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MEP (Portugal) hosts lunch debate on dementia

Alex Neil
discusses the Dementia Strategy for Scotland

Vytenis Povilas Andriukaitis
talks about Europe in the context of an ageing society

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“Patient empowerment is crucial”
Prioritising Dementia

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Welcome

This edition of the magazine is being launched during Alzheimer Europe’s 23rd Annual Conference in Malta, where I hope to meet many of you! The challenges which people with dementia and their carers face in Malta are highlighted in this issue, not least by the moving account of carer Anne Cuschieri. Charles Scerri provides insight into how the Malta Dementia Society has striven to ensure that the needs of people with dementia are addressed and talks of the Society’s involvement in the development of the forthcoming national strategy. Dr Franco Mercieca, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing in Malta, discusses the government’s role in the national strategy and Joseph Cushieri, MEP (Malta), talks about the importance of making dementia a European priority.

Support at EU level is vital. I am encouraged by the interview with EU Commissioner Tonio Borg, who, whilst highlighting the achievements made in the fields of dementia and Alzheimer’s disease, gives recognition to the crucial function of patient groups. Marisa Matias, MEP (Portugal) and European Alzheimer’s Alliance member, hosted a lunch debate on dementia in June which we report on. These debates are absolutely vital, facilitating an exchange of information between people with dementia, carers, national Alzheimer’s associations, pharmaceutical companies, EU representatives and policy makers.

In times of austerity, the work carried out by national Alzheimer’s associations is critical. Iva Holmerová, Czech Alzheimer’s Society, explains the frustrations resulting from the current economic and political uncertainty in the Czech Republic. In such challenging times, it was uplifting to read of the vast achievements three national associations have made (Italy, Switzerland and Portugal) as they celebrate their anniversaries.

Finally, I am sure those of you who know Dianne Gove will all join me in extending heartfelt congratulations to her for successfully attaining her doctorate in dementia in July.

Heike von Lützau-Hohlbein,
Chairperson of Alzheimer Europe
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Joint Action on “Alzheimer Cooperation Valuation in Europe” (ALCOVE): findings and recommendations

Alzheimer Europe reports on its 16th lunch debate which was dedicated to ALCOVE and hosted by Marisa Matias, MEP (Portugal).

Marisa Matias, MEP (Portugal) opened the debate by explaining that the work on issues surrounding Alzheimer’s disease in Europe needs to continue and will indeed continue. She thanked her Parliamentary colleagues, MEPS Martina Anderson (UK), Sirpa Pietikäinen (Finland) and Angelika Werthmann (Austria), representatives from the European Commission, the pharmaceutical industry and national Alzheimer associations for supporting the debate.

Armelle Leperre-Desplanques, PhD, Manager of the Pilot Programmes, Division of Quality and Safety Improvement in Healthcare, French National Authority for Health, presented an overview of the results and recommendations from ALCOVE. It was a collective work that enjoyed the commitment of 19 countries, 30 organisations, 100 authors and contributions from Alzheimer Europe and many national Alzheimer associations for supporting the debate.

ALCOVE arose from a need to share knowledge and experiences between European Member States, in order to make health policy recommendations to improve care for dementia in Europe. The project’s scientific methodology is available on the ALCOVE website (www.alcove-project.eu). Once data was collected it was reviewed and analysed by European experts. The teams compared the situation within the EU and identified good practices to ensure that their recommendations were based on reality and offer ways in which situations could be improved. By working together and also alongside other EU initiatives, Dr Leperre-Desplanques said that the proposed recommendations are well-adapted to the continuous evolution of our current knowledge and that they respect the links between social, medical care and research issues. The recommendations are directed at each of the four core areas [epidemiology, timely diagnosis, behavioural and psychological symptoms of dementia (BPSD), support systems and ethics] and also the additional topic of antipsychotics.

Dr Leperre-Desplanques highlighted the issues raised when trying to understand prevalence and epidemiological data about dementia. Analysis revealed that different studies on prevalence...
employed different criteria. A better estimation of dementia prevalence, based on shared quality criteria will better inform policies and help planning. Consequently, the first recommendation is to promote the highest quality epidemiological studies, which in turn will enable the monitoring of dementia prevalence.

There is a lack of information in many countries regarding the use of antipsychotics for dementia. Nowadays there are other possibilities yet they are not always applied. This situation needs to be monitored if changes are to be achieved and ALCOVE recommends that data collection on antipsychotics for dementia be urgently improved.

Health and social systems need to be adapted to meet the needs of people with dementia and we also need to establish whether treatment is effective. This can only be done by having access to the best available knowledge. ALCOVE conducted a survey of more than 80 databases across the EU and found many cases where information was inconsistent or missing. Another recommendation is that a minimum data set, shared among different Member States, should be adopted for administrative, clinical, epidemiological and other relevant data sources. The dataset should include general data on chronic diseases and specific data on dementia.

Dr Leperre-Desplanques explained that the issue of diagnosis is complex, as there are many competing views on when a diagnosis can or should be made. There are some who are keen to work at the very beginning of the disease process, while others believe that a diagnostic policy should be concrete but also beneficial for the maximum number of people. Then there are those who focus on the importance of the consequences that a diagnosis brings, as dementia happens to real people with families and has profound consequences on all. Therefore, a double approach was taken when considering various diagnostic opportunities: this considered not only the science and literature, but also the reality of what a diagnosis means to a person at the receiving end.

At the moment, approximately 50% of people with dementia in the EU are still left undiagnosed and existing diagnoses are generally made at a late stage of the disease. ALCOVE recommends that the point of diagnosis move to an earlier stage in the disease. This would respect the individual’s right to know, adjust, plan, make decisions and also allow for the possibility of an improved quality of life with access to treatment, intervention and services. It would also give families more time to adjust and obtain support. However, these benefits will only be realised if health and social policies are adjusted and services are in place and accessible: without these, an earlier diagnosis could result in a misdiagnosis, potentially leading to feelings of isolation and negative attitudes.

The four principles of diagnosis identified by ALCOVE are that (i) it should be timely and accessible, (ii) fear and stigma about dementia need to be addressed if an increase in the number of people coming forward for a diagnosis is to be achieved, (iii) the rights and wishes of the person should be paramount and (iv) giving and receiving a diagnosis of dementia is a key intervention in the adjustment process. These principles may be used in each country to assess where they are on issues of diagnosis and also to plan national and EU strategies to improve timely diagnosis.

ALCOVE considered the best strategies for dealing with the behavioural and psychological symptoms of dementia (BPSD). These represent the main causes of a dramatic impairment of quality of life.
Sirpa Pietikäinen emphasised the importance of ensuring that people realise advance directives are about choice: to accept or reject specific care.

for people with dementia and carers and are also the principal cause of institutionalisation. ALCOVE recommends a patient pathway with dedicated “3D support systems” for BPSD. These consist of how to develop and/or implement (i) structures and care organisations for BPSD (ii) individualised patient and family carer interventions and (iii) a skilled workforce.

Bénédicte Gombault from the King Baudouin Foundation presented an overview of work package 7, which focused on the ethical and legal aspects of competence assessment and advance directives for people with dementia. The team carried out a literature review, a survey of 27 countries and held three workshops. It was clear that whilst there are many different religious and philosophical backgrounds in the EU, there are also some basic common values: the most important being that human dignity needs to be respected. She explained that the issue of competence is of particular importance in cases of dementia, as it will change over time, and that it is essential to strike a balance between the autonomy of the person with dementia and his/her protection. Two tools may help: Advance Directives can facilitate the dialogue between the person with dementia and professional carers and competence assessments can be used to support the presumption of competence whilst taking into account the capacity of the person with dementia. Recommendations for Advance Directives include that they should be part of the broader context of advance care planning. The team found the process of defining competence assessment to be highly complex. Ms Gombault said that much work remains to be done on this issue and that there is an urgent need for additional research.

Dr Leperre-Desplanques concluded the presentation by explaining that a detailed report from each work package is available on the ALCOVE website. She noted that there is a particularly nice presentation of the toolbox to reduce antipsychotics which includes a concrete proposition of programmes. There are now 53 recommendations based on science, exchange and collaboration. Over the next two years, the results of ALCOVE will be shared and discussed in order to ascertain how best to implement the recommendations. In this regard, she thanked Alzheimer Europe for providing a platform to do so at the organisation’s conference in Malta in October.

Sirpa Pietikäinen, MEP (Finland), thanked the presenters and added that it was necessary for politicians to push the message that people with BPSD can be helped at home and that it is not always necessary to be institutionalised. In addition, she emphasised the importance of ensuring that people realise advance directives are about choice: to accept or reject specific care. She believed that many people immediately associate advance directives with the rejection of care and that it is essential that this be corrected (or cleared up). Lastly, Ms Pietikäinen asked whether these issues could be raised as human rights issues on a national level.

Ms Matias supported the ALCOVE recommendations and embraced the holistic approach which the project adopted. She also spoke of the huge chal-
The challenge of lack of resources, faced in particular by southern EU countries. Ms Matias believed that the Parliament wants to support these measures but asked how MEPs can fight for their implementation when there is a constant demand to cut back on resources in the public health domain. Dr Lepere-Desplanches agreed that people with dementia and their carers need a response to this dilemma. She reflected that the situation was the same in France, where there is an Alzheimer plan with only limited resources. She said it is important to enlighten decision makers about the balance to be struck between research and care. Investment in research is certainly required and national strategies can provide solutions which offer a balanced approach. As an example, she highlighted psychosocial intervention programmes, which have proved effective and yet less costly than other solutions. Dr Lepere-Desplanches explained that it was the need to strike this balance which necessitates the need for concrete discussions between experts and governmental policy makers. She also believed that the EU should have a key role in facilitating these discussions.

Hegla Rohra, who lives with dementia and is the Chairperson of the European Working Group of People with Dementia, raised the issue of addressing the special needs of younger people with dementia. Dr Lepere-Desplanches explained that the project was limited to two years so they had not been able to explore every issue but agreed that a better understanding is required of the issues which arise for younger people with dementia. There is a specific recommendation for this included in ALCOVE.

Jean Georges, Executive Director, Alzheimer Europe, thanked the presenters for the recognition given to Alzheimer Europe’s work. He said that one of Alzheimer Europe’s roles is to highlight differences between countries. He explained that the organisation is developing a benchmark known as the “Dementia Monitor” that will monitor these differences. He said that in times of austerity, we owe it to people with dementia to offer the best possible care, treatment and diagnosis and that he hoped to be able to use the data from ALCOVE to this end.

Ms Matias thanked the presenters. She said that we should all work together and even create a “revolution” to build on this information.

Heike von Lützau-Hohlbein, Chairperson, Alzheimer Europe, emphasised the importance of sharing, saying “We need to be sensitive to the fears of people with dementia and of their families. We know it works both ways: just as a person with dementia can be in denial, a family may also be in denial because they do not want to accept that a loved one is getting memory problems.”
A snapshot of Alzheimer Europe’s 16th lunch debate on dementia

Markus Löfström, Aino Valtanen and Sirpa Pietikäinen, MEP all from Finland

Angelika Werthmann, MEP (Austria)

Marisa Matias, MEP (Portugal)

Štefanija Zlobec (Slovenia) and Nino Mimica (Croatia)

Martina Anderson, MEP (UK, Northern Ireland), Marisa Matias, MEP (Portugal), Annette Dumas (Alzheimer Europe) and Maria do Rosário Zincke dos Reis (Portugal)

Maria Moglan (Romania), Gökçe Elkap (Lundbeck) and Ersi Grammatikou (Greece)

Delegates at the lunch debate meeting

Armelle Lepierre-Desplanques

Bénédicte Gambault (King Baudouin Foundation) and Jean Georges (Alzheimer Europe)

Irina Ilieva (Bulgaria)
DECIDE: A new service that assists in the earlier diagnosis of dementia

Fulvio Galeazzi, project coordinator, discusses the future of the DECIDE service after the end of the project lifetime.

DECIDE was an EU project that ran from September 2010 to February 2013 and involved 13 partners from five countries. They developed and launched a service that assists in the earlier diagnosis of Alzheimer’s disease and other forms of dementia. Alzheimer Europe collaborated in the project by supporting the dissemination of the project’s results and achievements. The service has been operational since April 2012.

To give a simple illustration, a neurologist can upload an MRI (Magnetic Resonance Imaging) scan of a patient that is showing signs of mild cognitive impairment. The DECIDE system compares this with the thousands of existing images in the system. Less than half an hour later, the neurologist receives a report showing the levels of dozens of indicators of dementia within the scan. This allows the physician to make a more timely and accurate diagnosis. The benefit for patients is clear: early diagnosis also means earlier therapy, including more appropriate inclusion in clinical trials or advanced therapies.

The service is also very fast and reliable, as each application was developed and tuned with clinical praxis in mind. DECIDE uses the distributed services and grid/cloud computational resources made available by EGI (European Grid Initiative) and the high-bandwidth network connectivity made available by the pan-European GÉANT and national research and education networks.

By capitalising on the work of leading dementia experts, a physician at any remote hospital can analyse a MRI or PET scan in a few minutes, whereas the same task on a single computer might take weeks or months. More importantly, an in-depth knowledge of each of the involved applications may be extremely hard or impossible to find in a remote location.

Fortunately, the DECIDE service will continue to operate. This is mainly due to the Italian Ministry of Health, which has approved funding for several follow-on projects that involve the service. These include GRIDCORE – which aims to assess the effects of cognitive rehabilitation Alzheimer’s and Parkinson’s disease – and MINDBRAIN, developed within the context of “PON Smart Cities” and aiming to develop further applications. The project partners have also sought a role for DECIDE in other European FP7 projects. In addition, there has been a formal offer for the DECIDE diagnostic service for daily clinical practice to a group of leading European memory clinics.

“A physician at any remote hospital can analyse an MRI or PET scan in a few minutes, whereas the same task on a single computer might take weeks or months.”

FULVIO GALEAZZI

DECIDE was funded by the European Commission within the 7th Framework Programme (FP7) under Grant Agreement RI-261593. FP7 was the main EU instrument for funding research in Europe during 2007-2013. More information is available at www.eu-decide.eu
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A commitment to care

For over 50 years, Novartis has been a leader in neurology care. Our neuroscience products have touched the lives of millions of patients worldwide. In dementia care, we continually strive to translate scientific innovation into therapies and technologies that matter.

Together our goal is to help patients with dementia live with the dignity they deserve.
European Working Group of People with Dementia (EWGPWD)

Nina Baláčková, Vice-Chairperson of the European Working Group of People with Dementia reports on her visit to the 28th international conference of Alzheimer’s Disease International which was held in Taipei on 18-20 April 2013.

I am grateful to the Czech Alzheimer Society and Alzheimer’s Disease International (ADI) for supporting me to attend the conference of ADI in Taipei this April.

It was very interesting and useful for myself and my carer. We heard many important speeches and met colleagues with dementia from all over the world.

My attention was drawn to presentations which were given by colleagues who live with dementia – from Australia (Kate S.), Japan and also carers from Indonesia and Taiwan. I heard that handicapped people and also elderly people in Asia, Japan and Taiwan are held in much respect within their communities. There is a wish to improve their life conditions. I would be glad if it would be the same here, in the Czech Republic.

The atmosphere between people with dementia was great. After two days we were like old friends. Our Japanese colleagues were dancing for us! I was interviewed for a Japanese magazine!

I learned a lot about food issues for people with dementia. I am often very hungry, but I don’t like to add any more kilos. The doctor explained to me that people with Alzheimer’s disease need more food than other people of the same age and that I should not be anxious about obesity. Apparently, people with Alzheimer’s disease usually have the opposite problem: malnutrition. After this speech my carer laughed and told me that she can now understand why it is better to dress me than feed me :) .

