Lydia Mutsch sets priorities for Luxembourg’s EU Presidency term

Kathleen Lynch discusses Ireland’s national dementia strategy

Vytenis Andriukaitis, European Commissioner for Health & Food Safety, discusses the Commission’s ongoing dementia programmes

Hilary Doxford describes her experiences on the Board of the World Dementia Council
Welcome
by Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe

Prioritising Dementia

AE Public Affairs meeting
Alzheimer Europe’s Public Affairs meeting was attended by delegates from 14 AE member organisations

AE creates Expert Advisory Panel
The new panel will bolster AE’s scientific coverage of dementia research

Glasgow Declaration campaign
AE and its members call for a pan-European dementia strategy

The European Alzheimer’s Alliance in Action
An update on recent activities by EAA members

EPAD: a new IMI project for the prevention of Alzheimer’s dementia
The EPAD partners aim to prevent dementia and understand aspects of the disease before it develops

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WHO dementia conference sparks a global Call for Action
Global delegates recognise the need for coordinated efforts to combat dementia

Final G7 Dementia Legacy event held in US
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Photo credits

Layout
binsfeld corporate

Print
Imprimerie Centrale, Luxembourg
I was greatly saddened to hear of the passing of my friend and colleague Alicja Sadowska. Alicja was the driving force of the Polish Alzheimer Association for many years and was deeply concerned with improving the lives of people with dementia and their families in Poland. As a member of the Alzheimer Europe Board, she contributed with valuable insights that helped AE’s work – including our successful 2011 Annual Conference in Warsaw, which was hosted by Alicja and her colleagues at the Polish Alzheimer Association. Though her work was often hampered by lack of political support and funding, Alicja never gave up her ambition to make dementia a health priority in Poland and in every other country. We will remember her as a tireless campaigner for those in need and will miss her friendly presence at our conferences and meetings.

In this issue, we cover AE’s new Expert Advisory Board, which will improve our scientific coverage of dementia research, as well as an update of our Glasgow Declaration campaign. I am very grateful for the collaboration of our member associations in this new effort to make dementia a European and global issue. We also present EPAD – the new project for the prevention of Alzheimer’s dementia – and IMI’s new joint Alzheimer’s Disease Research Platform.

Our main policy story is a look at the Commission’s ongoing programmes on dementia with Vytenis Andriukaitis, EU Health & Food Safety Commissioner. We also have an interview with Luxembourg’s Minister of Health Lydia Mutsch, who describes the country’s health priorities during its EU Presidency term. Minister Mutsch was also a participant in the WHO dementia conference in March 2015, along with AE Executive Director Jean Georges, where delegates recognised the need for coordinated efforts to fight dementia. This issue also covers the national dementia strategies in Ireland and Malta, the latter being the first in the world to be published in a dementia-friendly format.

Our news section covers the “Young European leaders” event, where young experts in various fields gathered to address issues in dementia. We also feature Hilary Doxford, Vice-Chairperson of the European Working Group of People with Dementia, who is currently serving on the Board of the World Dementia Council. Hilary recounts her experiences in this new position and she will also be chairing the EWGPWD’s symposium at AE’s 25th Annual Conference in Ljubljana.

Finally, this issue includes a special section on Slovenia, as a preview to our 25th Annual Conference in Ljubljana during 2-4 September. There is clearly a tremendous amount of support and motivation to improve the lives of people with dementia in Slovenia. President Pahor is the official patron of our conference and Minister of Health Milojka Kolar Celarc is actively working to launch a national dementia strategy. Minister Kolar has also signed the Glasgow Declaration, along with Slovenia’s Ombudsman, the Mayor of Ljubljana and six of eight Slovenian MEPs. Our colleagues at Spominčica, the Slovenian Alzheimer association, have been at the forefront of all this activity and we very much look forward to cohosting the conference with them.
Prioritising Dementia

AE Public Affairs meeting
AE creates Expert Advisory Panel
Glasgow Declaration campaign
The European Alzheimer’s Alliance in Action
EPAD: a new IMI project for the prevention of Alzheimer’s dementia
EIP AHA’s summit promotes active and healthy ageing
AE holds Public Affairs meeting in Luxembourg

On 25 February, Alzheimer Europe (AE) held a Public Affairs meeting in Luxembourg which was attended by delegates from 14 AE member organisations.

Current AE projects

Executive Director Jean Georges opened the meeting with a discussion on some of AE’s current projects:

**Clinical Trial Watch**: the main aim of this project is to make information about ongoing clinical trials more accessible to people with dementia and their families. The active involvement of people with dementia is a key feature of this project, which also includes partners from pharmaceutical companies.

**Dementia Monitor**: the monitor aims to be a European benchmark of national dementia policies, based on data provided by AE’s member associations and pharmaceutical partners. A group of delegates from AE members and pharmaceutical companies is currently evaluating the information gathered in 2013-14 and their conclusions will be presented later this year.

**Alzheimer’s Association Academy**: AE’s latest initiative is a series of workshops to be held at its annual conference in Slovenia in September 2015. During the meeting, the delegates agreed on the following topics:

- The involvement of people with dementia in national organisations.
- The impact of the changing definition of Alzheimer’s disease on the work of national associations.
- The role of national organisations in informing people about and promoting the involvement of people in clinical trials and research projects.
- The role of national organisations in funding and participating in research.

Maintaining ties with the European Parliament

Jean was followed by AE staff members Annette Dumas (Public Affairs Advisor), Kate Boor Ellis (Communications Officer) and Alex Teligadas (Director for Communication). In turn, they explained that AE’s Glasgow Declaration campaign would target Members of the European Parliament (MEPs) but also international and national organisations. The possibility of translating the declaration was also raised, so that AE members could reach their MEPs and national Members of Parliament directly. This was widely perceived as a benefit and several delegates agreed to provide translations. They also discussed the logistics of the campaign that will run until November 2015. Annette also outlined ways of involving MEPs in the activities of national organisations, including the participation of people with dementia. Jean pointed out that the EWGPWD (European Working Group of People with Dementia) will meet in Brussels in December 2015; this meeting will include a visit to the European Parliament.

The data protection debate

This topic generated considerable discussion, as the data protection debate continues in the European Parliament. There is still no agreement on the final text of the legislation, which will have implications for clinical trials and other projects that are relevant to people with dementia. The reuse of existing data is a key issue: it is expected that researchers will need to recontact every participant...
to ask for specific consent to use data in new projects. The legislation may also have implications for patient registries, as these may no longer be considered lawful. Alzheimer Europe believes this is a significant issue and Jean will consult with member associations on whether and how AE could be involved in these discussions.

**Dementia friendly communities**

The 2015 Dementia in Europe Yearbook – “Is Europe becoming more dementia friendly?” – was introduced by AE Project Officer Ana Diaz. She also spoke about experiences on dementia friendly communities in Belgium and this was followed by similar presentations from Julie Meerveld (Netherlands) and Jim Pearson (Scotland). Helga Rohra, Chair of the EWGPWD, described various projects that are currently ongoing in Germany. By the end of the session, the methodology, contents and timeframe for the yearbook were agreed by the delegates. The yearbook will be published in December 2015.

**National campaigning activities**

The last part of the meeting was an update of campaign activities in AE members’ countries. Some of the highlights are summarised below. Austria is currently developing a national dementia strategy and the government is keen to ensure that the main source of information about needs should come from people with dementia and carers. Croatia produced a draft of a national dementia strategy that includes ten main points and covers a five year period. The draft was presented at Alzheimer Croatia’s annual conference which attracted over 200 delegates. Finland was expected to enact new legislation on self-determination and Muistiliitto launched a major campaign for April’s parliamentary elections. At the time of the meeting, 330 candidates had pledged to work with the association if elected. Greece’s new dementia observatory is operational, but activities are hampered by lack of funding – which also threatens the future of dementia day care centres. Even so, campaigns are ongoing to raise awareness and to train priests and police officers. In Italy, Alzheimer Italia has developed a training initiative for newly qualified occupational therapy students to deal with dementia. Malta’s new national dementia strategy will run from 2015 to 2023 and contains 82 recommendations, with a strong focus on empowering change. The strategy is the first in the world to include a dementia-friendly version. In the Netherlands, the “Delta Plan” has resulted in the launch of 22 research projects and an online platform for people with dementia and carers to help them obtain care which is suited to their needs. Norway has allocated EUR 230 million to fund dementia activities over five years. A substantial amount will be spent on research, but there is also a new programme for individual training for carers to accompany people with dementia in their favourite activities. In Portugal, a study is underway to define the needs of people with dementia and their families. The results will help to determine guidelines for the national strategy. Alzheimer Scotland is promoting self-help seeking behaviour and how the advanced illness model is a key area of development. Another current focus is health and social care integration, which was recently the subject of legislation. Slovenia is developing a national dementia strategy and Spominčica is actively involved in the process, as are people with dementia. The association also holds training sessions for police officers and other civil servants. In Turkey, the Alzheimer association is developing a new day care centre and also conducting awareness and education campaigns. At the time of the meeting, the association had just added a new local branch and was looking forward to its annual conference. The next Public Affairs meeting will be held in Brussels on 1st July.

<table>
<thead>
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<tr>
<td>Austria</td>
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<td>Croatia</td>
<td>Ninoslav Mimica</td>
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<td>Cyprus</td>
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<td>Finland</td>
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<td>Greece</td>
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<td>Mario Possenti</td>
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<td>Malta</td>
<td>Charles Scerri</td>
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<td>Netherlands</td>
<td>Julie Meerveld</td>
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<td>Norway</td>
<td>Randi Kill</td>
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<td>Maria da Rosário Zincke dos Reis</td>
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<td>Romania</td>
<td>Daniela Delametra</td>
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<td>Slovenia</td>
<td>Stefanija Lukić Zlobec</td>
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<tr>
<td>Turkey</td>
<td>Füsun Kocaman</td>
</tr>
<tr>
<td>UK (Scotland)</td>
<td>Jim Pearson</td>
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</table>
Alzheimer Europe bolsters its scientific coverage of dementia research

Launched in January 2015, a new Expert Advisory Panel will enhance AE’s reporting on medical and scientific breakthroughs in dementia. The expert group will also provide commentaries to research developments and advise AE on its EU project work.

AE’s Expert Advisory Panel (EAP) consists of scientists and researchers who are well established in their organisations and are acknowledged as leaders by their peers. Their areas of expertise may include aetiology, care, caregiver support, diagnosis, epidemiology, genetics, health economics, perceptions and stigma, prevention, psycho-social interventions, research ethics, quality of life and treatment. In addition, they are active in the European research environment and have previously worked with patient and carer organisations.

Providing scientific commentary and advice

The EAP experts will be called upon to advise on Alzheimer Europe’s work programme, such as identifying relevant experts, assisting with the preparation of new publications or disseminating information among the scientific community.

AE will periodically ask EAP members to provide commentaries on current dementia research topics. The aim is to bridge the gap between scientific terminology and plain language, in order to clarify misleading or exaggerated media coverage of so-called “breakthroughs” in dementia research. These commentaries will be published in AE’s newsletter and Dementia in Europe magazine.

The EAP will also be involved in planning Alzheimer Europe’s annual conferences, in order to propose themes and assist in the evaluation of submitted abstracts. In addition, EAP members will support AE’s growing involvement in scientific research – such as projects funded by IMI or Horizon2020 – by providing advice on which research programmes and research projects to prioritise.

Expanding Alzheimer Europe’s network

The advisors are appointed by the Alzheimer Europe Board for a three year period and their mandate may be renewed. Ideally, the EAP will assist Alzheimer Europe in developing closer relationships with organisations or groups relevant to its work. This could be as simple as pointing out research projects where AE can represent the point of view of people with dementia carers or contribute to ethical discussions. Similarly, EAP members may be aware of upcoming research topics that could raise important issues for AE or its members.

