Deirdre Clune hosts Alzheimer Europe’s lunch debate in European Parliament

Shekhar Saxena explains WHO’s Global Action Plan on the Public Health Response to Dementia

Marianne Thyssen, European Commission, Employment, Skills, Social Affairs and Labour Mobility discusses the European Pillar of Social Rights
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I am pleased to welcome you to the 25th edition of our Dementia in Europe magazine.

The first section highlights some of our recent efforts to make dementia a European priority, including a lunch debate in the European Parliament, focusing on the current and future treatment of Alzheimer’s and other dementias. I would like to personally thank our host, MEP Deirdre Clune (Ireland) as well as MEPs Heinz Becker (Austria), Nessa Childers (Ireland), Sirpa Pietikäinen (Finland) and Sofia Ribeiro (Portugal) for their active participation.

Our new publication, the European Dementia Monitor, was also launched during this lunch debate and has since received a considerable amount of positive feedback and media attention. Its objective is to provide a benchmark of national dementia policies to compare and rate the responses of European countries to the dementia challenge.

Another area of our work we are proud of is our involvement in European research projects and we are pleased to present the SMART4MD project in this edition. This project is building an app especially for the needs of people with mild dementia. We also include a special supplement, which takes an in-depth look at the important work being done by the PredictND project, developing and validating new, more efficient procedures for the earlier diagnosis of neurodegenerative disorders.

Empowering people with dementia to take part in research, if they so desire, is another important aspect of our work. We hope you will find the update on our Clinical Trials Watch project interesting and useful. Alzheimer Europe aims to provide correct and current information on available clinical trials for people with or at risk of developing dementia in Europe, all in an accessible format. Highlighting the important contribution people with dementia can make to research, our last article in the AE section showcases some of the recent work done by the European Working Group of People with Dementia (EWGPWD), supporting researchers involved in the INDUCT and MinD projects. We are very grateful to the members of this group, all living with a dementia diagnosis, for their invaluable input in projects like this, and in all aspects of our work.

The Policy watch section opens with our European stories on the newly-launched European Pillar of Social Rights, the impact of Brexit on European dementia research, and the recent Maltese EU Presidency. We are delighted to report on the joint statement signed by the trio of Presidencies calling for more support and coordination on dementia. We also present the European Disability Forum, of which we are proud to have become a member this year.

At a global level, we include an in-depth report on the WHO’s recently-adopted global action plan on dementia and, at national level, we take a closer look at the third National Dementia Strategy for Scotland and the upcoming Welsh dementia strategy.

In the Dementia in society section, we focus on the five national dementia working groups currently in Europe and hear from members about their experiences. We then present some recent projects and events from our members in Denmark, Luxembourg and Portugal and take a look at the real story behind recent media headlines on the impact of physical exercise on dementia.

Our Special section shines a spotlight on our German member, the Deutsche Alzheimer Gesellschaft – Selbsthilfe Demenz, which is co-hosting our 27th Alzheimer Europe Conference (#27AEC) “Care today, cure tomorrow” in Berlin. If you are reading this at the conference, I warmly welcome you to Berlin, where we will be focusing both on ongoing research aiming at finding better treatments and interventions to prevent or delay the onset of dementia and on concrete solutions to help improve the quality of life, support and care of people currently living with dementia.

Iva Holmerová
Alzheimer Europe lunch debate at European Parliament focuses on treatment of Alzheimer’s dementia

On 27 June Alzheimer Europe held a successful lunch debate in the European Parliament chaired by MEP Deirdre Clune (Ireland)

The lunch debate gathered over 50 people including MEPs Heinz Becker (Austria) Nessa Childers (Ireland) Sirpa Pietikäinen (Finland) and Sofia Ribeiro (Portugal) and a representative from MEP Hilde Vautmans (Belgium). The audience included representatives from 19 Alzheimer Europe member associations and several pharmaceutical companies.

The number of people with dementia in Europe is increasing and still there is no cure for Alzheimer’s disease (AD) or any other common type of dementia.

Medicines have been developed for AD that can temporarily alleviate symptoms, or slow down their progression, in some people but these treatments have limited efficacy.

Yet despite an unprecedented research focus on AD and dementia at European and global level, attempts to develop new drugs for treating Alzheimer’s disease have so far been unsuccessful.

However our understanding of the underlying disease processes causing Alzheimer’s dementia has increased. The four speakers at the lunch debate presented an overview of past present and future treatment and research into treatments for AD.

Pharmacological treatment and non-pharmacological management options

The first speaker Prof. Alexander Kurz, (Technical University of Munich, Germany) highlighted the current pharmacological treatment and non-pharmacological management options.

Even today, there are a number of evidence-based treatment and management options for Alzheimer’s dementia, including pharmacological and non-pharmacological approaches but often, they are underused and poorly coordinated.

Prof. Kurz said, “Using both a drug based treatment and on top of that cognitive and physical exercise with occupational therapy works at all stages of the disease and combined they can have an additional effect.”

Current understanding of Alzheimer’s disease and Alzheimer’s dementia

The second speaker, Prof. Simon Lovestone, (University of Oxford, United Kingdom) gave an update on researchers’ latest understanding of Alzheimer’s disease and Alzheimer’s dementia. He was hopeful that a treatment can be found despite the current failure rate of research compared to other diseases. He started by asking what if we have done too little too late?

He emphasised the benefits of working together “I think we can end AD. This is in an achievable aim but we can only achieve this if we work together in Europe and internationally. AD is one of the hardest medical problems we face today.”

Prof. Lovestone went on to explain that “there needed to be diversification of drug development,
Clinical Trials

Prof. Bengt Winblad (Karolinska Institutet, Sweden) gave an overview of ongoing clinical trials including preventative strategies. He highlighted that the majority of trials targeted various stages of the so-called “amyloid hypothesis” but that increasingly new targets are being researched including preventative and tau related disease modifying treatments. He concluded that the best approach would probably include a “cocktail” of different treatments.

IMI research

Dr Elisabetta Vaudano (Innovative Medicines Initiative (IMI)), presented the public private partnership of IMI, their efforts to speed up the drug discovery process and how the European Union and IMI are supporting efforts to identify new treatments for AD.

Dr Elisabetta Vaudano stressed the importance of increased funding made available for AD research and the importance of collaboration at all levels, she said “IMI is a neutral platform where all involved in drug development can engage in open collaboration on shared challenges. It is at the forefront of cutting-edge research, providing a combination of funding, expertise, knowledge, skills and resources to build a collaboration with a creative spirit, innovative and critical thinking.”

Through IMI researchers can gain from each other, new knowledge, skill and ways of working to make a difference in drug development and ultimately to patients’ lives.

The impact of Brexit on research

The question and answer session was very lively with MEP Sofia Ribeiro kicking off with a question on Brexit and the impact on research, and what would be the effect for the rest of Europe since so much research was taking place within the UK.

Simon Lovestone stated that “Brexit will have a terrible impact on AD research with the risk of loss of funding and of leadership”. He went on to explain that “the UK bats above its weight in dementia research and is in fact a world leader. This is something the UK Government understands, but for it to continue, we need to ensure that participation in EU funded projects continues after Brexit”.

Dr Elisabetta Vaudano said “It is important to keep working closely with the European Medicines Agency (EMA) after its relocation post Brexit and to ensure there is a mechanism in place to keep UK scientists in research.”

MEP Heinz Becker stated he was very impressed with the debate and offered the full support of the European Parliament asking what academia and research needed. “Is it to put pressure on Member States or is it simply a need to increase the research budget?”

In reply Prof. Winblad said “We need research at all levels, we already have advances in the quality of care due to research and from a politician’s perspective we need to get more of the Eastern European countries involved, good diagnosis and more clinical trials.”
It is important to keep working closely with the European Medicines Agency (EMA) after its relocation post Brexit and to ensure there is a mechanism in place to keep UK scientists in research.

Elisabetta Vaudano

Prof. Lovestone also replied that “Science depends very much on freedom of movement. For example roughly two thirds of those working in my laboratory in the UK are EU citizens and the UK needs to keep this wealth of experience. The issue of freedom of movement is one for politicians to solve as well as more funding and pressure to co-ordinate Member States.”

Prof. Kurz emphasised the need for more research and that politicians can help it become more efficient. “We also need to make sure no area is neglected. Pharmacology needs to be complemented with a dementia friendly society.”

Data and data collection

Both Prof. Lovestone and Dr Vaudano brought up the topic of data and data collection and regulation saying that this is more critical than ever in this digital age. Getting regulation right will be one of the keys to success to make sure data used is secure and respects the rights of citizens and that its use can be maximised within proper regulation.

MEP Sirpa Pietikäinen thanked AE for an inspiring interactive and a high quality meeting but commented “What if we have got it wrong? How serious is this? Could it be “the 4th type of diabetes”? Helen Rochford-Brennan from the European Working Group of People with Dementia (EWGPWD) also asked are we really looking in the right place?

Prof. Simon Lovestone went on to say “together we have an extraordinary opportunity to end AD and have a result” and highlighted that researchers have greatly expanded he targets and mechanisms that are currently being focused on.

Hope for a future treatment

AE Executive Director Jean Georges commented, “It is great to hear this message of hope and the new focus on preventing Alzheimer’s dementia. What are the perspectives for people already at the dementia stage or those with other forms of dementia?”

Prof. Kurz said “We need hope for a novel treatment to slow down or modify the pathology of AD but we do also need to look at other dementias such as fronto-temporal dementia and Lewy body dementia. The importance of behavioural interventions will increase with early diagnosis and disease-modifying treatments becoming available, prolonging time spent in mild and moderate disease stages. They represent key contributions to much needed empowerment and self-management of people with dementia.”

MEP Deirdre Clune summed up and thanked all the speakers and said that she felt inspired and that with the collaboration at European level she had more hope for a new treatment and eventually a cure for AD.

Deirdre Clune MEP (Ireland)

AE presents new report

Prof. Iva Holmerová Chair of Alzheimer Europe closed the lunch debate with the launch of AE’s new publication, the “European Dementia Monitor 2017” which highlights the existing inequalities in access to dementia care and treatment across Europe. The objective of the report is to provide a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge.

Prof. Holmerová said she was sorry to see that there is still a clear East/West divide in Europe. “It is time therefore that all European countries and in particular those in Eastern Europe recognise dementia as a national priority and develop national dementia strategies.”

The next Alzheimer Europe European Parliament lunch debate will be held on 5 December 2017.
The European Dementia Monitor

New Alzheimer Europe publication highlights inequalities in access to dementia care and treatment across Europe

During the lunch debate in the European Parliament in Brussels in June 2017 Chairperson Iva Holmerová presented the new Alzheimer Europe report to Members of the European Parliament (MEPs), highlighting the existing inequalities in access to dementia care and treatment across Europe.

The objective of the report entitled “European Dementia Monitor 2017” is to provide a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge. The survey covered all Member States of the European Union (with the exception of Estonia), as well as Albania, Bosnia & Herzegovina, Jersey, Israel, Monaco, Norway, Switzerland and Turkey.

Jean Georges, Executive Director of Alzheimer Europe, stated: “Our organisation has been lobbying for the recognition of dementia as a public health priority and called on European governments to develop national dementia strategies. The aim of the European Dementia Monitor is to assess which countries provide the most dementia-friendly policies and guarantee the best support and treatment of people with dementia and their carers”.

The European Dementia Monitor compares countries on 10 different categories:

1. The availability of care services
2. The affordability of care services
3. The reimbursement of medicines
4. The availability of clinical trials
5. The involvement of the country in European dementia research initiatives
6. The recognition of dementia as a priority
7. The development of dementia-friendly initiatives
8. The recognition of legal rights
9. The ratification of international and European human rights treaties
10. Care and employment rights

According to the findings of the European Dementia Monitor, no country excelled in all ten categories and there were significant differences between European countries. Some of the key findings were:

- Finland scored highest on care availability and affordability since it provided the most care services and ensured that these services were accessible and affordable for people with dementia and their carers.
- On treatment, Belgium, Ireland, Sweden and the United Kingdom (both England and Scotland) came first, as all anti-dementia treatments were fully reimbursed and the countries had a policy in place to limit the inappropriate use of antipsychotics.
- Germany, France and Spain scored highest in the clinical trial category, as it was possible for people with dementia to take part in all nine phase III clinical trials currently being conducted in Europe.
- Italy was the country that was the most committed to and active in European dementia research collaborations.
- Ireland and Norway came first in the recognition of dementia as a national policy and research priority.
- Finland, the Netherlands and the United Kingdom (England) had the most inclusive and dementia-friendly initiatives and communities.

“As a rule, countries with national dementia strategies scored better in all categories. It is time therefore that all European countries and in particular those in Eastern Europe recognise dementia as a national priority and develop national dementia strategies.”

Iva Holmerová
• Germany, France, Israel, the Netherlands, Slovenia and the United Kingdom (England and Scotland) complied with Alzheimer Europe’s four recommendations with regard to respecting the legal rights of people with dementia and their carers.
• Finland and Norway had ratified the most international and European human rights conventions.
• Ireland came first with regard to the care and employment rights which are recognised.

Deirdre Clune, MEP (Ireland) welcomed the findings of the European Dementia Monitor: “As a Member of the European Parliament and the European Alzheimer’s Alliance, I am interested in how European countries differ in their approaches to dementia care and treatment. I hope that this report will be an incentive for some countries to further improve their support to people with dementia and their carers and to learn from those countries which have put more dementia-friendly policies in place. As an Irish MEP, I was happy to see that Ireland excelled in some key areas with the development of our national dementia strategy, the Irish Working Group of People with Dementia and the recognition of care and employment rights. However, my country is also lagging behind in other areas and it is time, for example, for Ireland to ratify the UN Convention on the Rights of Persons with Disabilities.”

Overall ranking
On the basis of the findings in the 10 identified categories, Alzheimer Europe established a ranking of countries (with each domain contributing 10% to the overall score) with Finland coming first with an overall score of 75.2% followed by the United Kingdom (England) (72.4%), the Netherlands (71.2%), Germany (69.4%) and the United Kingdom (Scotland) (68.8%).
In order to calculate the overall ranking of countries, Alzheimer Europe based the global score on a combined score of the ten different categories with each contributing 10% to the overall score. This score is presented as a percentage of the overall maximum score which countries could have achieved and leads to the following ranking as shown in the figure below:

Sirpa Pietikäinen, MEP (Finland) and Vice-Chairperson of the European Alzheimer’s Alliance welcomed the findings: “I was delighted to see that Finland came first in this extensive survey of Alzheimer Europe. There has been a very strong commitment in my country to finding practical solutions and concrete support to the many people living with memory-disabling diseases. This high ranking should therefore encourage Finland to learn from countries which excel in those categories where Finland did less well.”

Iva Holmerová, Chairperson of Alzheimer Europe, concluded: “I was sorry to see that there is still a clear East/West divide in Europe with most of the Western and Northern European countries scoring significantly higher than Eastern European countries.”

Overall score of European countries

Ireland excelled in some key areas with the development of our national dementia strategy, the Irish Working Group of People with Dementia and the recognition of care and employment rights. However, my country is also lagging behind in other areas and it is time, for example, for Ireland to ratify the UN Convention on the Rights of Persons with Disabilities.”

Deirdre Clune, MEP
Alzheimer Europe develops dementia-friendly information on clinical trials

We continue to develop and improve on our Clinical Trials Watch – an innovative online resource providing up-to-date, accessible information on clinical trials

To date there is no cure for dementia. Some drugs exist for Alzheimer’s dementia that can for some people temporarily alleviate some of its symptoms.

Ongoing research worldwide may lead to new ways to diagnose, treat, or even prevent or halt the development or progression of dementia. Clinical trials are key for advancing medicine. In clinical trials, drugs (either new ones or sometimes, existing ones, which can be re-purposed) are tested to see whether they are safe and effective for humans.

Information about clinical trials and pharmacological treatments is very relevant for people living with dementia, their families and also for the general public. However, this type of information is currently difficult to find and often written in language that is difficult to understand. Based on this, in 2014, Alzheimer Europe (AE) decided to develop an online resource for anyone interested in clinical trials for the prevention and treatment of dementia.

Who is involved in this work?

For this innovative new resource, AE collaborated closely, with members of its European Working Group of People with Dementia (EWGPWD) from 2014–2016 and also asked several pharmaceutical companies conducting trials to present basic information. Five members of the EWGPWD, all living with dementia, were involved in the development of an easy-to-read template with information about trials and in ensuring that the information provided in each template is understandable for a lay person, regardless of whether the person has (or not) a diagnosis of dementia. In September 2016, AE announced the launch of the resulting Clinical Trials Watch (CTW) – a service bringing together up-to-date information on clinical trials investigating drugs for the treatment and prevention of Alzheimer’s and other dementias, in an accessible format.

Once a new trial is identified, AE develops a table to present basic information on it. The pharmaceutical company running the trial is asked to provide feedback on the contents of the table. Then, each study is reviewed by a member of the EWGPWD, before being published on the AE website.

What do the tables contain?

The tables provide information on phase III clinical trials for Alzheimer’s disease and/or dementia. All the clinical trials included are currently recruiting participants in at least one European country. However, it is important to bear in mind that recruitment may not happen in all countries at the same time and that the table is not an exhaustive source of information.

