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Alzheimer Europe Board
Heike von Lützau-Hohlbein (Germany), Chairperson
Iva Holmerova (Czech Republic), Vice-Chairperson
Maria do Rosario Zincke dos Reis (Portugal), Honorary Treasurer
Charles Scerri (Malta), Honorary Secretary
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Marie-Odile Desana (France)
Sabine Henry (Belgium)
James Pearson (UK-Scotland)
Sirpa Pietikäinen (Finland)
Jesus Rodrigo (Spain)
Štefanija Lukšič Zlobec (Slovenia)

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Dianne Gove, Director for Projects
Gwladys Guillory, Event and Conference Coordinator
Stefanie Peulen, Finance Officer
Alex Teligadas, Director for Communication
Grazia Tomasini, Administrative Assistant
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Welcome

The latter half of 2015 has been a busy time for all of us at Alzheimer Europe. I would like to begin by welcoming Vanessa Challinor, our new Policy Officer. At the same time, I bid farewell to Annette Dumas with a great appreciation for her excellent work in keeping us abreast of dementia-related activities in the various EU bodies over the past ten years.

AE has now released both of its annual research publications: the ethics working group has produced a training booklet for professional carers, while the 2015 Yearbook is dedicated to an overview of dementia-friendly initiatives in Europe. There is also a special report to celebrate Alzheimer Europe’s 25th anniversary.

In June, Austrian MEP Heinz Becker hosted our lunch debate on the global efforts that are underway to combat dementia – efforts that are now supported by many world leaders and include tangible plans for international cooperation. I am very pleased to see such progress, particularly as a former carer from a time when dementia was virtually unknown or ignored.

As you read this, we will be holding another lunch debate in Brussels with a focus on European cooperation on dementia. Alzheimer Europe will present the results of its Glasgow Declaration campaign, which calls for a pan-European dementia strategy and a national strategy in every country. I would like to express my profound gratitude to all the individuals from the organisations who worked to gather signatures from policy makers, organisations and citizens in their countries.

Our loyal readers will notice that the back cover of this issue differs from the usual invitation to the next AE conference. Exceptionally, we invite all Members of the European Parliament to support the new Written Declaration to have Alzheimer’s disease recognised as a public health priority. We are also counting on our member associations to remind their MEPs to sign up before the end of the year.

Dementia is also on the EU Presidency agenda: during an informal meeting held in September in Luxembourg, policy makers agreed on the necessity to improve dementia care and that dementia will remain a priority for the upcoming Dutch EU Presidency term. This is also the case for funding future dementia research: in June, the Innovative Medicines Initiative (IMI) named Pierre Meulien as its new Executive Director and he assures us that IMI will continue to help improve the lives of people with dementia.

Also in June, Switzerland hosted a conference of Europe’s German-speaking countries to discuss the challenges of dementia. I was very glad to participate in this event, where the Health Ministers from these five countries agreed to strengthen cooperation in key areas and also, with a further 11 nations, to recommend action within the World Health Organisation.

Our member organisations have also, as always, been very active. In Spain, a survey conducted by CEAFA has led to an official mandate to draft a national dementia strategy. France Alzheimer appointed a new president, Joël Jaouen and also held a conference to explore the influence of research on public policy. The Swiss Alzheimer Association also has a new Executive Director, namely Stefanie Becker. We wish both Ms Becker and Mr Jaouen every success in their new roles! This issue also includes a retrospective by Birgitta Martensson, who recently stepped down after a long tenure as head of the Swiss association.

Finally, this issue contains a special section on our 25th Annual Conference in Ljubljana. I am very pleased that we succeeded in attracting so many dedicated people who are willing to work together to improve the lives of people with dementia and their carers in every country in Europe. See you in Copenhagen in 2016!
Prioritising Dementia

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18 AE: an active partner in European projects
AE lunch debate focuses on global action against dementia


Mr Becker welcomed the participants and also gave a special mention to his fellow MEP Sirpa Pietikäinen (Finland) as “a driving force in improving care for people with dementia.” Ms Pietikäinen is a Vice-Chairperson of the European Alzheimer’s Alliance (EAA) and also sits on the Alzheimer Europe Board. Mr Becker introduced the topic by saying that the global view is the next step from the European view and the reverse is true as well: we can all benefit from efforts in other regions.

Dr Tarun Dua, Medical Officer for the Programme for Neurological Diseases and Neuroscience, WHO, was the first of three speakers. She presented “Dementia as a global priority for the World Health Organisation and report on the First Ministerial Conference on Global Action Against Dementia.”

Dr Dua noted that the number of people with dementia worldwide has tripled since 1950 and will almost triple again by 2050. Currently, there are some 47 million people living with dementia, of which 58% are in low and middle income countries – and this is expected to rise to 71% in 2050.

Dementia clearly has a huge economic impact, which was estimated in 2010 at USD 604 billion or EUR 545 billion. This amounts to 1% of global GDP (gross domestic product), making dementia the equivalent of the world’s 18th largest economy.

In economic terms, these costs are unevenly distributed: in low-income countries, they represent 0.24% of GDP or USD 868 (EUR 783) per capita while in high-income countries the costs are 1.24% of GDP and USD 32,900 (EUR 29,700) per capita.

There is also an uneven distribution in the societal costs of dementia, as the cost for informal care is predominant in countries with lower income. A growing and ageing population will only increase the reliance on informal care, even as advances are made in the formal care sector.

Finally, there is a need for a better public understanding of dementia, which is often considered as a normal part of ageing. The associated stigma leads to social isolation and delayed diagnosis and this can be exacerbated by unhelpful or dismissive service providers.
Dr Dua summarised the current state of affairs as follows: dementia is a major cause of disability in later life that is under-diagnosed or diagnosed late worldwide. There is currently no cure and medicines play only a limited role, while a substantial proportion of care takes place outside the formal health sector. Current care needs include early diagnosis, symptom management, and long-term support.

As a response to these needs, she presented several WHO dementia activities, starting with the “Dementia: a public health priority” report. This was published in cooperation with ADI (Alzheimer’s Disease International) in 2012, aiming to raise awareness of dementia as a public health priority at global level, articulate a public health approach and advocate for action at international and national levels. In 2013, Dr Margaret Chan, WHO Director General, took part in the G8 Dementia Summit and also attended the First Ministerial Conference on Global Action Against Dementia in March 2015. This conference attracted more than 450 delegates from 89 countries and had the following objectives:

- highlight the evidence on the global burden and impact of dementia
- encourage governments to take action to prevent dementia and improve care services
- discuss the need for assessing dementia care and monitoring progress
- stress the development of cures or disease-modifying therapies for dementia
- emphasise the need for increased investment and international collaboration in dementia research
- explore opportunities for supporting global cooperation and to move from commitment to action
- raise the priority accorded to global efforts to tackle dementia
- strengthen capacity, leadership, governance, multisectoral action and partnerships
- promote a better understanding of dementia, raising public awareness and engagement, including respect for the human rights of people living with dementia
- advance prevention, risk reduction, diagnosis and treatment of dementia
- facilitate technological and social innovations to meet the needs of people living with dementia and their caregivers
- increase collective efforts in dementia research and fostering collaboration
- facilitate the coordinated delivery of health and social care for people living with dementia
- support a gender-sensitive approach
- promote further work to identify and address barriers to dementia care, particularly in low-resource settings
- strengthen international efforts to support plans and policies at all levels
- support the efforts of the World Health Organization, within its mandate and work plans, to fulfil its leadership role in full collaboration with national and international partners to promote and monitor global efforts to address dementia
- facilitate the coordinated delivery of health and social care for people living with dementia
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- promote further work to identify and address barriers to dementia care, particularly in low-resource settings
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- support the efforts of the World Health Organization, within its mandate and work plans, to fulfil its leadership role in full collaboration with national and international partners to promote and monitor global efforts to address dementia

The delegates agreed on a call to action that includes the following points:

- highlight the evidence on the global burden and impact of dementia
- encourage governments to take action to prevent dementia and improve care services
- discuss the need for assessing dementia care and monitoring progress
- stress the development of cures or disease-modifying therapies for dementia
- emphasise the need for increased investment and international collaboration in dementia research
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- strengthen international efforts to support plans and policies at all levels
- support the efforts of the World Health Organization, within its mandate and work plans, to fulfil its leadership role in full collaboration with national and international partners to promote and monitor global efforts to address dementia

Dr Dua explained that the WHO’s main role will be to establish a Global Dementia Observatory that will provide data and analyse trends in dementia burden and response. This includes global epidemiological trends, policy formulation and adoption, country implementation through health and social care systems, research and partnerships. The organisation will also coordinate and facilitate global action and act as a link to other global initiatives through existing networks.

“’I can think of no other condition that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other condition that places such a heavy burden on society, families, communities, and economies. I can think of no other condition where innovation, including breakthrough discoveries, is so badly needed.”

Dr Margaret Chan, WHO Director General, at the G8 Dementia Summit (December 2013, London)
The second speaker was Dr Raj Long, UK Government Director for Integrated Development and Senior Regulatory Officer for Integrated Development at the Bill & Melinda Gates Foundation. Dr Long is also a member of the World Dementia Council and she explained that the UK Department of Health is developing an assessment of regulatory pathways for dementia. The aim is to provide a central information source that can optimise regulatory and patient access.

She also described the bottlenecks in developing medicines for dementia, citing an overall success rate of only 0.5% versus an average 4.1% rate for the entire pharmaceutical industry. This is being addressed by a new international expert group that aims to remove obstacles and improve on current methods of drug development.

**“This is the first time that ten leading regulatory agencies have convened with the EU to tackle dementia.”**

**RAJ LONG**

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### Global action against dementia

**What we must do**

<table>
<thead>
<tr>
<th>CIVIL SOCIETY</th>
<th>GOVERNMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise awareness and increase understanding</td>
<td>Develop and implement policies and plans</td>
</tr>
<tr>
<td>WHO</td>
<td>Increase investment in research</td>
</tr>
<tr>
<td>Provide a knowledge base</td>
<td>Improve health and social care</td>
</tr>
<tr>
<td>Assist countries with dementia plans</td>
<td></td>
</tr>
<tr>
<td>Monitor progress</td>
<td></td>
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</tbody>
</table>

**Source:** World Health Organization

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<table>
<thead>
<tr>
<th></th>
<th>HCV</th>
<th>Alzheimers Disease</th>
<th>MRSA</th>
<th>Industry average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preclinical</td>
<td>30.2</td>
<td>119.3</td>
<td>13.0</td>
<td>14.6</td>
</tr>
<tr>
<td>Phase I</td>
<td>10.5</td>
<td>33.6</td>
<td>4.7</td>
<td>8.6</td>
</tr>
<tr>
<td>Phase II</td>
<td>6.6</td>
<td>23.0</td>
<td>2.9</td>
<td>4.6</td>
</tr>
<tr>
<td>Phase III</td>
<td>1.7</td>
<td>5.8</td>
<td>1.8</td>
<td>1.6</td>
</tr>
<tr>
<td>Registration</td>
<td>1.1</td>
<td>1.0</td>
<td>1.1</td>
<td>1.1</td>
</tr>
<tr>
<td>Launch</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Overall success rate</td>
<td>2.0%</td>
<td>0.5%</td>
<td>4.6%</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

**Source:** Nature Reviews
Dr Long noted that this is the first time that ten leading regulatory agencies have convened with the EU to tackle dementia. They will mainly focus on clinical trials, with each agency working on individual aspects such as attrition analysis or the development of composite end points. The EMA (European Medicines Agency) will be the central coordinator for this project.

The final speaker was Gill Ayling, Deputy Director of Global action against dementia in the UK. Ms Ayling explained that the efforts of the WHO and Global action against dementia are in step with similar efforts funded by the EU. These include JPND (EU Joint Programme – Neurodegenerative Disease Research), IMI (the Innovative Medicines Initiative) and the ALCOVE project. The latter is being followed by the 2nd European Joint Action on dementia, which will be led by Scotland.

Ms Ayling also reminded the delegates that no single country, organisation or sector can “solve” dementia on its own; dementia does not recognise national boundaries, status or wealth – and neither will the solutions.

Mr Becker thanked the speakers for their informative presentations, which highlighted the need for these efforts to be supported at all levels, including the European Parliament and national governments. He was joined by Ms Pietikäinen, who said that people with dementia must not be considered as second class citizens and that they should be involved in all of these worthwhile projects. She also praised Alzheimer Europe and its members for their tremendous work to support people with dementia, adding that they deserve all the funding and resources we can give them.

Delegates at the lunch debate included MEPs Deirdre Clune (Ireland) and Ivo Vajgl (Slovenia), representatives from the pharmaceutical industry and the Innovative Medicines Initiative (IMI), as well as delegates from 23 Alzheimer Europe member associations.

Alzheimer Europe’s next lunch debate will take place in early December 2015.

“No single country, organisation or sector can ‘solve’ dementia on its own; dementia does not recognise national boundaries, status or wealth – and neither will the solutions.”

GILL AYLING
As Alzheimer Europe’s Strategic Plan (2011-2015) is coming to an end, it is important to evaluate past achievements and identify shortcomings before embarking on the development of a new strategic plan for Alzheimer Europe’s activities.

