to see a concrete example of how Europe had responded to this call by supporting this coordinated research effort and she hoped it would result in the development of new treatments slowing down the progression of Alzheimer’s disease. Ms Lützau-Hohlbein thanked the speakers and said that on a personal note that she had appreciated finding out what is happening in the area of research as both her mother and her mother-in-law had lived with dementia.

Ms Morin-Chartier thanked her colleagues who help to put dementia on the European agenda and stressed the importance of policy makers making sure they were engaged to try and understand the disease and to help carers. Support at all levels was evident at the debate by the attendance of nearly 50 people including MEPs [Heinz Becker (Austria), Frieda Brepoels (Belgium), Sean Kelly (Ireland), Astrid Lulling (Luxembourg) and Marina Yannakoudakis (UK)], MEPs’ assistants, national policy makers and representatives from the European Commission, Alzheimer associations and pharmaceutical companies.

Closing the debate, Ms Morin-Chartier said that the need to develop partnerships between researchers in all countries was clear and she thanked the researchers for the work they carry out.

“All studies are designed to improve the ability to identify successful new medicines and stop the development of those medicines destined to fail as early as possible.” Alexandra Auffret

The PharmaCog consortium consists of the following partners coming from 10 different EU Members States:

1. Alzheimer Europe (Luxembourg),
2. AstraZeneca (United Kingdom),
3. Boehringer Ingelheim (Germany),
4. Centre National de la Recherche Scientifique (France),
5. Eli Lilly and Company (United Kingdom),
6. Exonhit Therapeutics (France),
7. F. Hoffman-La Roche (Switzerland),
8. GlaxoSmithKline (United Kingdom),
9. H. Lundbeck (Denmark),
10. Innovative Concepts in Drug Development (France),
11. Innovative Health Diagnostics (France),
12. Institut d’Investigacions Mòmèdiques August Pi i Sunyer (Spain),
13. Institut de Recherche Servier (France),
14. Institut National de la Santé et de la Recherche Médicale (France),
15. Istituto di Ricerche Farmacologiche “Mario Negri” (Italy),
16. Janssen Pharmaceutica (Belgium),
17. Merck (Germany),
18. Novartis Pharma (Switzerland),
19. Ordine Ospedaliero di San Giovanni di Dio Fatebenefratelli (Italy),
20. Qualisima (France),
21. SAS Alzprotect (France),
22. UCB Pharma (Belgium),
23. Universidad de Murcia (Spain),
24. Università degli Studi di Foggia (Italy),
25. Università degli Studi di Verona (Italy),
26. Universität Leipzig (Germany),
27. Universitätssklinikum Essen (Germany),
28. Université de la Méditerranée, Aix-Marseille II (France),
29. Université de Lille 2 (France).
A snapshot of Alzheimer Europe’s lunch debate in the European Parliament
Policy Watch

21 Dementia and Alzheimer’s disease: Europe takes stock and moves forward
John Dalli, Commissioner for Health and Consumer Policy, discusses the various activities being carried out in the fight against Alzheimer’s disease.

24 The place of dementia in the new EU public health programme
A look at Health for Growth, the new EU Public Health Programme. Contributors include MEPs Françoise Grossetête (France), Glenis Willmott (UK), Milan Cabrnoch (Czech Republic), Maria Badia i Cutchet (Spain) and Angelika Werthmann (Austria).

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34 The British Prime Minister’s Dementia Challenge
Andrew Chidgey, Alzheimer’s Society, considers the commitment given by British Prime Minister, David Cameron, to tackle dementia.

35 The view from Romania
Oana Antonescu, MEP (Romania) discusses the challenges faced by people with dementia and their carers in Romania.

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Henry Simmons, Chief Executive of Alzheimer Scotland, explains how the organisation campaigned to ensure that people in Scotland who receive a diagnosis of dementia are offered one year of post-diagnostic support.
DEMENTIA AND ALZHEIMER’S DISEASE:
EUROPE TAKES STOCK AND MOVES FORWARD

The European Commissioner for Health and Consumer Policy, John Dalli, highlights the state of play of current activities and the upcoming health programme in the fight against Alzheimer’s disease and dementia in Europe.

In 2010, there were more than 7 million Europeans living with some kind of dementia. While neurodegenerative diseases affect all age groups, they are the major cause for disability and dependence in people aged over 65.

With the increased ageing of the population, the number of people with dementia is set to rise, reaching 14 million by 2030 and 19 million by 2050. This is why the European Commission has acknowledged the growing prevalence of dementia and has called for coordinated action in its Communication on a European initiative on Alzheimer’s disease and other dementias of July 2009. Commission action pursues three main objectives: acting early to diagnose dementia; improving the knowledge-base and research coordination; and sharing best practices on caring for people suffering with dementia.

In this context, the Commission has set a two-year joint action between European Member States called “ALCOVE” to both improve knowledge on dementia and its consequences and to promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia and their carers. This joint initiative, funded by the Health Programme, focuses on prevention and diagnosis, improvement of existing practices of care, assessing the competence of elderly people with cognitive impairments and epidemiological data. ALCOVE is further complemented by a coordinated research initiative on combating neurodegenerative diseases, which brings together twenty-three European countries seeking to align their scientific competencies, medical strengths and social approaches to tackle Alzheimer’s. The European Commission allocated a budget of approximately EUR 2 million to this initiative.

Research in this area is not new. The European Commission has been supporting research on Alzheimer’s disease and other dementias since the 1980s. From 1998 to 2006, the European Commission invested EUR 85 million on Alzheimer research through its Research Programmes. The current Seventh Research Programme covers research on various aspects of mental health, prevention strategies for healthy ageing, and equality of access to care. Research is also conducted in drug development. In 2008, the partnership “PharmaCOG”, made up of 32 academic and industry actors from 7 countries was launched to tackle bottlenecks in Alzheimer’s disease research and drug discovery.

Promoting effective prevention and treatment of chronic disease is essential to enable people to spend a greater proportion of their lives in good health. The European Commission’s proposal for a “Health for Growth” programme illustrates the Commission’s commitment to protect the health and well-being of its citizens. The Commission proposes that the programme focuses on supporting EU Member States in reforming their health policies and focuses on four main
objectives: developing innovative, efficient and sustainable health systems; increasing access to better and safer healthcare; promoting health and preventing disease; and protecting people from cross-border health threats.

The Programme will further back up concrete actions foreseen within the European Innovation Partnership on Active and Healthy Ageing to funnel innovation into real products, devices and services to benefit older people, including those with dementia. This Partnership aims to improve older people’s health and well-being through innovation, and focuses on prevention and early diagnosis; care and cure; and independent living and active ageing. Many of the activities identified by the Partnership seek to address the issue of cognitive impairments in older Europeans.

The Partnership can play a role in fostering collaboration and communication between all actors, i.e. care providers, people with dementia, the research community, informal caregivers, pharmacists and pharmaceutical industries.

For instance, health providers and social workers in charge of managing care to dementia people are not always well coordinated. This impinges on the appropriate care delivery and leads to inadequate use of resources. The Partnership encourages greater cooperation, cross-disciplinary sharing, new ways of working and transparency to secure effective, innovative and tailored care interventions. This is particularly important for patients in the last stages of dementia, as they require specific home and palliative care.

The Partnership can further help patients with dementia and their caregivers by supporting the uptake of a range of technologies and e-health solutions to overcome problems at home. They reduce risk levels, help patients feel safer and support relatives and caregivers. However, these solutions are not always affordable or commercially viable. The Partnership will also seek to develop interoperable standards that enable people with dementia and their caregivers, to benefit from independent living solutions. In addition, it will launch tele-monitoring programmes targeting people with cognitive impairments, to help dementia patients access the best medical expertise in the comfort of their own home and live more active and independent lives. This in turn should reduce hospital care and help alleviate the pressure on public health and social budgets.