The last day of the conference started with the event, “International Memory Walking”. Everybody got an orange shirt to wear. We started by exercising to music. Only later did I understand that this was the same exercise we had seen every morning where the young, old, individuals and groups exercise on their balconies and parks. Everyone walked for about one kilometer whilst holding banners of various national Alzheimer Societies from around the world. Finally we heard young Taiwanese singers and watched young dancers. Afterwards there was a talk on dementia and the chairperson of ADI spoke at the end of this wonderful event.

All of the time everyone – young and old – felt cheerful and full of solidarity.

“The atmosphere between people with dementia was great.”

NINA BALÁČKOVÁ
I recently accompanied my husband Jean-Pierre to Brussels, where he was to attend a meeting of the EWGPWD. Jean-Pierre is a Vice Chair and a member of the Executive of the group, along with Helga, Agnes and Nina. Over the next two days, they would plan the activities of the Group during Alzheimer Europe’s 23rd Annual Conference in Malta.

Upon our arrival, we received a very warm welcome from Jean, the other members of the Executive and their carers. I was immediately struck by how pleased we all were to see each other again. Clearly, the common bond of the illness has created strong links among the group members and their carers. This motivates all of us to do our best during these meetings; during our last several encounters I’ve noticed a growing sense of good-will and motivation among the members to do the best they can.

This became increasingly evident as we went through the meeting agenda. Everyone was active and eager to participate, with Jean providing an occasional gentle nudge to get us back to the topic at hand. I must say that he was always very considerate and respectful of everyone’s opinion.

It was heartening to see that the group members openly admitted their limitations due to dementia. There is a clear sense of trust that one’s weakness will be compensated by the strength of a fellow group member. This is surely a tremendous asset for a working group!

In my opinion, this group dynamic more than justifies the existence of the EWGPWD. The members have developed a growing assurance that they are working at their best capacity, which in turn further strengthens the bonds between them.

On the morning of the first day, we attended a conference on neurodegenerative diseases at the European Parliament. It appeared to me that our elected representatives are willing to take action on behalf of patients – but are hampered by the sluggish pace of legislative bureaucracy coupled with financial constraints. This prevents them from giving the proper impetus to meaningful policies for people with neurodegenerative diseases.

Even so, these conferences – and other such participatory events – are helping to raise awareness that patients can and will stand up to state their needs. The stigma of their illness is slowly receding and they are no longer marginalised; each person is recognised as an individual citizen like any other, despite living with a disease.

However, the fact remains that people with neurodegenerative diseases cannot bear their burdens alone. They have a large and growing need for support, such as specialised homes where they can live with the safety, comfort and dignity they deserve.

During our stay I often found myself admiring my husband and the others for their mutual respect and friendship toward one another, but also for their determination to campaign for the cause despite their afflictions.

At the end of the meeting, each group member was assigned various action items in preparation...
for the Malta conference. I am convinced that if any one person reports any trouble with a task, the others will all immediately and willingly offer to help solve the problem.

I would never have met these wonderful people if it were not for Jean-Pierre’s illness, and, during the past year, I’ve become quite attached to them all. I’ve also noticed that being with the group has given me a new perspective as a caregiver. I feel that I am able to better understand Jean-Pierre’s needs and I try to meet them as best I can. For example, I’ve been more confident – and successful – in guiding us through difficult moments that may otherwise have led to bouts of depression. This allows me to view the future with a little more assurance and even, perhaps, serenity.

I often feel that caring for a person with dementia is like walking a tightrope: the way ahead is clearly marked, yet progress can be difficult because conditions are constantly changing. Even so, Jean-Pierre’s gentle character and good humour, coupled with my affection for the other members of the group, have given me new strength and motivation: I feel better able to give him the best of myself, to help preserve the humanity which is slowly being wrung from him.

“Each person is recognised as an individual citizen like any other, despite living with a disease.”

MARIE-ANNE SCHREDER
**Ethical issues and dementia**

Dianne Gove, Information Officer, Alzheimer Europe, highlights the main discussions from the first meeting of AE’s ethics working group on perceptions and the portrayal of dementia.

The aim of this first meeting by Alzheimer Europe's 2013 ethics working group was to discuss various perceptions and portrayals of dementia and to agree on the methodology to adopt, as well as on the structure of the future report. The group includes participants from Belgium, Denmark, France, Finland, the Czech Republic, the Netherlands and the United Kingdom. Participants are from a range of backgrounds including old age psychiatry, psychology, dementia, philosophy, cultural sociology, nursing and media studies. One member of the group has dementia, one is a current carer and some have past experience as carers.

The meeting started with a presentation by Associate Prof. Baldwin van Gorp on framing and its relevance to the way that dementia is perceived and portrayed. He suggested that frames, which are perspectives or socially shared organising principles, lead to different ways of interpreting “reality”. For example, a common frame is that of “the invader”, a kind of personification of dementia (other alternatives being a monster or a thief), often accompanied by fighting or defensive terminology. The proposed counter-frame for this is “the strange companion”, a more positive personification which still symbolises a second person but not the kind of loss of control, fear or threat of the former. Baldwin demonstrated how various frames are used in the media and emphasised the importance of making greater and more resolute use of counterframes without minimising the seriousness of dementia or denying the last phase of dementia.

Dr Daphne Wallace, shared her perception of dementia, based on having recently been diagnosed with dementia but also having worked for many years as a consultant old-age psychiatrist. Daphne felt that there is an over-generalised perception of dementia which results in the neglect of forms of dementia other than Alzheimer’s disease. Daphne strongly objected to the way that people with dementia are frequently perceived and portrayed as being absent, fading away or the person not being there anymore, which she felt led to inappropriate responses, which fail to respect their personhood, dignity, autonomy and individuality. Daphne is also representing the European Working Group of People with Dementia on this project.

Prof. Jan Oyebode, from the University of Bradford, discussed how people with dementia are perceived by others in terms of personhood, focusing on infantilisation, being different, separate, less, “gone” and not the person they once were. She also highlighted how family carers are often sandwiched between their (often loyal and empathic) understanding of the person with dementia and the (usually negative) views of the society in which they live, and how informal carers and those working in the domain of dementia care may experience “stigma by association”. Ethical issues raised
Jan highlighted how family carers are often sandwiched between their (often loyal and empathic) understanding of the person with dementia and the (usually negative) views of the society in which they live.

included “protective deception” versus honesty, balancing protection with positive risk taking, disenfranchisement from having a legitimate opinion and loss of credibility, and the risk of valuing the well-being of carers over that of people with dementia.

Dr Christine Swane’s presentation focused on perceptions of ageing in relation to dementia and the issue of stigma. She drew attention to the way that people are constantly interpreting what they perceive and constructing meaning through their interaction with other people, hence the importance of understanding perceptions and the way that dementia is portrayed. She explained how people with dementia are often objectified in the sense that they are perceived as the “cause of the problem”, thus detracting attention from the social problem which may be caused by a range of factors such as the environment, cultural practices, staffing levels and sufficient knowledge of carers. Christine highlighted the consequences of adopting a medicalised perspective of dementia (focusing on “emotional incontinence”, the hyper-cognitive paradigm and severe dementia) as opposed to one based on humanisation and a more complex understanding of dementia which highlights the PERSON with dementia rather than the person with DEMENTIA.

Finally, Dr Debby Gerritsen presented the results of a recent study into the portrayal of dementia in fictional movies. A search on an Internet film database for films addressing dementia, Alzheimer’s disease or “senility” between 2000 and 2012 resulted in 22 films. The films were independently rated by three researchers and a consensus meeting led to the creation of a taxonomy of symptoms. This revealed the way in which dementia was portrayed in these films. The symptoms most frequently addressed were impaired memory, disorientation, being in one’s own world, issues linked to awareness/insight, anger/frustration and dementia being a progressive condition.

The next steps will include completing a literature review, drafting a report explaining the different ways that dementia and people with dementia are perceived and portrayed (also by people who have dementia) and developing ethical recommendations. Our aim is not to declare certain perceptions or portrayals of dementia “unethical” as this would imply a judgement of what is morally right or wrong in the absence of a full understanding of the individual, social and cultural context of each perception or portrayal, which could be interpreted differently and reflect different meanings by different people. Rather, we would like to raise awareness and foster reflection about the possible ethical implications for people with dementia of being perceived or portrayed in certain ways.
EMIF: the European Medical Information Framework project

Simon Lovestone (SL): The EMIF project aims to establish a pan-European platform that will enable re-utilisation of data for medical research. The data will come from a wide range of sources, including highly focused research projects, large epidemiological programmes and routine patient care. The data types include clinical information and data from research such as imaging and molecular studies.

We have potential access to more than 20 research cohorts, each of which has gathered information for its own purposes. Our intention is to combine all this information and make it accessible from a common, open source platform called “tranSMART”. We believe that this will provide great benefit to clinicians and dementia researchers.

This has never been done on such a large scale and we are facing a number of unique challenges. For instance, tranSMART must be further developed and tested, but I am glad to report that we already have a prototype up and running. More importantly, we must address the issues of mapping data from many different sources: these include very large general population studies, very specialised clinical trials and everything in between. In addition, we’re working on a data governance policy. This will ensure that data assets are properly managed, particularly with regard to security and privacy.

EMIF currently has two research aims, namely the discovery and validation of biomarkers for Alzheimer’s disease and for metabolic diseases such as diabetes. The discovery of new biomarkers - specifically biomarkers for very early detection and prediction of outcomes - is one of the most important goals in Alzheimer’s disease (AD) research and is widely considered a necessary step before successful trials can be delivered.

EMIF is one of the largest IMI projects in terms of both budget and number of partners.

What were the criteria for selecting partners?

SL: IMI – the Innovative Medicines Initiative – held a highly competitive selection process where groups of academics applied for funding. The EMIF-AD consortium includes some of the most productive scientists in the AD field, with access to the very best research cohorts in Europe. That is why this team was selected and the same applies to the EMIF-metabolic disease and EMIF-platform teams.

How will EMIF collaborate with other EU projects in the field?

Bart Vannieuwenhuyse (BV): EMIF will collaborate closely with EU projects, both in the field of dementia and IT/informatics. We are already looking at several projects that deal with electronic medical records for research. A good example is IMI’s eTRIKS project: this aims to develop an open system capable of efficient storage and analysis of translational research data.

As far as dementia is concerned, EMIF is already a large collaboration of AD programmes across Europe. As the project progresses, we will remain open to the possibilities of extending the collaboration to further studies.

For example, the platform gives us access to some 48 million subjects from eight European countries. We’ll be looking to increase that number, which will hopefully bring us into contact with other project teams.

We are also collaborating with international studies,
In particular with GAAIN. This data-integration study is taking place in the US and includes the American Alzheimer’s Association, UCLA, Italy’s National Centre for Alzheimer’s disease and other partners.

**AE: What are the main achievements of the project so far?**

SL: It is still early days! We have been going for less than six months but have already made significant progress. For example, we identified four cohorts that we can work with (including AddNeuroMed and Descripa) and have started to load the data from these programmes onto the tranSMART platform.

This process will be completed in late 2013 and will provide access to data for biomarker studies on more than 3,000 subjects. As a comparison, ADNI is a study of less than 1,000 people. We are very pleased that EMIF will include data from ADNI, which has been the reference for AD study data since 1995.

**AE: What do you hope will be the achievements of EMIF at the end of the project in December 2017?**

SL: We are looking at transforming the way we conduct research in Europe. Research cohorts will no longer be analysed in an independent and unconnected manner, as EMIF will enable larger, more efficient and powerful studies through collaboration and data sharing.

Beyond that, EMIF will provide a much-needed platform to make use of de-identified routine care data. Every day, a huge amount of clinical data is collected all over Europe as part of normal medical practice. EMIF will enable the use of that data to improve health through research.

In dementia research, EMIF will be the basis for the world’s largest ever studies for biomarkers through collaboration and data sharing. The new biomarkers can then be used for better, earlier detection and for clinical trials.

**AE: How will EMIF benefit people with dementia?**

SL: There is currently a crisis in dementia research, due to serial failures in clinical trials. These failures almost certainly happened because trials were conducted too late, with people who were too far advanced in the disease.

We need to conduct trials earlier in the disease process, ideally before the onset of clinical symptoms. In order to do that, we need new biomarkers and this is where EMIF will deliver. People with dementia today are unlikely to benefit from EMIF. However, we can hope that the project will give a significant boost to the development of biomarkers for clinical trials that can help people with dementia in the future.

**AE: Patient information is generally held under legal and ethical obligations of confidentiality. How is patient privacy addressed in this project?**

BV: We are well aware of the requirement to stay in line with all national and European regulations regarding confidentiality and privacy, and of course this has our full attention.

The data from the cohorts are already anonymised from the source, so there is no issue there. For the population data sets, we are involving a trusted third party partner (TTP) who is specialised in patient privacy protection technology. I would point out that presently we only have aggregated results. If we were to access individual patient data in the future, we would naturally employ our trusted partner to de-identify all personal data.

**“EMIF will be the basis for the world’s largest ever studies for biomarkers through collaboration and data sharing.”**

**SIMON LOVESTONE**
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There are now 71 MEPs who are members of the European Alzheimer’s Alliance.

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Policy Watch

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Dementia and European health policies

Tonio Borg, European Commissioner for Health, highlights progress made with European initiatives in the fields of dementia and Alzheimer’s disease. He also outlines how the Commission seeks to build on these achievements to improve the lives of patients and their carers.

Alzheimer Europe (AE): Commissioner, how will the “Social Investment Package” respond to the specific needs of people with dementia and their carers?

Commissioner Borg (CB): In the Social Investment Package adopted last February, we urged Member States to invest in people’s health, in sustainable health systems and in reducing health inequalities with support from EU funds. These are the messages we have put forward in our paper “Investing in Health”.

The Package also ponders the strengths and limitations of different ways of providing long-term care to the elderly, including those suffering from severe mental and physical disabilities. Work with Member States on long-term care should focus on a social investment-oriented strategy, which combines healthy and active ageing initiatives with productivity drives in care delivery and measures to increase the ability of older men and women to continue independent living. The Package showcases good practices in Member States that give an insight into the potential of a social investment approach to the long-term care challenge.

AE: How is the European Innovation Partnership on Active and Healthy Ageing (the Partnership) progressing in addressing the concerns of people with dementia and their carers?

CB: The Partnership includes an action group dedicated to the “Prevention and early diagnosis of frailty and functional and cognitive decline in older people”. This group focuses on detecting and treating frailty at an early stage and preventing the decline of patients’ health conditions.

In this context, partners develop and deploy innovative solutions to understand the factors of frailty, critical to shape effective preventive measures and management programs for frail people, including those with dementia. I expect that the use of Information and Communication Technology solutions will contribute to reduce the functional and cognitive decline of older people and ultimately increase their independence and self-reliance.

The group is currently working on collaborative projects that specifically target older adults with deteriorated cognitive function. They include smart ageing games software platforms for early assessment of cognitive impairments and innovative web-based and digital applications that provide intellectually and physically stimulating social activities. The group also works on developing a community-based screening programme for mild cognitive impairment, as well as a screening programme to detect prevalence of dementia, and mild cognitive impairment among older adults admitted in hospital.

You may wish to read the excellent article “Active and Healthy Ageing” by Annette Dumas in your February edition, which clearly presents the way the Partnership operates, around six action groups.

AE: Can you update our readers on the Commission’s reflection process on chronic diseases and how dementia will be addressed?

