Zsuzsanna Jakab, WHO Regional Director for Europe, discusses how the World Health Organization is addressing dementia at the international level.

Sabine Oberhauser, Austrian Minister of Health, presents the country’s new national dementia strategy.

Martin van Rijn, State Secretary for Health, Welfare and Sport, outlines the activities of the Netherlands’ EU Presidency.

Agnes Houston speaks about a new publication inspired and written by people with dementia.
Welcome
by Heike von Lützau-Hohlbein,
Chairperson of Alzheimer Europe

Prioritising Dementia

Dementia, a priority of two EU Presidencies
MEP Keith Taylor (UK) was the host of AE’s latest lunch debate

AE organises its first Alzheimer’s Association Academy
This new interactive event introduced many topics of interest to AE members

Alzheimer Europe surpasses its target for the Glasgow Declaration campaign
AE and its members gathered nearly 12,000 total signatures

From the AFE-INNOVNET Thematic Network to the European Covenant on Demographic Change
AGE Platform Europe led the effort to create a support network for older people

Policy Watch

WHO Europe: addressing dementia at the international level
WHO Europe is active in numerous dementia activities in Europe and beyond

Luxembourg’s EU Presidency conclusions emphasise support for people with dementia
EU Council calls on Member States to address dementia as a priority

Improving the lives of people with dementia: a key aim of the Netherlands’ EU Presidency
The Dutch government continues to support dementia-friendly initiatives

DEM 2: continuing the pan-European effort to improve the lives of people with dementia
“DEM 2” will turn ALCOVE’s conclusions into sustainable actions

122 MEPs support a Written Declaration on Alzheimer’s disease
122 MEPs expressed their support to make dementia a public priority

Implementing Austria’s new national dementia strategy
The new strategy includes seven targets and 21 recommendations for action

“A more dementia-friendly society”: Norway renews its national strategy
New goals and a framework for further cooperation among partners

Dementia in the news

Looking back: 25 years on the Board of the German Alzheimer Association
Heike von Lützau-Hohlbein recalls challenges and successes from her long tenure

Aiming to make Ireland the best country for people with dementia
Collette Kelleher expresses her ambitions as the new Chief Executive of the ASI

Comprehensive care for people with dementia in Israel
Israel offers citizens support from prevention to end of life care

Advocating for better care for people with dementia in Bosnia and Herzegovina
Udruženje AiR operates the country’s only dedicated service hub for people with dementia and their carers or guardians

AE member news
Alzheimer Europe highlights some recent activities of its member organisations

“Dementia and Sensory Challenges”: an award-winning publication inspired and written by people with dementia
Common-sense solutions for living with dementia from a unique personal perspective
Welcome

I am very pleased to report that Alzheimer Europe’s work continues with unabated vigour and enthusiasm. Our Glasgow Declaration campaign ended with nearly 12,000 total signatures, well above our expectations. I wish to thank all the people from our member associations and other supporters who made it possible to conclude the campaign successfully. I am convinced that our collective effort has had a positive impact on EU and national policy makers, reminding them that dementia must be a public health priority and that every European country must develop effective strategies to deal with it.

In December, we held our first Alzheimer’s Association Academy, a series of interactive presentations that introduced many interesting topics to our member associations. These included experiences of people with dementia, scientific updates from our IMI research projects and new ways of becoming involved in clinical trials. We were glad to receive a lot of positive feedback and look forward to organising another session at the end of this year.

The Academy was preceded by a lunch debate that was very well-attended. We were once again fortunate to have MEP Keith Taylor as our host and MEP Sirpa Pletikäinen to provide closing remarks. Alzheimer Europe is grateful to both Members of the European Parliament for their continued support and commitment to our work. The speakers included representatives from the EU Presidencies of Luxembourg and the Netherlands and we greatly appreciate that both countries have maintained dementia as a public health priority during their terms. I particularly look forward to attending the “Living well with(out) Dementia” conference, which will be hosted by the Dutch EU Presidency in May 2016. The European Commission also remains very active, funding various dementia research programmes and working together with the World Health Organization (WHO).

In the European Parliament, interest in dementia has clearly increased as 122 MEPs recently supported a Written Declaration on Alzheimer’s disease. Many of these MEPs had also supported the Glasgow Declaration. This issue also covers “DEM 2”, the second European Joint Action on Dementia that will follow up on the excellent work of the ALCOVE partners. DEM 2 is being managed by the Scottish Government on behalf of the United Kingdom and Alzheimer Europe looks forward to actively participating in the three year project. Another fine example of cooperation is the European Covenant on Demographic Change, which succeeds the AFE-INNOVNET Thematic Network. AGE Platform Europe has done a remarkable job in developing a new network to support older citizens in every EU country.

This issue also carries an interview with Zsuzsanna Jakab, WHO Regional Director for Europe. Ms Jakab describes the varied dementia activities carried out by the agency, including the development of the Global Dementia Observatory, where Alzheimer Europe will act as a project advisor. Ms Jakab also speaks about the agency’s strategic decision to concentrate on healthy ageing and its determinants.

In our member countries, Austria has launched a new dementia strategy and Norway has refreshed its strategy with new goals. Collette Kelleher, the new Chief Executive of the Alzheimer Society of Ireland, speaks about how the Irish strategy will improve the lives of people with dementia. We also have articles from AE’s newest members: a presentation of Israel’s national dementia plan from EMDA and an overview of Udruženje AiR’s activities in Bosnia and Herzegovina. I was very honoured to contribute an article about my experiences over 25 years with the German Alzheimer Association. While I am no longer involved in German dementia affairs, my duties as Chairperson of Alzheimer Europe keep me firmly rooted in improving the lives of people with dementia and their carers.

Finally, Agnes Houston presents a new publication written by and for people with dementia about sensory experiences. Agnes is a tireless campaigner and we are proud to have her at the heart of Alzheimer Europe’s activities as a Vice-Chairperson of the European Working Group of People with Dementia.

Issue 23 of our magazine will appear in October at the 26th Alzheimer Europe Conference in Copenhagen. Before that, our next lunch debate will take place in June in Brussels, with a focus on the UN Convention on Human Rights and the new European Accessibility Act. We look forward to seeing you at one of our events soon!
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Dementia, a priority of two EU Presidencies

On 1 December, MEPs Keith Taylor (UK) and Sirpa Pietikäinen (Finland) co-hosted an AE lunch debate entitled “Dementia, a priority of two EU Presidencies” in Brussels

Mr Taylor, who is also a Vice-Chairperson of the European Alzheimer’s Alliance (EAA), welcomed the delegates and included personal mentions for each member of the European Working Group of People with Dementia. He noted that EAA membership had reached 125 MEPs from 27 Member States and all political groups. Mr Taylor also congratulated Alzheimer Europe on its 25th Anniversary and looked forward to continue working with AE in 2016.

AE exceeds Glasgow Declaration campaign goal

The first speaker was Jean Georges, Executive Director of Alzheimer Europe, who presented “Making dementia a European priority: results of Alzheimer Europe’s Glasgow Declaration campaign”. The campaign ran from February to November 2015 in support of the Glasgow Declaration adopted by AE’s members in October 2014.

In broad terms, the campaign called for the development of a pan-European dementia action plan and the appointment of an EU Dementia Coordinator. This would allow for efficient coordination of all the various EU programmes and initiatives, in order to avoid waste and duplication. The campaign also urged the development of national dementia strategies in every European country. These should actively involve people with dementia and their carers, as well as national Alzheimer associations.

At the time of the meeting, the campaign had attracted the support of 190 organisations, 148 policy makers (including 82 Members of the European Parliament) and more than 11,400 individual citizens – thus exceeding the original goal of 10,000 signatures.

A multisectoral approach to dementia care

He was followed by Anne Calteux, Senior Policy Advisor at the Luxembourg Ministry of Health. Ms Calteux reviewed the dementia activities of her country’s EU presidency term, which ran during the second half of 2015. She noted that Luxembourg had followed the good precedent set by the French and Italian presidencies in making dementia a priority during their tenure.

During its term, Luxembourg worked to improve access to information and develop information into
policies, thus ensuring that dementia remains a public health priority in every EU country.

A key activity was the informal meeting held in Luxembourg in September, which was attended by representatives from European health ministries, EU agencies and the World Health Organization.

Among other presentations, Luxembourg presented its national dementia strategy – which was launched in 2013 – and the new “Programme Démence Prévention” (PDP) prevention programme that began in June 2015. The PDP aims to improve the quality of life of people who are at the earliest stages of dementia, offering personalised care based on both medical and lifestyle factors. The delegates generally agreed on the validity of such a multisectoral approach, as it would most likely bring care closer to people and closer to their homes.

Mr Vytenis Andriukaitis, European Commissioner for Health & Food Safety, also attended this meeting: he assured the delegates that the European Commission is fully behind the efforts to combat dementia, by funding international research programmes and also in individual countries.

Living well with(out) dementia

The next speaker was from the Netherlands, which will hold the EU Presidency for the first half of 2016. Dr Jacqueline Hoogendam, Senior Policy Advisor at the Ministry of Health, Welfare and Sports, presented “Living well with(out) dementia”. The Dutch presidency team will focus on two main areas, an approach that should also lead to financial sustainability of the state care system:

- scientific research for better prevention, early diagnosis and a cure
- enabling people with dementia to maintain quality of life and to remain worthy members of society, with autonomy and dignity, for as long as possible

The main public event of the presidency will be a conference in Amsterdam on 9–10 May that will largely focus on the journey through dementia:

- living well without dementia: scientific evidence and daily practice of prevention
- living well with dementia at home: latest insights in diagnostics, treatment and support for people with dementia
- living well with dementia in nursing homes: improving institutionalised care and end of life care

The conference will also feature activities that simulate what it is like to live with dementia. Dr Hoogendam added that the Dutch Presidency will pursue the expansion of the JPND – the EU Joint Programme for Neurodegenerative Disease Research. She pointed out that Australia recently joined the programme and Japan had expressed considerable interest as well.

Constant EU support for dementia programmes

The next speaker was Michael Hübel, from the European Commission’s Directorate-General for Health and Food Safety. His presentation “Dementia, an EU health policy priority” clearly showed that dementia remains a public health challenge for EU member states and also in the rest of the world. He also outlined the growing international efforts to share priorities in dealing with dementia.

Mr Hübel gave an overview of the EU’s public health policy actions and how these lead to funding dementia research programmes. These include ALCOVE (the Joint Action Alzheimer Cooperative Valuation), the European Innovation Partnership for Active and Healthy Ageing (EIP-AHA) and the Human Brain Project, which is using modern ICT techniques to better understand the brain. He continued with the EU’s collaborative research programmes, namely Horizon2020, IMI (Innovative Medicines Initiative) and JPND.
He also described the Commission’s eHealth Action Plan 2012–2020, whose elements include research, development and innovation in neurodegenerative diseases and mental health. This plan is part of the overall Digital Agenda for Europe. Another current effort is the second EU Joint Action on Dementia. Mr Hübel noted that discussions would very likely be concluded by the end of the year, so that the project could launch in 2016. The aim is to promote the implementation in Member States of coordinated actions to improve the situation of people with dementia and their carers, building on the outcomes of ALCOVE.

Mr Hübel went on to cite the activities of the “Global Action Against Dementia” (GAAD) programme, following the G8 Dementia Summit in 2013. During its two year lifetime, the GAAD raised considerable awareness of dementia among the highest levels of the world’s governments and the WHO, as well as promoting initiatives on cooperation for research and care.

“The European digital agenda must incorporate the needs of people with memory problems.”