It was therefore vital for us to get an understanding of how satisfied or dissatisfied our member organisations were when it comes to the various activities which we carried out over the past years. Over three quarters (76%) of our members (see map for more details) participated in a survey to identify in how far our members were happy with how the organisation had addressed the four key strategic objectives identified in our strategic plan:

1. Making dementia a European priority
2. Supporting policy with facts
3. Basing our actions on ethical principles
4. Building a stronger organisation

We were delighted to see that all our past activities were rated as “excellent” or “good” by at least 75% of our member organisations which confirmed the verbal feedback we had already received on a number of activities (see table 1 for more details). Certain activities such as our Annual Conference, the campaign on the Glasgow Declaration, our monthly newsletter or the European Working Group of People with Dementia even received more than 90% of positive replies.

Based on this positive feedback, it seems clear that our members wish to see an evolution in our strategic thinking rather than a radical revolution and a break with the past. The new Strategic Plan (2016-2020) of Alzheimer Europe which has now gone out to consultation to our member organisations therefore builds on the success of past activities.

Our new strategic plan reiterates the focus our organisation gives to the respect of the rights of people with dementia and to the promotion of a rights-based approach to dementia. For that reason, a chapter on our organisation’s values has been included (See below).

Based on the feedback of members, the following strategic objectives were included in the first draft of our new Strategic Plan (2016-2020):

- **Objective 1:** Providing a voice to people with dementia and their carers
  – Aim: People with dementia and their carers should be full partners in policy development, research and service design
Objective 2: Making dementia a European priority – Aim: All European countries should have a comprehensive dementia strategy and the European Union should develop a European Action Plan

Objective 3: Promoting a rights based approach to dementia – Aim: Policies and research for people with dementia and their carers should be based on ethical principles

Objective 4: Supporting dementia research – Aim: Alzheimer Europe should become a trusted partner to represent the views of people with dementia and their carers in European dementia research

Objective 5: Strengthening the European dementia movement – Policy makers and researchers should fully involve Alzheimer Europe and its national member organisations in their activities

We look forward to discussing this draft with our members and to working in close collaboration with them to work towards our mission of “changing perceptions, practice and policy in order to improve the quality of life of people with dementia and their carers”.

Our values

Alzheimer Europe and its members fully commit to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

Alzheimer Europe and its member organisations affirm that every person living with dementia has:

- the right to a timely diagnosis
- the right to access quality post diagnostic support
- the right to person-centred, coordinated, quality care throughout their illness
- the right to equitable access to treatments and therapeutic interventions
- the right to be respected as an individual in their community
The Glasgow Declaration campaign: calling for a pan-European dementia strategy

Alzheimer Europe’s Glasgow Declaration campaign was launched in February 2015, aiming to collect 10,000 individual signatures from interested citizens all over Europe. The campaign also targeted organisations and policy makers in the EU and in every European country.

The Glasgow Declaration campaign ended on 30 November and the results would be presented at the European Parliament on 1 December 2015. As of 30 October, AE had collected over 7,600 total signatures from 7,400 individuals, 143 organisations and 96 policy makers – including 80 MEPs – who are shown in the table below. Alzheimer Europe wishes to thank all the signatories for their support. We are particularly grateful to our member associations for promoting the campaign in their countries.

### Policy makers who have signed the Glasgow Declaration

<table>
<thead>
<tr>
<th>Country</th>
<th>Signatories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>Heinz K. Becker, MEP; Barbara Kappel, MEP; Paul Rübig, MEP</td>
</tr>
<tr>
<td>Belgium</td>
<td>Frédérique Ries, MEP; Bart Staes, MEP; Hilde Vautmans, MEP</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>Ivo Komšić, Mayor of Sarajevo</td>
</tr>
<tr>
<td>Croatia</td>
<td>Biljana Borzan, MEP; Tonino Picula, MEP; Ruža Tomašić, MEP</td>
</tr>
<tr>
<td>Cyprus</td>
<td>Costas Mavrides, MEP</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>Jan Žaloudík, Member of the Senate; Milan Pešák, Member of the Senate</td>
</tr>
<tr>
<td>Estonia</td>
<td>Urmas Paet, MEP; Johanna Karimäki, MEP; Merja Kyliloen, MEP; Merja Mäkisalo-Ropponen, MP; Member of the Municipal Council; Sirpa Pietikäinen, MEP; Ulla-Maj Salin, Member of the Municipal Council; Sari Tanus, MEP; Pentti Tiusanen, Member of the Municipal Council</td>
</tr>
<tr>
<td>Finland</td>
<td>Lotta Ahola, Member of the Municipal Council; Anneli Jääätteenmäki, MEP; Johanna Karimäki, MEP; Merja Kyliloen, MEP; Merja Mäkisalo-Ropponen, MP and Member of the Municipal Council; Sirpa Pietikäinen, MEP; Ulla-Maj Salin, Member of the Municipal Council; Sari Tanus, MEP; Pentti Tiusanen, Member of the Municipal Council</td>
</tr>
<tr>
<td>France</td>
<td>Dominique Bilde, MEP; Françoise Grossetête, MEP; Elisabeth Morin-Chartier, MEP; Udo Voigt, MEP</td>
</tr>
<tr>
<td>Germany</td>
<td>Sofia Ribeiro, MEP</td>
</tr>
<tr>
<td>Greece</td>
<td>Marisa Matias, MEP; Sofia Ribeiro, MEP; Cristian-Silviu Busoi, MEP</td>
</tr>
<tr>
<td>Portugal</td>
<td>Sofia Kefalogiannis, MEP; Dimitrios Papadimoulis, Vice-President of the European Parliament; Sofia Sakorafa, MEP; Maria Spyra, MEP; Eleftherios Synadinos, MEP; Elissavet Vozemberg, MEP; Sofia Ribeiro, MEP; Cristian-Silviu Busoi, MEP</td>
</tr>
<tr>
<td>Romania</td>
<td>Sofia Kefalogiannis, MEP; Dimitrios Papadimoulis, Vice-President of the European Parliament; Sofia Sakorafa, MEP; Maria Spyra, MEP; Eleftherios Synadinos, MEP; Elissavet Vozemberg, MEP; Sofia Ribeiro, MEP; Cristian-Silviu Busoi, MEP</td>
</tr>
<tr>
<td>Ireland</td>
<td>Matt Carthy, MEP; Nessa Childers, MEP; Deirdre Clune, MEP; Luke ‘Ming’ Flanagan, MEP; Marian Harkin, MEP; Brian Hayes, MEP; Séan Kelly, MEP; Mairead McGuinness, MEP</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>Elena Gentile, MEP; Remo Sernagiotto, MEP; Damiano Zoffoli, MEP; Tom Jung, Mayor of Roer; Viviane Reding, MEP</td>
</tr>
<tr>
<td>Malta</td>
<td>Therese Comodini Cachia, MEP; Roberta Mutsola, MEP; Alfred Sant, MEP</td>
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<tr>
<td>Netherlands</td>
<td>Linda Voortman, Member of the House of Representatives</td>
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<tr>
<td>Poland</td>
<td>Elżbieta Katarzyna Lukacjewska, MEP; Krystyna Lybacka, MEP; Jan Olbrycht, MEP; Marek Plura, MEP; Dariusz Stopa, Siedlce County Executive: Bogdan Wenta, MEP; Sofia Ribeiro, MEP</td>
</tr>
<tr>
<td>Portugal</td>
<td>Marisa Matias, MEP; Sofia Ribeiro, MEP; Cristian-Silviu Busoi, MEP</td>
</tr>
</tbody>
</table>

(continued opposite)
Policy makers who have signed the Glasgow Declaration

Slovakia: Anna Záborská, MEP
Slovenia: Violeta Bulc, EU Commissioner for Transport; Tanja Fajon, MEP; Ivan Hršak, MEP; Zoran Janković, Mayor of the City of Ljubljana; Jana Jenko, MEP; Franc Jurša, MEP; Milojka Kolar Celar, Minister of Health; Anja Kopač Mrak, Minister of Social Affairs; Vlasta Nussdorfer, Human Rights Ombudsman of the Republic of Slovenia; Alojz Peterle, MEP; Jernej Rovšek, Deputy Human Rights Ombudsman of the Republic of Slovenia; Igor Šoltes, MEP; Patricija Šulin, MEP; Romana Tomc, MEP; Ivo Vajgl, MEP; Milan Zver, MEP

Spain: Rosa Estarás Ferragut, MEP; Juan Carlos Girauta Vidal, MEP
Sweden: Jytte Guteland, MEP; Peter Lundgren, MEP
United Kingdom: Anneliese Dodds, MEP; Ian Duncan, MEP; Theresa Griffin, MEP; Ian Hudghton, MEP; Linda McAvan, MEP; Alex Neil, Cabinet Secretary for Health and Wellbeing, Scottish Government; Alyn Smith, MEP; Catherine Stihler, MEP; Keith Taylor, MEP; Derek Vaughan, MEP; Julie Ward, MEP; Glenis Willmott, MEP

Alzheimer Europe thanks the following international organisations for their support
Alzheimer Europe’s ethics working group produces training materials for professional carers

The 2015 ethics report is aimed at health and social care professionals in care homes and hospitals who are faced with ethically sensitive situations and dilemmas. Dianne Gove, Director for Projects at Alzheimer Europe and Chair of the working group, speaks about the report.

In 2014, Alzheimer Europe’s ethics working group produced a report on the ethical dilemmas faced by informal carers and people with dementia based on vignettes (short stories) and ethical commentaries as well as background information to help readers make sense of some of the difficulties they may encounter and feel better equipped to tackle them.

Our aim in writing this year’s booklet was to provide training materials for health and social care professionals, in care homes and hospitals, faced with ethically sensitive situations and dilemmas, which will:

- enable them to reflect on a range of ethically challenging situations,
- empower them to tackle any they might encounter,
- enable them to reflect on the approach they adopt and
- (if they feel the need) enable them to justify the approach they adopt to themselves and anyone who might ask...
The booklet was produced by a group of renowned experts and highly trained professionals in the field of ethics and dementia care. The working group was chaired by Dianne Gove (Director for Projects, Alzheimer Europe) and also included a member of the European Working Group of People with Dementia and representatives from Alzheimer Associations. The final draft of the booklet benefited from feedback from independent health and social care professionals in the United Kingdom, Portugal and Finland.

Caring for people with dementia in an ethical manner is not an option but a fundamental component of good care. However, professional carers of people with dementia in care homes and hospital settings sometimes find themselves in situations in which it is hard to decide what, if anything, would be the right thing to do. It is particularly difficult to make such decisions when each possible option seems to be good for some people but not for others. In addition, professional carers may hold very different ideas about what is (morally) right or wrong (some may even insist that they know best) and on what basis a certain approach would or would not be ethically justifiable. Such issues are further complicated when acting ethically in the context of professional dementia care is incompatible with respecting established professional and institutional procedures or formal guidelines for care. Although the wellbeing of the person with dementia must be the central concern when providing care in care homes and hospitals, this must be balanced against other concerns related to the wellbeing and rights of other people such as informal carers (i.e. relatives and friends), co-residents with and without dementia and professional carers. In everyday practice, it can sometimes be a challenge to achieve this.

Achieving ethical care and learning how to deal with such situations takes place in a particular working environment, which is affected by a range of factors such as staffing levels, skills and training, collaboration with colleagues, the hierarchical structure, budgets, laws and organisational procedures. Despite these constraints, which determine to some extent the range of actions options available to individuals and teams, we emphasise the need for each health and social care professional to accept personal responsibility for ethical care and to address ethical dilemmas and challenging situations when encountered. To achieve this, they must be able to count on the support of their organisation. Ethical care must be a priority for those responsible for running the care homes and hospitals in which they provide care for people with dementia. It is essential that those responsible for the organisation/provision (rather than the direct/person-to-person delivery) of dementia care build an organisational ethical infrastructure (i.e. a general context/environment allowing ethical analysis and empowering professionals who have to tackle ethical dilemmas with skills and opportunities to share their thoughts). The last section of the booklet contains a message to organisations along with a few ideas on how to build up such an organisational ethical infrastructure.

The materials in the booklet should be used in the context of ongoing professional care training (e.g. with moderated group discussions, professional guidance and role playing). Ideally, the various information, guidelines, vignettes (short stories), commentaries and activities should be presented in stages (not all at once) and discussion adapted to the level of experience and knowledge of different health and social care professionals. We hope that this booklet achieves its goals and that it is both enjoyable to read and thought provoking. Copies are available online at: www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice

Acknowledgements

Alzheimer Europe would like to express its gratitude to the members of the working group (June Andrews, Lydie Diderich, Chris Gastmans, Jean Georges, Debby Gerritsen, Dianne Gove, Fabrice Gzil, Dana Hradcová, Julian Hughes, Caroline Kilty, Denis Mancini, Alistair Neimeijer, Lucilla Nóbrega, Eila Okkonen, Jan Oyebode and Nathalie Rigaux) and to the independent reviewers (Aileen Beatty, Patrícia Castro, Deolinda Fernandes, Gonçalo Fernandes and Roland Mbé Ngang).
Is Europe becoming more dementia-friendly?

Ana Diaz, Policy Officer of Alzheimer Europe, presents the main findings of the organisation’s 2015 Yearbook dedicated to an overview of dementia-friendly initiatives in European countries.

“From early on it has been important for me to make other people aware of my situation. Whether I have lived in a large or small community, my experience is that being open about my situation has made everyday life easier. People around me are accommodating and I feel included.”

