

Issue 24

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# DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE



**Nessa Childers**  
hosts Alzheimer Europe's lunch  
debate in European Parliament



**Michal Novak**  
discusses plans for a national  
strategy for Slovakia



**Chris Roberts**  
discusses the current situation for  
people with dementia in Wales



Justyne Caruana MP, Parliamentary Secretary  
for Rights of Persons with Disability and  
Active Ageing discusses how the Maltese  
EU Presidency is addressing dementia

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by Iva Holmerová Chairperson of Alzheimer Europe

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### Alzheimer Europe Board

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Vice-Chairperson: Charles Scerri, Malta

Honorary Secretary: James Pearson, UK - Scotland

Honorary Treasurer: Maria do Rosário Zincke dos Reis,

Portugal

European Working Group of People with Dementia

(EWGPWD): Helen Rochford-Brennan

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## Welcome



New Chairperson Iva Holmerová thanks former Chairperson Heike von Lüttau-Hohlbein October 2016, Copenhagen.

I have been working in collaboration with Alzheimer Europe for many years. The Czech Alzheimer's Society was founded in 1997 and immediately afterwards became a member of the recently-established Alzheimer Europe. As the then Chairperson of the Czech Alzheimer's Society, I had the opportunity to follow the development of Alzheimer Europe and to form beneficial connections with many other Alzheimer's societies across Europe.

Prague played host to the Alzheimer Europe Conference in 2004 and during this and many other meetings over the years, I have really appreciated and greatly valued the friendly, cooperative atmosphere and mutual support offered. I was delighted to accept my nomination to the Board of Alzheimer Europe, serving for many years as Vice-Chairperson, and was honoured to be elected as Chairperson at the 2016 Annual General Meeting (AGM), following Heike von Lüttau-Hohlbein's decision to stand down after six years (2010 –2016).

The Alzheimer Europe team, with Jean Georges at its helm, has been highly professional and reliable from the outset and has grown over the years to include experienced specialists in all areas. I consider the organisation's collaboration with the European Working Group of People with Dementia (EWGPWD) to be immensely important and inspiring. The group brings wisdom, experience and insight into the issues around dementia, providing a vital anchor for our work.

Thanks to these and many other experts, Alzheimer Europe continues to provide key materials and to do vital work to make dementia a European priority.

I am pleased to welcome you to the 24<sup>th</sup> issue of our Dementia in Europe magazine, showcasing some of this important work, including our recent lunch debate in the European Parliament on "comparing

and benchmarking national responses to the dementia challenge" at which I was proud to present our two new publications – a comparative report on decision making and legal capacity in dementia, and a discussion paper on ethical issues linked to the changing definitions and use of terms related to Alzheimer's disease. Thank you to our host, MEP Nessa Childers (Ireland) and MEPs Heinz Becker (Austria), Deirdre Clune (Ireland), Sofia Ribeiro (Portugal) and Olga Sehnalová (Czech Republic) for participating.

We are also pleased to present three new EU-funded projects in which we are involved, our new Board (2016 –2018) and two new member associations from Albania and Hungary, who joined us officially at the 2016 AGM.

The "Policy watch" section looks mainly at the Slovak and Maltese EU Presidencies and the continuing work on dementia at a European level. At a global level, we take a look at the progress being made by the World Health Organization (WHO) on a global dementia strategy.

In the "Dementia in society" section, we take a look at some of the important work being done by our national member organisations – specifically, Ireland's recent campaign, "Dementia care begins at home" and the ambitious dementia-friendly community initiative being rolled out in Italy. Newly appointed Vice-Chair of the EWGPWD, Chris Roberts gives us some insights into living with dementia in Wales and into the process unfolding there to get a national strategy up and running in the near future. We also take a look "Behind the headlines" at several research studies linking air pollution and dementia.

Last but not least, our "Special section" shines the spotlight on the 26<sup>th</sup> Alzheimer Europe Conference (26AEC) in Copenhagen, "Excellence in dementia research and care", organised under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark, who was also the first speaker. As well as providing an overview of the opening ceremony, the plenary sessions and the EWGPWD symposium, this section showcases the best of the poster presentations, as voted by conference delegates and provides some great snapshots of the conference. Enjoy!

Iva Holmerová

**"Alzheimer Europe continues to provide key materials and to do vital work to make dementia a European priority"**

## Alzheimer Europe members elect new Board and Chairperson

On 31 October 2016, Alzheimer Europe's member associations voted in a new Board during the Annual General Meeting in Copenhagen. The new Board members, including a new Chairperson, will serve until 2018



*The Alzheimer Europe Annual General Meeting, October 2016, Copenhagen.*

Alzheimer Europe's Board of Directors is comprised of the office bearers – Chairperson, Vice-Chairperson, Honorary Secretary and Honorary Treasurer – and up to seven further members directly elected by a General Meeting. The Chair of the European Working Group of People with Dementia (EWGPWD) is an *ex-officio* member of the Board of Directors. All directors must be members of full member organisations of Alzheimer Europe.

### **Iva Holmerová (Czech Republic) – Chairperson**



Iva Holmerová is the Chair of the Czech Alzheimer Society, which she co-founded in 1997. A practicing physician since 1981, she is qualified in general and geriatric medicine and also holds a PhD in social gerontology.

She is also the Director of the Czech Centre of Gerontology (since 1992), the President of the Czech Society of gerontology and geriatrics (since 1997) and a committee member of the International association of gerontology and geriatrics (IAGG) since

1997. She is an Associate Professor of humanities at Charles University (Prague) and was named visiting Professor at the University of the West of Scotland in 2014. Iva has been a Board member of Alzheimer Europe since 2008 and served as Vice-Chairperson from 2010 to 2016.

### **Charles Scerri (Malta) – Vice-Chairperson**



Charles Scerri received his PhD degree in 2004 from the University of Dundee in Scotland and currently lectures in neuropharmacology at the University of Malta.

He is the co-founder and general secretary of the Malta Dementia Society, former Honorary Secretary and current Vice-Chairperson of Alzheimer Europe and is a member of the Mediterranean Alzheimer Alliance. He is also a member of the JPND scientific Advisory Board and of INTERDEM.

In July 2013, he was appointed as the National focal point on dementia in Malta. Amongst his recent



publications is the national dementia strategy document: “Empowering change: a National strategy for dementia in the Maltese Islands (2015 –2023).”

#### **Jim Pearson (UK - Scotland) – Honorary Secretary**



Jim Pearson is Alzheimer Scotland's Director of policy & research and is currently responsible for all of Alzheimer Scotland's public policy engagement. This includes the involvement of people living with dementia through the Scottish dementia working group and the National dementia carers action network.

Jim has a background in welfare rights and has a particular interest in promoting and protecting the rights of people living with dementia. He played a significant role in developing Scotland's Charter of Rights for people with dementia and their carers, which puts human and other legal rights at the heart of each commitment of Scotland's first and second dementia strategies. Jim has recently completed an MBA at Glasgow Caledonian University.

#### **Maria do Rosário Zincke dos Reis (Portugal) – Honorary Treasurer**



Maria do Rosário has been practicing law in Portugal since 1987, with a focus on family law and the legal rights of people with incapacity. She is also a visiting Professor at the University of Aveiro, teaching “Legal approach on social gerontology”.

She served as Chairperson of Alzheimer Portugal during 2001 –2012 and currently coordinates the association's Training and projects department. In addition, she is a member of the JPND PPI (Patient and public intervention) Advisory Board.

Maria do Rosário has been a member of the Alzheimer Europe Board since 2008 and the Honorary Treasurer since 2010.

#### **Helen Rochford-Brennan (Ireland) – Chair of the European Working Group of People with Dementia**



Helen Rochford-Brennan is from Tubbercurry in County Sligo, Ireland. She spent many years working in the tourism and disability sectors and has also devoted tireless years to community activism, working at board level in several organisations.

In July 2012, Helen was diagnosed with early onset Alzheimer's disease. She is Chair of the Irish Dementia Working Group, which is resourced by The Alzheimer Society of Ireland. She has used her time with the Irish Dementia Working Group to raise awareness of dementia and raise the profile of human rights for people with dementia.

Helen joined the European Working Group of People with Dementia (EWGPWD) in October 2014 and served as a Vice-Chairperson for two years. On 30 October 2016, she was elected as Chairperson for a two-year term.

#### **Stefanie Becker (Switzerland)**



Dr Stefanie Becker is the Director of Alzheimer Switzerland. A trained psychologist and gerontologist, she holds a PhD in psychology from the Karl-Ruprechts University of Heidelberg in Germany. She has also been

employed by the University of Heidelberg, where she worked for several years in applied research on the question of stabilising and promoting quality of life for people with dementia.

Former employers in the field of gerontology were the German Centre for research on ageing and the research group of psycho-geriatrics at the Centre of mental health – a psychiatric clinic in Mannheim, Germany.

She has also worked with professional caregivers in providing stress management assistance and training. In addition, she has handled several consultancy projects, such as developing and implementing dementia strategy and concepts in different nursing homes and a hospital, developing curricula for training caregivers, designing specialised dementia care units and quality evaluation in different gerontological fields. In Switzerland, she held the presidency of the Swiss Society of gerontology and geriatrics from 2012 –2016 and is still a member of the committee. Stefanie also worked from 2010 –2015 at the University of applied sciences in Bern as director of the Institute of aging.

#### **Marie-Odile Desana (France)**



Marie-Odile is the former President of France Alzheimer, a position she held from 2010 to 2015. Previously, she served as Vice-President (2008) and Administrator (2006). She is also the former carer of her mother, who lived with

Alzheimer's disease. During that time, Marie-Odile created an association of family caregivers of people with Alzheimer's disease in Aix-en-Provence. She joined France Alzheimer's Bouches-du-Rhône chapter in 2003 and has been the chapter President since 2004. Marie-Odile was elected to the Alzheimer Europe Board in October 2014.

#### **Sabine Henry (Belgium)**



Sabine Henry is the president of the National Belgian Alzheimer Association LINAL and also of Ligue Alzheimer ASBL, the association serving Belgium's French-speaking community.

She trained as a social psychologist at the Palo Alto School and is a collaborator at the Faculty of Psychology of the University of Liège – the same career as her mother-in-law, who lived with Alzheimer's disease. Sabine was also the founder and Chairperson of the former "League of health care users" (LUSS).

Sabine was elected to the Alzheimer Europe Board in October 2014. She had previously served as Vice-Chairperson from 2004 –2010.

#### **Sabine Jansen (Germany)**



Sabine Jansen is the Executive Director of the German Alzheimer Association. She has worked for the association since 1997. She has a background as a social worker with working experience in a university hospital and a nursing home.

Sabine is a member of different advisory boards, such as the German Ministry of health in respect of the long term care insurance and also plays an active role in the National Alliance for people with dementia in Germany.

#### **Sirpa Pietikäinen (Finland)**



Sirpa Pietikäinen is a Finnish member of the European People's Party (EPP) in the European Parliament. She is a former Finnish Minister of the environment (1991-1995) and her career at the Finnish parliament is extensive,

ranging from 1983 to 2003.

At the European Parliament, Ms Pietikäinen is a member of the Economic and monetary affairs

committee and substitute member of the Environment, public health and food safety (ENVI) committee as well as of the Women's rights and gender equality committee. She is also a Vice-Chairperson of the European Alzheimer's Alliance (EAA), supporting Alzheimer Europe and its members to make dementia a public health priority in Europe.

Ms Pietikäinen has been a member of the Alzheimer Europe Board since 2010. In Finland, she is Vice-Chair of the Council of the national memory organisation (Muistiliitto). In her private life, she has been a carer to both of her parents.

#### **Jesús Rodrigo (Spain)**



Jesús Rodrigo has a degree in sciences of education and has spent his entire professional career in non-profit organisations, in positions of increasing responsibility.

He is currently the Executive Director of the Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), a position he has held since 2005. Working directly with the Board, he has contributed to developing the various strategic plans of the organisation and in positioning the entity as a reference point for the central Government with regards defining a national dementia strategy.

#### **Štefanija Lukič Zlobec (Slovenia)**



Štefanija has been the President of the Alzheimer Association of Slovenia since January 2014 and was Vice-President for two years before that. During this time, she successfully guided the association to full membership of both

Alzheimer Europe and Alzheimer's Disease International (ADI). Štefanija also initiated Slovenia's "Alzheimer Cafés" in 2012. These have been a huge success and continue to gain popularity around the country.

Štefanija became involved with dementia when her late husband began developing symptoms of Alzheimer's disease at the age of 50. She became active in associations assisting relatives of people with dementia and was also an initiator for the establishment of the Working Group for the preparation of the National work plan for dementia. This Working Group was established in 2012 by the Ministry of health.

## Welcome to our new members from Albania and Hungary

At our 2016 AGM, our membership voted unanimously in favour of accepting Alzheimer Albania and Hungary's Social Cluster Association as new provisional members of Alzheimer Europe. We are delighted to welcome them both

### Alzheimer Albania

Albania is one of the European countries which has always been distinguished by its young population. Nowadays, more and more people are diagnosed, mostly in the latest stage of dementia. The number of persons living with dementia is estimated at around 37,000 in a population of 2.9 million people. The challenges faced are both social and medical.



The Alzheimer Albania team at the country's first ever conference on dementia, December 2015

#### A lack of support

Diagnosis is often delayed, underestimated or misinterpreted due to the lack of information available to families and healthcare professionals. The drugs available for treatment are expensive and none of them is reimbursed.

Supportive structures for patients and their families do not exist. A diagnosis of dementia represents a big struggle for families, with social care authorities placing little or no focus on this and with the condition still being surrounded by stigma.

#### Early days

Alzheimer Albania was founded in 2015 by five founding members, including health care professionals

and family members of people with dementia. Based in Tirana, our association has the following main objectives:

- Support, assist and inform the families of those affected by dementia.
- Undertake and support research on the causes, prevalence and other aspects of dementia.
- Develop and guide legal issues for those affected by dementia and intervene on their behalf whenever/ wherever necessary or feasible.
- Educate the general public about dementia.
- Provide training to healthcare personnel in geriatrics and dementia care; Organise and conduct training programmes for dementia carers.
- Write, develop and update a guide for these carers, to create self-help groups and build a network of support services to make them more efficient and more economical, as well as integrating them into the social and cultural environment in Albania.
- Cooperate with various governmental agencies at central and local level, in particular with structures covering health and welfare – NGOs, other national Alzheimer organisations, Alzheimer Europe, Alzheimer's Disease International and other international agencies – to achieve the above objectives and, further, to encourage the exchange of medical and research personnel between institutions.

#### First dementia conference

In December 2015, we held our first national conference, led by an important and influential neurologist. It was a first step to present the organisation to the public and to bring healthcare professionals together. This was also the first ever conference in Albania addressing ageing and dementia.



Alzheimer Albania is a young organisation, which is honoured to be a member of Alzheimer Europe and is looking forward to contributing as an active partner in multi-country projects.

### Raising awareness

During 2016, Alzheimer Albania was part of a global campaign to promote the new mobile game “Sea Hero Quest”, which aims to help researchers better understand dementia. We used this opportunity to raise awareness by engaging experienced doctors to inform the public about the symptoms of dementia, good approaches for families of people diagnosed with dementia and how to influence policy makers to provide adequate support.

Our Board members are often involved in discussions to ensure that people with dementia may have better access to their rights and to support from healthcare and social care authorities.

### Looking to the future

We are excited to be part of a network of similar organisations, to collaborate, to learn best practices and to help implement projects.

Some of our prospective projects/programmes are:

- Free telephone helpline
- Support groups
- Alzheimer Cafés
- Public information and education programmes
- Continuing medical education of healthcare professionals
- Development programme to provide a network of branches.

[www.alz.al](http://www.alz.al) is our webpage. It is available in Albanian language and provides scientific information. You can also find us on Facebook and Twitter.

Alzheimer Albania is a young organisation, which is honoured to be a member of Alzheimer Europe and is looking forward to contributing as an active partner in multi-country projects.

## Social Cluster Association Hungary

The Social Cluster Association was established in 2001 and by 2015 had over 100 active members.

Our main goals are:

- To provide adequate information about the government’s newest directions for caregivers;
- To create communication channels between the representatives of health and social services;
- To organise national and international conferences to find innovative solutions for daily difficulties in care.



We maintain good relationships with a number of medical and social societies, developing cooperation through formal and informal forums and networks. We work especially closely with the Hungarian Association of Gerontology and Geriatrics.

In 2013, we organised the first “Common Speaking Experts” international conference in Budapest, which was a big success.

The focus of the Social Cluster Association is not limited to dementia, but issues related to Alzheimer’s disease and dementia are definitely our main concern and, since 2015, our professional efforts, projects and research have been concentrated exclusively in this area.



Dr Katalin Hegedűs, Gabriella Kiss, Dr Ágnes Egervári,  
Dr Norbert Vajda, Dr Lajos Szabo, Dr Győző Pék

### The INDA project

The concept of this project began several years ago with a conversation between professional caregivers, who found that the existing health and social services could handle neither the wider care needs of, nor the negative attitudes associated with dementia.

In recent years, an EU grant has provided us with the opportunity to develop a new programme and together with the Roman Catholic Charity, we launched the Interprofessional dementia approach (INDA) project, in April 2015.

The aims of INDA are to increase knowledge about dementia, reduce stigma and improve integration and acceptance in society. It is a complex

### The scope of our activity

The guiding principle of our work is interprofessional collaboration. In the last few years the Social Cluster Association has organised many conferences about long-term care, with particular emphasis on dementia. These conferences have all emphasised the importance of interprofessionalism.



programme for the care of older people living with dementia and for those around them – be they professional or informal carers, friends, or relatives.