SIRPA PIETIKÄINEN
AE presents new annual publications

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe, was the final speaker of the day and she introduced AE’s latest publications.

“Ethical dilemmas faced by health and social care professionals providing care in care homes and hospital settings” is intended as a training aid, featuring vignettes and commentaries on ethically challenging situations.

The 2015 Dementia in Europe Yearbook looks at the development of dementia-friendly communities in Europe and is based on input from 33 Alzheimer associations. The report gathers the latest national initiatives and highlights best practices in improving physical environments for people with dementia.

Keeping up the good work

MEP Sirpa Pietikäinen, who also sits on the Alzheimer Europe Board, provided closing remarks. She expressed her appreciation of the fact that dementia was a key agenda item for the Luxembourg and Dutch EU Presidencies.

She also emphasised the continuing need to protect the legal rights of memory-disabled people. Despite their memory problems or related conditions, these people are still active citizens with needs, hopes and aspirations. These must be considered at the earliest possible stage and the people should be involved throughout the whole development and launch of new products and services.

Finally, Ms Pietikäinen praised Alzheimer Europe for 25 years of working to improve the lives of people with dementia and their carers. She added that we should all work at least as hard as we have done, because there is at least as much work to be done.

Alzheimer Europe was pleased to welcome 67 total delegates to the lunch debate, including the members of the EWGPWD and their carers, senior officials from the European Commission and IMI, representatives from the pharmaceutical industry and colleagues from 18 AE member associations.

"Cure tomorrow, care today."

JEAN GEORGES
PRIORITISING DEMENTIA

AE organises its first Alzheimer’s Association Academy

AE recently changed the format of its Public Affairs meetings to produce the Alzheimer’s Association Academy, a format better-suited to exchanging best practices and introducing topics of interest to its members.

On 1–2 December 2015, Alzheimer Europe (AE) hosted its first ever Alzheimer’s Association Academy in Brussels. This interactive event featured presentations from 11 experts over a two-day period, including ample time for discussion and questions.

Involving people with dementia in Alzheimer associations

The first day began with a session on “Involving people with dementia in Alzheimer associations”, moderated by Dianne Gove, AE Director for Projects. This session included presentations by EWGPWD members Alv Orheim (Norway) and Helen Rochford-Brennan (Ireland).

Alv was born in Norway in 1947 and was diagnosed with vascular dementia in 2010. Prior to joining the EWGPWD in 2014, he was already an active member of the Norwegian Dementia Working Group. The two groups work in a similar fashion, providing people with dementia and their carers with a structure, communication channels and the opportunity to be as active as they wish. Alv said this was a very effective way – and sometimes the only way – to connect with other people with dementia and their carers but also local communities and the government. In fact, the Norwegian group has provided considerable input to the Ministry of Health about the country’s dementia policy and how best to meet the needs of people with dementia. Alv was pleased to report that Norway’s national dementia strategy included many of the group’s recommendations. He encouraged all member organisations to create similar working groups, as they can play a key advocacy role for people with dementia.

His sentiment was shared by the next speaker, Helen Rochford-Brennan. Helen is from Ireland and joined the EWGPWD in 2014, at which time she was also elected as a Vice Chairperson of the group. She is also a member of the Irish Dementia Working Group, which began in 2009 to gather a group of people with dementia who wanted to advocate on behalf of themselves and others. In 2013, the Alzheimer Society of Ireland (ASI) developed a new strategic plan for itself, where the role of people with dementia was a core priority. Helen said that “we were delighted that the working group was seen as a crucial part of the ASI’s Strategic Plan. We saw ourselves working hand in hand with them to improve the lives of people with dementia.” The working group was formally launched in February 2013 and currently has members from all parts of Ireland. Helen is the Chairperson of the group and said that “we want to bring dementia out of the shadows and people to

“We want to bring dementia out of the shadows and people to hear our stories but also to understand that we can live well with the right supports.”

HELEN ROCHFORD-BRENNAN

Amy O’Connor

Alv Orheim & Helen Rochford-Brennan
hear our stories but also to understand that we can live well with the right supports.”

**Integrated campaigning thanks to social media**

The next session focused on the growing use of social media for building awareness and conducting campaigns. The featured speaker was Amy O’Connor, Senior Director of Digital and Social Media Communications at Eli Lilly. She noted that building partnerships is a fundamental element of campaigning and that social media channels such as Twitter can provide various cost-effective benefits to any organisation. These “socialnomic” benefits can be measured as the value created and shared via social media and its influence on outcomes. Ms O’Connor also pointed out that social media campaigns must accommodate the shorter attention spans that are common to many users of such media. It is essential to gain peoples’ attention as quickly as possible with a concise message, along with the means to easily share the message and comment on its content. Ideally, the target audience will pass it on to people in their own networks and the cycle will continue so that the original message reaches an increasing number of viewers. Ms O’Connor illustrated the concept of being concise with an example of promoting a new report: she suggested to show only a “sneak preview” highlight or infographic that can be quickly digested and entice further interest. Ms O’Connor was convinced that the applications and influence of social media will continue to increase, suggesting that organisations such as AE and its members could only benefit from their use.

**IMI and EU dementia research**

Day two began with a session on “The Innovative Medicines Initiative (IMI) and EU dementia research”, moderated by AE Chair Heike von Lützau-Hohlbein.

Dr Elisabetta Vaudano, IMI’s Principal Scientific Officer for Neuroscience, showed how dementia continues to be a research priority for Europe’s largest public-private initiative. She said that AD therapeutic attempts are increasingly focused on disease prevention and interception, but also on better collaboration between academia and industry. These will all be important factors in AD research, which has seen the investment of substantial resources for only small returns. IMI’s measures of success, based on the equation “Better Science = Better Decisions” are to publish excellent science, set new standards, see use by industry and impact regulatory framework. There are currently over 7,000 people involved in IMI initiatives, including four dementia projects: AETIONOMY, EMIF, EPAD and PharmaCog, all of which include Alzheimer Europe as an active partner. Dr Vaudano described the EMIF project and the others are also covered in this article. The European Medical Information Framework project is connecting data on 52 million individuals to decipher links between genetic background, biological abnormalities, brain imaging changes, mental symptoms and disease progression. EMIF’s main objective is to create an environment that allows for efficient re-use of existing health data. Dr Vaudano closed by saying that IMI would continue to fund dementia projects as there is a high unmet medical need for effective disease-modifying and symptomatic interventions in neurodegenerative disorders in general and Alzheimer’s disease in particular.

She was followed by Dr Régis Bordet, Academic Coordinator of the PharmaCog project who presented “A new way to develop drugs”. Similar to other IMI projects, PharmaCog was conceived amid the growing prevalence of dementia and its social and economic burdens. The project has developed new biomarkers and a pharmacological database that can be used to test new dementia compounds. In particular, there are tools to provide measures for stratification of patient populations, classification of disease severity and predictions of treatment outcomes and drug response. Dr Bordet commented that “we need to tackle all three areas of treatment – preventive, disease-modifying and symptomatic – one is not enough.”
enough.” The project team also worked on the stratification of patients that could be involved in clinical trials; as in AETIONOMY, the PharmaCog members addressed the growing need for clusterisation.

EPAD: prevention of Alzheimer’s dementia

The second session of the day was on “Prevention of Alzheimer’s dementia”, moderated by AE Executive Director Jean Georges. The two speakers were both involved in the European Prevention of Alzheimer’s dementia (EPAD) initiative.

Dr Craig Ritchie, Project Co-coordinator, spoke about prevention of Alzheimer’s disease and “the need for a new disease understanding.” He commented that delaying the onset of dementia by five years would cut prevalence in half, since age is the biggest risk factor. Dr Ritchie also noted that primary prevention occurs before a person contracts a disease, whereas secondary prevention happens after the disease begins to develop. In dementia, this is defined by physical changes in the brain – such as tau and amyloid buildup – followed by memory impairments and mild cognitive impairment (MCI). The EPAD project partners are working to improve the chance of successfully preventing Alzheimer’s dementia and to better understand early aspects of Alzheimer’s disease before it develops. More specifically, the team aims to deliver a standing Proof of Concept adaptive trial for the secondary prevention of Alzheimer’s dementia. The ultimate goal, Dr Ritchie explained, is the prevention of dementia in people with evidence of the disease but few or no complaints or clinical symptoms.

He was followed by Dr Edo Richard, who spoke about the ethical issues arising from secondary prevention trials. He stressed the importance of having clear definitions of all the key terms associated with such trials, citing the differences between “preclinical” and “prodromal” Alzheimer’s disease as an example. Dr Richard also pointed out that primary and secondary prevention points are not fixed; for instance, the perspective of pathological brain changes is different to that of clinical symptoms. In secondary prevention trials, it is crucial that potential recruits are well-informed, as they have already been identified as being at higher risk. This identification carries an implication of risk disclosure, yet researchers must accommodate those people who do not want to be informed about their risk. Dr Richards showed the results of a case study of preclinical diagnosis for Huntington’s disease: people had a high level of interest in pre-symptomatic testing, but the interest dropped quite sharply when they realised that the diagnosis was not certain. Dr Richards also noted that a systematic review of risk disclosure was currently underway in the EPAD project. He concluded that a redefinition of AD and dementia will elicit new ethical challenges and also that the consequences of risk disclosure are not yet well-known.

“Our ultimate goal is the prevention of dementia in people with evidence of the disease but few or no complaints or clinical symptoms.”

CRAIG RITCHIE
Data protection and privacy in big data projects

The third session was on “Data protection and privacy in big data projects” and was moderated by AE Honorary Secretary Charles Scerri.

Laurène Souchet, Policy Officer for the European Patients’ Forum (EPF), spoke about the complex subject of EU data protection legislation. She explained the basis of data protection legislation and how it relates to public health and research. In 2012, the European Commission proposed to develop general data protection legislation, aiming to give citizens more control over their data and provide clearer obligations to data users. By 2015, the European Parliament (EP) had adopted a text that set stringent conditions on specific consent and the use of pseudonymised data. At the time of AE’s meeting, the EP was discussing the final text with the Commission and the Council of the EU. In the view of the EP, the EP’s strict provisions may hinder important research and Ms Souchet cited two recent examples where this would be the case. The EP’s position is that informed consent should, as a rule, be required in research. At the same time, there is a need to protect patients’ privacy while allowing processing of data for legitimate healthcare and research purposes.

She was followed by Dr Duncan McHale, co-ordinator of the AETIONOMY project. He presented the work of the project as an example of data-sharing in current dementia research. AETIONOMY aims to bring together all publically available data from people with Alzheimer’s disease and to organise that data in a systematic way in order to reclassify the disease according to its causes. This is a significant change from the current practice of phenotyping, which classifies people based on observation of their symptoms and a description of the pathological changes in their brain. Dr McHale said that the reclassification would lead to new drug targets that focus on the disease process and identify which person should get which drug. The ultimate aim of the project, he said, “is to turn data into knowledge and knowledge into solutions for people at risk of Alzheimer’s disease.”

Informing the public about clinical trials and dementia research

The final session of the Academy dealt with “Informing the general public about clinical trials and dementia research” and was moderated by AE Vice-Chairperson Iva Holmerová.

The first speaker was Adam Smith of Join Dementia Research (JDR), a UK initiative to connect researchers with people with dementia and their carers. The initiative stems from Prime Minister David Cameron’s “Dementia Challenge 2012” pledge to have 10% of dementia patients involved in research. JDR operates a website where people can join a register used by researchers to populate clinical trials. This system offers advantages to both sides: citizens are often unaware of new clinical trials and trial managers have limited means to reach potential participants. A corollary benefit is that people are better matched up to research projects, as researchers can choose among a larger pool. Mr Smith also noted that JDR brings scientists closer to people, which is a long-term ambition of the project. As of December 2015, JDR had signed up over 13,500 volunteers, of which some 3,000 have been enrolled in research projects. Mr Smith expected to see many more volunteers in the future, especially as JDR is developing a mobile application and will continue to actively promote the service.