<table>
<thead>
<tr>
<th>Study</th>
<th>Study sponsor</th>
<th>Name of the drug</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMARANTH</td>
<td>Eli Lilly</td>
<td>LY3314814</td>
<td>Early Alzheimer’s Disease</td>
</tr>
<tr>
<td>COGNITE</td>
<td>AZTherapies</td>
<td>ALZT-OPi</td>
<td>Evidence of Early Alzheimer’s Disease</td>
</tr>
<tr>
<td>CREAD &amp; CREAD2</td>
<td>Hoffmann-La Roche</td>
<td>Crenzumab</td>
<td>Prodromal to Mild Alzheimer’s Disease</td>
</tr>
<tr>
<td>DAYBREAK-ALZ</td>
<td>Eli Lilly</td>
<td>Lanabecestat</td>
<td>Mild Alzheimer’s Disease Dementia</td>
</tr>
<tr>
<td>EARLY</td>
<td>Janssen</td>
<td>JNJ-5486911</td>
<td>Risk for developing Alzheimer’s dementia</td>
</tr>
<tr>
<td>EMERGE</td>
<td>Biogen</td>
<td>Aducanumab</td>
<td>Early Alzheimer’s disease</td>
</tr>
<tr>
<td>ENGAGE</td>
<td>Biogen</td>
<td>Aducanumab</td>
<td>Early Alzheimer’s disease</td>
</tr>
<tr>
<td>GENERATION</td>
<td>Novartis</td>
<td>CAD106 and CNP520</td>
<td>Risk of developing Alzheimer’s dementia</td>
</tr>
<tr>
<td>MISSIONAD1 &amp; MISSIONAD2</td>
<td>Eisai</td>
<td>Elenbecestat</td>
<td>Early Alzheimer’s disease</td>
</tr>
<tr>
<td>SYMBAD</td>
<td>University of Sussex</td>
<td>Mirtazapine and Carbamazepine</td>
<td>Alzheimer’s Disease and Agitated Behaviours</td>
</tr>
</tbody>
</table>
Each table contains the following sections:

1. Study Information
2. Information about the drug that will be tested in the study
3. Information about participating in the trial
4. Who can participate in this study?
5. Where and when will the study be conducted?
6. Information for your doctor

Information is given by country, study name and condition. The content is updated regularly, based on information available on public registries.

**How many trials are reported in the CTW?**

The CTW was developed one year ago (at the time of print) and 16 trials have already been reported via this service. Although some trials have been removed since they are no longer recruiting participants, new trials have also been added, resulting in 12 clinical trials currently reported in the database. These trials are listed in the table on the previous page.

Please note that a dementia-friendly version of each study is available as a PDF file on the AE website.

**What is the plan for the future?**

It is important to AE that this database provides information in a dementia-friendly way. Consequently, the glossary available on the AE website is currently being updated and a global folder is being developed, with the most difficult words, which will then be available for download as a PDF file.

The current database provides information on phase III clinical trials for Alzheimer’s disease and/or dementia. In the future, AE plans to expand this innovative resource to include Phase II studies also.

Additionally, to provide updated information in a dementia-friendly way through the CTW, AE has identified two key areas that could be further explored in the future:

- Gaining a better understanding of clinical trials in dementia, to explain the main features of a clinical trial and its relevance to dementia, all in an accessible format.
- Supporting people with dementia and carers in navigating the world of clinical trials, by providing an FAQ, put together through a series of interviews with others who have already taken part in clinical trials.

**Additional information**

Please note that the information provided in the CTW service should not be interpreted as a recommendation to use a particular treatment, nor to participate in a particular study.

Further information on clinical trials and on the studies appearing in the CTW is available at: [http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch](http://www.alzheimer-europe.org/Research/Clinical-Trials-Watch)

Alzheimer Europe is very grateful to the EWGPWD members and companies involved for their contributions, for their help in creating and continuing to improve and update the CTW, in its accessible and dementia-friendly format.

Helga Rohra is one of the members of the EWGPWD involved in the CTW. She said: “This is a great resource, as it provides support to people living with dementia and their families in Europe so that they are better informed about dementia research. This adapted format is a big step towards making information on clinical trials more accessible and understandable for people with dementia and we hope it may also help encourage them to take part in research, as well as inspiring people with other diseases to do the same. As a member of the EWGPWD, and Chair of the EWGPWD at the time of the CTW launch, I am proud to have been involved in this project from the very beginning. Thanks to the support provided by the AE team, I was able to contribute to this valuable work in an equal and meaningful way. Actively involving people with dementia in projects like this helps change society’s perceptions of them. People with dementia have a valuable and important contribution to make. I would like to thank the AE team for its support and hard work, which made my contribution possible.”

Laura Campo, Advisor – International Corporate Affairs, Alzheimer’s disease at Eli Lilly and Company, also commented:

“Today, at least 150,000 volunteers, both with and without Alzheimer’s disease, are urgently needed to participate in more than 130 actively enrolling clinical trials across the industry for Alzheimer’s disease and related dementias. If we can’t quickly enrol these trials, we won’t be able to find the solutions we desperately need. Thank you to Alzheimer Europe for their support providing a great resource through the Clinical Trials Watch project.”
The SMART4MD project

SMART4MD is developing an app to improve the quality of life of people with dementia and their carers

The four year SMART4MD (Support Monitoring and Reminder Technology for Mild Dementia) project is developing a computer tablet-based platform especially for the needs of people with mild dementia, to help remind them to take prescribed medication, as well as allowing them to share health-related data with their caregivers and doctors.

As well as giving people more control over their care, the app, also called SMART4MD, aims to help slow functional decline, relieve pressure on caregivers, and reduce costs for healthcare providers.

In order to customise the SMART4MD platform to the needs and capabilities of people with dementia, two rounds of focus groups consisting of people with dementia and carers were carried out in Spain, Belgium, Sweden and the Czech Republic. This also involved a first testing of the system and its main features. The user-centred design-led prototype has already been developed to be used in three languages, and three more are underway. The newly-launched feasibility study, involving 20 dyads of participants (20 people with dementia and 20 informal carers) paved the way for the main study in September 2017. The main study involves 1,200 volunteers in five participating centres around Europe and will run until late 2019.

SMART4MD aims to improve the quality of life of people with dementia and their carers, increase treatment compliance, reduce dementia-related costs by helping reduce the number of missed appointments and of hospital re-admissions and help reduce functional decline.

The project has an initial budget of around EUR 4 Million, distributed across a total of 10 partners from the private and academic sectors:

- Alzheimer Europe (Luxembourg)
- Anglia Ruskin University (United Kingdom)
- Athena ICT Limited (Israel)
- Blekinge Tekniska Hogskola (Sweden)
- Consorci Sanitari De Terrassa (Spain)
- Dex Innovation Centre (Czech Republic)
- Pow Health (United Kingdom)
- SAS-IBIMA (Spain)
- UC Limburg (Belgium)
- Universidad Politecnica De Madrid (Spain)

For more information: http://smart4md.eu/

SMART4MD is co-financed by the European Union under an EU Framework Programme for Research and Innovation – Horizon 2020, with grant agreement number 643399.

Key features of Smart4MD

- A powerful customisation tool to improve usability.
- A daily planner with activity, medicine and appointment reminders to aid independent living and better health management.
- Photo albums as visual aids to keep people connected with friends, family and healthcare teams.
- Quality-of-life and health tracking for dementia and any other conditions being managed.
- Simple charts to help visualise health progress and medicine compliance.
- Sharing of controlled health data with doctors, carers and family.
James Hampton-Till, Project Coordinator

**AE: What issue are you aiming to address with the SMART4MD project?**
**James Hampton-Till:** As Europe’s population is ageing, long-term care for older citizens is becoming an increasing cost for society. To manage this transition, healthcare policies in the EU and individual Member States are heavily focussed on extending the independent life of older people, with the dual aim of increasing their quality of life and reducing the costs of care. Dementia affects more than 6% of people aged 60+ and has a considerable effect on their independence.

In this project, we are building on an innovative patient support tool to develop an mHealth (mobile health) application that is specifically targeted at people with mild dementia. The tool will help users adhere to their treatment and share data with their carers and doctors; carers will use the same application to monitor their changes more easily and share information about their own well-being with doctors. We believe this will help improve independence and promote a better quality of life for people with mild dementia and help avoid carers getting exhausted, as well as reducing costs of emergency care.

**AE: How is the SMART4MD consortium uniquely composed to address this issue?**
**JHT:** This project, coordinated by Anglia Ruskin University, brings together 10 partners from 7 EU Member States. Each partner organisation is a Key Opinion Leader in its field. In addition to its breadth, the Consortium boasts a considerable wealth of knowledge and experience offering – for example – expertise in progressive technologies, innovative clinical interventions, lobbying and dissemination in practice.

**AE: What are the concrete objectives and actions being undertaken?**
**JHT:** Our project comprises two phases: first we are using digital accessibility tools to design an application for people with mild dementia. This development is being steered by the people with dementia themselves, as well as carers and doctors. Through user-centric design, we are collecting feedback on each new version of the application until the design is perfectly adapted to our users’ needs. In the second phase, we will pilot the optimised application with users (people with mild dementia and carers) and controls. This will show the clinical and social benefits, as well as financial benefits for the healthcare system.

It is hoped that successful delivery of the pilot will increase users’ adherence to treatment, while improving the quality of life of carers and people with dementia alike. By our calculations, it could save healthcare providers EUR 1,818 per patient per year in care costs and generate revenue of over EUR 18 million per year for the consortium within five years.

Johan Berglund, Clinical Lead

**AE: What are the benefits of delivering SMART4MD as a clinical trial?**
**Johan Berglund:** I see two major benefits with the possibility to implement the SMART4MD project in the form of a clinical study.

Firstly, we have had the opportunity to find, with user-driven design, the needs and wishes of people with dementia and together with them, develop features to meet these wishes. With this step, along with the review of the scientific literature and expertise in the field, we have developed a model app that can serve as a template for continued development in IT support for people with mild dementia.

Secondly, the SMART4MD study, with its randomised controlled design, provides a unique opportunity to demonstrate whether we can have a positive impact on clinical parameters and on people’s wellbeing. Despite developments in applications to support people with cognitive decline, impact has been difficult to establish, although the individuals often perceive these applications as beneficial.

**AE: What are your expectations from and hopes for the project?**
**JB:** I do not want to anticipate any results, but the hopes of the project are of course that we develop a support that gives people with mild dementia and their carers an improved quality of life and enables their independence for a longer period. It may also help them to move their focus away from their difficulties and become more socially engaged. In other words, we hope to enable people with mild dementia to better manage their own everyday lives. In addition, helping people to remember to take medication and making it easier to share health data with close relatives or healthcare professionals may also have significant health-economic effects and allow people with dementia to remain in their own homes for longer.

“We are building on an innovative patient support tool to develop an mHealth application that is specifically targeted at people with mild dementia.”

**James Hampton-Till**

“We hope to enable people with mild dementia to better manage their own everyday lives.”

**Johan Berglund**
At Roche, we work with a purpose.

We discover and develop innovative medicines and diagnostic tests to help people live better, longer lives.
The European Working Group of People with Dementia supports research

The EWGPWD is involved in a number of European research projects in which AE is partnering and the group’s input is highly valued.

Since it was formed in 2012, the European Working Group of People with Dementia (EWGPWD) has been supporting and informing all aspects of Alzheimer Europe’s work, including the European projects in which we are partners. This year, the group has been involved in two projects, INDUCT and MinD.

**INDUCT**

Developments in technology, such as mobile phones and tablet computers, may help people living with dementia by improving their quality of life and supporting them to live independently.

INDUCT, the Interdisciplinary Network for Dementia Using Current Technology funded through H2020 Marie Skłodowska Curie Actions (676265), is a multi-disciplinary, inter-sectorial educational research collaboration supporting 15 early stage researchers/PhD students across Europe who will develop special training and expertise in technology and dementia care.

The advanced multidisciplinary scientific expertise and the complementary partnerships with industry, the health care and social sectors, plus user representative organisations will enable INDUCT to develop and empower future leaders in technology and dementia care.

The collaboration between the European Working Group of People with Dementia (EWGPWD) and the researchers has led to great benefits and insights in training and research and aims to ensure that the research delivered is relevant and meaningful for people with dementia and their families. For example, the members of the EWGPWD have actively participated in training activities and academic discussions in which they provided support and advice for the INDUCT researchers regarding their individual research projects. They also delivered a presentation to all network members about the importance of involving people with dementia in research in the last INDUCT School in Maastricht-NL, in January 2017. The members have also supported the network members with management and dissemination matters, aiming to ensure that INDUCT is constantly improving and progressing towards the aimed outcomes.

In this way, INDUCT will help Europe remain at the forefront of technological developments in dementia care. The network is looking forward to continue establishing this great partnership with the EWGPWD and welcome the members to the upcoming INDUCT School taking place in Salamanca, Spain, in September 2017.

**Alv and Chris talk about their involvement in the “INDUCT school”**

Regarding his involvement in the “INDUCT School” in January 2017, Alv Orheim (Norway), Vice-Chairperson of the EWGPWD said:

“My contribution was a short presentation about myself, giving them my ‘story’, and emphasising the importance of this kind of open dialogue between both professionals/students, persons with dementia and their carers.

Before meeting with the students we had been given information about INDUCT and a list of questions, which the students had prepared. This gave me and my wife a chance to think through answers and relevant aspects to these questions in advance, and so be better prepared. During the meeting we split into groups and addressed some of the questions. This was a very interesting session, which could or should have lasted much longer, but unfortunately there was not enough time for this.”

On why it is important for people living with dementia to be directly involved in research projects such as INDUCT, Alv said:
“I believe everyone with a dementia diagnosis will face questions like how, why, what now and of course why me?

The only way I may contribute to improve the level of understanding is to take the opportunity to become involved with researchers and offer them some insight into my own personal dementia world. Thereby I hope they may be better equipped to continue their work. “Doing” dementia every day makes us experts in this particular field, giving us experiences which are valuable to students and professionals, insight which is hard to come by, unless they involve us and our carers.

Although many questions still remain unanswered I am encouraged when listening to researchers tackle issues related to my own situation. It might even give my life a new meaning!

So to sum up, I found the dialogue with the students and supervisors a very positive happening in my life.”

Chris Roberts (Wales, UK), Vice-Chairperson of the EWGPWD gave a presentation at the INDUCT School, alongside AE Project Officer Ana Diaz, on “Involving people with dementia as advisors in Alzheimer Europe’s research and activities”:

“I wanted to remind the researchers that one doesn’t suddenly get diagnosed with dementia in the late stages, that there is a beginning and middle before one reaches that stage in the illness and also that we are experts in our own experience with insight and knowledge that one can only get in our position.

Nobody should ever make assumptions about one’s mental capacity – you must see the person first, not the diagnosis, to remember and find out who the person is – a tradesman, doctor, astronaut, even a scientist or researcher.

Even though we are living with dementia, we still have a lot to contribute and want to be involved, it gives us purpose, value and focus, which can easily be lost after a life changing illness, especially when there is no cure, research gives us hope where there was none, for the future and for our families.”

When asked why it is important for people living with dementia to be directly involved in research projects such as INDUCT, he said:

“Because patient experience is very valuable and brings learning to life and should be more than tokenism – we bring so much practical knowledge to the table, which is why we shouldn’t just be advisors but sometimes also co-researchers and part of the research team.

Due to the very nature of dementia we need support, but also the complexity of the various symptoms means that professionals need our support too, so the phrase which is used in the disability sector, “Nothing about us without us” becomes “Nothing about Us, Without ALL of Us”

We all need to work together if any progress is to be made and we need to be involved in the research and work around our illnesses.

We, people living with dementia appreciate everything that is being achieved on our behalf and hope that we can be part of the momentum to these achievements.”

MinD

MinD is a 48-month project funded through the European Commission’s Research and Innovation Staff Exchange. It focuses on the identification of novel uses of design to complement existing care approaches to empower people with dementia in everyday social situations. Additional expected project outcomes and benefits are:

- A framework for development and evaluation of designs in dementia care settings
- A holistic, mindful model of designing
- A model for mindful care for social engagement for people with dementia
- Policy recommendations for the inclusion of design within dementia care.

The project is now in its second year. Year 1 focused on data collection through a series of interviews and focus groups with people with dementia and their carers, which took place in Germany, the Netherlands and Spain. As a supplement to the interviews, an activity book was also given to people with dementia, so that they could provide more information around two particular areas. These were: personal information about e.g. goals, attitudes, experiences, motivation, capabilities, and social context that could
be used to develop rich personas, and information about areas of change and needs for preservation in peoples life with respect to activities of daily living, leisure activities, social engagement and wellbeing. The activity book allowed for more active participation and could be worked on at the times the participants wanted to.

During a secondment in Luxembourg in May, researchers analysed the data collected, to identify a number of common themes across the countries and participants, which will steer the direction of the design moving forward. The consortium presented these themes to the EWGPWD, through a series of lively and insightful discussions which generated very valuable feedback. This type of collaboration and knowledge sharing between people with dementia and the MinD project’s design team is essential for the project. It is hard to imagine how the team could possibly start designing things for people to use without getting their help, preferably at every stage of their work. The involvement of people with dementia is therefore vital to ensure that the designs created in the project will help them with areas of importance to them in their daily life.

Helga and Karin talk about their involvement in the MinD consultation

Talking as rapporteur at the MinD project consultation in May 2017, Helga Rohra (Germany), member of the EWGPWD, said:

“For the EWGPWD, it was important to have face-to-face communication in an appropriate language so that terminology could be explained, as well as a safe environment and the brilliant support of both the focus group moderator and the AE staff.

The views of those of us who are living and dealing with dementia are extremely valuable: it is part of life, and we can help to cross check the facts for people on the outside. We can change the outlook of medical experts on dementia. We are able and are valuable as co-partners. By being involved in projects like this, we people with dementia – in our different stages, at our different ages and from different countries – can show that behind each diagnosis is a person living with it, who still has many capacities. This work can add to the information that is in the books and help to educate researchers about the relevance of the person.”