ALV ORHEIM (EWGPWD)

The report: approach and methods

The 2015 Dementia in Europe Yearbook contains information on the development of dementia-friendly environments in Europe. It has been produced as part of the 2015 Work Plan of Alzheimer Europe, which has received funding from the European Union in the framework of the Health Programme.

33 organisations representing 31 countries have participated in this Yearbook (see table below). The European Working Group of People with Dementia (EWGPWD) has also contributed to this report and their members have provided personal accounts for each of the topics addressed in the report. Their testimonies provide a powerful insight into how people with dementia would like to see communities, villages, cities and countries become more dementia inclusive and dementia friendly.

Countries participating in the AE 2015 Yearbook

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Dementia-friendly communities in Europe

The 2015 Yearbook highlights the huge relevance of the work towards creating a society that is more inclusive and respectful of every citizen, and in particular of those living with dementia. This means a society where people with dementia can live well, enjoy meaningful lives, and feel safe, empowered and enabled to take decisions about how they want to live their lives as members of the community.

Good examples of such societies are provided in the concept of dementia-friendly communities. The term dementia-friendly community (DFC) has emerged in recent years and has developed rapidly in some parts of Europe. In the report examples of towns, cities, counties and organisations that are working towards becoming dementia-friendly are illustrated. The reports show that there are some countries in Europe where this concept has been implemented (Austria, Belgium, Germany, Ireland, Netherlands, Norway, UK), and many other countries where this concept is currently being developed or that are planning to develop it in the future (Denmark, Finland, Jersey, Luxembourg, Malta, Switzerland).

Whilst the concept of DFC is particularly suitable for creating communities that are more inclusive and where people living with dementia and their carers feel respected, supported, and included in everyday life, there are many other examples in Europe of countries that pursue this endeavour though more focused initiatives. The World Health Organisation (WHO, 2007) has developed a framework for creating age-friendly cities. The framework identifies the features of age-friendly cities in eight domains of urban life, namely outdoor spaces and buildings; transportation; housing; social participation; respect and social inclusion; civic participation and employment; communication and information; and community support and health services. These features overlap and interact.

Building on this framework, the report presents examples of policies and practices in Europe that may reflect efforts to become more inclusive and dementia friendly. The following core features are addressed in the report:

- outdoors: spaces and safety
- housing: adaptation schemes and the use of technology
- transportation: driving and public transportation
- social participation: participation in daily life and in social, cultural and spiritual life in the community
- social inclusion: stigma and involvement of people with dementia in the community
- civic participation: voting and employment

Some people with dementia and their carers feel isolated in their communities. This report has described multiple and varied examples of initiatives that are working towards making businesses, local shops, restaurants, government institutions, libraries, banks, theatres, grocery stores, museums, emergency service personnel, and any other sector of the community, more inclusive and respectful of people with dementia.

A main core action relates to tackling the stigma of dementia in our communities. Another priority could be to provide adequate training and skills to people in the community who are not part of the health and social systems, but who are part of the day-to-day lives of people with dementia, and to provide them with support so they can make small changes that can help to adapt their businesses or services to the needs of people with dementia. Tackling the stigma associated with dementia, promoting a more positive image, and changing societal attitudes to dementia are the stepping-stones for building a more inclusive and dementia-friendly Europe.

Another major change is the involvement of people with dementia in the policies and practices that matter to them. Understanding what is relevant to people with dementia and how they want to live their lives is paramount. People with dementia should be kept at the heart of the work to become dementia-friendly. In some countries, small or large scale consultations with people with dementia themselves have been carried out. In other countries, consultations take place, but often involve carers or the Alzheimer organisations as representatives of the rights and needs of people with dementia. An exceptional example of the involvement and participation of people with dementia is the development of working groups of people with dementia at local, national, European and International level.

Alzheimer Europe is very grateful to the EWGPWD and to the organisations and member associations that provided and reviewed the content of this year’s report.

“Your working life does not end on the day you receive the diagnosis, nothing has changed since yesterday other than you have an explanation for your difficulties. Do not make a quick decision, you will probably regret it”

HILARY DOXFORD (EWGPWD)
Alzheimer Europe: an active partner in European projects

AE reports on the recent progress of several European research projects

AETIONOMY project holds successful IMI review

On 29 September, the AETIONOMY project partners held an internal review with IMI experts in Brussels. The agenda included presentations from all five work packages, with a particular emphasis on the results achieved during the first 18 months of the five year project. The reviewers gave a very positive initial opinion – particularly on the imaging and clinical correlation work – and also provided guidance toward achieving the next set of deliverables.

The project also reached a recruitment milestone in September, as the first participant was included in its clinical study in France. The project partners look forward to more recruitment activity, notably in Sweden and Germany, once ethical approvals have been obtained. www.aetionomy.eu

AFE-INNOVNET promotes EU Covenant on Demographic Change on UN Older Persons Day

Each year on 1 October, UN International Older Persons Day is celebrated, this year for the 25th time. AFE-INNOVNET used this day as a platform to promote its upcoming EU Covenant on Demographic Change, via a press release and the use of social media.

The Covenant aims to gather all local, regional and national authorities, and other stakeholders, that commit to cooperate and implement evidence-based solutions to support active and healthy ageing as a comprehensive answer to Europe’s demographic challenge. It will be launched on 7 December 2015 at the Committee of the Regions in Brussels. www.afeinnovnet.eu

EMIF holds 2nd General Assembly

The EMIF project partners held their 2nd General Assembly in Ghent, Belgium on 22-24 June 2015. The assembly coincided with the halfway point of the project lifetime and was attended by some 100 delegates from all 16 work packages.

On the first day, the delegates heard updates from the EMIF-AD (Alzheimer’s disease), EMIF-Metabolic and EMIF-Platform project areas. The AD updates included three new papers published in the JAMA and Brain Journals and overall good progress on collecting new data. There are now four complete Alzheimer’s disease cohorts available on the platform and 21 further cohorts are nearing completion. The EMIF-AD partners are also working together with colleagues from AETIONOMY and EPAD, which are also IMI-funded projects.

The second day included the presentation of results from a study on dementia prevalence in electronic health records and outlines of two related studies that will investigate risk factors and treatment pathways for dementia. This was followed by a series of breakout sessions that dealt with specific topics, such as analysing a recent study that linked dementia with obesity, developing tools to support treatment pathway analysis and the ongoing development of the fingerprint browser.

The day ended with scientific presentations for each topic. On the EMIF-AD side, Dr Pieter Jelle Visser presented “Amyloid positivity in non-demented and demented subjects: prevalence and outcome.” This paper shows that amyloid positivity increases at high age, that not all subjects with AD are amyloid positive and that amyloid positivity is common in non-AD dementia. A clear conclusion is that subjects for clinical trials should be selected based on amyloid status and not only on clinical criteria. www.emif.eu
EPAD launches a new website on World Alzheimer's Day

On 21 September – World Alzheimer’s Day – the European Prevention of Alzheimer’s Dementia Consortium (EPAD), announced the launch of its new website. The website (www.ep-ad.org) is devoted to informing different audiences about the project’s existence, its progress and its achievements, including the scientific community, companies, people living with dementia, families and carers of people with dementia, as well as Alzheimer associations and the general public. http://ep-ad.org

NILVAD partners hold 4th General Assembly

The 4th NILVAD General Assembly took place in Thessaloniki, Greece on 13-14 May 2015. NILVAD’s clinical trial of nilvadipine for mild to moderate Alzheimer’s disease is progressing well, having met its recruitment target of 510 people on 31 March. The trial sites are located in nine European countries and 47 people have already completed the 18-month trial period. Several NILVAD partners are conducting sub-studies on frailty, blood flow and cerebrospinal fluid which are also well populated.

Also in May, NILVAD was featured on the European Commission’s Research & Innovation website. An article entitled “Major human drug trial underway for Alzheimer’s” covered all the aspects of the project, including a quote from Dr. Brian Lawlor, project coordinator: “We are trying to see if it alters the rate of progression of the disease. Animal trials gave promising results and the earlier pilot trial did give an efficacy signal as well.” www.nilvad.eu

PharmaCog researchers at the ECCN and EACPT conferences

The PharmaCog project has been very well represented at scientific conferences in the past several months, particularly at the ECCN and EACPT events.

ECCN, the 15th European Congress on Clinical Neurophysiology, took place in Brno, Czech Rep. during 30 September–3 October 2015. Susanna Lopez, Claudio Babiloni and Wilhelmus Drinkenburg presented a total of six papers at the congress.

In June, researchers Claudio Babiloni, David Bartrés-Faz, Régis Bordet and Pablo Martinez Lage all attended the 12th biennial Congress of the European Association for Clinical Pharmacology and Therapeutics (EACPT) in Barcelona.

Alzheimer’s disease was the focus of a key session of the conference, including presentations by all four PharmaCog delegates. They also featured in an interview where they discussed the development of new treatments and why previous treatment approaches may not have worked. In addition, they presented PharmaCog’s novel approach to develop new biomarkers in order to speed up successful drug development.

www.alzheimer-europe.org/Research/PharmaCog
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At Janssen, we understand that living with a mental illness or pain can feel confusing and isolating.

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That’s why we continue to make extraordinary efforts to help people lead healthier, happier lives. After all, a world free from the challenges and stigma of these conditions is our greatest wish.

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The image depicted contains models and is being used for illustrative purposes only.

Janssen Pharmaceutica NV
MEPs are making dementia a European priority
Dementia, a priority for Luxembourg’s EU Presidency
Pierre Meulien takes up office as IMI Executive Director
Swiss conference focuses on the challenges of dementia
Spain advances toward a national dementia strategy
France Alzheimer symposium focuses on policy and research
MEPs are making dementia a European priority

Members of the European Parliament have launched a Written Declaration calling for a European Alzheimer’s disease strategy

A group of 23 Members of the European Parliament (MEPs) have joined forces to issue a call to the European Commission and the European Council to recognise Alzheimer’s disease and related diseases as a public health priority in Europe. More specifically, the MEPs ask for the adoption of a comprehensive strategy to meet the challenges presented by Alzheimer’s disease and to promote research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers. The signatories as of 3 November are shown below:

“Alzheimer Europe gratefully acknowledges this initiative,” said Executive Director Jean Georges. “We are delighted that 23 MEPs from eight different political groups have given their initial support for a European dementia strategy. We fully support the proposal to have Alzheimer’s disease recognised as a public health priority, it echoes what we are calling for in our Glasgow Declaration. We hope that Members of the European Parliament will overwhelmingly support this call.”

Gerolf Annemans (Belgium, ENF)
Philippe De Backer (Belgium, ALDE)
Bart Staes (Belgium, Greens/EFA)
Filiz Hyusmenova (Bulgaria, ALDE)
Andrey Novakov (Bulgaria, EPP)
Georgi Pirinski (Bulgaria, S&D)
Biljana Borzan (Croatia, S&D)
Ivan Jakovčić (Croatia, ALDE)
Davor Ivo Stier (Croatia, EPP)
Ruža Tomašić (Croatia, ECR)
Lefteris Christoforou (Cyprus, EPP)
Neoklis Syllikitis (Cyprus, GUE/NGL)
Kateřina Konečná (Czech Rep., GUE/NGL)
Jiří Maštálka (Czech Rep., GUE/NGL)
Stanislav Počáek (Czech Rep., EPP)
Urmas Paet (Estonia, ALDE)
Merja Kyllönen (Finland, GUE/NGL)
Dominique Bilde (France, ENF)
Marie-Christine Boutonnet (France, ENF)
Mireille D’Omano (France, ENF)
Gilles Lebreton (France, ENF)
Dominique Martin (France, ENF)
Sophie Montel (France, ENF)
Georgios Epitideios (Greece, NI)
Stelios Kouloglou (Greece, GUE/NGL)
Sofia Sakorafa (Greece, GUE/NGL)
Eleftherios Synadinos (Greece, NI)
Theodoros Zagorakis (Greece, EPP)
Lara Comi (Hungary, EPP)
Tibor Szanyi (Hungary, S&D)
Matt Carthy (Ireland, GUE/NGL)
Seán Kelly (Ireland, EPP)
Luke Ming Flanagan (Ireland, GUE/NGL)
Brian Hayes (Ireland, PPE)
Liadh Ní Riada (Ireland, GUE/NGL)
Goffredo Maria Bettini (Italy, S&D)
Mara Bizzotto (Italy, ENF)
Gianluca Buonanno (Italy, ENF)
Aldo Patriciello (Italy, PPE)
Remo Sernagiotto (Italy, ECR)
Andreijs Mamikins (Latvia, S&D)
Petras Aušreličius (Lithuania, ALDE)
Valentinas Mazuronis (Lithuania, ALDE)
Rolandas Paksas (Lithuania, EFDD)
Bronis Ropė (Lithuania, Greens/EFA)
Therese Comodini Cachia (Malta, EPP)
Adam Gierek (Poland, S&D)
Jarosław Kaniowski (Poland, PPE)
Julia Pitera (Poland, EPP)
Bogdan Brunon Wenta (Poland, EPP)
Marisa Matias (Portugal, GUE/NGL)
Sofia Ribeiro (Portugal, PPE)
Liliana Rodrigues (Portugal, S&D)
Daniel Buda (Romania, EPP)
Cristian-Silviu Busăoi (Romania, PPE)
Maria Grapini (Romania, S&D)
Marian-Jean Marinescu (Romania, EPP)
Emilian Pavel (Romania, S&D)
Mihai Țurcanu (Romania, EPP)
Ivan Štefanec (Slovakia, PPE)
Jana Žitňanská (Slovakia, ECR)
Igor Šoltes (Slovenia, PPE)
Patricia Čulin (Slovenia, PPE)
Romana Tomc (Slovenia, PPE)
A Written Declaration is a text of a maximum of 200 words relating exclusively to a matter falling within the competence of the European Union. A Written Declaration can be submitted with a minimum of ten MEPs’ signatures from at least three political groups. They then have three months to present it to their colleagues for signature. For the declaration to get to the next stage and be forwarded to the EU institutions named in the text, it must attract more than half (376) of all MEPs’ signatures. If it has not been signed by at least half of the MEPs it will lapse. The Declaration is open for signatures until 5 January 2016.