The final speaker of the Academy was Karine Fauria, Scientific Operations Manager at Fundació Pasqual Maragall (FPM), who gave a presentation on the foundation’s activities and its current “ALFA” (Alzheimer’s & families) project. This project, managed by FPM together with the Barcelonaβeta Brain Research Center, includes a biomarker study and a primary prevention study in healthy adult children of people with Alzheimer’s disease. The partners’ initial recruitment efforts focused on traditional sources such as hospitals, medical specialists and patient groups. However, these were unsuccessful so the researchers decided to hold a public press conference and place ads in the local media. The result was a flood of positive responses that led to the creation of a registry with over 6,500 people. After screening, the researchers created the ALFA parent cohort, from which some 800 participants will be selected for the two arms of the clinical trial. The ALFA+ study will examine a set of biomarkers while ALFA-life will monitor lifestyle habits and blood pressure changes over the life of the trial.

Alzheimer Europe wishes to thank all the presenters for sharing their expertise. After receiving positive feedback from many of the participants, AE looks forward to organising a similar event at the end of 2016.
Alzheimer Europe surpasses its target for the Glasgow Declaration campaign

The campaign ran during 2015 in cooperation with all of AE’s members. Their active participation was intrinsic to the success of the campaign, which gathered nearly 12,000 total signatures.

Alzheimer Europe’s Glasgow Declaration campaign ended on 30 November 2015 and we heartily thank all the people who worked very hard to help us surpass our ambitious goal of 10,000 individual signatures. This includes our member organisations, sponsors, social media followers and other kind individuals and groups who espoused our cause. The final signature counts were as follows:

- 11,613 individuals from more than 40 countries
- 203 national and international organisations
- 153 policy makers (including 84 MEPs) from 25 European countries

We are pleased to give a special mention to top “scorers” Finland, Italy, Slovenia and the UK, each of which contributed more than 1,000 signatures. Our member associations are to be congratulated for helping us to reach these citizens, who accounted for nearly half of all individual signatures.

On 1 December 2015, we presented our campaign and its results to representatives of the European Parliament, the Commission and two EU Presidencies (Luxembourg and the Netherlands) at our lunch debate in Brussels. Shortly after this meeting, the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council adopted the Luxembourg EU Presidency conclusions, which recognise some of the demands made in the Declaration for greater EU collaboration.

In 2016, Alzheimer Europe looks forward to collaborating with the Governmental Expert Group on Dementia, with the upcoming 2nd Joint Action on Dementia and with the Dutch EU Presidency (1 January – 30 June 2016) for the organisation of its Presidency Conference on dementia.

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

The status of national dementia strategies in Europe

Alzheimer Europe, April 2016
Glasgow Declaration

As signatories, we commit ourselves fully 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.

We 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

We welcome the growing recognition of dementia as a public health priority on a national and European level and call upon European governments and institutions to recognise the role that they have in ensuring that the rights of people living with dementia are respected and upheld. In particular, we:
- call upon Members of the European Parliament to:
  1. Join the European Alzheimer’s Alliance
  2. Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority and create a European Dementia Strategy
  3. Make themselves available for people with dementia, carers and representatives of Alzheimer associations from their country
- call upon national governments to:
  1. Develop comprehensive national dementia strategies with allocated funding and a clear monitoring and evaluation process
  2. Involve people living with dementia and their carers in the development and follow up of these national strategies
  3. Support national Alzheimer and dementia associations

We welcome the international recognition of dementia as global priority and acknowledge the work of Alzheimer’s Disease International and the G7 group of countries in driving forward global action on dementia and call upon the international community to:
- call upon the European Commission to:
  1. Develop a European Dementia Strategy
  2. Designate a high level EU official to coordinate the activities and research in the field of dementia of existing programmes such as Horizon 2020, the Ambient Assisted Living Programme, the European Innovation Partnership on Active and Healthy Ageing, the Joint Programme on Neurodegenerative diseases research and the Innovative Medicines Initiative
  3. Set up a European Expert Group on Dementia comprised of Commission officials, representatives of Member States and civil society to exchange best practices
  4. Financially support the activities of Alzheimer Europe and its European Dementia Observatory and European Dementia Ethics Network through its public health programme
  5. Build on the success of European collaboration on dementia and involve European initiatives in the development of a global action plan on dementia
  6. Include and consult Alzheimer associations and people with dementia in the decision making process and definition of a global research agenda
  7. Adopt a holistic approach to research priorities to include psycho-social, care, socio-economic and health systems research to ensure that research aims to benefit people living with dementia now, as well as people who will do so in years to come
  8. Substantially increase the funding dedicated to all areas of dementia research
  9. Promote dementia as a priority in other international bodies including among the G20 group of countries, the Organisation for Economic Co-operation and Development (OECD), the World Health Organization (WHO) and the United Nations
From the AFE-INNOVNET Thematic Network to the European Covenant on Demographic Change

Anne-Sophie Parent, Secretary General of AGE Platform Europe, speaks about the process of gathering diverse organisations into an effective and sustainable network that aims to improve the lives of older citizens in every European country.

“A key objective of the AFE-INNOVNET thematic network was to mobilise a large group of stakeholders across the EU and launch a European Covenant on Demographic Change to support local and regional authorities in developing environments for active and healthy ageing.”

ANNE-SOPHIE PARENT

The AFE-INNOVNET Thematic Network project, funded by the European Union ICT Policy Support Programme, was launched in February 2014 and ended in January 2016. Its consortium was composed of 29 stakeholders from 16 EU countries: 13 cities, six regions, five large EU networks active in the field of ageing or representing large numbers of local authorities or seniors’ organisations – among which AGE Platform Europe and Alzheimer Europe – as well as four research centres specialised in ICT and ageing policies and a communication agency with vast EU experience.

A key objective of the AFE-INNOVNET thematic network was to mobilise a large group of stakeholders across the EU and launch a European Covenant on Demographic Change to support local and regional authorities in developing environments for active and healthy ageing and thus contribute to the EIP-AHA’s aim to improve the Healthy Life Year indicator, enhance opportunities for independent living of older persons and support a society for all ages.

Within two years the AFE-INNOVNET partners managed to mobilise more than 350 stakeholders interested to join forces to promote age-friendly environments across the EU and help local and regional authorities answer their demographic challenges and invest in sustainable, smart and innovative solutions for the future.

To ensure that they would be able to continue to work together on the longer term they designed the European Covenant on Demographic Change, fostering synergies between other relevant stakeholders while connecting with existing initiatives such as the WHO Global Network on Age-Friendly Cities and Communities, the WHO-Europe Healthy City Network and the European Innovation Partnership on Active and Healthy Ageing.
WHO Global Network of Age-Friendly Cities and Communities

From the beginning of the project, the WHO Global Network of Age-Friendly Cities and Communities (GNAFCC) was identified as a key network to link up with. Following extensive exchanges with WHO, local authorities which join the Covenant as full members can also join the GNAFCC with no further administrative requirement.

WHO Age-Friendly Environments in Europe

In addition, the AFE-INNOVNET TN worked very closely with WHO European region (Manfred Huber and his team) to build synergies with WHO Europe Age-Friendly Environments in Europe (AFEE) Project. This project was funded by DG EMPL and sought to support the Covenant by adapting WHO age-friendly environments methodology to the European context. The AFEE tools were developed in close consultation with the AFE-INNOVNET network and are now available for the Covenant members.

The 2013 Dublin Declaration on Age-Friendly Cities and Communities

The Consortium also identified the 2013 Dublin Declaration on Age-Friendly Cities and Communities in Europe as another initiative with which the Covenant should build synergies to ensure that there would be no competition between the two networks which should on the contrary support each other. Contacts were established in early 2015 with Age-Friendly Ireland which runs the network of signatories of the Dublin Declaration. It was agreed that the best way to reinforce synergies between the two networks would be for the Covenant to request from its members to “accept the Dublin Declaration on Age-Friendly Cities and Communities in Europe 2013 as the shared values and principles of action” as the Covenant’s vision. The Covenant Statutes were adopted by the Consortium in October 2015 and signed on 29 January 2016 by the 68 Covenant Founding members, including this requirement for all membership categories.

Setting up the Covenant as a legal entity

Initially the Covenant was planned to continue as an informal network building on the AFE-INNOVNET TN. However it soon became obvious that it should rather be established as a legal entity and the easiest solution would be to set up an international non-profit organisation under Belgian law. This will allow its members to develop a stronger sense of ownership with the Covenant. It will also allow the Covenant to apply directly for EU funding and to become a WHO GNAFCC affiliate programme. These were perceived as three important elements to ensure long-term sustainability.

Statutes were drafted and agreed by the Consortium in October 2015, setting the aim, membership structure and governance rules of the Covenant. An official launch was organised at the Committee of the Regions on 7 December 2015 and workshops were organised on 8–9 December together with WHO and the European Commission to discuss the outcomes of both the AFE-INNOVNET and AFEE projects and the way forward for the Covenant.

On 29 January 2016, the Covenant Statutes were signed by 68 Founding members who elected its first Board of Directors. It is composed of nine women and six men from nine EU countries, including Dianne Gove, Director for Projects, Alzheimer Europe.

The way forward

A major challenge facing the Covenant is finding sustainable funding to cover its activities now that the AFE-INNOVNET project has ended. Various options will be explored by the Board at its first meeting in June 2016, such as applying for EU funding, raising membership fees, looking for suitable sponsors and finding ways for the Covenant to function despite having no dedicated funding. Covenant members are aware of this challenge and are committed to mobilise as much as possible their own resources and contributions in kind from other supportive stakeholders to move forward while the Covenant builds its capacity to raise the income it will need. AGE is currently running the Covenant secretariat and the first Board meeting will be hosted by the City of Groningen during the conference “Building the Future of Health” on 1–4 June 2016.
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WHO Europe: addressing dementia at the international level

Luxembourg’s EU Presidency conclusions emphasise support for people with dementia

Improving the lives of people with dementia: a key aim of the Netherlands’ EU Presidency

DEM 2: continuing the pan-European effort to improve the lives of people with dementia

122 MEPs support a Written Declaration on Alzheimer’s disease

Implementing Austria’s new national dementia strategy

“A more dementia-friendly society”: Norway renews its national strategy
WHO Europe: addressing dementia at the international level

The WHO Regional Office for Europe is one of six WHO regional offices dealing with public health within the United Nations system. Zsuzsanna Jakab, WHO Regional Director for Europe, speaks to AE about the agency’s numerous activities regarding dementia.

AE: In March 2015 the WHO hosted the very first Ministerial Conference on Global Action Against Dementia: what concrete actions have resulted from this?

ZJ: This first WHO Ministerial Conference on Dementia was exciting. It was attended by 89 Member States including many European countries, 58 philanthropic foundations and 37 NGOs. Alzheimer’s Disease International (ADI) and Alzheimer Europe were of course both there. The participants supported a call for action to promote awareness of the burden and impact of dementia and encourage governments and stakeholders to take action. www.who.int/mental_health/neurology/dementia/call_for_action/en/

At the Ministerial Conference, governments committed themselves to advance dementia research and care. The UK Government announced that they would invest over USD 100 million in a pioneering new global Dementia Discovery Fund. Pharmaceutical companies committed themselves to invest in research efforts for dementia through the project, together with Alzheimer’s Research UK and the UK Government. WHO will lead and coordinate efforts on dementia and also pledged at this conference to establish the Global Dementia Observatory.