Karin Gustafsson (Sweden), member of the EWGPWD, commented on her experiences at the project consultation:

“The most positive thing for me personally was to participate in the group, thus gaining knowledge of other people’s experiences and thoughts about Alzheimer’s disease and also being able to share my own experiences with regard to the disease.”

When asked what the benefits of involving people living with dementia in research projects, like MinD, Karin said:

“It is crucial that researchers in the field involve those affected by Alzheimer’s disease to build knowledge about the disease and understand how to facilitate and support people with Alzheimer’s disease. It is of great importance to look after the individual’s needs and wishes regarding treatment and integrity.”

Helga Rohra

“By being involved in projects like this, we people with dementia – in our different stages, at our different ages and from different countries – can show that behind each diagnosis is a person living with it, who still has many capacities.”

Karin Gustafsson

“It is crucial that researchers in the field involve those affected by Alzheimer’s disease to build knowledge about the disease.”
The European Pillar of Social Rights

Marianne Thyssen, Member of the European Commission, Employment, Skills, Social Affairs and Labour Mobility discusses the European Pillar of Social Rights including the new “work life balance” initiative for carers

AE: Why do we need a European Pillar of Social Rights?

MT: The world we live in is rapidly changing, and this can very much be seen in the world of work. Digitalisation and globalisation are having a huge impact on the way we work. Some jobs will disappear, other jobs will be transformed and new ones will be created. Teleworking is no longer an exception and new types of work are emerging – think about new players in an increasingly collaborative economy, such as Uber and Airbnb. At the same time, the effects of the crisis, which has deepened existing inequalities, and other structural trends, such as the fact that European societies are ageing, are putting pressure on the sustainability of our social model and social protection.

In short, the evolution of world of work brings many opportunities, but challenges too. We can’t and shouldn’t try to avoid the change, but make sure that we are ready to embrace and harness it. For this, we need to adapt our social models taking account of these changes in society as a whole and the labour market in particular. This is the essence of the European Pillar of Social Rights that we launched this year. It contains 20 principles and rights, which serve as a reference framework to screen the employment and social performance of Member States and to drive the process of reforms at national level. It is our compass for a future in which our children, and next generations, will have the same – if not more – opportunities as their parents to prosper and advance; being oblivious to these changes would risk that our children could be worse off than their parents. As the challenges we are facing are similar for the whole European Union, the Pillar could be relevant for all Member States. It provides a roadmap for moving forward together towards a fairer and inclusive society which works better for all.

AE: Europe is ageing and dementia is a major cause of disability and dependency amongst older people. What can the European Pillar of Social Rights do to address these concerns?

MT: People live longer, but not necessarily in good health. Care is becoming ever more important. By 2060, the number of over-64-year-olds will increase by 1.6%. The number of people needing long-term care is expected to climb by 30%, while the number of long-term carers will tend to decline.

The European Pillar of Social Rights mentions access to affordable and good quality long-term care as a priority. It is the first time that such a right is affirmed at EU level. Services should allow dependent people to maintain their health and functional status for as long as possible and improve their autonomy, for example through home-care and community-based services. This is an excellent example of the inclusive and empowering society we want. This principle is of course to be seen in conjunction with other principles under the Pillar which support the aim to ensure a decent life for disabled and older people.

At the same time, the Pillar aims at ensuring the sustainability of our social model. The demographic ageing of our society does not only increase the need for long-term care, but also causes a shrinking working age population. According to projections, in 2060, for every retired person there will only be two people of working age, compared to four today. It is my firm belief that activation and investment in people’s skills and life-long learning are key to anticipate this demographic change and mitigate the burden of this evolution on future generations. In this context it is a conscious political choice the fact that the very first principles of the Pillar are about investing in ‘education, training and lifelong learning’ and access to ‘active support to employment’.

“The European Pillar of Social Rights mentions access to affordable and good quality long-term care as a priority. It is the first time that such a right is affirmed at EU level.”

Marianne Thyssen
AE: Alzheimer Europe welcomes the new “work life balance” initiative particularly with respect for carers. Can you tell us more about this and how it will be implemented?

MT: The ‘work-life balance’ initiative is one of our first initiatives at European level to underpin the implementation of the European Pillar of Social Rights. With our work-life balance proposal, we try to tackle several challenges at a time – increasing women’s participation on the labour market, taking account of the increasing need for long-term care and therefore carers, and generally creating a better balance between professional and private life for working parents and carers.

As regards caring in particular, the directive on work-life balance for parents and carers introduces the right to carer’s leave of at least 5 working days per year per worker to take care of a seriously ill or dependent relative. The leave is proposed to be compensated at least at sick pay level. Our proposal on work-life balance now needs to be adopted by the European Parliament and the Council, before becoming legislation. I discussed the proposal for the first time with the Ministers of Employment, Social Affairs, Skills and Mobility of our Member States during an informal meeting in Tallinn from 19 July till 20 July. The meeting was fully dedicated to the issue of work-life balance. Our proposal was quite well-received, and I hope this meeting will now stimulate the debate in a positive way and that together with all actors, we can make this important initiative a reality on the ground.

AE: Dementia can develop during working years. What are the key concerns for employment and social policies in Europe regarding this?

MT: Figures show that employment of people aged 55–64 is quite low, at 55.3% in 2016 in the EU. Employment of persons with disabilities in this age group is even lower, at only 34.5% in 2014. In the context of an ageing society, we can’t leave our human capital untapped. We need to enable and support people to stay in the labour market as long as possible. Indeed many people continue to work after getting the diagnosis of dementia. We already have EU antidiscrimination legislation in place, which protects workers against discrimination on the grounds of a disability. But under this legislation, employers are also obliged to provide appropriate accommodation for workers with disabilities. This includes physical adaptation of the workplace, but – and this is particularly relevant for dementia – it could also include adaptation of working arrangements and flexible working hours.

Also through our funding we invest in the inclusion of people with disabilities in the labour market. There is a significant budget of the European Structural and Investment Funds available for support of employment including for persons with disabilities and those with dementia.

Another priority is ensuring mental and physical health of people in the workplace. The EU Policy on Health and Safety at Work aims at protecting workers against all kind of workplace risks, including psychosocial risks. All aspects related with Mental Health, including the prevention of dementia, are particularly relevant in view of keeping workers in good health, not only during the active life, but also after retirement.
The European Accessibility Act

The European Disability Forum explores how the Accessibility Act is an opportunity to improve the lives of persons with disabilities and persons with dementia in Europe

What is the Accessibility Act?

In December 2015, the European Commission published a proposal for a law which is known as the “European Accessibility Act”. The European Disability Forum have been campaigning to ensure the adoption of an ambitious law that will make a real difference in the lives of persons with disabilities and older people.

Once this proposal is adopted, it should lead to common accessibility requirements covering products and services across the European Union (EU). Currently, there is no specific EU legislation on accessibility for persons with disabilities. The proposed Accessibility Act has a lot of potential to make several products and services accessible for all people in Europe, including 80 million persons with disabilities and 150 million older people.

The European Disability Forum (EDF) has been closely following the development of this legislative proposal; as a matter of fact, the adoption of a strong Accessibility Act has been one of the main objectives of its “Freedom of Movement” campaign.

The proposed Accessibility Act takes the form of a Directive, which is legally binding, meaning that the EU Member States have an obligation to apply what the Act mentions. However, the proposal foresees that only certain products and services need to be accessible. These are mainly:

- Smartphones, tablets and computers
- Ticketing machines and check-in machines
- Televisions and TV programmes
- Banking and cash machines (ATMs)
- E-books
- Online shopping
- Websites and mobile applications

A unique opportunity for the EU

The European Accessibility Act is a unique opportunity for Europe. It will give EU businesses the chance to take the lead on the world market for accessible products and services. Moreover, it will start to pave the way for all EU citizens to participate in society on an equal basis with others. It has the potential to enable persons with disabilities and persons with dementia to live more independently and be included in the community, by creating a fully accessible mainstream services and products; thus people won’t anymore be obliged to use “special” services and products, that are often more expensive.

The proposed law will for example include provisions to make ticketing machines in train stations as well as cash machines (ATMs) in banks easier to use and to understand. This will facilitate the life of many persons who have troubles clicking through complex menus and using complicated electronic payment systems.

The proposal of the European Commission does not bring up something unreasonable or even anything particularly new, it is rather a means to implement the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) that the EU and all its Members States – except Ireland – have already ratified. Furthermore, many EU Member States such as France or Austria, for example, already have binding accessibility legislation at the national level that goes beyond what the proposed Accessibility Act is requiring.
But most important of all: making things accessible is not a cost per se; it is an investment. Accessibility is also not a “luxury”; it is an essential part of products and services that consumers in the EU are buying every day. Some decades ago, it was also considered a luxury to have electricity and running water at home. Nowadays we cannot imagine living without it, not to mention wireless internet.

**What are the challenges?**

Nevertheless, since its publication the Accessibility Act has been consistently portrayed by its opponents as a law that will ruin the EU economy and add unnecessary and burdensome “red tape” for businesses. It is a pity that it is often not seen as it really is: a business opportunity.

As we recently saw in the vote of the Internal Market and Consumer Protection Committee (IMCO) of the European Parliament on 26 April 2017, the perceived interests of businesses were clearly put before the interests of persons with disabilities. The IMCO Committee’s report includes numerous provisions that are unfavourable from the point of view of persons with disabilities. For instance, the report:

- **limits the link to public procurement and EU Structural Funds.** It will be possible that EU funding and taxpayer’s money are used to pay for a school building that is not accessible, as there are still no binding accessibility requirements. As a result, entering a public library, a town hall, or a school will continue being impossible for many children with disabilities in Europe.

- **completely excludes microenterprises from making their products and services accessible to all people.** This means that many e-commerce services and e-books of small publishers will be inaccessible. As a result, millions of people in Europe, including persons with disabilities, will continue being excluded from buying things online or reading e-books.

Ultimately, the IMCO Committee’s report does not only go against the interest of the EU citizens that voted for the Members of the European Parliament, but it also disadvantages European business in the long run. Therefore, it is high time to make the EU politicians realize that they are missing a business opportunity if they continue watering down and opposing the Accessibility Act.

EDF and its members therefore keep on campaigning actively and lobby the EU decision-makers. We will not accept just any law; it will have to be a sufficiently wide-reaching Act that deserves the name “Accessibility Act”.

The European Disability Forum (EDF) is an independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a front runner for disability rights. We are a strong, united voice of persons with disabilities in Europe. More information at: [www-edf-fehp.org](http://www-edf-fehp.org)
Lilly and Alzheimer’s Disease

For nearly 30 years, Lilly has been committed to Alzheimer’s disease research and development. During this time we’ve made significant scientific advances and we’re not slowing down. In fact, our commitment is stronger than ever. Through perseverance and discovery, our goal is to make life better for those affected by Alzheimer’s disease around the world.
European governmental experts on dementia discuss rights-based policies for people with dementia

As part of its programme of the Presidency of the European Union, Malta collaborated with DG SANTE of the European Commission to convene the group of governmental experts on dementia to meet in St Julian’s on 15–16 May 2017

Jean Georges represented Alzheimer Europe and Iva Holmerová, Chairperson, Charles Scerri, Vice-Chairperson of Alzheimer Europe and Nino Mimica, Chairperson of Alzheimer Croatia were also in attendance and represented their respective countries at the meeting.

Dr Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing opened the meeting and welcomed the participants to Malta and outlined some of the key priorities of the Maltese Dementia Strategy. During the same day, she signed a declaration with her colleagues from the Dutch and Slovak Presidencies calling for greater European collaboration on dementia (see article on page 24).

Jean Georges, Executive Director of Alzheimer Europe, presented the findings of the organisation’s 2016 Yearbook and gave an overview and comparison of national policies on legal capacity and decision making systems. Both presentations led to interesting discussions and the group decided to further consider this issue and develop a recommendation outlining some of the principles of importance when discussing the rights of people with dementia.

Sofía Lourenço from DG Employment provided an update on the European Accessibility Act and the European Union’s obligations resulting from the UN Convention on the Rights of Persons with Disabilities and Maja Groff presented the Hague Convention on the International Protection of Adults which provides important rules for the cross-border recognition of powers of attorney.

European dementia strategies

The welcome was followed by a tour de table of national health ministry representatives from 20 European countries presenting their latest national initiatives in the dementia field. Of these countries, 13 already have a dementia or neurodegenerative diseases strategy in place (Czech Republic, Denmark, Finland, France, Ireland, Italy, Luxembourg, Malta, Netherlands, Norway, Slovenia, Spain and the United Kingdom which was represented by Scotland) whilst an additional 4 countries (Germany, Portugal, Romania and Slovakia) announced that they were working on the development of such a strategy and hoping to announce it in the coming 12 months. Only Bulgaria, Croatia and Cyprus who were participating in the meeting currently had no plans for the development of such a strategy.

Update on the Joint Action on Dementia

The meeting was also an opportunity for the national representatives to be updated about the progress of the Joint Action on Dementia and its focus on timely diagnosis and post-diagnostic support, care coordination, residential care and dementia-friendly communities, as well as about other international efforts by the World Health Organisation and its global action plan on dementia and global dementia observatory and by the OECD and its work on care indicators in dementia.

The second day of the meeting was primarily dedicated to discussing a rights-based approach to dementia. Helen Rochford-Brennan, the chairperson of the European Working Group of People with Dementia talked about her own experience of living with dementia and gave an impassioned call on national representatives to involve people with dementia in the development and monitoring of dementia policies.
Joint Statement on Dementia – 15 May 2017

The trio of Presidencies of the Council of the European Union 2016–2017, The Netherlands, Slovakia and Malta:

Taking into account

• that worldwide 47.5 million people live with dementia, of which 58% live in low and middle-income countries; in the EU an estimated number of 6.4 million people live with dementia;
• that dementia is a major cause of disability and dependency among older people worldwide, having a significant impact not only on individuals but also on their carers, families, communities and societies; dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease; in light of the improved survival globally, this figure is expected to increase further;
• that dementia may develop at a relatively young age leading to unique challenges for the person with dementia, relatives and friends;
• that dementia leads to increased costs for governments, communities, families and individuals, and to loss in productivity for economies;

Referring to

• the council conclusions on supporting people living with dementia: improving care policies and practices, adopted by the EU Council of Health Ministers, under the Luxemburg Presidency, on December 7, 2015;
• the outcomes of conferences on dementia organised under the Netherlands’ and Slovak Presidencies on May 9–10 and November 29, 2016 and the proceedings during the meetings of DG Sante’s Governmental Expert Group on Dementia on November 28, 2016 and May 15–16, 2017, hosted by the Slovak and Maltese Presidencies;
• the activities of the World Health Organisation, resulting in the expected adoption of the Global Action Plan on Public Health Response to Dementia by the seventeenth World Health Assembly, on May 23–31, 2017, and the development of a Global Dementia Observatory;
• the human rights of people with dementia, as stipulated in the United Nations Convention on the Rights of People with Disabilities;
Wishing to emphasise the importance of:

- research into all aspects of dementia, including, but not limited to, finding a cure, prevention and improvement of care;
- providing good care for both patient and informal carer, referring to the key principles of good dementia care, attached to this statement;
- preserving the best possible quality of life for a person with dementia;
- the creation of dementia-inclusive communities;
- public awareness of dementia and its consequences, including risk and protective factors;
- patient advocacy by national and international Alzheimer organisations;

Call upon the European Commission

- to promote and support the international cooperation in dementia research and improve the coordination of existing European research programmes, e.g. in the European Joint Programme on Neurodegenerative Diseases Research (JPND), Innovative Medicines Initiative, Horizon2020, Active and Assisted Living (AAL) programme and related research and innovation programmes;
- to promote and support the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- to stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;
- to support patient advocacy by national and international Alzheimer organisations.

Call upon our fellow EU-Member states

- to participate in, promote and support the international cooperation in dementia research, e.g. in the European Joint Programme on Neurodegenerative Diseases Research (JPND) and related research and innovation programmes;
- to work together in the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- to support persons with dementia to have the best possible quality of life, to live a life with dignity and to participate in society, in accordance with their human rights;
- to stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;
- to support patient advocacy by national and international Alzheimer organisations.

Mr Martin van Rijn,
State Secretary for Health, Welfare and Sport
The Netherlands

On behalf of Ms Andrea Kalavská
State Secretary for Health
Dr Boris Banovsky,
Medical Director Ministry of Health Slovakia

Dr Justyne Caruana,
Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing
Malta

ANNEX 1

Key Principles on Dementia Care

1. Dementia is a neurocognitive disorder
2. People with dementia are entitled to respect and dignity
3. People with dementia are worthy members of society
4. People with dementia are entitled to a correct and timely diagnosis
5. People with dementia and their relatives are entitled to appropriate treatment, care and support
6. Medical and care professionals have adequate knowledge of all aspects of dementia
7. Treatment of people with dementia is aimed at:
   • maintaining their independence in daily life
   • delaying progression of the disease
   • coping with co-morbidities
8. Care provides necessary assistance when a person with dementia loses functions due to the dementia, while conserving as much independence as possible
9. Support helps people with dementia and their relatives to:
   • cope with the disease
   • remain in control of their lives
   • maintain social activities
   • prepare for the effects of the progression of the disease, while using methods to prevent or delay symptoms of the disease
10. Public health raises awareness on and promotes ways contributing to the prevention of dementia.
The impact of Brexit on dementia

Jean Georges, Executive Director, Alzheimer Europe looks at the impact of Brexit on people with dementia, their carers and families, as well as the many professionals involved in the treatment, care and research fields.