CB: The reflection process on chronic diseases focused on the factors that are common to all chronic diseases as regards prevention and management. It raised awareness about the growing
burden of chronic diseases and the need to develop and deploy innovative integrated care models to efficiently prevent, treat and manage these diseases. The reflection process' work has been picked up by the Partnership on Active and Healthy Ageing, in the context of its work on chronicity issues of older people.

A report on the outcomes of the reflection process will be discussed in the Council this autumn. Furthermore, the Commission has launched a call for a joint action with Member States addressing chronic diseases and promoting healthy ageing across the life cycle, under the Health Programme.

AE: How will the results of the European Joint Action on Dementia “ALCOVE” be taken forward by the European Commission?

CB: Over its two-year mandate, ALCOVE focused on four crucial questions in the field of dementia: epidemiology and prevalence, diagnosis and systems for diagnosis, care for behavioural disorders in view of limiting antipsychotic use and institutionalisation, and the rights and dignity of people living with dementia. I am pleased that ALCOVE delivered new evidence and concrete recommendations in all four areas, calling on Member States to take action.

Upon receiving ALCOVE’s final report, the Commission will circulate the key findings to relevant Directorate Generals and invite Member States to attend to ALCOVE’s recommendations. It will also inform the European Innovation Partnership of the results. Finally, the Commission intends to present a report to sum up the outcomes of the ALCOVE Joint Action and the EU Joint Programme “Neurodegenerative Diseases Research” in 2014.

AE: What role do you see patient groups play in supporting and implementing European recommendations?

CB: Patient empowerment is crucial to patients and also to Member States, particularly in the field of chronic diseases treatment. We have to help willing patients learn to recognise warning systems, adhere to their medical treatment and decide the treatment that is best suited for them. The change in attitudes is already taking place before our eyes, as an increasing number of patients are using eHealth in their day-to-day self-management routine.

Let me be very clear: self-empowerment is not a replacement for professional care. However, I believe that if patients learn to self-manage, they will keep playing an active part in society, and this will also alleviate the healthcare burden on health systems.

The Commission launched earlier this year a study on “Empowering patients in the management of chronic diseases”. I expect that this study will provide an insight into the concept of patient empowerment, identify the related advantages and barriers and identify good patient empowerment practices. The first results of the call should be available before summer 2014.

A second study about the promotion of self-care systems in the European Union will also be launched to help us get a clearer focus on the cost/benefit of self-care.

“Patient empowerment is crucial to patients and also to Member States, particularly in the field of chronic diseases treatment.”

TONIO BORG
AE: Do you see a need for greater European collaboration on dementia?

CB: We already see European collaboration at work through the European Innovation Partnership on Active and Healthy Ageing as well as through Alzheimer Europe. In May 2013, the Commission promoted the European Month of the Brain that highlighted Europe’s support to European projects on brain research. Between 2007 and 2013, the European Commission allocated EUR 1.9 billion to brain research and innovation from its Research Framework Programme (FP7).

The number of people with dementia is on the rise and dementia will therefore remain on our agenda. ALCOVE has shown that Member States are willing to continue working together in this field as such cooperative work delivers highly valuable results.

The Commission has not yet made any decision on new collaboration initiatives. First, we need to see the outcomes of the ALCOVE Joint Action and the Joint Programme “Neurodegenerative Diseases Research” released in 2014.

1 http://ec.europa.eu/social/main.jsp?catId=1044&langId=en
2 SWD(2013)43
3 ec.europa.eu/social/BlobServlet?docid=9799&langId=en
4 Alzheimer Cooperation Valuation in Europe
5 http://www.alcove-project.eu/images/pdf/ALCOVE_SYNTHESIS_REPORT_VF.pdf
6 DG Employment, Social Affairs and Inclusion, as well as Research and Innovation

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Together we make a difference.
The ageing society – a future challenge to Europe at large. What should we accomplish together?

The European Presidency is currently held by Lithuania. In this article, Vytenis Povilas Andriukaitis, Lithuanian Minister of Health, considers how Europe can address the issue of an ageing society.

Global demographic changes bring about the quantitative growth of the older population. The ageing of the population is one of the most topical challenges in the sphere of health in any society. Changes in lifestyle and progress in the treatment of diseases which earlier had been the main causes of death have extended life expectancy and increased the prevalence of chronic health disorders, including mental diseases. The incidence of mental disorders among older people is very high.

The main reason of disability and of dependency amongst the elderly population is dementia. In 2010, 9.9 million residents of Europe were living with different sub-types of dementia with Alzheimer’s disease accounting for the largest share (World Alzheimer’s Report 2010). With increasing life expectancy, in particular in the developed countries, the incidence of dementia has grown considerably and now the number of people suffering from this disease is forecasted to double every 20 years. Accordingly, the share of retired pensioners per one employed individual keeps growing and increases the socio-economic burden associated with neurodegenerative diseases. It is estimated that the cost borne by the 27 EU Member States on the treatment of Alzheimer’s disease and other dementias amounts to EUR 160 billion: 56% of which can be attributed to the costs of informal care of patients.

At the level of the European Union the subject of these diseases is addressed in the Communication from the Commission to the European Parliament and Council on a European initiative on Alzheimer’s disease and other dementias (COM(2009)380), in the Fifth, Sixth and Seventh Framework Programmes for Research, and in particular in the Alzheimer Europe project of the European Collaboration on Dementia (EuroCoDe). In addition, the Era-net Neuron project competition and as well as the political debates on long-term and good quality care services for a reasonable price also address the issue of dementia.

The White Paper of 23 October 2007 “Together for Health: A Strategic Approach for the EU 2008-2013 (COM(2007), 630) developing the European Union Health Strategy also identifies the better understanding of neurodegenerative diseases such as Alzheimer’s disease as an important issue to be addressed against the background of the ageing of the population and calls for measures to be taken to ensure that such diseases are diagnosed and treated. It emphasises the need to receive the diagnosis of Alzheimer’s disease at an early stage, to provide people living with this disease with a possibility to live at home as long as possible and to benefit from social and healthcare services at home satisfying their special needs.

In 2009, the Council adopted the conclusions on the common obligation of Member States to fight the neurodegenerative diseases, in particular Alzheimer’s disease. The ALCOVE (Alzheimer COoperative Valuation in Europe) project implemented in 2010-2012 was aimed at raising awareness about addressing the problems of timely diagnosis of Alzheimer’s disease is too low in the European Union.”

Vytenis Povilas Andriukaitis
“We must encourage society to change its attitude to the phenomenon of ageing.”

VYDENIS PAVILA ANDRIUKAITIS

Alzheimer in patients suffering from this disease, its treatment and care and provision of support to their carers. Lithuania participated in this project.

In order to draw attention to problems elderly people may encounter and to stimulate the resolution of these problems, the European Parliament and the Council declared 2012 the European Year for Active Ageing and Solidarity between Generations. Pursuing common goals with Europe, Lithuania has drafted the National Programme for the European Year for Active Ageing and Solidarity between Generations (2012) aimed at facilitating the creation of an active ageing culture in Europe based on a society for all ages.

Dementia is an incurable and progressive health condition which causes disability, deprives a person of the ability to take care of himself/herself and makes him/her dependent on surrounding people. It is both a medical and a social problem because a person with such disease needs care. Therefore, dementia affects both people who live with this disease and their carers. The incurable disease affects the lives of all people surrounding the person who live with the disease often depriving the carer of their personal life, opportunity to work and free time because this care requires complete commitment. It is estimated that if the family of each patient has on average three members who have to carry the greatest burden of care, that there are about 19 million of Europeans directly exposed to problems caused by dementia. Therefore, the earlier the disease is noticed, diagnosed and treated, the greater the possibility is to stop it and improve the quality of life for the person living with dementia and also family members.

In order to improve awareness about Alzheimer’s disease and other dementias and to change the approach which is not always correct, it is very important to change the attitude of people towards this disease. Awareness-raising programmes about this disease among society members (patients, social workers, carers and family) need to be put in place. Better knowledge would facilitate the nursing and care of the person with dementia, reduce inconveniences that arise and improve their quality of life and of his/her family. Today we can already welcome the achievements made in the sphere of treatment of Alzheimer’s disease which help to slow down the process of loss of memory and to maintain the person’s ability to live an independent life. However, the diagnosis rate of Alzheimer’s disease is too low in the European Union. Almost half of people aged 85–90 are living with this disease.

In order to achieve good health, comfort, safety, full-fledged social integration and independence until old age, the use of gerontechnology for strengthening the abilities of older people is insufficient. Also, psychological interventions which facilitate social integration of an elderly person are of great importance. Ageing is accompanied by changes in the personality and cognitive processes. Inadequate education of society on this subject and a lack of specialised departments and clinics jeopardise social integration of people living with dementia resulting in their (and their carer’s) social exclusion. Lithuania started its Presidency of the Council of the European Union with the Informal Council of the Ministers of Health. One of the matters of the Council’s agenda was mental health and
well-being of older people. I am glad to note that this subject was unanimously supported by all Ministers of Health of the EU Member States during their discussions. It was emphasised that the achievement of further advancement of scientific research requires effective and coordinated action at the European level. Member States should keep developing long-term policy and action plans which will ensure not only healthy ageing but an improvement in quality of life and ageing with dignity. Problems of mental health of older people should be addressed at all levels: individual, family and community.

We must do everything we can in order to ensure that there is no correlation between old age and disease (including mental disorders).

During the Informal Council the issue of mental health at workplaces was highlighted as a very important aspect, particularly in terms of early interventions. It is necessary to improve the work environment in order to reduce work-related stress and tension.

Such actions should also seek to address both the current and projected social and demographic changes that are taking place in Europe. They should focus on the provision of support to the families who take care of their loved ones, while concurrently providing vulnerable people suffering from dementia with social protection.

It is equally important for Member States to ensure solidarity and the exchange of good practices, in order to avoid the wasting of resources and enabling greater attention to be given to a multidisciplinary approach. This would facilitate the provision of early prevention and intervention measures in the primary stages of the disease, diagnosis, treatment as well as support for patients under care and their families. Currently, the medical and social burden of this disease poses great danger to the sustainability of our healthcare and social system. Therefore, I think that first of all we need to strengthen the multidisciplinary approach.

I believe that we will be able to support the innovative actions in this sphere which can facilitate in addressing the problem of Alzheimer’s disease and other dementias. We will also devote greater attention to the financing of scientific research creating new medicines for treatment of such diseases and will also look for simple preventive measures which can be applied by everybody, such as, for example, change of a lifestyle.

We must encourage society to change its attitude to the phenomenon of ageing. There must be solidarity between generations, society needs to seek the active participation of older people in family and social life and in the labour market and we must fight poverty and social exclusion. As the population of elderly people keeps growing, it is necessary to ensure that they also have access to all the technological innovations available. A successful organisation of support and care for older people can only be achieved through the understanding, willingness and close cooperation between generations and institutions.

“We will also devote greater attention to the financing of scientific research.”

VYTENIS POVILA ANDRIUKAITIS
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Making dementia a European priority
Joseph Cuschieri, MEP (Malta) talks about the need to address dementia at European level.

Governmental support for people with dementia and their carers in Malta
Dr Franco Mercieca, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, discusses the national dementia plan.

The Malta Dementia Society – past, present and future
Charles Scerri, General Secretary, reflects on the work carried out by the Society.

Rosa
Anne Cushieri talks about caring for her mother, Rosa.
Making dementia a European priority

Joseph Cuschieri, MEP (Malta) talks about his involvement with the European Alzheimer’s Alliance and the need to address dementia at European level.

Governments and health authorities everywhere in Europe are becoming increasingly aware of the need to tackle the problem of dementia, a physical and mental condition mostly associated with Alzheimer’s disease, although there are other causes. With the continent’s ageing populations being a social reality that cannot be ignored, it has become even more imperative to make dementia a European health priority.

Dementia is a syndrome which typically involves serious loss of global cognitive ability in a previously unimpaired person, beyond what might be expected from normal ageing. Aside from the impact from dis-orientation in relation to time, place and person, it also affects areas such as memory, attention, language and problem solving – hence it presents a real and on-going threat to both present and future generations.

It has been claimed that fewer than 10% of cases of dementia are due to causes that may be reversed with treatment. This represents a huge challenge, but a good number of MEPs have chosen to take up the gauntlet by forming and joining the European Alzheimer’s Alliance: a non-exclusive, multinational and cross-party group set up in 2007 and bringing together MEPs committed to supporting Alzheimer Europe and its members to making dementia truly a public health priority in Europe.

I am proud to be the first Maltese member of the European Alzheimer’s Alliance during this parliamentary term, particularly since dementia is considered as no less a growing and disturbing reality in Malta today. This is evidenced by the sheer hard work being carried out at the national and international levels by the Malta Dementia Society.

Interestingly, Joseph Muscat, our new Prime Minister, was actually one of the first European Alzheimer’s Alliance Vice Chairs when he was still an MEP and described by many at the time as really supportive of the cause.

The European Alzheimer Alliance’s mission is to:

• give the political signal that immediate and concerted action is needed at European and national level in the field of prevention, diagnosis and treatment of Alzheimer’s disease, research and social policies,
• influence the European political agenda,
• foster a favourable environment at European and national levels where adequate resources are devoted to address the public health issue raised by Alzheimer’s disease,
• promote actions that will give dementia and Alzheimer’s disease the priority they deserve at European and national levels,
• exchange information and work closely with European networks active in the field of Alzheimer’s disease,
• ensure the priorities listed in the Paris Declaration become a reality.

Over the past six years the Alliance, which currently has 71 members from 23 member states of

“The higher the awareness, the more committed we become.”

Joseph Cuschieri
the European Union and all seven political groups in the European Parliament, has been very instrumental in raising awareness about dementia in Europe. Thanks to the support of its members, a series of EU developments have now put dementia on the European health, social and research agenda, though it is recognised that a lot still needs to be done.

This year, Alzheimer Europe’s Annual Conference is being held in Malta between 10 to 12 October and will have as its theme: “Living well in a dementia-friendly society”.

Hopefully, this event will continue to spur our efforts at better informing the Maltese public about the problem of dementia and how to best tackle it and help both those living with the disease as well as their families and circle of friends. The higher the awareness, the more committed we become. Greater awareness enables us to synchronise work between the activities of the Malta Dementia Society and the European Alzheimer’s Alliance within the European Parliament, and with developments (scientific or other) in Europe as a whole.

**Estimated number of people with dementia in Malta (2009)**

There were 4,524 people with dementia in Malta in 2009.

- **Men**
- **Women**

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<tr>
<th>Age Group</th>
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N.B. Prevalence figures for 30-59 age group taken from EURODEM (Hofman et al) and for 60+ age group from EuroCoDe (Reynish et al).
Governmental support for people with dementia and their carers in Malta

Franco Mercieca, Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing, discusses the development of the national dementia plan, the role of patient organisations and need for European collaboration.

Alzheimer Europe (AE): What do you see as the main challenges for people with dementia and their carers in Malta?

Dr Franco Mercieca (FM): As with other European countries, the local number of individuals with dementia is on the increase. Currently, there are over five thousand individuals with dementia in the Maltese islands, a figure that is expected to more than double in the next twenty five years. This presents a number of challenges, not only for policy makers, but also to individuals with dementia, their caregivers and family members. Although there was a noticeable improvement in various aspects of dementia management and care in the recent years, lack of awareness among the general population may still be hindering timely diagnosis. Other important challenges include the absence of community services and post-diagnostic care pathways. Local research suggests that family members are more than willing to provide care for relatives with dementia in the home setting. Our aim is to offer them the best possible support.

AE: Your party has always been supportive of people with dementia and their carers. How will this support be turned into action?