Alzheimer Europe will publish a list of all scientific advisors on its website and in its Annual Report. The input of advisors will be acknowledged in the documents to which they contributed. This also applies to members of the EAP who contribute to the work of the Programme Committee of Alzheimer Europe conferences: their names will be included in conference materials and the associated section of the AE website.
### Members of the Expert Advisory Panel (2015-2018)

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Country</th>
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<tbody>
<tr>
<td>Prof. Sube Banerjee</td>
<td>Brighton and Sussex Medical School</td>
<td>UK</td>
</tr>
<tr>
<td>Prof. Maria Barcikowska</td>
<td>Centralny Szpital Kliniczny MSWiA</td>
<td>Poland</td>
</tr>
<tr>
<td>Dr Rafael Blesa</td>
<td>Autonomous University of Barcelona</td>
<td>Spain</td>
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<tr>
<td>Dr Mercè Boada</td>
<td>Fundació ACE</td>
<td>Spain</td>
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<tr>
<td>Prof. Suzanne Cahill</td>
<td>St James Hospital</td>
<td>Ireland</td>
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<tr>
<td>Prof. Bruno Dubois</td>
<td>Salpêtrière University Hospital</td>
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<td>Prof. Dr Murat Emre</td>
<td>Istanbul Faculty of Medicine</td>
<td>Turkey</td>
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<tr>
<td>Prof. Dr Dieter Ferringer</td>
<td>University of Luxembourg</td>
<td>Luxembourg</td>
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<tr>
<td>Prof. Giovanni B. Frisoni</td>
<td>University of Geneva</td>
<td>Switzerland</td>
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<tr>
<td>Prof. Chris Gastmans</td>
<td>KU Leuven</td>
<td>Belgium</td>
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<tr>
<td>Prof. Graham Jackson</td>
<td>Alzheimer Scotland Centre for Policy</td>
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<tr>
<td>Prof. Mila Klivipelto</td>
<td>Karolinska Institutet</td>
<td>Sweden</td>
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<td>Prof. Brian Lawlor</td>
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<td>Prof. António Leuschner</td>
<td>University of Porto</td>
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<td>Prof. Dietmar Mieth</td>
<td>University of Erfurt</td>
<td>Germany</td>
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<tr>
<td>Dr José Luis Molinuevo</td>
<td>ICN Hospital Clinic i Universitari and Pasqual Maragall Foundation</td>
<td>Spain</td>
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<td>Prof. Eamon O'Shea</td>
<td>NUI Galway</td>
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<td>Prof. Marcel G. M. Olde Rikkert</td>
<td>Radboud University Medical Centre</td>
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<tr>
<td>Prof. Anne-Sophie Rigaud</td>
<td>Broca Hospital</td>
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<td>Prof. Nathalie Rigaux</td>
<td>University of Namur</td>
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<tr>
<td>Mr Anthony Scerri</td>
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<td>Prof. Dr Philip Scheltens</td>
<td>VU University Medical Center</td>
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<td>Dr Sigurd Sparr</td>
<td>University Hospital of Northern Norway</td>
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<td>Prof. Debbie Tolson</td>
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<td>Prof. Magda Tsolaki</td>
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<td>Prof. Bob Woods</td>
<td>Bangor University</td>
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The Glasgow Declaration campaign: aiming for 10,000 signatures

Alzheimer Europe and its member associations are conducting a campaign to gather signatories to the Glasgow Declaration, which calls for the creation of a European dementia strategy and national strategies in every country in Europe.

In January 2015, AE launched an online campaign to gather 10,000 signatories to the Glasgow Declaration and invited its member organisations to raise awareness of the campaign and collect signatures in their countries. The campaign will run until 30 November 2015 and the results will be presented during a lunch debate at the European Parliament in early December.

AE launched the campaign by inviting its member associations, all Members of the European Parliament and various international organisations to sign the declaration. This was followed by a request for translations to member associations, which proved to be a resounding success. The Glasgow Declaration text and the signup procedures are currently available in Croatian, English, French, German, Greek, Italian, Portuguese, Slovenian and Spanish. AE hopes to add Dutch, Finnish and Turkish versions in the near future.

As of 1 June 2015, there were 2,382 total signatories in three categories:

- **Individuals**: 2,269 signatures from 39 countries
- **Policy makers**: 57 signatures, including 51 MEPs (see table below)
- **Organisations**: 56 international and national organisations

The chart below shows the countries with the most individual signatories as of 1 June 2015. Alzheimer Europe wishes to thank all the people who are helping to make the campaign a success!

### Individual signatories of the Glasgow Declaration by country (2,269 signatories as of 1 June 2015)

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<td>Luxembourg</td>
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<td>Others</td>
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#GlasgowDeclaration because #DementiaMatters

Alzheimer Europe presented the Glasgow Declaration at its Annual General Meeting on 20 October 2014, where it was adopted unanimously by delegates from 26 AE member organisations. The declaration calls for the creation of a European dementia strategy and national strategies in every country in Europe – and also calls upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia. The full text of the declaration is available in nine languages on the Alzheimer Europe website.

www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014

**MEP signatories to the Glasgow Declaration (as of 1 June 2015)**

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<th>Country</th>
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<td>Belgium</td>
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<td>Costas Mavrides</td>
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<td>Estonia</td>
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<td>Finland</td>
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<td>France</td>
<td>Françoise Grossetête, Elisabeth Morin-Chartier</td>
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<td>Slovakia</td>
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<tr>
<td>United</td>
<td>Anneliese Dodds, Theresa Griffin, Ian Hudghton, Linda McAvan, Alyn Smith, Catherine Stihler, Keith Taylor, Derek Vaughan, Julie Ward, Glenis Willmott</td>
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The European Alzheimer’s Alliance in Action

Annette Dumas, EU Public Affairs Advisor for Alzheimer Europe, provides an update on recent activities by EAA members.

Cristian-Silviu Busoi (Romania) participated in the opening of the international conference “National and international policies in dementia – Timely diagnosis, care and research” organised by the Romanian Alzheimer Society on 26 February. In his presentation, Mr Busoi spoke about the European Union’s work on ageing and health and the role of the European Alzheimer’s Alliance in shaping the European dementia agenda.

Nessa Childers, Alliance Vice-Chair (Ireland), hosted The Alzheimer Society of Ireland (ASI) at an information session for Irish MEPs in the European Parliament on 3 March. The Society updated the MEPs on Ireland’s first National Dementia Strategy and discussed how to make dementia a national and European priority. Helen Rochford-Brennan, Chair of the Irish Dementia Working Group and a Vice-Chairperson of the European Working Group of People with Dementia spoke about her experience living with dementia and about her role as an advocate. Alliance members Deirdre Clune, Mairead McGuinness and Matt Carthy took part in the event while Marian Harkin was represented by her assistant.

Nessa Childers and Lynn Boylan represented the European Parliament at an event on “Promoting Good Health in Older Age: Engaging with Europe” organised by the European Parliament Office in Ireland on 13 March. They took part in a discussion on the future of health issues in Europe.
EPAD: a new IMI project for the prevention of Alzheimer’s dementia

The new European Prevention of Alzheimer’s dementia (EPAD) initiative is a collaborative research effort to improve the chance of successfully preventing Alzheimer’s dementia and to better understand early aspects of Alzheimer’s disease before dementia develops.

EPAD aims to create a “machine” operating across Europe that can deliver a standing Proof of Concept adaptive trial for the secondary prevention of Alzheimer’s dementia. The ultimate goal is the prevention of dementia in people with evidence of the disease but few or no complaints or clinical symptoms.

The EPAD partners will identify people who are at high risk of developing Alzheimer’s dementia and willing to participate in a secondary prevention study. They will also select the drug or drugs to be tested in the study, which will feature new “go/no go” decision points. Finally, they will conduct the trial with 1,500 participants in Europe.

The key steps of this process are shown below:

- Define criteria to identify Alzheimer’s disease pathology early in the course of disease, in people who have minimal or no symptoms.
- Create the EPAD Register of 24,000 people that meet these criteria. This will be taken from existing sources, such as population and clinical cohorts or registers in Europe.
- Develop the EPAD Cohort, which will consist of 6,000 people from the register. Their records will be used to create high quality data for AD disease models.
- Conduct the EPAD Proof of Concept Trial for secondary prevention of AD, with the participation of 1,500 people from the cohort.

The EPAD project includes 35 partners from 11 countries – see table below. Their efforts are coordinated by Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh and Serge Van der Geyten, Director for Neuroscience External Affairs at Janssen Pharmaceutica N.V. Alzheimer Europe (AE) is co-leading dissemination activities together with Novartis Pharma.

Jean Georges, AE’s Executive Director, said: “Preventing the development of dementia in biomarker-positive people would be a fantastic step forward in our fight against Alzheimer’s disease. The EPAD project and its novel trial concept will hopefully help speed up the drug discovery progress and bring us closer to this ambitious aim.”

Serge Van der Geyten added that “this project has numerous advantages over current approaches. These include the excellent pre-trial characterisation of subjects to inform selection and reduce screen failure, the establishment of the highest possible quality study sites across Europe, the rapid decision making on the likely success of a drug (or combination of drugs) in subsequent confirmatory trials as well as access to a shared placebo group.”

All data collected from the cohort and trial will become publically available for analysis to improve disease models in the pre-dementia phase of Alzheimer’s disease. This should lead to more accurate stratification for trial selection, improved measurements of outcomes and a greater under-
standing of Alzheimer’s disease processes before dementia develops.

EPAD is also part of the IMI Alzheimer’s Disease Research Platform, along with its sister projects AETIONOMY and EMIF. The platform was established in March 2015 to aid collaboration among the three dementia-related initiatives.

**IMI’s joint Alzheimer’s Disease Research Platform**

On 19 March, the Innovative Medicines Initiative (IMI) and its AETIONOMY, EMIF and EPAD projects announced the creation of the IMI Alzheimer’s Disease Research Platform, which will aid collaboration between the projects and help them to deliver results faster. Concurrently, IMI and the Global Alzheimer’s Platform (GAP) announced their plans to sign a Memorandum of Understanding to accelerate Alzheimer’s drug development by building a global, standing, trial-ready platform for Alzheimer’s drug development.

The three projects in the new platform have a combined budget of EUR 138 million and address complementary areas of Alzheimer’s disease research. AETIONOMY is paving the way towards a new approach to the classification of neurodegenerative diseases, particularly Alzheimer’s and Parkinson’s diseases. EMIF is developing a common information framework of patient-level data that will link up and facilitate access to diverse medical and research data sources, opening up new avenues of research, particularly in the fields of Alzheimer’s disease and obesity.
GAP was initiated by the Global CEO Initiative (CEOi) on Alzheimer’s Disease and the New York Academy of Sciences. GAP’s objectives are to establish a global standing, trial-ready platform, to more rapidly test the effectiveness of drugs through an adaptive proof of concept trial mechanism. This platform will enable the delivery of efficient and effective proof of concept and confirmatory trials and ultimately the more rapid delivery of effective therapies to patients or those at risk.

“The European Union has a long tradition of fostering research collaboration,” said Jean Georges from Alzheimer Europe, a partner in all three projects. “The creation of the IMI Alzheimer’s Disease Research Platform is another great example of European research projects working together to improve our understanding of dementia and to give hope to the 8.4 million Europeans affected by dementia of a cure of the condition in the future. Alzheimer Europe is delighted to support all three projects by representing the views of people with dementia and their carers in the research consortia and by making the research results available to the wider general public.”

Irene Norstedt, IMI Acting Executive Director commented: “Alzheimer’s disease is a global challenge that requires a global solution, and it is in this spirit that the IMI Alzheimer’s Disease Research Platform is reaching out to other initiatives on Alzheimer’s disease around the world. Everyone working on Alzheimer’s disease needs to pull together if we want to deliver results that will help us to end the suffering caused by this terrible disease.”
### The EPAD partners

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<th>Country</th>
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<tr>
<td>Belgium</td>
<td>Amgen NV, Janssen Pharmaceutica NV, UCB Biopharma SPRL</td>
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<td>Denmark</td>
<td>H. Lundbeck A/S</td>
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<tr>
<td>France</td>
<td>Centre Hospitalier Universitaire de Toulouse, Hôpital de la Salpêtrière, Institut National de la Santé et de la Recherche Médicale, Sanofi-Aventis Recherche &amp; Développement</td>
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<tr>
<td>Germany</td>
<td>Boehringer Ingelheim International GmbH, Fraunhofer-Gesellschaft zur Förderung der angewandten Forschung e.V.</td>
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<td>Luxembourg</td>
<td>Alzheimer Europe</td>
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<td>Netherlands</td>
<td>Erasmus Universitair Medisch Centrum Rotterdam, Stichting Katholieke Universiteit (RUMC) Stichting VU-VUmc</td>
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<tr>
<td>Spain</td>
<td>Aracron Biotech S.L, BarcelonaBeta Brain research centre, Synapse Research Management Partners S.L</td>
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<td>Sweden</td>
<td>Karolinska Institutet</td>
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<td>Berry Consultants LLP, Cardiff University, Ely Lilly and Company Ltd, IXICO Technologies Ltd., Medical Research Council, Pfizer Limited, Quintiles Ltd., Takeda Development Centre Europe Ltd, The Chancellor, Masters and Scholars of the University of Cambridge, University of Edinburgh, University of Leicester, The Chancellor, Masters and Scholars of the University of Oxford</td>
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<td>United States</td>
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The research leading to these results has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007-2013) and EFPIA companies’ in kind contribution.
EIP AHA holds a European Summit on Innovation for Active and Healthy Ageing

The summit held on 9-10 March 2015 was organised in the frame of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA). Dianne Gove, Alzheimer Europe’s Director for Projects, reports that the summit successfully brought together stakeholders with a common goal and vision of active and healthy ageing.