Few recent political decisions were as hotly debated as the place and future of the United Kingdom within the European Union. Amongst the key issues on both sides of the debate were the economy and immigration, but also more philosophical views about sovereignty and the place of the UK in a more globalised world.

The now infamous ‘battle bus’ raised the issue of health and promised additional funds to the NHS in case of a vote to leave the EU. The potential impact of Brexit on dementia was however rarely discussed and received little attention by the media.

Almost one year after the referendum vote and after the triggering of Article 50, there still seems very little clarity on what exactly the future relationship will be between the UK and the European Union and it is therefore impossible to provide a definitive and final answer on how Brexit will affect people with dementia, their carers and families, as well as the many professionals involved in the treatment, care and research fields.

In this article, I will try, as much as possible, to provide a balanced view on some of the challenges and threats, but also some of the opportunities which arise from the referendum result. I will mainly focus on how Brexit will affect staff in the research and health industry, the organisation of clinical trials, the authorisation of new medicines and European research collaboration.
An end to free movement?

One hotly debated topic during the Brexit campaign was the free movement of people between Member States of the European Union.

An interesting statistic shared by the NHS is that 10 per cent of doctors and 5% of nurses are from the EU. Similarly, a report of the House of Lords estimated that around 5% of the workforce in the adult care sector were EU nationals.

Within the research community, the proportion of EU nationals is significantly higher with EU citizens making up 16% of academics and 14% of PhD students. The situation of those EU nationals already working in the research, health and care sectors will need to be addressed quite promptly, as will the fate of UK citizens living in EU countries.

There will of course be opportunities for UK nationals to be trained and upskilled in order to take on new available positions, but there will also be real challenges to avoid staff shortages in these essential industries in the future.

What about common standards for data protection and clinical trials?

The competence of the European Union within the health field is actually quite limited, but there are a number of key regulations where the framework provided by the European Union applies to all its Member States.

That is the case for the regulations which clarify the rules for data protection and for the conduct of clinical trials. The EU Regulation of 27 April 2016 will institute a single set of rules on data protection, valid across the EU and will eliminate a number of unnecessary administrative requirements. At the same time, a high level of data protection and the right to be forgotten are also recognized in EU legislation.

The EU Regulation of 16 April 2014 provides a framework applicable in all EU countries for companies and academic sponsors who wish to carry out clinical trials.

Once the revision enters into force, it will be possible for sponsors to submit one single dossier to a central portal which will be assessed according to a harmonised process. This system should speed up the approval process for clinical trials without

The European Medicines Agency (EMA) with its current seat in London is another example of how European countries collaborate efficiently to provide one common solution to a complex issue facing every European country.

Jean Georges
adversely affecting the safety requirements for such trials. In addition, new transparency rules regarding the publication of clinical trials will also come into force EU wide.

For both of these frameworks, a United Kingdom outside of the European Union could choose to improve on the existing systems and address some of the concerns that still exist when it comes to these regulations.

However, any new system will also create a new level of bureaucracy and in future researchers will have to submit their applications for clinical trials under two different systems with different and potentially conflicting sets of rules.

It would be premature to judge at this stage what the implications will be, but companies conducting trials will undoubtedly carefully balance the cost of submitting their dossiers to different systems against the effectiveness of the systems when deciding in which countries to start their trials.

Quo vadis, European Medicines Agency?
The European Medicines Agency (EMA) with its current seat in London is another example of how European countries collaborate efficiently to provide one common solution to a complex issue facing every European country. Thanks to the EMA, people across the European Union can benefit from one centralised system for the evaluation of the safety and efficacy of new medicines and their EU-wide market authorisation.

In addition to the approval of medicines for humans, the agency has acquired true expertise in the fields of advanced therapies and orphan drugs for rare diseases, but also in the setting up of a European pharmacovigilance network to ensure the safety of medicines across the whole of the EU.

In my opinion, this is a true lose-lose situation, as Europeans will lose the fantastic expertise of UK regulators who play a very important role in the different committees of the European Agency and often take leadership positions in its work.

At the same time, the UK will have to redevelop a full regulatory agency for the evaluation and approval of new products without being able to rely on the insights and experience of other countries. Whether this will lead to faster approval of medicines or significant delays in the future remains to be seen.

The future of European dementia research collaboration is at stake
A final area which is of particular concern for Alzheimer Europe and all our member organisations is how the Brexit decision will impact research in general and dementia research in particular.
Although the UK was one of the net contributors to the European budget, paying in more than it was able to receive back, this was different in the research field where, between 2007 and 2013, the UK actually received 8.8 billion Euro although it only contributed 5.4 billion Euro to the research programme.

In the dementia field, a number of European initiatives exist which support researchers and EU-wide collaboration.

The JPND, or Joint Programme for Neurodegenerative Diseases currently brings together 30 countries. This programme already includes a number of non-EU countries and national funding is used to fund researchers from the same country. It should be relatively straightforward for the UK to continue its collaboration in this programme and make its own funds available for UK researchers to stay involved in pan-European research collaborations.

For other programmes, such as the EU research or health programmes, this may not be as simple and it is in these programmes where UK centres have been particularly successful in securing funds.

The first programme of the Innovative Medicines Initiative for example co-funded 4 key and ambitious Alzheimer’s projects with overall funding of 168.8 million Euro with the University of Oxford playing a key role in the European Medical Information Framework project and the University of Edinburgh coordinating the European Prevention of Alzheimer’s Dementia project.

Under the second phase of the Innovative Medicines Initiative, 80.4 Million Euro have already been allocated to six new collaborative Alzheimer’s projects and UK partners play a vital role in a number of those. The allocated funding for these ground-breaking initiatives is secure, but the place of UK institutions in future stages of development of these projects and in completely new applications still needs to be discussed.

Another worthwhile initiative to mention is the current Joint Action on Dementia which is coordinated by the Scottish Government and which is funded by the EU health programme. Under the leadership of Geoff Huggins, representatives of health ministries and academic partners are collaborating in order to compare policies in four key areas: timely diagnosis and post-diagnostic support, crisis management and care coordination, residential care and dementia-friendly communities. The aim is to identify existing good practices, learn from other countries and see how good practices can be implemented in new settings.

The future of Scotland and the UK in all of these programmes will be up for discussion during the Brexit negotiations and different models already exist.

There are for example 13 Associated Countries which provide funding to the EU research programme allowing researchers from these countries to access EU funds to the same extent as EU researchers. However, these countries have no say in the definition of research priorities.

There are also a number of third countries where researchers can participate in EU research projects only if their country provides matching funding for their participation.

A growing need for good will and compromise

As with the other questions I highlighted previously, there is no definitive answer on the future collaboration of the UK in EU research efforts on dementia. All will depend on the good will of the negotiators to find compromise solutions which will ensure that researchers and academics can continue to collaborate with the ongoing research efforts to find better ways of treating, delaying or preventing Alzheimer’s dementia.

Alzheimer Europe will of course be happy to continue its relationship and collaboration with Alzheimer Scotland and the Alzheimer’s Society which were founding members of our European movement. They have led by example and contributed effectively to the growth of national Alzheimer’s organisations, the development of national dementia strategies, the inclusion of people with dementia and their carers and the promotion of a human-rights based approach in all policies.

Whatever deal politicians will come up with in the final Brexit negotiations, I look forward to our continued collaboration. I remain convinced that we can learn a lot from one another: Only by pooling our resources and knowledge, will we be able to improve the lives of the 8.4 million Europeans currently living with a form of dementia.
The World Health Organisation’s new Global Action Plan on the Public Health Response to Dementia

Dr Shekhar Saxena, Director, Department of Mental Health and Substance Abuse talks about how the WHO will be addressing dementia with the new action plan

AE: What led the WHO to develop the Global Plan of Action on the Public Health Response to Dementia?

Shekhar Saxena: Dementia is an important cause of mortality and morbidity globally. In 2015, around 47 million people worldwide had dementia, a figure that is predicted to increase to 75 million by 2030. Nearly 60% of people with dementia live in low- and middle-income countries and most new cases are expected to occur in those countries. Deaths due to dementias more than doubled between 2000 and 2015, making it the 7th leading cause of global deaths in 2015. The economic costs of caring for people dementia are US$818 billion worldwide and will rise to US$ 2 trillion by 2030.

A number of international efforts have been undertaken in recent years to address the global challenges posed by dementia. Examples include the joint WHO/ADI report on dementia as a public health priority; the G8 dementia summit; the formation of the World Dementia Council; and the First WHO Ministerial Conference on Dementia.

These events created a lot of momentum. However, the response to dementia can be greatly enhanced by shared commitment at global level and thus Member States requested WHO to develop the global action plan on public health response to dementia. Dementia is associated with complex needs and high levels of dependency and morbidity in its later stages and thus an integrated response from all relevant sectors to tackle this challenge is required through a targeted, comprehensive action plan.

AE: What are the key objectives and targets?

SS: The global dementia action plan envisions a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

A set of actions have been outlined in the plan that represent strategies to improve health and social response for dementia in seven action areas. These strategies are applicable to countries from all income groups. However, they would need to be adapted to account for national circumstances.

For each of the seven action areas, the plan sets global targets to help measure the overall progress of implementation at national, regional and global levels. The specific action areas and their associated global targets are:

- **Dementia as a public health priority:** 75% of countries have national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans by 2025.
- **Dementia awareness and friendliness:** 100% of countries have at least one functioning public awareness campaign on dementia by 2025. AND: 50% of countries have at least one dementia-friendly initiative by 2025.
- **Dementia risk reduction:** The relevant global targets defined in the Global NCD action plan are achieved for risk reduction.
- **Dementia diagnosis, treatment, care and support:** In at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025. Support for dementia carers: 75% of countries provide support and training programmes for carers and families of people with dementia by 2025.
- **Information systems for dementia:** 50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every two years by 2025.
Dementia research and innovation: The output of global research on dementia doubles between 2017 and 2025.

**AE:** The Global Action Plan on the Public Health Response to Dementia was finally adopted at the 70th World Health Assembly on 30 May this year. What are the next steps?

**SS:** Much of the required action will take place within countries, including in low- and middle-income countries where the majority of people with dementia live. To ensure a comprehensive public health response Ministries of Health, WHO and civil society alike are required to take actions and work collaboratively.

WHO is carrying out a range of activities that align with the seven action areas in order to assist Member States in implementing the action plan at the national level. (see Figure).

The tools that would be made available to Member States include policy guidance, dementia-friendly initiatives toolkit, evidence-based dementia risk reduction guidelines, dementia model of care, online carer training iSupport, Global Dementia Observatory (GDO) and tools to develop dementia research agendas.

Some of these tools are already available, others are currently in preparation. WHO will work very closely with Member States and all relevant stakeholders to implement them in individual countries. Civil society like Alzheimer Europe and national associations will be important partners in this undertaking.

**AE:** Currently only 29 governments out of the 194 WHO member states have developed a plan on dementia. How will the global action plan on dementia help/support countries to develop plans?

**SS:** By endorsing the global action plan, Member States have committed to developing national strategies and implementation plans; either as stand-alone documents or integrated into existing general mental health, ageing, noncommunicable diseases or disability policies or plans, depending on their national context. The target stated in the action plan is to have dementia covered by a policy document in at least 75% of countries globally.

WHO is developing information sheets to provide practical guidance to policy makers and planners on how to develop dementia plans or effectively integrate dementia into other strategies to improve the response to dementia in the following ways:

- enhance the public health response to dementia
- advocate for dementia awareness
- implement risk reduction strategies
- improve treatment and care for people with dementia and their carers
- support information systems, research and innovation in dementia.

**AE:** How can European countries but also the European Commission support the global action plan?

**SS:** Member States can be guided by the global targets when setting their own regional and national goals and decide how these global targets should be adapted for regional and national planning processes (including data collection systems), policies and strategies. For example, Member States are called upon to develop national dementia plans; promote dementia awareness and risk reduction; create a dementia-friendly society; improve diagnosis, treatment and care for people with dementia; support dementia carers; and build information systems that are able to monitor service needs and facilitate planning for the future. Finally, Member States are encouraged to set dementia research priorities; support dementia innovation; mobilise funding; and promote research collaborations at national and international scale.

Initiatives funded by the European Commission such as the EU governmental expert group on dementia,
The global action plan also calls upon civil society organisations such as Alzheimer Europe to continue their active roles in advocacy and awareness raising, protection and promotion of human rights of people with dementia and their active involvement in all matters that concern them.\textit{Shekhar Saxena}

A road less travelled

Tania Dussey-Cavassini former Vice-Director General of the Swiss Federal Office of Public Health and former Swiss Ambassador for Global Health (2013–2017) talks about the hidden diplomatic work that is required in order to obtain the agreement of 194 Member States

At last, on May 29, 2017 the 70th World Health Assembly adopted unanimously a global action plan on the public health response to dementia 2017–2025. This is the result of the tenacity of a small group of people that includes my colleagues Dr Shekhar Saxena, Director of the Department of Mental Health and Substance Abuse of the World Health Organisation (WHO), and Marc Wortmann, former CEO of Alzheimer’s Disease International.

Diplomatic work

People rarely imagine the hidden diplomatic work that is required in order to obtain the agreement of 194 member States around one common agenda. Mobilising governments, convincing and rallying stakeholders is like a chess game that lasts for months, even years.

When 89 countries agreed to the Call for Action at the first WHO Ministerial Conference on Global Action against Dementia in March 2015 in Geneva, my colleague from an African country told me: “Tania, as long as I do not have a global action plan or a resolution from the World Health Assembly stating that dementia is an urgent public health burden of global concern that requires concerted actions by all countries, I will not be able to mobilise my own government for action. And women suffering from dementia in my country will continue to be chained to trees with the hope that the devil will leave them.”

This conversation triggered something in me. Yet when I suggested to my colleagues of the Swiss Health Foreign Policy that Switzerland should be leading the work and ask the Bureau of WHO to put dementia on the agenda of the governing bodies,
my proposal was welcomed at first with much scepticism and reluctance to act.

**Dementia on the agenda**

Still, within three months, by August 2015, Switzerland supported by 16 other States submitted its request to WHO. The bureau declared a month later, in September 2015, during Alzheimer’s month, that the topic was important but not so urgent, and that it could be put on the agenda of the 139th session of the Executive Board in May 2016. This was delaying my hopes for a resolution at the 69th WHA in May 2016. As when playing chess, you adapt your tactical moves keeping in mind your endgame objective.

In order to secure a decision at the end of May 2016 by the Executive Board that would ask WHO Secretariat to develop a global action plan within one year only, we needed to draw attention to the importance of dementia and the urgency to act. During the first four months of 2016, together with my team, we spent endless hours mobilising key Ministers of Health from all regions that would agree to call for urgent action during a side-event to be held at the 69th World Health Assembly. Each year more that 70 requests for side-events are submitted to WHO, but only 24 official side-events are granted after a tedious selection process. Our perseverance paid off. On May 22, 2016, when 14 Ministers of Health, among them Foreign Minister of Ethiopia Dr Tedros Adhanom Ghebreyesus, today the new Director General of WHO, called for a decision and a global action plan to address dementia, I knew we were getting closer to our goal.

**A draft action plan**

Later that month, on May 30, 2016, the Executive Board urged WHO to take action and requested the secretariat to develop a draft global action plan. But, it nearly failed. During the several hours’ debate, member States and the secretariat put roadblocks that threatened to jeopardize the adoption of the decision. Some member States wanted last minute changes to the draft decision that required parallel lobbying and caucusing on the spot. In addition, a person was suddenly requesting to delay the process by one additional year. I remember moving from delegation to delegation in the Executive Board room, negotiating or calling on some of my colleagues from other member States who had not taken the floor yet to demand that the draft plan of action be developed within one year. Marc Wortmann, who was speaking last as an NGO representative nailed it: “We cannot wait another year, we cannot wait that another 11 million people worldwide be diagnosed with dementia.”

Dr Saxena and his small team at WHO did outstanding work in drafting a global action plan in a record time. This document was widely welcomed during the consultation process in the fall of 2016, as well as during the Executive Board session in January 2017. Its adoption by all 194 member States in May 2017 is proof that the commitment and will power of a small group of convinced people can move mountains.

The adoption of the global action plan may be the end of a diplomatic process, but it is the beginning of action by governments. Today, member States worldwide own a tool that can guide them in their public health response to a rampant and devastating illness. Today patient organisations and Alzheimer’s associations can claim action from governments and mobilise resources for the implementation of this plan. It is now our responsibility to do one thing only: ACT.
Stefanie Becker, Director of Alzheimer Switzerland says:

From the point of view of a member of Alzheimer Europe the Global Action Plan on the Public Health Response to Dementia could be deemed very beneficial and supportive from multiple perspectives:

1. In countries currently working on their own dementia strategy or plan it strengthens the campaign/lobbying efforts towards governments.
2. In countries already having an dementia strategy or plan it further underlines the importance and the necessity to promote implementation.

The WHO announced to further advance the support of Member States by activities in three domains:

Governance:
- Providing policy guidance
- Developing the Global Dementia Observatory tool and platform

Paola Barbarino, CEO, Alzheimer’s Disease International (ADI) says:

“The adoption of a global plan marks the start of a new era for people living with dementia and their families. The plan gives us the unique opportunity to increase awareness, access to diagnosis, healthcare, support and risk reduction. It will also support our aim to ensure that each of these areas is informed and led by those living with the condition, in a way that is inclusive and empowering.