AE: Can you give us an update on the planned Global Dementia Observatory and its objectives?

ZJ: We work closely with WHO HQ in Geneva, who are now putting great efforts into the establishment of this Observatory. It is welcomed by our European Member States, since they agree on the need for greater awareness on the burden of dementia, and of information about good practice in one country that can be applied elsewhere. The observatory is working in close collaboration with a range of stakeholders. Both ADI and Alzheimer Europe are engaged, with Marc Wortmann and Jean Georges acting as project advisors.

The Observatory has four domains: burden and impact of dementia; policy in countries; available resources; and research planned or in progress. Presently we are developing indicators for these domains in partnership with pilot countries. So far, in the European Region, four countries have...
volunteered to take part: Italy, the Netherlands, Sweden and the UK, while Luxembourg and Hungary are considering to become engaged. It is of course an Observatory covering countries with a wide variety of needs and resources, even within the European Region. It will be very interesting to identify prevalence, morbidity and burden and compare how countries deal with their needs.

**AE: The Pan-American Health Organization (PAHO) has become the first WHO region to adopt a Regional Plan of Action on Dementia, encouraging its Member States to develop national dementia plans. Will WHO Europe support the development of a similar regional dementia strategy in Europe?**

**ZJ:** The vision of WHO Europe is formulated by Health 2020, our European policy framework that was adopted by all our Member States in 2012. The first priority is “Investing in health through a life-course approach and empowering people”. Last October, we held a very successful Ministerial Conference in Minsk on the life-course approach. The central belief is that actions earlier in life can protect health at a later stage. This is of course backed up by a growing amount of evidence that suggests that life style choices such as nutrition, smoking, alcohol and lack of exercise are all important risk factors for dementia.

Thus, to complement the aspects of dementia and its consequences that are covered well by our colleagues at HQ with the Observatory and that are also the focus of activities of NGOs such as Alzheimer Europe and many national and local organisations, WHO Europe has made the strategic decision to concentrate on healthy ageing and its determinants. The goal is to ensure that all special needs of older men and women are taken fully into account in the implementation of relevant regional action plans. Central to this thinking is prevention and facilitation by policies of healthy life styles. For example, we are supporting cities to become “age friendly”, increasingly important at a time when growing proportions of citizens retire and grow old in cities. This has implications for transport, leisure and services. We are also committed to mainstream healthy ageing into regional actions for health promotion and disease prevention, including intersectoral policies.

Obviously we are not ignoring people with dementia and their carers. Their specific needs are a cross-cutting concern of the “Strategy and action plan for healthy ageing in Europe, 2012–2020”. (www.euro.who.int/en/health-topics/

**Life-stages/healthy-ageing/publications/2012/eurr6210-rev.1-strategy-and-action-plan-for-healthy-ageing-in-europe-20122020). This action plan highlights four strategic priority areas for action: 1) Healthy ageing over the life-course, 2) Supportive environments, 3) People-centred health and long-term care systems for ageing populations. 4) Strengthening the evidence base and research. In implementing these areas of action, attention is paid to the potential additional needs of people who are both older and have dementia. The action plan outlines priorities and supporting interventions for implementation in countries including improving the quality of dementia care and long-term care as well as strengthening the support given to caregivers.

This is spelled out in a range of actions and priority interventions in this strategy and action plan that support people living for dementia. For example, one of the supporting interventions to which Member States and the Regional Office are committed under healthy ageing action plan, is putting in place quality of care strategies for older people, including for dementia care and palliative care for long-term care patients.

Some actions related to dementia care are part of our work to support Member States in reforming health service delivery and improve cooperation between a broad range of health and social services. To give an example: in order to improve the quality of life of older people living with dementia, a patient pathway on dementia was developed in Serbia in November 2015. Pathways are routes for patients that highlight prevention, control and management of diseases, and support trajectories for patients to transit and liaise with other sectors.

**AE:** Many European countries are dealing with an ageing population, the increase of age-related diseases like dementia and a growing vulnerability of their health system. How is WHO establishing health policies to deal with this?

**ZJ:** The very large majority of disease burden in Europe, at least 80%, can be attributed to non-communicable diseases (NCDs). Mental disorders including dementia contribute to this significantly, over 15% of the total burden, but much more when we concentrate on disability. In some Western countries, between 30–40% of the disease burden is due to mental disorders, mostly depression, but dementia is also a major and growing burden. It is therefore self-evident that prevention of the group of NCDs is a priority for public health.

**“WHO Europe has made the strategic decision to concentrate on healthy ageing and its determinants. The goal is to ensure that all special needs of older men and women are taken fully into account in the implementation of relevant regional action plans.”**

**ZSUZSANNA JAKAB**
It is important to note that many of the risk factors are the same across the NCDs. There is also a considerable co-morbidity between NCDs such as diabetes, cardiovascular diseases and cancers on the one hand, and mental disorders such as depression and anxiety on the other. The prevalence of all these disorders increases with age. And all these disorders are also associated with dementia, not only because evidence is growing that the risk factors of NCDs such as alcohol and smoking are also risk factors for dementia, but also because the NCDs themselves are major risk factors for dementia. Think of high blood pressure, CVDs, diabetes and probably depression. This leads us to several conclusions. First, as I mentioned in the previous questions, that common risk factors need to be addressed: we should no longer consider disorders as individual conditions, with their own causes, pathways and outcomes – these are all connected. Second, that prevention is essential, since health systems need to cope with the growing demand that is due to the demographic transition, i.e. the ageing of the population with its higher prevalence of chronic diseases.

WHO Europe is addressing this by focusing on a set of integrated strategies, with a strong emphasis on health promotion. A few relevant policies, in addition to the Healthy Ageing Strategy, all approved by our Member States are: the European Food and Nutrition Action Plan 2015–2020; the European action plan to reduce the harmful use of alcohol 2012–2020; Making tobacco a thing of the past: Roadmap of actions to strengthen implementation of the WHO Framework Convention on Tobacco Control in the European Region 2015 – 2025; Physical activity strategy for the WHO European Region 2016–2025; and the European Mental Health Action Plan 2013–2020. We are now preparing the European Action Plan for the prevention and control of non-communicable diseases (NCDs) 2016–2025. This plan follows up on the “Action Plan for implementation of the European Strategy for the Prevention and Control of Noncommunicable Diseases 2012–2016” and its commitments to strengthen integrated action on risk factors and strengthen action of the health system for improved prevention and control of NCDs. The new plan is currently under consultation and will be submitted for approval at the Regional Committee at its 66th meeting in Copenhagen during 12–15 September 2016.

“Alzheimer Europe is an organization with which WHO has a strong record of partnership, and we are keen to continue this.”

ZSUZSANNA JAKAB

AE: In December 2015 the Council of Ministers adopted conclusions with a call for greater EU collaboration on dementia. How does WHO Europe collaborate with the European Commission in implementing these recommendations?

ZJ: We are working closely with the European Commission (EC) in a number of relevant fields. The EC and WHO Europe agreed in 2010 to support the WHO Framework Convention on Tobacco Control. How does WHO Europe collaborate with the European Commission in implementing these recommendations?

WE: In December 2015 the Council of Ministers adopted conclusions with a call for greater EU collaboration on dementia. How does WHO Europe collaborate with the European Commission in implementing these recommendations?

ZJ: We are working closely with the European Commission (EC) in a number of relevant fields. The EC and WHO Europe agreed in 2010 to support our Member States to deal with the chronic disease challenge through action on addressing determinants of health across the life course, including social and environmental determinants and health-related behaviours. This includes work on capacity building, technical assistance, information sharing and monitoring.

Specifically, WHO Europe and the EC have in the past two years intensively collaborated in the area of supportive environments. There has been a fruitful exchange with Alzheimer Europe to comment on the direction of this project and comments on existing drafts were considered to explicitly link and integrate concerns of dementia friendly environments under the umbrella of age-friendly environments. Publications of the Age-friendly Environments project are forthcoming in the first half of 2016.

WHO and the EC are also collaborating in several other relevant activities. We are participating in the EC Joint Action on Dementia that will start soon. We were also engaged on the Joint Action on Mental Health and Wellbeing that has just finished. The EC was in turn a partner in the development of the European Mental Health Action Plan and other relevant policies. Moreover, WHO Europe is also a partner in the European Innovative Partnership on Active and Healthy Ageing (EIP AHA), which aims to develop synergies between their respective actions including dementia.

We are conscious that dementia remains high on the agenda of countries in the European Union, as demonstrated by the frequent prioritisation of dementia by the EU Presidency. All EU countries are also Member States of WHO Europe, although about half of our Member States are outside the European Union. We advise our EU Member States on technical matters related to health, but we are also always aware that it is important to disseminate the experiences and recommendations of the EU countries to the whole of the European Region. This requires a good understanding of local needs, cultures and resources. Partnerships with local organisations are essential if we want to be relevant for local challenges. Alzheimer Europe is an organisation with which WHO has a strong record of partnership, and we are keen to continue this.
Luxembourg’s EU Presidency conclusions emphasise support for people with dementia

On 7 December 2015, the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council adopted the Luxembourg EU Presidency conclusions on various health-related items, including “Supporting people living with dementia”, which calls on all Member States to address dementia as a priority, develop national strategies and strengthen collaboration between European countries.

Currently, 47.5 million people around the world are living with dementia, including 6.4 million in the EU. “With our ageing population, the figures will increase in the years to come, reaching 9 million people in the EU by 2030”, said Lydia Mutsch, Luxembourg’s Minister for Equal Opportunities and Health. She added that “this condition affects not only the patients, but also those close to them, and indeed society in general.”

The EPSCO conclusions include a particular emphasis on the need to uphold the human rights of people living with dementia, on dementia as a cause of disability, on the need to promote healthy lifestyles – especially where brain health is concerned – to reduce the risk of dementia, but also on the importance of recognising that people can live well with dementia. The Council specifically invites Member States and the European Commission to:

- recognise that continued collaboration across sectors among Member States and at EU level will allow for a valuable contribution to improve the support of people living with dementia;
- recognise the benefits of the empowerment of people living with dementia and encourage their inclusion in decision-making processes;
- support a gender-sensitive, individual- and research-based approach in the elaboration of strategies, plans and programmes on dementia;
- recognise the important role of families and caregivers;
- emphasise the work of non-governmental organisations and voluntary work in the field of dementia aiming to contribute effectively to national strategies, action plans or programmes.

“Dementia is a real socio-economic challenge that puts not only patients and their families, but also the viability of our health systems to a serious test.”

LYDIA MUTSCH
The Council also mentioned several key EU initiatives in its conclusions:

- JPND – the Joint Programming Initiative on Neurodegenerative Diseases
- Horizon2020 – the new EU Framework for Research and Innovation
- the Declaration of G8 Health Ministers on Dementia (December 2013) to foster innovation to identify a cure or a disease-modifying therapy for dementia by 2025
- the Italian Presidency Conference “Dementia in Europe: a challenge for our common future”, held in November 2014
- the Call for Action signed by participants at the first WHO Ministerial Conference on Global Action Against Dementia in March 2015
- the informal meeting of EU Health Ministers in September 2015 on fostering development and implementation of national strategies, action plans or programmes on dementia
- the Governmental Expert Group on Dementia
- the European Innovation Partnership on Active and Healthy Ageing (EIP AHA)
- the ALCOVE Joint Action

“Dementia is a real socio-economic challenge that puts not only patients and their families, but also the viability of our health systems to a serious test. That is the reason why we addressed dementia as a societal phenomenon that requires multispectral responses”, said Ms Mutsch. She also called for “stronger cooperation, emphasising the role of preventing risk factors, including secondary prevention, early diagnosis and adequate post-diagnosis treatment, in order to reduce the burden represented by dementia in an ageing population.”