The INDA programme has included various different platforms: trainings, events and pilot research studies. One approach used was to join a mobile screening programme, focusing on the reduction of lifestyle-related health risks, such as smoking, alcohol consumption, obesity and unhealthy nutrition. The programme provides people with information on many issues, from first aid to healthier lifestyle choices, with a special emphasis on the dissemination of information. The “screening truck” visits 125 locations every year and visitors can take a mini cognitive test. The INDA project has been featured several times by local and national media.

### Training programme

A team of dedicated interprofessional experts linked to Social Cluster Association evaluated an educational programme for different professionals. The main themes on the curriculum are:

- demography concerning the elderly;
- elderly people living with dementia;
- dementia symptoms, cures and progression of the disease;
- methods of nursing and caregiving;
- interprofessionalism in caregiving;
- supporting families;
- person-centred care;
- possibilities for skill development in dementia.

An innovative e-learning course book was developed to support the learning process. The curriculum offers training for social workers and healthcare professionals, giving them well-founded knowledge of some of the physical, psychological and social changes associated with dementia. As a first step, 350 people were trained.

After the course, the participants had a better understanding of the problems concerning dementia and were better able to recognise dementia, give advice to families, identify the proper services and keep professional contact with the entire team within the care system. This can be the basis of a specialist network. This network can help other professionals and collect practical experiences, leading to a professional staff with new approaches.

These trainings provide a completely different point of view regarding dementia care, with the main focus being on the dignity of the person with

dementia. We are continuing with our training programmes and hope to contribute to increasing the number of experts in the care system in Hungary.

### Forums for dementia carers

There are thousands of helpless and desperate families in Hungarian society, who need to have access to prompt answers about dementia. To achieve this, a nationwide project was started: “Forums for dementia carers”.

In 2015, there were only a few Alzheimer Cafés available in our country. The INDA project has helped us to increase the number significantly, and today, these Cafés have become an important platform for communication and for families to exchange their experiences with dementia. To build on these first Alzheimer Cafés, we are working towards creating a national network to support the operation and collaboration of existing Cafés, as well as to create new ones.

We believe that attitudes towards dementia can be changed, so relatives of people who live with dementia will not need to hide or feel ashamed, but rather will create active, supportive communities.

### Spreading the word

Social Cluster Association is the only Hungarian initiative where people with dementia, medical doctors with different specialisms – such as geriatricians, psychiatrists and neurologists – psychologists, social workers and informal carers meet and act together. Our goal is to secure proper living conditions and professional care for people with dementia, as well as to educate and raise awareness of Alzheimer’s disease and dementia. We do this through the media of films, spots, booklets, and conferences across Hungary.

We are pleased to say that we continue to receive an ever-increasing number of enquiries concerning dementia, from a variety of national institutions, care centres and private individuals.

### Award-winning booklet on informal dementia care

Last but not least, we want to mention a Hungarian booklet, called “Handhold(s)”, which gives practical guidance for family members and those living with dementia. This booklet was written within the INDA programme operated by our Association. The publication received a prestigious award in December 2016, called “It speaks to me! Health literacy award 2016”. The award was given by Thomas Straumits, Chairperson of the Association of innovative pharmaceutical manufacturers (AIPM).

“This is a highly important step forward for Hungarian dementia care. People living with dementia in our country, Alzheimer Cafés across Hungary, professional and informal caregivers, will all benefit from this partnership.”

DR ÁGNES EGERVÁRI

## Alzheimer Europe presents European Dementia Monitor results at the European Parliament

On 6 December 2016, Irish MEP Nessa Childers hosted a lunch debate that focused on the results of AE's European Dementia Monitor and the latest OECD efforts to measure the impact of dementia

On 6 December 2016 Alzheimer Europe (AE) held a successful lunch debate in the European Parliament, chaired by MEP Nessa Childers (Ireland, EPP), which focused on comparing and benchmarking national responses to the dementia challenge.

The lunch debate gathered over 60 people, including MEPs Heinz Becker (Austria), Deirdre Clune (Ireland), Sofia Ribeiro (Portugal) and Olga Senhalová (Czech Rep.) as well as representatives for MEPs Patrizia Toia (Italy) and Jana Žitňanská (Slovakia). The audience also included representatives from several pharmaceutical companies and 18 Alzheimer Europe member associations.

The ageing population and increasing numbers of people living with dementia is one of the greatest social and economic challenges facing Europe today. Being able to benchmark and use comparative figures is essential to create the need for more awareness on a political level.



*Nessa Childers MEP, Ireland*

### Priority areas of the European Dementia Monitor

- Availability and reimbursement of AD medicines
- Availability and affordability of care services
- Availability of clinical trials
- Involvement in EU dementia research
- Recognition of dementia as a priority
- Recognition of legal issues
- Recognition of human rights
- Carer employment support
- Dementia-friendly communities / inclusiveness



Jean Georges, Executive Director, Alzheimer Europe

Jean Georges, Executive Director of Alzheimer Europe kicked off the presentations showing the concept and the results of Alzheimer Europe's 2016 European Dementia Monitor, an AE survey of national dementia strategies and policies

Jean Georges showed the comparison charts for each priority area and explained that the report is mainly based on data obtained from AE's member associations and experts in the field. The Monitor is intended as tool to allow policy makers to identify both gaps and best practices, in order to improve care and support of people with dementia and their carers all over Europe and to give national associations a means to lobby for change within Member States by comparing their country to others.

### Measuring dementia: an OECD priority

Mr Muir explained: "Dementia is a growing priority in many OECD countries, hence the organisation's interest to measure its current burden and determine future needs". He went on to say: "Dementia prevalence will continue to increase, mainly due to an ageing population and dementia is globally the second biggest cause of disability for people over the age of 70". Mr Muir also presented figures on the costs of dementia to national health systems and noted that the global overall cost of dementia is estimated at over half a trillion US dollars.



Tim Muir, OECD

"The European Dementia Monitor provides national associations with a means to lobby for change by comparing their country to others."

JEAN GEORGES

"The global cost of dementia is estimated at over half a trillion dollars."

TIM MUIR







*Sofia Ribeiro MEP, Portugal*

Looking to the future, Mr Muir said that OECD would soon launch a pilot set of indicators, including the use of antipsychotics and the rate of avoidable hospital admissions of people with dementia. The organisation is also evaluating patient-reported measures, which can be especially valuable in the early stages of dementia. Mr Muir concluded that these measures would be a major theme at OECD's Health Ministerial forum in January 2017.

Portuguese MEP Sofia Ribeiro congratulated AE and OECD for their excellent work and said that she intended to use the presentations to lobby the European Parliament to recognise dementia as a priority on a European level.

Heinz Becker, MEP (Austria) remarked that both studies are very helpful and valuable and highlighted the need for more awareness on a political level. He said: "There is clearly a need for more dementia support and with significant gaps between countries, but this is still underestimated at EU level."

There was also a discussion about the use of antipsychotic medicines, where it was noted that these medicines can be very useful, especially in palliative care, but must be handled very carefully. They are often prescribed off-label for the wrong use to people with dementia, but unfortunately there is no good alternative to replace them.

In her concluding remarks, Ms Childers cited the problem of how Member States will be able to fund health programmes. She added that: "in public health, dementia competes with other disease areas, so the kind of research we've seen today is very important to be able to persuade policy makers to fund dementia efforts."

### **AE presents new dementia reports**

Prof Iva Holmerová, Chairperson of AE presented a brief introduction of two new Alzheimer Europe publications. The first is a discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease and the second is AE's 2016 Yearbook, entitled "decision making and legal capacity in dementia". These are described in more detail on page 17 of this issue.





## MEPs speak out on Alzheimer's disease

Alzheimer Europe asked all the MEPs who attended the lunch debate to further contribute to the debate. “From a policy maker’s perspective, why do you think it is important to bring the challenge of Alzheimer’s disease to the front and centre of European Parliament and what could be done to meet this public health challenge?”

### Heinz K. Becker, MEP (Austria)

How to bring Alzheimer’s disease to the front of European Parliament’s work.

Following the efforts of the Slovakian EU-Presidency as well as Netherland’s presidency, it is tremendously important to deliver strong signals to the Maltese Presidency to keep dementia and in particular Alzheimer’s disease at the top of Europe’s health agenda. At the same time it is important to continuously remind the Commission not to slow down in realizing their ambitious objectives, described

in the Commission’s Communication on Alzheimer’s disease and other dementias, adopted in 2009.

As one of the most widespread forms of dementia, Alzheimer’s disease is also one of the most common neurodegenerative diseases – causing tremendous problems to millions of Europeans and enormous costs to the EU-health systems. To date, no curative treatment exists and access to services, treatment and support is still unequal between the EU member states. It is evident that a European strategy on Alzheimer’s disease is desperately needed.

The current situation does not only lead to severe difficulties in the person with dementia’s life, but also in the indispensable work of their formal and informal carers, friends and relatives. We cannot stand by any longer whilst this situation remains unchanged.

A European strategy on Alzheimer’s disease should focus on EU-wide cooperation on research on the root cause of Alzheimer’s disease as well as ways of early diagnosis of Alzheimer’s disease and other forms of dementia. Furthermore, the free and direct access to any form of necessary health care for European citizens with Alzheimer’s disease as well as professional support for their informal carers must be secured for everybody.

By showing patients respect and dignity as well as decreasing fear and stigma associated with the disease, we can increase their level of participation in society and a higher level of independence as well as streamline the public healthcare spending.

“A European strategy on Alzheimer’s disease should focus on EU-wide cooperation on research on the root cause of Alzheimer’s disease as well as ways of early diagnosis of Alzheimer’s disease and other forms of dementia.”

**HEINZ K. BECKER**



“People with dementia could have much longer and better quality of life if they received properly planned, person-centred care with good quality facilities and trained healthcare professionals working in respect of the dignity of the individual.”

NESSA CHILDERS

### Nessa Childers (Ireland)

Far too often, when setting health policies, short-term budgetary pressures and priorities fail to live up to the socio-economic case for tackling the challenge of chronic and degenerative diseases such as Alzheimer's. There is no doubt that the burden of cost is greater on national health systems in countries where prevention is not a priority. Care costs will continue to rise as numbers of people with Alzheimer's disease are expected to double or even treble by 2050, not to mention the pressures on people caring for those with dementia.



“There are a number of ways we can continue to develop dementia policy, including addressing dementia as a European public health priority in all Member States.”

DEIDRE CLUNE

Across Europe, it's true that the majority of people with Alzheimer's are cared for at home, and problems arise with how people with dementia are supported as their condition deteriorates. Furthermore, dementia does not only affect those with the disease but also their loved ones. This often means that people are not receiving adequate support. The European Parliament must champion the needs of the citizens who elect it directly across the EU and resist the self-defeating subordination of public policy to some arbitrary, short-term macroeconomic targets.

As the condition of people with dementia deteriorates, it can become difficult to provide care in their own home. People with dementia could have much

longer and better quality of life if they received properly planned, person-centred care with good quality facilities and trained healthcare professionals working in respect of the dignity of the individual. For this you need resources and the means to carry out, and act upon, research. Again, the EU institutions are well placed to pool our knowledge and develop networks which will help us overcome the limitations we face at national level, not least due to prescriptions which have left the public provision of care under serious strain.

It's vital that policy makers confront this and that our approach changes to ensure people with dementia are properly diagnosed, supported to live meaningful lives and able to participate in the decisions that affect them.

### Deirdre Clune (Ireland)

Every year 1.4 million Europeans develop Alzheimer's or a related form of dementia, with the WHO estimating that there are 6.4 million people living with dementia in the European Union. Such a significant public health challenge makes it an important task for us MEPs to highlight Alzheimer's disease in the European Parliament.



Studies have shown that improved cardiovascular risk factors and higher education levels can lead to a reduction in national dementia cases, meaning there are concrete steps that can be taken in the fight against Alzheimer's which has such a tremendous impact on those it affects as well as their families and caregivers.

Proactive steps have already been taken in the area of European dementia care and policy such as the 2015 Luxembourg EU Presidency Council Conclusions “Supporting people living with dementia: improving care policies and practices”, the growing number of Member States with a dementia strategy, action plan or programme and the launch of the Second Joint Action Plan on Dementia.

There are a number of ways we can continue to develop dementia policy, including addressing dementia as a European public health priority in all Member States, developing a European dementia action programme to better coordinate dementia research at EU level, designating a high level EU official to coordinate activities and research in the field of dementia for existing programme and strengthen the cooperation of Member States in the Governmental Expert Group on Dementia to promote the identification and exchange of good practices.

The ultimate goal of these steps should be to improve the care and quality of life of people living with dementia and their carers, as well as decrease occurrence rates throughout the member states.

### Sofia Ribeiro (Portugal)



The figures of Europeans with Alzheimer's disease, (AD) in the EU, are alarming. There are about 10 million people with AD (which means 10 million families are also coping with this disease), and it is estimated that this number will increase about 50% in the next 20 years. Europe's average age is increasing alarmingly, and since dementia, in its multiple forms, is associated with age, that also

implies a rise on the social and economic impact of the disease. Those growing figures will have an increasing impact on health and care systems as well as on the need for resources in the fields of formal and informal health care.

Besides continuing investing in prevention and scientific research, it is necessary to ensure more effective and socially more responsible forms of care, including special conditions for family members. Formal and informal care providers are an essential element in responding to the rapidly increasing needs of future delivery systems in Europe. It is important to improve the social protection of family carers, who are often forced to reduce paid working hours to provide unpaid care, thus losing their social security rights. It is also important that non-formal and informal skills and competences acquired in care settings are duly recognized by a sort of European Skills Validation System, like the European Qualification Framework, in order to improve the employability of young people and people who have been removed from the labour market for reasons of care. There is a whole subsystem of family work that must be validated, safeguarding the labour rights of the carer, including the right to training, which should be facilitated.

### Olga Sehnaľová (Czech Republic)

For policymakers it is an obligation to react to challenges of our societies. As a starting point, these challenges have to undergo a broad and open debate at all levels from local to European based, on facts, expertise and context. In this regard, the European Parliament can play an important role in prioritising the agenda and bringing it to the focus of the other EU institutions. This fully applies to the public health challenge of Alzheimer's disease with its many aspects which will only grow over time and which has to be addressed in a holistic way.

“Besides continuing investing in prevention and scientific research, it is necessary to ensure more effective and socially more responsible forms of care, including special conditions for family members.”

SOFIA RIBEIRO







# It's about understanding. **Greater understanding.**

Just like medicine itself, GE Healthcare never stands still. Everything we've achieved to date makes us even more aware of how much still needs to be achieved. Nowhere is this more apparent than in the field of dementia, where there remains a huge demand for further solutions to aid patient management.



## AE launches Yearbook on legal capacity and report on changing definitions of AD

We continue to support the rights and dignity of people living with dementia, with two new publications launched at the European Parliament

During a lunch debate in the European Parliament in Brussels in December 2016, newly appointed Chairperson Iva Holmerová presented two new Alzheimer Europe (AE) publications to Members of the European Parliament (MEPs), representatives from the Organisation for Economic Co-operation and Development (OECD) and a number of

European organisations including the European Patients' Forum (EPF), the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), as well as representatives from the pharmaceutical industry and the press.

### Decision making and legal capacity in dementia: a European overview

The 2016 Dementia in Europe Yearbook is a comparative report focusing on decision making and legal capacity in dementia. Project Officer Ana Diaz invited AE member organisations, as well as experts from Lithuania and Latvia to contribute to the report, resulting in a truly European overview covering 31 countries. In addition, members of the European Working Group of People with Dementia (EWGPWD) and two carers provided personal accounts of their experiences related to the main topics discussed.

Decision making and legal capacity are not new topics for AE. We started looking at these issues almost two decades ago in 1997, with our Lawnet project on legislation relating to the rights of people with dementia from the then 15 Member States of the European Union. Lawnet was presented in our 2010 Dementia in Europe Yearbook, while the 2009 publication focused on national laws in Europe on healthcare decision making by people with dementia. The new publication provides an update on information collected in these earlier reports.

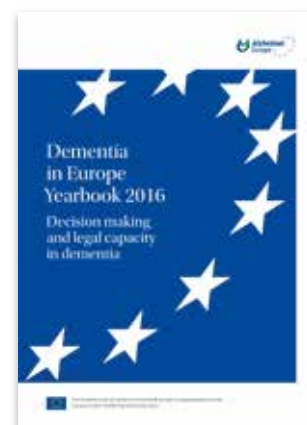
The first part of the 2016 report provides information on how legislation regulates the issue of legal capacity in questions such as: contractual capacity, testamentary capacity, criminal responsibility, civil responsibility/liability, marriage and political rights (the right to vote). The second section looks at issues related to consent to treatment and research, as well

as referring to the legal framework in each country and provisions for consent for people lacking the capacity to consent. The final section introduces systems of substitute decision making and reviews the existing legislation across Europe applying to court-appointed decision makers (guardians) and powers of attorney.

With this report, we hope to support Alzheimer's associations and other campaigners wishing to promote a human rights-based approach to dementia, as well as policy makers interested in reforming their legal systems to better promote the rights of people living with dementia.

#### Moving in the right direction: empowering people with dementia

Some of the new legal approaches move away from public protection as the main priority, towards an approach that safeguards and promotes the rights



Representatives from Croatia, Germany and Finland discussing the 2016 Yearbook, Luxembourg 2016

and dignity of the person, but also highlights the need to balance care and protection, against empowerment and rights. In line with this and following the requirements of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), some of the most recent legislation has moved away from proxy to supported decision-making approaches.