The time to act is now. By 2050 the population of older persons worldwide is forecast to more than double and, in less than a year’s time, the global cost of dementia will have exceeded that of the world’s most valuable companies at over a trillion dollars. Governments must ensure that this first step is followed by the implementation of their own plans that address each of the 7 targets adopted, and that these are backed with a clear commitment and funds tailored to the health, economic and social needs of each country.

Underpinning this effort we need a global endeavour to raise public awareness and reduce the risk of developing dementia, and to address the urgent gap in dementia research and understanding.

ADI proposes that nationally 1% of the societal cost of dementia should be devoted to funding this research in basic science, care improvements, prevention and risk reduction, drug development and public health.

Alzheimer associations everywhere are ready to support the implementation of the plan and offer a critical focal point for the future of dementia.”
A third dementia strategy for Scotland

Maureen Watt, Minister for Mental Health talks to AE about the challenges of a third dementia strategy

**AE: This is Scotland’s third dementia strategy. From your perspective which of the commitments of the new strategy have priority and what is still the biggest challenge?**

**Maureen Watt:** Scotland’s third National Dementia Strategy builds on progress over the last ten years in transforming services and improving outcomes for people with dementia and their families and carers. While there has been considerable progress in improving care and support for people since the first strategy was published in 2010, we know there is more to do. Our shared vision is of a Scotland where people with dementia and those who care for them have access to timely, skilled and well-coordinated support from diagnosis to end of life which helps achieve the outcomes that matter to them.

With a continued focus on improving the quality of care, this strategy sets out 21 commitments around work on diagnosis, including post-diagnostic support; care co-ordination; end of life and palliative care; workforce development and capability; data and information; and research.

One of the most important outcomes for this new strategy is that more people with dementia are able to live safely and with as good a quality of life as possible at home or in a homely setting for as long as they and their family wish. To this end, we will support and encourage Integration Authorities to further develop and embed home-based, enabling and preventative supports for people with dementia – supports which keep people safe and sustain quality of life at home or a homely setting for as long as possible. Such supports might include helping the individuals with dementia to attend to their other health needs such as hearing, eyesight and dental care.

There probably isn’t one single challenge which is the biggest or most important. However, at the heart of this strategy we recognise the need to ensure a person-centred and flexible approach to providing support throughout all stages of the care journey.

**AE: What lessons have been learned from the previous two strategies?**

**MW:** It is ten years since this Government made dementia a national priority for Scotland. In that time we believe we have made significant progress.

Our first strategy was published in 2010 and focused on improving the quality of dementia services through diagnosis, care and treatment. The second focused on improving post-diagnostic support and strengthening integrated and person centred support. Other areas where we believe progress has been made are in diagnosis rates, post-diagnostic support, workforce development and in improving the experience of people with dementia and that of their families and carers in hospital and other settings. This has been based on strong collaboration in developing and implementing the strategies in a coordinated way.

The key outcomes we want to see are:

- More people have increased say and control over their dementia diagnosis and are diagnosed early enough that they can take as full a part as possible in their own care planning
- More people get earlier access to good quality, person-centred post-diagnostic support in a way that meets their needs and circumstances
- More people with dementia are enabled to live well and safely at home or in a homely setting for as long as they and their family wish
- More people get timely access to good quality palliative and end of life care
- During the process of diagnosis and through all parts of the care journey, the critical input of family carers is encouraged and facilitated, and carers’ own needs are recognised and addressed
- People with dementia’s rights to good quality, dignified, safe and therapeutic treatment, care and support are recognised and facilitated equally in all care settings – at home, in care homes or in acute or specialist NHS facilities
- There are more dementia-friendly and dementia-enabled communities, organisations and institutions and initiatives

“At the heart of this strategy we recognise the need to ensure a person-centred and flexible approach to providing support throughout all stages of the care journey.”

Maureen Watt
Members of the Scottish Dementia Working Group (SDWG) and National Dementia Carers’ Advisory Network participated in a series of meetings of a national expert advisory group to ensure that their needs and aspirations were central to the development of the new strategy. 

Maureen Watt

AE: How were people with dementia and their families and carers involved in the development of the strategy?

MW: We’ve taken a consultative approach, with over 500 taking part in a series of National Dementia Dialogue Engagement Events between 2015 and 2016. We have additionally worked with experts from a range of organisations including Alzheimer Scotland, CoSLA, Healthcare Improvement Scotland, the Alliance, Scottish Care, the Scottish Social Services Council, NHS Education for Scotland, the Care Inspectorate, Integrated Joint Boards, academics and people with dementia and their carers to develop the new dementia strategy to ensure that people get the right care, in the right place, at the right time.

Members of the Scottish Dementia Working Group (SDWG) and National Dementia Carers’ Advisory Network participated in a series of meetings of a national expert advisory group to ensure that their needs and aspirations were central to the development of the new strategy. I was also delighted that Archie Noone, Chair of the SDWG was able to join me at the launch of the new strategy at a GP practice in North East Edinburgh where we are testing the delivery of post diagnostic support in primary care settings. The cooperative approach to the development of this third dementia strategy, underpinned throughout by a rights-based approach and endorsed by Alzheimer Scotland, and the Convention of Scottish Local Authorities, has been greatly valued and is vital to its future success.

AE: Since dementia became a priority in Scotland 10 years ago what have been the main achievements?

MW: Over the past 10 years, we have developed a greater understanding of people diagnosed with dementia, not least through our recent research report Estimated and Projected Diagnosis Rates for Dementia in Scotland 2014–2020. This shows that many people are diagnosed with dementia later in life and often live with other significant and life-limiting conditions.

We have introduced a guarantee that everyone newly diagnosed with dementia will be entitled to at least a year’s worth of post-diagnostic support coordinated by a named link worker;

We are continuing the Promoting Excellence workforce skills and development programme, including the development of a large suite of accessible educational resources, which has been used by thousands of staff across health and social care services, and the provision of a breadth of training programmes provided. Promoting Excellence has also been embedded in pre-registration nursing programmes.

Additionally we are embracing the principles of personalised dementia care in acute and specialist NHS dementia care settings and have successfully completed a project to test and independently evaluate Alzheimer Scotland’s 8 Pillars Model for intensive, home-based support.

We commissioned the International Consortium for Health Outcomes Measurement (ICHOM) to develop global outcomes for measuring and reporting on outcomes for people with dementia; and are coordinating the three year, second EU Joint Action on Dementia – Act on Dementia. Launched in March 2016, this work seeks to ensure collaboration among participating EU institutions to review good practice and ensure successful uptake of evidence-based approaches.

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

MW: Our leadership of the EU Joint Action Act on Dementia in involves us in cooperative working with partners from across Europe on the key area of diagnosis and post-diagnostic support, crisis and care coordination, residential care and dementia-friendly communities. The stated aim of the Joint Action is to promote the implementation in Member States of coordinated actions to improve the situation of people living with dementia and their carers. The role of Alzheimer Europe in this Joint Action is key to ensuring that the interests of people living with dementia and their carers are at the heart of this work.

There is much good practice across Europe, but there appear to be barriers to implementation. This Joint Action will seek to find out what those barriers are and how they can be overcome.

The Scottish Government also participates in regular meetings of the European Governmental Experts on Dementia. As well as commissioning ICHOM to develop global outcomes for measuring and reporting on outcomes for people with dementia, the Scottish Government also contributed to the consultation to develop the Global Plan of Action on the Public Health Response to Dementia 2017–2025 which was adopted by WHO Member States at the 70th World Health Assembly in May 2017.
Henry Simmons, Chief Executive, Alzheimer Scotland welcomes the third national dementia strategy for Scotland.

We believe that it demonstrates a long term commitment of the Scottish Government to improving the lives of people with dementia and those who care for them in Scotland.

Alzheimer Scotland along with our National Dementia Carers Action Network (NDCAN) and the Scottish Dementia Working Group (SDWG) have been key partners in the development implementation and monitoring of Scotland’s first and second national dementia strategies. As in the previous strategies we worked with the Scottish Government and other partners to hold national dialogue events, across Scotland, to provide the opportunity for people with dementia, carers, health and social care, and other professionals to inform the new strategy by telling us what is important to them. Alzheimer Scotland, SDWG and NDCAN will continue to be important partners in monitoring the implementation of the commitments set out in this third national strategy.

In 2013 the Scottish Government gave a guarantee to provide a minimum of one year’s post diagnostic support, based on Alzheimer Scotland’s 5 Pillar Model. In this third strategy, there is a new commitment to go beyond the initial guaranteed minimum of one year’s post diagnostic support. This means that people who are diagnosed earlier in the illness should be offered a named “Link Worker” who will now provide support until their needs change and they require greater care co-ordination. This also means that those diagnosed later, when they may have more complex needs and are needing support from health or social care professionals should be offered post diagnostic support our 8 Pillar Model of Community Support receive their post diagnostic support from a named Dementia Practice Coordinator from that point through to the advanced stages of the illness.

Alongside this is the commitment to test Alzheimer Scotland’s Advanced Dementia Practice Model and the focus on end of life care takes us closer to achieving our shared vision of the best possible support for people living with dementia from the point of diagnosis to the end of life.

Promoting Excellence

The ongoing commitment to Promoting Excellence (a knowledge and skills framework) and the new Allied Health Professionals framework “Connecting People, Connecting Support” adds depth to our practice base, as does the ongoing work to improve our Acute Hospitals, Specialist Dementia Units and Care Homes.

It is ten years since dementia was made a national priority for Scotland and in that time we believe that significant progress has been made. However, despite this progress much more remains to be done. The gap between the policy commitments found in all three strategies and the real life experience of many people is far too wide. We recognise that delivering the aspirations of this strategy will require local investment and commitment to make dementia a key priority for every local area.

We will do all that we can to work with local partners to deliver on this strategy and to make sure the collective voice of people with dementia, their families, carers and our members are as strong and as engaged as possible throughout Scotland.
At Otsuka, we know that disease and health know no boundaries. Today, more than ever, addressing unmet medical needs for people living with long term illness must go far beyond the conventional.

In central nervous system (CNS) disorders, there is still a lot that isn’t understood, and developing new treatments is a challenge.

Over 30 years ago, Otsuka took the first steps towards the development of a new treatment for millions of sufferers of schizophrenia and bipolar disorder. Today, this treatment is one of the world’s most widely used antipsychotics.

As a pioneer with a venture company spirit, we work with global partners to develop innovative new options in under-served areas such as Alzheimer’s disease.

We see treatment with medicines as only one part of the total care package that is needed and that we can offer. From ingestible sensors* to data analytics*, we are also exploring how digital healthcare* technology can help our patients, caregivers and healthcare professionals.

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*under development and not available yet
45,000 reasons to “get it right for people with dementia in Wales”

Wales’ first dementia strategy is a historic step forward and an enormous opportunity to improve the wellbeing of people affected by dementia in Wales. Ed Bridges of Alzheimer’s Society Cymru welcomes the progress made to date and the ambition of the Welsh Government to create a dementia friendly Wales.

In January 2017, the Welsh Government launched a consultation on the draft of Wales’ first ever dementia strategy. It sets out actions over the next five years and will be reviewed and refreshed after three years to ensure it remains relevant and appropriately targeted.

The Welsh Government wanted to make sure that as many people affected by dementia from Wales could be involved in the development of their first dementia strategy. Therefore when Alzheimer’s Society Cymru was informed about the proposed dementia strategy in 2016, a proposal was made to deliver a variety of engagement events throughout Wales to ensure that the development of the strategy echoed the needs of people affected by dementia in Wales worked in collaboration.

Alzheimer’s Society Cymru worked in collaboration with DEEP (the dementia engagement and empowerment project) to ensure people with dementia had a voice in the development of the Wales dementia strategy.

The consultation saw events being held across Wales in two phases between October 2016 and April 2017, to inform and then respond to the draft strategy. The events allowed people affected by dementia to share their experiences and outline their priorities. Their views were summarised into a report for Welsh Government “The views of people affected by dementia about the emerging Wales Dementia strategy.”

Alzheimer Society Cymru campaigning outside the Welsh Assembly

Ed Bridges

Otsuka: Proud to take the road less travelled

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How Alzheimer’s Society Cymru developed the two consultation responses:

- Jointly facilitated ten consultation events for people affected by dementia in Wales;
- Ran an online survey eliciting nearly 550 responses (predominantly from carers and family members of people with dementia) on the draft strategy’s proposals;
- Held specific consultations with underrepresented communities;
- Supported two meetings of the Welsh Assembly’s Cross-Party Group on Dementia which saw attendance from a range of people living with dementia from across Wales and allowed them to contribute their thoughts on the proposals;
- Supported six people affected by dementia to give evidence and share their stories with the Welsh Assembly’s Health, Social Care and Sport Committee during their inquiry into the draft dementia strategy;
- Had detailed discussions with Alzheimer’s Society Cymru’s own Service User Review Panels across Wales and incorporated comments from many of our own service users, their family and friends and Alzheimer’s Society Cymru staff.

In addition, Alzheimer’s Society Cymru consulted extensively with a wide range of partner organisations and set out key areas where there was consensus over how a strategy should drive change.

The most common themes as reflected by people affected by dementia included:

- The call for a referral and diagnostic pathway which is consistently used and monitored across Wales.
- A call for GPs to have education about the benefits of an early diagnosis, including the impact of delaying a diagnosis.
- The need for a key point of contact for people affected by dementia to provide information and support, including signposting, from the point diagnosis.
- Support services to be open to people going through the dementia diagnostic pathway, to prevent crisis situations when a diagnosis is received, including pre and post diagnostic counselling for all people affected by dementia.
- People affected by dementia to be aware of their rights as an individual and how these rights can support challenges over finances, respite and employment.
- Peer support groups and user involvement opportunities to be recognised as forms of valuable support for people affected by dementia and for them to be resourced and sustained across Wales.
A roll out of information and support hubs across Wales, to ensure engagement and support for the general public and people affected by dementia in both urban and rural areas across Wales.

Carers and wider family support networks to be recognised in their own right and for their needs to be assessed and supported by adopting a person centred approach.

Respite services for people affected by dementia, including their carers and wider family support networks to be flexible and not limited to residential care.

Dementia friendly communities to be sustained as a way to raise awareness and help break down stigma, but for the approach to be refined and based on local need, including the involvement of people affected by dementia to inform and make decisions on what constitutes a dementia friendly community.

Greater education about and awareness of dementia, with particular priority given to staff in health, social care and the third sector.

A holistic support plan, where support is informed and given by therapies such as speech and language, nutritionists, occupational therapists and psychologists.

Dementia awareness, support and information to be inclusive of people from the BAME, LGBT+, and other minority communities, including better engagement to understand their needs and priorities.

A palliative care and end of life care pathway to be established for people affected by dementia.

Improving diagnosis rates

Improving access to Dementia Support Workers

Greater training for health and social care professionals

More attention to be given to the specific needs of people with young onset dementia

Ensuring that the dementia strategy reflects the needs of the widest possible range of people with dementia, including:

First language Welsh speakers

People in rural areas

People from LGBT (Lesbian, gay, bisexual and transgender) groups

People from BAME (Black Asian and Minority Ethnic) and GRT (Gypsy, Roma, traveller) communities

People with disabilities and sensory loss

People living alone.

One of the recurring themes from the consultation events and engagement with stakeholders was that the draft strategy draws too much from the “medical model” of dementia. Alzheimer’s Society Cymru believes the dementia strategy could reflect the wider social needs of people living with dementia not simply the narrow medical approach. More broadly there needs to be better understanding by providers of the social model.

It is heartening to see dementia being recognised as one of the most significant health and social care issues we face. Initially the strategy was due to be published in May 2017; however due to the extensive and detailed consultation on the draft strategy, the Welsh Government want to take into account comments and submissions so it is now expected to be published in the autumn.

Next Steps

Alzheimer’s Society Cymru look forward to working further with the Welsh Government and other partners – in particular, people affected by dementia – as part of any group overseeing the strategy’s implementation and delivery. We also believe that there is a huge opportunity during the next three years prior to the strategy’s refresh for a wider conversation to happen with people from across Wales affected by dementia to feedback on the strategy’s impact on the ground. The consultation events which helped to inform the strategy demonstrated that there is a largely untapped resource of experts across the country who have strong and constructive views on how support and services could be improved. We must listen to them.

“This strategy means service and health authorities will have a better idea of what support we require and need it will also be a guide to help stop the post code lottery of the provision of services. We have a right to care, support and relevant services; this strategy will help with access and achievement. Well done Wales for developing a co-produced rights based strategy, inclusive of the very people it is written for.”

Chris Roberts, Living with Dementia
Living with dementia in Europe – a look at national dementia working groups

We asked each of the five national dementia working groups currently in Europe to introduce itself, and asked one or more members of the group to tell us about their involvement. We start with the Scottish Dementia Working Group, which was the first such group to be formed (2002) and which continues to inspire others.

Scotland (2002)

The idea for the Scottish Dementia Working Group came about in 2001, when James McKillop, who was diagnosed with vascular dementia in 1999, met social researcher Heather Williamson and had a discussion about why no group existed to be the ‘voice’ of people with dementia in the same way that there was for carers and for professionals.

The group was formally established in 2002 when a constitution was agreed and James McKillop was elected as the group’s first Chairperson. The members at this time agreed to accept an invitation from Alzheimer Scotland to receive support and come under their umbrella, rather than forming an entirely separate organisation. This arrangement continues to this day, with the group enjoying a positive and close relationship with Alzheimer Scotland while remaining an independent voice within the organisation.

Throughout the following years, the membership of the Scottish Dementia Working Group continued to grow and more funding allowed for an increased staff team to support the work of the group. Today, the group are supported by seven members of staff (all part-time): two Joint National Coordinators, a team of four Development Officers and an Administrator. These staff support a committee of twelve and a wider membership spread out across Scotland.