To conclude, the European Commission is doing its share to help people with dementia and their families.

1 www.alzheimer-europe.org/FR/content/.../file/AE_BRO_CONF_WEB.pdf
2 World Alzheimer Report for 2009
4 http://www.alcove-project.eu/
5 http://www.alzheimer-europe.org/Research/PharmaCog

“Promoting effective prevention and treatment of chronic disease is essential to enable people to spend a greater proportion of their lives in good health.”
Commissioner John Dalli
THE PLACE OF DEMENTIA IN THE NEW EU PUBLIC HEALTH PROGRAMME

Françoise Grossetête, MEP (France), Chairperson of the European Alzheimer’s Alliance and Rapporteur for the new EU public health programme, Health for Growth, talks about the importance of addressing neurodegenerative diseases and the issue of ageing within the context of the Programme.

The budget allocation for the “Health for Growth” Programme for the period 2014-2020 is EUR 446 million, which is an allocation of over EUR 60 million per year. The Programme objective is to concentrate on the main areas in which the European Union can bring real added value such as health. It is written into the EU 2020 strategy and aims to boost innovation in healthcare systems and ensure their sustainability while improving the quality of life of the European citizens.

These funds will complement a series of health-related measures through the structural funds and the framework programme for research and innovation for the period 2014-2020.

The public authorities, the private sector, international institutions and non-governmental organisations will be eligible beneficiaries for grants through co-financing. It is essential that the procedures and accessibility to these funds be as simple as possible so that the Member States and the health professional make the best use of them.

The general constraints that weigh on the public finances impose a reform of the health systems in order to manage the costs while optimising the profitability of the sector and innovation. These reforms are essential for the health systems to respond to the increasing demand for healthcare caused by the ageing of the population, and to continue to offer quality healthcare to future generations.

We are now facing the big challenge of the 21st century: the ageing of the population.

It is important that the programme focuses on neurodegenerative diseases such as Alzheimer’s disease and other forms of dementia. These are chronic diseases with specific characteristics: They affect primarily elderly people, lead to a complete dependency of the person with the disease. These diseases currently affect a large number of people (over 7 million people suffer from some form of dementia in Europe).

In my capacity as Rapporteur, I have been keen for the ageing dimension to be included as part of the general objective of the programme.

In addition, it seems important to me that the European Innovation Partnership on Active and Healthy Ageing launched by the European Commission focuses on its three priorities: innovation in awareness, prevention and early diagnosis; innovation in treatment and healthcare, in particular for neurodegenerative diseases; and innovation to enable active and independent living.

Since the French Presidency of the EU nearly four years ago, a lot has been done to combat the scourge presented by Alzheimer’s disease and other forms of dementia.

This third health programme will also contribute to fighting age-related diseases by focussing
both on prevention and innovation. By keeping the individuals in good health for as long as possible as well as maintaining their capacity to remain physically and socially active, we will also be able to optimise their positive impact on productivity and competitiveness.

By clearly defining the objectives, the programme thus seeks to avoid duplication and make better use of the dwindling financial resources. As a matter of fact, we must avoid having a list of measures because this would lead to scattering of the available resources and it is not the aim of the programme to provide an exhaustive list of pathologies.

The financial split between the programme’s four goals (boost innovation, improve access to better and safer healthcare, boost diseases prevention and protect the citizens from cross-border health threats) must not be static. Classifying these objectives and granting each of them a predefined budget line could limit the scope of some projects.

Regarding the prevention objective, risk factors must be better identified so that more efficient strategies are put in place. The main risk factors – including unhealthy eating habits and sedentary life-style – must be taken into account for appropriate and efficient prevention of chronic diseases.

To-date, it is still difficult to understand how to prevent age-related diseases for which no cure is available on the market. It is imperative to include these diseases in the programme, and share best practices between the Member States in the field of early diagnosis, access to treatment (pharmacologic or non-pharmacologic) and support to the patients and their carers. This will help address these latter needs and support the Member States in their willingness to maintain the sustainability of their health systems.

The Programme must better integrate the ageing of the population with age-related diseases. This is a horizontal theme which answers three of the programme’s objectives:

- objective 1 (contribute to innovative and sustainable health systems)
- objective 2 (increase access to better and safer healthcare for EU citizens) and
- objective 3 (prevent diseases and promote good health).

The consequences of the ageing of the population must also be anticipated so the necessary resources for the training and qualifications of the healthcare workforce are put in place. The European Union will have to promote the creation of new jobs in order to better respond to the current societal challenges, such as home care, institutions specifically devoted to dependent people (be they old or young), and regularly assess them and adjust them to the real needs of the sick and their carers. The problem of dependence and ageing of the population will also need to be taken into account and regularly assessed too.

We have to combine intelligence and scientific talents and ensure they are provided with the best possible support available. Alleviating the suffering of the sick and their carers is a cause that unites us all. It is far too important for national particularities and administrative slowness to prevail.

“Alleviating the suffering of the sick and their carers is a cause that unites us all.”
Françoise Grossetête
PrioritisinG Dementia

PoLicy WatcH

"The health for growth programme can provide a forum for national experts to share their experiences of what works well, and what has gone wrong."

Glenis Willmott, MEP (UK)

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During this time of economic crisis it is vital that we have a strong public health programme from the EU. It's not just financial problems that we're facing, people's health is suffering too. In Greece the suicide rate has increased by 40% over the last year. In my own country we are seeing our National Health System pulled apart.

And while the economic crisis loudly rumbles on, a much quieter crisis is happening around us, in every country in the European Union. Our populations are ageing, and with that comes more and more people suffering from neurodegenerative diseases. Already over 35 million people are living with Alzheimer’s disease and other dementias worldwide. The World Health Organisation estimate that this number will double by 2030, and triple by 2050.

The Health for Growth Programme will be vital in helping EU countries face up to this huge challenge. Of course each government has responsibility for their own healthcare system and how they care for their aging population. But by working at EU level we can provide real added value.

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Our next step is to co-ordinate our research into the disease, something that has already begun with the Joint Programming Initiative, the first of its kind in the EU. Although research projects themselves will be funded with other EU money, the Health for Growth Programme can provide a framework to pull this research together and use it in the best interest of dementia patients.

And finally, with the data and the research behind us, we have to look at policies. How can we make sure people are diagnosed early with the disease? How do we ease the burden on the loved ones of the patient? How do we remove the stigma from dementia? While these decisions are made at a national level, the Health for Growth Programme can provide a forum for national experts to share their experiences of what works well, and what has gone wrong. This work has begun under the ALCOVE Joint Action Programme, and should continue in the future, with funding from the Health for Growth Programme. Together, European countries can find the way to tackle the challenges posed by Alzheimer’s and other dementias.

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The Health for Growth Programme is not perfect as it stands. The name alone is a big problem, because health should not be about growing our economies. But that aside, we can achieve something with this Programme. Of course the modest funding cannot get very far on its own; we need commitment from governments, researchers, medical professionals, patient groups and NGOs. But this is an opportunity for us to come together to take on one of the biggest challenges we face.
Milan Cabrnoch, MEP (Czech Republic)

The multi-annual programme of the European Union for promotion of health is one of the key documents in this area. Health is not just a precondition for growth but also for satisfying and happy life of the individual as well as for society as a whole.

The Health for Growth Programme sets out goals and objectives for the next seven years (2014-2020) and focuses on selected issues, where it is reasonable to expect the European added value. The European Commission, which has submitted the proposal, is aware of the limited competencies of the European Union in this field. Policy in the area of health care lies in the competence of Member States. The EU can support and complement national policies, support and encourage cooperation between member states and work actively in the areas, where the Member States cannot act individually or where the common “European” solution is more advantageous than solutions at the level of individual states.

