Dennis Gillings discusses his role as Global Dementia Envoy.

Alex Neil speaks about Scotland's new national dementia strategy.

Health Minister Bent Høie discusses Norway's new plan to improve services for people with dementia.

Henry Rankin describes his life after a dementia diagnosis.
04 **Welcome**
by Heike von Lützau-Hohlbein,
Chairperson of Alzheimer Europe

Prioritising Dementia

06 **AE members prepare for European dementia strategy**
A report on AE’s latest public affairs meeting, whose topics included the EU elections and a proposal for a pan-European dementia strategy

08 **EWGPWD ends its first term of office**
A look back at the first term of office of the European Working Group of People with Dementia

10 **European Alzheimer’s Alliance: making dementia a European priority**
The EAA, in existence since 2007, continues to make dementia a priority in the new European Parliament

13 **PACE: advancing research in the effectiveness of palliative care**
A new project that compares the effectiveness of palliative care for elderly people in long-term care facilities in Europe

15 **PredictND: developing tools for earlier diagnosis and treatment of dementia**
Project Coordinator Kari Antila discusses the objectives and challenges of this new research project

Policy Watch

18 **Norway’s new plan to improve services for people with dementia**
Norway’s dementia strategy expires in 2015 and Minister of Health Bent Høie is already planning for the future

21 **Exploring the financial and social impact of investing in dementia**
The first Global Dementia Legacy Event was another step forward for global action against dementia

23 **Battling dementia on a global level**
Dr Dennis Gillings, World Dementia Envoy, describes his role in coordinating global efforts against dementia

25 **Scotland holds international dementia conference**
The Scottish government’s first international dementia event was part of the increasing worldwide collaboration to tackle dementia in all its forms
## Dementia in the news

### 28 Dr Ana Diaz
AE Project Officer Ana Diaz earns a PhD for her thesis on the effects of anti-dementia medication

### 30 Dementia Friends campaign
Launched in 2012, this Alzheimer’s Society campaign has gained over 370,000 followers in the UK

### 32 News from Alzheimer Europe members
A selection of news updates from Alzheimer Europe’s member associations

<table>
<thead>
<tr>
<th>S</th>
<th>Scotland’s national dementia strategy</th>
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</thead>
<tbody>
<tr>
<td>IV</td>
<td>New Scottish MEPs in Brussels</td>
</tr>
<tr>
<td></td>
<td>Scotland’s new MEPs express their views on making dementia a priority at home and abroad</td>
</tr>
</tbody>
</table>

| VII | Alzheimer Scotland: 20 years of Action on Dementia |
|     | A guided tour of Alzheimer Scotland, including the association's history, current activities and plans for the future |

| XI | Living with dementia |
|    | Henry Rankin, chair of the Scottish Dementia Working Group, describes his life after diagnosis |

| XII | Caring for a relative with dementia |
|     | Christine Beaton, a member of the National Dementia Carers Action Network, shares her experience of caring for her mother who had vascular dementia |
Welcome

As always, collaboration is at the heart of Alzheimer Europe's activities. In this issue we cover the latest AE public affairs meeting, which was attended by representatives of 16 member associations. Amongst other topics, they agreed to a united call for a pan-European dementia strategy. We also bring you an update on the recent EU elections and our collective campaign to garner political support for dementia. The results of the campaign speak for themselves: the new European Alzheimer’s Alliance has begun life with 83 MEPs, more than we had before the elections. As a useful bonus, we all learned more about the growing importance of social media in campaigning.

This month marks the end of the EWGPWD’s first term of office. I heartily congratulate all 11 members of the European Working Group of People with Dementia for their outstanding contributions over the past two years. These are covered in detail in this issue and by the time you read this, the group has re-formed for its second two-year term and new officers have been elected. If you are at the conference in Glasgow, be sure to visit the EWGPWD’s dedicated stand: you will meet some very dedicated people who are making the most out of living with dementia.

In the policy section, the Norwegian Health Minister speaks about the successor to the country’s Dementia Plan 2015. We also cover the Global Dementia Legacy event that took place in June – including an exclusive interview with Dr Dennis Gillings, World Dementia Envoy. Our policy coverage concludes with a report about Scotland’s first international dementia conference. This was part of the increasing worldwide effort to tackle dementia and there is no doubt that Scotland will have much to offer.

The Special Section also focuses on the host country of our conference. It is clear that Scotland has made – and continues to make – remarkable progress in looking after people with dementia and their families and carers. These advances are made possible by the Government’s human rights-based approach to services, but also by the steadfast support and continual efforts of our colleagues at Alzheimer Scotland. I am very pleased to showcase the excellent results achieved by all of these dedicated individuals.

In closing, I would like to thank all my colleagues from Alzheimer Europe and Alzheimer Scotland for their efforts to make our 24th Annual Conference a great success. We are expecting over 600 delegates from more than 35 countries. This exceeds our recent attendance records and I take it as a sign that our theme “Dignity and autonomy in dementia” was appropriately chosen.
Prioritising Dementia

06 AE members prepare for European dementia strategy
08 EWGPWD ends its first term of office
10 European Alzheimer’s Alliance: making dementia a European priority
13 PACE: advancing research in the effectiveness of palliative care
15 PredictND: developing tools for earlier diagnosis and treatment of dementia
AE members prepare for European dementia strategy

In early July, 22 delegates gathered in Luxembourg to discuss AE projects, the results of the EU elections and a proposal to call for a pan-European dementia strategy.

Collaboration in AE projects

On 9 July, Alzheimer Europe (AE) held a public affairs meeting in Luxembourg that was attended by 17 representatives from 16 member organisations and five AE staff members. AE Chair Heike von Lützau-Hohlbein welcomed the delegates and emphasised the importance of these meetings, as they offer opportunities to share experiences and learn from each other.

Jean Georges, Executive Director, gave updates of AE’s Dementia Monitor, Clinical Trial Watch and Guideline Watch projects. All of these projects rely on the participation of AE’s member associations and Jean expressed his gratitude for their ongoing efforts.

Project Officer Ana Diaz also expressed her appreciation for the commitment of 29 member associations to AE’s survey on national care pathways for people with dementia living at home. Ana reported on the progress of the project that forms the basis of Alzheimer Europe’s 2014 Yearbook. This will appear in December 2014, detailing national pathways to diagnosis and also post diagnostic treatment and support all over Europe.

EU elections and the European Alzheimer’s Alliance

Annette Dumas, AE’s Public Affairs Advisor, presented the results of the European elections. The tables below show the composition of the new European Parliament and also those MEPs who previously held posts as Prime Ministers or Commissioners.

### Political party ranking in the new European Parliament

<table>
<thead>
<tr>
<th>Party</th>
<th>No. of MEPs</th>
<th>% of all MEPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPP</td>
<td>221</td>
<td>29.4%</td>
</tr>
<tr>
<td>S&amp;D</td>
<td>191</td>
<td>25.4%</td>
</tr>
<tr>
<td>ECR</td>
<td>70</td>
<td>9.3%</td>
</tr>
<tr>
<td>ALDE</td>
<td>67</td>
<td>8.9%</td>
</tr>
<tr>
<td>GUE/NGL</td>
<td>52</td>
<td>6.9%</td>
</tr>
<tr>
<td>Greens/EFA</td>
<td>50</td>
<td>6.7%</td>
</tr>
<tr>
<td>EFDD</td>
<td>48</td>
<td>6.4%</td>
</tr>
<tr>
<td>NI (non-attached)</td>
<td>52</td>
<td>6.9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>751</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
Annette also spoke about AE’s election campaign that focused on committing candidates to make dementia a priority. The campaign yielded signatures from 220 candidates, largely thanks to the participation of AE’s member organisations. The delegates heard details of the national campaigns in numerous member countries, sharing their best practices and experiences. Among the candidates who signed the pledge, 40 were elected as Members of the European Parliament (MEPs) and also became members of the European Alzheimer’s Alliance or EAA. The activities of the EAA are covered separately on page 10 of this issue.

Former occupations of new MEPs

<table>
<thead>
<tr>
<th>Prime Ministers</th>
<th>Commissioners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrus Ansip</td>
<td>Karel De Gucht</td>
</tr>
<tr>
<td>(Estonia)</td>
<td>(Belgium)</td>
</tr>
<tr>
<td>Jerzy Buzek</td>
<td>Janusz Lewandowski</td>
</tr>
<tr>
<td>(Poland)</td>
<td>(Poland)</td>
</tr>
<tr>
<td>Valdis Dombrovskis</td>
<td>Viviane Reding</td>
</tr>
<tr>
<td>(Latvia)</td>
<td>(Luxembourg)</td>
</tr>
<tr>
<td>Anneli Jäättäenmäki</td>
<td>Olli Rehn</td>
</tr>
<tr>
<td>(Finland)</td>
<td>(Finland)</td>
</tr>
<tr>
<td>Lojze Peterle</td>
<td>Maroš Sečovič</td>
</tr>
<tr>
<td>(Slovenia)</td>
<td>(Slovakia)</td>
</tr>
<tr>
<td>Alfred Sant</td>
<td>Antonio Tajani</td>
</tr>
<tr>
<td>(Malta)</td>
<td>(Italy)</td>
</tr>
<tr>
<td>Theodor Stolojan</td>
<td></td>
</tr>
<tr>
<td>(Romania)</td>
<td></td>
</tr>
<tr>
<td>Guy Verhofstadt</td>
<td></td>
</tr>
<tr>
<td>(Belgium)</td>
<td></td>
</tr>
</tbody>
</table>

Finally, Annette gave an outline of the G7 Global Dementia Legacy Event that took place in June 2014. Following this, the delegates discussed the future implications of the “Global action against dementia” group at local and national levels. The G7 event is covered in detail on page 21 of this issue and an interview with Dr Dennis Gillings, World Dementia Envoy, can be seen on page 23.

Aiming for a European dementia strategy

Jean proposed that AE issue a “Glasgow Declaration” during its annual conference, which will take place in October 2014 in Scotland. He explained that the new declaration would aim for the adoption of a European dementia strategy, but also the development, implementation, monitoring and evaluation of a national dementia strategy in every European country.

The Glasgow Declaration could also include a call for better coordination of existing programs, exchange of best practices, support of national Alzheimer associations and more involvement of people with dementia. The delegates agreed on the relevance and content of the declaration and also that the annual conference would provide a good opportunity to present it.

The growing role of social media

Kate Ellis, Communications Officer for Alzheimer Europe, talked about AE’s experiences of using social media in recent campaigns, with a particular focus on Twitter during the European elections. She was joined by colleagues from Finland, Ireland and the UK who shared their organisations’ experiences of using new media in national campaigning activities. These examples showed that the use of social media is increasingly important for campaigning, but personal contact is still the most essential element of a successful campaign.

Alzheimer Europe wishes to thank all the attendees (see below) for their active participation and support. The next meeting will be held in Brussels on 3 December 2014.
The European Working Group of People with Dementia ends its first term of office

The European Working Group of People with Dementia (EWGPWD) was set up in Vienna in 2012 on the occasion of Alzheimer Europe’s 22nd Annual Conference. In May 2014, the group met for the last time in their current term of office. Looking back at the last two years’ work, it is clear that the EWGPWD has achieved a great deal.