Membership of the Scottish Dementia Working Group is open to anyone in Scotland with a diagnosis of dementia. The group’s remit is to be the voice of people with dementia in Scotland and to campaign to challenge stigma and improve public services. The group enjoy great influence in Scotland, meeting regularly with the Scottish Government’s Mental Health Minister and having a seat at the table for high-level discussions and decision-making, for example during the development of Scotland’s new National Dementia Strategy.

Although the SDWG are a campaigning group, there is an awareness that people can have their voices heard in different ways and so some members, for...
example, like to give presentations and take part in filming, while others take part in different types of activity such as smaller meetings or social media and blogging, amongst other things.

The group regularly review their campaigning priorities in order to focus their work and the current work plan details four main priorities of: Diagnosis, Post-Diagnostic and Continuing Support; Supporting a well-trained workforce; Building the capacity of SDWG; and Working in Partnership: Local, National and International. The group have made great progress with these priorities in the past year. For example, members lobbied their local council candidates during Scotland’s May 2017 election around these issues, successfully persuading many to sign up to Alzheimer Scotland’s election pledge. Members have also been involved in a lot of staff development activity for professionals working in the field of dementia, as well as taking part in our own SDWG training programme where our committee have increased their knowledge and understanding of different types of dementia as well as the issues facing the LGBT community when it comes to dementia and support services.

The group now enjoys a large membership across Scotland and a busy schedule throughout the year. SDWG members are currently working on a variety of projects, including Chair Archie Noone who is preparing to present at Alzheimer Europe’s annual conference in Berlin this October on the group’s work with Alzheimer Scotland Occupational Therapy interns.

The Scottish Dementia Working Group continues to go from strength to strength 15 years after its official formation, providing great and diverse opportunities for members and being a strong and influential voice for people with dementia in Scotland.

Carol Hargreaves, member of the SDWG (and the EWGPWD), tells us about herself and her involvement in the group

“I joined the Scottish Dementia Working Group in 2014 and became Vice-Chair in 2016. Getting my diagnosis was a horrific experience: I was alone without any family and was told to ‘get my affairs in order’ and to come back in six months. My husband and family were told to keep a close eye on me and I felt that they wrapped me up in cotton wool, which led me to feel very down and depressed. Luckily things have changed since then and I am now very independent and love my life.

Getting involved with SDWG changed my life. It gave me a new life, a better one – and my family can’t believe the change in me. I’ve met lots of new friends and I found that I did have a voice. Most importantly, I feel like I am making a difference for the next generation.

We campaign for so many things. My favourite activity with the SDWG is our I.T. classes; it proves we can still learn with dementia. I love learning how to use an iPad. Our group gives lots of presentations and has meetings with lots of different people to challenge stigma and show that you can live well with dementia.”

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Netherlands (2009)

The Working Group (landelijke kerngroep Alzheimer Nederland) started in 2009. A group of 6–8 people with dementia joins together 5 times a year and talk about issues such as diagnosis, relationships, day time activities and driving. At the moment, Henk van Pagée, Dick Rijksen, Moniek Bloemen, Dick Zeelenberg and Henk van Leest participate in the group. Their spouses are also very welcome and an Alzheimer Nederland volunteer attends to the spouses in a separate conversation. Once a year, there is a working visit to a project for people with dementia. Past annual visits have included a museum, a nursing home, a farm and a bee-keeper.

The main goal of the group is to be open about dementia and to respect the points of view and needs of people with dementia: “Speak with me, instead of speaking about me”. We share the outcomes of the discussions on the Alzheimer Nederland website, in articles, magazines, newspapers, in politics (national and local) and on social media. In this way, we influence policy makers, public and society on the perspective of people with dementia: about their needs, feelings and thoughts.

Henk van Pagée talks about his involvement in the landelijke kerngroep

“I experienced a culture shock when I got the diagnosis, but I decided I don’t want to be a victim. I want to see my life as a challenge, despite the dementia. I started as volunteer at Alzheimer Nederland and joined the Kerngroep in 2014. First of all,
I found fellowship in this group. We have great conversations and often have a good laugh. I want to show the world that there is another point of view, a positive view, of dementia. So my “Alzheimer career” started: I spoke at a European congress in 2016, I spoke to members of the Dutch Parliament in Den Haag, I give guest lectures, I have been interviewed for magazines and so on. I have even heard it said that you can live according to the “Henk van Pagée-format”. That’s nice, isn’t it?

There is still a taboo around dementia. Sometimes I say: “Oh sorry, that’s my dementia”, or I say “You may laugh”, because I want to relativise my mistakes, the gaps in my cognitive brain and, hopefully, I break the taboo with a smile.”

Henk helped come up with the group’s five “cries of the heart”. These “cries”, written from the viewpoint of people with dementia, aim to emphasise some important things to consider, when communicating with them.

1. Focus on what I still can do
2. Speak with me
3. Give me clear information
4. Think along with me
5. Let me participate and enjoy.

“At this time, I am assisting in the national Dutch campaign ‘Dementia friendly society’. My message is: I want to live my life, but you can give me a little support by asking: ‘Can I be of any assistance to you?’”

Ireland (2013)

The Alzheimer Society of Ireland (ASI) established the Irish Dementia Working Group (IDWG) in early 2013. The purpose of the Working Group is to explore ways to promote and encourage the direct involvement of people with dementia in the work of the ASI and to ensure that the voice of people with dementia has an outlet to influence the public policy that impacts on their lives.

The IDWG grew its roots when a small number of people living with dementia came together in 2012 to inform the ASI submission on the development of Ireland’s first National Dementia Strategy.

In early 2014, the Working Group took another giant leap in its development when the members appointed Helen Rochford-Brennan as the first Chair and since then, the group has taken great strides in terms of governance and setting priorities.

As an organisation, the ASI has used the expertise of the people on the Working Group to support discussion and debate around important issues for others living with dementia.

Members of the IDWG have also been the key drivers and faces of a number of campaigns including a pivotal nationwide effort in 2015, “Forget the Stigma”.

Another significant event for the IDWG was the launch of Ireland’s first National Dementia Strategy at the end of 2014. Members had campaigned...
for this and continue to play a critical role in its implementation.

In April 2016, the ASI and the IDWG published “A Charter of Rights for People with Dementia”, which called for greater participation, accountability, equality, empowerment, and legal recognition for the rights of people with dementia and was launched by former President of Ireland and UN High Commissioner for Human Rights Mary Robinson.

There are a number of key factors which have allowed for the success and ongoing development of the IDWG, but most important has been the leadership, commitment and openness of the people that are involved.

Each member has brought their own unique skills and experiences which they are very willing to share. As an organisation, the ASI is very privileged to work with such an extraordinary group of people and we are very proud of all that they have achieved.

Ronan Smith, Chair of the IDWG, talks about his journey with Alzheimer’s and his work with the group

“This is actually my second Alzheimer’s journey. Back in 1980s Ireland, I was a carer for my father when he went through his own Alzheimer’s journey. During this time, I first engaged with the Alzheimer Society of Ireland (ASI), seeking help, assistance and information initially, but quickly moved on to becoming involved in campaigning and advocating for better services for people with dementia.

I joined the small, entirely voluntary committee with no paid staff, which ran the ASI at the time and saw in the appointment of the first salaried executive. After another two years on the committee, I resigned and got on with my life, which was then busy with a young family and work.

It transpired that Alzheimer’s disease was not finished with me. After a number of watchful years during which I was growing increasingly suspicious, I felt sufficiently concerned to seek a diagnosis and in 2014 I received a positive result of genetically confirmed Familial Alzheimer’s Disease.

I immediately re-engaged with the ASI and committed to advocacy work to improve awareness, understanding and better services. This work is hugely important to me: firstly, to contribute to helping achieve improvements, and secondly, to keep me active, motivated, and engaged in the world. It makes me feel I am wrenching some good from a bad thing.

I have recently been appointed Chair of the Irish Dementia Working Group (IDWG), a small body of people living with the condition who give time and effort into supporting the professional staff of the ASI in their work. I have the unenviable task of following in the footsteps of Helen Rochford-Brennan, who has been an excellent Chair for the last three years.

An equally important function of the IDWG is to be a sounding board for discussing new proposals for action being considered by the ASI. This is a truly win-win relationship, and models a potential kind of engagement between people living with dementia and the wider population.”

Timeline of key events for the Irish Dementia Working Group

2013
Irish Dementia Working Group established

2014
Helen Rochford-Brennan is appointed as the Group’s first Chair

2015
Group takes part in a nationwide campaign “Forget the Stigma”

2016
Ireland’s first Charter of Rights for People with Dementia is launched

2017
The Irish Dementia Working Group hosts its first election for Chair and Steering Group

“This work is hugely important to me: firstly, to contribute to helping achieve improvements, and secondly, to keep me active, motivated, and engaged in the world. It makes me feel I am wrenching some good from a bad thing.”

Ronan Smith

The IDWG 2016 (Ronan Smith, third from the right, back row)
Finland (2013)

The Finnish national dementia working group Memory Activists was founded in 2013. In the Finnish model, the members of the group are both people with dementia and family members. The group brings forward together the expertise gained from first hand experiences with memory diseases and supports the work of the Alzheimer Society of Finland (Muistiliitto), as well as and highlighting important themes, ideas and views which could otherwise be overlooked.

- The group meets four times a year
- The members are selected based on recommendations from our local associations
- In practice, the group has:
  - influenced to the Alzheimer Society of Finland so, that for couple of years we have had a person with diagnosis as an advisor to our board of directors
  - given ideas and written articles to our quarterly “Memory” magazine. One of the Activists is in the editorial board of the magazine
  - voiced concerns over for example the insufficient services for the people with early onset dementia and the role of people with memory disorders in society
  - given opinions and advice to all our development projects and commented many materials and publications
  - given speeches and interviews around Finland
- We have started a process to build local activist groups in each of the 18 regions of Finland.

Some Memory Activists tell us more about themselves and about the work they do

Petri Lampinen got his diagnosis of frontotemporal dementia in 2015, when he was 52 years old. He has been a Memory Activist since 2016.

“Being an Activist has been very meaningful and rewarding”, Petri says. “This activity has given me an opportunity to meet people, network and make people more familiar with frontotemporal dementia especially from the perspective of those of a working-age.”

Petri has gained a lot of positive publicity and feedback by talking about his disease openly and spreading information. “It has been a good way to decrease stigma”, he says. In his local memory association, he has been involved in planning dementia-friendly services.

Juha Lehtinen got his Alzheimer’s disease diagnosis in 2011 and has been a member of the Memory Activists for couple of years. In addition, he has been a support worker himself. Juha and his wife are educated volunteers called “memory buddies”.

Juha knew Alzheimer’s disease well when he got the diagnosis, as his mother had it previously. Becoming a part of the Memory Activists has given him even more information and a chance to share it. However, he thinks the group should accomplish even more and he also finds it difficult to make a difference at national level: “I’m worried about the future of the services and the situation in small municipalities”, he says.

Liisa Kinnunen, a retired photography studio owner, is one of the founders of the Memory Activists. Liisa’s husband had Alzheimer’s disease and getting involved in the Memory Activists was a good way to get information while she was taking care of him at home.

After Liisa’s husband passed away, she wanted to continue to help people with memory diseases and their families. She thinks the group does important work, for example by speaking out and standing up for the rights of persons with memory diseases, as well as influencing attitudes: “Memory diseases are like any other diseases”, she reminds us.
Norway (2014)

With inspiration from the Scottish Dementia Working Group and the European Working Group of People with Dementia, the Norwegian Health Association established a working group of people with dementia, in 2014. The group meets four times a year and consists of eight people with dementia and their carers. Together they provide the organisation with advice based on their experiences of living with dementia. The group has been involved in the development of the organisation’s health policy, on-going projects and information brochures, as well as awareness-raising activities. The members of the working group are experts on dementia; and by meeting and discussing issues of importance to both them and the organisation, they contribute to increased openness and public understanding about dementia.

By listening and acting on the views of the working group and placing it at the heart of our organisation, we are able to make a strong case for involving people with dementia among our partners, which include local authorities and government departments. Therefore, the group strengthens our organisation and legitimacy.

In the long term, our aim is to establish more working groups in some of our local branches. We have already established one local working group in the northern part of Norway, in Bodø.

Alv Orheim, member of Norway’s dementia working group (and Vice-Chair of the EWGPWD), tells us about himself and his involvement in the group:

“I was diagnosed with vascular dementia in 2009 and for a few moments I was knocked out. Me, only 62 and still active and working! How could that be?

My wife helped to bring things into perspective. We shall be open about your condition. We will go about our daily life much the same as before, doing the things we like, and what we would have done regardless of the diagnosis. Eat well and keep physically active.

This attitude eventually took me to my first meeting with the Norwegian Working Group in May 2014, not long after the group was established.

To be a member of this group has meant a lot to me and my family. It has given both purpose and direction to my everyday life, when I had to stop my work as an advisor on geological matters. It enables me to continue to contribute to society for an important cause, and to stay informed about dementia care issues, research and policy. It is also good to meet with other persons in a similar situation and to know that, together, we play an important part in improving dementia care.

The Working Group gives advice and input to the Norwegian Health Association on matters that relate to their dementia strategy and related projects. For me, I think the most important work we have done was to take part in the development of Norway’s second national strategy on dementia, which was acknowledged in December 2015.

I have given presentations, interviews and talks in many different settings, in order to raise awareness about living with dementia and about shortcomings in dementia care, the same as other members of the group. When people have told me they have found my presentation eye-opening, I feel my time has been well spent.

There is still a lot of work to be done. I’m grateful that the Norwegian Health Association works so well with our Working Group. Together, we can continue to improve dementia care and research.”

“To be a member of this group has meant a lot to me and my family. It has given both purpose and direction to my everyday life.”

Alv Orheim
Snapshots of national working groups

Irish Dementia Working Group at Human Rights launch, April 2016

A recent Memory Conference with some of Finland’s Memory Activists in the audience, and Helga Rohra, EWGPWD

The Landelijke kerngroep Alzheimer Nederland, September 2017

The Scottish Dementia Working Group hard at work, 22 June 2017

The Scottish Dementia Working Group at Christmas

A meeting of the Scottish Dementia Working Group

Southern Dementia Working Group, Ireland, June 2016

Local group in Bodo, Norway

Forget the Stigma campaign launch, Ireland

Norwegian dementia working group meeting
Association Luxembourg Alzheimer celebrates its 30th anniversary

Association Luxembourg Alzheimer (ALA) has 30 years’ experience in the field of dementia and is celebrating with a series of events throughout 2017

The Association Luxembourg Alzheimer (ALA) is a specialised care and support organisation for people with dementia. Since our beginnings in 1987, we have been committed to advocating for people with dementia and their families, both nationally and internationally.

Our various care structures – six daycare centres and one residential care home – allow us to offer people affected by dementia all the benefits provided by the long-term care insurance system in Luxembourg.

With 30 years of experience, we consider our organisation to be an expert in the field of dementia. The guiding principle underlying each of our actions is respect for the dignity and uniqueness of human life. Our top priority is to provide people with dementia and their families the best possible quality of life and maximum personal well-being.

As an association, ALA also offers many other types of assistance that go beyond the benefits provided by Luxembourg’s long-term care insurance. Since February 2017, for example, we offer a help and home care service called ALA Plus.

Overview of Areas of Activity

- Advice and support
- Day care
- Residential care home
- Continuous training for relatives and professionals
- Awareness-raising
- Emergency assistance
- Self-help groups
- Home help and care service
- Ethics Committee
- Alzheimer Café

Triple anniversary celebrations

In 2017, ALA is celebrating not only its 30th anniversary, but also the 25th anniversary of the Fondation Alzheimer and the 10th anniversary of its residential dementia care home “Beim Goldknapp”. This triple anniversary is being marked with a series of events and celebrations. For the occasion, we have set up a rich and varied programme aimed at the general public, professionals and relatives of people affected by dementia, including seminars, an art festival and an open house event, among others.

Past events

16 March – Seminar for families: “People with dementia and their loved ones – How to cope”

As an advisor and a diagnostician, Professor Sabine Engel has often met people with dementia and relatives who have been able to manage their situation through targeted support, training and counselling. It is these services and their effects on the persons concerned that Prof. Engel aimed to explain and analyse during this seminar.

26 April – Seminar for professionals: “Dementia in training – Where are we now?”

This seminar took stock of the situation in Luxembourg and explored whether training really prepares professional for the practical reality faced in the field, as well as looking at whether professionals (educators, caregivers ...) are sufficiently trained to ensure the best possible support for people living with dementia and their relatives.
ALA had the pleasure of presenting works made by people affected by dementia at the “Konstfestival” on 23 June 2017 in the town of Lellingen, in the north of the country. Under the theme “Art makes us visible,” the exhibition invited visitors to take a fresh look at people with dementia and at what they are capable of.

21 September – 10th anniversary of the “Beim Goldknapp”


22 September – Open House

The “Beim Goldknapp” residential care centre opened its doors to visitors, to showcase what it offers residents with dementia – an environment fully adapted to their needs. It also demonstrated the concepts of management used by the ALA.

23 September – Memory Walk 2017

This annual, international event is organised by Alzheimer’s associations around the world, on the occasion of World Alzheimer’s Day. Memory Walks aim to raise public awareness, as well as funding, and this tradition is observed every year by the ALA.