AE Executive Director Jean Georges said:

“I am delighted to see how many positive legislative changes we have been able to identify. Whilst previously we had quite a number of legal frameworks that described capacity as an “all or nothing” affair, this is very much the exception today.

Overall, the new mechanisms in place appear to be more flexible and potentially better suited to the evolving needs of people with dementia and their families due to the progressive nature of the disease.

Everyone should have the right to decide how he/she wants to lead his/her life and a diagnosis of dementia should not change that. Whilst the wellbeing

of the person should always be safeguarded, the emphasis should be on empowering rather than on simply protecting the individual.”

AE would like to thank all contributing member organisations, members of the EWGPWD and the experts from Lithuania and Latvia, for contributing to this publication.



*Representatives from Monaco and Ireland discussing the 2016 Yearbook, Luxembourg 2016*

The 2016 Dementia in Europe Yearbook received funding under an operating grant from the European Union’s Health Programme (2014–2020).

## The evolving language of Alzheimer’s disease: some ethical issues



The second publication presented at the European Parliament is a discussion paper on ethical issues linked to the changing definitions and use of terms related to Alzheimer’s disease (AD), authored by a working group of 11 experts from across Europe, chaired by AE Director for Projects Dianne Gove.

Recent and ongoing developments in the field of research into the causes and development of AD have led to new ways of understanding this condition. Researchers now suggest AD should be considered as a continuum, ranging from normal cognition, to being at risk of developing AD dementia, right through to having severe dementia, and emphasising AD as a possible cause rather than form of dementia.

We welcome continued work towards a better understanding of AD, resulting in the possibility of preventive measures, effective treatments and good quality care. At the same time, we recognise the need to try to ensure these definitions have a positive impact on people who already have or may later be diagnosed with AD and ensure they are adequately supported, fully respected and fairly treated.

With this in mind, the Ethics Working Group – comprised of experts in the fields of ethics, the

experience of dementia, ageing, psychiatry, psychology, dementia research and policy – reflected on a range of ethical issues linked to the new AD model, for the “discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer’s disease”.

### Alzheimer Europe’s position

Section 7 contains AE’s position on ten key issues addressed in the discussion paper:

1. Careful consideration should be paid to the possible social, psychological and practical impact of the new definitions of AD on personal identity, relationships and citizenship (e.g. in relation to personhood, dignity, social exclusion, discrimination and/or stigma). Every effort should be made to prevent any negative impact by attention to the words used, the stance taken by researchers themselves and by encouraging positive social attitudes.
2. Research should be carried out into the possible impact of the new definitions and to understand better how lay people and healthcare professionals understand the terminology surrounding the new model of AD.

3. When assessing potential benefits of diagnosing what is currently defined as prodromal AD or MCI due to AD, there should be a focus on issues which are of relevance to patients.
4. Politicians, the media and the general public should be provided with information about the new definitions and the new AD model to promote informed debate, avoid creating or perpetuating stigma and contribute towards more inclusive attitudes towards people with AD.
5. Efforts should be continued to reduce negative stereotyping (i.e. which focuses on very advanced symptoms and on an absence of quality of life) of AD dementia.
6. There should be an open and informed public debate about the prioritisation and public funding of research, treatment, care and support.
7. People with AD (including those who do and do not have dementia) should be given a voice in the abovementioned debate. Alzheimer Europe, national Alzheimer associations and working groups of people with dementia need to consider how to ensure that this happens.
8. The findings of research should be used to develop awareness-raising programmes targeted at the general public and appropriate educational and communication materials to be used by healthcare professionals and researchers when communicating with patients and research participants.
9. Policies and legislation should be developed to ensure the protection of the rights of people with AD (e.g. in relation to confidentiality, decision making, access to services and support, and discrimination) to ensure that they can continue to play an active role in society and remain valued citizens and members of their communities.
10. Careful attention should be paid by researchers to terminology surrounding what is currently defined as pre-clinical AD and to its possible impact on research participants and the general public. For example:1) researchers should use the term “disclosure of risk status” rather

than “diagnosis”, and “people” or “participants” rather than “patients” in all communication with research participants who are classified as asymptomatic, at risk for AD. This may change in the future if, with increasing knowledge, the “at risk” state comes to be more clearly linked to the future disease state (as is the case with pre-symptomatic AD); 2) people classified as being in the asymptomatic “at risk” for AD group, should be described as being at risk of AD rather than as having preclinical AD.

We are confident that recent research leading to the new terminology surrounding AD will improve understanding of the stages preceding the development of dementia and hopefully one day provide better treatment to prevent, halt or delay the apparition of symptoms.

On the importance of this discussion paper, AE Chairperson Iva Holmerová stated:

“I think it is important that we reflect on the possible ethical implications of the changing definitions of AD. As a caring, responsible society, it is important that we are all aware of these implications at the level of the individual, communities and wider society. In this way, we can try to ensure that people affected by AD can continue to enjoy the same rights and opportunities as everyone else.”

AE would like to express its gratitude to all the members of the Ethics Working Group – Dianne Gove (Chair), Jean Georges, Hilary Doxford, Karine Fauria, Julian Hughes, Tina Leonard, Anneli Sarvimäki, Mark Schweda, Sarah Smith, Hinesh Topiwala and Guy Widdershoven – for their valuable contributions.

The discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer’s disease received funding under an operating grant from the European Union’s Health Programme (2014–2020).



The Ethics Working Group meeting, Amsterdam 2016

## Alzheimer Europe's involvement in three novel collaborative initiatives

We present a brief overview of AMYPAD, MOPEAD and ROADMAP, sponsored by Horizon 2020 under the auspices of IMI and EFPIA. The perspectives of both the academic and pharmaceutical partners are presented, regarding the rationale behind the projects and the concrete actions being undertaken

### AMYPAD (Amyloid imaging to prevent Alzheimer's disease)

AMYPAD officially started on 1 October 2016 and has a duration of five years. The project has a budget of EUR 27.3 million distributed across a total of 15 partners. The Consortium is led by Stichting VUmc and GE Healthcare Life Sciences (on behalf of EFPIA).



In this project, Alzheimer Europe will co-lead the work package dedicated to ethics, communication and dissemination in close collaboration with GE Healthcare Life Sciences. It will include all communication related-activities as well as a guidance document on ethical issues. Alzheimer Europe is also involved in the overall project governance and management.

#### Gill Farrar and Frederik Barkhof, the two main project leaders present the overall vision of AMYPAD

##### What is the problem you are aiming to address with AMYPAD?

**Gill Farrar:** AMYPAD will help determine the value of  $\beta$ -amyloid as a diagnostic and therapeutic marker for AD, which represents an untreatable illness estimated to cost society 1% of the global GDP. Since the deposition of  $\beta$ -amyloid is an early and necessary step on the path towards the development of AD, the possibility of assessing levels of  $\beta$ -amyloid *in vivo* by means of Positron Emission Tomography (PET)

presents great potential. In fact, it is already recognised that  $\beta$ -amyloid PET can improve early diagnosis and, if recognised in a pre-symptomatic population, has also the potential for secondary prevention in AD.

Currently, great efforts are being undertaken in order to develop effective disease-modifying therapies aimed at lowering  $\beta$ -amyloid burden. However, a more detailed understanding of the sequence of events on the path towards AD is needed, especially for determining the optimal window of opportunity for possible intervention in the  $\beta$ -amyloid pathway. AMYPAD is set out to contribute to these efforts by developing optimal generation and utilisation of  $\beta$ -amyloid PET data. In that process, AMYPAD will improve the chances of 1) detecting specific changes in  $\beta$ -amyloid deposition, and 2) accurately measuring the impact of novel therapies in clinical trials. For that purpose, AMYPAD will be carefully and thoroughly studying a large cohort of subjects from early stages of  $\beta$ -amyloid deposition, providing a unique opportunity to select patients for proof-of-concept treatment trials aiming to reduce, revert, and eventually prevent  $\beta$ -amyloid burden.

##### What are the concrete objectives and actions which will be undertaken by AMYPAD?

**Frederik Barkhof:** AMYPAD aims at better understanding the role of  $\beta$ -amyloid for the diagnosis, the patient management, and the current and future therapies targeting  $\beta$ -amyloid deposition. For that purpose, AMYPAD plans to: 1) make early diagnosis more accurate and cost-effective, 2) improve patient selection for clinical trials, and 3) enable proper quantification of the impact of novel therapies, improving the chance of clinical trials to detect specific changes in  $\beta$ -amyloid deposition.



Gill Farrar, Project Co-lead



In line with the first goal, AMYPAD will first scan a large population cohort (n=4100) suspected of possible AD at different time points within a diagnostic setup. There, AMYPAD will help determine the value of  $\beta$ -amyloid PET imaging regarding diagnostic confidence, change in diagnosis and/or patient management, and healthcare resource utilisation.

In order to achieve the second goal, AMYPAD will leverage a Europe-wide network in close collaboration with EPAD to study the earliest stages of AD in a longitudinal fashion (n= 1900). In that process, AMYPAD will contribute to building a trial-readiness cohort while improving the understanding of

AD pathophysiology. As a result, the natural history of the early stages of AD will be better understood, allowing to determine and explore the optimal window of opportunity for secondary prevention of AD.

Finally, AMYPAD will perform full quantitative analysis of dynamic PET data and go beyond currently applied metrics and towards model disease progression. Therefore, AMYPAD will work towards achieving high quality standards for both acquisition and quantitative analysis of  $\beta$ -amyloid PET data. As a result, the third goal will be met by improving statistical power and minimising technical and biological factors affecting  $\beta$ -amyloid PET measurements.



Frederick Barkhof,  
Project Coordinator

## MOPEAD (Models of Patient Engagement for Alzheimer's disease)

MOPEAD officially started on 1 October 2016 and has a duration of 33 months with a budget of EUR 4.0 million. The Consortium consists of 14 partners and is led by Fundació ACE (FACE) and Eli Lilly & Company Ltd (ELI).



approach does not support or emphasize the need for early detection, diagnosis or action when symptoms of AD first begin. To compound the issue, many physicians are reluctant to provide a diagnosis, because they perceive AD as an incurable disease without adequate treatment and supports.

This lack of urgency compromises the quality of patient care and also robs patients of access to available support resources and services. The field must shift to greater public awareness of the importance of an early diagnosis and improved medical efficiency in identifying AD as soon as clinical symptoms emerge.

Alzheimer Europe will contribute to this project by providing a guidance document on the ethical implications of the project and will be engaged in the communication and dissemination activities. A special symposium will be organised in October 2018 at Alzheimer Europe's Annual Conference to present the outcomes and recommendations developed in the project.

**Laura Campo and Mercè Boada who are leading the project present the idea behind MOPEAD**

**What is the problem you are aiming to address with MOPEAD?**

**Laura Campo** The clinical paradigm for Alzheimer's disease (AD) largely engages patients in the later clinical stages of disease, with the majority of patients and their caregivers not seeking and/or receiving care until moderate or severe dementia has ensued. This

Not only could these efforts improve clinical access to treatment and support resources and patient engagement earlier in the stages of disease, but they would also help widen the funnel for clinical trial recruitment and earlier treatment development.

The magnitude and complexity of the issue is such that it can only be addressed by a major public-private-partnership involving a variety of stakeholders. This is a programme that cannot be accomplished by an individual research group or company, and will require a strong collaborative effort to be successful. This effort can only be achieved through a consortium of industry, academia, practitioners, advocacy groups, and other committed stakeholders who are willing to test new solutions.

Ultimately, MOPEAD will respond to the urgency of finding interventions to halt AD by stimulating a faster recruitment of patients into clinical trials.



Laura Campo, Project Leader



Mercè Boada, Project Coordinator

### What are the objectives and actions taken when implementing the MOPEAD project?

**Mercè Boada:** In Alzheimer's disease (AD), it has been shown that patient involvement and engagement improves the accuracy of diagnosis and care. Yet one of the main causes of delayed AD diagnosis is the lack of awareness in the general population of how cognitive decline is manifested. The MOPEAD objective is to clarify the meaning of cognitive decline and to raise awareness of the early signs and symptoms of AD. MOPEAD aims to identify efficient approaches for early diagnosis by comparing different models of patient engagement (Runs) across Europe.

In order to achieve the latter, MOPEAD will test, examine and prove the efficiency of four different models of patient engagement within the partnering institutions of the consortium. These four models will be implemented in four different scenarios and will be directed to four different target populations, as described in more detail below.

One of the features of the applied models includes a pre-screening procedure in order to identify the reasons for which the patient will be included in a more extensive neurodegenerative set of tests. Consequently, the patient will undergo an immediate diagnostic process, and as a result, we will be able to offer them important resources: pharmacological and non-pharmacological interventions,

experimental medicine (e.g. taking part in clinical trials), and recommendations that would improve their quality of life.

We will try to recreate similar conditions in each one of the scenarios in order to get the most accurate results across five European countries. The process will include recruiting the same number of patients for each of the models, to then include them as part of the process of diagnosis. MOPEAD clinical core has been designed in two stages, pre-screening and diagnosis, working as a funnel-shaped.

The first model, Run1, will consist of a citizen-science based web page, aimed at the general public. Run2 will be conducted by neurologists and neuropsychologists at memory unit offices, and will aim to identify cognitive disorders. The third model, Run3, will be conducted by primary-care physicians who will work to identify vascular risk factors, which are a risk factor for AD. Lastly, Run4 will be conducted by endocrinologists specialised in treating type 2 diabetes, as it represents another of the risk factors to developing AD.

The beneficiaries of this project will not only be the patients, but also healthcare professionals and the public at large. The MOPEAD project works with a true spirit of collaboration and aspiration to bring value to the people living with AD, their loved ones and health care systems



## ROADMAP (Real world outcomes across the Alzheimer's disease spectrum for better care: multi-modal data access platform)



ROADMAP officially started on 1 November 2016 and has a duration of two years with a budget of EUR 7.7 million. The consortium consists of 24 partners and is led by the University of Oxford and Novartis (on behalf of EFPIA).

Alzheimer Europe is leading the communication and dissemination activities throughout the project in close cooperation with Eli Lilly. It will also include the perspectives of people with dementia and their carers for the definition of relevant outcomes and on patient attitudes towards the specific platform and data integration proposed by ROADMAP, and contribute to a review on ethical, legal and social issues in the real world evidence.

**Frederic de Reydet de Vulpillieres,  
Project leader and John Gallacher  
Project coordinator present the  
overall vision of ROADMAP**

**What is the problem you are aiming to address  
with ROADMAP?**

**Frederic de Reydet de Vulpillieres:** Alzheimer's Disease (AD) and related dementias affect nearly 50 million individuals worldwide with prevalence projected to double over the next twenty years. Recent scientific progress indicates the potential for the first round of effective therapies for AD in the near-term. Successfully delivering these therapies to the tens of millions in need will depend on building a sustainable approach that addresses the challenges and opportunities around treatment access at time of approval. In AD this will very much depend on the integration of Real World Evidence (RWE) within health care systems to support evidence for approval as well as Health Technology Assessment and funding allocation. But are health care systems prepared? And what can we do to help be prepared?

**AE: What can we do to help be prepared?** By 2018, the ROADMAP public private consortium with its 24 EU partners, coordinated by the University of Oxford and Novartis, aims to deliver guiding principles and recommendations on incorporating RWE in healthcare systems. In this manner, the project will help to better inform consensus and decisions in support of better care for people with AD.

**What are the concrete objectives and actions  
which will be undertaken by ROADMAP?**

**John Gallacher:** ROADMAP aims to build a EU-wide database with Real World Evidence (RWE) outcomes for better care. To accomplish this, data will be used from 6 EU Member States involving 75 national databases and clinical registries.

During the project, the partners will involve diverse stakeholders (patients, carers, regulators, HTA bodies, payers, industry and researchers) to identify and prioritise possible outcomes of clinical trials with regard to their individual relevance but also health-economic importance. Using the information from the different cohorts and databases, new and ground laying analyses will be developed and realised.

This will lead to the creation of theoretical disease models of Alzheimer's disease, starting from no evidence of impairment (cognitively healthy), through subjective memory complaint and mild cognitive impairment (MCI) diagnosis, to AD and dementia diagnosis. Using and comparing different models throughout the project's progression, it will be possible to identify biomarkers for the disease which can inform clinical decision making.

In addition, ROADMAP will explore how different treatment pathways affect disease progression in different groups, allowing treatments to be more closely linked to patient response. In order to estimate the overall societal impact of treating dementia, ROADMAP will also model the long-term economic impacts of different disease trajectories and treatment pathways.

Definitive responses to these complex questions cannot be sought within the duration of the project. Therefore, information on the analyses and the stakeholder engagement (with special emphasis on patients, HTA, regulators and payers) will be used to identify data and knowledge gaps. This information will be used to lay the foundation for the development of phase 2 of the ROADMAP initiative for a long-term European based world-leading RWE environment.



Frederic de Reydet de Vulpillieres,  
Project Leader



John Gallacher,  
Project Coordinator

These three projects have received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement Nos 115952 (AMYPAD), 115985 (MOPEAD) and 116020 (ROADMAP). The Joint Undertaking receives support from the European Union's Horizon2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).



