Margaret Chan, WHO Director General, identifies dementia as a key priority for all governments.

Helen Rochford Brennan presents the Irish Charter of Human rights for people with dementia.

Yves Joanette recently became the new Chairman of the World Dementia Council.

Sophie Løhde, Minister for Health and the Elderly, speaks about Denmark’s new action plan on dementia.
Prioritising Dementia

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VI **UNCRPD: the United Nations Convention on the Rights of People with Disabilities**
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Nine members of the European Alzheimer’s Alliance (EAA) were among the numerous MEPs who spoke out in favour of the EU implementing the UNCRPD

X **Ireland launches a Charter of Rights for people with dementia**
Affirming that people with dementia in Ireland have the right, regardless of diagnosis, to the same civil and legal rights as everyone else
Welcome

Exceptionally, this issue contains a special section called “Human Rights in the spotlight”. The main body of the UN’s Convention on the Rights of Persons with Disabilities (UNCRPD) is in the process of being adopted into European law and this has engendered new interest for the rights of people with dementia.

We recently held a lunch debate in the European Parliament on this topic and I am very grateful to our hosts, MEP Sirpa Pietikäinen (Finland) and MEP Marisa Matias (Portugal), for their excellent support to our cause. The special section also includes an overall view of the UNCRPD, as well as expressions of support from MEPs Marian Harkin (Ireland) and Marek Plura (Poland). The final article in this section covers the launch of the Charter of Human Rights for People with Dementia in Ireland.

Our policy section features coverage of the Netherlands’ EU Presidency conference on dementia. I am pleased to see that dementia continues to attract the high-level attention it deserves in many EU countries – including Slovakia, which will host a similar conference in November 2016.

This has also been a good year for new dementia strategies. Slovenia officially adopted its first national strategy and Flanders has refreshed its regional plan with new views on prevention and care. In addition, delegates at a recent Swiss conference agreed that the country’s strategy was progressing well compared to other countries.

As you read this, many of our friends and colleagues are attending the 26th Alzheimer Europe Conference in Copenhagen – where we will also celebrate the launch of Denmark’s new dementia strategy. This issue includes an article by Sophie Lahde, Danish Minister for Health and the Elderly, who kindly provided an overview of the strategy. Meanwhile, Alzheimer Europe and its members are working to develop a model dementia strategy. During a recent Public Affairs meeting, we compared existing strategies and identified good practices that may be useful in other countries.

On a global level, this issue covers the progress of the WHO in developing a global action plan for dementia, as well as an interview with Yves Joanette, the new Chairman of the World Dementia Council – which is also working to make dementia a global health priority.

In our news section, there is an article about a new report that discusses the issues concerning dementia in the countries surrounding the Mediterranean. This study was produced by the Mediterranean Alzheimer’s Alliance (MAA), an association that shares many members and values with Alzheimer Europe. This is followed by a trio of profiles from the new heads of the national Alzheimer associations in Germany, Spain and Switzerland. Between them, they bring a wealth of experience to their organisations and I am sure Alzheimer Europe will continue to report on their accomplishments in the future.

You will have noticed that this issue was accompanied by our 2015 Annual Report and a special supplement about the EPAD project. We are very glad to share these publications, as they show both AE’s past activities and our ongoing involvement in research projects to improve the lives of people with dementia and their families.
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AE and its member organisations discuss development of a model dementia strategy

On 29 June 2016, Alzheimer Europe hosted a meeting of its member organisations to compare national dementia strategies and identify existing good practices.

The meeting was opened by AE Chair Heike von Lützau-Hohlbein, who welcomed the participants. She was followed by Executive Director Jean Georges, who explained that the aim of this meeting was to start the development of a model dementia strategy. This would be done by combining best practices from countries that already have operational strategies: the agenda featured presentations from Austria, France, Ireland, Malta and Switzerland, as well as England and Scotland from the UK.

Recommendations on involving people with dementia, living well with dementia, combating stigma, raising awareness and dementia-friendly communities

George McNamara, Head of Policy and Public Affairs and Strategic Lead for Integrated Care at the UK Alzheimer’s Society (AS) presented “From national strategy to dementia challenge”. He gave a brief history of UK dementia policies since 2009 and cited several achievements, including a sharp increase in diagnosis rates and the continuing success of the Dementia Friends (DF) programme.

Despite these and other successes, there are still issues to address, including co-morbidity: 70% of Britons with dementia are living with at least one other long-term health condition, yet the health and social care system still often treats illnesses and conditions in isolation. George proposed the following elements for a national dementia strategy:

Raising awareness and reducing stigma
George pointed out that the DF training programme has turned out more than 1.5 million Dementia Friends at home and has also been adopted in several other countries. He added that UK Scout groups have also developed initiatives for children and young adults.

Reducing the risk of dementia
This could be an educational campaign on aspects related to prevention, such as vascular aspects and lifestyle changes in middle age. There is also a need to work with other health charities, in order to integrate risk reduction messages.