**Written Declaration N° 0057/2015**

**Call on all MEPs to sign the European Parliament Written Declaration N° 0057/2015 on Alzheimer’s disease**

1. Alzheimer’s disease is an incurable neurodegenerative disease of the brain tissue that causes progressive and irreversible loss of mental functions, including memory

2. Six million people are affected by Alzheimer’s disease or related diseases in Europe, and the number of new cases diagnosed each year continues to increase

3. There is currently no curative treatment for Alzheimer’s disease, but some drug treatments can help to slow the process and early detection can assist in better supporting patients and their carers

4. The Commission and the Council are invited to recognise Alzheimer’s disease and related diseases as a public health priority in Europe

5. The Commission and the Council are therefore called upon to adopt a comprehensive strategy for meeting the challenges presented by Alzheimer’s disease. Research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers should be promoted

6. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission

Please sign the Written Declaration before 5 January 2016

Thank you

Ivo Vajgl (Slovenia, ALDE)
Milan Zver (Slovenia, PPE)
Clara Eugenia Aguilera García (Spain, S&d)
Izaskun Bilbao Barandica (Spain, ALDE)
Enrique Calvet Chambon (Spain, ALDE)
Agustín Díaz de Mera García Consuegra (Spain, EPP)
Juan Carlos Girauta Vidal (Spain, ALDE)
Esteban González Pons (Spain, EPP)
Luis de Grandes Pascual (Spain, EPP)

Pablo Iglesias (Spain, GUE/NGL)
Josu Juaristi Abaunz (Spain, GUE/NGL)
Paloma López Bermejo (Spain, GUE/NGL)
Ernest Maragall (Spain, Greens/EFA)
Maite Pagazaurtundúa Ruiz (Spain, ALDE)
Peter Lundgren (Sweden, EFD)
Martina Anderson (United Kingdom, GUE/NGL)
Ian Duncan (United Kingdom, ECR)
Emma McClarkin (United Kingdom, ECR)
Dementia, a priority for Luxembourg’s EU Presidency

In September 2015, European health ministers met to discuss priorities on dementia and the need for future collaboration amongst Member States and further action at EU level.

On 24-25 September 2015, health ministers along with EU Health Commissioner, Vytenis Andriukaitis gathered in Luxembourg for the Informal Meeting of Health Ministers (EPSCO) to share experiences on dementia, to allow for an overview on dementia policies within Member States and to reflect on common ground for further action with a particular focus on timely diagnosis and post diagnostic support.

The Luxembourg Presidency asked health ministers to address the following four questions:

**Question 1:** Is dementia a public health priority in your country and, if so, by what measures is it addressed?

**Question 2:** How can prevention, timely diagnosis and post-diagnostic support contribute to the reduction of the burden of dementia?

**Question 3:** How can EU level cooperation – through formal cooperation of Member States in the EU Governmental Expert Group on Dementia and through stronger coordination with relevant WHO initiatives – facilitate sharing of good practices and how can it support countries to develop and implement national dementia strategies/plans?

**Question 4:** Is there added value to discuss an EU strategy in the field of dementia and, if so, which aspects should be covered?

Health ministers were invited to keep in mind the ambitious initiatives that had already been brought forward by the World Health Organisation (WHO), the Organisation for Economic Cooperation and Development (OECD) as well as G8 health ministers at the summit in December 2013 under the G8 presidency of the UK. These initiatives were further developed at the first Ministerial Conference on Global Action Against Dementia held in Geneva in March 2015.

During the meeting, Luxembourg unveiled its multidimensional secondary prevention programme launched in June 2015, which could be used as a model of best practice amongst EU Member States. Ministers agreed that sharing of best practices was paramount and that many examples of good practice existed at national level. The added value of closer cooperation and coordination in the field of dementia was also highlighted.

― Lydia Mutsch
The Luxembourg Minister for Health, Lydia Mutsch went on to talk about the stigma of dementia, the need for greater investment in research and an adaptation of the role and training of healthcare professionals to deal with dementia and give the best care possible and policies to ensure opportunities for early diagnosis and ensure that those diagnosed, have appropriate individualised treatment.

At the press conference following the meeting Lydia Mutsch, said that dementia constitutes “a real socio-economic challenge, which seriously tests the viability of our healthcare systems and requires a multi-sectoral response”.

According to her, the ministers deemed that it was necessary “to adapt policies and improve care practices so that each person suffering from a dementia-related illness can receive the best care possible”. They also favoured an exchange of good practices via the existing EU and WHO forums, she explained.

Dementia is not only a priority of the Luxembourg Presidency, it was also recently addressed in 2014 under the Italian Presidency and will again be a priority in 2016 when the Netherlands take over the Presidency and continue to build on the work already carried out.

EU responsibility to act

Since 2008 when the French Presidency Council Conclusions kicked off the dementia agenda calling on the Commission to adopt an initiative in 2009 to combat neurodegenerative diseases, numerous initiatives at EU level have acknowledged dementia as a priority in the context of demographic ageing. Several Member States have now adopted either national dementia strategies or plans.

More and more Member States are attaching a high priority to dementia but still there is a lack of cooperation at EU level and Member States find it difficult to pool existing knowledge and make use of it in every day practice in the fields of health and social care. In February 2014, a group of governmental experts was created which aims at further promoting the exchange of good practices and experiences in the field of dementia. It is hoped the European Commission will change the status of this to a formal EU-expert group.

EU Health Commissioner, Vytenis Andriukaitis talked about the challenge dementia has added to health systems and said now was the time to act. He continued to say the Commission would work closely with Member States to tackle the growing number of people with dementia.

“...but the fight against dementia also requires an individualised approach and an intervention in due course, after an early diagnosis of the illness.”

LYDIA MUTSCH
The Innovative Medicines Initiative – forging partnerships to tackle Alzheimer’s disease

Pierre Meulien took up office as the new IMI Executive Director on 15 June 2015. In this article, he speaks about the dementia projects that have already been funded by IMI and the partnership’s continuing commitment to help improve the lives of people with dementia.

Alzheimer’s disease has been a priority for the Innovative Medicines Initiative (IMI) since the beginning. Earlier this year, three of IMI’s Alzheimer’s disease projects teamed up to form the IMI Alzheimer’s Disease Research Platform, something that will facilitate collaboration between the projects and accelerate progress. The platform also has close ties to the US-based Global Alzheimer’s Platform, further extending the reach of IMI’s activities. Alzheimer Europe is a partner in all three projects, and their input helps to ensure our projects remain focused on patients’ needs. Looking to the future, more projects on Alzheimer’s disease are in the pipeline, a clear demonstration that IMI remains committed to delivering research that will make a difference to the lives of people with dementia as well as their families and carers.

Alzheimer’s disease is a major priority for IMI, and the reasons for this are simple. It is an area where there is a huge unmet medical need, where safe, effective treatments are urgently needed, and where the burden on patients, families and society as a whole is immense. Most importantly, given the enormous complexity of the disease, it is an area where open collaboration, bringing together leading experts from universities, pharmaceutical companies, small biotechs, and (of course) patient organisations is essential for progress to be made, and that is where IMI comes in. By bringing these diverse partners together around a neutral platform, and by providing funding, IMI makes this large-scale open collaboration possible.

The first ever IMI project in this area is PHARMA-COG, which is now drawing to an end. PHARMA-COG’s focus was on improving our ability to identify the most promising new medicines of the future. The project team carried out research into tools and methods designed to improve our ability to identify successful new medicines as early as possible in the drug development process, while halting work on those destined to fail.

In March 2015, IMI’s work on Alzheimer’s disease was given a boost when three IMI Alzheimer’s disease projects, EMIF, AETIONOMY and EPAD, decided to form the IMI Alzheimer’s Disease Research Platform. Creating the platform facilitates collaboration between the projects and so will enable faster progress. In addition, a Memorandum of Understanding between IMI and the US-based Global Alzheimer’s Platform (GAP) gives the IMI platform a global reach.

Between them, the three IMI projects have a combined budget of EUR 138 million, and they jointly address many key challenges in Alzheimer’s research and drug development.
Using old data to get new results

Recent years have seen an explosion in the number of databases containing medical and research data, yet because this data is scattered across diverse platforms and stored in a variety of formats, it cannot be fully exploited. IMI’s EMIF project is developing a common information framework of patient-level data that will link up and facilitate access to diverse medical and research data sources, opening up new avenues of research. To provide a focus for the development of the framework, which also addresses legal and ethical issues, the project is focusing initially on Alzheimer’s disease (particularly the need to identify mechanisms that make some people more susceptible to dementia), and obesity. One of the project’s main achievements so far is the integration of four existing databases into one, single database which is now one of the largest databases of its kind in the world and therefore represents a unique tool for researchers to generate new findings.

Getting to the underlying causes of Alzheimer’s disease

Today, diseases are defined largely on the basis of their symptoms, yet while two patients may share the same diagnosis, the underlying causes of their symptoms may be very different. This means that a treatment that works in one patient may prove ineffective in another. There is now broad recognition that a new approach to disease classification is needed, and that is where the AETIONOMY project comes in. It is paving the way towards a new, mechanism-based classification of neurodegenerative diseases, particularly Alzheimer’s and Parkinson’s diseases, thereby improving drug development and increasing patients’ chances of receiving a treatment that works for them. The project has already developed an online knowledge database, a great tool for Alzheimer’s researchers. It is also making progress on generating information on potential underlying causes of Alzheimer’s disease.

EPAD – European prevention of Alzheimer’s dementia

One important way of tackling dementia could lie in treating people while they are in the very earliest stages of the disease, when they may have little or nothing in the way of symptoms. The EPAD project is creating a pan-European platform to identify and follow up patients identified as being at risk of developing dementia symptoms. EPAD will then draw on the platform to test a number of novel treatments designed to prevent the onset of Alzheimer’s dementia. By using a pioneering ‘adaptive’ clinical trial model, the project will be able to test multiple treatments at the same time, and analyse the results continuously. The adaptive trial model also allows a more rapid assessment of treatments and the identification of groups of patients that respond best to them.

Partnering with patients

At IMI, we are keen to ensure that patients are fully involved in medicines research and development. Alzheimer Europe is a partner in all of IMI’s ongoing Alzheimer’s disease projects, and their input on the needs and wishes of Alzheimer’s patients is a highly valuable contribution to the project. More broadly, through its EUPATI project, IMI provides in-depth information and training on medicines development for all patients wishing to get involved in research. Advice and guidance for patients can also be found on the IMI website.
An ongoing commitment to Alzheimer's research

Looking to the future, Alzheimer’s disease will continue to be a priority for IMI. Recent IMI Calls for proposals have included several topics on Alzheimer’s disease, and the resulting projects will be launched in the coming months. These projects will address issues such as the underlying biological causes of neuropsychiatric symptoms in Alzheimer’s patients; the genetics of Alzheimer’s disease; the use of imaging for diagnosis and drug development; and the use of ‘big data’ for Alzheimer’s research. In addition, a recent Call for proposals included a topic on Alzheimer’s disease and patient engagement. The goal of this topic is to identify the most effective ways of identifying and engaging with people who are in the very earliest stages of the disease. This will add to our understanding of the early stages of the disease, help patients access support from early on in their disease, and facilitate recruitment for clinical trials.

In summary, IMI remains committed to supporting projects that will make a very real difference to the lives of people with dementia as well as their families and carers, and we count on organisations like Alzheimer Europe, and their members and supporters, to help us achieve that.

About the Innovative Medicines Initiative (IMI)

The Innovative Medicines Initiative (IMI) is working to improve health by speeding up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need. It does this by facilitating collaboration between the key players involved in healthcare research, including universities, the pharmaceutical and other industries, small and medium-sized enterprises (SMEs), patient organisations, and medicines regulators.

IMI is a partnership between the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by the European Federation of Pharmaceutical Industries and Associations, EFPIA). Through the IMI 2 programme, IMI has a budget of €3.3 billion for the period 2014-2024. Half of this comes from the EU’s research and innovation programme, Horizon 2020. The other half comes from large companies, mostly from the pharmaceutical sector; these do not receive any EU funding, but contribute to the projects ‘in kind’, for example by donating their researchers’ time or providing access to research facilities or resources. Many IMI projects focus on specific health issues such as neurological conditions (including Alzheimer’s disease, as well as schizophrenia, depression, chronic pain, and autism), diabetes, lung disease, cancer, rheumatoid arthritis and related disease, infectious diseases (including a major programme on Ebola), and obesity. Others focus on broader challenges in drug development like drug and vaccine safety, knowledge management, the sustainability of chemical drug production, the use of stem cells for drug discovery, drug behaviour in the body, the creation of a European platform to discover novel medicines, and antimicrobial resistance. In addition to research projects, IMI supports education and training projects.