One of the challenges our society is facing is demographic ageing. We live longer than any time before and this is a great success. Longer life is the result of extraordinary progress in medicine and, at the same time, of a large improvement in living conditions.

With ageing the prevalence of Alzheimer’s disease and other dementias increases. The number of those in need of long-term care and support is thus rising.

The EU programme, Health for Growth, is important for Alzheimer’s disease for several reasons.

The Programme supports innovation and international cooperation in the area of science and research. This is the best way to help us find effective treatment for Alzheimer’s disease.

The international exchange of experience supports dissemination of successful models of quality long-term care, which is the precondition for dignity and quality of life for people with Alzheimer’s disease. The support of NGOs and associations of patients and their relatives helps people with disabilities to better cope with restrictions caused by the disease.

The regulation speaks about the development of common solutions and tools to increase the quality of health care and safety of patients. Such solutions to which individual member states sign up can significantly help in the effort to achieve better quality and safer care.

Each of us wishes to live at home with their relatives. The modern technologies help chronically ill and often lonely patients to live at their home, instead of living in an institution.

One of the most important aspects of the proposed regulation is the aim to strengthen the position of the patient. An active role of the patient in health care, prevention of disease as well as in its treatment and long-term care is the key to a more effective use of human and financial resources. Patients and their families need easy access to information. The communication between patients and health care facilities should be on a continual basis.

An important part of the proposed regulation is an effort to support the development of human resources, which means ensuring the availability of qualified doctors, nurses and nursing assistants. At present, there is shortage of such workers in some countries.

From my point of view, the EU can be most helpful and efficient in addressing Alzheimer’s disease especially in the areas of science and research to find the real causes of the disease and effective treatment, to improve the quality and safety of care with an emphasis on strengthening the role of the patient and dignity and quality of his or her life, if possible, in the home environment.
“It is essential to take advantage of the Health for Growth Programme to translate the research breakthroughs into medical applications and get them coordinated across the EU.”

Maria Badia i Cutchet, MEP (Spain)

The Health for Growth Programme arises at a time in which Europe has to face great challenges. Challenges linked to globalisation, to the fragile economic situation and to an ever-ageing society. In this context, investing in people’s health is the way to make growth possible and health systems sustainable.

The Commission proposal presents a wide range of initiatives to strengthen EU’s actions in different health-related areas. To that extent, the European Parliament points out in its report the fields where improvements can be made to widen the scope of the Programme’s proposals.

First of all, age-related diseases such as Alzheimer’s disease and other forms of dementia, that require further research to set early detection measures and improve the living conditions of the affected persons, is one of the fields to prioritize. Therefore, it is essential to take advantage of the Health for Growth Programme to translate the research breakthroughs into medical applications and get them coordinated across the EU. These actions will help to enhance the population’s health in Europe, facilitating cooperation and making health systems stronger and more sustainable.

Secondly, Health for Growth fosters new chances to fight inequalities in the health sector, particularly when they come to different regions and population sectors. Hence, putting vulnerable groups – such as elderly people, who are most likely to suffer from dementia diseases – in the spotlight, becomes essential.

Moreover, additional actions can be carried out under the Health for Growth programme, especially those concerning white jobs strategies related to the flagship initiative “New skills for new jobs”. Most of people with dementia are looked after in their own homes by informal carers or relatives. Therefore, it is crucial to provide proper training and life-long learning to health sector workers, particularly those developing specific assistance care and those involved in geriatric medicine.

For all these reasons, age-related diseases need to be pushed forward on the EU political agenda to become top priorities. Taking advantage of the European Year of active ageing, the European Parliament calls the European Commission to make Health for Growth Programme a platform to support public health systems as they are an essential mechanism to keep social welfare, tackle inequalities and offer all the required support to the most vulnerable.

In any case, age-related diseases, in the context of ageing societies, are indeed an issue of common concern across Member States.
Angelika Werthmann, MEP (Austria)

The “Health for Growth” programme is an extremely useful tool for the European Union which does not only serve to improve the well-being of the European citizens but also emphasises the links between economic growth and a healthy population to a greater extent than the previous programmes. Consequently, it provides a clear EU-added value and should therefore be made known to our citizens and used as such.

It is commonly recognised that a healthy population reduces public costs of the EU and Member States.

We have to keep in mind that Alzheimer’s disease is the most frequent form of dementia. In the European Union 7.3 million people are diagnosed with dementia and about 50 to 70 percent of these have Alzheimer’s disease.

At the same time, the European population is an ageing one and this poses serious public health, social and thus economic challenges.

Alzheimer’s disease is a chronic, unpreventable, age-related and terminal disease and the number of people with dementia will increase. Thus, we will all have to deal with this challenge.

When one takes into account the informal carers of people with dementia (usually family members), it is commonly accepted that the number of those directly affected by the disease is estimated to be 20 million. This has an immense impact on the physical and mental health of this group of people, on their social life, as well as on their working-life and their pension rights. It also results in a huge rise on the public costs of the EU.

An early diagnosis of any form of dementia would definitely be more cost-effective and, even more importantly for the individuals concerned, it would contribute to a healthier and better quality of life for all the people concerned.

The “Health for Growth” programme has some clear general objectives, including the sustainability of the health systems as well as the improvement of health in the EU citizens.

The financial support provided by the programme is essential to further develop research both at national and European level, whilst allowing for the fact that the situation regarding innovation differs in the individual Member States.

Due to these aforementioned important facts, Alzheimer’s disease, in my view, would definitely qualify for inclusion on the “Health for Growth” Programme.

1 “Der Wert des Wissens”. Ergebnisse der Alzheimer Europe Studie in fünf Ländern zur öffentlichen Wahrnehmung von Alzheimer und Ansichten zum Stellenwert der Diagnose, pg. 5
Restoring the Tradition of European Medical Innovation

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

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DEMENTIA: A PUBLIC HEALTH PRIORITY

On 11 April 2012, the report “Dementia: a public health priority” jointly developed by World Health Organisation (WHO) and Alzheimer’s Disease International was launched. Yutaro Setoya, Technical Officer and Tarun Dua, Medical Officer, Department of Mental Health and Substance Abuse, World Health Organisation, highlight the main outcomes of the report.

The report “Dementia: a public health priority” is the first global report on dementia by WHO, and has been well received by many academics and policy makers as well as covered widely by the media.

Objectives of the report
The main objectives of the report are to raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels. The target audiences are national and state ministries of health, policy-makers health and social sector planners, as well as academics and researchers.

The report provides information and aims to encourage countries to be prepared by strengthening or developing policy and implementing it through plans and programmes which enhance dementia care in order to improve the social well-being and quality of life of those living with dementia and their caregivers.

Development of the report
In all, well over 100 experts from all WHO regions contributed to development of the report. The information included in the report was derived from three primary sources:

- four working groups reviewed existing literature and collected case examples on the epidemiology of dementia, national policies, plans and resources for dementia, awareness and the health workforce and caregivers
- a survey of available resources in 30 countries selected to represent high, middle and low incomes across the six WHO regions
- information gathered at a stakeholder meeting held in Geneva in September 2011, which was attended by representatives from 16 countries, representing public health, academia and advocacy organisations.

Summary of the report
The key messages of the report are summarised in table 1. The report highlights the burden of the disease in terms of the increasing number of people with dementia and the economic cost, and provides available knowledge of dementia on the health and social system, support of the caregivers and awareness raising.

“There is an urgent need to improve the awareness and understanding of dementia across all levels of society.” Yutaro Setoya and Tarun Dua
“Governments worldwide need to respond to the growing burden of dementia.”
Yutaro Setoya and Tarun Dua

**Table 1: Key messages of the report**

- Dementia is not a normal part of ageing.
- 35.6 million people were estimated to be living with dementia in 2010. There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds. The accelerating rates of dementia are cause for immediate action, especially in low- and middle-income countries where resources are few.
- The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence. The costs are estimated at US$ 604 billion per year at present and are set to increase even more quickly than the prevalence.
- People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.
- Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems.
- Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders – at international, national, regional and local levels.
- People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.