Addressing a growing societal need

The aim in setting up the group was to give people with dementia a greater say and involvement in the activities of the organisation but also for Alzheimer Europe to benefit from their knowledge and experience when developing projects and carrying out policy and advocacy work. The EWGPWD has been skilfully chaired by Helga Rohra (from Germany) and by the Vice-Chairs, Agnes Houston, Nina Baláčková and Jean-Pierre Frognet from the United Kingdom, the Czech Republic and Belgium respectively.

The EWGPWD is not a support group but sometimes the collective strength of the group enables individual members to step outside their comfort zones and to achieve more than they might have thought themselves capable of alone. This has led to members of the working group debating and sharing their experience in project meetings alongside researchers, ethicists, health and social care professionals, care providers and politicians.

Others have made television appearances, been interviewed for newspapers and magazines, been invited to high level political debates and given speeches to hundreds of people at conferences. Some have been invited by state leaders and royalty to discuss various issues or have been nominated for prestigious national awards.

Whilst this is satisfying and boosts self-esteem, such achievements testify to the increasing recognition within society of the need to hear their voices. Members of the EWGPWD have also demonstrated a desire to work around obstacles, to compensate for and use each other’s strengths and weaknesses and to learn new skills such as using a closed Facebook group for internal communication.

An international meeting of minds

The members of the EWGPWD cover ten different countries, have different forms of dementia, are at different stages of dementia and there is a good balance of men and women. However, they are not expected to be representative of all people with dementia. Rather, their own personal experiences and ideas are sought. Consequently, at their last meeting, it was decided that for Alzheimer Europe’s Annual Conference in Glasgow, Jean-Pierre would talk about his negative experience of day care. His aim is not to criticise day care, which can be beneficial to many people, but to emphasise that it needs to be suited to each person and in his case, it was a fairly painful experience.

Stig Atle Aavik (from Norway), on the other hand, would like to emphasise that life goes on; people with dementia do not necessarily give up all their activities once they are diagnosed with dementia and just sit at home. He will tell people in Glasgow about his strict morning routine of getting up early, running in the woods, reading the newspaper and enjoying a good breakfast, as well as his activities with the Norwegian national association.

For Agnes, it is important to raise the issue of people with dementia being diagnosed with dementia increasingly early and living for many years with moderate dementia. She feels that a lot is being done for people with dementia following diagnosis and in the more advanced stage but that there is a huge gap in the middle. She is concerned that
health and social care professionals tend to presume that after a number of years, people with dementia should be considering moving into a nursing home and this does not correspond to the needs of this sizable group of people.

**Looking toward the future**

The first two years have been a kind of test and trial phase for the EWGPWD and Alzheimer Europe. The EWGPWD has passed with flying colours. The efforts of Alzheimer Europe to provide a place and opportunity for people with dementia to be heard have been hugely rewarded and we are constantly learning how to do things better.

Jean Georges, Executive Director, emphasised at the last meeting that everyone had contributed greatly to the current group and should be proud of what they had achieved, irrespective of whether they remained for a further term of office. The role of carers and representatives of Alzheimer associations in supporting members of the group must also be applauded. We look forward to the continuation of the EWGPWD and to building on the fantastic work that has been accomplished so far.
European Alzheimer’s Alliance: making dementia a European priority

Since 2007, the European Alzheimer’s Alliance (EAA) in the European Parliament (EP) has played a major role in helping Alzheimer Europe (AE) and its members make dementia a European priority. Thanks to our concerted efforts, a series of EU developments have firmly put dementia on the European public health, social and research agenda while an increasing number of Member States have progressed in tackling the disease at national level. These impressive developments encourage us all to continue the work of the Alliance and to seek the support of as many Members of the EP (MEPs) as possible during this new mandate.

The dementia case

Some 8.7 million people have dementia in Europe. The disease generally affects people over the age of 65 but an increasing number of people are affected at a younger age. Dementia is a progressive disease that leads to the complete dependency of the person affected and creates a heavy toll on carers. The costs associated to dementia are high (EUR 21,000 per patient per year, of which 56% is for informal care). The ageing of the population, new societal patterns and the fragile sustainability of the healthcare systems compel us to continue raising awareness and shaping the health, social and research policy agenda to ensure the specific needs of people with dementia and their carers are effectively addressed.

AE’s European Dementia Pledge

The recent European elections were an opportunity for AE and its members to further raise awareness about the challenges of dementia and rally broad support to ensure that public health priorities, medical and research priorities and social and care priorities in the field of dementia are duly addressed at European and national level.

The European Alzheimer’s Alliance

The EAA is a non-exclusive, multinational and cross-party group that brings together MEPs committed to support AE and its members to make dementia a public health priority in Europe. Through their engagement, the Alliance members give the political signal that immediate and concerted action is needed at European and national level. They foster a favourable environment at European and national level to raise awareness about the challenges of dementia and rally broad support to ensure that public health priorities, medical and research priorities and social and care priorities in the field of dementia are duly addressed at European and national level.

The response was outstanding: 220 candidates signed the pledge. This was done in close cooperation with AE’s members who eagerly embarked in the awareness and political campaign.
The new face of the EAA

Before the 2014 elections, the EAA consisted of 71 members, representing 22 countries and the major EU political groups. The missing countries were Bulgaria, Croatia, Estonia, Hungary, Latvia and Sweden.

Well over half of these 71 EAA members (43) were reelected and 40 pledge signatories were elected. To date, the EAA can count on 83 members representing 26 countries and, again, the major EU political groups. Estonia and Latvia are our only missing countries.

For the first time since 2007, all MEPs of one single country, Ireland, are members of the Alliance.

AE and its members are very appreciative of their collaboration with the Alliance in the past and highly impressed by the impact of this collaboration on EU developments in dementia. They would like to express their warmest thanks to the departing MEPs and also to the re-elected and newly-elected MEPs for their support.

What’s next?

The main axes of AE’s and the Alliance's work will be raising awareness, sharing knowledge and best practices, influencing the debates and shaping policy.

As a first step, the Alliance Chair and Vice-Chairs need to be identified. We will endeavour to have a fair representation of the EP major political groups (ALDE, ECR, EFA/Greens, S&D and GUE/NLG), as well as a balanced geographical and gender distribution. One immediate goal will be to increase the Alliance membership as an indication of the MEPs’ recognition of the high stakes related to dementia and their willingness to act alongside AE.

AE will continue seeking the support of Alliance members to host regular lunch debates in the EP, where AE research will be presented or guests invited to address a specific topic related to dementia or EU developments.

Alliance members will be given opportunities to present their work and speak about their

<table>
<thead>
<tr>
<th>Political group</th>
<th>Members</th>
<th>Countries</th>
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<tbody>
<tr>
<td>ALDE</td>
<td>8</td>
<td>Belgium, Denmark, Finland, France, Ireland, Luxembourg, Slovenia, Sweden</td>
</tr>
<tr>
<td>ECR</td>
<td>4</td>
<td>Croatia, Ireland, UK</td>
</tr>
<tr>
<td>EPP</td>
<td>35</td>
<td>Austria, Bulgaria, Cyprus, Czech Republic, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxembourg, Malta, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, The Netherlands</td>
</tr>
<tr>
<td>Greens/EFA</td>
<td>5</td>
<td>Belgium, Slovenia, UK</td>
</tr>
<tr>
<td>GUE/NLG</td>
<td>7</td>
<td>Finland, Ireland, Portugal, UK</td>
</tr>
<tr>
<td>S&amp;D</td>
<td>24</td>
<td>Belgium, Croatia, Czech Republic, Denmark, Finland, France, Ireland, Italy, Lithuania, Romania, Spain, UK</td>
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</table>
engagement in dementia in AE’s policy magazine, Dementia in Europe. In addition, AE will provide background information to the Alliance members to substantiate their parliamentary work or participation in events.

AE and its member associations will provide a steady stream of communication about the work of the Alliance through their newsletters, websites and on Twitter and Facebook. EAA members will also be most welcome to communicate via their Twitter accounts and websites.

Members of the European Alzheimer’s Alliance (September 2014)

**Austria:** Heinz K. Becker  
**Belgium:** Mark Demesmaeker, Frédérique Ries, Bart Staes, Marc Tarabella, Kathleen van Brempt  
**Bulgaria:** Andrey Kovatchev  
**Croatia:** Biljana Borzan, Tonino Picula, Ruža Tomašić  
**Cyprus:** Christos Stylianides, Eleni Theocarous  
**Czech Republic:** Olga Sehnalová, Pavel Svoboda, Tomáš Zdechovský  
**Denmark:** Ole Christensen, Jens Rohde, Christel Schaldemose  
**Finland:** Liisa Jaakonsaari, Anneli Jäätteenmäki, Miapetra Kumpula-Natri, Merja Kyllönen, Sirpa Pietikäinen  
**France:** Nathalie Griesbeck, Françoise Grossetête, Philippe Juvin, Elisabeth Morin-Chartier, Gilles Pargneaux  
**Germany:** AngelikaNiebler  
**Greece:** Manolis Kefalogiannis  
**Hungary:** Ádám Kösa  
**Ireland:** Lynn Boylan, Matt Carthy, Nessa Childers, Deirdre Clune, Brian Crowley, Luke ‘Ming’ Flanagan, Marian Harkin, Brian Hayes, Seán Kelly, Mairead McGuinness, Liadh Ni Riada  
**Italy:** Pier Antonio Panzeri, Aldo Patriciello, Patrizia Toia  
**Lithuania:** Vilija Blinkevičiūtė  
**Luxembourg:** Georges Bach, Frank Engel, Charles Goerens, Viviane Reding  
**Malta:** Roberta Metsola  
**Netherlands:** Esther de Lange, Lambert van Nistelrooij  
**Poland:** Elżbieta Lukacijewska  
**Portugal:** Carlos Coelho, Marisa Matias  
**Romania:** Daciana Octavie Sarbu, Claudiu Ciprian Tanasescu, Renate Weber  
**Slovakia:** Miroslav Mikolášik, Anna Záborská  
**Slovenia:** Franc Bogovič, Tanja Fajon, Alojz Peterle, Igor Šoltes, Ivo Vajgl, Milan Zver  
**Spain:** Soledad Cabezón Ruiz, Rosa Estarás Farragut, Luis de Grandes Pascual, Sergio Gutiérrez Prieto, Juan Fernando López Aguilar, Pablo Zalba Bidegain  
**Sweden:** Cecilia Wikström  
**United Kingdom:** Martina Anderson, Richard Ashworth, Ian Hudghton, Jean Lambert, Linda McAvan, Claude Moraes, Keith Taylor, Derek Vaughan, Glenis Willmott
Advancing research in the effectiveness of palliative care

The PACE project will compare the effectiveness of palliative care for elderly people in long-term care facilities in Europe. Alzheimer Europe speaks to Project Coordinator Lieve Van den Block about the five year project that began in January 2014.

Bridging the research gap

The proportion of the world’s population aged over 60 is expected to rise considerably. This will lead to more people dying in late old age with generalised frailty or neurological failure, following a slow dying course with multiple chronic diseases and years of disability and complex palliative care needs.

These developments have enormous clinical, societal and socio-economic implications common to all EU countries, as is recognised in the European Innovation Partnership on Active and Healthy Aging.

The World Health Organisation (WHO) defines palliative care as a multidisciplinary approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual/existential.

In the past, palliative care was offered mainly to cancer patients. Nowadays, it is recognised that older people with age-related, chronic and/or mental health problems can also benefit from a palliative care approach integrated earlier into disease management.