## Maltese EU Presidency: Keeping dementia on the European agenda

Hon Dr Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing, discusses how Malta is addressing dementia during the Maltese EU Council Presidency



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

**JC:** Dementia is a major cause of disability and dependency among older people worldwide, having a significant impact not only on the individuals themselves but also on their carers, families, communities and societies. In light of the improved survival globally, this figure is expected to increase further. This entails that any discourse about dementia is to include the immediate effect on families and carers.

A direct consequence of this is the increased costs for governments, communities, families and individuals, and to loss in productivity for national economies.

In 2015, dementia costs were estimated at US 818 billion, equivalent to 1.1% of global gross domestic product, ranging from 0.2% for low- and middle-income countries to 1.4% for high-income countries. By 2030, it is estimated that the cost of caring for people with dementia worldwide will have risen

to US 2 trillion, a total that could undermine social and economic development globally and overwhelm health and social services, and specifically long-term care systems. This was highlighted during the first WHO Ministerial meeting where dementia was described as the contemporary challenge.



*Hon Dr Justyne Caruana,  
Parliamentary Secretary for Rights  
of Persons with Disability and Active  
Ageing*

People with dementia and their families face significant financial impact, both from the cost of health and social care, and from reduction or loss of income. In high-income countries, the costs related to dementia are roughly shared between informal care and social care. In contrast, in low- and middle-income countries social care costs pale in comparison to informal care costs.

The expected disproportionate increase in dementia in low- and middle-income countries, including European countries, will contribute further to increasing inequalities between countries and populations.

The biggest priority for Europe in the fight against dementia should be to shrink the gap between the need for prevention, treatment and care for dementia and the actual provision of these services. Dementia is under-diagnosed worldwide, and, if a diagnosis is made, it is typically at a relatively late stage in the disease process. Long-term care pathways for people with dementia are frequently fragmented if not entirely lacking. Lack of awareness and understanding of dementia are often to blame, resulting in stigmatisation and barriers to diagnosis and care. People with dementia are frequently denied their human rights in both the community and care homes.

In addition, people with dementia are not always involved in decision making processes and their wishes and preferences for care are often not respected. The biggest challenge for Europe is to embark and full commit, to a comprehensive and multi-sectoral approach, including coordinated services of the health and social sectors, with an emphasis on promotion of well-being and overall health, prevention, treatment, rehabilitation and care of people with dementia. We also need to bridge the gap that exists between European countries in terms of dementia awareness, management and care.

“The biggest priority for Europe in the fight against dementia should be to shrink the gap between the need for prevention, treatment and care for dementia and the actual provision of these services.”



**AE: What are the health priorities of Malta's Presidency of the EU Council? Will there be any specific action on dementia?**

**JC:** During the Maltese Presidency of the Council of the EU in the first half of this year, Malta will be hosting in May the technical meeting of the EU Group of Governmental Experts on Dementia. The theme will revolve around 'The Promotion of the Rights of People with Dementia', thus focusing particularly on the social and human rights perspective.

With this in mind we recently enacted an important legislation with regards to mandates given by a person in anticipation of his/her incapacitation with the introduction of legal safeguards and Court scrutiny to ensure the proper execution of mandates given prior to the triggering of incapacity.



*Justyne Caruana speaking at the Slovak EU Presidency Conference*

Against the background of demographic ageing and the digital transition, mention also has to be made of the European Pillar of Social Rights, the first preliminary outline of which is currently undergoing public consultation, with the final version expected to be published in the early part of 2017. This will also feature during the Maltese Presidency.

Malta is taking a very proactive approach in addressing the dementia challenge. Our long-term vision is for Malta to become a dementia-friendly nation. However challenging it may seem, it is a vision which I am sure is endorsed by the EU and all Member States.

During the Presidency Meeting we intend to present our new pilot project called "Dementia Friendly Village", in the small but closely-knit locality of San Lawrenz, in Gozo, Malta's sister island. This pilot project is being carried out by my Secretariat's experts together with the local municipal council

and represents a first in the concept of a dementia-friendly community. The locality of San Lawrenz is ideal as it can serve as a model for other localities, given its small size and elderly population and high incidence of dementia.

This project will not only benefit elderly persons with dementia but also those around them and the community in general. Families and residents have shown encouraging enthusiasm in the induction lectures about coping with and supporting their relatives and neighbours with dementia.

The Local Council is also helping with purposely designed directional signage around the village, hence making individuals with dementia more aware of their physical surroundings.

We are determined to share our experience in this and other social solidarity sectors with all Member States of our European Union during Malta's Presidency in the first six months of 2017. This has already been an ongoing process over the past three years in our multi-lateral and bi-lateral meetings with our counterparts. Indeed, it is with this cautious but real sense of achievement that we look forward to further enshrine social inclusion as a major endeavour of Malta's Presidency of the European Union's Council.

The fundamental elements of our growth as a model have and will always be based on equality, equity and social inclusion - which are the basic principles towards which Malta will strive during its Presidency of the European Union's Council. We need to revive the original foundation values of the EU and stress the basic social aspects that are to make the Union more relevant to its people.

We are being confronted with long-term challenges like globalisation, an ageing society and changing work patterns. It is vital that we embrace the opportunities that these will offer. It is important to respond effectively to make sure that these new changes do not lead people with dementia on a path to exclusion and stigma.

So far until this day, such stages of data-sharing, scientific knowledge and high level debate are all important and vital for a healthy outcome. However diligent and informative our several meetings can be, millions of people, together with their families and caregivers out there are keenly expecting us to come up with proposals that effectively meet their expectations. This is the strong message that the Maltese Presidency will convey. Research and

**"People with dementia and their families face significant financial impact, both from the cost of health and social care, and from reduction or loss of income."**

“Malta is taking a very proactive approach in addressing the dementia challenge. Our long-term vision is for Malta to become a dementia-friendly nation. However challenging it may seem, it is a vision which I am sure is endorsed by the EU and all Member States.”

debate are most necessary, but action is what people expect from our end.

**AE: Many EU countries are dealing with an ageing demographic and the increase of age related diseases such as dementia. How can we be assured that dementia is kept high on the agenda for future presidencies?**

**JC:** It is important that all EU countries recognise Alzheimer’s disease/dementia as a major public health challenge and develop national action plans. Designing and implementing health programmes for universal health coverage must include financial risk protection and ensuring equitable access to a broad range of promotional, preventive, diagnostic and care services (including palliative, rehabilitative and social support) for all people with dementia and their carers. These plans should also be supported by the provision of social support to people with dementia and their carers.

Plans should also be supported by a long-term financial programme. Although an increasing number of countries are launching their dementia plans, only a few have the required financial backing.

With this in mind we had meetings with the Dutch and Slovak Presidencies to ensure that all the work done in the field of dementia by the two respective Presidencies is further enhanced in the coming months and years. In fact we proposed a joint declaration to be submitted to the EU Commission to further stress the need to keep dementia high up on the EU Agenda.

**AE: How will Europe continue to address dementia as a European health priority? Would you support the development of a European dementia strategy?**

**JC:** In Malta, we fully recognise the importance of having a national plan on dementia with the overarching aim of enhancing the quality of life of these individuals, their caregivers and family members especially at community level. The Maltese National Dementia Strategy entitled ‘Empowering Change’ is in its first year of implementation and huge strides in its execution have already been taking place. The strategy sets out a work programme for the next eight years with a view to enhance the quality of life of individuals with dementia, their caregivers and family members through the implementation of a number of intervention streams in different priority

areas, including awareness and understanding of dementia, timely diagnosis, workforce development, research and dementia management and care.

I strongly believe that dementia cannot be defeated by a single country. It is through a collaborative and coordinated European/global effort that we can successfully face the challenges of dementia.



With this in mind Malta co-sponsored a side event about dementia in Geneva last year during the WHO AGM and we also pushed to have dementia as an Item on the WHO AGM agenda next year.

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

**JC:** Global commitment and action is required to truly create effective plans for combating the effects of dementia. Policies, plans, legislation, programmes, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia. Full attention is to be included for all formal and informal carers of persons with dementia, as they are among those mostly involved in all phases of care-giving.

Malta believes in a global approach to dementia and has actively encouraged and supported the drafting of a WHO – global action plan on dementia. We fully support the decision of the World Health Organization to develop a global plan of action. The WHO connects all the related Ministries around the world and the draft for this plan means, that all will be encouraged to cooperate and consider their role and position in dementia policies for the future. The plan will guide and encourage policymakers – individually and collectively – to truly commit themselves towards working out a comprehensive and holistic approach to dementia.

# Slovak EU Presidency conference: “Alzheimer’s disease – epidemic of the third millennium: Are we ready to face it?”

On 29 November 2016 the Slovak Presidency of the European Union organised an international conference on Alzheimer’s disease in Bratislava



The conference brought together over 100 experts from different EU Member States and was an opportunity to highlight policy and research initiatives at global, European and national level. The programme was centred around four key themes which were discussed by four separate panels.

## First Panel “Dementia as a global health priority and scientific challenge”

This panel included presentations from Herta Adam, European Commission, Health programme and chronic diseases Unit on “Dementia from a public health perspective at European level”. Prof. Bengt Winblad from the Karolinska Institute, Sweden presented “What can the EU do for Alzheimer’s research” and Shekhar Saxena from the World Health Organization presented “Dementia as a global public health priority”.

## Second panel: “Prevention and Intervention strategies in Alzheimer’s disease”

This included presentations from Simona Adamovičová from the Memory Centre, Slovakia on “Alzheimer’s disease prevention strategies”, Serge Van Der Geyten from Janssen, Belgium on the “European Prevention of Alzheimer’s Dementia (EPAD)” project and Petr Novák from the Institute of Neuroimmunology, Slovakia on “Pharmacological and non-pharmacological strategies”.

## Third panel: “National programmes and Action plans on dementia”

This panel included Alzheimer Europe’s Executive Director Jean Georges who presented Alzheimer Europe’s expectations for a “A pan-European dementia action plan”, Michal Novák from the Slovak Academy of Sciences outlined Slovakia’s draft



Slovak EU Presidency Conference, Bratislava 2016



“National plan to conquer Alzheimer’s disease and other forms of dementia”. Justyne Caruana, Malta’s Parliamentary Secretary for Rights of Persons with Disability and Active Ageing and Charles Scerri, Focal Point for Dementia from Malta highlighted their country’s vision for dementia and Malta’s plans for the current EU Presidency.

**Fourth panel: “Alzheimer’s disease trip through the EU Presidency”**

Gillian Barclay from the Scottish Government presented the EU Joint Action on Dementia, Martin van Rijn, State Secretary for Health, Welfare and Sports from the Netherlands highlighted the actions of his country when it held the rotating EU Presidency in the first half of 2016 and the country’s campaign to make the Netherlands more dementia friendly. Finally Petra Brandoburová from the Memory Centre, Slovakia showed the results of a campaign to destigmatise Alzheimer’s disease.

“Alzheimer’s disease is not an isolated problem of a few countries. It is a common challenge for the whole European and global society, which requires international cooperation.”

**MIROSLAW MIKOLÁŠIK**

**AE asked Slovak MEP Miroslaw Mikolášik: From a policy makers’ perspective, why do you think it is important to bring the challenge of Alzheimer’s disease to the front and centre of European Parliament and what could be done to meet this public health challenge?**

Alzheimer’s disease is not an isolated problem of a few countries. It is a common challenge for the whole European and global society, which requires international cooperation. It seems to be one of the biggest challenges of the 21<sup>st</sup> century with its impact not only on human health but also on the economies of states and society as a whole.

In 2011, the European Parliament encouraged the EU member states to set up national action plans on Alzheimer’s and other forms of dementia.

Their objectives are wide-ranging: to reduce the risk of dementia but also to create a more inclusive society for affected people who will be more visible in aging European societies.

In March 2016, the second Joint action on Alzheimer’s, known as ALCOVE, was launched focusing on post-diagnostic support, use of medical products and care for family carers.

The goal we want to reach one day is to be able to treat underlying disease and stop or delay cell damage, which leads to the worsening of symptoms. This vision requires financial support for research from the state but also enough volunteers to complete clinical trials, whose absence is often identified as one of the main obstacles.



Miroslaw Mikolášik and Dutch Minister Martin van Rijn at Slovak Conference

## European Commission: Addressing dementia at the European level

Herta Adam from the Health programme and chronic diseases Unit, DG Health and Food Safety, European Commission, speaks to Alzheimer Europe about the involvement of the Government Expert Group on Dementia in the Slovak EU Presidency and her involvement in the Alzheimer Europe Conference



*Dementia as a global health priority and scientific challenge, Shekhar Saxena, Prof. Bengt Winblad, Herta Adam, Michal Novak*

**AE: The European Commission Government expert group on dementia recently met at the Slovakian EU Presidency conference on dementia in Bratislava. Can you tell us more about why this group was set up, its aims and achievements so far?**

**HA:** For the European Commission, expert groups play an important role in enabling the Commission to collect advice and expertise from stakeholders as a basis for sound policymaking.

Initiated by the European Commission, the governmental expert on dementia met for the first time in February 2014, to review the implementation of the “European initiative on Alzheimer’s disease and other dementias”, which had already been adopted by the Commission back in 2009<sup>1</sup>, and to support the Commission in the preparation of a report about the implementation of this initiative.<sup>2</sup>

Given the growing impact of dementia, the group was considered a good platform for exchange of information between public health authorities in the EU Member States and the EFTA-countries, and also a forum to discuss joint actions at European level. Since

then the group has met twice a year and discussed, for example, the need for a further large cooperation project between the Member States to identify best evidence for diagnosis and post-diagnostic support, quality of care and dementia-friendly communities and then to test this evidence. The group also discussed the World Health Organization (WHO) initiative to set up a Global Dementia Action Plan and a Dementia Observatory as well as developments at global level including actions endorsed by the G7 countries and the Organisation for Economic Cooperation and Development (OECD).

The members of the expert group – representatives of public health authorities from the Member States – have an important role to ensure that the EU countries implement the Council Conclusions on “Supporting people living with dementia”<sup>3</sup>, where the EU Health Ministers agreed in December 2015 on action to improve care policies and practices to support people living with dementia. How to make progress in these areas was the particular focus of the expert group meeting in Bratislava on 28 November 2016.

“It would also be great to have a representative from Alzheimer Europe’s ‘European Working Group of People with Dementia’ as a speaker during the governmental expert group meeting.”

**AE: What are the future plans for this group and how can it support countries in developing and implementing national dementia plans and strategies? Is there a role for Alzheimer Europe in such a group?**

**HA:** The next meeting of the governmental expert group will take place in May. Important items on the agenda will be the relevance of the UN Convention on the rights of persons with disabilities for people affected by dementia and how to involve these people more in decision-making processes.



Members in the governmental expert groups are real experts on dementia. Their discussion should inspire and motivate other countries to follow and implement and/or improve their national dementia plans or strategies. In the future the expert group will be associated with the work the Commission is carrying out on chronic diseases. The approach to chronic diseases includes all chronic conditions, also neurodegenerative diseases, and focuses on common factors in the prevention and care of these diseases. In this context, the Commission will support the implementation of best practices, for example to further transfer or scale up positive experiences that have already proven successful.

Alzheimer Europe is an umbrella organisation of 37 Alzheimer associations from 32 countries. It has tremendous experience in the field of Alzheimer's disease, follows the policy development at national, European and international level and represents in particular the interests of people affected by dementia and their caregivers. Alzheimer Europe has been invited to the group since the first meeting and provides its expertise as a participant with "observer" status.

**AE: In light of the Luxembourgish Presidency Council conclusions in December 2015 on supporting people living with dementia: improving care policies and practices. How can/should we continue to build future collaboration on dementia?**

**HA:** As Member States have the competence for their health care systems and the way they organise care, it is their responsibility to develop national strategies, to provide appropriate treatment to patients and to support families and caregivers. However, the Health Ministers also acknowledged the need to cooperate at European level and to address, for example, the role of prevention and health promotion, the need to focus on the ethical dimension of dementia in order to ensure healthy ageing in dignity and the added value of exchanging best practices.

During its meeting in Bratislava, the governmental expert group discussed how to follow up the Council Conclusions. To facilitate the reporting of progress, a new IT- tool, the EU Health Policy Platform will be an important instrument.

"The members of the expert group, representatives of public health authorities from the Member States, have an important role to ensure that the EU countries implement the Council conclusions on: Supporting people living with dementia".



Herta Adam speaking at the round table discussion:  
Making dementia a European priority at Alzheimer Europe Conference, Copenhagen 2016



By the way, this EU Platform can also be used by stakeholders to exchange views and to develop policy initiatives and statements.

**AE: What other plans does the European Commission have to continue to address dementia as a European health priority?**

**HA:** Indeed, the Commission considers dementia as a key health priority. The EU and its Member States have been pioneers in building-up cross-national collaboration on dementia over recent years and will continue to do so.



In addition to developing policy, the Commission also provides funding.

The Health Programme provides this financial support in the area of public health. Currently, Member States are cooperating in a so-called “joint action” entitled “Act on Dementia” and are organising collaboration on diagnosis and post-diagnostic services, crisis and care coordination, residential care and dementia-friendly communities. Work started in 2016; we have high hopes that the findings and best practices developed over the next 2 years will help to improve the situation of people living with dementia.

Dementia is also a priority of EU-research policy. Since 2007, more than 816 million EUR have been invested.

**At global level the World Health Organization is currently drafting a global dementia strategy, how is the European Commission engaging with these activities?**

**HA:** The Commission works closely with the World Health Organization (WHO) and takes part in the policy discussions. 500 000 EUR from the Public Health Programme are earmarked to support WHO to setup a European dimension of the planned WHO Global Dementia Observatory, which will pool country information and dementia situations and policies.