**Burden of dementia**

The number of people living with dementia worldwide in 2010 was estimated at 35.6 million. This number will double by 2030 (65.7 million) and more than triple by 2050 (115.4 million). Currently 58% of people with dementia live in low- and middle-income countries: this proportion is projected to rise to 71% by 2050 (see figure). Western Europe is the region with the highest number of people with dementia (7.0 million, with Germany (1.5 million), France (1.1 million), and Italy (1.1 million). The total number of new cases of dementia each year worldwide is nearly 7.7 million: the equivalent of one new case every four seconds.

**Dementia policy and plans**

Governments worldwide need to respond to the growing burden of dementia, and national approaches should be clearly articulated in either a stand-alone dementia policy or plan or by integrating a plan and policies within health, mental health or old-age policies. Some high-income countries like Denmark, France, Netherlands, Norway, Switzerland and UK have launched national/subnational policies, plans, strategies or frameworks to respond to the impact of dementia. In 1992, Sweden developed a social policy on dementia arguing for a “normalisation process”, making a radical change over previous theories and in 2010 presented specified national guidelines for dementia care. In addition, several other countries such as Belgium, Cyprus, Czech Republic, Finland, Luxembourg, Malta and Portugal have initiated steps towards the development of a national dementia policy or plan.

The priority areas of action that need to be addressed within the policy and plan include raising awareness, timely diagnosis, commitment to good quality continuing care and services, caregiver support, workforce training, prevention and research. A sustainable financial commitment is crucial for the successful implementation of plans and programmes. Universal social support through pensions and insurance schemes could
provide protection to people with dementia and their families.

**Health and social systems development**

Governments need to develop and improve services for people with dementia, focusing on earlier diagnosis, provision of support in the community and a responsive health and social care sector. Improved community support will assist families to provide care for longer and to delay or reduce reliance on high-cost residential care.

Building the capacity of the workforce is essential to improve knowledge and awareness of the benefits of a coordinated response to care. Dementia care, long-term care and chronic disease management incorporating a multidisciplinary team should form part of professional education and should be supported by the development of appropriate practice guidelines.

**Support for informal care and caregivers**

Dementia has an immense impact on the lives of the family, and particularly on the person who takes the primary role in providing care. Most care is provided by family and other informal support systems in the community and most caregivers are women. A range of programmes and services have been developed in high-income countries to assist family caregivers and to reduce strain. The beneficial effects of caregiver interventions in decreasing the institutionalisation of the care recipient have been clearly demonstrated.

Support is needed to enable informal caregivers to be able to continue in their role for as long as possible. Support includes information to aid understanding, skills to assist in caring, respite to enable engagement in other activities and financial support.

**Awareness-raising and advocacy**

Despite the growing impact globally, a lack of understanding of dementia contributes to fears and to stigmatisation. For those who are living with dementia (both the person and their family), the stigma contributes to social isolation and to delays in seeking diagnosis and help.

There is an urgent need to improve the awareness and understanding of dementia across all levels of society as a step towards improving the quality of life of people with dementia and their caregivers. Governments have a role to play in resourcing public awareness campaigns and in ensuring that key stakeholders are involved in such campaigns.

**Expected impact of the report**

The launch of the report and its findings were well covered by the media (including social media such as twitter and facebook) in high-income countries as well as low- and middle-income countries. The report provides the knowledge base for a global and national response to facilitate governments, policy-makers and other stakeholders to address the impact of dementia as an increasing threat to global health. This is particularly so for low- and middle-income countries, which face the largest growth in numbers of persons with dementia and have limited infrastructure and health workforce capacity to address health and social problems.

A range of actions is required to improve care and services for people with dementia and their caregivers. These actions include advocacy and awareness-raising, developing and implementing dementia policies and plans, health system strengthening, capacity-building, supporting caregivers and research. The actions need to be context-specific and culturally relevant. National action is essential for systems change to become a reality. The time to act is now by:

- promoting a dementia friendly society globally
- making dementia a national public health and social care priority worldwide
- improving public and professional attitudes to, and understanding of, dementia
- investing in health and social systems to improve care and services for people with dementia and their caregivers
- increasing the priority given to dementia in the public health research agenda.

“The time to act is now by:”

Yutaro Setoya and Tarun Dua
THE BRITISH PRIME MINISTER’S DEMENTIA CHALLENGE

Andrew Chidgey, Director of External Affairs, Alzheimer’s Society, considers the commitment given by British Prime Minister, David Cameron, to tackle dementia.

On 26 March the British Prime Minister David Cameron made a keynote speech about dementia at the Alzheimer’s Society’s Dementia 2012 conference and launched “The Prime Minister’s Challenge on Dementia”.

In the first ever speech by a British Prime Minister on dementia Mr Cameron stated his personal commitment to action, recognising dementia as a challenge that needs tackling in the same way as other big challenges:

“We need an all-out fight-back against this disease; one that cuts across society. We did it with cancer in the 70s. With HIV in the 80s and 90s. We fought the stigma, stepped up to the challenge and made massive in-roads into fighting these killers. Now we’ve got to do the same with dementia. This is a personal priority of mine, and it’s got an ambition to match. That ambition: nothing less than for Britain to be a world leader in dementia research and care.”

On the day of the Prime Minister’s speech the Alzheimer’s Society published the report “Dementia 2012”, setting out current evidence on how well people are living with dementia. The report shows mixed progress since the publication of the National Dementia Strategy for England in 2009. Public awareness about dementia is higher and more people are going to specialist memory services. However, diagnosis rates remain stubbornly low and many families report not being able to get the information and the support they need.

In responding to the report at the Dementia 2012 conference the British Prime Minister announced a series of commitments to improve life for people with dementia and their carers. These include:

- more than doubling UK government investment in dementia research from EUR 32 million a year to EUR 82 million by 2015
- including dementia checks in routine health checks for people over 65
- committing that there will be local targets for diagnosis by April 2013
- committing to create dementia friendly villages, towns and cities across the country working with businesses
- government funding for continual dementia awareness campaigns up to 2015
- agreeing a target for 10% of people with dementia to be in clinical trials.

Three champion groups have been appointed to consider how to meet the commitments set out and these groups will have to report to Mr Cameron by September 2012 with an action plan and then report again on progress in March 2013.

As part of the Prime Minister’s Challenge on Dementia the Alzheimer’s Society has taken the lead in working with organisations including banks, shops the police and fire brigade to look at what can be done to create dementia friendly communities. The Alzheimer’s Society is also working with partners in England’s Dementia Action Alliance to create local dementia action alliances of many organisations to lead change.

For more information about the Prime Minister’s Challenge on Dementia please go to: http://www.dh.gov.uk/health/2012/03/pm-dementia-challenge/
If you would like to find out more please contact andrew.chidgey@alzheimers.org.uk
THE VIEW FROM ROMANIA

Oana Antonescu, MEP (Romania) and member of the European Alzheimer Alliance speaks with Alzheimer Europe about the challenges and situation for people with dementia in Romania.

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

Ms. Oana Antonescu (OA): In my opinion, the key challenges that people with dementia and their carers face in Romania are the difficulties encountered in the process of early diagnosis as well as the continued increase of the informal costs that bear on the families of people suffering from dementia. Moreover, many communities are faced with a severe lack of local services. Currently, there are no legal provisions regarding the rights of the patients or their caregivers.

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?