Palliative care has only recently begun to be developed in long term care facilities (LTCF) and there is very little research on comparative effectiveness. The PACE researchers will provide new scientific insights, including a database with data on some 1,150 deceased residents from 288 LTCF facilities in six European countries. According to Lieve Van den Block, “PACE will investigate how palliative care in nursing homes can be optimally implemented in Europe and what the effects are in terms of quality of life, quality of care, and costs”.

The overall project objective is to inform and assist policy and decision-makers at different national and European levels by developing specific tools and products that will enable evidence-based decisions on optimal palliative care delivery in LTCFs.

PACE project meeting in Brussels (February 2014)

“Older people with age-related, chronic and mental health problems can benefit from a palliative care approach integrated earlier into disease management.”

LIEVE VAN DEN BLOCK

PACE has received funding from the European Union’s Seventh Framework Programme for research; technological development and demonstration under grant agreement no 603111. http://eupace.eu/
Advancing research in palliative care

PACE will perform two large scale and innovative research studies:

Study 1: Effectiveness of end-of-life care in LTCF

PACE will compare effectiveness of end-of-life care in long term care facilities without formal palliative care structures (Finland, Italy, Poland) and with formal palliative care structures (Belgium, The Netherlands, United Kingdom) by performing large scale cross-sectional studies of deaths of residents in long term care facilities in these six countries, obtaining representative nationwide data on dying in these facilities. In each country, all participating facilities retrospectively report all deaths of residents in and outside the facilities over a three month period. For each case, structured after-death questionnaires including validated instruments are sent to a staff member most involved in care, treating general practitioner and a relative or family member. PACE aims to include 48 facilities in each country, providing a database of at least 1,152 deceased residents.

Study 2: Implementing a health service intervention

PACE will implement a health service intervention called “The Route to Success in long-term care facilities” that was originally developed in the UK. This programme enhances palliative care through facilitating organisational change and supporting staff to develop their roles around palliative care. The PACE partners will perform a Phase III clinical trial to compare the “Route to Success” with care as usual, studying its impact on patient and family outcomes, quality of dying, quality of palliative care, cost-effectiveness and staff knowledge, practices, and attitudes. The intervention will run for 15 months in four facilities in each country, after which a second cross-sectional study of deaths will be performed. PACE aims to include 12 facilities (6 controls and 6 interventions) in each country, providing a database of at least 240 deaths.

A lasting legacy for palliative care

The results of these studies will allow PACE to furnish new, solid evidence concerning the effectiveness of palliative care. This will focus on quality of dying, quality of end of life care and cost-effectiveness – and provide baseline cross-country evidence to inspire further research in this domain. The project will also advance the field of long-term care practice: large scale population-based databases in the PACE countries provide important opportunities for national and international health care agencies to benchmark their own performance.

The introduction of a palliative care approach into facilities is also very new – and challenging: today, palliative care is still perceived as “terminal care”, or care for people in the final days/weeks of life. However, as described by the WHO, palliative care is applicable early in the disease course when possibly life-prolonging treatments are still available. Even though residents of facilities are not all terminally ill, facilities can benefit from a palliative care culture, screening residents for palliative care needs in a systematic manner.

PACE project partners

<table>
<thead>
<tr>
<th>PACE project partners</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vrije Universiteit Brussel (Coordinator)</td>
<td>Belgium</td>
</tr>
<tr>
<td>AGE Platform Europe</td>
<td>Belgium</td>
</tr>
<tr>
<td>Universiteit Gent</td>
<td>Belgium</td>
</tr>
<tr>
<td>National Institute for Health and Welfare</td>
<td>Finland</td>
</tr>
<tr>
<td>European Association for Palliative Care</td>
<td>Italy</td>
</tr>
<tr>
<td>Università Cattolica del Sacro Cuore</td>
<td>Italy</td>
</tr>
<tr>
<td>Alzheimer Europe</td>
<td>Luxembourg</td>
</tr>
<tr>
<td>European Forum for Primary Care</td>
<td>The Netherlands</td>
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<td>Stichting Katholieke Universiteit</td>
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<td>Stichting VU-VUMC</td>
<td>The Netherlands</td>
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<tr>
<td>Uniwersytet Jagiellonski</td>
<td>Poland</td>
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<tr>
<td>Lancaster University</td>
<td>UK</td>
</tr>
</tbody>
</table>
PredictND: earlier diagnosis and quicker treatment of dementia

The PredictND project will develop tools to enable earlier diagnosis of neurodegenerative diseases and thus provide quicker access to treatment. Mr Kari Antila, Project Coordinator, speaks to Alzheimer Europe about the objectives and challenges of the new project.

What is the PredictND project and what are its aims?

PredictND (an acronym for From Patient Data to Clinical Diagnosis in Neurodegenerative Diseases) is a four year, EUR 4.2 million European project that started in January 2014. Our primary aim is to develop tools and means for earlier, evidence-based and data-driven diagnosis of a range of neurodegenerative diseases (NDs) such as Alzheimer’s disease, vascular dementia and fronto-temporal dementia. Our approach was successfully demonstrated in helping to diagnose Alzheimer’s disease¹ and now we are extending it for a range of other diseases. Specifically, we will develop a clinical protocol with a range of tests suitable for an evidence-based diagnosis for differentiating these NDs. We also plan to develop a low-cost battery of tests for cost-effective and earlier detection of NDs in a larger, non-clinical population. This data will be analysed in a software tool developed earlier for a computer-assisted diagnosis of Alzheimer’s disease that is now being extended for the purposes of the differential diagnosis of NDs.

PredictND consortium members are VTT Technical Research Centre of Finland (Finland), GE Healthcare (UK, Sweden), Imperial College London (UK), University of Eastern Finland (Finland), Rigshospitalet (Denmark), VU/VUmc (the Netherlands), Università degli Studi di Perugia (Italy) and Alzheimer Europe (Luxembourg). The project is partly funded from the European Union’s Seventh Framework Programme for research, technological development and demonstration.

What are the main achievements and challenges of the project so far?

During the first six months we have done an extensive study on the archives of our clinical partners to

see which data they have collected from their patients with memory problems. The study of this data is essential not only to learn which tests are considered valuable in different clinics, but to build a reference database to be used with the software. When the test results of a new, yet undiagnosed patient come in, they will be compared against a pool of data for patients with known outcome with the developed software. The heterogeneity and variation of the data forms a big challenge. However, it also gives a unique opportunity to learn which tests have the best power of prediction of the patient outcome.

**What do you hope will be the achievements at the end of the project?**

Dementia is a very widely and thoroughly studied subject. Quite naturally much of the research is very basic and fundamental and the results are probably years away. During this project we hope to produce results that can almost immediately impact on the clinical world. Much of our research work is based on existing results that we hope to implement to real hospitals in a practical and efficient way. Based on the data collected from the hospitals we hope to identify the most useful tests and develop the clinical protocol accordingly. In terms of software tools we hope to develop something that is usable, informative and technically feasible in a highly demanding environment such as a large hospital or a healthcare system.

**How will PredictND collaborate with other EU projects in the field?**

Brain images require processing and quantification to convert the key properties from visual to numerical form – and thus be included in the analysis. We have a close collaboration with the VPH-DARE@IT project that is also focused on differential diagnostics of people with dementia, but on a more technical level. We plan on using the models and tools developed in VPH-DARE@IT as we move closer to clinical practice. We will also closely monitor the technological and methodological progress around the Virtual Physiological Human (VPH) initiative and the activity of dementia-related trials, cohorts and research in Europe and beyond.

**How will this project benefit people with dementia?**

We hope that as a result of this project, people with dementia can get an earlier diagnosis and can better benefit from current and future therapies. Both doctors and patients should also have better confidence in the given diagnosis. Success on designing low-cost dementia tests would enable screening and detection of the first indications of dementia on an unprecedented scale. For European citizens, cost-effective diagnoses would give much-needed economic relief in a rapidly ageing population.
Policy Watch

18 Norway’s new plan to improve services for people with dementia
21 Exploring the financial and social impact of investing in dementia
23 Battling dementia on a global level
25 Scotland holds international dementia conference
Norway’s national dementia strategy will expire in 2015 and the government is already planning for the future. Minister of Health Bent Høie speaks to the Norwegian Health Association about both current and upcoming activities to support people with dementia in Norway.

Active involvement of people with dementia

“I think it is very sensible to involve people with dementia in the planning of our future dementia care”, began Minister Høie. “I am interested in having the patients themselves be involved when we make plans that can affect their lives. We are very much inspired by Scotland and the work they do, and have learned a lot about it through our communications with the Norwegian Health Association.”

The planning period for the Norwegian Government’s plan for dementia care, Dementia plan 2015, is expiring next year. The planning of a new strategy for dementia has already started, and according to Minister Høie, it will be natural to involve people affected by dementia in this work:

“It is logical for us to collaborate with the Norwegian Health Association in the planning of a dementia strategy, and to also have a direct dialogue with those who are affected by dementia. Norwegian Health Association has a lot of experience in this area, in addition to an international network, so it is natural for us to cooperate with the organisation.”

The Minister did not reveal if there will be a new dementia plan, or if the strategy for dementia care will be in a different form. “The dementia plan ends next year, and we have to decide if there should be a new plan, or if we should do something else.

We are in the process of developing what form the new dementia strategy will have, and before that process has reached its conclusion, I cannot give an answer.”

More knowledge needed

Dementia Plan 2015 is the government’s plan to strengthen the services for people with dementia and their families and carers. According to Høie, one of the biggest challenges is to get all of the municipalities to implement the plan. “The degree to which the municipalities implement the plan varies. About 18% have made their own plan for dementia care and that is good.”

There are also significant challenges in diagnosing dementia. Mr Høie said: “We need more knowledge to be able to give a correct diagnosis. Most people believe that dementia is something you get at the end of your life, but you can get it earlier in life and live with it for a long time. Last year’s annual national telethon had a focus on dementia, which contributed to more general information, but still more people need to know that dementia can be contracted early in life. This is also important when the municipalities are planning their care services.”

The Minister also acknowledged the active role of the Norwegian Health Association. “We already have a good cooperation with the Norwegian Health Association. We work together on the Dementia Plan, and on several other projects. I also...
see the important work the organisation do locally in the municipalities, both for people with dementia and their family and carers. I hope we can continue this good partnership.”

A regimen of healthy and regular activities

The Dementia Plan 2015 has three main focus areas: more day programmes, living facilities adapted to patient needs and increased knowledge and skills. Since the plan was launched, more people affected by dementia have access to activities on a daily basis, but there are still many who lack such opportunities.

The Minister commented that “we subsidise these activities and we see that the number of applications from the municipalities is increasing, but there still is more money than there are applications. We are looking into the policies for getting subsidies, and at possible changes.”

Mr Høie did not elaborate on the nature of the changes or on when this work might be completed. However, he is very confident that Dementia Plan 2015 is making good progress. “The most important contribution is the progress towards the three main focus areas of the plan. We have subsidies for day programmes, even if we do not have as many applications as we would like. More living facilities are being built, and we are increasing our knowledge and skills in geriatrics and dementia in our care services, which is very important. We are at a different place today than we were before the Dementia Plan 2015 was launched. We are not yet where we want to be, but the plan is working.”