MEPs comment on the Council conclusions

Keith Taylor, MEP (UK) and Sirpa Pietikäinen, MEP (Finland) are both Vice-Chairpersons of the European Alzheimer’s Alliance. They provided the following statement about the Council conclusions.

“The EPSCO Council conclusions are a fantastic step in the right direction for the continued build-up of positive action on dementia across Europe. Now is the right time for these actions to be brought together. Already, dementia is testing the capacity of our health systems and represents a real socio-economic challenge. With the ageing of the population and an inevitable increase in the number of people with dementia – the forecasts are for 9 million in the EU by 2030 – we will need a co-ordinated approach to care and treatment.

Dementia is a difficult illness for families, many of whom are also primary carers, who need to be fully supported. The Council conclusions identify the importance of training for formal and informal caregivers as an area of work, alongside the removal of stigma, as well as an exchange of good practices and enhanced investment in research. We also need to recognise the importance of involving people with dementia in playing an active roles in care development.

The conclusions call on Member States to address dementia as a priority via national dementia strategies, actions plans or programmes, which it emphasises they should have in place. They also call on members states to identify further priorities at EU level, with particular emphasis on the need to uphold the human rights of people living with dementia, dementia as a cause of disability, and the need to promote healthy lifestyles, something which I very much welcome.

I am also delighted to see that the next three EU Presidencies, Slovakia, Malta and the UK will have dementia as a health priority.” – Keith Taylor

“The Council conclusions deliver a very welcome and important political signal: we need joint action to cope with the increasing population with memory diseases in Europe. However, to achieve efficient results, the conclusions should have been more ambitious, especially when it comes to safeguarding fundamental rights of people with memory disabling diseases. The right to be heard and be represented, the right to appropriate and adequate care and the right to decide on one’s own care plan should be guaranteed in all EU Member States. The Council also missed the opportunity to launch at the political level the idea of treating memory disease as a cognitive disability.” – Sirpa Pietikäinen
Improving the lives of people with dementia: a key aim of the Netherlands’ EU Presidency

Martin van Rijn, State Secretary for Health, Welfare and Sport in the Netherlands, speaks to Alzheimer Europe about how the Dutch government continues to support dementia-friendly initiatives, both at home and in all European countries.

“<br>My challenge is to contribute to an open society, acceptance of and respect for people with dementia. People with dementia should be able to participate in society for as long as possible.”

MARTIN VAN RIJN

AE: What do you see as the biggest priority and the biggest challenge in the fight against dementia?

MvR: More understanding of dementia will lead to better care. But as long as we’re not able to cure this terrible disease, we should make dementia as bearable as possible for all: the patient and family, friends and (informal) carers.

The standard of care for people with dementia in the Netherlands is relatively high. This is evident from, for instance, the fact that care concepts developed in the Netherlands are frequently applied abroad. But improvements are both possible and necessary in various areas. We owe that to the people who have dementia and to the carers of tomorrow. As the age demographics of the population shift, families grow smaller and smaller, and the number of single-person households increase, these people will have far fewer people to rely on and on their behalf, we cannot be satisfied with what we have now.

My challenge is to contribute to an open society, acceptance of and respect for people with dementia. People with dementia should be able to participate in society for as long as possible. Support for their friends and family, volunteers and for the professionals who support them are important goals.

AE: The Netherlands currently holds the EU Presidency under which dementia is a priority. You have initiated a two-day conference on dementia. Can you tell us more about the conference and what you hope will be achieved?

MvR: Dementia is a challenge that deserves worldwide attention and action. The conference will showcase the added value of international cooperation in research and state-of-the-art practices in care and social innovation.
On 9–10 May we invited policy advisors, board members of national Alzheimer offices and scientists to discuss how we can give as much dignity as possible to the lives of people with dementia. But we can only make the right call if we attach importance to the perspective of the person with dementia. Therefore, people with dementia and their carers will make an essential contribution to the conference.

I will launch the national campaign which raises awareness on dementia in the Netherlands and activate people to support people who suffer from dementia. I hope other member states will follow our example as we follow the example of the British and the Scottish governments. I hope to achieve to inspire the participants to start building a dementia-friendly society in all of Europe.

**AE:** How important do you think it is to have cooperation at the European, even global level?

**MvR:** Working together is the key. In neighbourhoods between informal and formal care, between hospitals and municipalities but also cooperation on all levels to make a movement fast forward to a solution for the people now living with dementia and next to cure and treatment for the future.

Alzheimer Netherlands is currently working on a dementia friends programme. I have launched a programme entitled Dementia Friends, based on Japanese and English examples. The essence of the initiative is for people to learn more about dementia and learn to deploy that newly acquired knowledge to help people with dementia. Various tools are used for that purpose, including an online forum, a service desk, and modules for informing people, equipping them with the right skills, and training them to use those skills. The programme is tailored to target groups (for instance hairdressers, bank tellers, policemen or neighbours). Companies, local governments, regional initiatives and youngsters will be approached directly, online and offline.

The aim is for one million people to be more aware of dementia within five years and for some of them to become actively engaged friends (310,000). The friends become the pivotal point in a movement. They learn how to recognise and how to act when you come across a person suffering from the impact of dementia. At the same time, while increasing awareness, we will break the taboo of dementia. Working from the bottom and from within, we can make society more dementia-friendly.

**AE:** How important is the Government’s relationship with Alzheimer Netherlands?

**MvR:** If we want to break the taboo of dementia – as I want to – than we cannot operate without Alzheimer Netherlands. They’ve been trying to do the same thing for years. And I hope they will continue for years to come as well. Alzheimer Netherlands have been for more than 30 years the eyes and ears in society who communicate with people living with dementia.

“Alzheimer Netherlands have been for more than 30 years the eyes and ears in society who communicate with people living with dementia.”

MARTIN VAN RIJN
DEM 2: continuing the pan-European effort to improve the lives of people with dementia

The second European Joint Action on Dementia is now operational and is led by Geoff Huggins, Acting Director of Health and Social Care Integration in the Scottish Government. We asked Geoff about how the partners will work together on this three year EU-wide effort.

Why a second Dementia Joint Action?
The first European Joint Action on Alzheimer Cooperative Valuation in Europe (ALCOVE) aimed to improve knowledge on the disease, its consequences and to reflect together on the best means of preserving quality of life, autonomy and the rights of people living with dementia. Alzheimer Europe was instrumental in building a strong and effective consensus on the need to act both individually and collectively. The action built a wealth of evidence and knowledge to support Member States in developing their dementia policies and operational capacity. At the time ALCOVE was operational, only a handful of member states had developed their policies on dementia. The creation of a network of specialists and interested parties was therefore very important at the time.

Whilst ALCOVE focused on creating consensus on evidence and knowledge, there is a sense that this hard-learned knowledge is not being put into practice consistently across Europe. As a result, we now have a wealth of good practice and toolkits available to improve the quality of life for people living with dementia and their families but a lack of skills or capacity at a local level to deliver improvements.

Dementia Two (DEM 2) is intended to take the good practice evidence and strong networking ethos a step further. The objective of this Joint Action is to test the delivery of tested principles of good practice in localities with the aim of increasing the successful uptake of evidence-based practices. The main methodology for achieving this aim is through improving our understanding of the challenges of implementation in different settings.

What will DEM 2 Cover?
The provision and quality of services for people living with dementia and their carers has improved, but it is not consistently good yet. The aim of this Joint Action is to promote the implementation in EU Member States of coordinated actions to improve the situation of people living with dementia and their carers. The Joint Action will focus on four key areas for action:

1. Diagnosis and post diagnostic support
The rate of dementia diagnosis varies greatly between member states and in many places post-diagnostic support is non-existent or underdeveloped. Where a diagnosis occurs later or is communicated poorly and without subsequent interventions, the risk of institutionalisation and other poor outcomes for the person and their family is significant.

Improving diagnosis rates and post-diagnostic support for people with dementia and their carers allows people with dementia, their families and those involved in their care to benefit from access to treatments, interventions, information and education as well as services which can improve quality of life, facilitate hope and the opportunity to live well with dementia. Better care planning facilitated by post-diagnostic support can also contribute to reducing health and social care expenditure on preventable hospital and residential care admissions for people with dementia.

"ALCOVE focused on creating consensus on evidence and knowledge and was much needed at that time, but today there is little sense of that knowledge being put into practice. So, there is plenty of good practice and evidence out there that could be used if local partners had the skills and capacity to do so."

GEOFF HUGGINS
2. Crisis and Care Coordination
People with dementia need different sorts of care and their need for care grows as the disease progresses. In most health and care systems dementia care will be provided by a range of different providers each working under different eligibility and funding rules and often without clear co-ordination with the outcome that the experience can feel fragmented.

In situations of crisis, admission to institutional care is often unnecessary and is a result of either limited access to alternative and more appropriate care, or lack of care coordination between health and care providers. Family caregivers often report significantly increased anxiety, apathy, resistance to care, and distress in these types of crisis situations.

3. Residential Care
A large proportion of nursing and residential care home residents have dementia (in some countries up to 80% of residents). As it is a progressive condition with no cure, many people with dementia who are admitted to a care or nursing home will remain there for the rest of their life. It is important to ensure high quality professional care, including palliative care, delivered with dignity and compassion is available in residential and nursing care establishments.

4. Dementia-Friendly Communities
As more Member States look at the costs to society of caring for people with dementia, alternative community supports are being developed to ensure that people can live in their own homes for as long as possible. Communities which are “dementia-friendly” can help support people with dementia to live more independent and fulfilling lives in their own communities. Evidence has shown that appropriate support in the community can reduce the numbers of people with dementia being admitted to hospital, and can delay their entry into care homes.

What will DEM2 provide?
The Joint Action’s outputs will provide practical guidance for policymakers developing and implementing their national dementia plans, policies and strategies. It aims to provide cost-effective practical examples of the core components of good dementia diagnosis, care and support with the aim of providing better quality care with the ultimate objective of improving the quality of life for those living with dementia and their carers. Look out for the launch of the website and invitations to meetings and test sites.

Who is taking part in this Joint Action?
The work package leaders are as follows:

- Scottish Government (Coordination and dissemination)
- Spain’s Agència de Qualitat i Avaluació Sanitàries de Catalunya (Evaluation)
- University Lyon 1 and the French Ministry of Health (Diagnosis and Post Diagnostic Support)
- Italy’s National Institute for Health and the Dutch Ministry of Health, Welfare and Sport (Crisis and Care Co-ordination)
- Norwegian National Advisory Unit on Ageing and Health (Residential Care)
- UK Department of Health (Dementia-Friendly Communities)

Participating partners include THL (Terveyden ja hyvinvoinnin laitos, Finland), Medical University of Lubin (Poland), Bulgarian Society of Dementia, The Norwegian Directorate of Health, CRE Alzheimer – Imserso (Spain), National and Kapodistrian University of Athens (Greece) and Bundeszentrale für gesundheitliche Aufklärung (Germany). There are also several collaborating partners, including Alzheimer Europe, who will play a pivotal role in ensuring that the voices of people living with dementia and their carers are heard throughout the three-year programme.

“I want this joint action to focus on building that capacity for consistent and sustained improvements in the way we care for people living with dementia and their carers.”

GEOFF HUGGINS
122 MEPs support a Written Declaration on Alzheimer’s disease

In October 2015, 23 MEPs submitted a Written Declaration on Alzheimer’s disease which invited the European Commission and the Council to recognise dementia as a public health priority in Europe and to adopt various related measures.