**AE: You recently attended the 26AE Conference. What was your highlight? Can you give us your top takeaway message?**

**HA:** What impressed me most was the active role that people affected by dementia played; their honesty, openness and courage in reporting the difficulty to accept and live with such a difficult and life-changing diagnosis, their interest to take active part and be involved in decisions that affect them, their determination to fight against discrimination and stigma and their will to live as long as possible in their normal social environment – and to do all of this in dignity.

It was for me all the more reason to put the topics of “relevance of the UN Convention on the rights of persons with disabilities for people affected by dementia and how to better involve them in decision making processes” on the agenda of the next meeting of the governmental expert group on dementia in May. It would also be great to have a representative from Alzheimer Europe’s “European Working Group of People with Dementia” as a speaker during the governmental expert group meeting.



*Making dementia a European priority at Alzheimer Europe Conference, Copenhagen 2016*

- 1 Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias, 22 July 2009. COM(2009) 380 final. [http://ec.europa.eu/health/archive/ph\\_information/dissemination/documents/com2009\\_380\\_en.pdf](http://ec.europa.eu/health/archive/ph_information/dissemination/documents/com2009_380_en.pdf)
- 2 COMMISSION STAFF WORKING DOCUMENT: Implementation report on the Commission Communication on a European initiative on Alzheimer's disease and other dementias, 16.10.2014. SWD(2014) 321 final; [https://ec.europa.eu/health/sites/health/files/major\\_chronic\\_diseases/docs/2014\\_impreport\\_alzheimer\\_dementias\\_en.pdf](https://ec.europa.eu/health/sites/health/files/major_chronic_diseases/docs/2014_impreport_alzheimer_dementias_en.pdf)
- 3 The Council of Minister adopted Council Conclusions on “Supporting people living with dementia: Improving care policies and practices” on 7 December 2015.

## Prioritising dementia in Slovakia

Michal Novák talks to AE about prioritising dementia and developing national dementia strategies in all European countries



**AE: Slovakia recently held the EU Presidency under which dementia was a priority. You initiated the conference on dementia. “Alzheimer’s disease – epidemic of the third millennium. Are we ready to face it?” Can you tell us about the conference?**

**MN:** Across the countries of the EU, the number of dementia patients is increasing every year. The Slovak Republic is no exception; on the contrary, alarming projections indicate that Slovakia is amongst the most vulnerable countries in the EU due to the increasing number of seniors. Aware of this dire state of affairs, we have decided to open the discussion on an international forum, aimed at the national dementia programmes and their connection to the activities of the managing authorities of the EU. The aim of our conference was to analyse the current state of national dementia strategies in individual EU countries, and to bridge three key pillars – the social, medical, and scientific aspects of the dementia plans. We feel that a harmonisation of the plans between individual countries is lacking; the same is true for the formation and realisation of steps necessary to address the challenges of dementia on multiple levels. The conference allowed to connect three subsequent countries carrying the torch of the EU presidency, and to relay experience and lay the groundwork for joint projects.

**AE: What needs to be done to meet the public health challenge of Alzheimer’s disease? Are we ready to face the Alzheimer disease epidemic?**

**MN:** All important opinion-leading health policy institutions not only in Europe, but worldwide define dementia as one of the most important medical priorities of the 21st century. Strategic plans, precisely formulated agendas and recipes for solutions all exist. The weakest point remains the fragmentation of individual activities across the EU. This trend is visible in research, where the JPND initiative originated; with time, the JPND transformed into yet another classic grant agency that funds only renowned teams, usually from Western Europe. The original intent of each member country funding the

research of its own scientific institutions is drifting out of focus. Large consortiums don’t arise anymore like they did initially; now, it is mostly small groups that do not reflect the diversity of scientific activities within the EU. A similar trend can



Michal Novák

be observed in other spheres as well – a harmonisation of diagnosis and therapy is absent. On the other hand, we believe that we do have the tools and excellent experts who have the potential to find the solutions to benefit EU citizens.

“All important opinion-leading health policy institutions not only in Europe, but worldwide define dementia as one of the most important medical priorities of the 21st century.”

**AE: Slovakia is developing a national dementia strategy. Can you tell us more about this and how and when it will actually be implemented?**

**MN:** Based on the experience from other EU countries, we have prepared the concept of a national programme which covers medical, scientific, and social aspects of dementia. Our goal is to build a diagnostic platform that will enable pre-clinical and early diagnosis. We wish to implement modern diagnostic tools in medical practice and educate general practitioners to identify signs of dementia early on, to guide the patients towards in-depth assessment. Another important pillar is

scientific research aimed at the identification of the causes of dementia. Slovakia is one of the leading countries in Alzheimer's disease research; the first vaccine aimed against pathological forms of tau protein originated here. Last but not least, we wish to educate the general public, and spread the concept of the 'Dementia-friendly society' in cooperation with our colleagues from the Netherlands. Our aim is to connect these efforts in a way that will multiply their effectiveness at achieving their goals.

"I would like the theme of dementia to resonate also through the EU presidencies of other countries, so that a network springs up across Europe, through which Member States can implement agreed upon best practices in everyday life."

**AE: How important is the Slovak Alzheimer's Society relationship with the Government?**

**MN:** The cooperation between the Slovak Alzheimer Society is key in the realisation of the national programme. The government of the Slovak Republic is aware of the seriousness of the challenges posed by dementia; this is reflected in the support of our conference, which was organised in cooperation with the Ministry of Health of the Slovak Republic. Currently, we are working on pathways to translate the concept of the national program into real-life implementation.

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

**MN:** I personally perceive international cooperation as an essential component of our activities. On one

side, we wish to learn from others, on the other we offer our expertise and experience. International scientific consortiums in which I had the opportunity to take part always were fertile soil for excellent ideas and simultaneously excellent tools for their swift and efficient realisation. I believe that this concept is universal, and transcends the borders of science. Our conference had an international dimension, we have shown the challenges of dementia from various viewpoints, and government representatives, EU delegates, representatives of EU institutions, doctors, scientists, and other experts from across the EU took part in the discussion. I would like the theme of dementia to resonate also through the EU presidencies of other countries, so that a network springs up across Europe, through which Member States can implement agreed upon best practices in everyday life.



Michal Novák at Slovak EU Presidency Conference



# World Health Organization (WHO) “Global Action Plan on the Public Health Response to Dementia”

In May 2016 the WHO Executive board unanimously adopted a draft decision to develop a global action plan for dementia. Following on from this in September 2016, WHO prepared a “zero draft” of global action plan on dementia



In response to the growing public health impact of dementia and following the “draft decision” on dementia in May 2016 urging the WHO to take action on dementia, WHO prepared a “zero draft” of the global action plan on the public health response to dementia. The “zero draft” was used as the basis for informal consultations, it included the proposed vision, strategic action areas and a set of recommended actions which will improve the care and quality of life of people with dementia, their carers and families and ultimately decrease the impact of dementia on society.

The “zero draft” included the proposed vision, strategic action areas and a set of recommended actions. It was used as the basis for informal consultations with Member States, UN agencies and other non-state actors such as relevant private sector entities, philanthropic foundations, academic institutions and nongovernmental Organizations.

**October 2016 Alzheimer Europe contributed to a joint response to the global plan on dementia**  
Alzheimer Europe and other key stakeholders including people with dementia were consulted on 7 key areas of the plan, including dementia treatment and research, improving awareness, dementia friendliness, risk reduction, information and care and support.

Led by ADI, Alzheimer Europe, Dementia Alliance International (DAI), and Global Alzheimer's and Dementia Action Alliance (GADAA) submitted a joint formal response to the plan in October 2016, including feedback from more than 40 Alzheimer associations in Sub Saharan Africa, the Americas, Europe, Middle East and Asia Pacific.

## **December 2016 WHO revised the “Global Action Plan on the Public Health Response to Dementia”**

Following feedback on the “zero draft”, the WHO revised its “Global Action Plan on the Public Health Response to Dementia”.

The plan emerged from the 139<sup>th</sup> session of the WHO Executive Board, which noted that “the response to the global burden of dementia can be greatly enhanced by a shared commitment among Member States and all other stakeholders to put in place necessary policies and resources for care of people with dementia, to promote research, to find disease-modifying treatments or cure, and to give adequate priority to action against dementia in national and global political agendas.” The Executive Board decisions requested the WHO Director-General to develop a plan, with the full participation of Member States and in cooperation with other relevant stakeholders and laying out clear goals and targets.

## **January 2017 WHO Executive Board adopted the “Draft global action plan on the public health response to dementia”**

The 140th WHO Executive Board took place in Geneva between 23 January and 1 February 2017 when a final version of the “Draft global action plan on the public health response to dementia” was adopted on 30 January. The report and accompanying resolution invite the Executive Board to recommend to the 70th World Health Assembly (WHA) to be held in May 2017 to endorse the Global action plan, including a set of global targets and indicators, to develop practicable and ambitious national implementation strategies, and requests the WHO Director-General to submit progress reports in 2020, 2023 and 2026 on the plan's implementation.



Photo credit: World Health Organization

**Marc Wortmann, from ADI says:**

“The decision of the Board of WHO and the strong support from all Member States is historic and finally puts dementia clearly on the agenda of global health priorities. If adopted by the Assembly in May, it means that every country has committed to action and WHO to support this action, especially in the less resourced parts of the world. There were three very supportive statements on behalf of regions, from Latin America by Dominican Republic, from Africa by Eritrea and from Europe by Malta that currently has the European Presidency. The European statement was impressive, with a focus on human rights and fully endorsing the WHO plan.

My hope is that those countries that don't yet have their own national plan will start working on it. Some countries, for instance Sweden, announced that at the meeting. For implementation of this plan it is crucial that Alzheimer associations actively approach their governments and held them to account. We now have this opportunity and should use it!”



Marc Wortmann, Executive Director, ADI

## European Working Group of People with Dementia receives prestigious international award

On 14 October 2016, the European Working Group of People with Dementia was honoured with the international “Mano Amiga” award in recognition of its outstanding work in the field of dementia. H.M. Queen Sofia of Spain was also honoured in these awards

“The voice of the person with dementia is very important and our involvement is now very relevant all over the world.”

HELEN ROCHFORD-BRENNAN



EWGPWD 2016 –2018, poses with the award, Copenhagen 2016

The international Mano Amiga awards were created in 2011 by Alzheimer León – an Alzheimer’s association in the Spanish province of León – to recognise and encourage outstanding work by individuals, organisations, institutions or groups, in the field of dementia. The awards seek to identify and showcase innovative research and initiatives that contribute in a meaningful and significant way to enhancing the health, wellbeing and quality of life of people with dementia and their families.

In Mano Amiga’s fifth edition, Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) received the award in the Institutional category. H.M. Queen Sofia of Spain and Spanish neurologist, Dr Pablo Martinez-Lage, who is a member of Alzheimer Europe’s Expert Advisory Panel, received awards in the “individual recognition category” and “individual category” respectively.

### A brush with royalty

The award ceremony took place on the 14 October 2016, at Auditorio Ciudad de León. A painting by the Spanish artist Luis García Zurdo was awarded to the winner of each category. Helen Rochford-Brennan, then Vice-chair and now Chairperson of the EWGPWD attended the ceremony together with Alzheimer Europe (AE) Project Officer Ana Diaz. Preceding the

awards ceremony, Helen and Ana were invited to visit Alzheimer León’s day care centre and were also welcomed by the Mayor of the city at the city hall.

During what was a deeply moving ceremony, Alzheimer León also presented two videos about their work and about the relevance of research, one of which featured a person with dementia, Senen Rodriguez. Mr Rodriguez presented H.M. Queen Sofia with her award and the guests, including Ms Rochford-Brennan and Ms Diaz had the opportunity to meet the Queen at the cocktail party following the ceremony.



The award-winners (left to right): Dr Pablo Martinez-Lage, H.M. Queen Sofia of Spain and Helen Rochford-Brennan (representing the EWGPWD), together with AE Project Officer Ana Diaz.



## A moving acceptance speech

Upon accepting the award on behalf of the EWG-PWD and of AE, Ms Rochford-Brennan gave a very moving speech:

"I would like to thank everyone involved with the Mano Amiga awards. It is truly an amazing honour for me to be here to accept this award on behalf of the European Working Group of People with Dementia. For people with dementia this is extra special, as many of us do not have the opportunity to advocate on behalf of people with dementia.

I have enjoyed every moment of my time as a member of the European Working Group of People with Dementia of which I am Vice-chair. Being involved in advocacy has changed my life completely. My family is thrilled to have some of the old me back.

I now have some renewed confidence and have moved from believing I could never do anything again to meeting all of you here in León especially Her Royal Highness, Queen Sofia.

In the course of our advocacy work we meet many Heads of Government and many politicians. We engage with the European Parliament and the Commission. We write speeches (writing is important to us). We advocate for the rights of all people with dementia. We have many speaking engagements, whether in our community, or with health forums, and we are involved in lots of research.

We travel the world to let people know we can live well with dementia in our communities with the correct supports. Personally I feel grateful and blessed to be here today.

I am also Chair of the Irish Dementia Working Group, the advocacy work we do is only possible with the support and encouragement of Alzheimer Europe. I do not have words to express what my own personal experience with the Alzheimer's Society of Ireland has been like. It's difficult to convey how wonderful the support I have received has been on limited resources.

The voice of the person with dementia is very important and our involvement is now very relevant all over the world. We are heard because we are participating in research and helping to remove stigma by speaking out at events such as this one.

We have to come out of the shadows and we have had our voice heard. The very best part of being involved in advocacy is all the new fantastic friends we meet along the way.

Having new friends in other European countries struggling with the same issues is such a special experience, because we can support each other and give each other all that we have to give which is "HOPE", because, sadly, we do not have a cure.

To finish up, may I quote Jane Goodall "What you do makes a difference and you have to decide what kind of difference you want to make". May I assure you the EWGPWD are working very hard to make a difference for people with dementia, not just in Europe, but all over the world.

More than anything we want to talk about the illness, just like we talk about heart disease. We want timely diagnosis and above all else we want to remove the stigma associated with dementia.

Muchas gracias!"

"We are heard because we are participating in research and helping to remove stigma by speaking out at events such as this one."

HELEN ROCHFORD-BRENNAN



Helen Rochford-Brennan delivering her acceptance speech on behalf of the EWGPWD. León, Spain, October 2016.

## Living with dementia in Wales

Chris Roberts, Vice-Chair of the European Working Group of People with Dementia, tells us a bit about himself and his life since being diagnosed with dementia, and about the situation in Wales for people living with dementia



Chris Roberts with his wife Jane and youngest daughter Kate

“I have to concentrate on what I can do, what I can achieve...and not to look back, try not to worry about my struggles, but embrace my new life...living with, and alongside, my dementia.”

“My name is Chris Roberts, I have 5 children and 2 grandchildren. I’m nearly 56 years young and I live in lovely Wales in the UK.

We, my wife and I, still run a property rental business, and I was the proprietor of a custom motorcycle shop. Motorcycles were a big part of my life until I was diagnosed with emphysema (Chronic obstructive pulmonary disease – COPD) about 8 years ago and then diagnosed with mixed dementia, vascular and Alzheimer’s nearly 5 years ago.

After doing lots of information gathering about the dementias, I decided I have to concentrate on what I can do, what I can achieve, sometimes with support and assistance, and not to look back, try not to worry about my struggles, but embrace my new life, which is, “living with, and alongside, my dementia”.

I’m now Vice-Chair on the European Working Group of People with Dementia, an Ambassador for the Alzheimer’s Society, a supporter of Alzheimer’s Research UK, a Dementia Friends Champion, a founding member of the newly-formed England, Wales and Northern Ireland Dementia Working Group - which will officially be launched in May 2017, a member of DEEP (the Dementia Engagement &

Empowerment project) and the Dementia Policy Think Tank. I’m on the NICE (National Institute for Health and Care Excellence) Dementia guideline review committee. I am also an affiliate member of the Dementia Action Alliance, a member of Dementia Alliance International, and previously sat on their Board and I’ve just been appointed an Honorary Lecturer with Bangor University Wales and contributed to our local, N. Wales Betsi Cadwaladr University Health Board (BCUHB) dementia strategy.

It really helps me to be busy and focused, it keeps me going and gives me purpose.

Yes it can be a struggle, but isn’t life in general like that anyway?

I’m lucky because I have a very supportive wife and family, without whose help and patience, I could do hardly any of the work we do. A lot of people with dementia are on their own. We mustn’t forget that.

I’m cognitively challenged, and not good at decision making, which is getting worse, but I still have my intellect and hope to be assistive in making changes on behalf of those with dementia less fortunate than myself, now and for the future.”

**AE: In February 2011, “A dementia vision for Wales” was launched. How have the six commitments in this vision had a positive impact on people living with dementia in Wales? Has this been sufficient, in your opinion?**

**CR:** The six commitments included in this document helped change, improve and support the lives of people affected by dementia, which includes family members and supporters who become carers.

Training was rolled out to all hospitals, clinics and health authorities. If people understand the problems, anxiety and stress that accompanies the dementias, then they can better help and support.

Funding was put in place for dementia support workers and advocates.

More emphasis was put around the Welsh language, and recognition that improved services were needed for younger people being diagnosed.

And a 24/7 national dementia helpline was launched, so no one needs to be alone, whatever the time.

Wales is doing some great things for dementia, but more needs to be done yet: more funding, more consistency in services, sharing of good practice, joined-up services, and research. Wales has one of the foremost centres with the work being undertaken at Bangor University’s Dementia Services Development Centre (DSDC).