Technology: the entry card to today’s society

Günter Oettinger, European Commissioner for Digital Technology, opened the conference and provided an overview of ageing in Europe. He pointed out that Europe is the continent with the oldest population in the world and that everything must be done to ensure that people are able to live healthy, long and active lives. He drew attention to the need to modernise the healthcare system, ensure that older people remain in employment and continue to pay pension contributions but at the same time that a younger workforce is brought in.

Mr Oettinger described today’s world as a digital society in which older people who cannot or do not want to use technology create a barrier, as technology is the entry card to today’s society. He stated the need to ensure a dialogue with older people and to produce smart devices, hardware, software and IT services, all of which represent a chance for economic growth and employment.

Sustainable healthcare for an ageing population

Martin Seychell (DG Sanco, European Commission) suggested that economic sustainability is not the end aim: this should be the provision of quality services and quality treatment. In his opinion, healthcare is not geared towards the needs of a multi-morbid, frail and older population; innovative practices are needed along with a shift from care to prevention. He criticised the current “hospital-centric” system which leads to people receiving care and treatment when their condition is already fairly advanced. He also explained that the EIP AHA has identified thousands of good practices and agreed on a scaling-up process which will be implemented in the next 12 months.

Finally, Mr Seychell noted that technology is the driver of increasing costs in healthcare and that innovation, by definition, is destructive as it challenges the system, demanding more than just a bit of tweaking here and there. Other speakers throughout the day came back to this issue, suggesting that it is important to encourage some degree of calculated risk taking: as it is often safer to do nothing, there must be a system of penalties for not implementing change as well as rewards for doing so.

Improving government efficiency

Mr Rafael Bengoa (Deusto Business School, Spain) highlighted the need for a stronger skill set to manage the paradigm shift that is needed. He felt that governments are not being sufficiently ambitious, that their responses must be related to the speed of change and that they are not pulling enough policy levers. He also questioned whether Europe had the necessary leadership to achieve its goals in healthcare provision for the ageing population. Mr Bengoa suggested that a key problem was the emphasis on cost containment: this may be to some extent necessary, but must be accompanied by an aggressive transformational agenda.

According to Jeroen Tas (Global CEO, Philips Informatics) people should not be paying for procedures but for outcomes. Lambert van Nistelrooij, MEP (Netherlands) suggested the need to think about investment policies and to give guarantees so that smaller companies can take on greater risk.
Impact of the growing silver economy

Throughout the summit, themes which frequently occurred included the need for stakeholder involvement, to think in terms of prevention rather than cure and a community-based rather than hospital-centric approach to the healthcare of older people. The “silver economy” was frequently cited as a considerable opportunity for growth but the possible need to avoid segregating older people as a potential source of economic growth was also raised.

Sarah Rochira (Older People’s Commissioner for Wales, UK) described the Welsh approach to healthcare for older people: a strong focus on human rights, frailty and decline (but not as an inevitable part of ageing) and integrated health and social care. She also emphasised the need to consider social fairness, equity and future sustainability.

Helen Campbell (Vice President of Age Platform Europe) drew attention to the heterogeneity of the 50-100 age group and the need to consider older people as living within a particular community. This highlights the importance of recognising the needs of older people as a group, many of whom may have or at some point develop dementia, but also of respecting individuality, relationships and autonomy.

“People should not be paying for procedures but for outcomes.”

What is the EIP AHA?

The partnership, a European Commission initiative, gathers stakeholders from the public and private sectors that work on shared interests, activities and projects to find innovative solutions that meet the needs of the ageing population.

The overarching target of the EIP AHA is to increase by two the average number of healthy life years in the EU by 2020. The main goal is to obtain commitment and investment from stakeholders – public and private, EU, national and local – who have jointly agreed on the following action areas:

- prevention, screening and early diagnosis
- care and cure
- active ageing and independent living

http://ec.europa.eu/active-healthy-ageing @EIP_AHA
Policy Watch

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Alzheimer Europe speaks with Vytenis Andriukaitis, European Commissioner for Health & Food Safety

Vytenis Andriukaitis, a qualified surgeon and former Minister for Health of Lithuania, took over his current post in November 2014. In this article, he discusses the Commission’s ongoing programmes on Alzheimer’s disease and other forms of dementia.

Commissioner, last October the European Commission presented a report on the implementation of its 2009 Communication on a European initiative on Alzheimer’s disease. In your opinion, what were the key achievements of this initiative?

The Commission’s Communication on Alzheimer’s disease and other dementias focused on key issues such as the early diagnosis of dementia, care, epidemiological knowledge and research and respecting the rights of people with dementia. Its key achievement, in my opinion, is bringing about cooperation at local, national and European level on Alzheimer’s disease and other dementias and contributing to global initiatives. Establishing such cooperation provides a solid foundation for continued progress in this area.

The initiative led to several valuable activities, including the ALCOVE (Alzheimer Cooperative Valuation in Europe) Joint Action, which ran from 2011 to 2013. Through its work, ALCOVE has promoted the exchange of information on dementia to preserve the health, quality of life, autonomy, and dignity of people living with dementia and their caregivers in EU countries. One of the key outputs of ALCOVE was a Toolkit for the timely diagnosis of dementia, which has been rolled out in the 19 EU countries involved in the Joint Action, and beyond. The initiative has also led to considerable research investments. For example, EUR 555 million has been provided under the 7th Research Framework Programme for research into dementia and neurodegenerative diseases and for the development of eHealth applications. This research funding was also used to launch a Joint Programming Initiative for Neurodegenerative Diseases (JPND), which provides a common research strategy and alignment of national programmes. Dementia has also been identified as a priority in the Commission’s research funding mechanism, Horizon 2020, which runs from 2014 to 2020. Finally, through its Innovative Medicines Initiative (IMI), the EU has joined forces with Europe’s pharmaceutical industry to bring new medicines and treatments to patients faster, including for Alzheimer’s disease and other dementias.

How will the European Commission continue to address dementia as a European public health priority? Would you support the development of a European Dementia Strategy as called for in the Glasgow Declaration adopted by Alzheimer Europe and its member organisations in October 2014?

According to the 2012 Ageing Report¹ between 2010 and 2060 the population in the EU aged over 65 will increase by 71.8% and the population aged over 80 by 157.4%. It is clear that diseases associ-

ated with ageing such as dementia, will continue to increase, and will continue to be a political priority at EU-level. Dementia is just one of the major chronic diseases which are set to increase linked to demographic developments. This is why we are working towards a framework for action to support Member States in reducing the burden of chronic diseases. In this context, Alzheimer’s disease and other dementias will be a priority area in the Commission’s approach.

The Commission has launched various actions to build on achievements since 2009. As a first step, a second Joint Action (JA) on Dementia, which is currently under preparation will focus on developing and putting in place intervention models for diagnosis, post diagnostic support and coordination, as well as quality of residential care and dementia-friendly communities.

The Commission-led European Innovation Partnership on Active and Healthy Ageing seeks to bring innovative solutions to the challenges of an ever increasing elderly population. Can you tell us how this initiative can address the particular concerns of people with dementia and their carers?

The European Innovation Partnership on Active and Healthy Ageing, launched in 2011, aims to help increase healthy life by two years by 2020. The Partnership brings together researchers, health authorities, health professionals, businesses, regulators and patient organisations to examine new ways of addressing the challenge of an ageing population and bring innovations to our healthcare systems. Six areas of action are covered by the Partnership, relating to various aspects of ageing. Two of these are pertinent to people living with Alzheimer’s disease and other dementias.

The first such strand deals with prevention of frailty and cognitive decline. The partners involved address this area from three different angles: the social perspective, the research perspective and the clinical perspective. Frailty and cognitive decline share risk factors, such as chronic diseases and inflammation, and both can lead to or be caused by social isolation. Understanding how and why frailty is linked to cognitive impairment has implications for the management of patients with dementia. The collaborative approach of the Partnership in this area is expected to lead to more evidence-based interventions aimed at people living with dementia and those at risk of developing dementia.

The second relevant strand is on age friendly environments. Here, the partners have explored effective and sustainable ways of creating supporting environments for people living with dementia, in communities, healthcare settings and homes. The aim is to improve the quality of life of dementia sufferers and help them remain independent for longer.

Innovative programmes are already being rolled out in both of these areas, and the Commission and the Partnership have also developed a strategy to scale-up successful practices. Through the wide deployment of innovative practices aimed at people living with dementia, we expect to bring about significant improvements to their quality of life.

At a global level, the G7 countries showed leadership on dementia by developing a Global Action Against Dementia and setting up the World Dementia Council. In March 2015, the World Health Organisation followed these developments by organising a first ministerial conference on dementia. How is the European Commission engaging and collaborating with these international activities?

Dementia is not just a challenge in Europe, or an issue for developed countries. It is truly a global problem. The Commission is very supportive of the case for global action against dementia, and endorses the World Health Organisation’s call for action. I completely agree that no single country, sector or organisation can tackle this challenge alone. I therefore support the Global Action Against Dementia, under the leadership of the World Health Organisation. The European Commission is actively involved in the process and is exploring concrete ways to contribute to and support this action.

Funding for the WHO through our Health Programme, our upcoming Joint Action on dementia, and the previously mentioned Joint Programming Initiative for Neurodegenerative Diseases and Innovative Medicines Initiative are concrete examples of EU collaboration.

I am very pleased that dementia will be a priority for the upcoming Luxembourg and Dutch EU Presidencies of the Council and look forward to working with them to advance work on dementia in the months to come.

VYTENIS ANDRIUKAITIS
Ireland launched its National Dementia strategy in December 2014. In this article, Minister Lynch outlines the main points of the programme to implement the 14 Priority Actions set out in the strategy.

Why does Ireland need a Dementia Strategy?

It is estimated that there are approximately 50,000 people with dementia in Ireland today. These numbers are expected to increase to more than 140,000 by 2041. As a result, the Government committed to developing “a national Alzheimer’s and other dementias strategy to 1) increase awareness, 2) ensure early diagnosis and intervention and 3) develop enhanced community based services.”

In early 2013 the then Minister for Health established a Working Group to assist in the Strategy’s development. The Group was representative of a broad range of stakeholders including clinicians, service providers and service users. “Creating Excellence in Dementia Care: A Research Review for Ireland’s National Dementia Strategy” (Cahill et al. 2012), was also used to underpin the development of the strategy. The Strategy was prepared having regard to the Working Group’s input but takes into account practical implementation issues in the light of current resource constraints. The Irish National Dementia Strategy was launched in December 2014 and implementation commenced immediately.

How is the Strategy being funded?

Initially, implementation of the Strategy was to focus on Priority Actions that could be progressed within existing resource envelopes including by redirecting or refocussing existing resources. However, the Department of Health and the HSE (Health Service Executive) have agreed a joint initiative with the Atlantic Philanthropies to implement significant elements of the Strategy. This National Dementia Strategy Implementation Programme will represent a combined investment of EUR 27.5m, with Atlantic Philanthropies contributing EUR 12m, and the HSE contributing EUR 15.5m.

How will this National Dementia Strategy Implementation Programme work?

Over the period 2014-2017 the Implementation Programme will promote a greater focus on timely diagnosis of dementia and on the value of early intervention, along with the long-term objective of making people in Ireland generally more aware and understanding of the needs of people with dementia, and of the contribution that those with dementia continue to make to our society. In addition, intensive home supports tailored specifically to meet the needs of people with dementia will be available under the programme.