More info on IMI: www.imi.europa.eu
Follow us on Twitter: @IMI_JU
Alzheimer’s disease concerns us all

Europe’s German speaking countries held a conference in June 2015 to discuss the challenges of dementia. Tania Dussey-Cavassini, Ambassador for global health and Vice-Director General of the Swiss Federal Office of public health, discusses the outcomes and priorities for the future

“Who from the two of us has Alzheimer’s disease?” asked Birgitta Martensson, Executive Director of the Swiss Alzheimer’s Association. “Isn’t it you?” answered Rita, “or you?” pursued Birgitta.

This was the opening dialogue at the “Challenges of Dementia” Symposium, which took place in Bern in June 2015. Rita Schwager, a person living with Alzheimer’s disease in Switzerland, had the courage to stand on stage and share with a full room what it means to her to live with a disease for which there is no cure.

Alzheimer’s disease concerns us all. Although it is not “obvious” to recognise a person suffering from this illness, it is very present in our societies and our day to day lives.

Today, according to the latest figures of a report published by ADI, there are over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds. It is one of the key health challenges for our current and future generations. Often hidden, misunderstood and under-reported, dementia affects individuals, families and communities and is a major cause of disability.

Nearly 60% of people with dementia live in low – and middle – income countries. Due to demographic developments, this proportion will increase rapidly during the next decade, which may contribute to increasing inequalities between countries and populations.

By 2050, the number of people affected by dementia will triple and may reach up to 135 million. This represents more people than the entire population of Germany, Austria, Luxembourg, Liechtenstein and Switzerland combined.
By 2050, the number of people affected by the disease will triple and may reach up to 135 million. This represents more people than the entire population of Germany, Austria, Luxembourg, Liechtenstein and Switzerland combined. It is our responsibility to act immediately. It is for this reason that the Ministers of Health of these five German speaking countries decided to strengthen cooperation in this particular area.

The first jointly organized Symposium on the “challenges of dementia” took place in Bern on 4 and 5 June 2015. In his introductory remarks, Swiss Federal Councillor Alain Berset presented the Swiss “National Dementia Strategy 2014-2017”, main instrument to improve the quality of life for people with dementia. He emphasised the importance of partnerships and the key role stakeholders play in the implementation of this agenda. The experts from the five German speaking countries who exchanged best practices in dealing with the disease were a living proof of the importance of these partnerships. In the course of the group discussions, we developed approaches to address the following current challenges:

1. **Raising public awareness**

   We must ensure that our society understands the disease and the needs of those affected. Through a targeted knowledge transfer, we can reduce stigma and better support persons with dementia in everyday situations. Information campaigns, such as the one launched by the Swiss Alzheimer’s Association and Pro Senectute Switzerland, reach a large portion of the population.

2. **Prevention**

   To this day, dementia cannot be cured. However, an early diagnosis and treatment can attenuate the symptoms and slow down the progression of the disease. It is therefore crucial that we strongly embed prevention and the related research in our national strategies and action plans. In this respect, we need to focus more closely on the role of the family doctors with regard to early detection and post-diagnostic treatment.

3. **We need contemporary models for health care provision**

   Many persons with dementia receive care at their homes by relatives. Health care provision models must enable good home care and support the relatives in providing care. We have to promote projects such as dementia-friendly communities.

4. **Last but not least: Improved cooperation**

   There are already many health care services available for people with dementia. What we need now are information centres and customised, inter-professional care services. To date, however, the various care providers have no financial incentive to work together. Therefore, we need to develop new financing models, which allow for a combination of different health care services. Only then will we be able to make the best use of the services already available.

   The Symposium has shown that innovative approaches to address these challenges are already available. Implementation remains the key. Alzheimer’s and other related diseases also have to become a topic for the international actors in the global health arena. Together with 16 other Member States, Switzerland has requested that this topic be discussed at the Executive Board of the World Health Organization, with the aim to adopt a resolution at the World Health Assembly.

It is crucial that we strongly embed prevention and the related research in our national strategies and action plans.
Spain advances toward a national dementia strategy

In April 2015, CEAFA – the national Spanish Alzheimer association based in Pamplona – organised a conference to present the results of a survey carried out among its members. These results will be used to produce a global document that proposes a national policy on Alzheimer’s disease in Spain. In this article, Jesús Rodrigo, Executive Director of CEAFA and Board member of Alzheimer Europe, explains the methodology and results of the survey.

Mapping dementia in local communities

The survey was developed by CEAFA, the Spanish Confederation of Associations of Families of People with Alzheimer’s and other Dementias, as a first step toward implementing a national dementia strategy. There were 19 responses to the survey that focused on four key areas:

1. The number of people affected by dementia
This included people with dementia and their family members and the survey asked for details and sources on how prevalence was calculated. Respondents also described the services offered by the local CEAFA chapters and regional authorities, as well as the number of people reached by these services.
2. Health and social care coverage
In this section, respondents gave details on specific aspects of care, such as the care pathway of a person diagnosed with Alzheimer’s disease and the key elements of treatment within the health care system. They also provided information on the social care structures that provide support to people with dementia.

3. Specific needs and deficiencies
The survey also asked about the perceived needs and deficiencies in the health care system, especially in post-diagnostic support and the types of treatment offered. In the social sphere, respondents gave details of any shortcomings in the application of existing legislation to support family caregivers. This included specific information on economic hardship and the challenges faced by caregivers who are also employed.

4. This section covered any additional issues that had not been addressed
The survey results were processed into an overview that was reviewed by the respondents during a workshop sponsored by Lilly España. The result was a global document that presented conclusions and proposals toward the establishment of a national policy on Alzheimer’s disease.

Presenting the needs of people with dementia
The presentation of the results took place on 23 April at the headquarters of IMSERSO – the Spanish Institute for Older People and Social Services – in the presence of César Antón (Director General of IMSERSO), Teresa Millán (Director of Corporate Affairs at Lilly) and Koldo Aulestia (President of CEFA).

The report enumerates such basic needs as maintaining a census of people with Alzheimer’s disease and calculating the global cost of dementia. It also calls for a consistent level of care in all regions, improved coordination among the main stakeholders and better training for health and social workers. In all, the report contains over 20 recommendations to improve the lives and care of people with dementia and their families.

Collaboration on a national level
On 19 May, these results were presented to Alfonso Alonso, Spain’s Minister of Health, Social Services and Equality, during a meeting of the Grupo Estatal de Demencias. This group was established by IMSERSO at CEFA’s request in May 2013.

It includes representatives from the Ministry of Health, Social Services and Equality, NGOs that support people with dementia (including CEFA), associations of healthcare professionals, the Reina Sofia Foundation, the Spanish General Prosecutor’s Office and the country’s autonomous communities.

The group members work to coordinate and advise the efforts of public and private entities that collaborate on dementia initiatives and studies. After the May meeting, the group established six working groups with specific deliverables that will culminate in the first draft for a national Spanish dementia strategy.
France Alzheimer symposium focuses on national policies and dementia research

The symposium took place on 21 May 2015 and addressed relevant aspects of medical, economic and psychosocial research on dementia. It also looked at the influence of such research on public policies, notably the successful “Plan Alzheimer” strategies that have operated in France since 2001. Ana Díaz, Project Officer for Alzheimer Europe, reports on the event.

The event was held under the patronage of President François Hollande and offered participants a better understanding of the medical complexities and challenges of dementia – but also highlighted the positive impact of new technologies on disease detection and diagnosis.

The delegates were welcomed by Marie-Odile Desana, President of Alzheimer France and Prof. Charles Duyckaerts, director of the Neuro-CEB biobank. The conference agenda included presentations in four main subject areas and a series of round table discussions. The delegates also had the opportunity to visit the Neuro-CEB biobank.

New approaches for prevention and treatment

Dr Jacques Gaucher, Professor of Clinical Psychology at Université de Lyon Lumière II, presented his work on prevention and explained that older adults are now healthier and have better cognitive functioning. This is mainly due to better health habits and living conditions and new research suggests that prevention may be possible.

Further presentations explored the complexities of dementia as well as the progress in understanding the disease thanks to technological advances. For example, delegates learned how new technologies have influenced the move from the traditional “functional” approach in dementia – based on symptoms and impairments – to an approach...
that focuses more on pathology, i.e. on genetic and mutation factors. This new and rather complex approach goes beyond the amyloid hypothesis; it invites us to re-imagine Alzheimer’s disease and to think more creatively about treatment.

**Focusing on capability, not impairment**

The audience was also introduced to the “capabilities” approach. During the round table, examples of how this approach could be used in dementia care were discussed.

The word capability goes beyond the capacity of the person and incorporates aspects of social justice and freedom, opportunities, personal choices and being valued by others. This approach invites us to look at what a person with dementia can still do, rather than focus on his/her impairments.

Examples of how this concept has been used in dementia care were presented, for example as part of home care services and also in an intervention involving people with dementia and theatre.

**A resurgence of French dementia research**

Prof. Joël Menard, one of the architects of the original Plan Alzheimer (2001-2005), provided a frank overview of the impact of the third plan (2008-2013) and explained that France’s contribution to European research is less than that of other countries, such as the UK. However, the past few years have seen an increase of publications from French researchers in international journals and more visibility of French researchers in European and global research.

This is also reflected in the new Neurodegenerative Diseases Plan (2014-2019): Prof. Michel Clanet, who heads the team implementing the plan, explained that there is a desire to better define the role France will play in research in Europe and worldwide, citing projects such as COEN, JPND and Global Action Against Dementia.

France Alzheimer has contributed some EUR 6.6 million to dementia research over the past five years. Most of this (approximately 75%) has gone to “basic” research, i.e. research that is conducted in laboratories, but also to psychosocial studies.

**The cost of dementia: a persisting challenge**

The cost of dementia was also discussed by Prof. Menard and Dr Bérengère Davin, an economist and researcher at INSERM, France’s Institute of Health and Medical Research. They stated that providing an accurate estimate of the cost of dementia is very complex, as is the case for most chronic illnesses. This is compounded by the difficulty in assessing costs of informal care. They added that several new studies are underway.

**Research as a democratic innovation**

Throughout the event, it was apparent that there has been a great deal of progress in dementia research and prevention, but also in the social aspects of support for people with dementia and their carers in France. However, there was also general agreement that much remains to be done.

In terms of research, there is a need for a more coordinated, interdisciplinary and coherent approach. This may help to better understand the pathology but also the human dimension of dementia. Most importantly, it will help people to live well “in spite of, with or outside of” dementia.

Seen from this perspective, research was defined as a “democratic innovation”, which is shared by researchers but also by the wider community – but this sharing is only possible with the involvement of private citizens.

In its 30 year lifetime, France Alzheimer has been very successful in building and maintaining channels between citizens, health and research professionals and policy makers. The association’s work and its achievements are well known and respected in France and also in many other European countries. We are sure that this excellent work will continue and look forward to further innovations from our colleagues at France Alzheimer.
Dementia in the news

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Meet Joël Jaouen, the new president of France Alzheimer and Related Diseases

The board of directors of the France Alzheimer and Related Diseases Associations’ Union (France Alzheimer) elected Joël Jaouen as its new president in June 2015. In this article, he gives us his first impressions of the job and his hopes for the future. Alzheimer Europe would like to thank Marie-Odile Desana, former president of France Alzheimer, for arranging this interview.

For the past thirty years, France Alzheimer has held that “for every patient, there is a whole family in need of help”. The new president is in line with this notion of support for the sick and their families. He hopes to improve the medical, social and financial support for patients and their families. Having supported his father for years, he was personally affected by Alzheimer’s disease. Having been a family helper, he got involved as a volunteer with France Alzheimer’s regional Finistère Association which he has presided since 2011. He was elected managing director of the national Union in 2008. Joël Jaouen is also vice-president of the CISS Bretagne, an umbrella organisation of non-profit groups that advise citizens on health care issues.

“Together, yes, we have the means to make progress.”

JOËL JAOUEN

After a few months as president, what is your state of mind?

Joël Jaouen: “It is the same as when I first volunteered in 2003, with some additional responsibilities. First, I applied only after having gone through a long and mature personal thought process. Also, I am by no means a superman, but rather a realistic blue collar determined to forward our cause and to do everything I can to help families.”
Finally, because this election’s foundation is a collective project which relies on the commitment of my administrator colleagues of the Union and that of my volunteer friends in the regional associations. One point I am absolutely aware of is that it will be a challenging task. But is this task as hard as the one which is faced by families which are weakened by the disease? I sincerely doubt so..."

**You seem extremely determined to succeed in your new position.**

JJ: “Following through with our ideas is an obligation because families, our donors, our partners and the professionals we train each year all trust us. Betraying them is unthinkable. This determination is fuelled by my personality, my professional background and my personal and family experience with the disease. This determination is above all a reaction to a situation which calls for action on everyone’s part. There is no other outlet, in light of today's needs in terms of care, information, support, social, legal and financial aid which families are expressing and which we observe on a daily basis.”