Diversity and cultural matters are being addressed, and the LGBT community has not been forgotten, a group whose exceptional needs are most often forgotten about.

And of course, better travel and internet access for rural areas are just a few of things that need improvement.

**AE: The Welsh Government is currently developing Wales’ first ever Dementia Strategy, together with the Alzheimer’s Society Cymru, among others. A number of public consultations have been set up. Have you been involved in any of these consultations? If so, what contribution were you able to make?**

**CR:** The Welsh Government is currently developing Wales’ first ever National Dementia Strategy.

Two large consultations were held in the North and South, with further smaller consultations, funded by the Welsh Assembly, being held all over Wales.

Then there are more of these to discuss the first draft of the strategy, the last being on 7 April 2017.

These meetings have been organised by the Alzheimer’s Society and DEEP. Feedback from these has informed the content of the draft, which has just been released.

A task and finish group was formed consisting of professionals, but once it was highlighted that they really needed to include the voice of people living with dementia and current carers of people living with dementia, they opened the doors and gave us seats around the table.

Wales has been very inclusive of people affected by dementia in the writing of this, a rights-based strategy, and the finished document will be something that Wales can be proud of.

**AE: What are your hopes for the future Welsh Dementia Strategy, for yourself and for others in a similar situation?**

**CR:** I hope the new strategy will continue and improve upon the great start we had with the “Vision”.

I’m also hoping that the implementation of a national dementia pathway might be a direct result of this, which will provide the consistency that services need throughout Wales, no matter where one lives.

Communities becoming more inclusive will lead to greater understanding, and acceptance of dementia will be commonplace.

More importantly, our rights will be recognised, will be used by those that need them, and adhered to by all that so we can ‘live well with dementia’.

Because of the very nature of this illness, we can’t make changes on our own. We need the governments, the professionals and people affected, to work together in collaboration and in true co-production:

**Nothing about Us without All of Us!**



Chris with his dog, Tyler

BBC Panorama

“Wales is doing some great things for dementia, but more needs to be done yet: more funding; more consistency in services; sharing of good practice; joined-up services; and research.”



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# Dementia care begins at home – an Irish campaign

In 2016 the Alzheimer Society of Ireland ran a high-profile campaign addressing the need for supports that allow people with dementia to remain living at home for as long as possible

## A powerful campaign video

During the six month “Dementia care begins at home” campaign, which the Alzheimer Society of Ireland (ASI) ran in 2016, over one million people watched a powerful video featuring Kathy Ryan, Vice-Chair of the Irish dementia working group, and her sons Andrew and Matt. Kathy was diagnosed with early onset Alzheimer’s at the age of 52 and in this video she and her sons highlighted the need for more home care supports that will allow people with dementia to remain living with their families.

## Petitioning for change

People all over Ireland and around the world responded to the video and by the end of the campaign over 25,000 people had signed a petition calling on the Irish Government to invest in home care supports for people with dementia. This petition was presented to Helen McEntee, Minister of State for mental health and older people, in October 2016. During the petition handover Kathy Ryan stated, “Andrew, Matt and I were completely overwhelmed by the response to our video and we want to express our sincerest thanks to everyone who signed this petition. It is so heartening to see people get behind a campaign for Alzheimer’s, which is so often shrouded in stigma...People with dementia who wish to be cared for in their own home need to be supported to do so.”



Joanna Joyce (ASI), Tina Leonard (ASI) Andrew Ryan, Kathy Ryan (IDWG) and Helen Rochford-Brennan (2016)

## The same human rights for all

Political engagement was an essential part of this campaign and a launch event was held in Dublin for political representatives. At this event Helen Rochford-Brennan, Chair of the European working group of people with dementia and then Chair of the Irish dementia working group, spoke passionately about the rights of people with dementia and called for a change in how people with dementia are cared for: “People with dementia have the same human rights as everyone else, but we often face barriers to fulfilling these rights. We have a right to information, to diagnosis, to post-diagnosis supports. We have a right to community-based services and to be cared for in the place of our choice. We have the right to be a part of our community no matter how progressed our dementia is. We have the right to remain in our own homes, with our families for as long as we can”.



Members of the Irish Dementia Working Group and Southern Dementia Working Group

## A far-reaching campaign with a lot of air time

Supporters also played a key role in engaging politicians in the campaign, sending several thousand letters to their local representatives which contributed to the campaign being mentioned in the Irish Parliament on six occasions. The campaign also received huge media coverage in Ireland, with several in-depth television interviews, articles in five

“People with dementia who wish to be cared for in their own home need to be supported to do so.”

KATHY RYAN

“When compared to other European countries, Ireland has the second highest proportion of people aged 65 and over resident in nursing homes and hospitals, and this is something that must be addressed.”

#### THE ALZHEIMER SOCIETY OF IRELAND



Minister Helen McEntee and Pat McLoughlin ASI CEO at the Petition Handover, October 2016

national newspapers and numerous radio interviews and online articles.

Over the course of the campaign an additional 7,000 people signed up to become ASI E-Campaigners and each of these supporters was taken on an ‘E-Campaigners Journey’, receiving regular campaign action alerts and updates by email. During the course of this journey, many people got in touch with the ASI to explain why community-based care is so important for people with dementia and their families. As one supporter explained, “we want to be allowed to continue to love and care for our relatives with dementia in our own homes for as long as possible”.

Following the campaign, the video featuring Kathy, Andrew and Matt was entered into the “Better together video story competition”, an annual competition that provides a platform for Irish charities, community groups and clubs to showcase their work, and won its category. The video was short-listed after receiving over 5,000 public votes and was selected as the winner by a panel of independent judges.

#### Pre-budget submission

It is important to note that all ASI advocacy work is evidence-based and the ASI pre-budget submission at the centre of this campaign was developed strategically over several months, following consultation with people with dementia, family carers and ASI staff. For the organisation, this campaign was an important opportunity to highlight the fact that in Ireland more money is invested in long-term residential care than in community supports, thereby channeling people with dementia into institutional care. When compared to other European countries,

Ireland has the second highest proportion of people aged 65 and over resident in nursing homes and hospitals, and this is something that must be addressed.

Through the “Dementia care begins at home” campaign, the ASI argued that community care should be seen as an integral part of long-term care in its own right. They highlighted the fact that home care can keep people well in the community and out of hospital and long-term residential care. It is also vital in supporting family carers, who provide the vast majority of home-based care for people with dementia.

#### A glimmer of hope

Disappointingly, when the Irish Government announced its annual budget in October 2016, it did not include ring-fenced funding for home care supports for people with dementia. Since then, however, it has been announced that a statutory scheme for home care will be developed in the country. The ASI welcomes this development and will continue to advocate for more home care supports for people with dementia in Ireland.

For more information on this and other ASI campaigns please visit [www.alzheimer.ie](http://www.alzheimer.ie)



Andrew and Kathy Ryan at the Petition Handover, October 2016

# Working towards a more dementia-friendly Italy

**Federazione Alzheimer Italia is working to help create a more “Dementia Friendly Italy”, with a community project in Abbiategrasso, near Milan**

The “Dementia Friendly Italy” project stems from the need felt by Federazione Alzheimer Italia – the biggest Italian non-profit organisation for people with dementia and caregivers – to spread this initiative, as is being done in a number of other countries around the world. It is an important cultural tool that can change the common perception of dementia and can help in a concrete way people with dementia to live fully their community.

## Choosing Abbiategrasso

Thanks to the support of the UK Alzheimer’s Society, Federazione has acquired the know-how and the experience needed to adapt and launch this project in the Italian context.

After a careful study, the choice fell on the town of Abbiategrasso, near Milan, as a pilot city for the first dementia-friendly community project in Italy. The choice of this town was dictated by the number of inhabitants (32,000) and by the fact that Abbiategrasso is already a friendly community with a great culture and tradition of solidarity, as demonstrated by the large number of voluntary associations present.

## A courageous testimony

The project started with baby steps in February 2016 and was officially launched in September 2016, with two conferences during the 5<sup>th</sup> “World Alzheimer’s Month”.



A video interview with Father Giancarlo, an Italian missionary priest living with dementia, being shown at the launch.

On these occasions, the first results of the questionnaires to assess the needs and expectations of people with dementia and caregivers in Abbiategrasso were presented, and for the first time in Italy the opening speech was made by a person with dementia, a missionary priest, who spoke about the discovery of the disease and daily life during this period of his life, full of essential human relations, huge support from family and his community, and about the relationship with the doctor and with medication.

The courageous testimony of Father Giancarlo tells the story of all people with dementia, who have the right to be heard and to come forward, and who demand the opportunity to live in a welcoming community that fights the stigma normally associated with dementia.

## Responding to the needs of people with dementia

With the strength given by his wonderful testimony, the promoting group for the Abbiategrasso dementia-friendly community project, which comprises the Golgi Cenci Research Foundation, the “Golgi Public Company for Service to the Person” of Abbiategrasso, the Municipality, the Association of Psychogeriatrics and the Local Health Unit began investigating the best way to respond concretely to the needs expressed.

The mayor of Abbiategrasso, Pierluigi Arrara, stated that “being the first city chosen in Italy to experience the dementia-friendly programme is for me and for my fellow citizens a challenge to which we adhere willingly because it is a challenge that looks to people, to the quality of their lives and to the future of the whole community aiming to help all people with dementia to feel accepted and supported in every moment of their daily lives. My hope is a community where the weak and the strong are supportive of each other, in which everyone can find their place, in which we help to overcome the difficult moments...”





**Gabriella Salvini Porro,  
Chairperson of Federazione  
Alzheimer Italia said:**

“We are only at the beginning: it takes years to fight the stigma and make a really dementia-friendly community, but we are sure that the project will be effective and that the Abbiategrasso experience will become a replicable example, helping to improve more and more the quality of life of people with dementia and caregivers. This is demonstrated by the growing number of organisations, municipalities and regions that are asking us to participate in the project.”

**A common purpose**

Thanks to the energy of all the stakeholders, a lot of initiatives and information activities were planned and completed: trainings specifically designed for law enforcement staff, for civil servants that work in contact with the public, for social assistants and library personnel, all with the common aim of raising awareness and fight the stigma that, still nowadays and unfortunately, dementia brings. In particular, the head of the library said, after attending the training course:

“It was very interesting to have this first information about the disease and how to behave. For us it would be important to be followed regularly in the future, as we plan to revise the books’ references and the signage inside the library, to make it easier to access our services and provide simpler consultation options for those with a cognitive impairment problem.”

In response to this request, Federazione has set up a working group to analyse the spaces of the library and help create a more dementia-friendly service.

**Local law enforcement joins in**

Moreover, even the local police force, which was followed in a training by psychologists in order to respond properly to the needs of people with dementia especially in distress, stated:

“For us it was important to understand what the best way to behave and communicate with a person with Alzheimer’s is, in the line of duty. These are training opportunities that should be extended as much as possible, because it could happen to anyone to have to deal within their family with this disease”.

Training for the local police is continuing during the months of March and April 2017.

**Getting everyone on board**

In parallel to the police trainings in March and April, training for local merchants will start. They have already been involved in the project and were able to share their experiences with customers who live with dementia: thanks to their enthusiasm in the project they volunteered to personally involve all their colleagues and to disseminate the information and material for the “Dementia Friendly Italia” project.

In the following months the involvement of the voluntary associations in the area will begin, and some recreational centres will be called upon to help restore a more sociable community, so as to increase the participation of people with dementia and their families in everyday life. Then it will be the turn of a project dedicated to schools and students, along with many initiatives that are being studied.

**Next steps in Italy**

The goal of the pilot project of Abbiategrasso is to achieve an experimental but reproducible experience of a dementia-friendly community, measurable in its results especially with regards a change in the perception of dementia among people.

The next step, in parallel with the growth of the experience of this pilot project, is to spread the “Dementia Friendly Italia” project throughout Italy, and for this reason Federazione Alzheimer Italia has prepared an accreditation process for all those interested, by adapting international guidelines to the social context of the national territory.

Any community in Italy wishing to become dementia-friendly may make an application to Federazione Alzheimer Italia. It will then receive all the information to start this process and will be granted the personalised, official logo after demonstrating a real commitment to meeting the needs of people living with dementia.



*Local law enforcement in Abbiategrasso are being trained to support people with dementia better in the line of duty.*



## A look behind the headlines

Live on a busy road? Then you're **SIGNIFICANTLY** more likely to develop dementia, shock study finds

Busy roads put millions at higher risk of dementia

Dementia rates 'higher near busy roads'

Air Pollution May Contribute to Dementia

### Dr Tom Russ comments on a number of recent studies leading to media headlines about a possible link between dementia and air pollution

Dr Tom Russ is an Intermediate clinical fellow and honorary consultant psychiatrist at the University's Centre for dementia prevention and Alzheimer Scotland dementia research centre, both at the University of Edinburgh. He works clinically in the UK National Health Service (NHS) with older adults, particularly those with dementia.

His research focuses on geographical variation in dementia risk and environmental risk factors for dementia, including air pollution and on 12 October 2016, his team published a study in the journal BMC Geriatrics on this topic.

Alzheimer Europe is grateful to Dr Russ for taking the time to give us a balanced "behind the headlines" perspective on recent media headlines linking air pollution and dementia.

#### Air pollution

Air pollution is a major global health problem and is implicated in one in nine deaths worldwide. Indeed, the World Health Organization (WHO) estimates that over 90% of the world's population is exposed to excessive levels of particulate matter, an important type of air pollution.

#### Particles in the brain

Last autumn, there was a great deal of publicity surrounding a study examining brain tissue from

38 people suggesting that particulate matter could enter the brain. In fact, we already knew from animal studies that inhaled particulate matter could get into the brain, but here was evidence from humans that air pollution can directly affect the brain. This is extremely interesting but, as is often the case, requires further careful investigation at this early stage. However, this may help us begin to clarify how air pollution could be detrimental to brain health.

The researchers examined samples from Mexico City and Manchester using techniques to identify the magnetic content in the brain – being scrupulous to avoid 'contaminating' the samples magnetically when they were preparing them. They identified two types of magnetite (an iron ore) in their samples: 1) angular particles which are likely to have been formed in the brain (and which have been previously observed) and 2) rounded particles, which resembled those seen in urban air pollution (e.g. from vehicle exhausts and other sources). The formation of such particles requires extremely high temperatures and so they must have been formed outside the body and made their way in, presumably by being inhaled. In general – headlines aside – the reporting of this study was appropriately circumspect, though some newspapers did lead with the potential link with dementia. This link is, in fact, an indirect one: magnetite is toxic to the brain and one of the ways it is toxic – by producing reactive oxygen species – has been linked to neurodegenerative diseases.



Dr Tom Russ



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1. Study involving 924 respondents (depending on question) from Canada, France, Germany, Italy, Sweden, UK and the USA. Results vary across countries. Kantar Health. LTC Brand Audit Study, August 2014;1-106. 2. No. 1 Global leader in continence care; Price Hanna, Global Outlook For Hygiene Absorbent Products, February 2015. 3. TENA provides products and solutions for consumers and professionals in more than 100 countries; SCA Data on file.



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## Living near a major road

More recently, an epidemiological study from Canada identified almost a quarter of a million cases of dementia in the adult population of Ontario from electronic medical records (hospital discharges, insurance data, and prescription records). They found that living close to a major road was associated with a small increase in the risk of developing dementia. While this was a very well-conducted study, the authors were limited in the data, which were available from the electronic databases. One of the main challenges of these 'observational' studies is that they can describe an association – in this case between living close to a major road, and dementia – but cannot prove a causal link. The possibility of an alternative explanation always remains and, in this study, there are at least two important factors: socioeconomic status and noise. In most parts of the world, the people who live closest to major roads tend to be the less well off (with some exceptions, such as Los Angeles) and these individuals are also at an increased risk of developing dementia. If you can't control for an individual's level of social deprivation in a study like this, it might be that that is the explanation for the findings, not just living near a road. Similarly, if you live near a road, you may experience more noise than if you live elsewhere, and there is also some evidence linking noise pollution to dementia.

## Genetics and the environment

Finally, a novel study from the US presents findings from human participants in the Women's health initiative memory study alongside experimental mouse model work. They found that the increased risk of dementia and cognitive decline associated with increased exposure to particulate matter was particularly noticeable in carriers of the e4 version of the APOE4 gene (the commonest genetic risk factor for Alzheimer's disease) – a highly interesting 'gene-environment interaction'. Similarly, in the mice, they found that exposure to particulate matter caused brain changes relevant to dementia, including increased production of amyloid and selective changes in some of the cells in the hippocampus (part of the brain related to memory, which is preferentially affected in Alzheimer's disease).

## What impact could this research have?

Approximately a third of dementia risk remains unexplained; genetic factors and known modifiable risk factors (smoking, diabetes, hypertension and obesity in midlife, low educational attainment, a lack of physical activity, and depression) also explain roughly a third each. Environmental factors might well explain a proportion of this as yet unexplained risk. These are likely to include air pollution, as well as exposure to excessive amounts of some trace elements, pesticide use, and vitamin D deficiency (which relates to sunlight exposure).

If a causal link with dementia were found, modification of the risk factor(s) in question would be crucial. In terms of air pollution, this could include low/ultra-low emissions zones, such as have recently been implemented in London. Furthermore, understanding how air pollution affects the brain could lead to advances, which allow us to prevent the detrimental effects of such exposure.

The growth in the number of people with dementia is projected to take place predominantly in low-to-middle income countries. Since many of these countries have substantial levels of air pollution, it might be here that reductions in pollution could have the biggest impact.