OA: The Romanian Alzheimer Society took the initiative to create the Romanian Alzheimer Alliance. The main purpose of the Romanian Alzheimer Alliance is to determine similar discussions in my country on a governmental and parliamentary level in order to set up a National Alzheimer’s Plan. The ageing process of the Romanian population means that the number of people with dementia will treble and this increase is reflected throughout Eastern Europe. The dementia epidemic will pose serious challenges to Romania’s health and social budgets.

AE: Do you believe that Romania will follow the example of Denmark, Finland, France, the Netherlands, Norway, Sweden and the UK (England, Northern Ireland, Scotland and Wales) and create a National Alzheimer’s Plan?

OA: I hope that Romania will follow the examples of other European countries to establish and implement a National Alzheimer’s Plan as soon as possible. If Romania is to bridge the already serious gap in terms of healthcare infrastructure and sanitary policies pertaining to the care of people suffering from Alzheimer’s disease or other mental illness, detailed and thorough public policies such as a National Plan are desperately needed.

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

OA: Firstly, I think that the policy priorities for Romanian policy makers should make dementia a priority on the general political agenda. Furthermore, appropriate laws are needed to protect the people with dementia from the illness, as well as their carers. Moreover, Romania needs to step up its efforts in order to create a national network of services for early diagnosis and to provide adequate and/or affordable support services, such as home help, day care and residential care. Last, but not least, we need to set up facilities for family support (counseling, education, support groups) and national educational programmes for the training of professional carers.

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

OA: I think that is very important that all elected MEPs support a European Action Plan in line with the ones that are already in place for cancer, human immunodeficiency virus (HIV) and heart diseases. In addition, we should also find ways to stimulate research in neurodegenerative disorders and to identify new modes of treatment (such as programmes that stimulate cognitive functions and hence slow down the progression of dementia). It is necessary at the same time to create medical technologies to support people with dementia, their families and carers.

The national and European authorities need also to devote resources for the promotion of the “healthy lifestyle for a healthy mind” concept, as it is widely acknowledged that a healthy lifestyle may delay or prevent Alzheimer’s disease and other forms of dementia. Last, but not least, we need to promote the training and development of care services that will provide psychosocial interventions added to the pharmacological ones.

THERE WERE 207,789 PEOPLE WITH DEMENTIA IN ROMANIA IN 2006

ALZHEIMER’S DISEASE

Wouldn’t it be great if Pete could find the way home?

Pete has Alzheimer’s disease. This condition not only has a profound effect on sufferers, it can also increase the burden on their families and carers. Sufferers can become increasingly vague and confused about everyday matters, which may be dangerous and upsetting for them. Late or incorrect diagnosis can exacerbate the situation. We want Pete and millions of patients like him to lead as normal a life as possible.

As well as Alzheimer’s disease, there are many other conditions with unmet medical needs: it is Janssen’s mission to develop innovative treatments for serious illnesses such as HIV/AIDS, schizophrenia, hepatitis C, tuberculosis, psoriasis, arthritis, multiple myeloma, cancer and diabetes. We make extraordinary efforts so that patients around the world can lead a better life.

Extraordinary efforts for a normal life.
FOCUS ON DEMENTIA STRATEGIES: NORTHERN IRELAND

In November 2011, the Minister for Health, Edwin Poots launched “Improving Dementia Services in Northern Ireland, A Regional Strategy”. In this article Alzheimer Europe speaks with Minister Poots about the reasons behind the launch, the priorities of the Strategy, the important role which patient groups must play and how European collaboration can help people with dementia and their carers.

Alzheimer Europe (AE): Why did you launch the Dementia Strategy for Northern Ireland?

Minister Poots (MP): Dementia is of increasing importance to Government, to our communities, to our families and to the individuals who have dementia – it is a major concern for us all – the scale of the problem is increasing in accordance with our ageing population.

In Northern Ireland we have the fastest growing elderly population in the UK. Currently, over a quarter of a million men and women are of a pensionable age, which is nearly one in six of our population. By 2028 that will have increased to nearly one in five and by 2050, nearly one in four.

Demographic changes have a very specific impact on demand for Health and Social Care services. As life expectancy rises, the number of people affected by conditions associated with old age will increase dramatically. Based on rates from across Europe, we may see dementia numbers in Northern Ireland rise from the current estimate of 19,000, to around 60,000 by 2051.

Our goal must be to ensure that people with dementia are given every chance to live their lives to the fullest capacity and as independently as possible. To help achieve this I launched the Dementia Strategy in November last year.

Better outcomes for people living with dementia can be achieved when we come to understand how to delay the onset of dementia; when we have better ways to diagnose it early and when we have effective treatments for dementia alongside high quality care.

I want to ensure that people with dementia are treated with awareness and respect, especially by those providing services, and that they are supported to maintain their independence for as long as possible. I believe that the Strategy can help shape the development of excellent services for people with dementia.

AE: What do you see as the main priorities and challenges of the Strategy?

MP: Meeting the increasing demand for dementia support services will require everyone from Health & Social Care professionals, voluntary and community organisations, and service users and carers, to work together to develop more efficient and effective systems of care, and to plan and implement better treatment and support programmes.

For those with a diagnosis of dementia, the Strategy requires us to look critically at the way we are delivering services. We all must ensure that it is not only what people with dementia and
their carers have said they want and need, but that it is supported by evidence of its effectiveness.

The key themes of our Strategy are:

- prevention - there is some scope to prevent or delay the onset of dementia through a healthy lifestyle approach and reduction in cardiovascular risk factors
- raising awareness and addressing stigma associated with the condition
- access to early diagnosis, enhancing existing memory services to agreed commissioning standards to provide assessment, diagnosis, information and support
- staged approach to care and support as the condition progresses, with the aim of maintaining daily living and independence as far as possible;
- improving staff awareness and skills to respond appropriately to people’s needs
- redesign of services to shift care as far as possible to people’s own homes and avoid admission to hospital or care home where possible and
- the need for worldwide research into causes, cure and care for dementia.

Also underpinning the Strategy has been the development of a set of Values & Principles, which are considered key to guiding the future development of services for people with dementia and the people who care for them. These are:

- dignity and respect
- autonomy
- justice and equality
- safe, effective, person-centred care
- care for carers and
- skills for staff.

As you can see there has been a focus through the development process on creating a Strategy that is centred on the person, aimed at addressing the things that concern people the most.

I am confident that we have produced a practical, realistic and achievable Strategy for people with dementia, one which is designed to deliver the best services and support arrangements we can, tailored to the individual’s particular needs and circumstances. And we must always remember that simple interventions can often have very important and significant outcomes.

AE: What role do you see patient groups playing in implementing the strategy?

MP: When I launched the strategy last year I tasked the regional Health and Social Care Board and the Public Health Agency in Northern Ireland with taking the strategy forward and implementing its actions.

The first stage of this process is to establish a steering group to oversee this work. This will include looking at how best to include people living with dementia, and their carers, so that they are actively involved in the work being done to improve the services they use.

This is a very important part of the process. The involvement of people living with dementia was at the heart of the development of our strategy. For example, the Alzheimer’s Society carried out a pre-consultation exercise with service users and carers to help inform the Strategy at an early stage. This was titled the “Listening Well” Report.

Also, accompanying the public consultation was a targeted exercise with service users and carers, carried out by the Dementia Services Development Centre. We must continue in this manner as we move forward with implementing the strategy and I am confident that we will do so.
AE: Do you see a need for greater European collaboration on dementia?

MP: Greater collaboration will undoubtedly lead to the development of better services for people living with dementia and their carers.

I believe one of the areas that can greatly benefit from collaboration is research. Research into dementia is vitally important if we are to provide improved diagnosis, more effective treatments and better outcomes for people living with dementia.

Any developments resulting from research into this condition, whether they are made locally or internationally, will benefit people living with dementia everywhere.