**Does France Alzheimer have the means to influence the evolution of care?**

JJ: “Not only does it have the means, but it has been doing so for the past 30 years. By offering concrete proposals, by putting forth numerous appeals to public authorities, by providing care for families, by triggering and responding to calls to action, by speaking out for families, it has become a major player in the field. It remains an uphill battle. But our association must now rely on its expertise and notoriety to further weigh in on political decisions. Again, France Alzheimer is backed by millions of families, thousands of volunteers and donors, hundreds of private and public supporters, etc. Together, yes, we have the means to make progress.”

**In September, you attended your first World Alzheimer’s Day as president of France Alzheimer. What can you say about this 22nd edition?**

JJ: “I can say there was an outstanding rallying of an entire network to shed light on a cause which affects us all. How wouldn’t I be confident in our ability to rally the public when I see the turnout at our events and the thousands of friendly and encouraging messages we received during this September 21st event? It is up to us to rely on the strength of our network of volunteers, our legitimacy and the broad confidence which we instil to suggest concrete solutions to the current challenges which are to support working family care-givers, to adapt care for younger patients, to fine-tune professional training due to the complexity of the disease, to address the disastrous financial difficulties which come from the disease and finally to target communication to show that life with the disease is possible and that those affected and their care-givers are above all humans who should not be marginalised.”

“**Our association must now rely on its expertise and notoriety to further weigh in on political decisions.”**

JOËL JAOUEN
Marketing skills also for dementia!

Birgitta Martensson is leaving the Swiss Alzheimer Association after 15 years as Executive Director. In this article, she looks back at the challenges of obtaining funding and gathering political support, but also the satisfaction of seeing the launch of the Swiss national dementia strategy. Birgitta has joined the board of ADI and continues to help improve the lives of people with dementia and their families.

From services to advocacy

The Swiss Alzheimer Association was founded in 1988 by family carers who despaired of finding appropriate help, information and services, along with the support of a few dedicated professionals.

In 2001, when I became the executive director, the association already had 18 regional chapters in the cantons and 6,000 members. Today we have 21 chapters covering the whole country, 10,000 members and 130,000 donors.

Our activities were mostly carried out by people directly concerned as family or professional carers and on a voluntary basis, with a focus on direct help and support for family carers. The national office provided information materials, training and supervision, organised holiday weeks for people with dementia accompanied by family carers and participated in various consultations. Money was scarce, but solidarity and collaboration saw us through our initial challenges.

My very first activity was to find more money, which was successfully achieved by launching a massive fundraising campaign. The results of our very first mailing were way ahead of expectations and we rapidly reached break-even. We also managed to secure increased financial support from the government. We could finally start planning a less precarious future.

Factbox: dementia in Switzerland (2015)

- 780,000 people are directly affected in their daily life
- 119,000 people with dementia
- 360,000 family carers
- 300,000 professional carers

Basing policy on facts and figures

My next concern was to collect facts and figures, in order to understand where we should place priorities and what we should “sell to society” (strongly influenced by my business and marketing background). There were no official data on dementia in Switzerland and prevalence was a mere guess. Looking for examples, I found Alzheimer Scotland’s report “Signposts for future” and we used this as a model for our first report on estimated prevalence, living conditions, probable needs for care and services. While a lot of hypotheses and guesses went into the report, our conclusions were solid enough to attract attention.

In the following years we continued producing reports on relevant topics, like the gap in care provisions, the consensus on diagnosis, treatment and care by the best dementia specialists in Switzerland. Our “Priority Dementia” manifesto attracted 50,000 signatures from people who supported our claims for better conditions for people with dementia and their carers.
In 2009, two motions were submitted to the federal Parliament, asking that Switzerland develop a national dementia strategy. Our study on the total costs of dementia (published in 2010) played a decisive role in getting the motions through both chambers in spring 2012 with a very solid support from parliamentarians from all political horizons.

Dementia on the national agenda

The strategy was elaborated in a surprisingly short time and involved participants from all concerned circles. It was adopted in November 2013 and defines four areas requiring priority action. Implementation is based on the federal division of tasks between the three levels of government – confederation, cantons and municipalities. Most of the sub-projects are initiated, specified and implemented by the stakeholders involved – and they are also responsible for financing and staffing.

The Swiss Alzheimer Association, together with partner organisation Pro Senectute, is leading a project to educate the public on various aspects of dementia, with a focus on the diverse realities in the lives of those affected. We aim to reduce stigma and help to overcome inhibitions with two specific deliverables: population – and community-based information and awareness activities and sector-specific information materials.

Wishes for the future

Although recent studies give us some hope that prevalence will not develop as dramatically as supposed so far, we must nevertheless be prepared for a very strong increase in the number of people affected. And this in a society that is rapidly changing: examples include more old people living alone in the community, fewer family carers within a reasonable distance, changing gender roles and rising costs.

Switzerland also needs to become a dementia-friendly society. We have started the process by publishing a new leaflet called “People with dementia as fellow citizens” and a factsheet for municipalities. Hopefully we will see pilot programs starting soon in every canton. Logically, politicians and authorities must be strongly involved to find solutions for the future – after all, people with dementia and their carers are also adults with votes!

Finally, we must increase the involvement of people with dementia in decisions affecting their lives; there has been a timid start in Switzerland and this should be encouraged to grow.

Speaking for myself, I will continue to be involved as a board member of Alzheimer’s Disease International (ADI). I hope that my experience and knowledge can be of use not only to ADI but also to other national associations. I leave the Swiss Alzheimer Association with a profound gratitude for having had the opportunity to invest my time, energy and competencies in one of the most important challenges that society is facing. My mother had dementia and going through that experience with her made me want to get involved. I hope that many more family carers with professional skills and capacities will join the cause and contribute to creating the conditions for the best possible life with dementia.

Know – Understand – Act

The concept of this long-term campaign is based on the premise that when you know about dementia, you can understand the situation of people living with dementia and can therefore act appropriately. The keynote of the campaign is the new website www.memo-info.ch that offers basic information (potential signs, symptoms, a test, etc.), sources for further information and testimonials. The website targets people over 40 and its main theme is the link between forgetfulness and possible dementia. The campaign started in May 2015 and will last for at least three years. It was received very positively and we feel confident of being on the right track. However, its future will depend on finding additional funding – so far it is financed only by the two partner organisations.

“Logically, politicians and authorities must be strongly involved to find solutions for the future – after all, people with dementia and their carers are also adults with votes!”

BIRGITTA MARTENSSON
World Alzheimer’s Day 2015

Alzheimer Europe looks at some of the activities to mark World Alzheimer’s Day on 21 September

**Bosnia and Herzegovina:** Udruženje AIR held a round table on “Dementia in the family in Canton Sarajevo” in the capital.

**Bulgaria:** student volunteers explained the benefits of early diagnosis and timely treatment on Alzheimer Bulgaria’s stand in Varna.

**Belgium:** Ligue Nationale Alzheimer Liga organised lawn bowling and many other activities on Brussels’ Grand-Place.

**Cyprus:** the Cyprus Alzheimer Association announced the launch of InformCare, a new web platform for informal carers funded through the Innovage project.

**Greece:** the Halkida chapter of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders held a conference on dementia symptoms and care.

**Ireland:** The Alzheimer’s Society of Ireland organised the exhibition “Letters to Remember” written by people with dementia.

**A Letter to Remember from Helen Rochford Brennan**

...don’t let this disease define who you are.
Italy: Alzheimer Uniti Italia held its annual conference at the Campidoglio in Rome, this year entitled “Science and Conscience: Towards a Friendly Community.”

Luxembourg: a stunning view of the capital city during the Memory Walk organised by Association Luxembourg Alzheimer.

Slovakia: the Slovak Alzheimer Society held its 7th international conference: “Senior training and non-pharmacological intervention for Alzheimer’s disease.”

Turkey: Board and staff members of the Turkish Alzheimer Association helped raise dementia awareness from their stand in downtown Istanbul.

Italy: Federazione Alzheimer Italia held the conference “Remember me – the last scientific research data in the light of the dementia-friendly community” in Milan.

Netherlands: the “Alzheimer’s socks” campaign was very effective in raising dementia awareness and funds for Alzheimer Nederland.

Norway: Alv Orheim won an award for distinguished services for people with dementia from his local chapter of the Norwegian Health Association.

Slovenia: Alzheimer Slovenia – Spominčica held a popular Memory Walk in the capital, sponsored by Zoran Janković, Mayor of Ljubljana.

Alzheimer Europe: our Twitter Thunderclap reached over 284,000 people, thanks to the support of our member associations and friends.
Putting a face to commitment

Alzheimer Europe highlights some recent activities of individuals in the dementia world

9 October: Jeremy Hughes receives a CBE

On 9 October, Jeremy Hughes, Chief Executive of Alzheimer’s Society was presented with a CBE for services to older people by Her Majesty the Queen.

Jeremy has been Chief Executive of Alzheimer’s Society since 2010. During that time, he has succeeded in significantly raising the profile of dementia among the general public, political leaders and on the world stage. Alzheimer’s Society endeavoured to shape the agenda for the 2013 G8 summit, which was dedicated to tackling dementia. One of the major outcomes of the summit was an international commitment to find an effective treatment or cure for dementia by 2025.

Jeremy has also steered a major shift in society’s attitudes towards people with dementia. He co-chairs the Dementia Friendly Communities Champion Group, which works to develop dementia-friendly communities and also oversaw the creation of Alzheimer’s Society’s Dementia Friends initiative.

Speaking about the award, Jeremy said: “I am honoured by this award and the recognition it gives to Alzheimer’s Society’s fantastic achievements. I am extremely proud of the advances we have made in increasing funding into dementia research. However, more still needs to be done to support the 850,000 people currently living with dementia. We must also address funding for our social care system, which is in crisis and failing many people. Alzheimer’s Society will continue to work hard to provide the best advice and support to anyone with dementia, and do all we can to enable those affected to live well.”

15 September: The Swiss Alzheimer Association names a new director

The Swiss Alzheimer Association’s Central Committee has appointed Stefanie Becker at the Association’s new head. Ms Becker has a doctorate in psychology and gerontology. In her previous position she was responsible for the “Institut Alter” within Bern University of Applied Sciences (BFH). Alzheimer Switzerland says it is pleased to have found in Ms Becker a specialist with a vast experience in dementia. She will succeed Birgitta Martensson at the end of December 2015.

15 August: Alzheimer Europe welcomes a new Policy Officer

Alzheimer Europe was pleased to welcome a new colleague, Policy Officer Vanessa Challinor, who joined us from 15 August. Vanessa’s role is to:

• support the campaign of Alzheimer Europe and its national member organisations in getting dementia recognised as a European priority
• develop policy statements and contributions to ongoing Commission consultations
• present the views of Alzheimer Europe to members of European institutions
Vanessa has been very busy since August: she has met several MEPs and their staff members, attended various EU meetings in Brussels and was a speaker at the WHO Regional Committee for Europe conference in Vilnius, Lithuania.

29 July: Helga Rohra is appointed “Commitment Ambassador” for people with dementia in Germany

European Working Group of People with Dementia (EWGPWD) Chairperson, Helga Rohra has been appointed as “Commitment Ambassador” in Germany.

Ms Elke Ferner, Parliamentary State Secretary to the Federal Minister for Family Affairs, Senior Citizens, Women and Youth, and Dr Ansgar Klein, Managing Director of the Bundesnetzwerks Bürgerschaftliches Engagement (BBE) – or National Network for Civil Society – announced the “Engagement Macht Stark – or “commitment makes us strong” – foundation’s Ambassadors for 2015 at an event on 29 July.

Helga, as an Ambassador for people with dementia, “shall work for a new image of dementia in society and for people who want to lead an active and independent life under the conditions of dementia.”

The other Commitment Ambassadors appointed were:

- Franz-Josef Fischer – who campaigns for a better future for children and young people
- Werner Rosemeyer, whose foundation “Little Nazareno” supports street children in Brazil
- Günter Reichert, founder of the “Nürnberger Asyllohek”, a centre providing accommodation, education and support for asylum seekers

25 June: France Alzheimer welcomes new President Joël Jaouen

At France Alzheimer’s 2015 AGM on 25 June, Joël Jaouen was elected as President. Mr Jaouen succeeds Marie-Odile Desana, who continues to work for France Alzheimer and remains on the Board of Alzheimer Europe (AE). See also the interview with Mr Jaouen in this issue.

17 June: EWGPWD member Nina Balackova speaks at Palliare conference

On 17 June at the Palliare conference in Prague, Nina Balackova gave a speech about her experience of living with dementia, called “Our voices have to be heard”.

Ms Balackova, a member of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) was very well received and her speech was praised on Twitter by delegates as being “inspiring”, “brilliant open and honest”.

- support the activities of the European Alzheimer’s Alliance
- liaise with other European carers’ and patients’ organisations
- report on relevant EU and national policy developments and contribute to the organisation’s monthly newsletter and quarterly Dementia in Europe magazine
- collaborate with the organisation’s national member associations in the development of national reports on dementia policies
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References:
ADIs World Alzheimer Report 2015 focuses on the global impact of dementia

In August 2015, ADI (Alzheimer’s Disease International) published “The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends”. The report includes recommendations for a global framework for action on dementia, a review of the evidence for and against recent trends in the prevalence and incidence of dementia over time and an analysis of the broader societal impact of dementia.