FM: The present government has always been supportive of the needs of senior citizens in general. It is thus the aim of my Secretariat to continue fostering social inclusion and participation of our senior citizens in the community. Of particular importance are those who, for various reasons, become vulnerable. Among these are individuals with dementia who may require assistance that can only be provided by specifically trained personnel. We need to continue delivering the right services whilst studying new ways through which we can enhance the quality of life of these individuals. Although dementia is more common in the senior age group, individuals with dementia who are relatively young will not be left out.

AE: The Dementia Strategy Group presented a number of recommendations in 2010 which were followed by a draft of the national dementia plan. What will be the next step(s)?

FM: Almost four years have passed since these recommendations were presented to the health authorities. In the meantime, a lot of other countries have moved on and published their dementia strategies. Understandably, a lot of good work has been done in the past but we need to revisit our local dementia plan to better reflect the societal needs of today. As a result, I have appointed a National Focal Point on Dementia whose aim is to advise the government on measures that need to be taken in the immediate and foreseeable future that would be of benefit to individuals with dementia and their caregivers. This includes a clear action plan that by the end of this year would lead to the revision of the current draft of the National Dementia Strategy. This will be followed by a consultative process with major stakeholders and the general public through the publication of a green paper. Our target is to publish our dementia strategy by the end of the coming summer.

AE: If you had to choose three key priorities to be included in a national strategy, what would they be and why?

FM: I would list the three key priorities as raising awareness, facilitating early diagnosis and commu-
nity support. Raising awareness on the various aspects of dementia is a major pillar in the design of any strategy aimed at enhancing quality care. This will not only help in reducing stigma and minimize social exclusion but act as a catalyst in encouraging help-seeking and thus promote timely diagnosis and management.

The majority of individuals with dementia are not diagnosed early on in the disease process. Patients and their caregivers may overlook the problem by believing that the observed changes are just transient or that such symptoms would be expected in old age. As a result, diagnosis is often made when the disease has already advanced to a stage that has a significant negative impact on the health and function of the individual with dementia. Early diagnosis does not only enhance the quality of life and dignity of the individual but also delays admission into care homes and institutionalisation. Although services such as the Memory Clinic and the Dementia Helpline have been running for quite some time, more needs to be done to cope with the increasing numbers of individuals with dementia who are seeking help, advice and support.

In Malta, the majority of individuals with dementia live within the community and most are willing to continue doing so for as long as possible. This is of particular importance in a small country like ours in which a significant number of senior citizens continue to live with the family. We are studying ways through which we will develop services that are reliable, flexible and have a holistic approach and through which decisions about care are taken by healthcare professionals, the patient and the family. Care in the community may also be enhanced by the use of new assistive technologies which help individuals with dementia to remain independent for longer.

**AE: What role do you see patient groups playing in implementing a dementia strategy?**

FM: Patient organisations play a pivotal role in the design and implementation of any dementia strategy. They represent the voice of individuals with dementia and their caregivers and the present government is keen to continue strengthening its collaboration with the Malta Dementia Society. The latter has been instrumental in increasing awareness of dementia in Malta as well as providing training to healthcare professionals and other members of the community.

**AE: Do you see a need for greater European collaboration on dementia?**

FM: In recent years, the European Union has devoted more attention to dementia. A significant number of initiatives have been launched with one of the latest being the European Initiative on Alzheimer’s disease and other dementias, calling Member States to declare dementia as a health priority whilst strongly urging them to develop a national plan to effectively deal with the medical and socio-economic consequences of dementia. Together, we need to ensure that there is indeed a political interest in continuing to enhance awareness and support. Even in these difficult financial circumstances we must not be disheartened by the significant public health problems posed by dementia. It is an exciting challenge, one that promises to enrich the lives of these individuals, their caregivers and family members.
At first it was the idea of just one, but two soon followed. In around a week the team got to half-a-dozen. It was summer of 2004. That is how the Malta Dementia Society came about. It’s the sole non-governmental, non-profit organisation in the Maltese islands representing the ideas and needs of individuals with dementia, their caregivers and family members. In September of the same year, while commemorating World Alzheimer’s Day, we launched the Society and invited everybody to share our experience. With hindsight, it was just a dream come true.

But not all was rosy. What we found was a Maltese society where stigma and discrimination against individuals with dementia and their families were still prevalent. Besides, we needed a statute that delineated our aims, our objectives and where our journey should take us. We were all inexperienced in so many aspects. None of us had ever managed an organisational structure like this before, with most team members coming from the medical field. All we had was a lot of enthusiasm fuelled by the urgent need to do something. We knew that the numbers of people with dementia were high considering that Malta has an ageing population and that information on this particular condition was lacking. Thus, we all agreed that our main mission must be that of informing the Maltese public about dementia and how it will affect their families and society in general. Other aims included those of encouraging and promoting the best methods of care, to provide and furnish support, help and assistance to families of individuals with dementia, instruct and train personnel in patient-centred dementia care and to foster international relationships in this field in order to keep abreast with recent advancements in this particular area.

We wanted to achieve these aims by bringing together all stakeholders: healthcare professionals, policy makers, individuals with dementia and caregivers just to name a few. Perhaps, we were too optimistic considering that the Malta Dementia Society would be run (and still is) solely by volunteers who would offer some of their free time out of their busy schedule towards the Society. But with the aid of so many who offered their support, a strong team emerged that, over the years, managed to change the local perception of dementia. Notwithstanding the lack of financial resources and thus the inability to provide services directly, the Society was instrumental in the launch of governmental services aimed at individuals with dementia and their caregivers. It is through such collective efforts that we hope to achieve what is our ultimate goal: a dementia-friendly nation.

The Malta Dementia Society works on various fronts. Awareness of dementia remains at the top of our agenda. Over the years, we have built up a strong relationship with the media and members of the Society are frequent contributors to the printed press and regularly appear on TV and radio programmes to discuss the various aspects of dementia management and care. With the advent and popu-
larisation of electronic media, the Society launched its official webpage (www.maltadementiasociety.org.mt) eight years ago and its Facebook page last year. These information portals are essential in keeping direct contact with our members and inform on events that are organised, including talks and seminars on various dementia topics intended for individuals with dementia and their caregivers as well as for healthcare professionals. In collaboration with the central health authorities we also managed to release a number of publications aimed at various strata of Maltese society in order to continue in our awareness campaign of making dementia a comprehensible topic among the general public. These include “Patient-centred Care – The Right Approach to Help a Person with Dementia” (a project part financed by the EU European Social Fund), In-Nannu nesa x’Jisimni (Grandpa Forgot my Name) targeting early secondary year students and now forms part of their educational curriculum and X’hin hu? Fatti dwar id-dimensja (What Time is it? Facts about Dementia).

Another facet of our awareness campaign takes us closer to our members. We frequently organise talks on topics related to dementia management at home and better ways to interact with individuals with dementia in general. The Society is regularly invited by other non-governmental organisations as well as professional bodies to meetings and discussions on issues pertaining to dementia. These events are important in continuing our efforts to develop a network through which we can get our message across. An event that clearly brings us all together is the Memory Walk, organised at the end of September of each year to celebrate World Alzheimer’s Day. Members of the general public, those of the Malta Dementia Society together with policy makers and healthcare professionals join in a commemorative walk to increase awareness on this condition and offer direct advice to the public.

Lately, we also launched the first issue of our newsletter, “Reachout” in addition to a support group, the latter being an important step towards offering the best assistance to dementia caregivers as well as organising activities that bring them together and share their experiences.

Through the years, the Malta Dementia Society has been involved in regular consultations with the central health authorities in introducing services aimed at individuals with dementia, their caregivers and family members. These led to the opening of the Dementia Activity Centre in 2007 with the role of providing a safe and creative environment together with respite facilities. For the first time in Malta, healthcare staff were professionally trained in the best methods of dementia care. This was followed by the launch of the Dementia Helpline and the specialised dementia ward units.

In 2009, the Malta Dementia Strategy Group was set up in order to specify a number of recommendations that should enhance the quality of
dementia management and care in the Maltese islands. Although the report was officially presented in early 2010, it has yet to be published. In July of this year, the Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing appointed a National Focal Point on Dementia with the aim of reviewing the current draft of the National Dementia Strategy. This will be followed by a public consultation process to which the Malta Dementia Society will take an active part. Publication and implementation of this plan will surely have a positive impact on the way dementia is managed locally.

Notwithstanding the lack of funding opportunities, members of the Malta Dementia Society are involved in research as part of their professional development. As a result, a number of contributions in medical and social fields of dementia relating to the local setting were published. Through these, we gained knowledge on the number of individuals with dementia in Malta, the organisation of dementia care by family members, pharmacotherapeutic aspects of dementia management as well as academic preparation of undergraduate healthcare professionals, amongst various others. By way of its membership with Alzheimer Europe and Alzheimer Disease International, the Society participates in international conferences and shares its experiences with foreign associations. It is thus indeed a great honour for a small society like ours, with a membership base of 250 individuals to host the 23rd Alzheimer Europe Conference.

Looking back, these past nine years have been challenging, yet deeply rewarding. Much has been done, but much more still remains to be done in making dementia a top health priority in Malta. It is indeed a long journey but one which we are all committed to.
Rosa

Anne Cuschieri talks about her experience of caring for her mother, Rosa, who lived with Alzheimer’s disease in Malta.

“In a passing moment you catch my eye
A smile, a flicker of memory.
You move your hand but then...you look down.
You let go...of whatever...but why?”

Sometimes I look at your picture and wonder if it was all a dream. It is strange to think that you are no longer with us and it is hard to accept. But then again, this whole experience over a very long twelve years has been one uphill struggle for all of us.

My mother started to repeat her sentences in September of 1999. She was a pharmacist and a highly intelligent woman. With her medical knowledge, she knew there was something wrong with her and this really frightened her. She would repeat the same thing and then slip into a sort of trance where she would say things totally unbecoming of her and completely out of the ordinary. Dad took mum to the psychiatrist who eventually diagnosed her with Alzheimer’s but that came months later. Mum started medication, trying different ones as the disease progressed. With each stage, we had to learn the tricks of the trade. My family and I sold our house and bought a place just a few doors away as dad could not cope anymore and I was tired of driving up and down continuously. Everyone made a sacrifice to adapt to the ever changing situation and you could never get comfortable as the next stage was always worse than the previous. She would climb out of the window to escape, she would call out names to strangers, she would eat raw food, shower in her clothes, eat continuously, cross the road without looking out for cars, and so it went on.

One of the hardest things we had to face was when she forgot who we were. She would phone me up and say there was a strange man in her bed... yet was it me she called...? She would leave the house while dad was hanging the washing out, dart across the road and ring my doorbell. When I would answer she would cry for her mother. I would then call my dad to tell him she was with me and safe. In the next moment she would tell me that her children were little and alone and she had to go to them...and I used to tell her...“mum...I am your children.”

Another stage saw her setting fire to the dustbin and locking dad out in the yard; walking up and down the house all night and slipping off chairs onto the floor causing a big problem with her dead
weight. Eventually, we had to convince dad to allow us to put her into a home because he was going to die of injuries or a heart attack. This decision was the first hardest decision we ever had to make. And the first week in the home was terribly hard for her...leaving her in desperation was the worst thing we could ever do and have to face.

Years went by and the carers loved her and looked after her. Dad went to visit her each and every day for the next 8 years of her life in a home. He never missed unless he was so ill he could not leave his bed. He talked to her and told her all about the daily things as though she would understand...and maybe she did. Did she recognize us anymore...yes and no. Whenever I arrived at the home she would give me this beautiful smile...who was I to her?

After twelve years she developed bedsores, no fault of the home, and the nurses treated her for months on end. In June of 2012 she stopped being able to eat and that was the beginning of the last stage...and I knew it the moment I saw her face that day. By this time, she could not move or speak. Her last few days came towards the end of November 2012 and I spent the last night in her room, never leaving her side. I prayed with her and spoke to her. She listened and wanted to say so much to me with her eyes...she reached out to me through her eyes...her breathing was fast for 2 whole days and then in the last hour she went into a trance and eventually slipped away in my arms and in the arms of two of her carers. Her 12-year ordeal was finally over, leaving us cold and numb for a very long time. We had cried and grieved for her for the whole 12 years and I didn't know if I had any tears left to cry.

Mum's disease taught me to appreciate every moment of my life and all the people I love...

Anne Cushieri

“Mum's disease taught me to appreciate every moment of my life and all the people I love.”

Anne Cushieri

Anne Cushieri, her mother, Rosa and daughter, Krista

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European Month of the Brain

Alzheimer Europe reports on two conferences on brain research and health held in May 2013 as part of the European Month of the Brain.

Around 165 million people in Europe are affected every year by some form of brain-related disorder. In order to raise awareness of both the achievements made and of the remaining challenges in the area of brain research, the European Commission launched the European Month of the Brain. The aims were to:

• increase awareness of the importance of brain research and healthcare matters,
• showcase EU achievements,
• outline foresight research and policy,
• improve the resource allocation for brain research and healthcare within and between EU member states and associated countries,
• lift taboos around mental health.

Within this context, two conferences were organised by the European Commission. The first conference entitled, “European Brain Research: Successes and next challenges” was held in Brussels on 14 May. It sought to (i) showcase and raise awareness about benefits, added value and impact of EU-supported research in the area of brain research and (ii) define the next scientific challenges for brain research (in particular in the fields of understanding how the brain works, disease prevention, diagnosis and therapy of brain diseases, and industry-driven research). It was targeted at all interested stakeholders: scientists, laypeople, industry and patient representatives, policymakers and media, attracting over 400 participants.

Research Commissioner Máire Geoghegan-Quinn acknowledged that brain research was pushing back the frontiers of science and helped us tackle pressing challenges such as neurodegenerative diseases and mental health. She reminded the audience that FP7 had supported brain research with over EUR 1.9 billion since 2007. However, it is still necessary to sharpen our knowledge about the brain. Horizon 2020 will respond directly to policy priorities and societal challenges identified in the EU 2020 strategy. It will provide a substantial boost to research. In particular, it will increase its investment in Excellence Science under the three Horizon 2020 priorities (health, demographic change and well-being). She called for better coordination and alignment of national financing of brain research (through Joint Programming Initiatives for instance) for better research and better value for money.

The conference was articulated around different themes:

• “Think smart! Understanding how the brain works”: this session focused on the importance of understanding how the brain works to live a better, healthier life. The challenge identified was the necessity to introduce a new revolution on how neuroscience is driven.
• “Think early! Preventing brain diseases”: this session focussed on how research can help to effectively prevent brain diseases and improve mental health and well-being. Genetics and the need for large sources of genetic data were presented as a mean to better understand specific diseases. Further research that leads to actions targeting specific parts of the pathogenetic process and effective prevention was identified as the main challenges.
• “Think right! Brain research at the service of patients”: this session explained how research can lead to the development of effective therapies and helpful devices for patients with brain diseases. The challenge there is that many forms and many different genes can

“Brain diseases present one of the biggest challenges facing the EU with almost every family in the EU being affected. Policy makers need think of effective solutions which favour research and innovation.”

MÁIRE GEOGHEGAN-QUINN
result in one single disease (over 150 different single gene defects can result in retinal dystrophy for instance). The BRAINABLE project was also presented: ICT can improve the autonomy in the daily life activities of disabled or elderly people. The challenges identified are the increase in the number of people with dementia and the lack of discovery of new drugs. Pre-clinical work is needed to justify the transition to the clinic (need for more robust and predictive tests of human diseases, clinical trials are too early without adequate toxological tests, and better clinical trials are needed).