But it is not just research that can benefit from collaboration. The impact of dementia in Northern Ireland, in Europe, and indeed world-wide, calls for a co-ordinated approach in all aspects of tackling this condition, and we can greatly improve the lives of those affected most through the sharing of good practice and dissemination of new ideas.

Alzheimer’s Society has been a key participant in the development of the Dementia Strategy. Elizabeth Byrne McCullough, Policy & Public Affairs Officer, speaks with Alzheimer Europe about the Society’s role in developing the Strategy and the challenges ahead.

Alzheimer Europe (AE): What role was played by Alzheimer’s Society in development of Dementia Strategy?

Elizabeth Byrne McCullough (EBM): Since the Northern Ireland Assembly Executive made its formal commitment to develop a dementia strategy in 2008, Alzheimer’s Society has been in the thick of the project set up by the Department of Health, Social Services and Public Safety (DHSSPS). Furthermore, the Society has played a pivotal role in ensuring the views of people with dementia and carers have been incorporated at a formative stage by directing and facilitating research undertaken by the Mental Health Foundation including people currently living with dementia in Northern Ireland. Alzheimer’s Society published documentation of those views in the Listening Well report in Belfast in November 2009. Recommendations from Listening Well form a key part of the Strategy which the Minister for Health, Edwin Poots presented to the Northern Ireland Assembly in November 2011.

AE: What impact will the Dementia Strategy have and what challenges does Alzheimer’s Society see?

EBM: The necessity for a strategic approach to the challenge of dementia is reflected in the policy direction of government and non-government bodies right across Europe and the various approaches have been outlined in the pages of Dementia in Europe in recent years.

The Dementia Strategy for Northern Ireland is very much part of that European-wide movement.
with the potential for huge positive impact on everyone living with dementia now and in the future.

Broadly speaking, the Strategy sets out to support people with dementia to live as well and independently as they can, to get quality information, care and support to make decisions and to live well in any setting from diagnosis to the end of life. It aims to raise public awareness of how we can all reduce our risk of developing dementia through lifestyle changes and tackles stigma and lack of understanding or dementia specific skills in the health and social care workforce.

Though the Society reserves some doubts that the Minister can accomplish the priorities he has outlined without additional funds for the strategy’s implementation, we share the Minister’s view that dementia is a considerable social challenge, we support his determination to address it and hope to be part of realising the Strategy’s vision in full for people living with dementia.

Finland: National dementia plan launched

On 8 May, Finland launched a national dementia plan called the “National Memory Programme 2012-2020”. The plan aims to create a “memory-friendly Finland” and was prepared by the Ministry of Social Affairs and Health along with other organisations. Dr. Eila Okkonen, Executive Director of Muistiliitto (the Finnish Alzheimer Society), highlighted four main areas of activity:

• the promotion of lifelong brain health and the prevention of memory-related diseases
• the promotion of positive attitudes towards people with dementia in order to guarantee their basic human rights
• the recognition, diagnosis and treatment of memory-related diseases as early as possible with a particular focus on the entire care chain and its quality
• support for high quality research and ensuring the competence of professionals.

Germany: German Ethics Council names dementia as a major challenge of our time

The German Ethics Council published an opinion on “Dementia and Self-determination” on 24 April 2012. It identifies dementia as one of the major health and social challenges of our time and highlights that people with dementia live with diminished mental, emotional and social resources. Therefore, it is essential to preserve “each remaining independence and self-determination” for as long as possible.

Switzerland: Swiss parliament votes to create a national dementia plan

On 12 March 2012, the Swiss Council of States (upper house of the federal Parliament) approved a series of proposals which effectively call upon the government to prepare a national dementia plan. The next step will be to establish priorities and assign action items to regional authorities and associations.
DEMENTIA AND AUSTERTY MEASURES

Maria do Rosário Zincke dos Reis, Chairperson of Alzheimer Portugal and Board Member of Alzheimer Europe, talks about the impact austerity measures are having in Portugal.

Austerity measures and unemployment\(^1\) in Portugal, which has an ageing population and has approximately 20% of the total population living in poverty, are having a strong impact on the quality of life of people with dementia and their carers, although it is very hard or even impossible to quantify.

Specific measures relating to dementia are few and far between. Unfortunately, Portugal does not have a National Dementia Plan and in these difficult times we are not optimistic about having one in the near future\(^2\). It is only when we examine the issues of drug reimbursement and retirement pension calculations that we are able to find concrete examples of dementia-related legislation. Fortunately, these are still in force and no changes are anticipated.

Dementia is not a priority of our government and whilst we strive to reverse this situation we are conscious of the fact that austerity measures may threaten our ability to do so. Both the work carried out and the economic contribution made by nongovernmental organisations (NGOs), such as Alzheimer Portugal, are invaluable to our economy and it is essential that the sustainability of these organisations is maintained.

Indeed, the economic importance of NGOs was highlighted in a report published in April 2012\(^3\). Portugal’s NGOs rank second in Europe for the contribution (1.7%) they make to the economy. In addition, they are significant employers.

In Portugal, NGOs’ budgets are greatly supported by governmental funds. 65% of Alzheimer Portugal’s annual budget is financed by the government and naturally this is a concern in the current climate.

Recognising the huge social and economic value of NGOs, the government, represented by the Social Security Minister, is actively involved in reducing the impact the economic and financial crises may have on the most poor and vulnerable population. This is largely supported by all stakeholders.

Putting this recognition into practice, a Social Emergency Programme was launched and is now being implemented. This Programme includes two main groups of measures: one relates to the running of nursing homes, day care centres and home services and the other concerns support to combat financial difficulties.

Alzheimer Portugal is seriously worried about the future of people with dementia in Portugal. Because of the crisis only emergency measures are being enacted. Alzheimer Portugal calls on the government to create and implement specific measures to protect people with dementia and their carers and, in particular, to develop a Dementia National Plan as soon as possible.

\(^1\) 14.8% in January 2012 according to Eurostat data, sharing third place in Europe with Ireland.

\(^2\) In 2010, two proposals on a National Dementia Plan were discussed and approved in the Parliament. However, these were only recommendations to a government that stepped down shortly afterwards.

\(^3\) “As instituições particulares de solidariedade social num contexto de crise económica” by Sónia Sousa, Professor at the School of Public Policy, George Mason University, Washington DC.
ONE YEAR’S POST-DIAGNOSTIC SUPPORT GUARANTEED FOR PEOPLE WITH DEMENTIA IN SCOTLAND

Late in 2011, Alzheimer Scotland asked the Scottish Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy, Nicola Sturgeon MSP, to guarantee that people in Scotland receiving a diagnosis of dementia would be offered one year of post-diagnostic support from a named and well trained person. It was a momentous decision when she said yes to this ground-breaking commitment. Here, Alzheimer Scotland’s Chief Executive, Henry Simmons explains the background to this campaign and outlines the organisation’s model of post-diagnostic support envisaged for people with dementia and their partners, families and carers in Scotland.

Alzheimer Scotland has campaigned for many years for improvements in timely diagnosis and post-diagnostic support. We were pleased that improved post-diagnostic information and support was one of the key service delivery areas in Scotland’s National Dementia Strategy, published in 2010. However, as the strategy began to be implemented, we were disappointed in the pace and lack of consistent improvement in delivering post-diagnostic support across Scotland.

There is clear evidence that high quality post diagnostic support, provided over an extended period, is essential in order to equip people with dementia and their families and carers with the tools, connections, resources and plans they need to live as well as possible with dementia and prepare for the future. We provided our own evidence of the benefits of this approach through our Facing Dementia Together pilot project which was funded by the Scottish Government.

Facing Dementia Together provides information and support to people recently diagnosed with early stage dementia, their families and friends. It also aims to help people take control of the supports they need throughout the illness, as well as putting them in touch with other people in the same situation.