The report relates that there are currently around 46.8 million people living with dementia around the world, with numbers projected to nearly double every 20 years, increasing to 74.7 million by 2030 and 131.5 million by 2050. There are over 9.9 million new cases of dementia each year worldwide, implying one new case every 3.2 seconds.

The current annual societal and economic cost of dementia is USD 818 billion, and it is expected to become a trillion dollar disease in just three years’ time. This means that if global dementia care were a country, it would be the 18th largest economy in the world.

The report updates ADIs data on dementia’s global prevalence, incidence and cost, highlighting dementia’s increasing impact on low and middle income countries (LMICs). It is estimated that 58% of all people living with dementia today reside in LMICs, a proportion that is anticipated to rise to 68% by 2050, driven mainly by population growth and an ageing global population. It is also expected that by 2050, nearly half of all people with dementia globally will live in Asia.

The updated estimates are based on new research led by Prof. Martin Prince from King’s College London’s Global Observatory for Ageing and Dementia Care. These new findings take into account both the growing numbers of older people (population ageing), and new and better evidence on the number of people living with dementia, and costs incurred. Prof. Prince noted: “We now believe that we underestimated the current and future scale of the epidemic by 12-13% in the 2009 World Alzheimer Report, with costs growing more rapidly than the numbers of people affected.”

In light of the findings, the report calls for a specific global work stream from all stakeholders focused on assisting LMICs to develop programmes to raise awareness and improve access to early diagnosis and care. ADI is urging policy makers around the
world to approach the issue with a broader agenda and a wider representation of countries and regions, particularly those in the G20 group of nations. A key recommendation of the report calls for a significant upscaling of research investment into care, treatment, prevention and cure.

Marc Wortmann, Executive Director of ADI, commented: “The rising global cost of dementia will pose serious challenges to health and social care systems all around the world. These findings demonstrate the urgent need for governments to implement policies and legislation to provide a better quality of life for people living with dementia, both now and in the future.”

Glenn Rees, Chair of ADI, outlined ADI’s urgent priorities: “We must use the findings of this report to advocate for action in international forums to fight back against the stigma of dementia and encourage the growth of dementia-friendly communities and countries. This action should include timely diagnosis and post-diagnostic support and improved access to support and care, especially in low and middle income countries.”

The World Alzheimer Report 2015 was researched and authored by Prof Martin Prince, Prof Anders Wimo, Dr Maelenn Guerchet, Miss Gemma-Claire Ali, Dr Yu-Tzu Wu and Dr Matthew Prina on behalf of the Global Observatory for Ageing and Dementia Care which is hosted at the Health Service and Population Research Department, King’s College London. The full report can be downloaded from the ADI website: www.alz.co.uk/worldreport2015
26th Alzheimer Europe Conference
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Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences
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AE conference opens with ambitious objectives

Dementia: putting strategies and research into practice

The EWGPWD at the annual conference

Snapshots from Ljubljana

Winners of the first AE poster awards

Charts and figures

SPOTLIGHT on Alzheimer Europe’s 25th conference in Ljubljana
AE conference opens with ambitious objectives

The 25th Alzheimer Europe conference opened on 2 September under the theme “Dementia: putting strategies and research into practice”

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, welcomed all the delegates and thanked Slovenian President Borut Pahor for his patronage of the conference, which attracted more than 500 people from 43 countries.

Ms von Lützau-Hohlbein was pleased to see that the AE conference remains unique in the way it brings together such a wide range of participants. These include people with dementia and their carers, policy makers and civil servants, health and social care professionals, colleagues from national Alzheimer associations and representatives from the pharmaceutical industry.

She also thanked the European Union for the generous support provided through the Health Programme for AE’s 2015 Work Plan and Annual Conference, as well as corporate sponsors Lilly, Nestlé, Piramal, Roche and SCA.

The next speaker was Štefanija Lukič Zlobec, Chair of Spominčica and co-organiser of the conference, who gave a brief overview of the Slovenian Alzheimer association.

Spominčica was established in 1997 by Dr Ales Kogoj, a psychiatrist and visionary who followed the example of other European Alzheimer associations. Unfortunately, Dr Kogoj is no longer with us but the conference was dedicated to his memory. He had a profound understanding and compassion for people with dementia and also for carers, always placing them at the centre of his attention.

Spominčica follows exactly the same approach, aiming to reach and help every person with dementia and every carer in the country. The association currently has 20 regional chapters whose members – amongst other activities – operate a telephone hotline, publish a magazine, hold Alzheimer Café meetings and organise educational programmes for carers.

The next speaker was Helga Rohra, Chairperson of the EWGPWD. She gave a warm welcome to all the delegates with dementia and their carers “without whom we could not be here”. She also invited the audience to attend the various conference sessions that would feature speakers with dementia, such as the special session that was entirely organised and moderated by the members of the EWGPWD.

Ms Rohra particularly emphasised the importance of involving people with dementia in all aspects of their lives, including decisions about treatment, care and support: “We will show you that a diagnosis of dementia is not the end – it’s the beginning of a different life.” She also called on national Alzheimer associations to form working groups of people with dementia, in order to help them stand up and speak for themselves.

She was followed by Anja Kopač, Slovenia’s Minister for Social Affairs. She said that the social development level of a society can be judged by its ability to handle dementia, particularly citing the relationship of young people with their older peers with dementia.

Nowadays, countries must pay special attention to the quality of life of people with dementia, particularly as it tends to affect individuals and their relatives at a time of their life when they are the most productive. Ms Kopač said that the ministry had noted a growing number of people with dementia and that its activities are aimed at adapting social welfare services for them, as well as educating service providers.

She added that the new national social protection programme would lead to faster expansion of social services in the home environment and the development of new services adapted to people with dementia, their relatives and informal caregivers.

Milojka Kolar Celarc, the Slovenian Minister of Health, noted that Slovenia has 32,000 people with dementia and a further 100,000 citizens looking after...
In order to handle their needs, the Slovenian ministry of health, together with various partners, was preparing a national dementia strategy that would run until 2020. Ms Celarc said that the strategy was in its final phase and would be available for public consultation by the end of September.

The strategy will focus on person-centred care and operate through collaboration and timely actions on the part of all stakeholders. The overall goals of the strategy are to create effective channels for early detection, treatment and care, but also to improve the inclusion of people with dementia in the daily activities of their communities. For the latter goal, Minister Celarc noted that Spominčica has already made excellent progress and that the association will certainly be called upon to continue this work.

The next speaker was Bojana Muršič, Vice-Chairperson of Slovenia’s National Assembly, who focused on the burden of dementia. She said that each person with dementia, each carer and each relative have one thing in common: they are dealing with a disease that burdens the whole family. This includes mental, physical, social and financial challenges that will only increase in our ageing society.

She also cited situations in which relatives of people with dementia were overwhelmed by the cost of care and thus compelled to take over the caregiver’s role themselves. However, the situation of these unpaid family carers is clearly not sustainable; we can no longer shift these serious responsibilities onto family members who may also be physically and emotionally vulnerable.

Ms Muršič emphasised the need for a financially sustainable programme that would provide improved working conditions for professional carers and better training for volunteers. In turn, these would lead to an improvement of quality of life for people with dementia and also for their carers, as well as allowing them to remain in their homes for as long as possible.

The ceremony’s keynote lecture was delivered by Jean Georges, Executive Director of Alzheimer Europe, who spoke about 25 years of AE activities and achievements. AE was formally founded in 1991 by ten member associations from nine countries, but has since grown 37 national associations from 32 countries.

AE initially worked on helping its member associations to develop and provide information for carers and raise awareness of dementia. The real start of its lobbying and advocacy work came at the 2006 Annual Conference, where AE and its members adopted the Paris Declaration.

In 2008, AE set up the European Alzheimer’s Alliance in the European Parliament. The Alliance is still active today, with 116 members from 27 countries and all political groups in the European Parliament. AE also launched the European Dementia Ethics Network to promote a European dialogue on ethical issues and maintains the European Dementia Observatory, which consists of various channels to monitor and report on dementia developments at EU and national level.

More recently, AE created the European Working Group of People with Dementia, whose members are nominated by AE’s national member associations. There are currently nine EWGPWD members and the chairperson of the group sits on the Alzheimer Europe Board with full voting rights.

Mr Georges expressed a real sense of pride in the many achievements Alzheimer Europe has been able to achieve and contribute to. None of these achievements would have been possible without the active support and involvement of AE’s member organisations.
Dementia: putting strategies and research into practice

Alzheimer Europe held its 25th Annual Conference in Ljubljana on 2-4 September 2015 together with Spominčica – Alzheimer Slovenia. This year’s event attracted over 570 delegates, including 26 people with dementia.

This year’s event included some 150 speakers and 140 poster presentations – including awards for the best posters. The conference was also an opportunity to celebrate AE’s 25th anniversary and to look back on the achievements of the organisation.

The 2015 conference was organised under the Honorary Patronage of Mr Borut Pahor, President of the Republic of Slovenia and dedicated to the memory of Dr Aleš Kogoj, founder of Spominčica in 1997 and a dementia pioneer in Slovenia.

Putting research into practice

The first plenary session was chaired by Dr Charles Scerri, General Secretary of the Malta Dementia Society, with a focus on putting research into practice.

Prof. Bengt Winblad, Director of the Center for Alzheimer Research at Karolinska Institutet, Sweden, presented new treatment strategies for dementia and outlined lessons learnt from past failures and perspectives for the future. We need to acknowledge, he said, that a single cure for Alzheimer’s disease is unlikely to be found and that the approach to drug development needs to be reconsidered.

He was followed by Dr Florence Pasquier, Professor of Neurology at the University Hospital of Lille (France), who spoke about improving timely diagnosis and providing adequate support to people with early memory complaints. She noted that many studies show the advantages of an early diagnosis, such as the relief of understanding what is going on, proper and timely care, and increased empowerment.

Dr Simon Lovestone, Professor of Translational Neuroscience at Oxford University, demonstrated the growing role of “big data” and public-private consortia in current dementia research. The lack of progress in dementia drug development has highlighted the need to diversify target development and reduce clinical trial lifetimes, but also to include indicators of early success in these trials. These issues are being addressed by the use of big data in two projects implemented by IMI, the Innovative Medicines Initiative. EMIF (European Medical Information Framework) is focused on the re-utilisation and aggregation of data and cohorts for dementia research. The European Prevention of Alzheimer’s Disease consortium (EPAD) is establishing a registry, a trials ready cohort and an innovative clinical trial that is dependent on the use of such biomarkers.

Finally, Prof. Zvezdan Pirtošek, Head of the Department of Neurology at University Medical Centre Ljubljana, gave a presentation on the myths, wishes and realities of dementia prevention. He emphasised the importance of understanding the basic science behind the disease, with a particular focus on risk factors. Prof. Pirtošek gave detailed explanations of the risks that are beyond our control, but also those that can be influenced by health, lifestyle and environmental factors. He cited the benefits of monitoring cardio-vascular health and blood pressure and cholesterol levels. Prof. Pirtošek also encouraged delegates to engage in social and intellectually stimulating activities – such as learning Slovenian and visiting interesting parts of the country during their stay!

“We need to acknowledge that a single cure for Alzheimer’s disease is unlikely to be found.”

BENGT WINBLAD
Dementia strategies and policies

The second plenary session was also chaired by Dr Scerri, with a focus on dementia strategies and policies.

Geoff Huggins, Acting Director for Health and Social Care Integration in the Scottish Government, presented the new EU Joint Action on Dementia. The three year project will promote the implementation of actions to improve the situation of people with dementia and their carers. The pillars of the joint action are diagnosis and support, care co-ordination, the quality of residential care for those living with dementia and the development of dementia-friendly communities. The partners will focus on implementation and evidence of best practice and also accelerate the uptake of best practices.

Peter Volasko, a National Coordinator for European projects in Slovenia, reported on the positive impact of the nation’s participation in the Joint Programme on Neurodegenerative Diseases Research (JPND). Slovenian researchers are actively involved in JPND projects such as DEMTEST and BIOMARKAPD and the programme is well known among researchers and policy makers alike. Their work has stimulated the Ministry of Health to develop a national strategy to address neurodegenerative diseases. In addition, an informal group named “Young leaders for the promotion of dementia-related issues” is being created in Slovenia – the direct result of similar JPND efforts in this area.

“Never hide your condition; stand on your feet and tell everyone who you are and how you are.”

ALV ORHEIM

Alv Orheim, who is living with dementia in Norway, gave a talk about changing the perceptions and image of dementia. He noted that the primary sources of information for people with dementia are the people who are directly affected by it and also highlighted the importance of staying physically and mentally active. Mr Orheim, with the support of his wife, maintains a regular schedule of activities that he follows as closely as possible. He recommends this to others, because a positive environment allows people to carry on as active partners every day. He also pointed out that dementia is not constricted by geographical borders, nor by intellectual or economic levels. His final words of advice were to “never hide your condition; stand on your feet and tell everyone who you are and how you are.”

The last speaker was Mark Pearson, Deputy Director, Employment Labour and Social Affairs at OECD (Organisation for Economic Co-operation and Development). Mr Pearson presented the OECD’s approach to comparing and benchmarking dementia care. Most OECD countries have implemented policies to improve dementia care and many have published dementia strategies. There is a strong desire to compare policies and their impact internationally, but currently this is very difficult. The OECD is working to change this by studying qualitative comparisons of quality of care and outcomes. This study has received wide support from the member countries and will provide a foundation for further studies.
Dementia-friendly society

Plenary session three, “Dementia-friendly society”, was chaired by Prof. Pirtošek.