The Declaration included the following statements:

- Alzheimer’s disease is an incurable neurodegenerative disease of the brain tissue that causes progressive and irreversible loss of mental functions, including memory.
- 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.
- 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.
- The Commission and the Council are invited to recognise Alzheimer’s disease and related diseases as a public health priority in Europe.
- 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.

The Declaration required the support of the majority of MEPs in order to proceed further. By the closing date of 5 January 2016, only 122 (of 751) MEPs had expressed their support. This was clearly short of a majority and caused the Declaration to lapse on the same day. Nevertheless, Alzheimer Europe wishes to thank all the signatories for expressing their support to improve the lives of people with dementia and their carers in all European countries.

Alzheimer Europe thanks the following signatories for their support:

- Austria: Georg Mayer, Harald Vilimsky
- Belgium: Gerolf Annemans, Philippe De Backer
- Bulgaria: Filiz Hyusmenova, Andrey Novakov, Georgi Pirinski, Vladimir Urtuchev
- Croatia: Ivan Jakovčić, Davor Ivo Stier, Ruža Tomašić
- Cyprus: Leftis Christoforou, Neoklis Sylikiotis
- Czech Republic: Kateřina Konečná, Jiří Maštálka, Stanislav Polčák
- Estonia: Tunne Kelam, Urmas Paet
- Finland: Merja Kylönén
- France: Dominique Bilde, Marie-Christine Boutonnet, Mireille D’Ornano, Nathalie Griesbeck, Gilles Lebreton, Dominique Martin, Sophie Montel, Franck Proust
- Germany: Sabine Lösing
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- Hungary: Lőrinc Komó, Ádám Kósa, Csaba Molnár, Tibor Szanyi
- Ireland: Matt Carthy, Luke Ming Flanagan, Seán Kelly
- Italy: Isabella Adinolfi, Goffredo Maria Bettini, Mara Bizzotto, Gianluca Buonanno, Giovanni La Via, Aldo Patriciello, Remo Sernagiotto, Patrizia Tota
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- Sweden: Peter Lundgren
- United Kingdom: Lucy Anderson, Martina Anderson, Ian Duncan, Afzal Khan, Emma McClarkin
Implementing Austria’s new national dementia strategy

Austria officially launched its strategy in December 2015. In this article, Health Minister Sabine Oberhauser speaks to Alzheimer Europe about the key elements and rollout of the new strategy.

AE: What are the main elements of Austria’s new dementia strategy?

SO: The Austrian dementia strategy is designed to form a joint framework for guidance on targeted cooperation between the stakeholders. The federal government, provinces, local authorities and social insurance institutions as well as numerous other institutions and organisations are already taking measures in relation to health promotion, prevention, and the care of people suffering from dementia. If this work is oriented towards a dementia strategy which has been jointly developed by actors from all policy areas, I am convinced that we can combine our funding and forces to achieve good results.

The targets and recommendations for action in the strategy form a joint basis for the organisations involved to specify their objectives and the measures to achieve them. Overall, seven targets and 21 related recommendations for action were drawn up in the working groups.

AE: Which objectives have the greatest priority?

SO: Due to the large number of recommendations for action, they are currently being ranked in order of priority. The first measure will be the establishment of a Dementia Strategy Platform. The platform will have the task of facilitating coordinated action and the implementation of a joint framework and...
recommendations. To this end, stakeholders, persons responsible for realisation, researchers and those affected will form a joint platform, whereby existing structures will be taken into consideration. At the same time, similar platforms will be established at a provincial level.

In addition, special attention will be given to target no. 2 “Extending the provision of information in a broad and target group-specific way”. As people suffering from dementia symptoms and those close to them have a great need for information, I see the development of comprehensive information and communications concepts as well as broadly-based public relations work as essential.

**AE: How will the strategy actually be implemented and how long will it take?**

**SO:** In order to be able to successfully implement the dementia strategy, suitable and adequate structures and processes are required in order to develop methodological expertise and subsequently be able to make it available. Networking will play a decisive role here. Our goal has to be to bring existing structures together and network them accordingly, and at the same time to make people familiar with a joint picture and joint objectives of a successful realisation of the dementia strategy in Austria.

At this point I am also appealing to the commitment of all of the stakeholders involved. The refined recommendations for action are intended to enable the respective decision-makers to plan and implement specific measures in their spheres of influence – at a national level and in the provinces and local authorities. In this way, we intend to reach the defined targets.

In which time scale the individual recommendations for action will be realised will become clear during the prioritisation process. While some recommendations for action can be implemented at short notice, a medium-term or long-term time frame will be selected for the realisation of certain measures.

**AE: How will activities be financed and staffed?**

**SO:** Here again I would like to refer to the division of competences among the participating stakeholders. Their commitment at the individual levels of implementation will play a decisive role here.

**AE: Alzheimer Austria was active in two working groups during the strategy’s development. How do you see the future role of the association?**

**SO:** Alzheimer Austria did excellent work during the drawing up of the dementia strategy – as did all the stakeholders involved. With its expertise, it contributed towards the fact that the dementia strategy will provide considerable help in improving the living situations of people suffering from dementia. The participating organisations will, of course, continue to be involved in the realisation of the dementia strategy.

**AE: Is there a need for closer collaboration on dementia on a European and/or global level?**

**SO:** International networking and cooperation is always of key significance. Even before the dementia strategy was drawn up, we looked at existing dementia strategies in other countries and were in continuous contact with international experts. This will continue to be the case in the future. Dementia is a worldwide issue, and the challenges of an ageing society can only be met by international cooperation at all levels.

“Dementia is a worldwide issue, and the challenges of an ageing society can only be met by international cooperation at all levels.”

**SABINE OBERHAUSER**

**Alzheimer Europe is very grateful to Antonia Croy and Monika Natlacen from Alzheimer Austria for their cooperation to produce this interview.**
“A more dementia-friendly society”: Norway renews its national strategy

Norway’s Dementia Plan 2020 sets new goals and provides the framework for further cooperation between state, municipalities and voluntary sector, so that people with dementia can live better with the disease. Lisbet Rugtvedt, Secretary General of the Norwegian Health Association, explains the goals of the new plan around the country. We are proud of the input our members have contributed, by giving politicians an insight in what it is like to live with dementia”, says Lisbet Rugtvedt, Secretary General of the Norwegian Health Association.

How far did the first strategy bring Norway?

The new strategy is both an extension and a renewal of the previous plan that ran from 2007 to 2015. The main goals in the former plan were to offer educational programmes and peer groups for carers in all municipalities, increased competence in dementia in the health sector, more people diagnosed, and governmental funding to raise the number of day programmes and nursing homes for people with dementia.

In 2015 the Norwegian National Advisory Unit on Ageing and Health did an extensive survey in all 428 municipalities to assess the progress that was made during the first dementia strategy since 2007.

- 71.5% of the municipalities have services for people with dementia as part of their municipal planning
- nearly 78% of the municipalities have organised dementia assessment in dementia teams and/or a dementia coordinator, compared with only 25% at the start of the planning period in 2007
- 305 municipalities offer day programmes, and number of persons receiving this service almost doubled from a similar survey in 2010–2011. This applies to around 15% of all people with dementia who live at home
- 289 municipalities conducted educational programmes for carers in 2013 and/or 2014, compared to only 20 in 2007

“We must be allowed to live full lives, even when we have dementia. Using our own resources makes it easier to cope with life and to live with the disease. Therefore, we want to facilitate that people with dementia can participate more actively in the society”, said Minister of Health Bent Høie when the plan was launched in December 2015.

He highlighted the Norwegian Health Association’s campaign for a more dementia-friendly society. And the new Norwegian dementia strategy has also been named “A more dementia-friendly society”.

“When the Minister of Health in 2014 started to work with a renewed plan, it was a great victory. We are particularly pleased with the process, where both people with dementia and their carers had the opportunity to participate in the preparatory work with the plan through dialogue conferences.”

LISBET RUGTVELD
• 396 municipalities have adapted housing for people with dementia in the form of shielded unit in nursing homes and/or multi-occupied houses for people with dementia in residential care
• over 20,000 employees in the municipal sector were registered as taking part in education on dementia

Continuation and new goals in the second strategy

The Norwegian Government’s stated objective for the entire health sector, is to create health and care services that is more centred around the patients, and the strategy explicitly states this also applies to people with dementia.

The new strategy’s main goal is to create a more dementia-friendly society that takes care of, and includes, people with dementia. In order to do this, the plan states, there is a need for more openness and knowledge about dementia in society in general, and in the health sector in particular.

The aim is also that the new strategy will contribute to better services, both for people with dementia and their carers.

The new strategy lists a number of areas with challenges that needs to be met. These include measures to prevent dementia, knowledge and competency in the health sector, diagnosis and follow up, flexible and differentiated day programmes, support and time off for carers, good and customised services throughout the entire course of the disease, and participation and involvement.

A number of strategies and measures are being targeted to meet these challenges.

• self-determination, involvement and participation
• prevention, what it is good for the heart is good for your brain
• timely diagnosis and close follow up after diagnosis
• emphasis on activity, coping and relief
• systematic follow up and customized services
• research, knowledge and expertise

Several measures from the previous strategy are continued in the new strategy. In particular this applies to educational programmes for carers, training in dementia care for employees in the sector, focus on assessment and diagnosis, governmental grants for day programmes, and investment grant for nursing homes.

New measures include educational programmes for people with dementia and models for systematic follow-up after diagnosis. From 2020 Norwegian municipalities will have a duty to offer day programmes. There will be programmes to develop good models for home care services for people with dementia, and development of tools to involve people with dementia and their carers in the design and provision of health-care systems. The strategy includes campaigns for raising awareness in different sectors of society. And since Norway, like most countries, does not have an overview of prevalence, better knowledge about the prevalence of dementia is also stated goal.

Will the plan work?

Overall, the Norwegian Health Association is satisfied with the new strategy. “We are concerned that both existing and new initiatives are to be implemented without granting additional resources”, said Ms Rugtvedt.

Surveys show that there is some way to go before the goals of the previous dementia strategy are reached. In particular only about 15% of those in Norway with dementia who live at home have a day programme. Moreover, far too few who work in dementia care have adequate education. Only 10% are nurses, and 30% have no formal health education.

The new dementia strategy has been well received among those who are most directly concerned, people with dementia and their carers, but it is too early to say what consequences the strategy will have locally. In the Norwegian working group one member summed up everyone’s feelings: “We need to talk about dementia as the most natural thing in the world.”
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Agnes Houston presented the award-winning poster at the 25th Alzheimer Europe Conference

Colette Kelleher
Chief Executive of the Alzheimer Society of Ireland

Heike von Lützau-Hohlbein looks back at 25 years with the German Alzheimer Association
Looking back: 25 years on the Board of the German Alzheimer Association

Heike von Lützau-Hohlbein recently retired after many years of service with the German Alzheimer Association. In this article, she discusses the numerous achievements and future hopes of the association.

The end of a tenure

My tenure as Chairperson of the German Alzheimer Association (Deutsche Alzheimer Gesellschaft, DAzG) ended with a standing ovation from the delegates at our annual meeting in Bochum in November 2015. For me this was a very emotional moment combined with a strong feeling of appreciation and support of the work that was done over the years. It was gratifying to see that the processes that were initiated by the board under my chairmanship and the tasks that were fulfilled by the board, the office and myself were so well appreciated. I was aware that the work of DAzG was always supported by the members, but this moment really felt like a global reward for all of our efforts.