Reduction of salt, sugar and fat

Norway has endorsed WHO’s goal of 25% reduction in deaths related to non-communicable diseases by 2025. According to Høie, the government has initiated several measures to reach this goal. “We want to reduce salt, sugar and fat in food, and have formed a council with representatives from the food industry. We launched a salt strategy in June, and the council has already, from the first meeting, agreed on common goals for reduction of salt in foods. This will be much better for the consumer, who will not have to read details on food packages to find out how much salt it contains.”

A long life in good health

In closing, Minister Høie provided a glimpse into future activities. “There will also be a new Public Health Report next year, focusing on two main issues: mental health and active ageing. One of the main goals is to reduce the number of early deaths related to nutrition and physical activity. Another goal is the quality of life through the lifecycle, and the importance of good mental health. We want to put mental health and physical health on an equal footing. The other new policy is active ageing. When people live longer, good and active ageing is important, so that we can sustain good health longer.”

“It is logical for us to collaborate with the Norwegian Health Association in the planning of a dementia strategy, and to also have a direct dialogue with those who are affected by dementia.”

BENT HØIE
**Dementia Plan 2015**

Dementia Plan 2015 is the Norwegian government’s plan to strengthen the services for people affected by dementia and their family and carers. It was launched in 2007, making Norway the first country in the world to have such a plan. The Norwegian Health Association was a strong advocate for this plan.

The Dementia Plan will emphasise three main focus areas:

- **Day programmes**: these programmes are meant to occupy and stimulate patients, be enjoyable and provide them with a meaningful daily existence.

- **Living facilities adapted to patient needs**: Nearly 80% of those who live in nursing homes have a dementia disorder. It is therefore important that new or renovated nursing homes and living facilities are built or adapted for persons with dementia or cognitive failure.

- **Increased knowledge and skills**: Medical expertise is to be increased both locally and through closer follow-up from the specialist health service with regard to diagnosis and treatment. It is important to use medical research to increase knowledge about causes, the development of disease and the forms of treatment.

**Involving people with dementia**

People affected by dementia are the experts on what it is like to live with dementia. The Norwegian Health Association is committed to user participation and believes that people affected by dementia can and should be involved in decisions about their care and should be able to influence decisions which can affect their lives. In 2014, the association established a group consisting of people affected by dementia.

The organisation of this group is based on the Scottish Dementia Working Group, which already has 100 members and whose mission is to be advisors for Alzheimer Scotland and the Scottish authorities in matters of dementia. The Norwegian group will operate in a similar manner, giving the Norwegian Health Association advice in relevant strategies and plans, participating in the development of specific projects and providing input to health policy. The objective is for people with dementia to become more involved and also contribute to the Government’s planning of a new dementia plan.

“More living facilities are being built, and we are increasing our knowledge and skills in geriatrics and dementia in our care services.”

**BENT HØIE**
Exploring the financial and social impact of investing in dementia

The first Global Dementia Legacy Event took place in London on 19 June 2014. After the nomination of Dr Dennis Gillings as World Dementia Envoy and the setting up of the World Dementia Council, this event was another step forward after the G8 Dementia Summit of December 2013 that set the Global action against dementia in motion.

There is now a global consensus that dementia is a challenge that has been ignored, down-played or mistaken for far too long. Against this background, Prime Minister David Cameron organised the 2013 summit that set the conditions for a global effort to raise awareness, delay the onset or find a cure for dementia. Lessons should be learned from cancer and HIV AIDS that have both benefitted from shared will and commitment to find a treatment.

Globally, the investment in dementia research is desperately low. The London School of Economics found that if a treatment were available, the onset of dementia could be delayed by 36 months and GBP 5 billion (EUR 6.2 bn) would be saved in the UK. Professor Martin Prince (King’s College, London) showed that the scale of dementia may be larger than thought before. Ageing is the most prominent risk factor and driver of the epidemic. By 2050, the bulk of the increase is expected to occur in middle income countries where the population is ageing at an unprecedented rate. The impact of dementia is overwhelmingly the largest contributor of disability and need for care out of all other chronic diseases.

Two factors determine dementia: brain development in early life, through nutrition and education, and exposure to cardiovascular risk factors. However, even if exposure to risk factors were reduced by a quarter, only 9% of the cases would be prevented.

Global solutions to fight back on dementia

At the Legacy Event, Mr Cameron and Dr Gillings identified four priorities to tackle dementia on a global level:

1. Market failure and incentives: only three out of the 101 dementia drugs developed between 1998 and 2011 have made it to the market. At the same time, pharmaceutical company losses reached around USD 50 billion (EUR 37.4 bn). The risks are high and the rewards too low. The development of genomics and personalised medicines is likely to be the way forward in the treatment of dementia and its causes. However, this would concern only a small group of people and make incentives for drug development even more critical. New incentives are critical in overcoming market failures, such as the extension of patent protection or lessons learned from orphan diseases.

2. Access to drugs: it takes far too long before a patient has access to a new drug. This reduces the financial benefits for the drug developer and patient access to innovative treatments.
Dementia is overwhelmingly the largest contributor of disability and need for care out of all chronic diseases.

The regulatory frameworks across the world are too rigid and not adapted to the specificity of dementia. Lessons learned from HIV AIDS show that, when faced with a terminal condition, some patients are ready to take a chance on a new treatment. Different proofs of success can be demanded while preserving the quality and course of patient safety. In case of unmet needs, the principle of allowing consenting patients earlier access to innovative treatments has to be right, both for the business and those who could benefit from a new treatment.

3. Lack of openness and collaboration: research is too disjointed with scientists working in different laboratories all over the world, using different data and trying different approaches. The creation of a digital platform could help join people with dementia, families, carers, academics, pharmaceutical companies, regulators and research funders to share knowledge and solutions in real time around the world. Another way forward is finding new ways to incentivise partnerships between science and business.

4. Generate higher levels of investments: funding must not only come from governments. Innovation in finance and the setting of priorities are fundamental. One possibility is more social finance. The UK has pioneered the growth of Social Impact Bonds: should social entrepreneurs solve a problem and save taxpayers’ money, they will be rewarded with state money. Other models are layered funds, like the Gates Global Health Innovative Technology Fund or the African Agricultural Capital Fund, where the donors take a first loss position to bring in new commercial investment.

Next steps

After the event, Prime Minister Cameron would write to the G7 leaders to encourage them to work on these four priorities together.
Dr Gillings indicated that he was exploring with the Bill & Melinda Gates Foundation how research barriers could be eliminated through adaptive licencing and new regulatory mechanisms.
Dr. Shekhar Saxena, a WHO Director, indicated that:
• WHO Global Health Observatory will proactively track global epidemiological dementia trends, partnerships, policy formulations and the implementation of care and support services; track investments in dementia research; improve the coordination of research and reduce duplication. WHO has the tools for this knowledge transfer and is ready to create such a network.
• WHO will include dementia in its programme on non-communicable diseases and provide guidance and support to national regulatory authorities to ensure equity of access to treatment.

Future Legacy Events will take place in Canada (organised jointly with France) and Japan in 2014 and the USA in 2015.
Battling dementia on a global level

Dr. Dennis Gillings was named World Dementia Envoy in February 2014. In this article, he speaks to Annette Dumas, EU Public Affairs Advisor for Alzheimer Europe, about his role in coordinating global efforts against dementia.

Alzheimer Europe: Congratulations for your appointment as World Dementia Envoy for the Global Action Against Dementia. Could you present this initiative and your role?

Dennis Gillings (DG): The clock is already ticking on the compelling declaration made at the 2013 G8 dementia summit in London which set in motion a global action against dementia. The creation of a World Envoy role was seen a vital element of the summit commitments because it presents a fantastic opportunity to champion the cause and stimulate much-needed action globally. I see my role as having two major strands of activity. First, supported by other members of the World Dementia Council (WDC) – more about which later – and other international experts, I will aim to stimulate innovation and coordinate global efforts to attract new sources of finance. Second, I will work with governments and stakeholders to tackle the financial, scientific and social barriers to innovation in dementia prevention, treatment, care, and, ambitiously, cure.

AE: Can you tell us about the remit and role of the World Dementia Council that was created by the UK Government?

DG: The WDC was created to identify and tackle the barriers to investment and faster progress on finding a disease-modifying therapy or cure by 2025. The way I see it, we have to be the activists that were so successful in agitating for action when the HIV AIDS epidemic hit in the 1980s. The Council is made up of experts in all aspects of this challenge: from the academic and research community, to philanthropy, to patient representative organisations and experts in care, as well as those from the world of pharmaceuticals and clinical research.

In harnessing all of this expertise, we are working on a plan to crack the main problems which are preventing more drugs being found more quickly and to increase investment in research.

AE: Which priorities have been identified by the World Dementia Council to achieve meaningful changes in the way dementia is addressed at global level?

DG: We are focussing on three priorities to achieve our target of finding a cure or disease-modifying therapy by 2025 and increasing investment into dementia research. The three areas are: barriers, finance and open science.

By barriers, we mean scientific hurdles such as the fact that too much research and investment is being lost at the point between pre-clinical research and in-human trials. This means we don’t have efficient translational research – the vital key to ultimately finding a cure. Also, candidate drugs often fail during the late phases and clinical trials (approximately 80% of new development projects fail during Phase II, another 50% fail through Phase III to launch). Thirdly, there are very high costs to developing a disease-modifying drug for Alzheimer’s, including the need for sophisticated biomedical technologies to scan the brain.

The second main area is finance. Investment in dementia research is woefully small when compared to other major diseases. In the UK from 2011–2012 investment in cancer research from government and charities was eight times higher than what was put into dementia. Why is this the case? I think the crucial problem is the ‘Risk-Reward Ratio’. Pharmaceutical companies will invest where there is some prospect of reward rather than an overwhelmingly high risk that the investment will be lost. In dementia drug develop-
ment the probability of successfully bringing a new drug to market is very low.
The third area is open science which includes big data and research collaboration. The potential of data is enormous when it comes to sharing research, ideas and failures in medical trials, so that the same mistakes aren't repeated. But before everything can be put out in the open, there are several challenges to overcome. These include how to ensure sufficient governance in order that 'big' data are used appropriately and confidentiality is respected; how to finance innovation sustainably; and building a highly trained workforce as a matter of urgency.

AE: Last June, the G7 Legacy Summit gathered a number of stakeholders who gave their views on how to address the current barriers and find solutions for greater investment in dementia research. What were the key recommendations and how will you measure the success of the implementation of these recommendations?

DG: First of all the event was a hugely encouraging step forward in the year of our work. It was exciting to see so many of the world's experts in all areas of the fight against dementia in one place, sharing ideas in investment, finance, prevention and care. I was pleased at the number of announcements on increased investment and research initiatives. For example, the UK launched the world's biggest study into dementia, led by the Medical Research Council and including major industry partners such as AstraZeneca and GSK.

Alzheimer's Research UK launched a new GBP 100 million (EUR 125 mn) research campaign, which builds on the announcement made last year by the Alzheimer's Society to spend at least GBP 100 million over the next 10 years on research.

The UK Prime Minister sent a letter to other G7 leaders marking the progress made since the 2013 G8 Summit and setting out the need for collective actions that will ensure the work is sustained on a truly global basis, including exploring the possibility of developing a Global Charter.

The overall conclusions from the legacy event were that it cannot be business as usual, otherwise we won't achieve the declaration commitment of a cure or disease modifying therapy by 2025. In order to do this we need global collaboration across the G7 and beyond, including WHO, OECD, as well as countries spanning the globe, particularly those with low to middle income. We also need to remember that there can't be a trade-off between care today and cure tomorrow, these things have to be done simultaneously with efforts going into improving both.