The first speaker was Bob Woods, Professor of Clinical Psychology of Older People at Bangor University (Wales), who examined the effects of arts programmes for people with dementia. Such programmes are very common, but systematic evaluations of their effects are few and far between. Prof. Woods focused on a series of studies where researchers are developing a methodological framework that is both rigorous and capable of capturing some of the key elements of arts programmes in dementia care. It is argued that engagement in arts activities may, for the person with dementia, be different from engagement in other activities, but not necessarily greater in impact. However, there may be a particular effect on others witnessing the engagement – including staff, families, artists and the wider community. Any evaluation should seek to take multiple perspectives, recognising that having a wider impact may bring a knock-on effect of reduced stigma for those living with dementia in the future.

Agnes Houston, Vice-Chairperson of the EWGPWD, presented “People with dementia as partners”. This was an overview of the activities of the Scottish Dementia Working Group (SDWG), of which she is the former Chair. The SDWG was launched in 2002 in order to improve services for people with dementia and their families. The group members are active in raising awareness at national and international conferences, appearing at local and national media events and lobbying policy makers. In addition, the group has worked with Alzheimer Scotland and the Scottish Government to develop Scotland’s two National Dementia Strategies and will begin work on the third this year. Ms Houston was pleased to note that the government is treating people with dementia as equal partners in dementia policy: “it would be rare that any high-level dementia policy meeting did not now include people with dementia, so we have come a long way.”

Jeremy Hughes, CEO of Alzheimer’s Society (UK), gave an overview of the Dementia Friends campaign, a vital element for the development of a dementia-friendly society in the UK. The campaign tackles stigma and the lack of understanding that causes many people to experience loneliness and social exclusion. From an initial commitment in 2012 to raise awareness of dementia and for 20 cities, towns and villages to be signed up to become more dementia friendly, there are now over one million Dementia Friends and over 90 communities committed and working to become dementia-friendly in England. The Alzheimer’s Society has now set a new target of creating four million Dementia Friends by 2020 and is pleased to share its experiences with other organisations.

Finally, Dr Nena Kopčavar Guček, Assistant Professor at the University of Ljubljana’s Medical School, presented various case studies of age and dementia as risk factors for domestic violence. Violence is the abuse of power and thus a violation of fundamental human rights. Among elderly people, violence and neglect cause unnecessary suffering, injury, pain or loss with a corresponding reduction of quality of life. Medical abuse, neglect, abandonment and economic violence are the most frequent forms of violence on people with cognitive impairment, including dementia. The prevalence of various forms of abuse in the elderly in developed countries is 4-6% in domestic settings, dementia being an important risk factor. Dr Guček cited better awareness and improving education of lay and professional audiences as effective prevention measures.
Innovation and care

The final plenary session was chaired by Ms von Lützau-Hohlbein with a focus on innovation and care.

Dr Mary McCarron, Professor of Ageing and Intellectual Disability at Trinity College Dublin, presented new aspects of meeting the needs of the growing number of people with intellectual disability (ID) and dementia in Ireland. She pointed out that in 2013, nearly 50% of all Irish people with ID were over 35 years old. In 1974 this figure was 28%, showing that people with ID, particularly Down syndrome (DS), are now living well into their 70s due to better care. Concurrently, these people are at much higher risk of developing dementia – at a significantly lower age than the general population. Dr McCarron noted that people with ID other than DS have a five-fold greater risk of developing dementia than people of a similar age in the general population. Clearly, this increasing population with dementia will require restructuring residential and day care centres, as well as training staff to respond to changing needs.

“Dementia-specific technologies are hardly beneficial if accessibility is forgotten.”

PÄIVI TOPO

Dr Päivi Topo, Adjunct Professor in Sociology and Social Gerontology at The Age Institute in Helsinki (Finland), provided insights on the increasing use of technology to assist people with dementia. Technology has become a part of our everyday activities, so it is worthwhile to examine how readily the benefits of technological development are accessible to people with dementia, their close ones and professional carers. Dr Topo emphasised that accessibility is the key: “dementia-specific technologies are hardly beneficial if accessibility is forgotten.” Once this hurdle is cleared, there are many examples of the benefits, such as being able to go outdoors alone, better sleep and improved social interaction, memory and other cognitive abilities.

She was followed by Vid V. Vodušek, Psychologist and Assistant Professor, University Psychiatric Hospital, Ljubljana (Slovenia), who gave a presentation about managing and preventing BPSD – behavioural and psychological symptoms in dementia. Typical examples include delusions and hallucinations, agitation, anxiety and aberrant motor behaviour. While cognitive dysfunctions are progressive, BPSD tend to fluctuate. Prof. Vodušek noted that such symptoms are often important factors in diagnosing dementia.

“Regardless of age, all individuals require companionship, intimacy and love.”

FRANS HOOGEVEEN

Dr Frans Hoogeveen, Associate Professor of Psychogeriatrics at The Hague University of Applied Sciences (Netherlands), was the last plenary speaker. He gave a talk on the taboo of sexuality and intimacy among people with dementia. These are basic human needs that are intrinsic to people’s sense of self and wellbeing. Regardless of age, all individuals require companionship, intimacy and love. However, for older people these are often denied, ignored or stigmatised. For older people with dementia the problem is even worse: they face the “double jeopardy” of being old and cognitively impaired. Prof. Hoogeveen clearly demonstrated that experiencing intimacy, including sexual activity, is vital for the quality of life of people with dementia.

See you in Copenhagen!

The conference ended with an invitation by Nis Peter Nissen from Alzheimer foreningen (Denmark’s Alzheimer association) to attend the 26th Alzheimer Europe Conference in Copenhagen next year.

The 25th AE Conference received funding under an operating grant from the European Union’s Health Programme (2014-2020).
The European Working Group of People with Dementia at the annual conference in Slovenia

The European Working Group of People with Dementia (EWGPWD) was particularly active this year in organising and participating in Alzheimer Europe’s annual conference in Ljubljana. Since the creation of the group in 2012 at the annual conference in Vienna, the group has worked tirelessly to help ensure that people with dementia are made to feel welcome and have an enjoyable experience at such conferences, whilst learning about the latest developments in the field of dementia and contributing to important debates.

The group’s work for the conference started with Hilary Doxford and Helga Rohra being invited to sit on the conference committee and subsequently evaluate hundreds of abstracts. Then, a few months before the conference, Rozel Snell and Bojan Spanja (accompanied by their respective partners, Brian and Michaela) visited the conference centre and advised on signposting, priority seating arrangements, lighting, transportation, a quiet room and refreshments. A welcome event was organised before the start of the conference in the group’s quite room at which the members of the EWGPWD welcomed people with dementia and their carers, shared coffee and cakes and then had a guided tour of the whole conference centre.

Throughout the conference, the group was keen to promote contact with other participants such as researchers, policy makers, representatives from Alzheimer associations, healthcare professionals and the general public, as well as people with dementia and carers. The stand was always busy. Conference delegates came forward readily to ask for information about the group, exchange ideas and learn a bit more about what it is like to live with dementia. At coffee breaks, there were always two members of the EWGPWD on the stand and whilst they were attending different sessions, there was a constant DVD running behind the stand so that delegates could see what the group has been doing and find out a bit about the members.
All members of the group were involved in the special EWGPWD symposium, a parallel sessions and/or the plenary sessions. The special symposium was a highlight of the conference. It was organised and orchestrated by the EWGPWD and skilfully chaired by Hilary Doxford. This year, a larger room was planned with a large area for the presenters, a huge screen and hundreds of seats in an amphitheatre. However, even more people turned up and despite the numerous seats, some people had to be turned away owing to fire protection regulations.

The first presentation was about Rozel’s journey. Her story, which was moving and uplifting, was skilfully presented by Brian (Rozel’s husband) who had the audience in stitches at times. Rozel accompanied him to the stage. Next, Agnes Houston explained to the audience what a difference a year makes, focusing on the sensory challenges experienced by people with dementia and presented her booklet on that topic – including contributions from Helen, Helga, Nina and Rozel.

The third presentation was from Raoul Grönqvist and was about the post-diagnostic support he had received and the impact this had had on his life. He was accompanied on stage by his wife, Milja Ahola, who presented slides showing first, the impact that dementia had had on his life and then how appropriate support had helped him to counteract some of the losses he had experienced. At the end, there was a video of Raoul playing a beautiful piece on the guitar. Finally, Nina Balackova took the stage and spoke about the impact of dementia on her life in relation to the issue of self-management.

Conferences should not be “all work and no play” though. In Ljubljana, there was also plenty of fun with a visit to the town hall followed by a lovely meal outside on a terrace, a guided tour around Ljubljana in special buggies and last but not least the gala dinner where everyone let their hair down and danced to the music of the eighties.
Snapshots from Ljubljana
Nis Peter Nissen from Alzheimerforeningen (Denmark’s Alzheimer association) invited the delegates to attend the 26th Alzheimer Europe Conference in Copenhagen next year.

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Congratulations to the winners of the poster awards!

The Alzheimer Europe Foundation is pleased to present the winners of our first-ever poster award competition

The 2015 poster awards marked a first at our 25th Alzheimer Europe Conference, as all delegates were invited to vote for their favourite poster in each of four categories. The lucky winners will each receive a cash award of EUR 500. The Alzheimer Europe Foundation would like to thank all the people who voted and congratulates the presenters for their excellent contributions. The winners are as follows:

**Category: Innovative care**

Agnes Houston, Vice-Chair of the European Working Group of People With Dementia (EWGPWD) for her poster “Dementia and Sensory Challenges”.

**Category: Dementia-friendly society**

Sahdia Parveen, Post-doctoral Research Fellow, School of Dementia Studies, Bradford University, for the poster “Dementia detectives: Busting the myths surrounding dementia in schools”. Dr Parveen’s poster was presented in Ljubljana by Prof. Jan Oyebode, also from Bradford University.

**Category: “Policies and strategies”**

Jim Pearson, Deputy Director of Policy at Alzheimer Scotland, with the poster “Focus on Dementia: Supporting People to Stay Connected within their Community”.

**Category: “Medical aspects”**

Vid V. Vodušek, Psychologist and Assistant Professor, University Psychiatric Hospital, Ljubljana (Slovenia), for his poster “Personal image and self in dementia: The perspective of the caregiver spouse."

The Alzheimer Europe Foundation also awarded a free subscription for the 2016 conference in Copenhagen to a lucky participant drawn at random from the poster evaluation forms: Dr. med. Paolo Prolo, Psychiatrist, Swiss Disability Insurance, Bellinzona (Switzerland). We look forward to seeing him next year!
Alzheimer Europe received feedback from 59 delegates indicating that:
Over 88% of delegates found all plenary sessions to be good / very good.
Over 91% of delegates found the topics in parallel sessions to be good / very good.
Over 88% of delegates found the poster exhibition to be good / very good.
Over 98% of delegates would recommend future Alzheimer Europe conferences to their colleagues.
### Table: Breakdown by category

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**Our members are helping people with dementia and their carers in 32 countries**

[Alzheimer Europe Members Map]

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**Alzheimer Europe** received feedback from 572 delegates indicating that:

- Over 88% of delegates found the poster exhibition to be good / very good.
- Over 88% of delegates found the topics in parallel sessions to be good / very good.
- Over 98% of delegates would recommend future Alzheimer Europe conferences to their colleagues.

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**Table continued**

| Category                  | Czech Rep. | Croatia | China | Algeria | Lebanon | Finland | Belgium | Netherlands | France | Denmark | Norway | Sweden | Slovakia | China | Algeria | United Kingdom | Italy | Spain | Portugal | Greece | Israel | Luxembourg | Jersey | Switzerland | Italia | Monaco | Turkey | Italy | Belgium |
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|                           | 14         | 1       | 1     | 1       | 1       | 1       | 1       | 1          | 1         | 12    | 2       | 10     | 8      | 3        | 6     | 2       | 21             | 133   | 19    | 2         | 2      | 4      | 1         | 20     | 44        | 10    | 10      | 24      | 13     | 4    | 9   |
ALZHEIMER EUROPE THANKS THE ABOVE MEPS FOR LAUNCHING THE EUROPEAN PARLIAMENT WRITTEN DECLARATION N° 0057/2015 ON ALZHEIMER’S DISEASE

1. Alzheimer’s disease is an incurable neurodegenerative disease of the brain tissue that causes progressive and irreversible loss of mental functions, including memory.
2. Six million people are affected by Alzheimer’s disease or related diseases in Europe, and the number of new cases diagnosed each year continues to increase.
3. There is currently no curative treatment for Alzheimer’s disease, but some drug treatments can help to slow the process and early detection can assist in better supporting patients and their carers.
4. The Commission and the Council are invited to recognise Alzheimer’s disease and related diseases as a public health priority in Europe.
5. The Commission and the Council are therefore called upon to adopt a comprehensive strategy for meeting the challenges presented by Alzheimer’s disease. Research aimed at developing sustainable treatment solutions and efforts to improve the efficient provision of information and support to carers should be promoted.
6. This declaration, together with the names of the signatories, is forwarded to the Council and the Commission.

Alzheimer Europe calls on all MEPs to sign the Written Declaration before 5 January 2016
Thank you