One person who benefited from this approach to post-diagnostic support was Henry Rankin, who has vascular dementia. Henry and his family spent months trying to find out the cause of his memory problems, receiving little in the way of answers. His experience of receiving his diagnosis was no better. “It was dreadful. Absolutely dreadful. There’s no other way to describe it. She said ‘You’ve got vascular dementia. Come back and see me in six months.’ Then she sent me on my way. No more information, no-one to speak to. I didn’t even know what vascular dementia was. I thought it was all over, that I had six months left to live. I walked out to the street and I burst into tears.”

Fortunately, the Rankin family were put in touch with Tracy Gilmour who manages Facing

“...We believe that this is a world first and a world-leading commitment and we commend the Scottish Government for making it. This is a significant milestone in dementia care.”

Henry Simmons, Chief Executive
Alzheimer Scotland
Dementia Together. “She put me at my ease straight away. She reassured me, gave me my confidence back. The way I’d got my diagnosis had knocked the wind right out of my sails, but she got me back on track. She spoke to my family too, gave them lots of information and advice. Best thing was; she was always there. We could speak to her at any time.”

Tracy was able to put Henry and his family in touch with the various people, groups, public sector agencies and other organisations required to help the Rankins plan for future legal, financial and care needs, as well as assisting them with the form-filling involved.

Tracy also put Henry into contact with the Scottish Dementia Working Group. He (with several other SDWG members) attended the Alzheimer’s Disease International annual conference in London this year and was asked to speak during one of the discussions – an experience he thoroughly enjoyed.

As Henry points out, “If someone is told they have cancer, they’re pointed toward people that can help them. That didn’t happen to me. They need to get diagnosis and post-diagnostic support right for people with dementia and their families. I’m glad the government’s made a commitment to making that happen. It’s brilliant news... and not before time!”

The Facing Dementia Together project made a film at one of their café sessions where people with dementia and their families, including the Rankin family, talk about the difference the project has made to their lives. You can watch the film at: http://dementiascotland.org/services/east-renfrewshire/facing-dementia-together/

Alzheimer Scotland has built on the knowledge gained from projects like Facing Dementia Together and from listening to people with dementia and their partners, family and carers to develop our “Five Pillars” model of post-diagnostic support.

Each pillar highlights a key area of activity recognised as essential to supporting people after their diagnosis. Various techniques and approaches can be used to deliver a given pillar, but it essential that the full range is offered to each person.

The purpose of the guarantee we sought from the Cabinet Secretary is to provide the security, for a minimum of one year, of a named person who has the flexibility to work alongside the person, their partner and family and ensure that, over a 12 month period, each person is given help and support to work through the five pillars.

By the end of the year it is expected that some individuals might need ongoing professional support; however the purpose of the post-diagnostic support is to enable the individual and their family to develop a robust personal plan that utilises all their own natural supports, that maintains newly developed peer support mechanisms alongside existing and new community connections and that will support each person to live well and independently with dementia for as long as possible.

We believe that this is a world first and a world-leading commitment and we commend the Scottish Government for making it. This is a significant milestone in dementia care and we expect it to be a life changing commitment for the 7,000 people in Scotland diagnosed with dementia each year, and for their families.

The challenge now is to deliver it. This will require a major shift in both practice and culture.
However few people do not support this approach and I am certain we will have the support of all professional groups to make this a success.

In a recent issue of Dementia in Scotland, Alzheimer Scotland’s quarterly magazine, Deputy First Minister Nicola Sturgeon stated her commitment to what we believe is a world first in dementia care. “For me, it is vital that I have a specific focus on this area of care – because I know that getting the right support in place at this stage of the illness can greatly help improve the quality of care throughout the journey of the illness. Underpinning this commitment will be a link worker, assigned to work with the person and their family and carers in co-ordinating support and building a person-centred support plan, based on Alzheimer Scotland’s “5-Pillar” model (see below). Providing this support will be key to supporting people in adjusting to a diagnosis and its likely impact – both emotionally and practically; and in helping them plan for the future and navigate through the key issues and supports available. We want the commitment to help people with dementia live well in their home and in their community for as long as possible.”

Alzheimer Scotland’s “5-Pillar” model

—I know that getting the right support in place at this stage of the illness can greatly help improve the quality of care throughout the journey of the illness.”
Nicola Sturgeon
**DEMENTIA IN THE NEWS**

**Spotlight on Romania**
The Romanian Alzheimer Society has carried out its work for 20 years. In this article Cătălina Tudose, President of the Society, reflects on its work and future challenges.

**Members’ news**
A brief look at some of the work carried out by national Alzheimer associations around Europe.

**The Scottish Dementia Working Group celebrates ten years of achievement**
Highlights of the work carried out by the Scottish Dementia Working Group are discussed by Jan Killeen, Alzheimer Scotland.

**Living with dementia in Portugal**
Maria do Rosário Zincke Dos Reis, Chairperson of Alzheimer Portugal and Board Member of Alzheimer Europe, shares her experience of caring for her mother, Teresa, who passed away with Alzheimer’s disease in February this year.
The Romanian Alzheimer Society celebrates 20 years' work this year. In this article Cătălina Tudose, President, reflects on the challenges and hopes of the organisation.

The Romanian Alzheimer Society was founded in 1992 when a group of professionals (doctors, nurses, psychologists) wanted to address the problems faced by elderly people who lived with this incurable and often undiagnosed disease. Initially, we focused solely on raising awareness of the disease.

The first service the Society offered was "Meals on wheels". This service also enabled us to carry out assessments and pass information on to the relevant doctor. It was in this way that we started to understand the real needs of people living with this disease.

We were able to offer health and social support once we opened our first day care centres in 1993 in Bucharest and in Galati. Shortly afterwards we opened our headquarters in Bucharest and received international recognition for our work, becoming members of Alzheimer Disease International and Alzheimer Europe.

Our activities expanded in 1995 when we opened a new day care centre in Nehoiu which was specifically aimed at helping people with Alzheimer's disease. From information we gathered it was clear that most people with dementia were not diagnosed and those that were diagnosed were in the very advanced stages of the disease. To help those people involved with people with dementia, we developed a system of continuous training for carers and short courses for family doctors, social workers and nurses.

Motivation at this time was high and we opened our fourth community centre in Timisoara. However, the situation changed dramatically for the worse after the funding and support which had been allocated to former communist countries ran out. We were forced to rely on funding from government bodies and this proved to be highly variable.

By 2005, the lack of governmental support together with a survey on the management of Alzheimer’s disease in Romania indicated to us how little people really understood about this disease. Even after strong awareness campaigns, there is still today an enormous need to raise awareness and understanding of the disease. To help achieve this, the Society took the decision in 2011 to host an annual national conference to facilitate the exchange and sharing of information between experts from the field of dementia via conference presentations, workshops and courses.

Despite all our work, it is extremely disheartening that dementia is still not a political priority in Romania. We need to lobby our politicians and this year we are developing a national Alzheimer’s Alliance to do just this. Only with a coherent national strategy which encompasses the medical, social, financial, personal and ethical issues, will the problems of over 1.5 million people in Romania who are directly or indirectly affected by this disease start to be addressed.
MEMBERS’ NEWS

Alzheimer Europe reports on some of the recent activities carried out by national Alzheimer association around Europe.

Greece: Alzheimer Hellas holds workshops on legal and social issues

On 9 March, Alzheimer Hellas initiated a series of workshops for 2012 which aim to inform professionals and caregivers about legal and social issues that are specific to dementia. The first workshop was officially opened by Deputy Health Minister Markos Bolaris and attracted nearly 200 people.

Italy: Alzheimer Uniti Italy hosts a book launch and publishes a new caregiver guide

On 2 March, Alzheimer Uniti Italy (AU) organised an event around the publication of a new book on the subject of ageing, entitled La Longevita Attiva, or An Active Long Life: The Pleasure of Knowing How to Age. Written by geriatrician Enrico Paciaroni, the book gives a positive look at ageing and reminds readers about the pleasures of ageing and about the value of living an active, enjoyable life.