Lastly, as far as governments are concerned, this is an issue which shouldn't be restricted to health ministries, but their counterparts in finance and trade departments must play a role because of the potential for future costs of care to increase exponentially. It is important to spend a little now to save a lot later.

AE: Do you see a specific role for people with dementia and Alzheimer associations in this Global Action?

DG: Absolutely. At the heart of everything we do has to be people with dementia, their families and carers. The reason I took on this role was that I saw my mother live with dementia for 18 years until she died last year. It is with her in mind that I take on this challenge.

This is something which the whole of the community affected by dementia can be part of. A large component of my role and that of the World Dementia Council is to bring people together to share ideas about how things can be done in the best possible way. That goes for all parts of this challenge: from care, treatment and prevention whereby ideas are shared between people with dementia, their families and carers, through to research and sharing data of where trials or tests have worked or not.

There are fantastic examples of care around the world which we can all learn from, such as the Hogewey care home in the Netherlands which has recreated the life of its residents from their earlier life, so that the jarring surprise of modern advances doesn't shock them every day. Instead they are able to live in the reality that they know. This is a fascinating example of how care can be adapted with patients' needs at the heart of it all.

Another example is the Dementia Friends initiative in the UK, the idea of which comes from Japan originally and it would be fantastic to see it adopted by other countries in order to raise awareness and understanding of those living with dementia.
Scotland holds international dementia conference

On 9–10 June 2014, the Scottish Government hosted its first international dementia conference, as part of the increasing worldwide collaboration to tackle dementia in all its forms.

The two-day event aimed to inform international delegates about Scotland’s approach to improving the quality of care for people with dementia and their carers. Coincidentally, Scottish stakeholders learned about various international activities stemming from the G8 Dementia Summit in December 2013 – and also heard about EU actions to support dementia research and care, as well as individual countries’ efforts to deal with these burdens. The conference was chaired by Geoff Huggins, Scotland’s Acting Director of Health and Social Care Integration, with support from Alzheimer Scotland.

A showcase for Scottish expertise

The first day consisted of a series of presentations paired with round table discussions on Scotland’s initiatives to improve service performance, re-design and outcomes in three specific focus areas: diagnosis, post-diagnostic support and care management. These are all underpinned by Scotland’s human rights-based approach to services.

Diagnosis: Dr Gary Morrison, Medical Director of Scotland’s Mental Welfare Commission and Professor Graham Jackson of The University of the West of Scotland presented “Increasing Dementia Diagnosis Rates in Scotland 2008-11 and beyond”. They explained that a collaborative approach helped NHS Scotland to meet its dementia diagnosis target. They also defined the benefits of post-diagnostic targets in supporting timely diagnosis and described future steps to further improve these processes.

Post-diagnostic support: the presentation “National NHS Scotland dementia post-diagnostic support target” was shared between Kate Fearnley, Deputy Chief Executive, Alzheimer Scotland and Stephen Lithgow, Dementia Support and Development Lead, NHS Greater Glasgow and Clyde. They covered Alzheimer Scotland’s Five Pillar Model of post-diagnostic support and the development of the national NHS Scotland post-diagnostic target. In addition, they pointed out the benefits of the service to people with dementia and their families and carers.

Care management: Michelle Miller, Improvement Lead, National Dementia Care Improvement Programme and Jim Pearson, Deputy Director of Policy, Alzheimer Scotland, jointly presented “Mid-to-late stage dementia care coordination”. They began with the rationale behind Alzheimer Scotland’s 8 Pillars Model of community support. They also showed how the model was tested and measured in five areas across Scotland, including the role and contributions of various workforce sectors.

Each presentation was followed by round table discussions where the participants circulated among groups so that everyone could get to know each other. The discussions clearly showed that dementia is one of the foremost public health challenges – with Mr Huggins remarking that “dementia is too big for any one nation” – and also that Scotland has made remarkable progress in defining and addressing these challenges. The delegates agreed on the importance of a timely and accurate diagnosis, as well as access to a range of effective, safe and person-centred services that recognise and promote the human rights of the person with dementia.

The international perspective

On day two, the delegates were greeted by Alex Neil, Scotland’s Cabinet Secretary for Health and
“Scotland aims to be a beacon of best practices for caring for people with dementia.”

POLICY WATCH

Wellbeing and former carer of his father, who lived with dementia. Mr Neil thanked all the participants for their presence, including the international visitors from Ireland, Japan, Luxembourg, New Zealand, South Korea and the United States. He said that dementia is not just a health problem, but also a societal challenge and affirmed that “Scotland aims to be a beacon of best practices for caring for people with dementia”.

The agenda consisted of three panel sessions that focused on “Dementia in Scotland”, “International and European Perspectives” and “Country Perspectives”.

**Dementia in Scotland:** Agnes Houston (SDWG - Scottish Dementia Working Group), Jeannete Maitland (NDCAN - National Dementia Carers Action Network) and Tommy Whitelaw (Project Officer, Dementia Carer Voices).

Ms Houston spoke about the activities of the SDWG to improve services for people with dementia. Ms Maitland showed how NDCAN provides a similar role for carers and Mr Whitelaw related his experiences as a campaigner raising awareness of the issues surrounding dementia.

**International and European Perspectives:** Gill Ayling (Director, Global Action Against Dementia, UK Department of Health), Alex Teligadas (Director for Communication, Alzheimer Europe) and Gerry Martin (CEO, Alzheimer Society of Ireland).

Ms Ayling explained the initiatives taken by UK Department of Health as regards the Global Action Against Dementia initiative. Mr Teligadas gave an overview of Alzheimer Europe’s activities to make dementia a priority within the EU institutions, while Mr Martin gave an update of Ireland’s national dementia strategy, which is in the last stages of development and expected to launch within 2014.

**Country Perspectives:** Professor Ki Woong Kim (National Institute of Dementia, South Korea), Drew Holzapfel (Executive Director, Global CEO Initiative on Alzheimer’s disease, USA) and Dr Kentaro Horibe (National Centre for Geriatrics and Gerontology, Japan).

Prof Kim profiled the numerous activities that are in place to support South Koreans with dementia. Mr Holzapfel described the ongoing work of the CEOi, a coalition of private corporations investing in Alzheimer’s disease, treatment and care. Finally, Dr Horibe showed how the Japanese health system provides a complete range of services to people with dementia.

Mr Huggins ended the session with a summary of the days’ events, including a list of opportunities for future international collaboration called “The Edinburgh Agreement”. There was unanimous agreement to prioritise this list and to continue working together. Mr Huggins thanked the delegates for their active participation and closed the conference.
Dementia in the news

28 Dr Ana Díaz

30 Dementia Friends campaign

32 News from Alzheimer Europe members
Ana completed her PhD thesis entitled “Quality of Life and Anti-dementia Drugs: An exploration of the experiences of people living with dementia and their care-partners” in October 2013. She defended it on 7 February 2014 and she was officially awarded the title of Doctor in Philosophy on 27 June 2014 at Trinity College Dublin. The study took place between 2009 and 2013 and was conducted in Dublin, Ireland. Her supervisor was Suzanne Cahill, National Director of the Dementia Services Information and Development Centre and Associate Professor of Social Work and Ageing in Trinity College Dublin. Ana had been successful in receiving a three year scholarship for writing her PhD by the Atlantic Philanthropies.

Ana explains that whilst some anti-dementia medications exist that can alleviate the symptoms of dementia, their efficacy and value remain highly controversial. A key unanswered question, for example, relates to the clinical significance of the benefits reported in clinical trials, and most importantly whether such improvements represent a meaningful change to the quality of life of people living with dementia. Despite much research being undertaken on this topic, the views, expectations and experiences of the individuals who take these tablets everyday have rarely been sought.

With this in mind, Ana decided to investigate this topic and write her PhD on quality of life and dementia, putting the person with dementia at the centre stage. Her work investigated the expectations and experiences of a small sample of people with dementia recently prescribed an anti-dementia drug (anticholinesterase inhibitors or memantine) and of their family caregivers. The interviews were conducted at the time the person was diagnosed and first prescribed the drug and six months later. While collecting the data, Ana decided to combine qualitative interviews and a quality of life scale. The analysis of the data was performed using Grounded Theory techniques and also, in the thesis, Ana explored in depth the advantages and disadvantages of using each approach (i.e. qualitative and quantitative).

Quality of life domains identified in the study were akin to those reported in other studies on quality of life for older people (i.e. family and friends, keeping busy, remaining independent, feeling well about themselves and remaining healthy). Nevertheless the findings suggest the need to frame quality of life in the context of dementia as a complex and dynamic concept and to consider it from different levels: biographical preferences and current expectations of what may be normal and acceptable at this stage of the person’s life for each domain; how the person with dementia is perceived and treated by others; and the person’s understandings and images of dementia. This multilevel approach helped to understand how most participants were continuing to enjoy what to them was an ordinary and good life despite having to face several challenges and changes sometimes but not always dementia-related, including widowhood and other chronic health problems. Participants’ narratives included elements of uncertainty, fears, concerns and at times clear efforts to explicitly ignore the implications of having been diagnosed with dementia.
“We have an easy life, just get up in the mornings and do your own bits and pieces.”

“I fear about the future but I am good at burying my head in the sand and not thinking about it.”

Participants’ discourses reflected a desire to hold on to their current good lives and for many, the anti-dementia medication represented a hope for not progressing to what was perceived as real dementia, something considered by most as devastating. Whilst representing an important hope for these people, the study showed the limited involvement and knowledge about the drugs that participants had at the time they started to use them.

“I have a good life, I just want to keep it.”

“I just take it [tablet]. I don’t even need to know, I just take it.”

Findings demonstrate the complexities surrounding the way in which participants evaluated their experiences with the anti-dementia drugs over time. Drug benefits occurred in the context of the progression of dementia and of other age-related health problems, and, most importantly in the context and complexities of the participants’ own lives.

“I think yes, the drug has worked but also I suppose I just came to terms with it [diagnosis] ... that I have this [Alzheimer’s disease] and this is the way it is, and I rather keep going and make the best for life.”

Participants talked with uncertainty, ambiguity and hope about the benefits (or lack of) of the anti-dementia drugs. Findings suggest that people living with dementia found it more meaningful to talk about changes experienced over time rather than about concrete benefits they could categorically say were exclusively associated with drug use.

Typically participants referred to gaining a greater sense of normality, feeling empowered and experiencing continuity with their former identities and lives rather than to whether their memory or functioning had improved. This is an important difference between what drugs may represent to people with dementia and their families and the agendas of other stakeholders (e.g. pharmaceutical industry and regulatory bodies) that most often focus on the impact of the drugs on cognitive and behavioural functions.

“I feel more confident in myself and I feel, others, like my sister as well have more confidence on what I can or can’t do.”

“She seems to be mentally stronger and more like her old self. Her sense of humour, it’s like her old self, like her personality started showing through again.”

An important implication for practice and policy arising from this PhD study is the need for individualised services and methodologies that can help people with dementia and their families to be meaningfully involved in the decision-making about drug initiation, continuation and discontinuation. In addition, the comparison of different research methodologies (qualitative – quantitative) allowed Ana to evaluate how each method of collecting data about quality of life in dementia could be improved.