Key elements of the initiative include:

1. the rollout of a programme of Intensive Home Supports and Homecare Packages for people with dementia;
2. the provision of additional dementia-specific resources for GPs, who are the critical and initial point of contact with the health system for those with dementia;
3. the creation of local dementia care pathways will also be considered as part of this element of the programme;
4. the provision of education and training for GP’s and Primary Care team members;
5. measures to raise public awareness, address stigma and promote the inclusion and involvement in society of those with dementia. This will be achieved through a media campaign and increasing targeted print and online resources for people with dementia. An attitude survey will also be carried out to measure...
the impact of this initiative.
6. The establishment of a dedicated office within the HSE to coordinate the implementation of the strategy;
7. A strong evaluation element will also form part of the overall strategy implementation to measure its effectiveness.

A Monitoring Group, chaired by the Department of Health, has been established to assist with and advise on implementation of the Strategy as a whole, including the National Dementia Strategy Implementation Programme.

From your perspective, which of the defined objectives have priority? What is the biggest challenge?

There are 14 Priority Actions set out in the Strategy and I would attach equal importance to each of them. The priority actions are considered to be key to implementation of the Strategy and originally to be capable of implementation within existing resources or by reconfiguring these resources. However, of the 14 priority actions, those addressed specifically in the National Dementia Strategy Implementation Programme are those which are being progressed fastest as they have specific resources attached to them. Furthermore, “Additional Actions” are identified which are no less important but will need additional resources in due course and securing a budget for their implementation would be seen as a challenge.

What was the involvement of The Alzheimer Society of Ireland (ASI) in developing the strategy?
How do you see the future role of the ASI?

The ASI made a submission to the Department of Health in 2012 in relation to the Strategy and in 2013 joined the Department of Health’s Working Group to oversee its development alongside other key stakeholders. To ensure the voice of people with dementia and carers were included in the process, the ASI assisted the Working Group by hosting two roundtable discussions between the Working Group and people with dementia and carers. The Department of Health and the HSE have a positive working relationship with the ASI and we can see this continuing into the future.

Is there a need for closer collaboration on dementia on a European or global level?

Of course, the more effectively we can collaborate and coordinate our efforts, the better are our chances of making progress against this challenge. As Margaret Chan, Director-General of the World Health Organization said at the WHO Ministerial Conference on Global Action Against Dementia in Geneva in March, the cost of dementia can bankrupt health systems, even in the richest countries. The Conference aimed to highlight the importance of coordinating the international effort on prevention, care and cure of dementia and to provide a mechanism through which countries and other partner organisations can engage in the work to tackle dementia on an on-going basis.

A Call for Action was adopted by participating countries and a Global Dementia Framework, to which Ireland has inputted significantly, has been developed. By collating information about dementia-related activities, this “live” document will be extremely useful in allowing countries and organisations to promote their work to a global audience and in identifying other organisations, nations and regions they might be able to collaborate with.

“The more effectively we can collaborate and coordinate our efforts, the better are our chances of making progress against this challenge.”

KATHLEEN LYNCH
Involvement of people with dementia and carers in the National Dementia Strategy

As part of its submission to the National Dementia Strategy entitled “Reclaiming dementia; transforming the lives of people with dementia”, the ASI undertook an in-depth consultation with internal stakeholders including people with dementia and their carers to ensure the submission accurately represented their needs. This 40+ page report outlined seven key priorities areas where opportunities existed to intervene to transform peoples’ lives.

The ASI campaigned for many years for the publication of a national dementia strategy and this work did not stop once the Government outlined its commitment to develop a strategy in 2011. The intervening years were spent campaigning hard for its publication. This included calls in submissions to government, making it a focus of our European election campaign, holding relevant events and importantly lobbying public representatives.

Following the call for public consultation in 2012, the Government convened an expert working group to develop the strategy. This group included clinicians and other healthcare professionals, researchers, and representatives from the Department of Health and the HSE. The ASI was represented by CEOs Maurice O’Connell and Gerry Martin.

To further ensure people with dementia were involved in the development of the Strategy, the ASI facilitated a number of workshops between people with dementia, carers and former carers and members of the expert working group.

During the 2016 General Election campaign, the ASI will ask all parties and representatives in Ireland to commit to the implementation of the National Dementia Strategy and the development of a follow-up strategy for dementia based on a review of the current strategy.

A short guide to the National Dementia Strategy produced by ASI is available at www.alzheimer.ie

An expert group of people with dementia

Since the strategy was published in December 2014 the Department of Health has convened a national dementia strategy monitoring group. Following pressure by the ASI to ensure the appropriate representation of people with dementia and family carers in this group, Helen Rochford Brennan (Chair of the Irish Dementia Working Group) and Sean Donal O’Shea (Dementia Carers Campaign Network) are now also on this expert group, alongside ASI CEO Gerry Martin. The ASI will support their engagement on the working group and will play its own role in monitoring how the strategy is implemented.

#forgetthestigma campaign

In May, the ASI launched a nationwide public awareness campaign entitled “#forgetthestigma” aimed at challenging stigma and encouraging the public to talk about the condition. Running in the month of June, the ASI hopes to dispel myths and stigma surrounding dementia by presenting facts about the condition and asking people to pledge their support to three simple tasks: know the facts, empathise and maintain relationships with those diagnosed with the condition.

The ASI hopes this campaign will help the public to understand that it is time to stop avoiding this condition and rethink how we interact with people with dementia. Only by understanding dementia and talking more openly about it, can we face our own fears and support individuals and families living with dementia.

Alzheimer Europe wishes to thank Tina Leonard (Head of Advocacy & Public Affairs) and Edel O’Connell (Communications Manager) from The Alzheimer Society of Ireland for their collaboration to produce this article.
Malta launches the world’s first dementia-friendly national strategy

Charles Scerri, PhD, is Malta’s National Focal Point on Dementia and a Senior Resident Academic in the Department of Pathology, University of Malta. He is also the Honorary Secretary of Alzheimer Europe. We asked him to summarise the main elements of the new strategy.

**Empowering change - a dementia roadmap for Malta**

Malta is one of the fastest ageing countries in the European Union with a population aged 65-plus set to increase by 16.1% between 2010 and 2060, to reach 31.2%. Currently there are over 6,000 individuals with dementia in the Maltese islands. This figure will reach 13,000 by 2050, equivalent to 3.3% of the population. This will invariably put greater demands on the national health care services resulting in considerable socioeconomic consequences.

On 2 April 2015, Malta officially launched its dementia strategy entitled “Empowering change: A national strategy for dementia in the Maltese islands (2015-2023)”. Malta was the first country to publish a dementia-friendly version of the national dementia strategy, in order to encourage people with dementia to participate more fully in decisions that affect their lives.

The overarching aim of the National Strategy for Dementia in the Maltese islands is to enhance the quality of life of individuals with dementia, their caregivers and family members through a number of intervention streams.

**Increasing awareness and understanding of dementia**

Increasing awareness would not only decrease stigma but should reduce the widespread misconception that the symptoms of dementia are a direct consequence of old age – leading to unwillingness to seek professional assistance. Enhancing dementia knowledge is also crucial in developing dementia-friendly communities. The strategy emphasises the need to develop continuing information campaigns targeting different sectors of the population, develop an online guide for caregivers and strengthen the Dementia Helpline which often acts as the first point of contact.

**Dementia diagnosis and intervention**

The majority of individuals with dementia are not diagnosed early in the disease process. Early diagnosis enhances the quality of life, limits institutionalisation and allows individuals to plan ahead and make personal choices for the future. The strategy emphasises the need to promote the value of early diagnosis by developing and distributing information on the various aspects of dementia at the point of diagnosis and throughout the disease process, setting up of the Dementia Intervention Team to support individuals with dementia in the community and provide opportunities for training in primary care.

**Workforce development**

Training of healthcare professionals is limited and not meeting current needs. Having a trained workforce is instrumental in delivering high quality dementia care. The strategy emphasises the need to ensure that staff working with individuals with dementia have the necessary training. The main recommendations in this area include the provision of patient-centred care training to health professionals caring for individuals with dementia, continuous professional development programmes for skills updating, training programmes for caregivers and supporting information technology platforms that facilitate online dementia training.
Improving dementia management and care

Poor and uncoordinated care contributes to increased rates of nursing home admissions. Furthermore, community services that are reliable, flexible and have a holistic approach enable individuals with dementia to remain active and independent for longer. The strategy emphasises on improving the delivery of dementia care through the provision of the necessary community support, ensure that individuals with dementia have access to medication and are reviewed regularly, have a care plan that addresses activities of daily living, promotes independent living and engagement in meaningful activities, ensure that caregivers and family members of individuals with dementia are involved in the decision-taking process, increase in the availability of respite facilities for individuals with dementia, facilitate access to assistive technology, provide the necessary support to caregivers to continue working whilst caring and ensure that residential and nursing homes accommodating individuals with dementia have the necessary quality standards.

Ethical approach to care

Individuals with dementia and their caregivers face difficult decisions in all stages of the disease process. Thus the strategy aims to provide access to training in ethical aspects of dementia care, respect for personhood and wellbeing whilst ensuring that individuals with dementia, their caregivers and family members have access to psychological support.

Research

Research on dementia currently receives minimal funding and there is limited data on how dementia is affecting the Maltese society. Research is essential for the planning, managing and distribution of health and social care resources. The strategy thus promotes research initiatives in the field of dementia management and care as well as highlighting the need to make dementia a national research priority.

The National Strategy for Dementia will span a period of nine years (2015-2023). Due to the challenging nature of dementia, it is envisaged that subsequent implementation of this plan will entail substantial investment in human, financial, technical and infrastructural resources. However, the delivery of the objectives laid out is projected to have a considerable positive impact on the quality of life of individuals with dementia, their family members and caregivers. The latter are carrying an enormous burden and thus require more solidarity from the government and society in general. Implementation of the measures set out in this strategy aims to create a system whereby all individuals with dementia have access to the care and support they require.

Malta was the first country to publish a dementia-friendly version of the national dementia strategy, in order to encourage people with dementia to participate more fully in decisions that affect their lives.
Dementia will be a priority during Luxembourg’s EU Presidency

Luxembourg will hold the EU Council Presidency for the latter half of 2015. We invited Minister of Health Lydia Mutsch to discuss the health priorities – including those for dementia – that will prevail during this term.

Alzheimer Europe (AE): What are the health priorities of Luxembourg’s Presidency of the EU Council? How will these priorities support people with dementia and their carers?

LM: The health priorities of the incoming Luxembourg EU Council Presidency will evolve around the objective to enhance the health of patients and the sustainability of health systems in line with the Europe 2020 Strategy. The patient will be put in the centre of the reflections on all the subjects that will be on the Presidency’s agenda, namely access to personalised medicine, implementation of the cross border healthcare directive and support to those living with dementia. Another priority will be to drive forward the negotiations on the revision of the medical device legislation with the core aim to strengthen the safety of patients when setting up a new framework for high quality, secure and innovative medical devices. Now, more specifically with regard to dementia: First of all, we know that the prevalence of dementia will rise. But it is not only a medical or social care issue. Dementia concerns partners, relatives, and friends. It is a common challenge for our communities. This cross-sectorial and comprehensive view on the multifaceted challenges of dementia should guide our further actions at national and at European level.

Contributing to healthy ageing in general should be a key policy goal. Besides the necessity to establish quality care for all people depending on care and especially dementia patients with their special needs, it is important to intervene at the earliest possible stage. This is the reason why I would like to emphasise as priorities in the field of dementia during the Luxembourg Presidency, prevention – especially at primary and secondary level – as well as early diagnosis and post-diagnostic support.

For most persons with prodromal dementia, diagnosis is not feasible without a parallel offer of preventive therapy and support. I firmly believe that we have to put into place a comprehensive approach allowing not only adequate standards on timely diagnosis, but also for multi-dimensional secondary dementia prevention programmes (post-diagnostic support) with advice on health related issues and additional counselling on social issues, general disease information, life-style related issues, family and financial matters, legal aspects and other related issues. Evaluation of these programmes will help us to enhance also primary prevention measures and can serve as best practice examples for other EU Member States.

So hopefully by setting up mechanisms for continuous support right from the first moment when patients find themselves confronted with early symptoms of dementia, we will address the overall challenge and coordinate all relevant actions and activities towards the best support for affected patients and their relatives. 

LYDIA MUTSCH

AE: Many EU countries are dealing with an ageing population, the increase of age-related diseases like dementia and the vulnerability of healthcare...
“Luxembourg welcomes the Global Dementia Framework elaborated by the United Kingdom and approved by the WHO Conference “Global Action Against Dementia” in March 2015. The idea to promote risk reduction and to foster dementia-related activities going on in various countries goes hand in hand with the priorities of the Luxembourgish Presidency.”