- “Think innovative! Collaborating with European Industry for the benefit of the patients”: this session explained how industry-driven research and innovation can lead to the development of effective therapies and helpful devices for patients with brain diseases.

- “Think big! Building large-international collaborations at European and global level”: this session explained the benefits and added value of programme-level collaborations among funding agencies. Health research is a priority for all. International initiatives are a way to build critical mass, share data and best practices, share the work and costs. The challenges identified were that work had been put into joint transnational calls and the European collaboration for research was rather new.

The second conference, which was held under the auspices of the Irish Presidency of the EU, “Healthy brain: healthy Europe. A new horizon for brain research and healthcare”, was held in Dublin on 27-28 May 2013 and aimed at delivering policy recommendations for brain research and healthcare. It was strongly supported by national and EU policy makers.

James Reilly, the Minister of Health for Ireland, emphasised the importance of collaboration and of translating research into practise. EU Commissioner Máire Geoghegan-Quinn concurred, adding that brain diseases present one of the biggest challenges facing the EU with almost every family in the EU being affected. She called on policy makers to think of effective solutions which favour research and innovation and emphasised that the challenges we face are global ones. Kathleen Lynch, Minister of State with responsibility for mental health in Ireland, suggested that perhaps the most devastating disorder for older people is dementia with an annual cost of EUR 1.69 billion. She said that she was convinced that if mental health becomes a more open issue then stigma will be addressed.

Isabel de la Mata, Principal Adviser for Public Health, DG for Health and Consumer Protection, European Commission, said that the financial crisis forced everyone to use public and private funds in the best possible way. She noted that healthcare budgets and social care budgets need to be seen as a whole rather than independently of each other.

Patrick Kennedy gave a moving account of his own struggle with brain disease and the stigma which he found associated with it. He spoke of the importance of open dialogue and the need to work together to understand fully the complexities of the brain.

The importance of understanding how the brain works to live a better, healthier life was emphasised. Presentations provided a greater understanding into what is currently understood about the
workings of the brain, how our understanding has developed and also the importance of social integration. The issue of data sharing was also mooted as was the need for openness in science.

There is a need to invest in brain research and healthcare in order to tackle the socio-economic costs of brain-related care. Insight into the experience of living with Multiple Sclerosis (MS) was given by John Golding, President of the Multiple Sclerosis Platform. He said that researchers should give attention not just to physical aspects of disease, but also the mental and social aspects. Delegates also heard about the ways in which the care costs associated with brain disease may be evaluated and measured. The consequences on care of demographic changes were highlighted and patient participation in research was advocated.

Although Europe continues to be a leader in brain research, it must continue to build on its strengths to maximise research and economic advantage. Obstacles identified included the gap between neurology and psychiatry, the fragmentation of effort and also the risks associated with drug research. The challenges we face have changed, for example, jobs today require mostly mental skills, whereas 50 years ago primarily physical skills were required. As the healthcare burden increases new ways need to be found which keep the population healthy and as a part of the workforce.

In order to improve treatment, reduce costs and attract investment, the right environment for research needs to be created, research results need to be fed into informed policy decisions and there needs to be a coordinated approach. The US experience was cited where it had been reported that for every dollar invested in the human genome project had a return of USD 140. How to reengage the industry with brain research was considered and many limitations identified (such as a lack of mechanistic understanding, the use of animal models of disease, the translation of models in mankind, a lack of reliable surrogate biomarkers, lack of clarity around regulatory and reimbursable endpoints and a perceived lack of success).

Patients can greatly enhance input in research and they are also the beneficiaries of research carried out. Radical new thinking was explored which required a paradigm shift in order that the infrastructure enables patient involvement from the beginning of research.

Enda Connolly, Chief Executive, Health Research Board, Ireland, drew conclusions and recommendations from each of the plenary sessions. These included a need to:
- raise awareness of brain diseases amongst policy makers,
- address stigma surrounding brain diseases,
- urgently invest in brain research,
- share data to avoid repetition and facilitate greater understanding,
- involve patients in research early in the research process,
- improve communication of research to society by ensuring results are more widely published,
- create a better collaboration between regulatory authorities and the pharmaceutical industry.

When closing the meeting, Mr Connolly explained that a full list of conclusions and recommendations of this conference were due to be published soon.
The challenges of neurodegenerative diseases in the workplace

Annette Dumas, EU Public Affairs Advisor, Alzheimer Europe, reports on the breakfast meeting held in the European Parliament on the challenges of neurodegenerative diseases in the workplace.

On 9 July 2013, Angelika Werthmann, MEP (Austria) and Member of the European Alzheimer’s Alliance, hosted a breakfast meeting in the European Parliament on the challenges of neurodegenerative diseases (NDD) in the workplace. This event was organised in cooperation with Alzheimer Europe (AE), the European Parkinson’s Disease Association (EPDA) and the European Multiple Sclerosis Platform (EMSP).

The aim of the meeting was to highlight the challenges faced by people affected by a NDD while still being at work and propose some recommendations for future actions at EU level. Angelika Werthmann stressed that the increasing number of people suffering from conditions such as Alzheimer’s disease, Parkinson’s Disease (PD) and Multiple Sclerosis (MS) must urge both national and EU policymakers to provide solutions to the plight faced by these people.

In Europe, over 9 million people suffer from NDDs: over 7 million have dementia, over one million PD and 600,000 multiple sclerosis MS. Few data are available on the number of people below 65 affected by a form of dementia. Those which are available show a prevalence of between 42 and 54 per 100,000 people aged between 30-65 and between 78 and 98 per 100,000 for people aged between 45-65. One in 10 people diagnosed with PD are younger than 50 and 70% of people with MS are diagnosed in their 20s and 30s.

Common challenges

The three neurodegenerative diseases represented at the meeting are chronic degenerative diseases that affect all aspects of daily living and having no cure.

Another common feature highlighted by the three speakers (Heather Clarke, European Political Affairs Officer, EPDA, Shana Pezaro, a person with MS representing EMSP, and myself) is that diagnosis is made far too late, when the symptoms are acute. This is particularly the case for dementia: the symptoms remain unnoticed by the person, the family and the work colleagues until the situation badly deteriorates. The misconception that dementia only affects older people is another factor that delays early diagnosis.

Although some interesting but rare initiatives are in place across Europe to help people with NDDs remain at work for as long as possible, all speakers agreed that a neurodegenerative diagnosis leads to common challenges in the workplace. For example, people with NDDs are no longer seen as a person with remaining competencies but as a person with a disease; they have to face colleagues who do not understand their diminishing performances and may behave in an unfriendly manner. Personally, people with NDDs will experience a loss of self-esteem and lack of support for their very specific situation.

Very often, no specific provisions are made for people with NDD still at work. This compels them to stop working much earlier than expected, thus putting them and their families in a dire financial situation. In the UK for example, only 18% of the people diagnosed with dementia under 65 and 27% of their carers continue to work after diagnosis.

Although the situation differs between EU countries, those who quit work earlier than anticipated usually do not get any support before the situation really deteriorates. These diseases are not readily...
recognised as disabling diseases. Support for this specific population may be non-existent, knowing what is available is a challenge.

Recommendations made by the speakers

Early diagnosis is paramount to set up specific work provisions, transition and work termination and financial planning.

Awareness raising will help the individuals recognise symptoms early and seek early diagnosis, the employers and co-workers to set up new work patterns, the policy makers to understand the situation and put in place innovative work and social policies.

Adaptation of social legislation will offer better protection and respect the rights of people on the workplace need to be duly recognised and respected.

Identification of met and unmet needs will substantiate all policy decisions and programmes.

People with NDDs must be involved in this identification and the planning of services and policies. The newly created European Working Group of People with Dementia was cited as an example.

What can the EU do?

A non-exhaustive list of current EU initiatives that can support people with NDD in the workplace was identified:

• The EU 2020 Strategy and its “New Skills, New Jobs” flagship must help people with NDDs stay in the workplace and allow for new jobs in the care sector.
• The Social Investment Package will guide Member States to use their social budgets wisely to ensure adequate and sustainable social protection and help people throughout their lives. The Package includes disabled people and recommends support for adapted workplace and social inclusion.
• The European Disability Strategy includes the right of citizens to participate fully in society and issues around employment.
• The European Year of the Citizens and the UN Convention on the Rights of Persons with Disabilities focus on rights of EU citizens.
• Horizon 2020, the EU research programme (2014-2020).

The European Commission perspective

Philippe Cupers, Head of Sector Neurosciences, DG Research & Innovation, European Commission, explained that the understanding of the brain and its diseases was a major challenge and very complex. He agreed with the three speakers that brain diseases were indeed costly (EUR 800 billion in Europe in 2010) and the ageing of the population another major EU challenge.

EU research has dedicated more than EUR 1.9 million to brain research under the current EU research Programme. Since 2007, EUR 400 million were allocated to research on neurodegenerative diseases, including EUR 200 million on Alzheimer’s disease. Horizon 2020 will include societal challenges under “Health, demographic change and well-being”.

Angelika Werthmann pledged to table a Written Declaration on the challenges of NDDs in the workplace by early Autumn.
Philippe Cupers explained that EU Joint Programming helps address societal challenges. This strategic process that involves Member States makes research in Europe more strategic, more focused, more effective with more impact. He gave the example of the Joint Programming of Neurodegenerative Diseases (JPND) which goal is to find cures for NDDs.

He also mentioned the European Month of the Brain organised by the European Commission in May 2013 to cap EU efforts for brain research.

The European Pact for Mental Health and Well-Being is a DG Health initiative launched in 2008 that brings together governments, stakeholders from various sectors. One goal is to take steps to involve the health and social sectors in the field of mental health and well-being at the workplace and support holistic approaches.

In addition, Mr Cupers advised the audience to follow the work of the Joint Action on Mental Health that started early 2013. This Joint Action will promote the exchange of best practices among the Member States, collect information and produce recommendations for a common framework for action on mental health and well-being. One component is the support to employees affected by a disease.

Towards EU action

Angelika Werthmann found the meeting to be eye-opening and emphasised the role and responsibility of politicians in taking appropriate steps. As a concrete and immediate step, she pledged to table a Written Declaration on the challenges of NDDs in the workplace by early Autumn.
Dementia strategies: Luxembourg

Mars Di Bartolomeo, Minister of Health, Luxembourg, talks about the National Dementia Plan which was launched on 14 May 2013.

Alzheimer Europe (AE): What were the main challenges that were identified by your Ministry that led to the development of the Luxembourg dementia strategy (“plan démence”)?

Mars Di Bartolomeo (MdB): Societies across Europe are ageing. Even if in Luxembourg the 25-55 age group is larger than in other countries, we see a similar pattern in our country. Our statistics show the same increase in life expectancy over the past decades – which of course is a positive development. But as the proportion of older people in our population is increasing we have to be prepared to provide a good and high quality offer of services to our elderly population to enable them to fully participate in society.

Contributing to healthy ageing is a key goal of our policy. We have to support mental health and well-being in our population. But we also need to establish quality care for all people depending on care and especially dementia patients with their special needs. Bringing all of this together in one strategy is the aim of the Luxembourg dementia plan.

We know that the prevalence of dementia will rise. But this is not only a medical or social care issue. Dementia concerns partners, relatives, and friends. It is a common challenge for our communities.

Providing adequate hospital and outpatient care is another challenge: so already in the 2009 Hospital plan for Luxembourg – and in the new plan 2013 which will be finalised shortly – specialised units for elderly people were foreseen to provide qualified care and support for the specific needs of these patients. Also, the need for cooperation with outpatient services is highlighted. In order to be successful, it is important that we ensure that there is a common approach in acute and long-term care for the elderly population, creating supportive structures both for patients and relatives.

Hopefully the national plan on dementia is a tool to address the overall challenge to coordinate and link all relevant actions and activities towards the best care and support for people with dementia and their relatives.

AE: What are the key priorities and aims that you have identified for the following years?

MdB: Three key priorities have been identified in the area of responsibility of the Luxembourg Ministry of Health:

- Prevention
- Diagnosis
- Medical care

Primary prevention is essential for healthy ageing with good physical and mental health. Maintaining social contacts is also important in dementia prevention – therefore we will include the dementia theme in our national prevention campaigns.

Following diagnosis, secondary prevention becomes even more important. We have started to develop a comprehensive national program for people who are at the beginning of their disease. People with dementia who will participate in the scheme will receive an individual prevention programme based on physical, cognitive training

“As the proportion of older people in our population is increasing we have to be prepared to provide a good and high quality offer of services to our elderly population to enable them to fully participate in society.”

MARS DI BARTOLOMEO
“Hopefully the national plan on dementia is a tool to address the overall challenge to coordinate and link all relevant actions and activities towards the best care and support for people with dementia and their relatives.”

MARS DI BARTOLOMEO

and social activities, a consultation in nutrition, control of medication and, if necessary, adequate treatment of depression, psychological and social support coordinated by a memory nurse in close cooperation with the doctor.

Secondly, diagnosis and especially early diagnosis will be improved and promoted and become easily accessible to all patients who wish to be examined. A two-step system where GPs perform firstly a screening test in cases of suspected dementia followed by differential diagnosis seems efficient and cost-effective. If we expand early diagnosis we also need to ensure that patients and relatives have the possibility to contact a counselor to obtain full information on health and psychosocial issues and to coordinate support following the diagnosis of dementia.

Thirdly, in medical care we will try to develop national therapeutic standards adapted to the situation in the country in order to guarantee patients with dementia high quality treatment according to international guidelines. This will be done in close cooperation with our partners in outpatient and hospital care and with international experts.

Therapeutic standards can only be applied and be successful to avoid deterioration and complications in case of hospitalisation if health professionals in all domains are be informed, qualified and advised to follow these guidelines – consequently continuous education is also one of our key priorities.

With this global approach we hope to preserve quality of life, slow down progression of the disease and avoid dependence on care as long as possible.

Beside theses key priorities for the Ministry of Health we will work together with the Ministry of Family and Integration on mistreatment and to protect the legal rights of patients with dementia, on better information and destigmatisation of dementia, help for informal caregivers and better training of health professionals.

AE: How will your Ministry collaborate with patients’ and carers’ groups such as Association Luxembourg Alzheimer for the implementation of the national strategy?

MdB: All the above-mentioned priorities and actions can only be successful if we work closely together with all actors in this field including patients’ and carers’ groups. Their longtime practical experiences are essential to ensure that the implementation of our actions is successful and our goals are achieved. Possibilities of collaboration will be evaluated and clarified in the oncoming months.

AE: How will the progress of the strategy be monitored?

MdB: Being adopted and financed by the Luxembourg Government the progress of the strategy will be monitored like any other national program by the competent supervisory authorities.

Other supplementary monitoring systems can be developed. For example, the secondary prevention programme will be evaluated by an independent external institution regarding its effectiveness to preserve quality of life, slow down progression of the disease and dependence on care.

AE: Would you support greater European collaboration on the aspects covered by your dementia strategy and the development of a European dementia strategy?

MdB: In the past a lot of work to understand dementia and to develop best practices in care and treatment has been taken forward by different organisations, universities, associations, cities and authorities all over Europe – I think this needs to continue in order to develop our understanding about interdependencies between dementia, Alzheimer’s disease, well-being in old age and healthy and active ageing.

We have to develop knowledge about how best to offer older people an adequate place and role in our societies to respond to their expectations and needs. Promoting well-being in older people is
essential to strengthen and mobilise the mental capital which we need for a successful future. In Europe, we need to implement ideas and concepts such as:

- understanding that dementia is linked to addressing the increasing problems we will face in mental health in general,
- acting early to diagnose dementia and to promote well-being as an important task of our health and social systems,
- promoting a shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research,
- sharing best practices for care of people suffering dementia,

and, last but not least

- respecting the rights of people with dementia is essential.