## The next steps

As with all novel findings, these results should be replicated. However, there is a growing body of consistent evidence in support of the association between air pollution and dementia. Therefore, these moves to elucidate the underlying mechanism is exciting. However, one unanswered question remaining for epidemiology is when exposure to air pollution is most detrimental to brain health – is it a gradual accumulation of damage or are there sensitive or critical periods of exposure? This life course epidemiology perspective, combined with further mechanistic work, should help shed light on the origins of Alzheimer's disease and other neurodegenerative conditions, and lead us closer to our ultimate goal – preventing dementia.

To find out more about the studies referred to in this article, please contact Alzheimer Europe Communications Officer Kate Boor Ellis on: [katherine.ellis@alzheimer-europe.org](mailto:katherine.ellis@alzheimer-europe.org)

“There is a growing body of consistent evidence in support of the association between air pollution and dementia”

DR TOM RUSS



## Snapshots from Copenhagen #26AEC





# Alzheimer Europe conference opens with ambitious objectives

The 26<sup>th</sup> Alzheimer Europe Conference opened on 31 October 2016 in Copenhagen under the banner “Excellence in dementia research and care”. The conference was organised under the Honorary Patronage of Her Royal Highness Princess Benedikte of Denmark



Sophie Løhde, HRH Princess Benedikte of Denmark and Birgitte Vølund

## A royal welcome for the delegates

The Opening Ceremony was led by Nis Peter Nissen, Executive Director of Alzheimerforeningen, Denmark’s national Alzheimer association and co-host of the conference. He welcomed all the delegates and introduced the speakers, beginning with Her Royal Highness Princess Benedikte.

Her Royal Highness expressed her great pleasure to officially open the conference and added her own welcome, with a special mention for the delegates with dementia and their carers. She pointed out that they were not mere spectators, but would actively participate as speakers and experts on the topic of living with dementia. Princess Benedikte noted that “dementia is too big an issue for any country to solve on its own. It will only be through collaborative efforts such as this conference that we will be able to come closer to our goal of developing a dementia-friendly society, of providing practical solutions for the care and support of people with dementia and of identifying better treatments for those affected in the future.” The Princess, who is a Patron of Alzheimerforeningen, also congratulated the members of the association for their excellent work in supporting the development of Denmark’s new national action plan on dementia.

## A new ambitious national dementia strategy

She was followed by Sophie Løhde, Danish Minister for Health and the Elderly. Ms Løhde congratulated the hosts and added that Alzheimer Europe has been a frontrunner in putting dementia on the forefront of the European political agenda. She also explained that the Danish action plan was inspired by input from people with dementia and also best practices from abroad: she had personally visited hospitals and care homes all over Denmark and also visited the Netherlands, Norway, Sweden and the UK to observe and collect such practices. Ms Løhde specified that the action plan aims to make all of Denmark a dementia-friendly society and also calls for an increase in dementia diagnoses, so that people can be treated as early as possible. In addition, the plan aims to halve the use of antipsychotic drugs by 2025.

The next speaker was Heike von Lützu-Hohlbein, outgoing Chairperson of Alzheimer Europe. She noted that the conference would once again be a showcase of many great achievements in improving the lives of people with dementia. She also referred to the need for more and better cooperation among countries, inviting the delegates to attend the plenary session that would specifically address this

“Dementia is too big an issue for any country to solve on its own.”

**HRH PRINCESS  
BENEDIKTE OF DENMARK**

**“Alzheimer Europe has been a frontrunner in putting dementia on the forefront of the European political agenda.”**

**SOPHIE LØHDE**

**“Diagnosis is the platform that leads to everything else in dementia care.”**

**GUNHILD WALDEMAR**

topic. Ms von Lützu-Hohlbein also recommended the special session organised by the European Working Group of People with Dementia.

### **Making Denmark a dementia-friendly society**

Birgitte Vølund, Chair of Alzheimerforeningen, was the next speaker. She said that the Danish association, which celebrated its 25<sup>th</sup> anniversary in 2016, is working to eliminate all the taboos and stigma that still affect public awareness. She hoped to see a Dementia Friend for every Danish person with dementia and pointed out that the dementia-friendly movement would show citizens that even a little help goes a long way to help people with dementia. The campaign was inspired by the original UK initiative – which now has over 1.5 million Dementia Friends – and has already attracted 25,000 people in Denmark. Ms Vølund wished for an increase to 500,000 Danish dementia friends by the end of the national action plan on dementia in 2025.

She was followed by Merete Lind Larsen, a Danish nurse who is living with dementia. Ms Larsen is 51 years old and was diagnosed one and a half years ago. She was pleased that the conference was taking place in Denmark, as this would raise awareness of dementia and its many challenges. Ms Larsen specifically highlighted a need for more openness and also praised Minister Løhde's dedication to the cause, as she is the one who brings the needs of people with dementia to the attention of policy makers.

### **Improving dementia health care**

The keynote lecture was delivered by Gunhild Waldemar, Professor of Clinical Neurology at Rigshospitalet, University of Copenhagen. Her presentation “Improving the quality of health care for people with dementia” highlighted the importance of an accurate and timely diagnosis: today there are an estimated 80,000 Danes with dementia, but only some 35,000 people are formally diagnosed. Prof Waldemar explained that the dementia action plan

called for the national average of specific dementia diagnoses to exceed 80% by 2025.

She also called for improved access to local programmes for treatment and education among physicians and professional carers. People with dementia are often unable to report symptoms and to follow treatment guidelines for conditions which are easily managed by people without cognitive impairment. This often leads to delayed identification of co-morbidities, which in turn may cause further deterioration and impairment of quality of life.

Prof Waldemar reported that the use of antipsychotic drugs is gradually declining in Denmark. However, the use of these drugs among people with dementia remains much higher than among those who are unaffected – despite the risk that prescribing inappropriate medications may worsen symptoms of dementia. Prof Waldemar fully supported the goal of the dementia action plan to cap the use of antipsychotic drugs at 10% of all people with dementia by 2025.

In addition, she highlighted the importance of access to care and appropriate education of care providers with a series of video interviews of Marion & Anne. Marion, aged 76, was diagnosed with dementia five years ago and recently moved into a nursing home. Anne, her daughter and former carer, praised the efficacy of memory centres, which combine medical, psychological and social care elements under a single roof. She was pleased to see that her mother is “treated as a human being instead of only a disease.” Marion is now in a care facility that offers various activities, with a dedicated carer whom she likes and trusts. Anne felt that her family is very fortunate to have such good care for her mother and wished the same for all people with dementia and their loved ones. She also hoped that researchers would eventually be able to find a cure. Prof Waldemar echoed this sentiment with the conclusion that defeating Alzheimer's disease and other dementias must be a priority of the European research agenda.



Merete Lind Larsen

## Excellence in dementia research and care

AE held its 26<sup>th</sup> Annual Conference on 31 October-2 November 2016 in Copenhagen together with Alzheimerforeningen, the Danish national Alzheimer association



Over 700 delegates, including 35 people with dementia attended the Copenhagen conference

### A rights-based approach to dementia

On 1 November the first plenary session, entitled “A rights-based approach to dementia” was chaired by Jim Pearson, Director of Policy & Research at Alzheimer Scotland.

The first speaker was Tina Leonard, Head of Advocacy & Public Affairs at the Alzheimer Society of Ireland, who presented “Putting people with dementia first: promoting a rights-based approach in national dementia strategies.” Ms



Tina Leonard

Leonard described the development and launch of “The Charter of Rights for People with Dementia” in Ireland. The charter was launched in April 2016 and stresses the need for a parity of rights for the estimated 48,000 Irish people who are living with dementia. It calls for greater participation, accountability, equality, empowerment and legal recognition for the rights of people with dementia. Ms Leonard also showed how the elements of the charter were

incorporated into the Irish national dementia strategy. She commented that all countries can take the human rights approach and apply it to existing or developing strategies.

She was followed by Christine Swane, Director of EGV Foundation (Eksamens Gamles Værn) in Copenhagen and a daughter and granddaughter of people with dementia. Her presentation “Balancing perspectives of persons



Christine Swane

with dementia and caregivers” focused on the words and expressions that we use among ourselves and in public to speak about dementia. Ms Swane explained that society creates expectations or labels based on nature, such as the difference in behaviour between men and women or between younger and older people. In dementia, this translates as distinctions between persons with dementia and their surroundings. It is impossible to avoid this “us & them” situation, as we highlight differences in



“Luxembourg made dementia a health priority during its 2015 EU Presidency to increase understanding of dementia and to coordinate efforts already underway in many Member States.”

ANNE CALTEUX,  
LUXEMBOURG MINISTRY  
OF HEALTH

order to define needs. This means that we forego the opportunity to emphasise the social and human similarities between people with and without dementia.

The following speaker was Adrian Ward, a legal consultant for the Council of Europe with 50 years' experience dealing with the issues of people with intellectual disabilities and those around them. He spoke about the Council's activities on legal capacity and proxy decision-making, noting a growing emphasis towards autonomy, self-determination, the full recognition of rights, personality and legal status. Mr Ward said that current legal systems need to be adapted to go beyond the simple characterisation of “capable adults” making decisions for “people with incapacity”. Excellent care can and should include the exercise of autonomy and self-determination to the greatest possible extent. However, if other people have a role in this, that role must clearly define all that can be understood and ascertained about the individual if he/she were capable of doing so.



Adrian Ward

The final speaker was Richard Milne from the Institute of Public Health at the University of Cambridge. He presented the latest aspects of ethical challenges in contemporary dementia clinical trials and research. Research efforts increasingly focus on earlier stages of the disease process, with the aim of preventing or delaying the onset of dementia. This “go early” approach reframes traditional ethics questions and introduces a requirement for robust processes for the communication of risk status within clinical trial recruitment. Dr Milne illustrated the distinct ethical and social challenges of these developments by drawing on the work of EPAD – the European Prevention of Alzheimer's Dementia consortium. The EPAD researchers are working with people who are at risk of developing dementia, to see if drugs can reduce this risk. These participants will learn that their test results may mean they are at increased risk of developing dementia. Dr Milne and his colleagues will ensure that participants fully understand what this information means to them.



Richard Milne

## Making dementia a European priority

The second plenary session took place on the same day, in the form of a round table discussion with five global, European and national officials with an interest in dementia. This was moderated by Nis Peter Nissen, who asked each expert for a statement on their work which was then discussed with members of the audience.

Herta Adam, Deputy Head of Health Threats Unit at the European Commission's DG Health and Food Safety, spoke about how the EU can support member states in their efforts to address dementia. She cited the provision of a political framework and the possibility to liaise with other international organisations such as WHO and OECD. She also mentioned that the EU provides funding for dementia research as well as grants to entities such as Alzheimer Europe.



Herta Adam

The next speaker was Tarun Dua, from the Department of Mental Health and Substance Abuse at the World Health Organization. She explained that the WHO has received a growing number of calls for action on neurodegenerative diseases, including dementia, from the UN member states in recent years. As a result, the WHO is providing support for countries to set up national dementia policies, such as a special report published in 2012. A dedicated Ministerial Conference held in 2015 cast additional light on the burdens of dementia and the need to make it a priority on the global public health agenda.



Tarun Dua

Mogens Hørdér, Professor at the Department of Public Health, University of Southern Denmark, spoke about the activities of JPND (EU Joint Programme on Neurodegenerative Disease Research) where he sits on the Patient and Public Involvement (PPI) Advisory Board. He said that JPND projects gather researchers from all over Europe and this helps to avoid



Mogens Hørdér

duplication of efforts and also serves to locate and fill research gaps in specific countries. Prof Hørdér added that the programme has recently seen a welcome increase in the number of young researchers.

He was followed by Anne Calteux, Senior Policy Advisor for the Luxembourg Ministry of Health. Ms Calteux explained the principles behind the rotating EU Presidency and how Luxembourg made dementia a health priority during its 2015 EU Presidency term.



Anne Calteux

She said that dementia was chosen as a favoured topic because of a lack of common awareness of how to coordinate the efforts underway in many Member States. Ms Calteux also stressed the importance of secondary prevention and of involving people with dementia in all activities concerning their care.

The final speaker was Hilary Doxford, Vice-Chairperson of the European Working Group of People with Dementia and Board Member of the World Dementia Council. She explained that WDC's role is to identify areas that may be being missed and to share knowledge from



Hilary Doxford

developed countries with those who are in need. Ms Doxford also commented on the activities of the other speakers from the perspective of a person with dementia.

### **Detection and timely diagnosis**

The third plenary session took place on 2 November and was moderated by Charles Scerri, General Secretary of the Malta Dementia Society and Vice-Chair of Alzheimer Europe.

The first speaker was Helen Rochford-Brennan, Chair of the European Working Group of People with Dementia, who spoke about the impact of receiving a diagnosis of early onset Alzheimer's disease. During the five years it took for her to be diagnosed, simple tasks had become a chore



Helen Rochford-Brennan

and a worry. When the diagnosis finally arrived, she felt a sense of relief but was soon overtaken by anger and frustration, as well as feeling ashamed to reveal her condition. She took early retirement and hid herself at home, refusing to face her family or make any plans for the future. Eventually, she decided to seek help and this led to her joining the Irish Dementia Working Group. Ms Rochford-Brennan pointed out that people with dementia have the right to information, diagnosis, post-diagnostic support and can live wherever they want. She called for every country to develop person-centred care and create a culture where people with dementia have a voice. After all, she concluded: "I am the same person before and after diagnosis: I am still Helen."



She was followed by Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh. He explained how the European Prevention of Alzheimer's Dementia (EPAD) project aims to improve the chance of successfully preventing



Craig Ritchie

Alzheimer's dementia and to better understand early aspects of Alzheimer's disease before dementia develops. More specifically, the project focuses on secondary prevention in healthy people who are at risk of developing dementia. The first step is to identify these people through various risk factors and biomarker evidence. This will be followed by tailored treatments that reduce risks and also include the use of specific drugs. During the treatment, each person will be monitored for improvements in cognition and stabilisation of biomarkers – indicating a decreased risk of dementia. Prof Ritchie emphasised the need for a large number of participants to validate this stepped approach, noting that the EPAD trial group will consist of 6,000 people.

The next speaker was Steen Hasselbalch, Consultant Neurologist for the Danish Dementia Research Centre at Rigshospitalet. Prof Hasselbalch showed how an early and accurate diagnosis leads to better targeted treatments. He said that



Steen Hasselbalch

diagnosing people with very mild symptoms should include a thorough process of information gathering that also involves family members, as this will help to increase accuracy. Following diagnosis, it is essential to immediately inform the person affected about the support that is available, including the supportive role that family, friends, and health professionals can provide. Prof Hasselbalch specifically cited multi-disciplinary memory clinics that offer close collaboration between the primary and secondary sectors. He added that treatment is much more than just medicine, as reducing risk factors may improve some symptoms of dementia.

Finally, Henry Simmons, Chief Executive of Alzheimer Scotland, showed how national dementia strategies can help to transform the rights to choice, power and control for people with dementia and their carers. Mr Simmons used



Henry Simmons

the example of his association's "5 Pillar Model" to demonstrate how Scotland deconstructed its existing medical-based model of dementia care and replaced it with a model based on citizenship and rights. The new model ensures that every person with a dementia diagnosis can benefit from a robust support system, with highly skilled practitioners who can guide them through the five pillars of post-diagnostic support: understanding the illness and managing symptoms; supporting community connections; peer support; planning for future care and planning for future decision-making.





## Treatment and management of dementia

The final plenary session was chaired by Prof Haselbalch.

Alexander Kurz, Professor of Psychiatry, Technische Universität München, began by discussing perspectives for the future treatment of Alzheimer's disease. He showed how dementia is caused by a cascade of pathological events, including the overproduction of beta amyloid, its aggregation into plaques and tangles and the resulting neuronal dysfunction. Current treatments focus on these "downstream" events, while future treatments will more likely aim at the "upstream" side – such as slowing or preventing the overproduction of beta amyloid so that aggregation is minimal or non-existent. This might be done in two ways: by inhibiting the activity of several enzymes called secretases or by the use of antibodies. Both of these methods are already showing encouraging results, which may allow treatments to start very early in the disease course. This in turn would delay or slow down the prevalence of severe cognitive impairment. Prof Kurz noted that affected individuals would spend more time in the milder stages of the disease but might avoid dementia altogether if they are also supported by non-pharmacological interventions.



Alexander Kurz

Geoff Huggins, Director for Health and Social Care Integration in the Scottish Government, followed with a presentation on the 2nd European Joint Action on Dementia. "DEM 2" will promote the implementation in EU countries of coordinated actions to improve the situation of people living with dementia and their carers. There are four key action areas: diagnosis and post-diagnostic support; crisis and care coordination; residential care and dementia-friendly communities. Mr Huggins added that Alzheimer Europe has a key role in involving people with dementia in this initiative. They will participate in every aspect of



Geoff Huggins

the project and AE will provide dissemination of project updates and news.

He was followed by Frans Verhey, Professor of Old Age Psychiatry and Neuropsychiatry at the University of Maastricht. He showed how the Actifcare "Access to timely formal care" project is helping to improve access to formal dementia care.



Frans Verhey

Despite a growing number of formal care services for people with dementia, many citizens are still not receiving the help they need. Prof Verhey explained that this is due to a mismatch between the need and the use of these services. He cited the complexity of making such a decision for people with dementia and their carers: the process is hampered by the strong emotions associated with a dementia diagnosis, often leading to an initial refusal to seek formal care. Prof Verhey also noted a lack of knowledge about services – including among health professionals – and a growing demand for a single contact person, especially among people with informal carers.