Poland: Polish Alzheimer’s Association wins prestigious award

On 10 February, the Polish Minister of Health awarded the Polish Alzheimer’s Association with the St. Kamil’s Award. This yearly award is given to local organisations for remarkable achievements during the year. The Minister cited the association for “its long lasting, comprehensive and tireless voluntary activities for the good of people with dementia and their families, and also for its significant contribution toward the development of the Alzheimer’s movement in Poland.” The award was accepted by Alicja Sadowska, head of the Polish Alzheimer’s Association and board member of Alzheimer Europe.

Romania: Romanian Alzheimer Society holds second Annual Conference

Societatea Alzheimer Romana held its second Annual Conference which was entitled “Alzheimer Dementia – a major public health priority in Romania” on 23-25 February 2012. Attracting some 400 participants, delegates were able to hear about a wide range of topics, including risk factors, prevention, preclinical dementia, diagnosis, drug development, future treatment strategies, pharmacological treatment and disease management.

Switzerland: Swiss Alzheimer Association discusses taboos in dementia

The Swiss Alzheimer Association held a seminar entitled “Taboos and Dementia” on 30 April 2012 which attracted more than 350 participants. It included topics such as negligence, abuse, aggression and sexuality. The aim was to determine the causes and to develop ways of managing these forms of behaviour. Due to the success of this seminar the Association plans to schedule further sessions.

UK: Alzheimer’s Society launches online dementia training tool

The UK Alzheimer’s Society, along with BMJ Learning, has launched a free online dementia training tool for GPs on 14 May 2012. The training programme was introduced after a survey by the society revealed that only 37% of UK general practitioners say they have received sufficient basic dementia training. The free programme includes sections on early diagnosis and non-drug treatments for behavioural symptoms such as hobbies, social interaction and music.
THE SCOTTISH DEMENTIA WORKING GROUP CELEBRATES TEN YEARS OF ACHIEVEMENT

Jan Killeen, Policy Consultant, Alzheimer Scotland looks back at the some of the highlights of the work carried out by the Scottish Dementia Working Group.

The Scottish Dementia Working Group (SDWG) is a campaigning group run for and by people with dementia within Alzheimer Scotland. The group has a committee and membership which has grown to 140. Membership is inclusive of all types of dementia– not only Alzheimer’s disease. The group sets its own objectives and priorities and decides how to take these forward. Alzheimer Scotland fully funds the group including a full time co­ordinator and part time development worker (selected by a panel of members). The group also receives support and training from Alzheimer Scotland’s awareness raising, and policy staff; also from individual dementia care specialist from other agencies, some of whom have been involved since its inception.

Lively open meetings are held every two months and the committee meets in between. Regular newsletters are sent to members. This helps those who are unable to attend meetings to be involved. Their views and ideas are always invited.

Influencing change

Training and awareness raising
The SDWG has made a huge impact on the attitudes of the public professionals and politicians, speaking at conferences, taking part in radio and television programmes, newspaper interviews and input to professional training. The group has produced several training DVDs as well as guides for people newly diagnosed with dementia and a joke book!

Campaigning
The influence of the group at national policy level has been remarkable, with representation on Scottish Government working groups to develop the National Dementia Strategy for Scotland and ongoing involvement in the monitoring and implementation of the strategy. The group is invited to meet with the Deputy First Minister, Cabinet Secretary for Health and Well-being four times a year to discuss progress on the strategy and to receive feedback on the experiences of members. The Scottish Government is honouring the 10th Anniversary of the group with a reception at Edinburgh Castle.

What has made the group successful?
How the group works is vital to its success: meetings are relaxed but well organised – ensuring everyone is welcomed and as involved as they want to be. Members work best when the agenda is short, with discussion in small groups and key points written up on a flip chart as a memory aid; and time allowed for people to absorb new information and formulate their views.

As the group has grown from strength to strength it has gained national and international recognition. Its participation is highly valued by a wide range of professional bodies, universities and the media. By 2009 the workload was becoming overwhelming – the group was a victim of its own success. Following a review, members agreed to focus on three campaigning priorities and a development plan to build a stronger group.
Priorities:

- Highlight the importance of early diagnosis and diagnostic processes
- Improve national-wide access to post diagnostic support
- Well-trained workforce

An action plan for each work area is in place which guides its work very effectively.

**How did the group start? From small acorns mighty oak trees grow!**

James McKillop, MBE, diagnosed with vascular dementia in 1999, was the inspiration behind the SDWG and continues to be after 10 years of dedicated work. He describes the SDWG as “the independent voice of people with dementia within Alzheimer Scotland, a marriage made in Heaven”.

James realised the power of speaking out when he was asked to talk at a research conference by social researcher, Heather Wilkinson. With Heather’s encouragement and others sharing James’ vision, a small group of people with dementia and their supporters came together to talk about how they might go forward, I was privileged to be part of that group. Alzheimer Scotland played a key role in the process, offering a firm foundation for its development and in 2003 the first birthday of the group was celebrated with over 20 members. The first strong-hold for the group was in Glasgow and groups gradually developed in other parts of Scotland. It is a remit of Alzheimer Scotland’s Dementia Advisers to offer people with dementia information about the group and to help them to participate if they wish to join.

The SDWG is represented on the Alzheimer Scotland Board and helps to fulfil one of our key aims: to be the voice of and for people with dementia in Scotland. The group’s contribution is unique and invaluable, not only to the organisation but to the whole community.

For further information about the Scottish Dementia Working Group, see: www.sdwg.org.uk or e-mail: sdwg@alzscot.org
LIVING WITH DEMENTIA IN PORTUGAL

Maria do Rosário Zincke dos Reis, carer, Chairperson of Alzheimer Portugal and Honorary Treasurer of the Alzheimer Europe Board, speaks about caring for her mother, Teresa, who lived with Alzheimer’s disease.

Being a carer

I lost my mother two months ago. She had Alzheimer’s disease. It was a long journey of 20 years. 20 years ago in Portugal only a few people were aware of this brain disease. In the family, at work and among friends no one could understand why she forgot things, places, names and appointments, why she was always losing glasses, money, gloves and other personal things. Everyone found it strange that she was always so tired and nervous and could not do her job properly as she had done before.

It was a long journey from these first signs to the very last moments. There was the time when she walked on the streets of Lisbon for hours, alone or with her baby grandson, because the family did not understand that it could be very dangerous. There was the time when she ate lots of chocolates and bananas. There were hilarious moments when she had no inhibitions and did things like dropping a glass over someone she did not like!

What remains as my most significant memory during this very demanding experience for all the family, is the incredible capacity of my mother to create and maintain affection. How can someone that does not speak or express herself by any other way and that was completely dependent, make people really love her?

Everyone loved her, not only my father, my sisters, myself, the grandchildren, which was natural, but even the doctor, the nurse, the carers, the hairdresser and anyone else that appeared in her life, even at the latest stage of the disease. No one could remain indifferent to her. She was always ready to connect emotionally with others. How? I really don’t know.

My mother succeeded in achieving things that many of us cannot: a marriage of more than 50 years having her husband always with her and providing the best care and love; a big family (four daughters and 11 grandchildren) all together and feeling this grandmother as the main reference of the family and the centre of their lives.

She died on the 14th February 2012, at home, very peacefully with her family around her.

I do miss her. We all miss her. But we can feel the comfort and happiness of having shared so much love with this special person.
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 29 COUNTRIES
22nd Alzheimer Europe Conference
Changing perceptions, practice and policy
Vienna / 4-6 October 2012
Mark the dates!

www.alzheimer-europe.org/conferences