Consequently Luxembourg has participated as a partner in the EU-funded ALCOVE joint action and supports this common effort to optimise the care of Alzheimer patients.

We also support work under the European Pact for mental health and well-being and the mental health joint action, as well as the European Partnership for Active and Healthy Ageing.

Alzheimer Europe talks with Association Luxembourg Alzheimer (ALA) about the strategy

What role was played by the Association Luxembourg Alzheimer in the development of the National Dementia Strategy?

The Association Luxembourg Alzheimer (ALA) participated in various working groups during the development of the plan. Our employees contributed their knowledge and experience in order to increase general awareness of the disease and to ensure people with dementia and their carers receive support.

What impact do you expect the strategy to have on people with dementia and their carers?

The main objective of the strategy is to support people living with disease by enabling them to exercise their legal rights. The strategy binds together the right to self-determination with an obligation to empower people with dementia and their carers. This will be achieved through the provision of objective information and guidance, enabling people to make informed choices in relation to their personal situation and needs.

What, if any, challenges do you foresee in implementing the strategy?

First, we must raise awareness of the issues surrounding dementia. In particular, we must take action to address the stigma associated with the disease in order to bring about a change of mentality and attitude toward this disease. Demographic changes indicate a relative increase in elderly and middle-aged people. Sufficient support will be needed if we are to provide quality care for these groups at home and, where necessary, in institutions. Carers play a crucial role, especially in enabling people with dementia to remain at home and be included in society. Therefore, it is essential that special attention be given to the health and needs of the carers.

The Strategy recognises that specific dementia training is required for healthcare professionals and ALA is committed to working alongside the Ministries to develop a psychogeriatric training programme.

“We must raise awareness of the issues surrounding dementia. In particular, we must take action to address the stigma associated with the disease.”

ASSOCIATION LUXEMBOURG ALZHEIMER
Dementia strategies: Luxembourg

Marc Spautz, Minister for Family and Integration speaks with Alzheimer Europe about the development of the Luxembourg dementia strategy and its launch earlier this year

Alzheimer Europe: What were the main challenges that were identified by your Ministry that led to the development of the Luxembourg dementia strategy?

Marc Spautz (MS): The governmental program for the years 2009-2014 provided for the elaboration of a Dementia Plan as one of the key issues for the elderly on behalf of the Ministry for the Family and Integration. In addition, this plan was developed in collaboration with the Ministry of Health which mission focused on a “programme of prevention and treatment of dementia”.

In 1999, Luxembourg introduced long-term care insurance (assurance dépendance) and since then a coherent network of services and supplies has been developed over the whole country. A range of nursing homes (maisons de soins) and homes for the elderly (centres intégrés pour personnes âgées) has been built.

In 2010, people with dementia constitute the second most important group of the nearby 12,000 beneficiaries of the long-term care insurance. If, in general terms, some 34% of the beneficiaries live in an institutional setting, for the group of people with dementia this average is closed to 61%.

At the end of 2010 we set up four working panels to discuss “dementia” presenting different perspectives. The main challenges we identified together with the professionals and family careers in these discussions were:

• the need for information and psychosocial guidance from the moment of the diagnosis onwards to the different stages of life of the person with dementia. This is a request not only from the patient himself but also from family members,
• the need for information about the conceptual frameworks of professional caregivers in the different settings (daycare, institutional care),
• many families still foresee formal care as the last resort and this decision is often accompanied by feelings of guilt and helplessness. It is obvious that they require good information to make the most adequate choice for their relative,
• the need to break the taboo around dementia. Not unexpectedly, this topic came first in all the working groups as a major key factor for the success of many other measures,
• the need to actively promote the integration of the concerned persons and their families in social and daily life.

AE: What are the key priorities and aims that you have identified for the coming years?

MS: Altogether we identified around 20 priorities for the coming years. While some of these priorities are of a more general interest to all of the elderly population or/and to all vulnerable elderly people, some are of special interest for people with dementia and/or their relatives.

Therefore, since the adoption of the strategy by the Luxembourgish Government in March 2013, the
Ministry of Family and Integration focuses on 4 main topics:

• The setting up of a vocational training in “psychogeriatrics” for professionals working in the field of long-term care. Based on our strategy “palliative care vocational training” set up in 2009, the first step consists in the definition of the curriculum itself.
• The setting up of an internet software to raise awareness and to inform on dementia as well as support available to people concerned by dementia.
• A collaboration with the police to set up an information sheet for situations of missing persons which will be ready in late autumn this year.
• The setting up of a national information and counseling centre for people with dementia and their relatives.

However, beyond all these new initiatives, I would like to stress that since 1999 the Ministry of Family and Integration leads a very active preventive strategy for the elderly. We introduced, together with local authorities and NGO-partners, 17 “Club Seniors” all over the country. These centres propose activities related to physical and mental health and promote actively the social participation of people aged 50+.

In addition to this and prior to the benefit of the long-term care insurance, people in the early stages of the illness can profit of a range of services like “meals on wheels” or the “Telealarm” (home-alarm system) which are available all over the country.

AE: How will your Ministry collaborate with patients’ and carers’ groups such as Association Luxembourg Alzheimer for the implementation of the national strategy?
MS: For the first three topics we have already set up working panels including persons from caregiver groups, professionals out of the field of vocational training and formal education. ALA – the Luxembourgish Association for Alzheimer disease is an active member in all these working schemes.

AE: How will the progress of the strategy be monitored?
MS: We will include the priorities mentioned above in the forthcoming “governmental programme” and will monitor the results at the end of this period.

It is rather difficult to give a general answer to the question – as the setting up of the four priorities need different timetables.

As an example, I like to stress our strategy of setting up a vocational training in “palliative care”. In 2009, we introduced, on an existing template of a vocational training a particular measure in our legal framework and it takes at least 5 years to fulfill this standard.

AE: Would you support greater European collaboration on the aspects covered by your dementia strategy and the development of a European dementia strategy?
MS: At the crossroad of three countries, Luxembourg generally looks beyond its borders while discussing and introducing new initiatives in order to find the best practice most appropriate to its specificities. For the introduction of the internet-software I mentioned before, we plan its setting up in close collaboration with a Belgian organization.

The Ministry of Family and Integration also took part in the European ALCOVE Project lead by France. The success of the project was essentially due to the good collaboration between all the partners. This, I believe should be a good practice to be promoted.
The Dutch Ministry of Health, Welfare and Sport announced in April they will be investing 32.5 million euros in the battle against dementia. This money is intended for the Delta Plan Dementia, a collaboration between public and private domains to stop the vast increase in the number of people who live with dementia. The announcement marks an important step from the Dutch government in addressing the issue of dementia.

The Delta Plan Dementia is an eight-year plan that requires a total investment of EUR 200 million. Keywords are: earlier detection of the disease; more understanding of the onset of the disease; better prevention and treatment options; and quality of care. The plan consists of three components: additional investment in scientific research; a national register with data on patient status to improve care; and an online portal for professionals, people with dementia and their carers. The research agenda that forms the basis of the plan has been drawn up by Alzheimer Nederland (Alzheimer’s Society in the Netherlands), with the help of people with dementia, their carers, citizens and scientists.

The Delta Plan Dementia is a unique collaboration between science, national government and private parties.

Unique collaboration

The Dutch Ministry of Health, Welfare and Sport labels the Delta Plan as “a unique collaboration between science, national government and private parties”. The plan contributes to solutions for different aspects of dementia and the many consequences it has for both the person who lives with it, their family, and the society as a whole. It will also contribute to increasing awareness about dementia.

Conscious choice

“Not only current and future patients benefit from the fight against dementia, it also supports everyone around them who also suffer,” says Else Bos, CEO of pension administrator PGGM. “Dementia puts an incredible amount of pressure on the people who care for a loved one with dementia, the so-called informal carers. They also deserve to be relieved of that pressure. That is why we consciously chose to be a partner in the Delta Plan Dementia.”

Provide support

In addition, PGGM and Alzheimer Nederland also
signed a letter of intent to collaborate in providing support to the large number of informal carers who are involved in caring for people with dementia. Both parties also intend to boost awareness and fundraising. All 570,000 members of the pension administrator work in care and social well-being. Else Bos: “People who work in healthcare will probably also take on the informal care for a family member with dementia. They will have to make big sacrifices, and risk overburdening themselves. We want to support them as much as possible.”

Unsustainable situation

Robbert Huijsman is senior manager Quality and Innovation at the division Care & Health of health insurance company Achmea: “All over the world there will be a large increase in the number of people suffering from dementia. The World Alzheimer’s Report shows that the annual costs of dementia are USD 600 billion worldwide. The number of people suffering from dementia in the Netherlands will double to more than half a million by 2040. Due to ageing, the healthcare costs in the Netherlands will double to EUR 7.5 billion by 2040. Still, more than three quarters of all people with dementia live at home, where they are cared for by family or acquaintances. Overburdening of these informal carers is the main reason for which patients move to a nursing home. The availability of nursing home accommodation is still relatively high in the Netherlands, but this will be unsustainable in the future.”

Knowledge, technology and resources

It is clear that public and private parties have to join forces to stop the increase in the number of people suffering from dementia. This can only be achieved by bringing together knowledge, technology, resources, and manpower. It demands a lot of skill and creativity to develop and test all kinds of new interventions using modern technology, such as home automation, robotics, e-health, and social media. It will be a tough challenge, but as President Obama of the United States of America stated when he announced his plans to fight dementia: “We can’t afford to wait any longer.”

Alzheimer Nederland will support the Delta Plan Dementia with an investment of EUR 12.5 million in the next four years. In combination with the contribution of the Dutch government, half of the money needed for research is already secured. An important first step, but to achieve the goals of the plan, it is important that more private partners and donors will support it.

Force breakthroughs

“We have to join forces now. Only then will we be able to force breakthroughs in research, such as those we have seen in cancer research.”

GEA BROEKEMA-PROCHÁZKA
There will be an increasing chance of a significant breakthrough in the treatment of, or even a cure for, dementia if we invest in scientific research.”

Maria van der Hoeven, President of the Supervisory Board of Alzheimer Nederland and former Minister of Economic Affairs regards the financial contribution of the Dutch government as a powerful signal. “Finally, dementia is being recognised as a major social problem for which we have to find a solution together. Moreover, the investment in scientific research shows that the government has a proactive long term vision on fighting dementia.”

Precursors

Prof. Philip Scheltens is a neurologist and director of the Alzheimer Centre at the VU University Medical Centre. This centre, and the other three Dutch Alzheimer Centres in Nijmegen, Maastricht and Rotterdam, play a prominent role in international scientific research on dementia. Prof Scheltens said: “There will be an increasing chance of a significant breakthrough in the treatment of, or even a cure for, dementia if we invest in scientific research. We have seen this in the field of oncology: more investment will bring us closer to a solution.

The Netherlands plays an important role in international research into dementia. We are pioneers in early diagnostics, genetics, and research into quality of life. These successes improve treatment and make care more efficient, more effective, and more personal. It is predicted that this will significantly save costs and improve the quality of life of both patients and their families.”

Prevent and cure

Prof. Scheltens, being a member of the American Initiative Dementia 2025, says: “By 2025, President Obama wants us to be able to treat dementia. But if we want to be able to prevent the illness in the future, we need to know more about its causes. I hope I will live to see that day. Sadly, I have nothing to offer to patients who suffer from dementia at this time. That is why I have invested a lot of time and energy in helping to draw up the Delta Plan Dementia. I became a doctor because I want to be able to cure people.”

Today’s patient

Research has given us important tools to help today’s patient and his carer. “Cognitive training...
and adaption of the patient’s living surroundings to his needs and wishes can improve quality of life and reduce behavioural problems.” Says sociologist, Director of the Radboud Alzheimer Centre in Nijmegen and Chair of Interdem Prof. Myrro Vernooij-Dassen. “Furthermore, research had provided us with therapies to help the informal carer to cope with the situation. Thereby suspending care in nursing homes and cutting costs. These successes make it very important to speed up the implementation of these proven effective therapies and treatments. This is a field in which research can help identify and overcome obstacles that delay the application of beneficial new ways to care for people with dementia and their carers.”

Early diagnosis

Prof. Frans Verhey, psychiatrist and director of the Alzheimer Centre in Maastricht sees that people want to know if they have dementia as early as possible. “Twenty years ago you didn’t mention the diagnosis to the patient. Now they want to know what’s the matter and what they can expect in the future. The Delta Plan Dementia can help us improve diagnoses and predict the progress of the disease. People find it very important to know if they can take care of themselves in the future.”

The status of national dementia strategies in Europe

[Map showing the status of national dementia strategies in Europe, colored according to the presence of national strategies, government commitment, other political support, or no support.]

Alzheimer Europe, July 2013
Dementia strategies: UK (Scotland)

Scotland published its second Dementia Strategy (2013-2016) in June 2013. Alzheimer Scotland interviews Alex Neil, Cabinet Secretary for Health and Well-being in Scotland, about the progress already made and outlining how this may be built upon.

Alzheimer Scotland (AS) What do you think have been the main success stories from the first Dementia Strategy and what emerged as the main challenges going forward into the next three year strategy?

Alex Neil (AN): The 2010 National Dementia Strategy led to publication of “The Standards of Care for Dementia in Scotland” and “Promoting Excellence Skills and Knowledge Framework” the following year. Implementation of both in tandem has been the bedrock for further improvement since 2011 and will continue to be important. We shared Alzheimer Scotland’s view about how important it was to improve service response in general hospitals. The last two years in particular have seen significant investment and advances in the capacity and capability of staff in hospitals. We supported Alzheimer Scotland in appointing Dementia Nurse Consultants to NHS Boards across Scotland and the Nurse Consultants will be key to helping their respective NHS Boards engage with the national action plan on improving dementia care in hospitals. There are now over 300 Dementia Champions – drawn from the frontline of services – trained and helping to lead and influence change in response to people with dementia at that frontline of care in hospitals and associated care settings.

Improving post-diagnostic support was also a key area in the first strategy and we’ve worked closely with Alzheimer Scotland and others to lay the groundwork for what is a world-leading national post-diagnostic commitment, which guarantees a year’s worth of high quality dedicated support after diagnosis. Implementation of this began on 1 April this year and services are expected to be delivering this commitment to everyone newly diagnosed by 2016.

I have identified three challenges which we need to focus on over the next three years: offering services which promote well-being and quality of life of people with dementia and their families, which also protects their rights and respects their humanity; improving care pathways to ensure they are person-centred; and continuing to embrace the process of redesign and transformation of services to ensure that we deliver services effectively and efficiently.

AS: The new Dementia Strategy sets out 17 commitments. How will the Scottish Government ensure that these commitments will be met and how will they be monitored?

AN: I wanted a strategy that was ambitious but deliverable. As in the first strategy, we acknowledge that while change and improvement will not be easy, we are confident that we are taking the right action nationally to help make real and measurable improvement over time. A national, overarching group will be tasked with implementation and monitoring of the strategy and we have a range of quantitative and qualitative measures and indicators of change and improvement.

I have also set up the National Dementia Care Improvement Programme to support implementation and delivery of key “big ticket” commitments (for example, post-diagnostic targets).

AS: How much of a priority do you place on Scottish dementia research becoming a world leader?
AN: Supporting world-class research into dementia remains a key part of our national approach to dementia. I recognise that people with dementia and their carers have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. We established the Dementia Clinical Research Network for Scotland in 2008 and funding has been extended to 2014. We will build on the research achievements of the first strategy. Support has been broadened across a wide range of world class research teams from basic science through to social studies. We want to integrate dementia research by working with and supporting the new Scottish Dementia Research Consortium as it seeks to maximise the impact of and funding opportunities for research in Scotland.