The final speaker was Prof Iva Holmerová, Director and Consultant Geriatrician at the Centre of Gerontology in Prague. She presented the results of two projects dealing with long-term care for people with dementia. The PALLIARE project (2014–2016) identified specific educational needs in dementia care in seven European countries and also provided best practice statements. The researchers notably found a lack of a common overall description of advanced dementia and also the perception that extended palliative care is often seen as synonymous with end of life care. DEMDATA is a new project that will investigate conditions in long-term nursing homes in Austria and the Czech Republic. The study will involve 1,000 people with dementia in several homes. The researchers will focus on their cognitive and behavioural status, but will also evaluate the burden on the care teams and the needs of the resident's relatives.



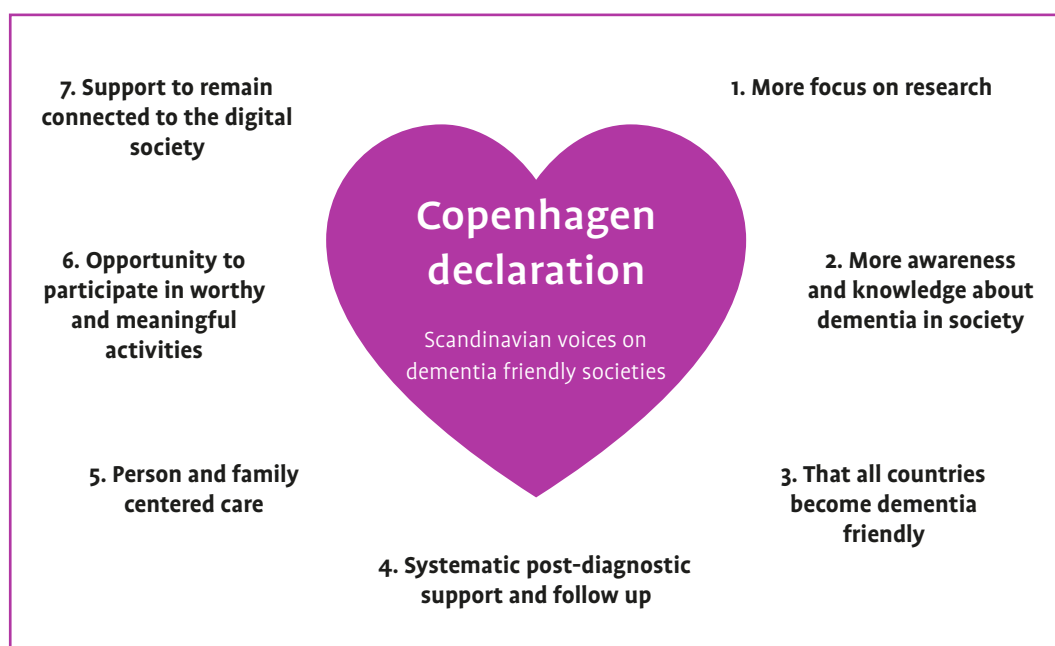
Iva Holmerová

**"Alzheimer Europe has a key role in involving people with dementia in the 2nd Joint Action on Dementia (DEM 2)"**

**GEOFF HUGGINS,  
SCOTTISH GOVERNMENT**



## The Copenhagen Declaration



Birgitte Vølund, Chair of Alzheimerforeningen, expressed her intention to listen to people with dementia on every aspect of their care. She demonstrated this by presenting “The Copenhagen declaration”, a list of the top seven requirements for a dementia-friendly society. This was produced by a dementia working group with members from Denmark, Norway and Sweden.

away from this conference and encouraged delegates to already start thinking about their abstracts for the 2017 event. She also initiated a special round of applause to honour all the delegates with dementia and their carers. Finally, she announced that this would be her last official appearance on behalf of AE and she was pleased to hand over to Iva Holmerová, the newly elected Chairperson of Alzheimer Europe.

## Berlin 2017

The final part of the conference was the closing ceremony. Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft, the German Alzheimer Association, invited all the delegates to attend the 27th Alzheimer Europe Conference in Berlin in 2017.

Prof Holmerová praised Ms von Lützu-Hohlbein for her creative and constructive approach in dealing with AE activities and challenges during her six-year tenure. She looked forward to continuing and expanding these activities and wished the delegates a safe return home.

Heike von Lützu-Hohlbein noted that “Care today, cure tomorrow” was a very effective message to take

**See you next year in Berlin!**  
**#27AEC**



## European Working Group of People with Dementia

In Copenhagen, the group welcomes six new members and elects a new Executive Board



Current and past members of EWGPWD in Copenhagen together with carers and staff



The European Working Group of People with Dementia (EWGPWD) began its third two-year term of office during a meeting on 30 October 2016 in Copenhagen. During this meeting, the group welcomed six new members and elected a Chairperson and two Vice-Chairpersons to the new Executive Board.

Old and new members of the group jointly planned their involvement in the activities of the upcoming AE conference. They also contributed to a consultation on Public and Patient Involvement (PPI) in research.

Finally, the EWGPWD thanked outgoing members Raoul Grönqvist (Finland), Hilary Doxford (UK – England) and Agnes Houston (UK – Scotland) for their strength, enthusiasm and determination during the second term of office of the group.

### Members of the EWGPWD (2016–2018)

- **Chairperson:** Helen Rochford-Brennan (Ireland)
- **Vice-Chairperson:** Alv Orheim (Norway)
- **Vice-Chairperson:** Chris Roberts (UK – England)
- **Members:** Idalina Aguiar (Portugal)
- Nina Baláčková (Czech Republic)
- Karin Gustafsson (Sweden)
- Amela Hajric (Bosnia and Herzegovina)
- Carol Hargreaves (UK – Scotland)
- Ib Holger Hegner (Denmark)
- Markku Parkkisenniemi (Finland)
- Helga Rohra (Germany).

### Speaking out on behalf of people with dementia

The group members were very active during the AE conference. Hilary spoke in the Plenary Session “Making dementia a European priority”, where she explained her role as a Board member of the World Dementia Council and also provided feedback to the other speakers from the point of view of a person with dementia. Helen presented “The impact of receiving a diagnosis of dementia” during the Plenary Session focusing on detection and timely diagnosis.

The group also organised a special hour-long session that was chaired by Alv, a member of the group since 2015. The session started with former group Chairperson Helga and her son Jens giving a speech on “Change in dementia: the mother-son relationship”. They were followed by Agnes Houston, speaking about “How people with dementia can contribute to/participate in research”. She made a special mention of her daughter and carer Donna, who was with her on stage and without whom “I just wouldn’t be here talking to you”. The final speaker was Helen, who kicked off her presentation on “How the CRPD can enhance my life living with dementia” with Bob Dylan’s “Blowing in the Wind”, to “get everyone in the mood to talk about rights”.

The packed session was attended by Her Royal Highness Princess Benedikte of Denmark, who graciously agreed to pose with the group for a photo after the session.



EWGPWD members with HRH Princess Benedikte of Denmark (centre)

The EWGPWD was launched by Alzheimer Europe and its member associations in early 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently with members electing their own Board and setting an agenda of activities. The Chairperson is also an ex officio member on the Board of Alzheimer Europe with full voting rights.

During the group's first two terms of office (2012–2014, 2014–2016), the members of the EWGPWD actively participated in the Alzheimer Europe conferences and gave keynote presentations in the European Parliament. In addition, they contributed to several consultations for different European projects where AE is involved and to the work that AE develops.

Members of the group have also contributed to research conducted by external organisations on topics such as outcome measures that are meaningful to people with dementia and their carers, social health and people with dementia as peer-researchers. They have attended various international dementia events and given numerous interviews, both in their countries and internationally.

[www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia](http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia)



An appreciative audience at the EWGPWD Special Session



# Congratulations to the winners of the poster awards!

The Alzheimer Europe Foundation is pleased to present the winners of the poster award competition

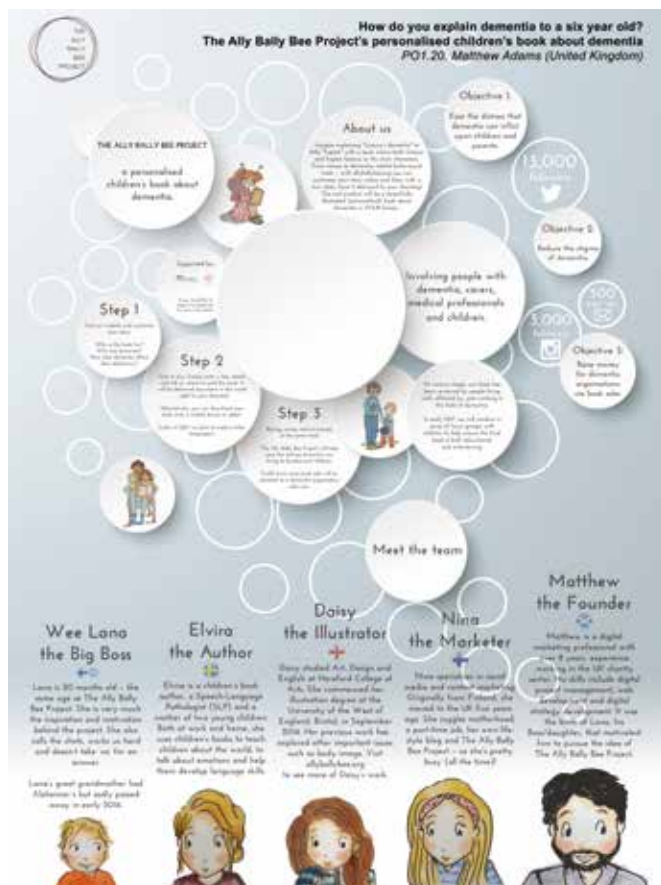


Each year, following the conference, the Alzheimer Europe Foundation awarded prizes to the top four poster presentations, as voted by conference participants. The winner for each day of the poster presentations (1 and 2 November) was awarded EUR 750 and the runner-up for each day was awarded EUR 250.

## Winners

The Ally Bally Bee Project is a social enterprise on a mission to create a personalised children's book about dementia. The book, which can be customised in terms of names, appearances and dementia-related behavioural traits, will initially only be available in English but will subsequently be translated into other languages.

The poster presentation focused on the importance of explaining dementia to children, the story behind the project and the steps taken so far.



**Winner Deirdre Fetherstonhaugh (Australia):** "Sex might be a taboo subject but we need to get it right! Resources to assist residential aged care staff and family carers".

People with dementia face many challenges when it comes to the expression of their sexuality. There is considerable scope for residential aged care facilities (RACFs) to increase the level of awareness of older people's needs, especially those living with dementia, and to improve practices accordingly. With this in mind, the Sexuality Assessment Tool (Sex-AT) and the consumer guide "Sexuality and people in residential aged care facilities" were developed, both of which were showcased in this poster presentation.

**Winner Matthew Adams (UK):** "How do you explain dementia to a six-year old? The Ally Bally Bee Project's personalised children's book about dementia".



## Runners up

As part of the Norwegian dementia plan 2015–2020, the Norwegian Directorate of Health tasked The Norwegian National Advisory Unit on Ageing and Health with developing services for children who have a parent living with dementia.

In Norway, one in four people in the early stages of the disease have dependent children, yet little follow up was done with them to help them understand and adapt. The project, explored in this poster presentation, developed a number of resources to rectify this.



**Runner up Trine Nordby Skjellestad (Norway):** "Who will see me? – Children who have a parent with dementia".

The Foundation also awarded a free subscription for the 2017 conference in Berlin to one lucky participant, drawn at random from the remaining poster evaluation forms: congratulations to **Aase Marie Ottesen (Denmark)** – we look forward to welcoming you to Berlin for #27AEC!

The Alzheimer Europe Foundation would like to thank all of the conference delegates who voted and all poster presenters for their excellent contributions to the conference.



**Runner up Wierke Jacobsen (Germany):** "Farm as a place for people living with dementia".

The Competence Center Dementia is a project of the Alzheimer Association Schleswig Holstein, Germany. The Center's mission is to improve and expand services for people living with dementia and their caregivers and one of its projects is explored in this poster presentation.

In 2016, about 500 alliances for people with dementia existed throughout Germany and this project is part of a federal programme encouraging and developing these alliances.

# 714 delegates from 41 countries attended Alzheimer Europe's 26<sup>th</sup> conference in Copenhagen

## Breakdown by country

Country	Delegates
Europe	
United Kingdom	168
Denmark	110
Sweden	52
Germany	43
Netherlands	43
Norway	36
Italy	31
Switzerland	21
Luxembourg	18
Ireland	17
Austria	15
Belgium	14
Iceland	14
Slovenia	14
Finland	12
Greece	10
France	9
Spain	9
Portugal	7
Gibraltar	6
Czech Republic	5

Country	Delegates
Romania	5
Malta	4
Poland	4
Hungary	3
Jersey	3
Bosnia and Herzegovina	2
Faroe Islands	2
Macedonia	2
Slovakia	2
Estonia	1
Israel	1
Rest of World	
Australia	9
USA	7
Canada	5
India	3
Japan	2
Singapore	2
Korea	1
Mexico	1
Taiwan	1
<b>TOTAL</b>	<b>714</b>

The 26<sup>th</sup> AE Conference in Copenhagen received funding under an operating grant from the European Union's Health Programme (2014–2020).

## Breakdown by category

	Delegates	%
Academics / researchers	204	29%
Alzheimer association staff and volunteers	154	22%
Health or social care professionals	143	20%
Industry representatives	55	8%
Students	50	7%
Carers	42	6%
People with dementia	35	5%
Policy makers	16	2%
Civil servants	15	2%
<b>Total:</b>	<b>714</b>	<b>100%</b>

### Alzheimer Europe received feedback from 117 delegates indicating that:

- Over 90% of delegates found the Opening Ceremony and keynote lecture to be good / very good.
- 83% of delegates found the plenary sessions to be good / very good.
- Over 86% of delegates found the topics in parallel sessions to be good / very good.
- **Over 93% of delegates would recommend future Alzheimer Europe conferences to their colleagues.**

## Snapshots from Copenhagen #26AEC





# Our members are helping people with dementia and their carers in 34 countries

■ Alzheimer Europe Members



**ALBANIA – TIRANA**  
Alzheimer Albania



**AUSTRIA – VIENNA**  
Alzheimer Austria



**BELGIUM – BRUSSELS**  
Ligue Nationale Alzheimer Liga



**BOSNIA & HERZEGOVINA - SARAJEVO**  
Udruženje AiR



**BULGARIA – SOFIA**  
Alzheimer Bulgaria



**BULGARIA – VARNA**  
Foundation Compassion Alzheimer



**CROATIA – ZAGREB**  
Alzheimer Croatia



**CYPRUS – LARNACA**  
Pancyprian Alzheimer Association



**CZECH REPUBLIC – PRAGUE**  
Czech Alzheimer's Society



**DENMARK – HELLERUP**  
Alzheimerforeningen



**FINLAND – HELSINKI**  
Muistiliitto



**FRANCE – PARIS**  
Association France Alzheimer



**GERMANY – BERLIN**  
Deutsche Alzheimer Gesellschaft e.V.



**GREECE – THESSALONIKI**  
Panhellenic Federation of Alzheimer's Disease and Related Disorders



**HUNGARY – BUDAPEST**  
Social Cluster Association



**ICELAND – REYKJAVIK**  
The Alzheimer's Association of Iceland



**IRELAND – DUBLIN**  
The Alzheimer Society of Ireland



**ISRAEL – RAMAT GAN**  
EMDA – The Alzheimer's Association of Israel



**ITALY – MILAN**  
Federazione Alzheimer Italia



**ITALY – ROME**  
Alzheimer Uniti Onlus



**JERSEY – ST HELIER**  
Jersey Alzheimer's Association



**LUXEMBOURG – LUXEMBOURG**  
Association Luxembourg Alzheimer



**MALTA – MSIDA**  
Malta Dementia Society



**MONACO – MONTE-CARLO**  
AMPA - Association Monégasque pour la recherche sur la maladie d'Alzheimer



**NETHERLANDS – AMERSFOORT**  
Alzheimer Nederland



**NORWAY – OSLO**  
Nasjonalforeningen Demensforbundet



**POLAND – WARSAW**  
Polish Alzheimer's Association



**PORTUGAL – LISBON**  
Alzheimer Portugal



**ROMANIA – BUCHAREST**  
Societatea Alzheimer



**SLOVAKIA – BRATISLAVA**  
Slovak Alzheimer's Society



**SLOVENIA – LJUBLJANA**  
Association "Forget-me-not"



**SPAIN – MADRID**  
Fundación Alzheimer España



**SPAIN – PAMPLONA**  
C.E.A.F.A.



**SWEDEN – LUND**  
Alzheimerföreningen i Sverige



**SWEDEN – STOCKHOLM**  
Demensförbundet



**SWITZERLAND – YVERDON-LES-BAINS**  
Association Alzheimer Suisse



**TURKEY – ISTANBUL**  
Alzheimer Vakfı



**UNITED KINGDOM – EDINBURGH**  
Alzheimer Scotland



**UNITED KINGDOM – LONDON**  
Alzheimer's Society

# 27<sup>th</sup> Alzheimer Europe Conference

## Care today, cure tomorrow

### Berlin, Germany

### 2–4 October 2017

[www.alzheimer-europe.org/conferences](http://www.alzheimer-europe.org/conferences)

 #27AEC