I announced my decision to step down from the post three years ago. After serving as Chairperson for 14 years and as Honorary Treasurer for another 11 years before that, I felt that it was time for a change. I was very pleased to see Monika Kaus elected as the new Chairperson and am convinced that the association is in excellent hands. Monika, a carer like myself, was previously the Honorary Secretary and is very knowledgeable about all our structures and activities.

From wishes to reality

Looking back at my many years of involvement, I would like to highlight some of the aims that we have achieved. The first is awareness of dementia in the public. For over 15 years, we've been talking about dementia on TV at prime time or seeing movies with dementia as a central theme. There have been several such movies in Germany, the most successful being “Honig im Kopf” (“Head full of honey”) that attracted more than eight million viewers in 2014.

Another DAzG aim was to have dementia featured as a common issue in the daily press, including the views of people with dementia, the carers’ view, the medical and professional aspects and also research news. Nowadays, these issues are routinely mentioned in the media.”

HEIKE VON LÜTZAU-HOHLENBEIN

"Another DAzG aim was to have dementia featured as a common issue in the daily press, including the views of people with dementia, the carers’ view, the medical and professional aspects and also research news. Nowadays, these issues are routinely mentioned in the media.”
medical and professional aspects and also research news. Nowadays, these issues are routinely mentioned in the media.

Sometimes I worry that this high visibility will generate fear: recent studies have shown that dementia is, after cancer, the most feared disease among the German public. Nevertheless, it is important to point out the many characteristics of dementia and the possibilities to cope with it, such as raising awareness about support for people living with dementia and their carers and encouraging people to seek appropriate support.

In my early years, we had the ambition that DAlzG should be the primary contact for public and political affairs when it came to dementia. I have no doubt that we have succeeded, as DAlzG is now always involved when the Ministries of Health, Social Affairs or Seniors deal with this issue. For instance, DAlzG was invited to be part of the process to reform long-term care insurance. This was a very long process, as it took more than eight years to define and implement a definition of need of care that is independent of the cause. When long-term care insurance was introduced in 1995, it was based on physical deficits while psychological causes were neglected. With various changes over the years, the situation of people with mental problems was enhanced. I am very pleased that, starting in 2017, there will be a new assessment instrument that no longer discriminates against people with psychological deficits and their needs, as it is based on support for autonomy.

Towards a National Strategy

In 2003 DAlzG was a partner in the “Alzheimer-Aktion” campaign, which aimed to draw attention to dementia and its health and social impact. The campaign gathered more than 50,000 signatures and we had planned a public event to hand them over.

“There is very good communication between DAlzG and its members, including an advisory board and frequent exchanges of ideas and initiatives.”

HEIKE VON LÜTZAU-HOHLBEIN
over to Chancellor Gerhard Schröder. However, he refused to see us and instead delegated the matter to the Ministry of Health, where we failed to make any further progress. Every idea has its time and not all ideas can be successful!

Our time came in September 2014, when the Minister of Health and the Minister of Family Affairs officially adopted the agenda of the “Alliance for people with dementia”. This Alliance has to be seen as a first step towards a national German dementia strategy. The introduction states that: “The Agenda is shaped by the principle of inclusion. The self-determination and participation of people with dementia stand at the forefront of all deliberations. The German Alzheimer’s Association, as the representative of people with dementia and their families, is therefore an important partner to the Alliance. Furthermore, people with dementia who are organised in self-help groups have formulated their own visions and expectations of the Alliance.” The next steps should be to create a body with a comprehensive responsibility and a budget to monitor and certify that the situation of people with dementia has really been enhanced by the actions of the Alliance.

A look inside DAlzG

With regards to the interior workings of the DAlzG, I am proud to see that we have succeeded in unifying and amplifying local and regional activities under the national umbrella of DAlzG. There is very good communication between DAlzG and its members, including an advisory board and frequent exchanges of ideas and initiatives. As can be expected, some members are more active than others. The biennial conferences and workshops organised by DAlzG are always well-attended and each event attracts ever more participants. All of this takes place in a friendly and constructive atmosphere, which is made possible by the excellent collaboration among the Board members, the Executive Director and her office staff.

As an umbrella organisation of self-help groups, we have made efforts to shape our profile so that we are not seen as just another interest group. DAlzG was inaugurated in 1989 as an association of carers and people interested in the field of Alzheimer’s disease. At the time, the perception of dementia consisted mainly of people in the late stages of the disease. Over the years, this picture has changed and today all phases of the disease are seen as equally important. As a consequence, people with dementia are increasingly willing to speak for themselves.

“...individual persons became the focus.”

HEIKE VON LÜTZAU-HOHLBEIN

International networking

In 2004 I was delegated to represent DAlzG on the Board of Alzheimer Europe. It was an honour to learn about the various tasks and projects on the European level, to see the difficulties and successes. When I took over the post of Honorary Treasurer in 2006 – and even more when I was elected as Chairperson in 2010 – the burden and the responsibility were always balanced with the conviction of trying to do what was best for people with dementia and their carers.

2012: Minister of Health Daniel Bahr signs the “Buch der Erinnerungen” (Book of Memories)
This naturally led to their becoming more and more involved in the bodies of the DAzG, initially in working groups and today included in the official statutes of the DAzG. This is a great gain for all of us, in the sense of “nothing about us without us”.

**Focusing on individual persons**

I would like to conclude with some personal remarks. The voluntary work I did over the last 25 years was a great benefit for me. In my professional experience as a computer specialist, I mainly solved technical problems and human involvement was an unavoidable side effect. But in my work for dementia organisations, individual persons became the focus. This was a new facet in my life, where I met people whom I would never have met without my voluntary involvement. It also gave me the opportunity to visit parts of Germany and Europe which I had not seen and to return to places where I had not been for years. I always tried to arrange some spare time in the cities where I was presenting the views of the DAzG. I used this time to just stroll through the town or visit museums or see friends or relatives of my huge family.

Despite the considerable work to prepare speeches and presentations, to learn about new projects, develop project ideas and remain informed about the newest developments, I have always welcomed the responsibility of putting forward the issues of dementia. After so many years I imagine this will always remain a part of my life, but currently I intend to enjoy my days as a retired person – excepting of course my duties as chairperson of Alzheimer Europe.
Aiming to make Ireland the best country for people with dementia

Colette Kelleher recently took over the helm of the Alzheimer Society of Ireland. In this article, she speaks about her remarkable career and how she hopes to improve the lives of people with dementia in Ireland.

Allow me to introduce myself: my name is Colette Kelleher and I was recently appointed Chief Executive of The Alzheimer Society of Ireland (ASI). I qualified as a Social Worker in the 1980’s and with an MBA in 2011, and have worked in a variety of NGO’s in both the UK and Ireland. The common thread that binds all of the organisations that I have worked for is the concern to achieve, through advocacy and services and supports, the best quality of life for children, people who are homeless, people with disabilities and now people with dementia. I also spent two years working in the UK’s Whitehall as a Special Adviser to the Minister and civil servants about how, following National Strategies on Childcare, to translate an unprecedented investment in children’s services by Tony Blair’s Labour Government into real services and supports on the ground for children and their families.

My own values, interests, professional background and the range of experiences I have had over the past three decades drew me to The Alzheimer Society of Ireland and its work. I passionately believe that we can create a world where a person can live well with dementia. The ASI is in a unique position to lead and mobilise others to make Ireland the best country in the world to have dementia and Europe the best continent.

My first five months in the role have been stimulating, challenging and moving. I am still in the process of visiting The ASI’s services and supports all over the country, meeting people with dementia, their carers, volunteers and staff. I have also been spending time with funders and supporters including the Health Service Executive (HSE), Atlantic Philanthropies and corporates, as well as with key partners in Government, other NGOs, professional bodies and universities and academics.

Alongside Helen Rochford Brennan, Chair of the Irish Dementia Working Group and Sean Donal O’Shea from our Dementia Carer’s Campaign Network, I sit on the Implementation Monitoring Group of Ireland’s first National Dementia Strategy which has met twice since I took up my role in September. I have also spent time with colleagues in Alzheimer Scotland and Alzheimer Society, Northern Ireland, who have generously shared their knowledge and wisdom with me.

“The Alzheimer Society of Ireland is in a unique position to lead and mobilise others to make Ireland the best country in the world to have dementia and Europe the best continent.”

COLETTE KELLEHER
Over the course of the last six months what has resonated with me the most, is the challenge of dementia for people living with the condition and their carers and “the system’s” ability to respond to it. I have been moved by people’s stories of courage and bravery. I have witnessed tremendous kindness, generosity, and sincerity. I have come across fun as well as frustration. I have been encouraged by people’s interest and optimism too. I believe that we are at a historic moment in the history of this challenging condition. I truly believe we are close to breaking through for dementia; from something that is experienced as primarily a private problem for the individual and their families to an all-of-society issue that demands a requisite all-of-society response.

There will be a number of key themes running through our work in 2016. We are in the final year of our current organisational strategy and are thinking about our “2020 vision” for dementia in Ireland, taking us from 2017 to 2020. We are continuing to focus on the experiences of people with dementia whom we support. To this end, we have been surveying people about their experiences of The ASI and using this feedback to improve what we do and how we do it. As a result of the latest feedback, we are working to improve practical and important issues such as choice of food, activities and better signage in 2016. We will be finalising our Day Services Audit tool, focusing on home care and looking at how we “safeguard vulnerable adults” including people with dementia.

In 2016, we will also be expanding the reach of our Helpline and thanks to the generosity of the Late Peggy Mangan, a person with dementia, and her family, we are going mobile with our new advice bus about to take to the road.

Having secured funding for eight Dementia Advisers from the HSE, The ASI will be independently evaluating their impact to date and looking to the future.

We will be sharing our experience of an ASI innovation, the Cognitive Stimulation Therapy (CST) project, which we developed and piloted in four settings last year. We will be sharing what we learned in 2016 and looking at how we can further develop this work amongst ourselves and others.

The ASI will also be working with the HSE to localise the National Dementia Strategy. Working with the HSE, The ASI will be facilitating the development of local area plans or “Dementia Strategies” in the nine HSE Community Healthcare Areas. We are currently planning this work which we will complete by the end of 2016.

2016 is the final year of Atlantic Philanthropy funding of ASI advocacy work. We will continue to build on our successes to date while also looking forward to the next phase of providing supports for people with dementia both in terms of the challenge they face and enabling them to seize emerging opportunities. Central to our work will be strengthening and supporting the voice of people with dementia and their rights. We will be supporting the Irish Dementia Working Group and the launch of a “Charter of Human Rights for People with Dementia” later in the year. We will also be supporting the development of self-advocacy groups regionally in 2016.

During this election year, The Alzheimer Society of Ireland will also be following up on our ‘Vote to Remember’ General Election campaign. We will be tracking all the pledges in support of people with dementia and their carers from the political parties and the candidates who get elected. We will also be working to ensure a strong commitment to the National Dementia Strategy will be in the next Programme for Government.

We will also, of course, continue to keep a close focus on the implementation of the National Dementia Strategy, inputting into the midterm review and thinking beyond this strategy to the next one.

Ireland has been through a number of tough years which has put a strain on organisations like The ASI and resulted in many challenges when it comes to maintaining services and supports for the growing number of people with dementia in Ireland. We are hopeful that with support, we can break even financially in 2016 and strengthen our organisation as we face the future.