LYDIA MUTSCH

services. Will they be assured that dementia is treated continuously by EU Council Presidencies?

LM: In order to achieve progress and make innovations possible and sustainable, it is necessary to collaborate in an international framework. I would therefore like to stress that dementia is not only a priority of the Luxembourgish Presidency but it has been also addressed recently under the Italian presidency and will be followed on after Luxembourg by the Presidency of the Netherlands, starting 1st January 2016 and will hopefully be continued thereafter.

In the conclusions of the Rome conference “Dementia in Europe: a challenge for our common future” on the 14th November 2014 it was stated that: “Member States are invited to continue addressing dementia as a core issue in their policies, to share information about their activities and to identify priorities for further dementia initiatives at EU-level.”

At the same time, the European Commission is invited to consider changing the status of the Group of Governmental Experts on Dementia into a formal EU-Expert Group, which could serve as the first forum for exchange, cooperation and coordination among Member States. The Group’s activities could comprise the development of a common approach on dementia and dementia strategies and to adopt a joint statement on dementia and on key elements of dementia strategies by Member States and the European Commission.

Both the European Commission and Member States are invited to bring forward the second Joint Action on Dementia, which is to be launched in 2015. This Joint Action should promote the exchange of good practices, develop recommendations for common action and encourage their implementation. It should be built on agreed good practice criteria and relevant indicators.

So Luxembourg will support during its Presidency the following objectives:

• to turn the Group of Governmental Experts on Dementia into a formal EU-Expert Group to strengthen its role,
• to adopt a joint statement of Member States and European Commission and
• to bring forward the second Joint Action on Dementia.

These initiatives are important tools and platforms to trigger public awareness and to discuss, to bring forward and to implement innovations in the field of dementia at a multicultural European level.

AE: Will Luxembourg be involved in the new European Joint Action on Dementia?

LM: Yes, Luxembourg has participated as a partner in the EU-funded ALCOVE joint action and will
participate in the new European Joint Action on Dementia. This new Joint Action offers in my view very interesting possibilities to promote a shared European vision to better understand dementia conditions and to exchange best practices for care of people with dementia. Beside this Luxembourg also supports the work ongoing under the European Pact for mental health and well-being, the mental health joint action, as well as the European Partnership for Active and Healthy Ageing. We need to develop better knowledge on how to integrate older people best and how to help them find their place in our societies, corresponding to their expectations and needs. Promoting well-being of older people is essential when aiming at strengthening and mobilising their mental capital which is the prerequisite for a successful future.

**AE: How will the Luxembourg Presidency engage with global initiatives on dementia, such as the World Dementia Council or the recent OECD/WHO activities?**

**LM:** As a health minister, I believe that a standalone national approach is not sufficient, even though it may be cross-sectorial and collaborative. It must be put high on the political agenda, beyond national borders, not only at European level but worldwide. The wide ranging commitment and engagement of the United Kingdom and the G8 initiative created a major political momentum and contributed to an unprecedented public awareness rising of dementia at global level.

Luxembourg welcomes the Global Dementia Framework elaborated by the United Kingdom and approved by the WHO Conference “Global Action Against Dementia” in March 2015. The idea to promote risk reduction and to foster dementia-related activities going on in various countries goes hand in hand with the priorities of the Luxembourgish Presidency. For the same reasons, I have expressed Luxembourg’s support and acceptance for the overarching principles and actions set out in the “Call for Action” which was also adopted during the above mentioned conference. I hope – and believe – that this document will become a future milestone for action at global level to enhance the chances for a better quality of life of people living with dementia and for their surroundings.

I want to conclude by expressing my deep wish that discussions during the Luxembourg Presidency will encourage national, European and global actors to successfully address the multi-faceted challenges of dementia and thus alleviate the burden on individuals and their families, friends and partners.
WHO dementia conference sparks a global Call for Action

On 16-17 March 2015, Switzerland hosted the World Health Organisation’s first Ministerial Conference on Global Action Against Dementia. Jean Georges, Executive Director of Alzheimer Europe, reported a clear consensus among delegates on the need for globally coordinated efforts to track the evolution of dementia, to create policies that address the impact of the condition and to conduct research for treatment and improved care.

The conference was attended by delegates from 80 countries – including ministers and experts from the research, clinical and NGO communities – who discussed global issues surrounding dementia. The participants agreed on a call to action on making dementia a global health priority and channelling the momentum on specific actions. In addition, a group of international NGOs issued a statement of support for the activities of Global Action Against Dementia (GAAD). This event was supported by the UK Department of Health and the Organisation for Economic Cooperation and Development (OECD).

A global call for action

As the conference drew to a close, participants adopted a call for action aiming to strengthen global efforts. The “Call for Action of the first WHO Ministerial Conference on Global Action Against Dementia” highlights the importance of the following principles:

• Empower and engage the full and active participation of people living with dementia, their caregivers and families, as well as overcoming stigma and discrimination.
• Foster collaboration between all stakeholders to improve prevention and care and to stimulate research.
• Balance prevention, risk reduction, care and cure so that whilst efforts are directed towards finding effective treatments and practices and risk reduction interventions, continuous improvements are made on care for people living with dementia and support for their caregivers.
• Emphasise that policies, plans, programmes, interventions and actions are sensitive to the needs, expectations and human rights of people living with dementia and their caregivers.

The delegates called for the following actions to be taken by governments worldwide:

• Raise the priority accorded to global efforts for dementia on the agendas of relevant high-level forums and meetings of national and international leaders.
• Promote a better understanding of dementia, raise public awareness and engagement, including the respect for human rights, reduce stigma and discrimination, and foster greater participation, social inclusion and integration of people living with dementia.
• Advance prevention, risk reduction, diagnosis and treatment of dementia, consistent with current and emerging evidence.
• Facilitate technological and social innovations to meet the needs of people living with dementia and their caregivers.
• Support a gender-sensitive approach in the elaboration of plans, policies and interventions aimed at improving the lives of people living with dementia.
• Support the efforts of the World Health Organisation to fulfil its leadership role to promote and monitor global efforts on dementia, in full collaboration with national and international partners.
International NGOs express their support

At the end of the conference, a group of international organisations issued their own call of support. This group effort was coordinated by Alzheimer's Disease International (ADI) and included 18 signatories, including Alzheimer Europe and ten of its member organisations. The full text is shown below.

We, the organisations below, welcome the significant impact of the G8 Summit on Dementia in December 2013 in London and the G7 Legacy Events during 2014 and 2015 and acknowledge the leadership of the UK government for making this possible and putting dementia on the global health agenda. Civil society organisations have been the strongest responders to the dementia challenge in the past and they have done that by creating support structures for those living with dementia and their relatives, gathering and providing information about many different aspects of dementia, advocating for improvements in the health and social care system and funding research.

We are delighted that this process is now moving from the G7 countries to a global platform where every country can contribute and are asking our governments meeting in Geneva for the WHO Ministerial Conference on Dementia on 16-17 March 2015 to:

1. Ensure that people with dementia and their families are put at the centre of all policies.
2. Implement and take the necessary steps towards the ambition to identify a cure or a disease-modifying therapy for dementia by 2025 as adopted by the G8 Summit in December 2013, and to increase collectively and significantly the amount of funding for dementia research to reach that goal. We suggest that every country should increase their public research budget to 1% of the amount the country spends on dementia care.
3. Increase efforts in other areas of research, such as research into effective care models; prevalence, incidence and mortality; and prevention and risk reduction to a comparable level, and increase the focus on translating research into practice.
4. Recognise the value of civil society organisations including Alzheimer associations and Alzheimer research foundations as key advocates for improvements in dementia care and policies and support these organisations. This should include a role for people who are living with dementia.
5. Create and fund a dementia work stream for lower and middle-income countries and develop programmes to raise awareness and improve health system response with the inclusion of partners from those countries.
6. Facilitate further collaboration on the exchange of best practices in dementia care and creating dementia friendly communities.
7. Make risk reduction for dementia a priority and link actions, including setting of some targets and indicators, to the general work stream on non-communicable diseases that is led by the World Health Organization.

In closing, Dr Margaret Chan (WHO Director General, pictured) applauded the participants for adopting the Call for Action, which she called “a very strong showing of solidarity”. Dr Chan shared her hope that this Call could channel the momentum started by the G8 Legacy event in December 2013. “WHO is here to support this effort,” she pledged.

Dr Chan also paid special thanks to Health Minister Lydia Mutsch from Luxembourg. Ms Mutsch announced during the conference that her country would prioritise dementia under its EU Presidency during July-December 2015.
Final G7 Dementia Legacy event held in US

The fourth and final G7 Legacy event took place on 11 February, following a two-day conference on the state of the science at the National Institutes of Health in Bethesda, Maryland.

The event was a half day meeting that featured updates from the World Health Organization on its research prioritisation project, as well as from the Organisation for Economic Development and Cooperation (OECD) on big data and on dementia research budgets from the G7 countries. The US has the largest budgets, but these are still far behind other major disease areas.

The G7 countries and the European Union gave updates as well. Canada, Japan and the UK are now planning big cohort studies looking at multiple chronic diseases – including dementia – and their risk factors.

The Canadian government reported the launch of a Dementia Friends programme with the Alzheimer Society of Canada, based on the experiences of Japan and the UK. France announced the launch of a new plan for neurodegenerative diseases, including Alzheimer’s disease and other dementias, Parkinson’s disease, Multiple sclerosis, Amyotrophic lateral sclerosis and Huntington’s disease.

Germany started local dementia alliances in September 2014 and more than 1,000 local info sites are now enrolled. They are also implementing Dementia Care Managers who serve as a link between patients and the health care system. The centre for neurodegenerative diseases (DZNE) has an annual budget of EUR 80 Million and has created partnerships with other European countries, Canada and the US.

The US Alzheimer’s Association released a report on how much money could be saved if dementia onset can be delayed by five years – a massive amount.

Italy launched its national dementia plan in November 2014, despite the challenge with the role of its regions. The plan will focus on prevention, network of services, integrated care, research, ethics, fight against stigma and integrated services.

Japan also launched a new “Orange plan” on 27 January, featuring seven pillars and aiming to enable people with dementia to live with dignity.

The UK is working on a number of initiatives and partnerships. One is “Join Dementia Research”, a database where people can register to take part in research.

The European Union is spending an impressive amount on research through its programmes, namely JPND (Joint Programming on Neurodegenerative Diseases), Horizon 2020, Human Brain Project and IMI. Patient organisations are now involved in policy making.

In the afternoon the World Dementia Council met to talk about the future of the G7 Dementia Legacy initiative. Simultaneously, the Alzheimer’s Association (US) and ADI hosted a meeting with non-profit organisations that fund research in the US and Europe.
Policy roundup

A look at recent policy developments that may impact people with dementia and their carers.

25 May: Norway’s daycare centres will have to provide activities for people with dementia from 2020

The Norwegian Parliament has adopted a law that will make it mandatory to provide activities for people with dementia in daycare centres in all municipalities. The law will be put in place from 2020.

Lisbet Rugtvedt, Secretary General of the Norwegian Health Association reacted to the news, saying “we have been campaigning for this for many years, and are pleased that all political parties now understand the importance of daycare activities”. Ms Rugtvedt continued, however, saying “we see no reason to wait as long us until 2020 for the law to take effect. And we will continue to campaign for the law to be as good as possible for people with dementia, and also for the law to take effect earlier”.

The Norwegian Health Association will also campaign for increased spending on daycare activities by Norway’s municipalities in the upcoming elections this autumn. “It is important that this area receives attention now, if there is to be services for those who need them in the years to come,” the association stressed.

5 May: Half of all French people living with dementia are undiagnosed, study says

According to a study published on 5 May, half of all people living with dementia in France are currently undiagnosed and therefore denied proper, personalised support. The study report says that while 500,000 people with Alzheimer’s or a related disease are diagnosed and supported, the disease is estimated to affect a total of more than one million people in France.

The report also notes huge disparity between geographic regions: areas such as Bouches-du-Rhône and Paris in the North have the highest rates of diagnosis and over 30% of estimated people with dementia being supported. However, in rural areas such as the Creuse, the Deux-Sèvres or Gers, this proportion is only 15%.

The study estimates that if all the people believed to be living with dementia were diagnosed, this would increase the current number of home help places 20 fold and would increase the number of day care spaces 10 fold.

Finally, the study revealed that although exercises (e.g. relaxation, music therapy) to slow the progression of the disease in people with moderate or severe dementia residing in nursing homes are considered “essential”, they are only offered in one in six facilities.