Developing dementia-friendly communities (DFC)
The UK began to develop DFC in 2010 and 150+ communities are working to become dementia-friendly. George pointed out various successful initiatives, such as city planning in Manchester and a growing number of dementia-friendly businesses and public services. The involvement of people with dementia is essential in DFC programmes, though this has been quite difficult to implement.
Recommendations on timely diagnosis, post-diagnostic support, acute and hospital care

Jim Pearson, Director of Policy & Research at Alzheimer Scotland (AS), gave a presentation about human rights and other aspects of the Scottish National Dementia Strategy.

Jim highlighted the need for support for people in institutional and acute hospital care. In Scottish hospitals, there is a general feeling that people with dementia should not be there; staff do not feel that caring for them is their core business. It is therefore important to provide them with the necessary skills to change this perception.

He also noted the importance of post-diagnostic support. Scotland currently guarantees one year’s support from a specialised social worker, which gives people access to peer support in their community. In turn, this helps to prevent isolation and its deleterious effects.

On the topic of involvement, he said that it is the right of every individual to be a citizen, to live in the community as long as possible and to be involved in policy development. He also stressed the importance of creating and involving groups of people with dementia or carers, as these are very effective and popular in Scotland.

All aspects of a dementia strategy must be evidence-based and result from working in partnership, e.g. with the government, health services or patient organisations. He added that three-year periods are ideal for strategies, as this makes it easier to monitor progress.

Recommendations on home support and care, living in the community, carer support and respite care

Stefanie Becker, Director of the Swiss Alzheimer Association, gave an update on the implementation of her country’s “National Dementia Strategy 2014–2017”.

Switzerland’s strategy addresses the needs of people with dementia, their families and health care professionals during the entire course of the disease, with foci on four areas: awareness and information, diagnosis and treatment, life at home and life in an institution. The main principles of the strategy are participation, integration and local initiation. Coordination and monitoring remains at national level, so cooperation among stakeholders is essential.

The stakeholders were expected to take operational responsibility for their areas, but this was widely misunderstood and has led to delays. Additional delays have been caused by lack of funding, as organisations struggle to complete new tasks without additional resources. An additional complication is that several cantons have developed their own regional strategies. These issues have sparked an initiative to prolong the overall lifetime of the national strategy so that all goals can be met.

In the area of timely diagnosis, there are projects to improve physical infrastructure and coordination, but also to harmonise procedures for detecting, diagnosing and treating dementia. The latter is no trivial task: there are 33 centres for diagnosing dementia but no national standards, so procedures and treatment may vary depending on the clinic.

Four further projects aim to improve post-diagnostic support, including day, night and long-term care facilities. Their main objectives are to improve education about existing resources and to improve individual care needs with better coordination, greater flexibility and the provision of appropriate services.

Finally, Stefanie noted that the Swiss Alzheimer Association was actively involved in the development of the draft strategy, but the role of the association has become less clear since implementation began.

Recommendations on timely diagnosis, post-diagnostic support, acute and hospital care

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Recommendations on home support and care, living in the community, carer support and respite care

Tina Leonard, Head of Advocacy & Public Affairs at the Alzheimer Society of Ireland (ASI) gave an overview of the Irish national dementia strategy that was launched in 2016.

The strategy is funded with some EUR 35 million to support four key areas: intensive home care supports, GP education and training, dementia awareness and research.

Diagnosis is one of the areas with funding and the PREPARED project is part of this package. PREPARED will develop, deliver and evaluate training and education interventions for primary care clinicians (GPs).
For home care, the following elements are part of the programme:

- review of existing health and social services
- determine best use of existing resources for home care and respite care
- evaluate the potential of assistive technology
- ensure access to information on services

There is also a programme to develop “Intensive Home Care Packages” which are linked to hospital discharge. The packages will be fully funded over the three-year lifetime of the strategy, but Tina expressed concern about what will happen after that.

Very little has been done in the area of respite care and family care – apart from the training programmes for carers and support groups run by the ASI. The association has also funded a few Demen-
tia Advisors who provide post-diagnostic support.

As always, the ASI has been very involved in raising awareness, another area that has secured funding. To date, there has been a nationwide public campaign, while efforts to develop dementia-friendly communities also contribute to awareness. There are seven such communities in Ireland, but the work is still at a very early stage.

**Recommendations on residential and nursing care, palliative care**

Monika Natlacen, Vice President of Alzheimer Austria, gave an overview of “Living well with dementia”, the national strategy text that was introduced in 2015 but has yet to be approved by Parliament.

The text outlines the strategy aims and includes references to the United Nations Convention on the Rights of Persons with Disabilities, pointing out the need to overcome barriers to participation in daily life and work. This could be partly achieved by developing a better understanding of dementia and overcoming stigma.