In 2016, The Alzheimer Society of Ireland will be looking to our “2020 vision” for people with dementia in Ireland and the role that our organisation can play over the next few years. We will be developing a new strategy for the organisation. We will need partners, allies and supporters to realise the “2020 vision” for people with dementia in Ireland and our strategy to get there. Alzheimer Europe has been, and will continue to be, a valued friend as we continue our work to make Ireland and Europe the best country and continent for people with dementia. I am looking forward to taking those next steps in that journey with courage and optimism.
Comprehensive care for people with dementia in Israel

Israel’s national dementia strategy offers comprehensive services from prevention to end of life care for every citizen. Avishag Ashkenazi from EMDA, The Alzheimer’s Association of Israel, explains how the strategy was developed and implemented.

Developing a comprehensive plan

In the years 2012–2013, a group of multi-organisational and inter-disciplinary experts worked to formulate recommendations for a National Plan for Addressing Alzheimer’s Disease and Other Types of Dementia. A draft document was developed by the Myers-JDC-Brookdale Institute and validated by experts in the various focus areas.

The group’s recommendations were presented to the Israeli Parliament Health and Welfare Committee, where they were adopted, and subsequently approved by the Director General of the Ministry of Health as a basis for the national plan. In September 2013, the Ministry of Health officially took the lead in implementing the plan.

From prevention to end of life care

The National Plan is steered by an implementation committee, appointed by the Director General of the Ministry of Health, whose members represent the relevant ministries – namely the Ministry of Health, the Ministry of Social Affairs, the Ministry for Social Equality and the National Insurance Institute as well as relevant non-governmental organisations including the four Sick Funds-HMOs (Health Maintenance Organisations), JDC-Eshel and the Myers-JDC-Brookdale Institute.

The vision of the national plan is to enable persons suffering from dementia and their families to lead dignified lives, with the assistance of the appropriate services. These services encompass all disease stages, from the stage of prevention, through timely diagnosis and treatment to the end of life. The plan is based on inter-disciplinary work, professional treatment principles for people with dementia, support of family members and collaboration of all parties involved in aging, both at the government level, the Sick Funds-HMOs, as well as with NGOs such as JDC-ESHEL, which promotes planning and implementing new programmes and EMDA, Israel’s Alzheimer’s Society and a member of Alzheimer Europe. The major goals of the national program are as follows:

- increase public awareness of dementia
- improve health care and social services
- support family members
- adapt nursing homes to the needs of people with dementia
- develop and expand training for professional and paraprofessional personnel

Research and development

Since its inception, the National Dementia Plan of Israel has seen the implementation of programs and processes in the areas of awareness, improving health services with the Sick Funds-HMOs, support programs for family members and training of professionals and non-professionals working with persons with dementia.

Involving people with dementia

EMDA is one of the initiators of the National Plan and remains active in its implementation. The society leads long-term processes in all domains related to caring for the caregiver and developing programs for improving the quality of life of people with dementia. EMDA was formed in 1988 and operates a support network of some 50 branches throughout the country.

A summary of the National Plan can be seen on the following website: www.health.gov.il/PublicationsFiles/Dementia_strategy-Eng.pdf

Alzheimer Europe wishes to thank the following for contributing this article: Avishag Ashkenazi, Head of Information Center at EMDA; John Lemberger, coordinator of the National Plan in the Ministry of Health; Gery Rot, CEO of EMDA.
Advocating for better care for people with dementia in Bosnia and Herzegovina

Udruženje AiR, the Alzheimer association of Bosnia and Herzegovina, joined Alzheimer Europe in September 2015. In this article, Executive Director Osman Kucuk presents an overview of the numerous activities of the association.

What does Association AiR do?

Association AiR (AiR) was established as a non-profit, non-governmental organisation in January 2013 in Sarajevo, followed by its Center for Dementia in September. There are an estimated 110,000–180,000 people with dementia in the country and the number of new cases is increasing.

The AiR Center is the first and only dedicated service hub for people with dementia and their carers or guardians in Bosnia and Herzegovina – and quite possibly in any country of the former Yugoslavia. The Center is staffed with specialists in neurology and neuropsychiatry, as well as psychologists, nurses and social care managers. It offers the following services:

- **help persons with dementia at home:** support for diagnosis, therapy, care, nutrition
- **help for carers:** education, psychological and social assistance, exchanges with other carers
- **help persons with dementia and carers at the Center:** daily activities, assistance for permanent accommodation
- **advocacy:** members are in talks with government agencies on issues such as health and social care, primary and secondary prevention and a national dementia registry

Advocating for change

Recently, the Center has been working to change social welfare legislation, which currently does not specifically recognise dementia. In 2015, AiR held a public debate about “Dementia in the family in Canton Sarajevo”. This successful event was attended by numerous government policy makers and officials, as well as prominent health and social care professionals. They agreed that the social welfare law needs to be amended: an initial step will be to induce insurance funds to fully reimburse memantine prescriptions.

The delegates also agreed to improve cooperation between AiR and the University of Sarajevo, including internships for Medical School students. In addition, they recognised the importance of the services provided by the AiR Center, which may help the association to obtain new facilities.

The country’s first dementia symposium

AiR, along with the University of Sarajevo, is organising the country’s first dementia symposium which will take place in September 2016 under the theme “Different aspects in the treatment of dementia”. As the title suggests, there will be many scientific topics and the target delegates are mainly clinicians, but the psychological and social aspects of dementia will also be covered.

This will be the country’s first symposium dedicated to dementia and will certainly help to raise awareness and reduce stigma. In addition, it will serve as a first step toward a national dementia strategy: the symposium conclusions will be used as a basis for a draft text that will eventually be presented to the government.

AiR is always glad to hear from colleagues in other Alzheimer associations, in order to exchange views and best practices. Please see contact details below:

Tel/Fax: +387 33 200 223 Email: bih@demencija.org
Web: www.demencija.org

“"The AiR Center is the first and only dedicated service hub for people with dementia and their carers or guardians in Bosnia and Herzegovina.”

OSMAN KUCUK
AE member news

Alzheimer Europe highlights some recent activities of its member organisations

24 March: Spominčica – Alzheimer Slovenia is growing fast

Next year, Spominčica – Alzheimer Slovenia will celebrate 20 years of activities. The association was launched in 1997 by Slovenian psychiatrist Dr Aleš Kogoj to answer the growing needs of carers for support and knowledge about dementia. Thanks to Dr Kogoj’s enthusiastic work, local associations began to emerge and in 1999 the association started an educational programme for carers and the first ever Spominčica magazine was published.

In 2012 Spominčica became a member of Alzheimer Europe and also began organising “Alzheimer Cafés”. These turned out to be a great success, with 50 events taking place all over the country during a one-year period.

Last year, Spominčica started working on its dementia-friendly society project, organising lectures about dementia for police officers and for medical staff at Ljubljana University Medical Centre. The association also co-hosted Alzheimer Europe’s 25th annual conference in Ljubljana, which was a great success. Spominčica works very closely with doctors and other dementia specialists and also has the support of the Ministry of Social Affairs, the Ministry of Health and particularly the local community and the Municipality of Ljubljana.

The association’s activities can no longer be managed only with volunteers, so Spominčica sought financial resources to employ staff members. In 2014, the Ministry of Social Affairs provided a grant for the programme “Living well with dementia in a dementia-friendly society”, allowing for a new employee to be recruited. This year, Spominčica received a grant from the Employment Service of Slovenia grant to employ two additional co-workers and a journalist has also been employed.

Today the Spominčica team (pictured) consists of four employees and four regular volunteers, who all work extremely hard in support of people with dementia and their carers in Slovenia and beyond.
22 March: Danish Alzheimer association’s 25th birthday wish is for a dementia-friendly society

2016 marks the 25th year of Alzheimerforeningen, the Danish Alzheimer association. On this momentous occasion, Chairperson Birgitte Vølund expressed the association’s “birthday wish”; that the combined efforts of professionals, volunteers and the general public will make Denmark a dementia-friendly society in the years to come.

Alzheimerforeningen has been working tirelessly towards this goal since 1991 – in the early years, stressing the importance of medical knowledge of the dementia diseases, their cause and treatment, and later, widening the scope to encompass support for people with dementia and their families in daily life.

Today, the activities of the association are thorough and comprehensive in addressing all aspects of life with dementia:

- financial support for research into the dementia diseases, publication of books and leaflets, and campaigning
- counselling via telephone, internet and social media
- offering a wide range of activities for people with dementia and their families, both locally and nationwide: holidays, highschool courses, Think Tanks, dementia cafés and public lectures with free admission
- influencing policy makers and policies at local and national level
- engaging and supporting volunteers in local activities, including the present campaign to recruit Dementia Friends (Demensven)
- last but not least, participating in international endeavours to build dementia-friendly societies, to better support people living with dementia and their families all over the world

14 March: The Alzheimer Society of Finland celebrates international Brain Awareness Week

The Alzheimer Society of Finland (Muistiliitto) celebrated international Brain Awareness Week during 14–20 March, alongside the Finnish Network for the Neurologically Disabled (NV), of which Muistiliitto is a member.

This year, the theme was the brain health benefits of our natural surroundings and everyday activities. Muistiliitto and its member associations organised over 130 events across Finland, including “brain health stations” (pictured) offering information and activities to support brain health.

Brain Awareness Week is one of the Society’s two most important campaign weeks in the year, with Memory Week in September being the other.
“Dementia and Sensory Challenges”: an award-winning publication inspired and written by people with dementia

Agnes Houston, an experienced dementia campaigner who also lives with the condition, headed the work to put together and present a booklet about common-sense solutions for living with dementia from a unique personal perspective with these changes. During campaigning I found other people with dementia were having these issues as well. So, with the help of my daughter Donna and funding from the Life Changes Trust, the “Dementia and Sensory Challenges” booklet was written.

In September 2015, we had the privilege to present a poster about the booklet and speak at Alzheimer Europe’s conference in Slovenia. I was overwhelmed by the positive response it received and so proud that the poster was voted as the best in its category. I would like to thank Anne Pascoe for believing in me, and the 24 people with dementia, whose words and lived experience of dementia and sensory challenges influenced the content of this free booklet. And thanks to all who voted for the poster.

Since then, I am happy to report that we received lots of positive responses and requests for the booklet: the original 1,000 copies were gone very quickly. Now Dementia Adventure is producing more for their own training purposes and the Life Changes Trust is printing 10,000 more for dissemination.

If you would like a PDF copy of the booklet, please visit www.lifechangestrust.org.uk/sites/default/files/Leaflet.pdf or www.sdg.org.uk

This booklet does not have all the answers, instead it shows how even with little or no help the people with dementia found their own answers and just got on with life the best they could. I hope this booklet will inspire professionals in the sensory world to use their skills to assist us to remain connected to family and friends, and remain safe in our communities. And to all people with dementia like those of us featured in this booklet: it is possible to have a good life, yes, even with dementia and sensory challenges!

Agnes Houston MBE

My name is Agnes Houston. I am one of the joint chairs of the European Working Group of People with Dementia (EWGPWD), a committee member of the Scottish Dementia Working Group (SDWG) and I serve as a board member of the Dementia Alliance International (DAI).

Since my diagnosis of dementia of the Alzheimer type I have been an advocate in raising awareness on what it’s like to live with a diagnosis of dementia and what you can do to assist us.

Dementia is more than memory but it was all I was being asked about. Six years ago I started having sensory challenges, nothing was in place to help me cope with these changes. During campaigning I found other people with dementia were having these issues as well. So, with the help of my daughter Donna and funding from the Life Changes Trust, the “Dementia and Sensory Challenges” booklet was written.

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AGNES HOUSTON MBE
Our members are helping people with dementia and their carers in 32 countries

Alzheimer Europe Members
26th Alzheimer Europe Conference
Excellence in dementia research and care
Copenhagen, Denmark
31 October – 2 November 2016
www.alzheimer-europe.org/conferences #26AEC