14 April: WHO publishes statement on public disclosure of clinical trial results

On 14 April the World Health Organisation (WHO) published a new statement on the public disclosure of clinical trial results.

The statement reaffirms “the ethical imperative of clinical trial results reporting” and also defines reporting timeframes. In addition, it calls for the reporting of older but unpublished trial results and outlines steps to improve linkages between clinical trial registry entries and their published results.
This new statement updates and expands the WHO’s 2005 statement that “the registration of all interventional trials is a scientific, ethical, and moral responsibility.”

26 March: Gibraltar pushes ahead with dementia strategy

On 26 March, Gibraltar’s Health Minister Dr John Cortes confirmed that the drafting of a Dementia Strategy is nearing completion and that the new Dementia Residential Home and Day Centre should open its doors in autumn of this year.

Gibraltar Alzheimer’s and Dementia Society (GADS) – which has raised over GBP 100,000 (EUR 136,000) for use in the new premises – had previously voiced concerns about delays over the completion date.

Dr Cortes reported that the delays were the “usual building contractors’ delays, with completion dates being reviewed. We are hoping the building works will be finished in the summer and that they will open in autumn.”

He also said that the Dementia Strategy would soon be under discussion with GADS and confirmed that the introduction of screening for dementia for people over 60 was being considered as part of the strategy.

The announcement came on the same day that the film “Still Alice” made its debut in Gibraltar.

11 February: Austria launches process for developing dementia strategy

On 11 February, the process of developing Austria’s Strategy for dementia was launched by Health Minister Sabine Oberhauser and Minister for Social Affairs Rudolf Hundstorfer during an international conference.

Keynote speakers at the conference included Volker Hirscher (Germany), who gave an overview of different dementia strategies throughout Europe and Verena Hanselmann, who talked about the national dementia strategy in Switzerland. The conference delegates also broke out into six working groups entitled “participation, removal of taboos and health support”, “research and data”, “professional care and support”, “coordination and cooperation”, “informal care and support services for living at home” and “quality and expertise”.

During the development of the strategy, Antonia Croy and Monika Natlacen – both from Alzheimer Austria – will join two working groups that are due to meet during the month of March. Alzheimer Austria is also seeking the active participation of people with dementia from its “Supported Self Help Group” in the process of developing the national dementia strategy.

In January 2015, the Ministries of Health and Social Affairs released the “Austrian Dementia Report 2014”, which will serve as the foundation of the national strategy.

29 January: World Dementia Council issues risk reduction statement

The World Dementia Council (WDC) has issued a statement about dementia risk reduction and has made this one of their five priority areas of work:

“The WDC considers dementia risk reduction to be a critical element of the global dementia agenda. At their third meeting in October 2014, members of the Council concluded that, while further research in this area is still clearly needed, the growing evidence base strongly suggests that cognitive decline at the population level could be affected by behaviour changes that reduce cardiovascular risk factors. The WDC is calling on governments around the world to focus on dementia risk reduction (or risk management) alongside work on finding a cure or disease-modifying therapy and continuing to improve diagnosis, care and quality of life for people with dementia.”
Dementia in the news

36 Young European Leaders hold workshops on dementia

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40 Living with dementia: Hilary Doxford
Young European leaders join global search for dementia cure

A group of young European leaders in various fields of expertise gathered in London on 27 February for a series of workshops on dementia research. The aim of the event was to creatively address the challenge set by the World Dementia Council (WDC), namely “How can we help people with dementia live independently for longer and what do we need to do to find a cure?”

The event was organised by the UK Science and Innovation Network to promote continued engagement with the UK’s G8 Dementia Summit. This was the fourth in a series of workshops for young leaders organised by the Science and Innovation Network to support global efforts to achieve the 2013 G8 Summit Declaration commitments. Previous Young Leaders workshops have taken place in the USA, Canada and Japan with the aim to create a global network of future young leaders which will continue to address the challenges presented by dementia. The workshops had the following objectives:

- Create a sustainable, virtual network of global young leaders in dementia.
- Agree a “Young Leaders Declaration” of innovative ideas to address dementia for the future and to be presented at the WHO conference on 16-17 March 2015.
- Contribute to the ongoing development of the GAAD and the WDC strategies.

Importing new perspectives to tackle dementia

The programme began with talks from Andrew Jackson (Deputy Chief Scientific Adviser of the UK’s Foreign & Commonwealth Office), Philippe Amouyel (Chairperson of the JPND), Jean Georges (Executive Director of Alzheimer Europe) and Hilary Doxford (World Dementia Council member), who is living with early onset Alzheimer’s disease.

Mr Amouyel said: “The scale of the dementia challenge demands a global response, beyond G7 countries. This latest young leader workshop is importing new perspectives and innovative ideas from all over Europe and beyond to tackle the dementia challenge. By harnessing the collective brains of these ambassadors of research we ensure the future of dementia research remains bright, efficient and globalised.”

The young delegates – who specialise in fields such as neurology, psychiatry, cellular biology and sociology – then split into groups that addressed the main challenges in four areas: care, cure, research and raising awareness. Their conclusions (shown below) emphasised the importance of adequate education in schools, early entry into clinical trials and standardisation for data and resource sharing. The delegates strongly supported the harmonisation and centralisation of research, guidelines, regulations and data platforms, as well as the concept of a global project registry.

Person-centred care at home

1. Develop a person-centred care (at home) framework for people with dementia and care-givers, to cover post-diagnostic support until end of life.
2. Priority for care at home, supported by a multi-disciplinary team of professionals.
3. Develop a European/international accreditation system for “dementia-friendly care homes”.
4. Democratic approach to care – develop innovative working practices to better support carers in employment, and reduce gender bias.
Harmonisation of global research activity

1. Harmonisation and centralisation of research by global legislation and preparation of guidelines and regulations, including open access to data, project registry, standardised data platforms and publication of negative results.
2. Generate new experimental models (in vivo on animals, in vitro on cells, and in silico by computational tools) for a better mechanistic understanding of the diseases underlying dementia, and reconsider the basic concepts of the disease to invigorate novel pharmacological treatments.
3. Large multi-factorial trials leading to the design of large unbiased datasets to generate novel and data-driven hypotheses of disease mechanisms.

Common data standards and early entry to trials

1. Generation of standards for data/samples/resource sharing and collection.
2. Early entry into clinical trials being actively offered to patients.
3. Creation of a virtual, interdisciplinary Global Centre of Excellence in Dementia working on the basis of Open Data dedicated to changing the direction of dementia research.

Increased awareness and education

1. Promote dementia to a broad public through positive role models in the media and by using lay language.
2. Address dementia risk factors as part of a healthy ageing campaign.
3. Educate and engage young people through schooling, contact with elderly people and promoting care as an attractive career choice.
4. Increase all healthcare professionals’ knowledge and skills, through specific dementia training and up to date information on treatment and risk factors.
5. Provide researchers with media training to better communicate their findings.

The recommendations of this Young Leaders workshop, along with those from Canada, Japan and the US were drafted into an EU communiqué that was presented at the WHO Ministerial conference in Geneva on 16-17 March 2015. See related article in this issue.
AE member news

Alzheimer Europe highlights some activities of its member associations.

17 March: Alzheimer Nederland and UK Alzheimer’s Society intensify their cooperation

Alzheimer Nederland and the Alzheimer’s Society agreed to intensify their cooperation to stimulate research into dementia. The first concrete product of the collaboration is a fellowship programme that enables scientists to exchange knowledge and expertise. The organisations have each invested EUR 60,000 to support the cooperation for two years.

Dr Doug Brown, Director of Research and Development of Alzheimer’s Society said: “We hope that our cooperation will stimulate other Alzheimer’s organisations to join us, so we can create new opportunities for researchers”. Gea Broekema, Director of Alzheimer Nederland added that “Alzheimer Nederland and the Alzheimer’s Society are two organisations with a long and proud history in funding research. It was a very logical decision to join our efforts.”

2 April: Turkish Alzheimer Association holds 5th national conference

The fifth National Alzheimer Conference of the Turkish Alzheimer Association (TAA) attracted more than 200 participants, including physicians, psychologists, pharmaceutical industry members and representatives from TAA’s 14 regional branches. The first day was devoted to TAA delegates sharing their experiences and activities. Ms Füsun Kocaman, TAA Secretary General, expressed her appreciation for their efforts to raise awareness and create new day care centres.

The scientific programme focused on the diagnosis, pathophysiology and the treatment of AD and other dementias. Keynote speakers included Dr Natalie Ryan (University College London), who presented new findings in AD neuroimaging and Dr David Wilkinson (Southampton University) who summarised current and future concepts in the non-cholinergic treatment of AD. The conference also featured panel discussions on geriatric and psychiatric issues in people living with dementia and a poster exhibition.

25 March – 4 April: Alzheimer’s in Morocco - a new project is initiated by the MAA

The Association Monégasque pour la recherche sur la maladie d’Alzheimer (AMPA) and the Sud Maroc Alzheimer association recently organised a series of events to combat dementia in southern Morocco. These events were all within the framework of the Mediterranean Alzheimer’s Alliance (MAA) and took place during the 25th edition of a desert road race called Rallye Aïcha des Gazelles. A medical caravan offered consultations for people living in the remote regions of southern Morocco and the first Alzheimer’s awareness campaign in the region reached 440 people. Local specialists carried out more than 100 neurology consultations and AMPA carried out a study on the perceptions and
knowledge of Alzheimer’s disease among 210 members of the public. The results of this study – also a first in the area – will be published by the end of 2015. Kate Williams and Laura Bouganne (pictured) participated in the rally, flying the colours of AMPA and the Principality of Monaco. After an eventful and memorable experience, they finished 95th out of 150 teams in the overall ranking.

Following the race, the first Moroccan Alzheimer Pilot Centre was opened in Essaouira in the presence of the Governor of the region and a number of Moroccan authorities. This centre will offer memory consultations and a day care centre for the southern region of Morocco.

21 April: Finnish dementia campaign yields 71 “memory friendly” MPs

The Alzheimer Society of Finland (Muistiliitto) and its 43 local branches managed to reach a third of all parliamentary election candidates with their Muisti15 (“Memory15”) campaign. Of the 761 signatories, 71 “memory friendly” candidates from eight political parties were elected to the 200-strong Finnish parliament for the next four years. The campaign highlighted the importance of building a dementia-friendly Finland and reminded the candidates to listen to the voices of the people with dementia and their families. Muistiliitto was pleased to report that “Memory15” was one of the most successful pledge campaigns in this election.

29 April: Croatian Ministry of Health supports Alzheimer Croatia's proposals

Croatia’s Ministry of Health has lent its support to a series of proposals made by Alzheimer Croatia at a meeting held on 29 April in Zagreb, Croatia. The Ministry adopted several important proposals and agreed on concrete actions aimed at supporting people with dementia and their family caregivers. Among other things, it was concluded that:

- Dementia medications must be on the “free list” (non-payable health insurance list).
- Society must give better general assistance to families living with Alzheimer’s disease and the status of family caregivers must be defined.
- Routine diagnosis of Alzheimer’s disease should include markers which are taken from the cerebrospinal fluid.
- Alzheimer’s disease must be seen as a public health priority and actions for its early detection implemented.
- Accommodation for people with Alzheimer’s disease must be facilitated in retirement homes and other specialised centres.
- Adoption of the National Dementia Strategy must be accelerated.

18 March: Alicja Sadowska, Chair of the Polish Alzheimer’s Association

We were deeply saddened to hear that Alicja Sadowska, Chairperson of the Polish Alzheimer’s Association, passed away on 18 March after struggling with a painful disease for three months.

Ms Sadowska had been a part of the Alzheimer movement since 1993 and was elected as Chair of the Polish Alzheimer’s Association in 2005 – a position she retained until her death. She was a member of the Board of Alzheimer Europe from 2006 to 2014 and was on the organising committee of AE’s successful 2011 conference in Warsaw, under the banner of “European solidarity without borders”.

Her colleague and friend, Mirka Wojciechowska, wrote:

“Her unexpected death is such a terrible loss not only to her loved ones, her husband Maciej and two sons, but also to the cause we have been fighting for in Poland, Europe and the world. She believed that by working together we could change the world and help people with dementia have better opportunities to live, their problems understood and their needs met. She inspired and helped many people in Poland. I cannot believe she is no longer with us.”
Hilary Doxford, Vice Chairperson of the European Working Group of People with Dementia (EWGPWD), was nominated to the Board of the World Dementia Council in January 2015. In this article, she speaks about her experiences of working to help people with dementia on a global level.