We believe that our “8 Pillars model” of community support is an essential way of ensuring integrated care for people with dementia in the mid to later stages of the illness.

AS: What do you see as the key challenges for people going through these later stages of dementia?

AN: I know how vital it is that people have good quality and seamless care and support as their symptoms advance and they begin to need more intensive support. People have their own individual experience and challenges but the 8 Pillars can be a means by which all individuals are comprehensively assessed and supported as their dementia becomes more challenging.

The full version of this article can be found at www.alzscot.org

1 The key aim of the 8 pillars model is to build the resilience of people living with dementia to enable them to live in their own homes for as long as possible. Central to the model is the role of the Dementia Practice Coordinator who will lead on and coordinate the care, treatment and support for the person on an ongoing basis.

A note from Henry Simmons, Chief Executive, Alzheimer Scotland

The launch of the second National Dementia Strategy for Scotland is very welcome. This is a practical plan, not a high level document which will sit on the shelf. It has the potential to result in really significant changes for the better for people with dementia and their partners, families and carers in Scotland.

The Scottish Government has made 17 clear commitments in the new strategy. Each of these addresses an area that we know must be improved, if people are to be able to rely on being properly supported to live as well as possible with dementia.

Alzheimer Scotland will continue to be a partner and a critical friend to the Government in taking forward the new strategy. And, thanks to the involvement and generosity of our members and supporters, we will continue to contribute our Dementia Advisors, our nurses, our Helpline and the research centres we fund. Together, let’s aim to make Scotland a world-leader in dementia support.

The National Dementia Strategy for Scotland can be found at: www.scotland.gov.uk/Resource/0042/00423472.pdf

“Supporting world-class research into dementia remains a key part of our national approach to dementia.”

ALEX NEIL
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.
The impact of economic and political instability in the Czech Republic

Iva Holmerová, Chair of the Czech Alzheimer Society and Vice-Chairperson of the Alzheimer Europe Board, talks about the impact austerity measures and political uncertainty have on people with dementia and their carers in the Czech Republic.

Alzheimer Europe (AE): The economic crisis across Europe has had far-reaching implications, including a reduction in services and support for people with dementia and their carers. Have austerity measures been put in place in the Czech Republic and, if so, what has the impact been on your work and the people you support?

Iva Holmerová (IH): The situation regarding care provision and indeed all the activities of our society have recently been impacted, but not only as a result of austerity measures. I think the political situation in our country has also played a part and also the fact there is a difficult or sometimes even absent collaboration between the sectors of health and social care (and Ministry of Health and Ministry of Social Affairs). Currently we are struggling with two legislative proposals: one prepared by the Ministry of Social Affairs omits to sufficiently reflect the needs of people who are sick (including people with dementia) in the context of social care provision. The other was prepared by the Ministry of Health and concerns rehabilitation, after care and long-term care. This proposal does not reflect the needs of people with long-term conditions such as dementia (including medical care in care homes, etc.). As an ex-President of the Czech Society of Geriatrics and Gerontology, I am particularly disappointed that the legislative proposal and strategy have proved to be so lacking, especially as they were prepared after collaboration with some leading geriatricians. This leads me to think that our challenges are not limited to those arising from austerity measures alone. I am convinced that even in a time of austerity measures that we could better organise our care for people with dementia and be more effective.

AE: In September 2010, the government of the Czech Republic announced that a national dementia plan would be developed and published by June 2011. What is the status of the national plan at the moment?

IH: The Ministry of Health has prepared a vision for the future strategy of care for people with dementia (the Czech Alzheimer Plan). This was published at the end of 2012. In Spring, the working group started its task of developing the strategy but came up against some significant obstacles with regards to legislation and funding but also with regard to the political situation. There are many personnel changes in all the ministries and this is not very positive climate for us to work in. Nevertheless, I remain optimistic and hope that we manage to continue with the development of the Alzheimer Plan and that we will at least achieve a modest plan which will result in a better outcome for people with dementia and their carers.

AE: What needs to be done to ensure that the draft plan becomes a reality and what role can the Czech Alzheimer Society play in this process?

IH: There are many things to be done in our country: There needs to be better collaboration between the Ministry of Health and the Ministry of Social Affairs on issues surrounding long-term care such as legislation and the allocation of resources. Current legislation does not address the situation for those people who are chronically ill and who need long-term care, many of whom are people with dementia. There are unnecessary obstacles to overcome before receiving care and these need to be removed. In addition, the quality of care and the reputation and status of professionals and family carers who work in the care field need to be
improved. On the other hand, there are many achievements and improvements which benefit people with dementia and their caregivers such as:

1. the existence of drug reimbursement – all four drug treatments (donepezil, rivastigmine, galantamine and memantine) are available and reimbursable in the Czech Republic,
2. the provision of a care allowance,
3. the involvement and interest of many professionals who are now involved in care,
4. the development of many projects aimed at improving care,
5. the provision of many good care homes, and
6. the Alzheimer Foundation – this has supported some interesting projects in care, education and research.

The Czech Alzheimer Society (CALS) has also made a significant contribution to the improvement of the quality of life for people with dementia. In particular, I would like to highlight that CAS has:

- developed a programme of quality certification “VAZKA” (the logo of CALS) and we are very happy to welcome more than 30 care homes into this VAZKA quality club,
- put in place the “Memory Days” project which enables us to offer free testing of cognitive functions to people who have memory problems,
- offered counselling, self-support groups for caregivers and people with dementia and respite care services,
- collaborated with the Ministry of Health to develop the framework of a Czech Alzheimer Plan. It is envisaged that this collaboration will continue.

I think that all these, together with other pilot projects and experiences, could be a good base from which to develop a really effective Alzheimer Plan. Alzheimer and dementia have already become a public issue. CALS communicates with many journalists and has found the responses to be very positive. What we must now secure, and is indeed vital to us, is the support and understanding of our politicians.

Overcoming everyday challenges in Alzheimer’s disease

At Lundbeck we are dedicated to overcome the challenges of Alzheimer’s disease. It is our goal to improve the quality of life for people living with the disease and for those who care for them.

Find out more on www.lundbeck.com
Dementia in the news

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In the Nordic countries we experience unity and solidarity when we get together. We gain confidence in ourselves and the others, and we can easily make contact when we have an idea," said Kari Espedal, the delegate from Norway, commenting on the conference from the 5th to the 8th of June 2013 of the Nordic Alzheimer’s and dementia associations.

Nordic conferences, with the participation of Iceland, the Faroe Islands, two associations from Sweden, Norway, Denmark, Åland and Finland, have taken place since 1993 every or every other year. Conferences include a report from each association on its daily work, a sharing of the latest knowledge in care practices and science and a social programme: sightseeing and experiencing the local culture.

This year the conference was held in Lund, Sweden, arranged by the the Alzheimer’s association of Sweden and it included an interesting scientific programme and inspiring settings for exchanging ideas.

The Nordic associations experience progress in their work. There is more cooperation with governments, and more acknowledgement from the public, but funding is increasingly difficult as there is less money in society. Some important and new activities were shared at the conference:

• In Finland part of the work of the Alzheimer’s association is financed by a government grant. This gave rise to some envy, but participants considered this to be a reasonable goal for all associations.

• The Norwegian association won a competition to benefit from a national lottery, which enabled it to launch a comprehensive campaign “No time to lose”.

• The Icelandic association engages participants in the Reykjavik Marathon to run for the Alzheimer’s association and make it possible for spectators to gamble on winners in order to benefit the association.

• An important aspect of the work of Demensforbundet in Sweden is influencing politicians and decision-makers. Demensforbundet has for example prevented a law to allow coercive measures in dementia care and at the moment is advocating minimum standards for the number of professional caregivers and effective control of care in nursing homes.

• Alzheimerforeningen in Sweden cooperates with other disease organisations to influence politicians and engages well known people on their board to enhance knowledge and interest from the public.

• The Danish Alzheimer’s association is working on a special seminar “The Nordic Care Model” for the Alzheimer’s association International Conference, AAIC, which will be held in Copenhagen in 2014. The association calls for assistance from the other Nordic associations in engaging journalists and the public in the conference.

• The delegates from Åland spoke about their work and challenges in the small community of the islands between Sweden and Finland.
Besides highlighting services for people with dementia and their carers (for example the inclusion of culture, music and dancing in their work) the Aaland Alzheimer Association is working on new guidelines for dementia care.

- Experts from universities in Sweden lectured on the progress in the diagnosis, prevention and treatment of dementia. The latest knowledge on Lewy Body dementia, the impact of heritability, the use of PET scans and tests on spinal fluids and preventing dementia by vaccination was presented to the close attention of the audience. The experts remained after the presentations in order to answer questions and participate in informal talks. This was greatly appreciated as an important way to increase understanding and learn more about the disease.

- A whole morning was spent at Minnesklinikken in Malmö, Sweden, the Centre of Diagnosis and Clinical Research into Cognitive Dementia Symptoms. Doctors, nurses and an assistant nurse lectured about research and care projects at the clinic. The goal of Minnesklinikken is to support “the good life” in spite of dementia through research, education and information.

- The “Migration School” is a web-based information project made in cooperation with the corresponding clinic in Copenhagen, Denmark. Foreigners in Sweden and Denmark can seek information on dementia diseases and the various possibilities for support in their own language on the sites where pictures and music, in the words of the lecturer, “create a scent of the country”.

- Another innovative project which is also being run at Minnesklinikken is the development of a national register of challenging behaviour, e.g. restlessness, alarm, anger or sleep disorders. At care units challenging behaviour is described and analysed as to the cause, and a plan of action is developed, carried out and assessed for each person. The information is anonymously channelled back to the national register and a report from the register can be ordered by care units to give support in the daily care.

At the end of the conference one of the hosts from Alzheimerforeningen, Krister Westerlund, offered to write a report on the knowledge shared at the conference and send it to each association to present to the politicians in their country as in inspiration for action.

The formal and informal cooperation achieved at this year’s conference will be built upon over the next two years. The next Nordic conference will be held in Aaland in 2015.
Dementia in the arts

Olivier Constant, Communications Officer at the Flemish Expertise Centre on Dementia, Antwerp, Belgium, talks about the Flemish solidarity campaign “Music for Life for dementia”.

With “Music For Life for dementia”, which was held from 14 until 21 December 2012, the Flemish Expertise Centre on Dementia, the Flemish Alzheimer League and the Alzheimer Research Foundation launched a new international initiative. It was the first time that the national media ran a highly effective campaign to reduce the stigma on dementia. Their tools: the power of music and memory, the creation of a badge to show your support for people with dementia and their caregivers, a massive launch of local actions to thank people who wear the badge and an online platform to register your personal memories through music, as a way to show the power of reminiscence.

The result: 625,000 “badges for life” were sold, more than 20,000 registered “songs for life” and the live performance of an intergenerational choir of people with dementia opening up for the rock band “Muse”. But most importantly: people with dementia, their caregivers and professionals could speak-out for a seven-day period, 24 hours a day.

Research of the Flemish Expertise Centre on Dementia was carried out six weeks after “Music For Life for dementia” took place and showed us the significant impact of the campaign. 75% of the respondents stated that they had seen/heard of the campaign throughout the media coverage. 87% of those people were aware of the fact that dementia is still a taboo subject. The main goals of “Music For Life” were: make people aware of the existence of this taboo and create awareness about dementia. These two goals were indeed achieved. Moreover, one out of three respondents indicated that they have spoken with colleagues, friends, family, about dementia and that’s essential if we want to reduce the stigma.

The research also revealed that Flanders already supports an image of dementia which focuses on the possibilities instead of the limitations of people with dementia.

OLIVIER CONSTANT
Spotlight on Italy, Portugal and Switzerland

We look back at the work of Federazione Alzheimer Italia, Alzheimer Portugal and Association Alzheimer Suisse as they celebrate their anniversaries.

I would like to dedicate our 20th anniversary to Ornella Possenti Porro, who suddenly and prematurely passed away last October. She was a key figure in our organisation, having the gift of making you feel at ease immediately and bringing clarity and peace to those with dementia. She will be missed by all who knew her.

Federazione Alzheimer Italia (FAI) began its work on 30 June 1993 with the slogan, “strength of not being alone”. Our aim was to create a national network of help for people with dementia and their families. In 1993 FAI consisted of just five associations and this has grown to now be 47 throughout Italy. Whilst we operate as one organisation, we have always been respectful of the autonomy of local member organisations.

I am immensely proud that during its 20 years’ work FAI has

- handled some 130,000 requests via the phone help line,
- provided 19,746 people with legal, social security, social and psychological advice,
- provided information via our website which has registered 4,315,493 visits,
- sent out 93,826 information kits,
- published thousands of copies of books and manuals on how to care for someone with the disease,
- participated in conferences, congresses and round tables,
- provided scientific and ministerial support,
- defended the rights and interests of people with dementia and their families,
- promoted medical research, and
- raised awareness of the social and economic impact of Alzheimer’s disease,
- been invited by the National Committee for Bioethics to help develop a document on the bioethical issues surrounding Alzheimer’s disease – work will commence later this year.

Together with Alzheimer Europe’s member associations we have been able to achieve our first and most important goal: to have initiated wide European recognition of the need to address the scourge of Alzheimer’s disease. On a national level, compared to when we began our work in 1993, Alzheimer’s disease is no longer an unknown disease and people who live with the disease and their families have more understanding of the disease. However, little has been achieved on an institutional level and so we, with all those who work with us (doctors, researchers, health and social workers and the invaluable volunteers), persevere to keep the dialogue flowing with all institutional levels.

We call on the scientists and politicians as they are in positions of responsibility and can influence the way forward, to ensure that a network of research, treatment and assistance is realised. By being united we are in a much stronger position to work together. Believe us: our passion is more than a promise, it is a commitment!

“Our passion is more than a promise, it is a commitment!”

GABRIELLA SALVINI PORRO
Alzheimer Portugal was launched in November 1988. At that time, Alzheimer disease was almost completely unknown, not only by the general public but also by the healthcare professionals.

Fortunately, Professor Carlos Garcia, neurologist, became especially interested and dedicated to the theme of dementia, choosing it as the subject of his PhD thesis “Doença de Alzheimer, problemas do diagnóstico clínico” (Alzheimer Disease and problems for clinical diagnosis), in 1985.

Professor Carlos Garcia pioneered the development of dementia study, diagnosis and treatment in Portugal. In particular, he created the first “dementia visit” whereby a person could go to a doctor who would allocate time for a specific consultation on dementia.

In 1979, he attended a specialised training programme in a unit dedicated to the study of dementia in the United States (Cornell University, New York Hospital, Dementia Research Service). There he made contact with people with dementia and their carers and was deeply moved by the suffering and the need for support of those people trapped in the dementia web. He became particularly fascinated when he saw a person with dementia driving his own car to attend that Dementia Research Service.

Some years later, in 1988, Professor Carlos Garcia created Alzheimer Portugal and the first meetings and support group of people with dementia carers took place.

In January 2003 Alzheimer Portugal opened the first Day Care Centre specific to people with dementia in Portugal. Ten years later, on the 6th January 2013, Alzheimer Portugal's first nursing home “Casa do Alecrim” was launched.

Nowadays Alzheimer Portugal develops its work in four main areas of action: 1) Services to people with dementia and their carers, including day care centres, home support services, counselling and social support (such as programs for the provision of technical aids, incontinence products and agreements with several products and services providers), psychological support, assessment and intervention and also visits to the neurologist or psychiatrist; 2) Family and professional carers’ training; 3) Information and public awareness campaigning and 4) Communication.