Upcoming events

18 October – Seminar for people affected: “Let’s give the floor to specialists in dementia”

Many studies have analysed the reactions triggered by a diagnosis of dementia and revealed very clear differences. Some people isolate themselves and deny their illness, while others speak about it publicly. Sometimes, the reactions of a person with dementia’s entourage can also lead to complications for them. Others’ lack of understanding and knowledge, and rejection by society can often lead to isolation and further hardship. This seminar will give the floor to dementia specialists, that is to say, to those affected by dementia themselves. They will talk about their feelings and how they manage their fears and frustrations.

25 October – Presentation of the ALA concept and workshops

Our priority is to offer people with dementia and their families the best possible quality of life and maximum personal well-being. During this seminar, three therapeutic methods will be presented by the ALA: “Richard’s Integrative Validation”, “Jaques-Dalcroze’s Rhythmic”, and Art Therapy.

29 November – Academic session

To close its 2017 celebrations, ALA is organising an academic session, in the presence of many of its public and private partners.

For further information

Association Luxembourg Alzheimer (ALA)
T. 26 007-1
info@alzheimer.lu
www.ala.lu

A limited edition 30th anniversary stamp

To celebrate its 30th anniversary, the ALA issued a postage stamp in collaboration with the national POST. With a face value of EUR 0.70, the limited edition stamp was printed in 150,000 copies.

Right: Denis Mancini, Jules Geisen, Lydie Diederich at the launch of the 30th anniversary postage stamp
Portugal’s Memory Cafés

Portugal has embraced the phenomenon of the “Memory Café” (a.k.a. Alzheimer Café) and has a steadily-growing network of these around the country. Alzheimer Portugal’s new Chairperson, José Carreira talks to us about his involvement in this project, and tells us a bit about himself and his role.

Memory Cafés started in Portugal as a pilot project in April 2013. At the time, we were not sure how this concept was going to be welcomed by our society. Four years later, we can say that it’s a well-known service for Portuguese people with Dementia and their caregivers.

After opening the first two Portuguese Memory Cafés, the first milestone was to address a request from a very important Portuguese charity (Santa Casa da Misericórdia de Lisboa) to replicate this initiative, by opening two more Memory Cafés in Lisbon in 2014.

Since then, the expansion of the project has been happening at a steady pace and in various parts of the country, working with local support such as municipalities and third sector organisations, as well as with the support of several companies from the business sector. There are currently 14 Memory Cafés in Portugal belonging to a network counting more than 50 partners.

One of these Memory Cafés is located on Madeira Island and has been operating since October 2016. This location is particularly important for us because many projects that aim to have a national scope do not include Portuguese autonomous regions. It was also at this Memory Café that we had recently the privilege of hosting Idalina Aguiar, member of the European Working Group of People with Dementia, who spoke about her experiences.

Since the beginning, a crucial feature of the project is volunteering. We have already trained about 400 volunteers who have dedicated nearly 10,000 hours of their time to Memory Cafés and have become ambassadors for dementia awareness in their communities. With regard to volunteering, we think that the most important success factors are specific training, evaluation meetings and coaching. Our goal is that the project contributes to the personal growth and social transformation of those involved.

Another positive aspect, highly valued by participants, is the presence of experts in some of the sessions, who address specific issues concerning dementia. This goes for members of the public also, who share their important testimonies as informal caregivers.

Despite the informal setting of Memory Cafés, the sessions are always led by two health or social care professionals. Until now, close to 40 professionals with dementia training (psychologists, occupational therapists, nurses, social workers, etc.) have been involved. They have all commented that they feel more fulfilled and more empowered to interact positively with people with dementia and their caregivers and families thanks to their experiences in the project.

This year, we look forward to another important milestone, presenting the results of our research study on the impact that attending Memory Cafés has on caregivers and volunteers’ lives, at several international scientific events.

In the future, we intend to continue the project’s geographical expansion and hope to reach the goal of 20 Memory Cafés in Portugal.

José Carreira

“Memory Cafés are an excellent example of what we are doing to combat stigma and social isolation, and to raise awareness in the community, regarding the challenge of dementia.”

José Carreira
Interview with José Carreira, Chairperson of Alzheimer Portugal

AE: Tell us a bit about yourself and why you are working for Alzheimer Portugal
José Carreira: I had been a teacher (graduated in Portuguese and History from the Portuguese Catholic University), but I have dedicated the last few years to social issues, including minorities and citizenship and the administration of non-profit organisations.

My particular motivation in helping people with dementia and carers comes from a visit I made with a friend of mine, in 2008, to the CRE (Centro de Referencia Estatal de Alzheimer) in Salamanca, Spain. There, I was introduced to the centre’s training coordinator, Victor Dominguez Ortiz and I came to understand the real challenges of promoting a better quality of life for people with dementia, and the importance of high-quality care and intervention.

I felt the need to get some theoretical knowledge about this issue, so I decided to study for a Master’s degree on Interventions for persons with Alzheimer’s disease, at the Faculty of Medicine of the University of Salamanca

Despite not having anyone in my family living with dementia I am committed to this cause since this time and I really want to contribute, via team work (people with dementia, families, associates, board colleagues and staff) to help promote a better quality of life for people with dementia and their carers.

I am from Viseu, in central Portugal, where together with Alzheimer Portugal, I have founded a centre for people with dementia and their families. I also coordinate the local Memory Café there and organise the annual Alzheimer Portugal Memory Walk in my home city. This is how I became involved with Alzheimer Portugal.

AE: What does your new role as Chairperson involve?
JC: My new role as Chairperson of the only nationwide organisation existing in Portugal, to promote a better quality of life for people with dementia, involves great responsibility and a heavy workload, both in the daily running of the organisation (centred on the delivery of services such as a nursing home, home services and day-care centres), and in developing awareness campaigns, as well as lobbying at national and local levels. It is a very challenging job.

In the framework of the European Movement on Dementia, we continue to fight for a national dementia plan, focused on three main areas: care, research and legal rights.

We are committed to making dementia a national public health priority and to fight the stigma surrounding dementia, which we do by following the recommendations of both Alzheimer Europe and the WHO.

In this vein, we are preparing, with the support of the UK Alzheimer’s Society, a Dementia Friends campaign, which we hope to launch early in 2018 – Alzheimer Portugal’s 30th anniversary year.

AE: The network of Memory Cafés is growing every year, it seems. How important are these events for people living with dementia and their families in Portugal?
JC: We are focused on promoting better quality of life and Memory Cafés are an excellent example of what we are doing to combat stigma and social isolation, and to raise awareness in the community, regarding the challenge of dementia.

A place where people feel safe, understood, involved where they can share their experiences in an informal environment, and create and strengthen friendship ties – all of this is absolutely fundamental to fulfilling and active participation in the community and in life in general.

We are all delighted with the meteoric rise of Memory Cafés in Portugal, where at the moment there are 14, with 2 more on the way shortly.

Our next goal is to have more Memory Cafés, not only in the larger cities and town near the coast, but also in some of the more hidden away, less accessible places, with smaller populations.
Involving people with dementia in Danish folk high schools

“It was the best week of my life – at least as far as I remember it”. “You are the best friends I ever had” – People with dementia commenting on participating in Danish folk high school courses

Since 1844, Danish “folk high schools” have offered residential courses on history and culture for young people, based on dialogue and mutual learning in a supportive social atmosphere. Originally, folk high schools were founded to give the peasantry a higher educational level to enable them to be active participants in the modern Danish state. The folk high school was and is “a school for life” with a focus on personal growth and enlightenment rather than formal education and exams.

Tailoring folk high school pedagogy for people with dementia

Recently, the folk high school pedagogy has been developed in Denmark in two new ways for people with dementia in the early and middle stages, living at home.

One was developed by the Danish Alzheimer Association (Alzheimerforeningen) as week-long courses at different folk high schools and was evaluated in 2014. The idea of offering ordinary high school courses came from the people with dementia themselves. The Danish Alzheimer Association asked a group of people with dementia what they would like to learn in a course on dementia. Contrary to expectations, they did not want to learn more about the dementia diseases or receive new advice about living with dementia. They wanted to participate in a real folk high school course like they had enjoyed in their youth.

The second, “Højskoledage” (A day at the folk high school) was developed by a local branch of the Danish Alzheimer Association, Alzheimerforeningen Østjylland, and consisted of activities for a group of seven participants with dementia, once a week for six months, at a former seaside hotel.

In both the week-long courses and the weekly course there were activities adapted to the abilities of the people with dementia, including lectures on subjects suggested by the participants, physical exercises indoors as well as outdoors, relaxation, singing, dancing and telling stories, as well as different art and creativity activities. For some, a new challenge; for others, skills long forgotten; for all, days of joy and togetherness.

Encouraging solidarity, support, personal growth

The pedagogy of Danish folk high schools stresses values such as solidarity and support in social groups, where living and experiencing together is the basis for personal growth. In the context of care for people with dementia this offers a perspective of hope and change rather than despair.

In both projects, participants experienced feelings of togetherness and confidence, as well as acceptance and acknowledgement from each other and from therapists and staff. The participants were able to help and share responsibility for what happened in the social groups. Their relatives got a much-needed break and some time for themselves, in

“There is common ground for recognition, enjoyment and sharing of values, and having dementia is no obstacle to being a contributor to that conversation.”

Bertel Haarder, MP
Areas of personal growth for the participants living with dementia could be described using values from folk high school pedagogy: Participation and engagement in social groups, confidence in communication and actions, and feelings of happiness and pleasure when participating in activities. “Flow experiences”

For some participants, the art and creativity courses created moments of complete involvement in the task at hand and oblivion to the world around them, so-called “flow experiences”. One participant with a history of creativity skills but now with severe communicative and spatial handicaps experienced acknowledgement from the others, because he was able to create works of art with the help of the therapist, who provided structure, minute guidance and encouragement throughout the process. Another participant said, “Singing in the gospel choir was fantastic. I didn’t know I could sing, but I could. I sang with my whole body (…) This was my best experience”.

Looking ahead

The knowledge gained from both the week-long and the weekly courses is important for the continuation of current courses and for the implementation of folk high school pedagogy in new settings of dementia care. The week-long courses are developed and implemented at two different folk high schools (Gerlev Idrætshøjskole and Brandbjerg Højskole) every year. Weekly courses are developed by local branches of the Danish Alzheimer Association, in cooperation with local municipalities, church groups and voluntary organisations.

Bertel Haarder, MP

Bertel Haarder, MP, former minister and high school teacher was the son of two folk high school teachers and grew up living with them at the school. He commented:

“Feelings of togetherness and personal growth are indeed core values of the folk high school pedagogy. Recognising and reliving important aspects of shared culture (for example, singing beloved Danish songs) in a warm, supportive atmosphere are meaningful activities for people with dementia. Caring for the mind and soul is as important as caring for the body, and must not be forgotten. Participation in shared culture is not only important for the people with dementia themselves, but also for the interaction between them and their relatives. There is common ground for recognition, enjoyment and sharing of values, and having dementia is no obstacle to being a contributor to that conversation.

Danish folk high schools are open to society and attract young and old, healthy and frail people alike to their courses. It is a tradition, which is now attracting European interest. But support for people with dementia and their relatives, by offering activities involving shared culture is not a Danish speciality. Caring for people with dementia in Denmark has a mostly secular basis, whether it is done by public employees or volunteers. Many countries in Europe offer activities based for example in local, religious communities.

It is important to share views on engaging people with dementia in meaningful, cultural activities with respect for diverse ways to do this.”
Is more better?
The major finding of this US study by Dougherty and colleagues is that in healthy young-old adults (their mean age was 63 years) „moderate“ but not „light“ levels of physical activity measured by accelerometers over one week was associated with increased brain glucose metabolism assessed with positron emission tomography. It is important to note what “light” and “moderate” activity means in this study. Examples for the former are dishwashing and vacuum cleaning, examples for the latter are taking a fast walk or lawn mowing. Sports was not involved in this study. Since reduced glucose metabolism in certain areas of the brain is a hallmark of Alzheimer’s disease, the authors conclude that more intense physical activity may confer the most advantage to combat Alzheimer-related brain changes. In short: more is better.

This study has not been designed to demonstrate that physical activity actually prevents the buildup of Alzheimer’s disease or its clinical manifestations. However, quite a number of prospective longitudinal studies have examined the relationship between physical activity and cognitive outcomes. The majority of these studies have shown that physical activity is associated with a lower risk of cognitive decline or dementia. Since the level of physical activity has been self-selected by the study participants, is closely linked to educational and cerebrovascular risk factors for dementia, and decreases many years before the onset of symptoms, these investigations do not prove a causal relationship. However, at least they suggest that physical activity should be encouraged in midlife and even in old age.

But which intensity is appropriate? Systematic reviews and meta-analyses on the association between physical activity and cognitive decline do not provide a clear answer to this question. It seems logical that in order to increase the brain’s resilience against pathological changes that ultimately lead to cognitive decline and dementia, physical exercise must impact on brain structure or function. There is ample evidence that physical activity indeed has significant effects on the volume, structural integrity, functional connectivity and task-related activation of relevant parts of the brain. These biological repercussions have been achieved with “aerobic” levels of physical activity. This means at least 30 minutes on 5 days a week of exercise that significantly increases the heart rate, as it is generally recommended for older adults. Thus, taking a walk or lawn mowing may not be enough to maintain heart and brain fitness into old age, and the conclusion of Dougherty and colleagues seems to be correct: more is better.

The challenge is how to motivate older adults to change their exercise behaviour and to stay active in the long term and in a safe way. A range of strategies and measures may be effective, including...
public education about lifestyle in old age, advice by healthcare professionals followed by booster telephone calls, providing diversity and novelty of exercises, using technology such as fitness trackers to motivate people, and particularly implementing social reinforcement via local networks or clubs. There is an urgent need for more knowledge translation research on this topic, to develop successful implementation programmes in the community, which allow adaptation to individual preferences. If this could be achieved, we all might be able to follow the mantra „more is better“.

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

Prof. Alexander Kurz is a senior scientist at the department of Psychiatry and Psychotherapy, which is part of the academic hospital of Technical University Munich. Since 1985, Prof. Kurz has been active in the field of geriatric psychiatry as a clinician and researcher. He has directed one of the leading memory clinics in the country. Currently he is designing and coordinating several transnational projects which aim at improving dementia education and care. Prof. Kurz has contributed to the development of patient and carer organisations on local, national and international levels and is a board member of the national Alzheimer’s Association.

Prof. Nicola Lautenschlager is an academic old age psychiatrist who received her undergraduate and postgraduate training at the Technical University, Munich, Germany. From October 2000 to June 2008 she worked at the University of Western Australia, Perth where her last position was Professor in Old Age Psychiatry and Deputy Head of School. In June 2008 she took up the position of University of Melbourne Professor of Old Age Psychiatry. Prof. Lautenschlager is the Director of Research for the North Western Mental Health, Aged Persons Mental Health Program at Melbourne Health. Her current research focus is diagnosis of cognitive impairment and intervention trials for older adults to improve mental health outcomes.

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History and activities of the Deutsche Alzheimer Gesellschaft

Heike von Lützau-Hohlbein, former chairperson of the Deutsche Alzheimer Gesellschaft and Alzheimer Europe looks at how far Germany’s Alzheimer association has come since its launch in 1989

In his closing speech at the Deutsche Alzheimer Gesellschaft (DAIzG) conference in Gütersloh three years ago Franz Müntefering, chairman of the German National Association of Senior Citizen’s Organisations (BAGSO), said, “If your organisation did not exist, the situation for people with dementia in Germany would look very different”. That same year DAIzG celebrated its 25th anniversary, and the statement is a description of the successful work over the past 28 years. Looking at the work of DAIzG it is important to always have in mind that it is a nationwide umbrella organisation and that local support is provided by local Alzheimer organisations.

Activities

Help and information
Help and information are the most important tasks of an Alzheimer’s association. Helpline, brochures and information taking are the main jobs of the human resources in the office. Brochures cover a variety of subjects concerning living with dementia, which are developed together and for our member organisations and the helpline serves people seeking help as a family carer or as a professional, giving advice in complex situations or just redirecting people to local services.

One of the main tasks over the past few years has been the involvement in the reform of the German long-term care insurance (LTC). Since early 2000 DAIzG has advocated for and together with other organisations initiated steps for better care for people with dementia and better support for their carers. In 1995 when the LTC insurance was put in place assessments were mainly physically oriented. The number of minutes needed for care was the measure which determined the level of financial support offered. LTC insurance is obligatory in Germany. People with cognitive deficits who only needed support in communication or guidance very often were not included.

It took nearly seventeen years until the beginning of 2017 to get equal treatment for people with cognitive deficits and those with physical handicaps, the measure is now the amount of support that is needed to live an independent life.

DAIzG has the honour and the challenge to be co-chair of the Alliance for Dementia, an initiative of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry for Health. The challenge is in the sense that this alliance is a collaboration of more than twenty organisations, i.e. medical, scientists, care professionals and care providers, therapists, communities, senior citizen organisations who have all their own interests and ideas on how to change society for a better life for people with dementia. The aim was to agree on an agenda and monitor the more than 150 measurements. This Alliance for Dementia is seen as a step towards a National Dementia Strategy for Germany.

Raising awareness is always one of the most important activities, in all types of media and at conventions. In September World Alzheimer’s Day is used locally and nationwide to draw attention to the subject. DAIzG uses its biennial conferences to gather the best people and ideas in the field to provide a platform for learning and discussions. Over the years there have been several projects together with partners or financed by them, like the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, that can be used as models, like “Allein leben mit Demenz” (Living alone with dementia), addressing the necessary changes of the aging society to take care of elderly singles, or “Alzheimer and you”, focussing on pupils and their engagement for the old generation with dementia. Actually projects like “Demenz-Partner” (Dementia friends) or “Demenz und Migration” (Dementia and Migration) are absorbing the DAIzG.