Since I was diagnosed with early onset Alzheimer’s disease I have met many inspirational people and experienced some incredible times. This includes being appointed to the World Dementia Council (WDC) in January this year. I was privileged to be offered a place on the WDC following lobbying by Dementia Alliance International and a presentation I made to the WDC in October 2014 highlighting my key areas of concern, some of which were already on their agenda.

My colleagues on the EWGPWD have been so supportive. I cannot represent the entire dementia community, I can only give a voice as a person with dementia informed by the experiences of others. I am aware that it is difficult for people with dementia to share their thoughts with me and Alzheimer Europe are planning to provide a communication channel to everyone on the EWGPWD so we can hear what is important to you.

My management and research background have helped me enormously, together with the welcome I was given on joining the Council. I am listened to and my comments taken on board. I am not a tokenistic gesture to the dementia community and in fact many members of the Council sadly have personal experience of dementia. More information about the function of the Council and its members can be found at https://worlddementiacouncil.wordpress.com

I have been sceptical of working groups set up by governments. You can accuse me of bias but I have been truly impressed, reassured and comforted by the work of the WDC. Impressed, as change is happening and progress being made. An example is the convening of a meeting of national drug regulators. This was considered near impossible, but the Council achieved it. We know every day counts for us, the good news is that once that cure/modifying agent is found, the preparatory work to get that drug to market as quickly as possible around the world will have already taken place. Reassured, because my fear of what lies ahead is diminishing with the information I have on projects and initiatives driven and supported by the Council. These will help us with dementia and our carers to live as well as we can for as long as we can. This brings me comfort and I hope it brings you renewed hope too.

The WDC was set up for one year. That term is complete. We are now discussing continuity plans and on 10 June the future of the WDC will be much clearer. I believe it should continue (with or without me), if it continues it will have a person with dementia as a member. I am unable at this stage to divulge plans, but one thing is very clear: the momentum gained over the last 18 months will not be allowed to dissipate nor will the work be lost.

I would like to take this opportunity to thank everyone from around the world who sent me their best wishes following my appointment. I will endeavour to do my best.

“I have been truly impressed, reassured and comforted by the work of the World Dementia Council.”

HILARY DOXFORD
Interview with Minister of Health
Milojka Kolar Celarc
Spominčica (Alzheimer Slovenia) talked about dementia with Mrs Milojka Kolar Celarc, the Slovenian Minister of Health.

Spominčica “Forget Me Not” has come of age
Slovenia’s Alzheimer association has come a long way since its launch in 1997.

Slovenian MEPs support the Glasgow Declaration
Six Slovenian MEPs explain why they support the aims of the Glasgow Declaration.

Living with dementia in Slovenia
Things become easier once you know the diagnosis.
Milojka Kolar Celarc, the Slovenian Minister of Health, supports the acceptance of the national plan for dementia

According to the World Health Organization (WHO), there are more than 44 million people suffering from dementia worldwide, including 9 million in Europe and 32,000 in Slovenia. On average, each person with dementia is cared for by three people. Due to population ageing, the number of patients will double in the next 20 years. Dementia is one of the most expensive diseases and a big social and economic burden of the society of today.

AE: The worldwide crisis has also struck Slovenia. How would you assess the condition of the Slovenian health system?

At the moment, we are preparing the analysis of our health system and “The resolution on the national plan of health care until 2025”, to assess our present situation and future directions. The European Commission recommended that Slovenia should prepare the review and calculation of expenses in health care.

We decided for the cooperation with the WHO. A comprehensive analysis will be prepared until the end of 2015 and the first part of it until September. The extent of the analysis will supersede the expenses themselves, and we will cooperate with different departments of the European Office of the WHO, for example the Observatory on Health Systems and Policies. Preliminary data show that Slovenia is on the right track as regards preventive measures, diminishing of the social determinants of health and fighting the consequences of unhealthy life habits.

On the whole, our conditions in the health field do not differ from the rest of the European countries: ageing population, long waiting periods in some areas, increasing costs of better new drugs and methods of treatment, etc. However, Slovenia’s health system is in good overall shape, as regards the availability of health services, as well as their quality: some specialities of medicine are near the very top in the world: let me just mention the number of heart transplants, which classifies Slovenia at the very top.

The recommendation of Alzheimer’s Disease International (ADI) and Alzheimer Europe is that persons with dementia should stay at home as long as possible, which is the most humane for them and the least expensive for society.

Only with support coming from outside can persons with dementia stay at home as long as possible, which is the most humane for them and the least expensive for society.

Milojka Kolar Celarc
However, there is still much to be done in this area. Most problems occur in the areas where health and social care intersect. This is not due to poor cooperation between the Ministry for Health and the Ministry for Labour, Family, Social Affairs and Equal Opportunities, as it may seem, but to the fact that the ageing of the population caught us unprepared. We were made aware of this fact by the Council of Europe and we were advised to reorganise long-term care. Together with the Ministry for Labour, Family, Social Affairs and Equal Opportunities we will prepare a draft of “The act on long-term care”.

The quality of life of persons with dementia depends on several factors. In the first place there is timely diagnosis, followed by appropriate post-diagnostic support. Also important is general awareness as well as reducing stigma, which can be achieved through a dementia friendly society. Relatives and carers of persons with dementia need help and support as during the long term care they are themselves exposed to great stress. They should be offered as much help and support at home as possible. They should be relieved of their burden, as their health is also at risk. Only with support coming from outside can persons with dementia stay at home as long as possible, which is the most humane for them and the least expensive for society.

For proper planning of activities in the field of dementia, a proper analysis of the situation is required: the number of the cases of dementia and prospects for the future.

The profession stresses the importance of gathering epidemiological data. Until now, no epidemiological survey on a reliable number of persons with dementia has been carried out. Gathering of epidemiological data is also a part of the national plan for dementia.

One of the extremely important factors of comprehensive care for persons with dementia is timely diagnosis. At this time, a drug for dementia has not been discovered yet. Drugs are effective in the first phase of the disease and can be prescribed by a psychiatrist or a neurologist. Waiting periods for the first check-up are very long. What should be done to shorten them?

Waiting periods for the first check-up are too long because there are not enough specialists in psychiatry and neurology. The specialisation in gerontology is unfortunately inexistent in Slovenia, while some other countries follow this practice and are very successful in diagnosing dementia.

I am aware of the fact that successful medical intervention in dementia is possible only on the basis of timely diagnosis. In this field, disease awareness in the society plays an important role so that those nearest to the patient can and do recognise the first symptoms of the disease.

A very important role in the recognition of dementia is played by family doctors, who are the first to notice the symptoms of dementia and refer the patients for a specialist check-up. Family doctors should receive additional training in the field of dementia. Family doctors would also need more time for the diagnosis, as dementia cannot be detected as quickly as angina, for example. The Ministry for Health, together with the profession, is preparing starting points for a pilot project in which family doctors would perform certain tests in the frame of reference clinics to ascertain possible cognitive deficits.

Dementias, among them Alzheimer’s disease, are becoming a pandemic. In Slovenia, the national plan on dementia has not been accepted yet.

As I have mentioned before, the national plan for dementia is in its final phase. With it, dementia will become one of the priorities of public health. The working group for the preparation of the national plan for the management of dementia was appointed in 2010. The working group consists of ten people – representatives of the Ministry of Health, the Ministry for Labour, Family, Social Affairs and Equal Opportunities, specialists from psychiatry and neurology and a representative of Spominčica – who are intensively working on the project.
The national plan for the management of dementia regulates the whole span of dementia: timely diagnosis, treatment, home and institutional care and raising awareness about the disease. Parallel to the increasing numbers of dementia cases, the national plan will predict a sufficient number of doctors and other health workers and their education, others working in the field, and will promote research. The document will delineate the comprehensive pathway for a patient, from the recognition of first signs, check-up with the family physician, timely diagnosis, treatment, home and institutional care, as well as help and support to the patient’s relatives and carers.

I sincerely hope that I will be able to announce at the 25th Annual Conference of Alzheimer Europe in September in Ljubljana that the national plan for dementia has been accepted.

Persons with dementia should stay at home as long as possible, along with a well-developed network of social support all over the country.

That is correct and our endeavours follow this direction. Home help is subsidised in some municipalities but does not cover all needs, especially not the specific ones of persons with dementia. In the national plan, interdisciplinary networks for consistent follow up of the patients are planned. These networks will enable the coordinated role of the primary health care, as well as support at home. In this project, the Ministry for Labour, Family, Social Affairs and Equal Opportunities is very active and has supported the pilot project called “Dementia friendly society” where non-governmental organisations such as Spominčica play an active role.

There are not enough specialised units for people with dementia in old peoples’ homes; also, the number of personnel is too low.

In this area, both ministries are very active. The Ministry for Labour, Family, Social Affairs and Equal Opportunities provided directives to old peoples’ homes for the treatment of persons with dementia in 2011. These homes are very actively educating their personnel, and some of them are not just waiting to get directions but have set up residential units where persons with dementia live almost like at home, which in turn enhances their well-being.

In October 2014, Alzheimer Europe announced the Glasgow Declaration, calling for a European strategy on dementia, national strategies and for the respect and care of the rights of persons with dementia.

I have already signed the Glasgow Declaration because I am well aware of the importance of a European strategy for dementia as well as national strategies. In the Slovenian national plan on dementia, we will do our best to follow the recommendations of the Glasgow Declaration that every person with dementia should have access to timely diagnosis and quality care throughout the illness and should be treated with respect and according to the standards of human rights.
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In 2010, following an initiative given by members of Spominčica - Alzheimer Slovenia to prepare a National Dementia Strategy, the Ministry of Health set up a working group for dementia.

Nationwide activities

We use every opportunity to raise awareness and to destigmatising the disease through the media. On the occasion of World Dementia Day in September, each year several activities are organised. In the spring of 2003, much public attention was raised by an event where painters produced works of numerous locations in Ljubljana. Their paintings were donated to our association which later sold them during an exhibition. Since 2005, a round table on dementia has been organised every year. In 2011, Spominčica successfully organised counselling sessions in sev-
eral shopping malls, calling attention to the ever increasing cases of the disease, mainly due to the ageing population.

The series of informal meetings called Alzheimer Cafés in public locations in several Slovenian towns raised much attention. These meetings were initiated by Štefanija Lukić Zlobec, who has had personal experience with the disease in her family. We first learned about Alzheimer Cafés in June 2012, at the Alzheimer Europe lunch debate meeting in Brussels. The first Alzheimer Café in Slovenia was organised at a nursing home in Fužine on 23 June 2012 and was widely promoted in the media. In addition to family members and carers of persons with dementia, we also invited journalists and others working or interested in this field. Already our first Alzheimer Café was a success!

As it turned out, these support meetings for families were very welcome in Slovenia. Alzheimer Cafés quickly spread all over the country and are now operating in more than 60 locations. Many of them take place in town centres, most often in bistros, libraries and hotel halls. Every event is widely promoted in national and local media, including the use of web sites to reach wide visibility of the subject and raise awareness about dementia. With this publicity we are able to contribute to the destigmatisation of dementia and to help build a dementia friendly society.

International contacts

Our international contacts have steadily intensified over the years. A significant boost to our endeavours was the visit of the members of the Alzheimer University in London in 2001, organised by Alzheimer’s Disease International (ADI).

In 2012, during the Vienna annual conference, Spominčica became a member of Alzheimer Europe, connecting professionals and persons with dementia from 31 countries. The goals of Alzheimer Europe became ours goals as well: to enhance community care for persons with dementia and their carers. Spominčica participates in numerous Alzheimer Europe events where professionals from the field, persons with dementia and their carers meet.

In 2013, the annual conference of Alzheimer Europe under the title “Living well in a dementia friendly society” was held in Malta, where Spominčica presented its work and also joined the Mediterranean Alzheimer’s Alliance, which has 20 members states. At the 24th Alzheimer Europe conference in Glasgow,
Spominčica participated with four presentations. We are proud that our activities were internationally recognised and also that we were officially conferred with the task of organising the 25th Alzheimer Europe Conference in 2015 in Ljubljana. The conference is organised under the Honorary Patronage of His Excellency Borut Pahor, President of the Republic of Slovenia.

Spominčica became a full member of ADI in 2014 at the conference in Puerto Rico. In the same year, ADI Executive Director Marc Wortmann came to Slovenia and held a working meeting with President Borut Pahor who supported our work on the National Dementia Plan.