ANA DIAZ

“The views, expectations and experiences of the individuals who take these tablets everyday have rarely been sought.”

Ana would like to express her gratitude to the Living with Dementia Programme and in particular to her supervisor, Associate Professor Suzanne Cahill for her guidance, support and intellectual stimulation throughout the way of completing the thesis. She also wishes to thank Jean Georges and her other colleagues at Alzheimer Europe for their support and encouragement over the last months of the thesis.
Dementia Friends: making society more inclusive

Dementia Friends was launched in 2012 as part of Prime Minister David Cameron’s Challenge on dementia. Since then, the initiative has garnered over 370,000 followers in the UK. Programme Manager Nikki Crowther speaks to Alzheimer Europe about the background and aims of this successful campaign.

“Dementia Friends is about learning more about dementia and turning that understanding into action.”

NIKKI CROWTHER

“My name's Gina and I have dementia”, announces 62-year old Gina Shaw from Liverpool in the TV ad which beamed into living rooms in England this Spring, encouraging people to become a Dementia Friend. In the ad, Gina bravely bursts into a solo rendition of the Beatles classic “I get by with a little help from my friends” and is swiftly joined by a host of celebrities including Chris Martin, Lilly Allen, Ruth Jones and Terry Pratchett, who are all supporting the campaign.

People with dementia get by with a little help from their friends and through Alzheimer’s Society’s joint initiative with Public Health England, anybody can become a Dementia Friend. It involves completing a short session either online or carried out in person by one of our Dementia Friends Champions. The idea is that it allows people to understand a bit more about dementia and the small things you can do to help people with the condition live well.

A better understanding of dementia

Recognising the difference between the natural ageing process and the first signs of dementia can be difficult. But understanding more about the disease and knowing where to turn for support can help people with dementia live better for longer. Dementia touches the lives of millions of people across the UK and beyond. We know from people who use Alzheimer’s Society services that all too often people with the condition experience loneliness and social exclusion. Alzheimer’s Society believes everyone has a role to play in gearing up to support people with dementia.

Whether people attend a face-to-face Information Session or watch the online video, Dementia Friends is about learning more about dementia and turning that understanding into action. From telling friends about the Dementia Friends programme to getting in touch and staying in touch with someone you know living with dementia, every action counts.

An Alzheimer’s Society survey found that less than half of people feel they have a good understanding of dementia. As the brain gradually shuts down, people with dementia sometimes need a helping
hand to go about their daily lives and feel included in their local community. This is what Dementia Friends wants to provide. We know from our 2013 report looking at dementia and loneliness that a third of people with dementia report to have lost friends after diagnosis and over two thirds have stopped doing things they used to because of a lack of confidence.

Developed by Alzheimer’s Society, the rationale for this idea came from the voices and experiences of people living with and affected by the condition. You cannot refute that initiatives which aim to make society more inclusive have an important place.

As part of the Prime Minister's Challenge on dementia, Dementia Friends was launched in 2012 and is funded by the Cabinet Office and the Department of Health. Since then the initiative has garnered widespread support from public and we’ve seen the numbers grow.

Making a difference in people’s lives

To date we have over 370,000 Dementia Friends across England and Dementia Friendly Community related activity is taking place in Wales and Northern Ireland too. In February 2014, Wales began a year-long pilot of the Dementia Friends programme funded by the Welsh Government. People across England, Northern Ireland, Wales and Scotland can also access the online Dementia Friends short film. We do recognise that Dementia Friends is not a fix all; people with the condition are more likely to experience loneliness, lose friends and feel excluded from society. This is not about pitting one thing against another. We need to tackle dementia on all fronts and we know from speaking to people who use Alzheimer’s Society services that social isolation has a huge impact on their day-to-day lives.

Alzheimer’s Society continues to campaign on issues affecting people with dementia and their carers. Our care system is underfunded. People are paying too much for inadequate care. Alzheimer’s Society has campaigned and will continue to campaign for our broken care system to be fixed. Dementia Friends is in no way designed to replace paid for carers or other trained staff. It is about helping more people with dementia live well in the communities by ensuring their neighbours and friends have a better understanding of dementia. We know that small actions by individuals can make a big difference to people’s lives and that is what the programme is about.

Join us today and help create more communities that are dementia friendly. Go to dementiafriends.org.uk to find out more about the Dementia Friends programme and how we are changing the way people think, talk and act about dementia. We hope that with help from around the world, it has even greater potential to succeed.

The Dementia Friends ad can be seen on www.youtube.com/watch?v=LfrnWrpPq54
AE member news

Alzheimer Europe highlights some activities of its member associations

7 May: Alzheimer Croatia celebrates 15 years

On 7 May 2014, Alzheimer Croatia (AC) celebrated the 15th anniversary of its founding. A special celebratory Alzheimer Café was held in Zagreb’s “Gradska Kavana” in the main square. Ambitious plans were presented, some of which are already in the pipeline. The “Forget me not” blog was launched, with useful tips and information and weekly advice given by caregivers. AC became active on Facebook, Twitter and Linkedin and contacts with the media also increased.

Recently, Alzheimer Cafés were also held in Pakrac and AC is currently preparing to spread this concept to other Croatian towns. The idea is to encourage the founding of local organisations which will be active under the umbrella of the national organisation. The first local organisation was founded in Lipik, the second in Dubrovnik and soon there will be others in Osijek, Split and Rijeka.

Raising public awareness about Alzheimer’s disease and the activities of AC is encouraging an increasing number of citizens, who up until now have battled the challenges of Alzheimer’s disease alone, to come to AC and seek help. The Alzheimer Croatia Caregivers Counselling Centre has doubled the number of hours spent with caregivers, doing individual and group counselling, education and giving support. The number of calls to the helpline have also significantly increased.

AC’s new activities have increased the number of members by 52% in the first half of the year. They now have almost 1,000 members, mostly from Zagreb.

Under the auspices of Croatia’s President, dr. sc. Ivo Josipović, AC is organising Alzheimer’s Disease Awareness Month, to be held this coming September in various towns and cities across the country. One of the activities that will be initiated during this event is the widespread education of professional caregivers and General Practitioners regarding the early signs of Alzheimer’s disease.

Iceland’s FAAS elects new chairman

The national Alzheimer’s association of Iceland, FAAS appointed a new Chairman, Árni Sverrisson on 15 May. Mr Sverrisson has been working in Iceland’s health sector since 1980. During this time he spent 31 years as CEO of St Joseph’s Hospital in the Icelandic port city of Hafnarfjordur. In 2006 he also became CEO of a nursing home and began to take an active interest in Alzheimer’s disease and other dementias. In 2010, his father was diagnosed with Lewy Body dementia.

He has been on the Board of FAAS for one year already and when he was asked to run for the position of Chairman earlier this year, he jumped at the chance.

Mr Sverrisson is 61 years old, married with four children and has a degree from the Commercial College of Iceland. In 2008 he took an AMP (Advanced Management Program) at the University of Reykjavik, Iceland and the IECE, Barcelona, Spain. He is very much looking forward to this new challenge at the helm of FAAS.
29 June: Monaco’s Kate Williams completes Ironman challenge

Kate Williams, Events and Public Relations Officer at AMPA Monaco, successfully completed an Ironman Triathlon challenge consisting of the following events: a 3.9 km swim, a 180 km bicycle ride and a marathon (42.1 km) run, raced in that order and without a break.

Competing under the AMPA colours, Kate raced alongside 2,800 participants and finished the event in 11 hours and 6 minutes with the following results: 5th in her age group, 29th overall woman and 607th overall racer.

Following the race, she said: “I think I can honestly say that it was one of the biggest days of my life, a fantastic experience that I will never forget. I sincerely believe that competing for Alzheimer’s disease gave me even more motivation and determination. Thanks to friends and sponsors, I have managed to raise EUR 4,500 for this noble cause.”

23 July: Slovenian President to patron 25th AE conference

President Borut Pahor has accepted to act as honorary patron of the 25th Alzheimer Europe conference, which will take place in Ljubljana in October 2015. President Pahor responded to an invitation from the Slovenian dementia association Spominčica and has endorsed the efforts of the association to raise awareness about dementia in the country.

Spominčica is also working to overcome the stigma surrounding dementia. In May 2014, six of eight Slovenian MEPs signed AE’s European Dementia Pledge as a result of the energetic campaign run by the association.

President Pahor is aware of the global problem of dementia. His support and patronage of the conference will also help Spominčica to prepare and adapt the Slovenian national dementia strategy, which will be finalised this year.

Slovenia’s Spominčica mourns the loss of Dr Aleš Kogoj

Spominčica regrets to announce the passing of Dr Aleš Kogoj, President of the association, following a mountaineering accident in early July.

Aleš Kogoj, M.D., Associate Professor of Psychiatry at the University in Ljubljana, was born in 1962. He studied medicine and later specialised in psychiatry. In 2000, he became head of the gerontopsychiatry unit at the University Psychiatric Hospital in Ljubljana, where he had worked since 1986.

For 25 years, he held lectures about dementia and patient care all over Slovenia. He was an excellent diagnostician and an engaged and patient listener, helping dementia patients as well as their carers. In recent years, with his support and help, Spominčica succeeded to substantially raise awareness about dementia in Slovenia.

All individual members and local groups of Spominčica will try to follow his example and continue with his endeavours in the field of dementia awareness and support.
A helping hand for more care

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Together we make the difference.
Scotland’s national dementia strategy
Minister Alex Neil discusses Scotland’s National Dementia Strategy 2013-2016

New Scottish MEPS in Brussels
Scotland’s new MEPS express their views on making dementia a priority at home and abroad

Alzheimer Scotland: 20 years of Action on Dementia
A guided tour of Alzheimer Scotland, including the association’s history, current activities and plans for the future

Living with dementia
Henry Rankin, chair of the Scottish Dementia Working Group, describes his life after diagnosis

Caring for a relative with dementia
Christine Beaton, a member of NDCAN, shares her experience of caring for her mother
Scotland’s national dementia strategy

Scotland continues to be a frontrunner in caring for people with dementia and their families and carers. Alex Neil, Cabinet Secretary for Health and Wellbeing, speaks to Alzheimer Europe about the new National Dementia Strategy for 2013-2016 and also Scotland’s plans to expand international cooperation on dementia.

Alzheimer Europe (AE): What have been the main achievements of the first national dementia strategy?


In 2011, we published the Standards of Care for Dementia as well as the “Promoting Excellence” framework, which supports the health and social services workforce to meet the standards. All of this work has been based on strong collaboration in developing and implementing the strategy in a coordinated way.

We were very pleased that our three year diagnosis target was achieved nationally: the UK Alzheimer Society’s second annual dementia map (published in January 2013) shows that at March 2012, around 64% of those with dementia in Scotland were being diagnosed.

In April 2013, we introduced a further target which guarantees that everyone newly diagnosed with dementia will be entitled to at least a year’s worth of post-diagnostic support, coordinated by a named Link Worker.

In addition, Scotland’s Chief Nursing Officer has led an improvement programme with NHS Boards on the care of older people in hospitals. Since 2011, Alzheimer Scotland Dementia Nurse Consultants have been appointed to Boards across Scotland and over 400 Dementia Champions are in place, with another 200 still to be trained.

We have also provided integrated improvement support across local health and care systems, in order to help facilitate local whole-system change in dementia services. A final evaluation of that work will be produced soon.

AE: What are the key outcomes for Scotland’s 2013-2016 dementia strategy?