Getting started and keeping things going
Looking at all these activities it is hard to remember the first steps. Today in the office in Berlin there are 15 employees, most of them with long experience
working for the DAlzG. This year Sabine Jansen as executive director celebrates her 20th anniversary.

It all started in November 1989. Representatives of already existing Alzheimer self help groups and interested people gathered at a convention centre near Stuttgart and discussed the need of a German umbrella organisation. The tasks were obvious:

- lobbying for people with dementia and their carers on the federal state level,
- becoming the representative of people with dementia and their carers in the public,
- developing plans and projects to enhance the lives for them.

After long and detailed discussions, statutes and rules and regulations were developed and agreed and the Deutsche Alzheimer Gesellschaft (DAlzG) came into existence. The board was formed mainly by doctors and medical professors even though family carers were the focus of the planned work. By that time Alzheimer’s – dementia as an overall term was not yet used – was considered as a disease with no hope and no treatment, and it was looked at only at the late stage of the illness. But it was clear from the beginning that only cooperation with all types of professionals, medical and care, therapists of all types, would change the situation for the people with dementia and their families. In the first years of its existence DAlzG was an organisation of family carers, it took many years to get people with dementia themselves involved in the organisation.

The first office was located in Munich with a very limited budget, with most of the work being done on a voluntary base. From the first moment raising awareness and to destigmatise the disease were the main tasks. Contacts with the media were built up and the first brochures were developed to inform the public.

In the nineties it turned out that a structure reform of the organisation was needed, from a single person membership to a future oriented effective membership of local and regional Alzheimer organisations. The office moved to Stuttgart and in 1997 to Berlin. By then the DAlzG was able to employ an executive director and pay free-lance for specific projects. With the move to Berlin a bigger office was possible. Thanks to the first two employees, Sabine Jansen and Hans-Jürgen Freter, the organisation was growing.

Germany is a federal State with strong power on state level which varies from region to region. Social care in its general framework is state law, the federal laws and rules shape the frame work under the conditions of each State. A structured plan had to be developed to define the tasks of the federal, the State and the local level. It was essential to find rules amongst the members to agree on common tasks which could be done by the umbrella organisation for all members and others which were tasks of the local associations and groups. Another topic was the problem that Germany has different state laws and self-help groups and associations are supported differently in different States.

Over the years several working groups were formed, for example: taking care of ethical questions; dementia and acute hospitals; participation of people with dementia, assistive technology or the quality of our work in general. The results of the working groups are important in two ways. On the one hand they show common statements for the public on the other hand they serve as common base for all members of the umbrella.

International contacts

During all the years it was important for the DAlzG to be part of the international network. The DAlzG has been involved in the work of Alzheimer Europe nearly from the beginning of Alzheimer Europe, it was and is essential to learn from other countries, to participate in the community. A close connection – from board to board – was installed for many years and is now continued by Sabine Jansen. Also the membership of the DAlzG in Alzheimer Disease International (ADI) is fruitful, for example looking at the twinning project with Turkey.

Looking to the future

For the next election period the DAlzG is hoping for a National Dementia Strategy in Germany.

Heike von Lützau-Hohlbein

“For the next election period the DAlzG is hoping for a National Dementia Strategy in Germany.”
Regional dementia strategy Schleswig-Holstein

Wienke Jacobsen, PhD-Student from the Competence Center Schleswig-Holstein writes that even though Germany may not have a national dementia strategy several German states have introduced regional strategies to meet the needs of their local dementia population.

Due to demographic changes and the increasing number of older people, dementia has become a public health priority for the World Health Organisation (WHO) and an important topic on the international political agenda. Many countries have developed nationwide dementia strategies however Germany does not have a national dementia strategy yet. Instead a “National Alliance for People with Dementia” on behalf of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Health in cooperation with the German Alzheimer Association (Deutsche Alzheimer Gesellschaft e.V./Selbsthilfe Demenz) was introduced in 2014.

Alongside the nationwide program, regional framework conditions, such as the lack of support and resources in rural and urban areas, have to be considered. Despite the “National Alliance of People with Dementia” the state of Bavaria was the first federal state within Germany to develop its own inter-ministerial dementia strategy in 2013. Within the last two years the federal states Saarland and Schleswig-Holstein have followed the example of Bavaria.

The first regional dementia strategy

Schleswig-Holstein was the first state to actually develop a dementia strategy on behalf of the state government and the Alzheimer Association Schleswig-Holstein e.V. which was commissioned as an advocacy organisation for people with dementia and their caregivers in order to coordinate the developmental process and compose the strategy.

Schleswig-Holstein is located on the German border with Denmark between the North Sea and the Baltic Sea and known for its rural areas and the importance of tourism and agriculture. Due to the low number of inhabitants and an increasing number of older individuals, the state Schleswig-Holstein faces problems especially in supporting people with dementia who are still living at home. Additionally the existing number of care groups or self-help groups for caregivers, is considered insufficient and there is little support for the long distances needed to travel to access to neurologists or care services.

Defining needs for action

The main objectives were to define needs for action and to create a coordinated concept as a political commitment for the future care planning. The “Dementia Strategy Schleswig-Holstein” is particularly characterised by the participatory approach and from November 2014 until March 2016 recommendations were collected by members of three interdisciplinary working groups, with a total of 15 members, which met three to four times.

Besides for example local authorities, health and nursing associations, scientists’ of the German
Center for Neurodegenerative Diseases Rostock/Greifswald (DZNE) and the University of Applied Science Kiel have been engaged in the process to discuss and later to agree on concrete measures. On top of that, ten interviews with further experts in this field were conducted and the results were included in the recommendations to make sure that different perspectives were considered.

**Nothing about us without us**

Regarding the demand “Nothing About Us, Without Us” of the “UN Convention on the Rights of Persons with Disabilities” the needs of people with dementia and their caregivers were also taken into account. Besides the inclusion of members of regional Alzheimer Associations within each working group, focus group discussions with individuals with dementia and their caregivers were conducted.

Each working group discussed special topics, which were comparable to the subject matters of the “National Alliance of People with Dementia”:

**Working group 1: Social responsibility**

One major topic this Working Group was to define the needs of an age and dementia-friendly community. This can be done for example by creating a society where persons with dementia can live with dignity in a pleasant and familiar environment, where most of them want and can live as long as possible. Aims were for example to promote the understanding of dementia among the society and professionals of different working fields and to raise awareness within the municipalities. Besides a social-space oriented infrastructure planning and the strengthening of interdisciplinary networks, the idea is to employ regional dementia coordinators in each municipality. The organisation can differentiate between the municipalities, according to individual existing support structures.

**Working group 2: Support of people with dementia and their families**

The “Dementia Strategy Schleswig-Holstein” focuses on supporting those, looking after people with dementia as well as people living with dementia. One aim is to increase the use and acceptance of advice, since early and comprehensive counselling for people with care needs and their loved ones can reduce supply deficiencies and the burden of caring. In particular in rural areas the need for a (mobile) consultation shall be examined.

**Working group 3: Medical support and care**

Medical diagnostic and therapy as well as the development and implementation of (mobile) concepts of diagnostic and therapy in rural areas depicted the main aims discussed within working group 3. Also the strengthening of outpatient rehabilitation and occupational therapy were considered future goals. Moreover the establishment and improvement of concepts of care and support of people with dementia in hospitals were highlighted.

**“Dementia Strategy Schleswig-Holstein”**

After the “Dementia Strategy Schleswig-Holstein” was adopted by all parties in March 2017, the main goal and further actions will be presented at the parliament of Schleswig-Holstein in October 2017. The strategy covers 77 pages and forms an important foundation to set priorities, define responsibilities and make decisions for specific actions for the further development of projects, offers and a dementia friendly environment within the municipalities.

The further implementation and advancement of the strategy is supervised by the Competence Center Dementia (Kompetenzzentrum Demenz Schleswig-Holstein), which is a project of the Alzheimer Association Schleswig Holstein e.V. and additional financial and personal resources until the year 2022 are already approved. The Competence Center Dementia is partly financed by the Ministry of Social Affairs, Health, Youth, Family and Senior Citizens and long-term care insurance companies. Since 2010 it pursues the mission to improve and expand the supply structures for people living with dementia and their caregivers and has already made an important contribution to this field of work. The coordination of countrywide activities, advisory functions, quality assurance of existing support and care structures or the development of innovative projects are solely some examples of the Competence Centre’s work.

**Addressing specific challenges**

This dementia plan addresses the specific challenges which must be mastered, in order to assure that people living with dementia can live as long as possible in their own homes.

**Wienke Jacobson**
Migration and dementia

Sabine Jansen, Executive Director of the German Alzheimer Association looks at a successful twinning program between the German and the Turkish Alzheimer Associations

Many countries have inhabitants from other countries who migrated for working reasons or arrived as refugees. More and more of these people have become older and are getting dementia. For them it is even more difficult than for native inhabitants to get entrance to the support system. In Germany 16.5 million out of 82 million people have a migration background. The biggest group are people from Turkey followed by Poland then Russia. On the other hand many German retirees enjoy the sun of Turkey.

Bringing Alzheimer associations together

In summer 2014 the Turkish and the German Alzheimer Association started a twinning programme. This initiative was backed by Alzheimer’s disease International (ADI) which brings together Alzheimer Associations to learn from and support each other.

A kick-off meeting took place in Berlin with board and staff members of both associations as well as ADI in August 2014 and a plan of action was developed. The first activity was the visit of the former chairperson of the German Alzheimer Association Heike von Lützau-Hohlbein to Alayna, Turkey at the beginning of April 2015. She held a speech addressing retired Germans informing them about dementia and support facilities.

A positive exchange

Füsun Kocaman, executive director of the Turkish Alzheimer Association, came to Germany in May 2015 for a two week visit to the German Alzheimer Association office. She learned about the work of the Alzheimer Association but also about institutional care in Germany. She also supported the German Alzheimer Association giving helpful advice in developing a first information brochure in Turkish.

The next meeting took place in Istanbul in December 2015. Following this as part of the mutual cooperation a one day conference was planned in the Sehitlik Mosque, Berlin. Prof. Isin Baral, psychiatrist at the University hospital in Istanbul and chair of the Turkish Alzheimer Association, and Füsun Kocaman came once more in February 2016 to Berlin and presented as speakers together with German speakers about dementia and the support system in Germany and Turkey as well. More than 100 participants attended the conference which was opened with a welcome by Ahmet Basar Sen, Turkish consul in Berlin.
Migration and dementia project

This successful twinning programme was the start of a three year project “migration and dementia” which is funded by the German Federal ministry for families, senior citizens, women and youth. The aim of the project is to collect existing information materials, counselling possibilities and other support facilities for different groups and languages and make that information available on a website.

The helpline of the German Alzheimer Association will also start to offer counselling in Turkish and more conferences are planned in different cities in Germany over the next few years. These activities are not only for Turkish migrants but also for Polish and Russian speaking people who also live in high numbers in Germany.

The cooperation between the Turkish and German Alzheimer Association has shown that working together in the field of dementia can be very fruitful.

From left to right: Füsun Kocaman (Executive Director of Turkish Alzheimer Association), Hans-Jürgen Freter (former staff member DAlzG) Isin Baral (Chair of Turkish Alzheimer Association), Marc Wortmann (former CEO, ADI), Sabine Jansen (Executive Director, DAlzG), Anastasia Psoma (staff member of ADI)
Demenz Partner – a growing movement in Germany

Saskia Weiß Project coordinator, Demenz Partner looks at the success of the project since it was launched just over a year ago in September 2016

"The aim of this initiative is to spread knowledge and information about dementia and to change the way people with dementia are treated in society."

Saskia Weiß

In April 2017 nearly 100 interested persons attended a course on dementia in Berlin. During the 90 minute session they learned the most important facts about the disease and received information on how to interact and speak with people with dementia. Furthermore they got information about regional Alzheimer associations and other advisory services.

These courses are free of charge and are part of the nationwide educational campaign “Demenz Partner”. The aim of this initiative is to spread knowledge and information about dementia and to change the way people with dementia are treated in society.

The German Alzheimer Association (DAiZG) has run the “Demenz Partner” initiative since it started on 6 September 2016 with the initial support of two ministers – the Federal Ministry of Health which gives some financial support and the Ministry for Families, Senior Citizens, Women and Youth which supports within the framework of the National Alliance for people with dementia. DAiZG was also very lucky to get a generous donation from Susanne Klatten, one of the richest woman in the world.

Forget-me-not

“Demenz Partner” uses the English initiative “dementia friends” as its' role model. Even though the content alignment is different, the same forget-me-not-logo is used to illustrate that this campaign is not just a German project, but a worldwide movement.

Several hundred organisations are part of the initiative and can register themselves and the courses they offer on the website www.demenz-partner.de.

Up until summer 2017 nearly 15 000 people have attended one of the 400 information events on offer.

Material for the lecturers including presentations, films and handbooks is provided by the German Alzheimer Association. Material for participants including a brochure and a forget-me-not-badge is provided.

Many institutions have joined the initiative including:

• Federal Ministry of Health,
• Federal Ministry for Family Affairs, Senior Citizens, Women and Youth,
**“And then there is Marie”**

As a member of the advisory council “Living with dementia”, Klaus Meyer is one of seven people with dementia advising the board of the German Alzheimer’s Association.

Klaus had to give up his job, but his living situation has stayed the same. For more than 20 years he has been living in a communal living project on the outskirts of Hamburg. Originally he shared his flat on the old converted farm with his wife and their daughter. But he and his wife separated and his daughter has gone off to university.

**Getting diagnosed**

“The diagnosis was a shock for me”, Klaus says, “and I have still not processed it completely”. He has always been very open about his condition with his colleagues, his family, and his friends: “I told everybody”, he says, “and they were actually not very surprised. They had already noticed that things weren’t going so well”.

**Communal living**

Fourteen other adults live on the old farm, together with five children and two young adults. They keep a few animals: cats, dogs, bees, and three „Heidschnucken“, a local breed of sheep. The farm is maintained collectively by the residents. As long as possible, Klaus wants to contribute like everybody else. “At some point this life may not be possible for me anymore”, he says, “If I have to use a wheelchair for example”. Recently he gave up his car and his motorcycle. Not to be able to drive his motorcycle is especially hard on him. But he has already thought of a solution: „I just have to find somebody who will take me for a ride once in a while. I still have all my gear“.

What does he do to keep himself busy? His answer comes promptly: “Politics”. Even if Klaus is not as

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**DAIzG’s first official demenz partner**

All those authorities and organisations have allowed their employees to join a course on dementia during working hours. Since May the Harz Region is DAIzG’s first demenz partner – model region. The Alzheimer Association here wants to make the region more dementia-friendly during the next years. They have for example contacted housing companies, fire departments and social associations, where they will offer courses on dementia.

In autumn DAIzG will start a big media campaign to make the initiative more known across Germany and to strengthen the movement. Posters, video spots and the support of well-known personalities will all be part of it.

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**Lina Sommer, Alzheimer’s Association Hamburg asked him:**

How he manages his life with the help of a student and living in a communal living project on the outskirts of Hamburg?

Klaus Meyer, 50 years old is used to talking. Before he was diagnosed with Alzheimer’s, he worked for a big insurance company, and later as an independent Works Council representative, an occupation he was passionate about. But it became increasingly difficult for him to keep up with the demands of his job. Meyer began to struggle and his colleagues noticed. It took two more years until Klaus Meyer received the diagnosis: Alzheimer’s disease.

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The “Demenz Partner” initiative spreads knowledge about dementia and sensitises for the needs of the families. We also want to change the image of people with dementia. They are not completely in need of care the day they get their diagnosis. They have difficulties in some parts of everyday life. But they also have lots of abilities, which they want to and are able to use. At this point we want to change the social attitude, allay fears and break down the stigma. An important step in this direction is information and sensitisation.

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**Federal Ministry of Food and Agriculture,**  
**Ministry for Social Affairs of Rhineland-Palatinate,**  
**The German Hospital Federation,**  
**three different health insurances.**
politically active as he was before, he is still a union member and visits events and meetings. He is very interested in computers and data security, carrying a computer magazine in his backpack most of the time. And he reads newspapers. „I read almost too many of them”, he says and laughs.

Klaus can still do many things by himself, but the other day he got lost: “There is this doctor I have to visit regularly. And there I was in front of the house and didn’t know whether it was the right one. But as long as I remember where to go, I am fine”. His neighbours on the farm help him along if they can.

Even though they live separately, his wife is still actively supporting him, helping him organise his daily life, reminding him of his appointments, accompanying him sometimes. This arrangement is not without conflict: „Sometimes I misplace the mail even though I am supposed to put it in a folder“, Klaus says. „Then I am in trouble“. His wife calls him almost daily, they meet once a week.

“And then there is Marie”

“And then there is Marie”, he says. With the help of his wife, Klaus has placed an ad offering “Living for Assistance” and Marie answered. The young woman is going to study Music in Hamburg in September and was looking for a place to live.

“Marie is helping me a bit”, Meyer says, “so I don’t mix up my socks for example and wear a blue one with a red one”. Marie reminds him to take his medication, to keep his appointments, and to fill out the form to order his lunch.

“Living for Assistance” is an established concept in many German cities providing students with a low rent in exchange for support and assistance, typically with household chores, garden work and babysitting. Nursing is exempt from these arrangements.

Marie has not lived with Klaus for a long time yet but they are both optimistic that they will get along well as roommates.
Our members are helping people with dementia and their carers in 34 countries.
28th Alzheimer Europe Conference
Making dementia a European priority
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