25 years after its foundation, Alzheimer Portugal had its role acknowledged at national level for its work as a leading reference on dementia, a source of knowledge and experience and for its key role of sharing best practices among families and professionals. Recognition for the organisations work has resulted in Alzheimer Portugal being:

• invited to train, offer advice and to assist with the development of protocols in private nursing homes, day care centres and home services,
• part of the team of experts which is preparing the Portuguese National Dementia Plan,
• invited to train nurses and other healthcare professionals from the National Healthcare system at the end of 2013.

Further, the high level and the growing number of Alzheimer Portugal partners are evidence of its recognition as a strategic stakeholder in what con-
cerns people with dementia and their carers when promoting their rights and quality of life of people.

In 2006, Alzheimer Portugal signed the Paris Declaration (which states the political priorities of the European Alzheimer Movement). From this point on, Alzheimer Portugal has been an active member of Alzheimer Europe, the leader of the European Dementia Movement. The awareness campaign and lobbying activities of Alzheimer Portugal have been shaped according to the main priorities laid down in the Paris Declaration.

Whilst there is not a national dementia plan or strategy in Portugal, some important achievements have already taken place: advance directives are now included in the Portuguese legislation and there are guidelines addressed to diagnostic and therapeutical issues in patients with cognitive decline or dementia.

A very important step in the development of a Portuguese Dementia Plan was taken in May 2013 when the Health Ministry organised a high-level meeting. Professor Joël Ménard, together with about 40 experts on dementia – psychiatrists, neurologists, general practitioners, researchers, members of the municipalities, representatives of Alzheimer Portugal - met to discuss dementia.

For the future, Alzheimer Portugal aims to a) strengthen the public recognition as the only nationwide association that, for 25 years, promotes the quality of life of people with dementia and their carers; b) keep its services as references to be followed by other stakeholders; c) keep working for a society that really involves people with dementia and respects their dignity, autonomy and rights.

Association Alzheimer Suisse by Birgitta Martensson, Executive Director

In 1988, when the Swiss Association was founded, people knew very little about Alzheimer's disease and other forms of dementia. Today a national dementia strategy for Switzerland is on its way. We have come quite far and the activities of the Alzheimer Association have contributed to that success.

It was the initiative and the vision of a handful of people that led to the foundation of the association. A group of carers gathered in Berne and initiated the first self-help group. It was a revelation. They found out that they were not alone and the support they experienced encouraged them to cope with daily life. But they wanted more than that: support for as many people affected as possible and making the public aware of dementia and the needs of the people living with the illness. With Professor Jean Wertheimer, a pioneer in geriatrics, they found a competent and committed ally. That’s how the Alzheimer Association Switzerland was founded. Ruth Ritter-Rauch was one of the driving forces. She took care of her husband Hans at that time. She remembers: “I was so happy. Now finally things would get moving. From now on people will know what dementia is and what it means to live with it.”

The Nineties

It was not an easy start. Knowledge of dementia was poor, social stigma important and very often people with dementia and their families were isolated and left alone. A lot of work had to be done. We owe deep gratitude towards the hundreds of people who shared the vision over the last 25 years. They helped build an association that today has
nearly 10,000 members and 130,000 donors. With 21 cantonal sections we are able to provide a nationwide network of information, advice and support. Today we have a strong and influential association to defend the interests of those facing dementia.

Tamensi movetur – but it does move!

Two years ago things started to move on a political level as well. The Swiss Parliament passed two motions asking for a national dementia strategy. The Swiss Alzheimer Association played a crucial role during the political process that led to the acceptance of these two motions. Jean-François Steiert, Member of Parliament (MP) and also a board member of the Swiss Alzheimer Association, was one of two MPs who presented the case for these motions. The facts and arguments used during this process were, inter-alia, based on the documentation provided by the Association.

In autumn 2011 a first meeting gathered a wide range of people able to explain what dementia is about: for the individual and for the society. After that, things progressed quickly. The Alzheimer Association is playing a very active part in the process as an esteemed and highly competent partner.

The fact that the best experts in Switzerland have come together to give their input to the strategy already signifies big progress. The main points of the strategy are timely diagnosis for all people with dementia, coaching for people with dementia and their carers from the very beginning and services and training adapted to the real needs. Of course, more work has to be done as health politics are mainly the responsibility of the cantons but at least now nobody has to start from scratch. The strategy should be adopted by the “National Health policy Dialogue” (a platform of the Swiss federation and the cantons) at the end of this year.

Let’s continue!

The situation for people with dementia and their carers has improved over the last 25 years – also thanks to the activities of the Alzheimer Association. But there is still a lot to do! We need better awareness and acceptance of dementia and the quality of life for people with dementia and their carers should be improved. The challenge is big not least because of demographic changes and scarce resources. We need a society where living with dementia is possible and allowed, not tolerated or hidden away! New priorities will be needed!
Dianne Gove, AE Information Officer, was awarded a PhD for her research work on dementia.

Dianne completed her PhD, “General Practitioners (GPs), stigma and the timely diagnosis of dementia” early this year. She successfully defended it on 11 February and it was officially awarded the title of PhD on 17 July 2013. The study lasted from 2008 to 2013. The supervisors were: Prof. Murna Downs, Prof. Neil Small and Prof. Myrre Vernooij-Dassen, as well as Prof. Rob Newell, early on in the study. Alzheimer Europe supported Dianne throughout her study.

Dianne said, “The study involved a qualitative exploration of GPs’ perceptions of dementia as a stigma, the development of a specific conceptualisation of the stigma of dementia and a consideration of the implications for timely diagnosis. GPs’ perceptions of dementia mapped onto the components of and contributing factors to stigma as identified in the literature but were dynamically related and organised within a unique structure which is not identical to that of other stigmas. The themes, which emerged from a combined approach involving grounded theory and framework analysis, reflected processes of making sense of dementia, relating perceptions of dementia to oneself and considering the implications of dementia. Lack of reciprocity was identified as underlying most perceptions of dementia as a stigma, and was closely related to cognitive separation and existential anxiety. GPs’ perceptions of dementia were similar in several respects to those they believed lay people to have.

“Most GPs felt that dementia was still considered a stigma within society but some emphasised the importance of talking openly about it and pursuing a diagnosis as a means to overcome such stigma. Nevertheless, GPs described the need for extreme caution and sensitivity when broaching the topic with patients, which may in practice interfere with the timeliness of diagnosis. Implications for policy and practice include the need to provide appropriate support to enable GPs to focus on their professional role as a means to bypass their existential anxiety.

“The findings suggest the need to consider the stigma of dementia from different angles and at different levels, considering the global concept and its various components, which together form a system and are part of a wider system. Practices and influences from wider society, which cause, maintain or perpetuate the stigma of dementia and interfere with timely diagnosis, must also be challenged in addition to perceptions of dementia. Moreover, the barriers to diagnosis highlighted by GPs (other than stigma) can also be meaningfully understood as being related to stigma. This study provided detail which was lacking about how GPs perceive dementia as a stigma. The findings provide a solid basis for addressing GPs’ concerns about balancing the need to diagnose dementia with the desire to protect their patients from the perceived impact of stigma.”

Dianne expressed her gratitude to Jean Georges and to the members of the Board of Alzheimer Europe for their financial support, encouragement and interest in the study. She also wished to thank her supervisors for having shared their knowledge, expertise and experience, and for their patience and support throughout.

“This study provided detail which was lacking about how GPs perceive dementia as a stigma.”

DIANNE GOVE
LIVING WITH DEMENTIA IN SLOVENIA

Bojan Spanja has Alzheimer’s disease. In this article his wife, Mihela, talks about their experience of living with the disease.

At only 58 years of age, Bojan is one of the youngest patients with Alzheimer’s disease in Slovenia, having been diagnosed three years ago. It started with an inability to follow simple requests, such as “Help me put the dishes away” or “Can you bring this or that to me” – he would say yes, but seconds later he would already proceed to do something completely unrelated. When similar things happened more often I suspected that something must be wrong. I have been married to him for 30 years and I knew that I must act quickly as he didn’t recognise that he had a problem.

We are very grateful to two people who helped us speed up the process of obtaining a diagnosis: his personal physician, Dr Angela Fonda, who immediately performed the “clock test” and Dr Ales Kogoj, Head of the Gerontopsychiatric clinic in Ljubljana and founder of the Slovenian organisation for people with dementia “Forget-me-not” (Spomincica). Dr Kogoj immediately took Bojan in, examined him and performed all the available tests over a period of two to three months. We were very lucky in comparison to many others faced with the same problems, not only in Slovenia but in general in the EU.

Bojan was always a very active person, both privately and in business; he worked as a computer programmer for over 30 years and he was an active sportsman. Suddenly, he became a different person and our lives changed. To this day, he chooses to ignore his condition – Alzheimer’s disease. He enjoys taking a walk with Maggie, our Yorkshire terrier, always following the exact same route twice a day. Consequently, a lot of people know them, especially the dog owners with whom he chats almost every day. I explained to them and to the others in our community about his diagnosis and the response of people we talked to is very warm and understanding.

His second passion is still his motorcycle, a Ducati. He still rides the bike, as his motoric abilities have not yet decreased, but as a precautionary measure I
Bojan and I (as his carer) are honoured to be a part of European Working Group for People with Dementia, which opened our minds and educated us on how to raise awareness among people in Slovenia, and especially help those that are already affected in some way or another by the consequences of dementia.

We have noticed a change in people’s general knowledge and understanding of dementia in the past three years. Several Alzheimer Cafés have opened in Slovenia, where, with an enormous amount of help from Stefka Lukic Zlobec, the Vice-president of Forget-me-not and a member of team in charge of writing the National dementia strategy in Slovenia, we organise lectures by experts in the field of dementia. We both enjoy exchanging experiences with other people and helping relatives and carers deal with this still-stigmatised disease. A lot of talk shows which host debates and feature documentary content regarding dementia on national TV together with articles in magazines contribute to the fact that more and more people now understand this disease.

Drive in a car in front of him, which is safer from my point of view – not his. However, he has made a decision to sell the motorcycle next year, which I see as progress, as it shows some awareness of the seriousness of his condition. For now, the medicine he takes helps him a lot, but he also takes other nutritional supplements, such as vitamin B12, Curcuma and Omega-3.

Society should listen to people affected by dementia and take into account their needs and requirements as they are still quite capable to think, feel and be active for many years following their diagnoses, even if in a somewhat different way to most people. People with dementia have contributed a great deal to society during their lives and they deserve a fair and decent reciprocity.

Also, it is necessary to adopt new guidelines and related legislature in order to organise both the physical and material assistance for carers as they carry the brunt of the tolls which this disease brings.

Bojan and I (as his carer) are honoured to be a part of European Working Group for People with Dementia, which opened our minds and educated us on how to raise awareness among people in Slovenia.”

MIHELA SPANJA
MEMBERS’ NEWS

Alzheimer Europe highlights some of the activities carried out by national associations.

**Bulgaria: Alzheimer Bulgaria launches dementia newsletter**

Alzheimer Bulgaria launched its first issue of a quarterly newsletter called “Dementia” on 1 June 2013. The newsletter is intended for families, caregivers and friends of people with dementia, social workers and health professionals. Each issue will feature articles on disease prevention, patient care, research health tips and the rights of people with dementia. The Dementia newsletter can be downloaded from the association’s website.

**Germany: Alliance campaigns for patient and carer rights**

The “Alliance for Good Care”, which includes the German Alzheimer’s society, ran an e-card campaign on behalf of patients and carers during Germany’s recent federal elections. The campaign urged citizens to send an e-card to the heads of all the political parties in the German Parliament. This card outlined the goals and demands of the alliance, including personalised services for patients and better benefits and recognition for carers.

**Ireland: Dementia Friendly Communities initiative**

The Alzheimer Society of Ireland embarked on the development of a new “Dementia Friendly Communities” initiative on 13 August 2013. The initiative aims to improve the inclusion and quality of life of people with dementia and their families. The Society is supporting and building the capacity of eight communities across the country to get involved and will provide these communities with an award of up to EUR 25,000 over the next three years.

**Norway: Norwegian Health Association lobbies for better dementia care**

The Norwegian Health Association made its first appearance at “Arendalsuka”, an annual forum for informal meetings between politicians, organisations, business and the media in Norway. The week-long forum started on 8 August 2013. Members of the Association lobbied politicians from all the Norwegian parties on day care, more funding for research and quality in nursing homes. In addition, the Association provided information about its work and about living with dementia.

**Slovenia: Ljubljana hosts dementia conference**

The mayor of Ljubljana and the city’s Department for Health and Social Affairs hosted a round table conference on dementia on 6 June 2013. The aim of the conference was to raise public awareness of dementia and to highlight the challenges faced by Slovenes with dementia. The keynote speaker was Dr. Aleš Kogoj, psychiatrist and President of Spominica, the Slovenian Alzheimer association.

**UK: Wales to launch nationwide community project for people with dementia**

On 17 July 2013, the UK Alzheimer’s Society was awarded over EUR 835,000 from the Big Lottery Fund for a project to support people living with dementia in Wales. The award will fund the society’s “Life not just a service” project, which aims to enable people with dementia and their carers to feel more supported and enjoy a full and active life. The project will be delivered through a programme of weekly community courses that include art, drama, patchwork quilting, family history, and photography. People with dementia will be involved in all aspects of the programme, which will run for three years.
Our members are helping people with dementia and their carers in 29 countries

AUSTRIA – VIENNA
Alzheimer Austria

BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liga

BULGARIA – SOFIA
Alzheimer Bulgaria

BULGARIA – VARNA
Foundation Compassion Alzheimer

CROATIA – ZAGREB
Alzheimer Croatia

CYPRUS – LARNACA
Pancypriat Alzheimer Association

CZECH REPUBLIC – PRAGUE
Czech Alzheimer’s Society

DENMARK – HELLERUP
Alzheimerforeningen

ESTONIA – TARTU
Estonia Association of Alzheimer’s Disease

FINLAND – HELSINKI
Musiillitto

FRANCE – PARIS
Association France Alzheimer

GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V.

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

IRELAND – DUBLIN
The Alzheimer Society of Ireland

ITALY – MILAN
Federazione Alzheimer Italia

ITALY – ROME
Alzheimer Uniti Onlus

JERSEY – ST HELEIN
Jersey Alzheimer’s Association

LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer

MALTA – MSIDA
Malta Dementia Society

NETHERLANDS – AMERSFOORT
Alzheimer Nederland

NORWAY – OSLO
Nasjonalforeningen Demensforbundet

POLAND – WARSAW
Polish Alzheimer’s Association

PORTUGAL – LISBON
Alzheimer Portugal

ROMANIA – BUCHAREST
Societatea Alzheimer

SLOVENIA – LJUBLJANA
Association “Forget-me-not”

SLOVAKIA – BRATISLAVA
Slovak Alzheimer’s Society

SPAIN – PAMPLONA
C.E.A.F.A.

SPAIN – MADRID
Fundación Alzheimer España

SWEDEN – LUND
Alzheimerföreningen i Sverige

SWEDEN – STOCKHOLM
Demensförbundet

SWITZERLAND – YVERDON-LES-BAINS
Association Alzheimer Suisse

TURKEY – ISTANBUL
Alzheimer Vakfi

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

UNITED KINGDOM – LONDON
Alzheimer’s Society
24th Alzheimer Europe Conference
Dignity and autonomy in dementia
Glasgow, Scotland, UK
20-22 October 2014

Mark the dates!

www.alzheimer-europe.org/conferences