AN: Our overarching ambition is to see more people with dementia living a good quality life, preferably in their own homes, for as long as possible.

The first element is a timely, accurate diagnosis of dementia, as well as better post-diagnostic support for people with dementia and their families. As mentioned above, Scotland has already achieved a high diagnosis rate and we will work to maintain and even increase this important benchmark. After diagnosis, our target is to provide everyone with at least one year of support, based on a person-centred support plan administered by a specialised care worker.

Another vital element is to develop dementia-enabled and dementia-friendly local communities. These will allow residents with dementia to continue participating in community life and also contribute to greater awareness and reduced stigma.

We are also aiming to ensure that more people with dementia and their families and carers are involved
as equal partners in care throughout the journey of the illness. In addition, we are seeking to improve the respect and promotion of rights in all settings, together with improved compliance with the legal requirements in respect of treatment. Clearly, people with dementia in hospitals or other institutional settings must always be treated with dignity and respect.

**AE: What role did Alzheimer Scotland play in developing and implementing the policy?**

AN: Alzheimer Scotland has been instrumental in all aspects of conceiving, developing and managing the many aspects of the national dementia strategy and has been both a key partner and critical friend. In the development stages of Scotland’s first and second national dementia strategies Alzheimer Scotland played a key role in arranging and hosting, alongside the Scottish Government, a series of dementia dialogue events, bringing together people with dementia and carers, health and social care professionals to identify the key priorities for Scotland’s national dementia strategies. Scotland’s current national dementia strategy has 17 commitments. Alzheimer Scotland are key partners in the working groups responsible for implementing and monitoring each of the 17 commitments, including the National Dementia Strategy Implementation and Monitoring Group which, oversees all aspects of the strategy. Alzheimer Scotland also supports the Scottish Dementia Working Group and Alzheimer Scotland’s National Dementia Carers Action Network to ensure that people with dementia and carer are fully involved in all aspects of the national dementia strategy.

Alzheimer Scotland’s approach to developing, and offering, evidence and human rights based solutions makes a significant contribution to delivering the shared aim of transforming the lives of people living with dementia. Two key examples of this are Alzheimer Scotland’s 5 Pillar Model of Post Diagnostic Support and 8 Pillar Model of Integrated Community Care. The 5 Pillar model forms the basis of Scotland’s world leading post diagnostic support guarantee. An important commitment of the current strategy is to test Alzheimer Scotland’s 8 Pillar Model. We are currently supporting five 8 Pillar test sites across Scotland. The learning from these sites will help inform how the 8 Pillar Model may be adopted nationally.

**AE: Do you see a need for closer collaboration on dementia on a European/international level?**

AN: Dementia is clearly too big a challenge for any single nation. The need for international collaboration was recently demonstrated by world leaders at the G8 dementia summit in December 2013. Following the G8 Summit Declaration, the Scottish Government convened a two-day event in June 2014 to discuss opportunities and priorities for sustainable international and cross-sectoral collaboration. We invited delegates from around the world to focus on improving the quality of care in dementia services and the outcomes for people with dementia and their families and carers. After a series of discussions, we concluded that dementia is one of the foremost public health challenges of our time and that it is imperative that people get a timely and accurate diagnosis and access to a range of effective, safe and person-centred services that recognises and promotes the human rights of the person with dementia. We also noted that there is much good work going on in each of the participating countries and that there is a shared commitment to respond effectively to the challenge and to work collaboratively to accelerate progress.

We are now focusing on processes to prioritise and take forward collaborative action, in parallel with the broader work of the G7 legacy work. We look forward to continuing cooperation between our Scottish stakeholders and their international colleagues.
Scotland’s new MEPs speak out on dementia

Alzheimer Scotland asked the country’s new MEPs to express their views on making dementia a priority, both in Scotland and in Europe.

MEP Ian Duncan

Dementia is one of those issues where international cooperation is important in driving progress. This is why UK Prime Minister David Cameron has not only identified dementia as a health priority for his government, but has pushed action globally among the G7 group of countries. European countries have a vital role to play, and the expertise that exists in dementia care and research in Europe can support efforts not only here but across the world to improve care, pinpoint causes and find a cure for dementia.

The Alzheimer Europe conference in Glasgow provides an opportunity for Scotland to share our own expertise with the rest of Europe, and to learn from what is happening elsewhere.

MEP Ian Hudghton

The EU has identified the importance of addressing dementia and recognises that it is crucial involve all stakeholders to ensure the best level of care and support is available for people living with the dementia, their families and carers.

It is therefore crucial to share with other Member States the excellent work of the Scottish Dementia Working Group and the European Dementia Working Group as a way in which people living with dementia can be empowered to take a pro-active role in shaping the direction of policies that affect their lives.

Tackling the issue of dementia requires a coordinated approach by all Member States governments working together with the institutions of the EU (both the Commission and Parliament) to deliver the best outcomes.

As an MEP, I believe that the EU provides a perfect forum for policy makers to work with both domestic and European wide dementia organisations, researchers and people with lived experience of dementia to share their knowledge and experiences to develop informed approaches that will improve outcomes for people living with dementia, their families and carers.

MEP David Martin

Dementia is one of the greatest challenges of our times – one that every country in Europe must respond to. The European Union affords us an opportunity to collaborate to meeting this challenge, to use the expertise and resources of all member states to strengthen our response.

I am delighted that Scotland is hosting this year’s Alzheimer Europe conference. This is a great opportunity for practitioners, researchers and policy makers to come together to learn from successes and challenges elsewhere, to develop new collaborations and to take forward this important agenda.

I look forward to the conference spurring on a newly strengthened European commitment to continued efforts to improve the lives of people living with dementia in all member states. The EU has much to offer this agenda through its existing research and other funding programmes, but more can be done. We can see from those countries where a national plan or strategy has been put in place for dementia that this brings focus and cohesion. The creation of a European Dementia Strategy would bring cohesion to existing efforts and drive further
improvements in tackling dementia across the EU – this conference can be a first step on the road to such a Strategy.

**MEP Alyn Smith**

My priorities for dementia in Scotland are to ensure the Scottish Government dementia strategy 2013-2016 is continued to be delivered in full. Speaking to experts, people with dementia and their families and carers, it is clear to me that post-diagnostic support is crucial in helping support everyone affected and providing the best quality of life.

That is why included within our dementia strategy is the world-leading commitment that all people newly diagnosed with dementia will receive a minimum of 12 months’ worth of post-diagnostic support. This is a fantastic tool of support which will help everyone. However we should always looks for ways to improve support and I look forward to contributing towards that over this Parliamentary term and beyond.

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**MEP Catherine Stihler**

The rate of Alzheimer’s diagnosis is on the rise across the EU so I want to see improvements made to how Member States work together to fight against it by sharing best practice. Through better co-ordination and sharing of research we can help better diagnosis, prevention and treatment. This would increase the quality of life for those diagnosed with Alzheimer’s, as well as their loved ones.

Working together across borders and political groups we can achieve positive change for the road ahead. With ageing populations making Alzheimer’s more prevalent we need to act now – and we need to act fast. I will continue to support more money for Alzheimer’s research across the EU and look forward to building links with Scottish organisations during this new mandate.

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*Alzheimer Europe would like to thank Amy Dalrymple and Kirsty Yanik, respectively Head of Policy and PR & Marketing Manager for Alzheimer Scotland, for coordinating the MEPs’ responses for this article.*
The CAIDE Dementia Risk score is a validated tool to predict dementia risk, based on the presence of vascular risk factors in mid-life.

The App is intended for use by patients and health care professionals. It allows patients to detect their risk and provides suggestions to modify their risk factors. Moreover, it allows physicians to discuss preventive measures and thereafter monitor whether the patients’ dementia risk has decreased based on interventions and guidance provided.

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PROGRESS AGAINST ALZHEIMER’S DISEASE

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Get the lowdown on EU policy matters and Lilly visit our blog: www.lilypad.eu
Alzheimer Scotland: 20 years of Action on Dementia

Jim Pearson, Deputy Director of Policy, takes us on a guided tour of Alzheimer Scotland that includes the association’s history, current activities and plans for the future.

History

This year marks Alzheimer Scotland’s 20th anniversary. The organisation was established in 1994 by the merger of Alzheimer’s Scotland (a service provider) and Scottish Action on Dementia (a campaigning organisation). This was pre-dated by our Dementia Helpline, which was created in 1989 and celebrated its 25th anniversary in June.

Alzheimer Scotland is Scotland’s leading dementia charity. We are a membership-based organisation with approximately 7,000 members. We have approximately 1000 staff and 700 volunteers. Our core mission is to make sure that no one goes through the experience of dementia on their own. To achieve our mission we have two main goals which drive all of our work:

- Being the foremost provider of information and support services for people with dementia, their partners, families and carers throughout Scotland, and
- Being the leading force for change at all levels of society, protecting and promoting the rights of people with dementia, their partners, families and carers.

We have over 60 sites across Scotland, which provide care services and support, including: day activities, home-based care, one-to-one support and carer information and training. In addition, we make a very significant contribution to supporting people living with dementia across Scotland.

We spend over GBP 4 million per year of fundraised income to fund a number of key initiatives. We fund a network of Dementia Advisors across Scotland that support people with dementia, their partners, families and carers and work with local communities. In partnership with the Scottish Government we also fund Alzheimer Scotland Dementia Nurse Consultants who work to influence change and improvement at an executive level within Scotland’s National Health Service (NHS) boards. We fund our 24 hour Dementia Helpline, a free service which runs 365 days a year and provides crucial support to people with dementia, their families and carers and professionals alike. We also fund a Dementia Research Centre and Brain Tissue Bank in Edinburgh and support a Centre for Dementia Policy and Practice at the University of the West of Scotland. We work closely with a range of academic institutions and partners to ensure the next generation of health and social care staff have the knowledge and skills they will need to care for and support people living with dementia. In recent years, we have funded and opened several Dementia Resource Centres (with more planned). Our dementia resource centres provide a community resource where people can drop in and talk to our staff and receive information about dementia. They play an important role – alongside our dementia friendly communities and Dementia Friends initiatives – in breaking down stigma and the fear of dementia by bringing dementia into the high street.

The creation of the Scottish Parliament in 1999 has provided greater opportunity to influence change and our achievements in the early years of the Parliament include our role, along with other partners, in bringing about reforms of the law relating to Adults with Incapacity, Mental Health Care and Treatment and Adult Support and Protection, all of which are underpinned by Human Rights principles to ensure that the rights of the individual are paramount.

“Alzheimer Scotland has played a vital role in driving change and improvement in health care for people with dementia.”

Jim Pearson
A key success was campaigning for dementia to be recognised as a national clinical priority. This was achieved in 2007 with a target to increase rates of diagnosis in 2008; this continues to contribute to Scotland’s (relatively) high rates of diagnosis compared to other countries.

In 2009, we worked with the Scottish Parliament’s Cross Party Group on Alzheimer’s and the Scottish Human Rights Commission to create the “Charter of Rights for People with Dementia and their Carers in Scotland”. The charter received widespread cross party support from Members of the Scottish Parliament and, crucially, the backing of the Scottish Government. The Charter places the human and other legal rights of people with dementia and their carers at the centre of Scotland’s National Dementia Strategies.