Upon the invitation of Spominčica, all eight newly elected Slovenian MEPs signed the European Dementia Pledge in 2014 and also became members of the European Alzheimer’s Alliance. Slovenian Commissioner Violeta Bulc was the first EU official to sign AE’s Glasgow Declaration adopted last year in Glasgow and she was followed by six MEPs. The city of Ljubljana and its Major Zoran Janković are also signatories and they were recently joined by Slovenian Ombudsman Vlasta Nusdorfer.

The National Dementia Plan

In 2010, following an initiative given by members of Spominčica – Alzheimer Slovenia to prepare a National Dementia Strategy, the Ministry of Health set up a working group for dementia. This was soon followed by a decree to form a working group for the preparation of the national plan and this group produced a report on the facts about the disease in Slovenia.

Spominčica is a member of the working group and aims to see that the rights of persons with dementia and their ethical considerations are ensured at all levels. We also commit to raise awareness about dementia and for assuring funds and organising a network of social services to provide for persons with dementia at their homes. The National Dementia Plan will enable us to face the ever growing number of cases of dementia, which are mainly the result of ageing population. The National Plan is now in the final stages of approval at the Ministry of Health and we are confident that it will be adopted very soon.

Looking to the future

Because of the ageing population, the number of persons with dementia is on the increase and this trend is expected in years to come. It is estimated that at present there are around 31,000 persons with dementia in Slovenia. Although we now have some drugs which can at least slow down the progress of the disease and alleviate its symptoms, and institutional health and social care are much better organised than some years ago, we cannot allow ourselves to rest. We have to do more to allow persons with dementia to stay at home for as long as possible, along with enough support from the social services.

We are convinced that the work we have done so far has produced results. Persons with dementia and their relatives now recognise the symptoms of the disease much earlier and ask for help sooner. We always try to provide for the needs of persons with dementia and their carers and also to bring experiences from other countries into practice in Slovenia.

In the years to come, Spominčica’s network will continue to spread, so that help and support will be available to persons with dementia, as well as their carers, no matter where they live. Additional attention must also be paid to specific groups of persons with dementia, including those with early onset of the disease. Cooperation between Spominčica, persons with dementia and their carers on one side and professional services on the other should become even closer and more intense. It is these mutual efforts that will bring the results in the end, the results from which all of us might some day profit.
Tanja Fajon

I signed the Glasgow Declaration for several reasons, demographic changes being one of them. A low birth rate together with higher life expectancy may affect a much larger share of Europe's population, which could be affected by any form of dementia.

The second reason is related to the illness itself, which for its recognition and proper deliberation of patients urgently needs the best possible technical support and innovative solutions. This of course involves close cooperation both at national and European level, exchange of good practices is therefore vital.

One of the reasons for support of this declaration stems from my personal experience and the difficulties and distress people with dementia and those around them face. The key to success for these measures to work effectively in everyday life is, in my opinion, close cooperation of all who in any way deal with people with dementia. Exchange of information and constructive cooperation can significantly relieve the life of patients and those around them and overcome many of the financial problems, too.

Alojz Peterle

As a Member of the European Parliament, Co-Chair of Health Working Group within the European Parliament's Environment, Public Health and Food Safety Committee, and Member of the Alzheimer Alliance, I will continue to pay particular attention to dementia and drive it forward as one of public health priorities in the EU. Together with many MEPs who have signed the Glasgow Declaration we are signalling to the European Commission that the time has come to develop the European dementia strategy. I believe that setting up a high-level official at Directorate-General and forming a team of experts, officials and representatives from organizations in charge of the monitoring of strategy implementation and of exchange of best practices would significantly contribute to fulfilment of the Strategy goals.

One of these is ensuring rights of the patients with dementia in everyday life. These rights are human rights, equal for all, regardless of personal circumstances, written down in the fundamental national and international law on human rights. Governmental bodies above all have a duty to recognise their role and the States must provide sufficient
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funds for their activities. In Slovenia, I do encourage NGOs to keep trying to open dialogue with all relevant stakeholders, in particular by presenting facts and worrying predictions, which would finally lead to the adoption of a National plan for dementia.

Last but not the least; let me congratulate Spominčica – Alzheimer Slovenia to host the 25th Alzheimer Europe Conference in Ljubljana, Slovenia this autumn, where the key debate will centre on the transfer of strategies and research into practice. I look forward to meeting you in Ljubljana!

I signed the Glasgow Declaration because of the necessity of raising public awareness of the presence of this disease around us. It is also at the level of preventive fight for the recognition of this disease as a disease of modern times. In particular, it is necessary to promote the focus on informing people about events and characters and identification of this disease, the need to respect the rights and dignity and independence of people living with dementia.

The faster the population ages, the more will be living with dementia and Alzheimer's disease present around us. We cannot pretend that this disease does not exist and cannot turn away from this fact because when it knocks on our door and we open the door, we have to be ready. That is why I signed the Glasgow Declaration, because there must be a willingness to prepare not only for patients but also for people living with and by the people with dementia.

Patricija Šulin

We still don't know enough about Alzheimer's disease. Therefore it is necessary to continue informing the public about both the pathological signs and particularly about the consequences faced by patients, their families and the society as a whole. This means informing the patients and their families in order for them to cope better with the disease, as well as us policy makers to be able to properly legislate about health issues. Information should be made available both to those who are directly affected, so that they can cope better with the disease, and to all those who take decisions about health policy.

Losing your memory means losing part of your life. It could be that tomorrow dementia affects us or our loved ones so it is in the interest of us all to help and get involved. We can get involved as members of the family of the patient and share our experience with others, or as caregivers, researchers or public officials: to support, highlight or legislate. In the past MEPs have made some promising starts and we shall continue and deepen their work during this mandate. The first steps have already been taken by MEPs in the past and I intend to continue this involvement. Most of all, we have to persist and build on what has already been done.

According to the data from the European Commission, before the European initiative on Alzheimer's disease and other dementias was adopted in 2009, only one Member State had a national plan on dementia, but today there are more than half of the Member States which have adopted national plans or strategies or have started working on them. The
data from the European Commission shows that at the time when the European initiative on Alzheimer's disease and other dementias was adopted in 2009, only one Member State had a national programme for dementia – now more than half of them have such programmes or are in the process of preparing them.

Ivo Vajgl

The difficulties that those who suffer from dementia and their relatives and friends have to confront stipulate our responsibility that we as a society have to join our forces and do more in order to: diagnose the illness better and faster, to offer those who are affected by dementia fulfilling, decent and safe living and to enable relatives and friends a proper expert help and support in their care of their beloved. We must not forget that the activity is the one that extends life and maintains its quality to people with dementia. This can be achieved only with the systemic solution of the problem.

We have to focus more on public awareness on this issue and to encourage those who suffer from dementia to speak up about their illness, obstacles and fears they have to overcome. I have already urged on the Slovene government to adopt a national strategy on dementia as soon as possible, as its member I've suggested the EP’s Intergroup on of active ageing, intergenerational solidarity & family friendly policies to put dementia on its agenda, I plan to organize a public debate in Slovenia, so the NGOs get the possibility to share with us their valuable experience and views. Namely, we should take into account that the empowerment of ALL vulnerable social groups contributes to the improvement of situation of people with dementia. There is a lot of work to be done!

Dr Milan Zver

I support the efforts of Alzheimer Europe, which calls for the formation of a European strategy on dementia and strategies on dementia in all European countries.

I share the opinion, that the European Commission should coordinate activities and research within programmes such as Horizon 2020, programmes for support in everyday life, the European innovation partnership on active and healthy aging, Joint Program for research on neurodegenerative diseases and Innovative medical program initiative. I am convinced that it is right that the European Commission sets up an expert group for exchange of good practices.

Given the demographic changes in society, the number of people who are faced with this problem is likely to grow in the future. We need to ensure early detection of dementia, mitigation of its effects, the search for new treatments and to maximise the inclusion of people with dementia in society.

At the same time I call upon the Government of the Republic of Slovenia to prepare a national programme and take the necessary steps to form an organised network of centres for cognitive disorders.
Living with dementia: things become easier once you know the diagnosis

Mojca Hladnik, a kindergarten teacher and her partner Matjaž Rižnarič, a croupier in a casino, made their home in Jesenice. Ten years ago, when their first baby was born, Mojca noticed Matjaž’s changed behaviour. He kept losing and forgetting things, usually his keys or wallet.

She was even more bewildered when he started coming home without doing what he went out for in the first place. She attributed his forgetfulness, absentmindedness and exhaustion to the thrill and stress accompanying the birth of their first child, and to his strenuous night shifts at the casino. Nowadays, Mojca knows these were the first signs of Matjaž’s disease, which went unrecognised – even by doctors some years later. At 42, he was too young for anyone to suspect dementia.

Unusual behaviour

Matjaž’s unusual behaviour slowly subsided, their child was growing up, Mojca went back to work and their life was back to normal. But not for long. When their second child was born four years later, the thrill at the birth of the baby daughter was tainted by strange behaviour from Matjaž again. Mojca realised that she could no longer trust him with errands anymore.

She remembered similar changes in Matjaž’s behaviour after the birth of their first child; however, this time the changes did not disappear but were aggravated. Among other things, Mojca noticed that Matjaž no longer recognised the value of banknotes, and he started to leave for work very early without being able to give any reason for it.

When she asked him whether he has any problems at work, he denied it. Soon after, she received a call from the casino and was told that Matjaž should take sick leave because he was unable to perform at work. She was also asked to accompany him to his doctor because he seemed unaware of any problems.

In search of a diagnosis

Following the first visit to the doctor’s office, the long process of searching for a diagnosis began. For a long time, nobody had a clue about the reason for Matjaž’s sickness. Tests were performed and doctors mentioned stress and depression, but nobody ever mentioned dementia.

“It is difficult to get the right diagnosis if someone does not fit the usual professional criteria. Matjaž was simply not old enough that anyone would suspect dementia. All the tests were more or less within normal frames, and he was not being far from being declared a malingerer,” Mojca recalls the difficult times.

She was also very upset by the remark of a psychiatrist that Matjaž’s referral to him was unnecessary. When additional reports were demanded by the disability commission, he was sent to a neurologist who performed the usual tests for dementia and the diagnosis was finally affirmed.

The long way to the right diagnosis was partly due to his young age and partly to his intelligence, which was above average and made the cognitive deficit less observable. Some more tests were performed, including a genetic one which showed a specific gene mutation. His parents were already deceased at the time, but some relatives testified that Matjaž’s father might have had dementia.

Problems

“The period of uncertainty was the hardest to bear,” says Mojca. “After the diagnosis was established, I felt a certain relief. It is easier to fight when you know what you are fighting and you know what
to expect, although I was aware of the fact that the disease is incurable.”
After the diagnosis in 2010, a formal solution came quickly and Matjaž became eligible for a disability pension in 2011. “But the problems were not over,” says Mojca. “What we needed most was down-to-earth practical advice, which you most often get from other people facing similar problems.”

Day care
Mojca still works and the question of what Matjaž would do while she is away bothered her. Even now, he can be at home alone for a short time, but cannot leave the house without an escort. She inspected several day care centres and finally found one close to their home. She drops him off in the morning and picks him up after work. Matjaž feels very well in day care and is included in several activities which are intended to diminish mental and physical decline. He has also been prescribed drugs which slow down the course of the disease and alleviate its symptoms.

Family
Mojca is trying to organise family life so that the children are least affected by their father’s disease and he is taken care of in the most effective manner. In this she is supported and helped by her parents. She gets a lot of understanding also at her workplace, where she can get a leave of absence whenever it is necessary for her to accompany her husband.
When she went for a holiday to the seaside with their children, Matjaž spent his holiday in the nearby old peoples’ home. Every change of routine upsets him and he does not want to go even on short family trips anymore. But the family found help in their own block of flats, in the form of a kind neighbour who is happy to take care of Matjaž when Mojca is absent.

Children
Their father’s disease is openly discussed in the family; nothing is ever covered up. “For now I have always been able to explain the children everything – on their level of understanding, of course,” says Mojca.
Although the children are only 10 and 6 years old, they understand their father’s disease very well and are well aware of his limitations. In spite of this relentless disease, they still function as a happy family. When you set eyes on the parents and children sitting cheerfully at the dinner table and playing with and cuddling their pet lizard Elizabeth – which Matjaž also likes to put around his neck – you can feel their optimism and courage.
Will Mojca get enough help and support in future to be able to support her children and husband through her own resilience?
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