**Current activities**

Alzheimer Scotland has been fully engaged as an equal partner in the development, implementation and monitoring of Scotland’s first and second National Dementia Strategies, published in 2010 and 2013. Listening to experiences of people living with dementia is extremely important to us. As well as listening to the experiences of our members and those who use our services, we also work in partnership with the Scottish Dementia Working Group and our National Dementia Carers Action Network. Both groups are equal partners and are represented alongside other stakeholders in every strand of the work to implement the national dementia strategy commitments.

Improving standards of hospital care for people with dementia has been a key priority of both Scotland’s first and second National Dementia Strategies. Alzheimer Scotland has played a vital role in driving change and improvement in health care for people with dementia. These include the development and implementation of National Dementia Standards and Promoting Excellence, a training framework which sets out the knowledge, skills, and behaviours expected of all health and social care staff. In partnership with the University of the West of Scotland we have trained 400 Dementia Champions who, supported by our Dementia Nurse Consultants, work within the NHS to act as change agents and promote best practice to improve the experience, care, treatment and outcomes for people living with dementia.
people with dementia, their families and carers. This includes the reduction in psychoactive medication and the promotion of non-drug therapies. So far, over 400 Dementia Champions have graduated. Another 200 Dementia Champions training places have recently been guaranteed by the Scottish Government. We recognised that our Dementia Nurse Consultants and Dementia Champions cannot deliver the improvements without leadership from NHS Board leaders. We worked with the Scottish Government, NHS Boards leaders and other partners to develop ten Key Actions to ensure each NHS Board and every hospital setting has a strategy to drive forward this improvement work.

A major landmark has been our role in obtaining a commitment from the Scottish Government to provide every person diagnosed with dementia in Scotland with a guarantee of a minimum of one year's post diagnostic support, from a named link worker, based on Alzheimer Scotland’s 5 Pillar Model of Post Diagnostic Support. One of the key commitments of the National Dementia strategy is to test Alzheimer Scotland’s 8 Pillar Model of Community Support. The 8 Pillar Model sets out a blueprint for coordinated and integrated community support for people living with dementia to enable them to live well in the community for longer. It builds on the one year Post-Diagnostic Support guarantee to ensure the impact of the investment in early intervention is not lost. We are currently working with a wide range of partner organisations to pilot the 8 Pillar Model at several sites across Scotland, with a view to adopting it nationally.
In addition, Alzheimer Scotland has been supporting improvements in care through Scotland’s Allied Health Professionals (AHPs) community. AHPs include occupational therapists; physiotherapists; speech and language therapists; podiatrists; and dieticians who work in hospital settings and within the community. The Alzheimer Scotland Dementia Nurses work extensively with AHP colleagues in their local NHS board areas. Many AHPs are also Dementia Champions and play a key role in delivering a range of non-pharmacological therapeutic interventions which tackle the symptoms of dementia.

**Future plans**

Alzheimer Scotland works to ensure that no one goes through the experience of dementia alone and to promote the highest quality of care, support and treatment for every person living with dementia. Working alongside people with dementia, carers and a wide range of other partner organisations we have made a significant contribution to bringing about real improvement for people with dementia, their families and carers. We are rightly proud of our achievements. However we also recognise that too many people still have poor experiences and that we cannot be complacent. We will continue to work with partners in Scotland and with the international dementia community, including Alzheimer Europe, to ensure that better outcomes are delivered for all people living with dementia. We will continue to work with partners to fully implement the commitments of Scotland National Dementia Strategy, including driving forward and consolidating the good progress on post diagnostic support and coordinated and integrated community support as set out in our 8 Pillar Model.

We are currently developing a multi-faceted awareness campaign to break down the stigma, fear and negative perceptions of dementia. The campaign is aimed at encouraging families to talk more openly about dementia so that they are more confident in seeking help earlier. We are also in the early stages of developing an advanced stage model for the highest quality of care and support of people with dementia as they go through transitions in the more advanced stage of the illness, including end of life care. As always, we will do so in partnership with a wide range of partners, including the Scottish Dementia Working Group and our National Dementia Carers Action Network. We will work with the Scottish Government and other partners to include a commitment to test the model in Scotland’s third National Dementia Strategy due in 2016. Our work in these areas will build on the post diagnostic support commitment and 8 Pillar model of integrated community support to ensure that people living with dementia receive the highest quality of care, support and treatment at every stage of the illness through seeking and getting a diagnosis, post diagnosis, living well with dementia for longer and end of life care. If successful, we will have made great progress in transforming the lives of people who live with dementia.

“Alzheimer Scotland has been fully engaged, as an equal partner, in the development, implementation and monitoring of Scotland's National Dementia Strategies.”

*Jim Pearson*
Living with dementia

Each person has a different experience of dementia. No two people have the same story to tell. Henry Rankin, chair of the Scottish Dementia Working Group, describes his life after diagnosis.

I was diagnosed with vascular dementia in 2011. When I was first diagnosed it took me a long time to come to terms with having dementia. It had a big impact on my confidence. I am a really sociable person but I was worried that I would meet someone and not remember their name so I didn't go out. I stopped walking to the shops as I panicked I wouldn't be able to find my way home. Overnight I started to doubt myself. I felt I could not talk about subjects I was passionate about as I felt as if my intellect was being challenged. I was scared to say something just in case it was wrong. I became frustrated with others but mostly with myself. In time I began to accept my diagnosis of dementia and I learnt to deal with some of the impacts on me and my family. I made contact with East Renfrewshire Carers Centre and then Alzheimer Scotland. They were incredibly supportive and I started to feel more positive for the first time since being diagnosed.

One of the most important things to me has to been to maintain my independence. For each challenge I face there can be adjustments made to help me. I now have a white board so I can remember daily tasks and also plan well ahead. When I was a police-officer I didn't use a diary but now I use one to keep track of what I'm doing each day. I have a mobile phone so I can contact family if I get lost. I speak to my grown-up children every day. Sometimes I think they're checking up on me but I like it as I can keep track of what they're up to as well!

Sometimes the word “can't” gets to you. One of the biggest impacts of my diagnosis was not being able to drive. Driving allowed me to be independent as well as being the family driver – I was always known as “dad's taxi”. I drove my children places to make sure they were safe and now I can't do that. I've had to change my routine and get used to my children driving me places or getting public transport. I try not to let this get me down. Now I like getting the bus and walking as these are things I didn't do very often before. I try to take every day as it comes. I don't think there is any point worrying about what you can or can't do, or what might happen in the future. There is always something that can be done to make my daily challenges easier and that is all I ever wanted. I don't want someone to do it for me, I want to do it myself.

“*I don't want someone to do it for me, I want to do it myself.***

*Henry Rankin*
Caring for a relative with dementia

Christine Beaton has been a member of Alzheimer Scotland’s National Dementia Carers Action Network (NDCAN) since 2011. In this article she shares her experience of caring for her mother who had vascular dementia and how she came to join NDCAN.

My Mum and I spoke on the phone every day. Although I didn’t think about it at the time, we were friends. When I think back it wasn’t Mum’s memory that made me think something was wrong. Mum was always very house proud. One day I walked into her living room and my eyes widened. The floor was dirty! You could usually eat your meals from Mum’s floor it was so clean. As I went to clean it I was filled with sadness and dread. What happened next is a blur of doctors’ appointments and social workers. Now I know that we were totally ignorant of what help was available. When Mum was diagnosed I ran my own business that I had to close. I didn’t know what was going to happen but I knew Mum needed me; however I didn’t know it would be for the next ten years. At first I wasn’t aware there was financial help available and when I did I felt weird about claiming to look after my own mother. Like so many others I didn’t see myself as a carer but as her daughter. There were times when I thought I would go mad with frustration. I got angry at times, I got fed up. More often than not I cried myself to sleep, if I got any sleep at all. Eventually I made the decision to move Mum into a nursing home for medical reasons. Nothing could compare with the guilt I felt that day. I felt I had no choice but the truth is I was offered no alternative. After a bad experience at the first nursing home we found another one Mum was happier in. I visited her every day and we went for walks or to a quiet room where I’d read to her or sing or just talk. By this time her vocabulary was limited but she occasionally laughed and engaged in her own way. It was around this time I got involved with Alzheimer Scotland’s National Dementia Carers Action Network (NDCAN). At the first meeting I met people from across Scotland, all of whom were supporting someone living with dementia – wives, daughters, husbands, sons. We talked briefly about why we’d come. Once we’d introduced ourselves we talked about what we could do to make carers’ lives less stressful.

That was over two years ago. NDCAN is now a cohesive group working towards improving the lives of carers of people living with dementia. We discuss issues relevant to carers and how to improve things; we meet regularly with Ministers at the Scottish Parliament; we speak at conferences; we train health and social care staff across Scotland – all from a carer’s perspective. We want to make positive change for carers of people living with dementia. Whilst for most of us it is too late to improve things for our loved ones and ourselves, we hope we can make things a little better for those who come after us.
Our members are helping people with dementia and their carers in 31 countries

- **Austria** – Vienna: Alzheimer Austria
- **Belgium** – Brussels: Ligue Nationale Alzheimer Liga
- **Bulgaria** – Sofia: Alzheimer Bulgaria
- **Bulgaria** – Varna: Foundation Compassion Alzheimer
- **Croatia** – Zagreb: Alzheimer Croatia
- **Cyprus** – Larnaca: Pancyprian Alzheimer Association
- **Czech Republic** – Prague: Czech Alzheimer’s Society
- **Denmark** – Hellerup: Alzheimerforeningen
- **Estonia** – Tartu: Estonia Association of Alzheimer’s Disease
- **Finland** – Helsinki: Muistiliitto
- **France** – Paris: Association France Alzheimer
- **Germany** – Berlin: Deutsche Alzheimer Gesellschaft e.V.
- **Greece** – Thessaloniki: Greek Association of Alzheimer’s Disease and Related Disorders
- **Iceland** – Reykjavik: The Alzheimer’s Association of Iceland
- **Ireland** – Dublin: The Alzheimer Society of Ireland
- **Italy** – Milan: Federazione Alzheimer Italia
- **Italy** – Rome: Alzheimer Uniti Onlus
- **Jersey** – St Helier: Jersey Alzheimer’s Association
- **Luxembourg** – Luxembourg: Association Luxembourg Alzheimer
- **Malta** – Msida: Malta Dementia Society
- **Monaco** – Monte-Carlo: AMPA - Association Monégasque pour la recherche sur la maladie d’Alzheimer
- **Netherlands** – Amersfoort: Alzheimer Nederland
- **Norway** – Oslo: Nasjonalforeningen Demensforbundet
- **Poland** – Warsaw: Polish Alzheimer’s Association
- **Portugal** – Lisbon: Alzheimer Portugal
- **Romania** – Bucharest: Societatea Alzheimer
- **Slovenia** – Ljubljana: Association “Forget-me-not”
- **Slovakia** – Bratislava: Slovak Alzheimer’s Society
- **Spain** – Madrid: Fundación Alzheimer España
- **Spain** – Pamplona: C.E.A.F.A.
- **Sweden** – Lund: Alzheimerforeningen i Sverige
- **Sweden** – Stockholm: Demensförbundet
- **Switzerland** – Yverdon-les-Bains: Association Alzheimer Suisse
- **Turkey** – Istanbul: Alzheimer Vakfı
- **United Kingdom** – Edinburgh: Alzheimer Scotland
- **United Kingdom** – London: Alzheimer’s Society
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Dignity and autonomy in dementia
Glasgow, Scotland, UK
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