With regard to the involvement of people with dementia, Monika reported a comment made by a person with dementia who suggested that “only someone who doesn’t have dementia could talk about living well with dementia”.

She added that the adoption of the strategy has been on the agenda of the Austrian Parliament three times, but there is a lack of political support to ensure a successful resolution. The result is that no funding is available to develop new programmes; for the time being, all that can be done is to opti-
mise existing initiatives.

**Recommendations on research funding and research coordination**

Alex Teligadas, Director for Communication for Alzheimer Europe, gave an overview of the research elements of the third French Alzheimer Plan (2008–2012) on behalf of France Alzheimer. This plan had very strong financial and political support from the government, with a total budget of EUR 1.6 billion over five years, including EUR 195 million for research.
There were three specific research goals: support new research efforts, develop epidemiological expertise and make Alzheimer’s disease a European priority. These were broken down into 15 specific tasks that covered all aspects of dementia research, including clinical, social, epidemiological and training/teaching. Funding was provided to establish new facilities and services and also to staff and operate them throughout the life of the plan.

A subsequent review of the plan showed mostly positive results, such as new research and imaging centres, progress in genetic research, new clinical cohorts and support for local and European research programmes. On an international level, the plan is still being used as a template worldwide, while President Sarkozy’s constant personal support was instrumental in persuading EU lawmakers to make dementia a public health priority.

On the negative side, there was insufficient recruitment of young French scientists to dementia programmes and very few proposals for human and social science projects, the latter due to a lack of a network for social research.

The third Alzheimer Plan was followed by a neurodegenerative diseases strategy that includes dementia but seems a paltry successor to the previous plans.

**Recommendations on funding, monitoring, coordination and evaluation**

Charles Scerri, General Secretary of the Malta Dementia Society, presented several aspects of Malta’s national dementia strategy. The strategy was launched in 2015 with an overarching aim to enhance the quality of life of individuals with dementia, their caregivers and family members.

The document has 85 recommendations in six intervention streams. Coordination and monitoring is done by a single person designated as the National Focal Point (NFP). The NFP sets priorities based on national needs, budget constraints and skill requirements which are shared with all stakeholders and also fed back to policymakers. This process has been very effective, leading to the early development of booklets for people with dementia and carers, a website and Facebook page, local community events and a 24/7 Dementia Helpline.

It also led to the establishment of Dementia Intervention Teams, consisting of social and health care professionals that contact people who are newly diagnosed. The skill sets needed by these teams are being developed via various training programmes, including a degree course at the University of Malta.

The strategy is funded by annual budget allocations, which have been satisfactory so far, even if they do not allow efficient long-term planning. There has yet to be a formal evaluation of the plan. However, Charles was confident that progress is being made, citing high turnout to seminars, successful training sessions and increasing social media activity.

This was the last presentation of the day. Jean thanked the speakers and the other delegates for their active participation in the discussions that followed each presentation. The next AE members’ meeting will be an Alzheimer’s Association Academy that will take place on 6–7 December 2016 in Brussels.
On 17–19 May, the EPAD partners held a General Assembly and Colloquium under the banner “Initiation and Delivery” in Barcelona.

The conference opened with project leaders Craig Ritchie, Serge van der Geyten and José Luis Molinuevo welcoming some 120 delegates to the meeting. They were glad to see such a large turnout, referring to the continued increase of participants in project meetings since the first General Assembly in January 2015.

They also presented the agenda, which featured updates from each work package, a colloquium and a visit to the new premises of the Barcelonaβeta Brain Research Center (BBRC). The partners would also discuss upcoming activities, including how EPAD will cooperate with other IMI research projects.

Following a series of breakout sessions, the work package leaders gave updates on their work toward fulfilling the project objectives. As the following highlights show, the project is progressing in a satisfactory manner:

**Finalisation of the Longitudinal Cohort Study (LCS) protocol**
The LCS protocol was almost complete and had received positive initial feedback from the European Medicines Agency. The protocol is the all-inclusive reference on how the EPAD non-interventional cohort study will be conducted. Amongst other content, it sets out operating procedures for the trial centres and provides routines for collecting, handling and analysing human samples.

**Recruitment of the first EPAD study participant**
Ms Julie Duffus from Scotland became the first volunteer to join the EPAD cohort, which will consist of people at varying degrees of risk of developing Alzheimer’s dementia. Along with the other research participants, she will undergo regular health checks that include blood tests, brain scans and mental agility tests.

**Publication of an ethics reference guide**
The partners had published an ethics reference guide that highlights key issues in the project. These mainly consist of informed consent, providing information to the participants during the study and external sharing of the final study results. The team members were also developing a policy regarding the provision of participant information related to randomisation within the EPAD clinical trial.

**Development of a communication strategy**
A dissemination and communication plan that included measurable objectives and target audiences had been developed. The partners had created tools such as the website, a Q&A leaflet and an external newsletter, while a publication approval process was also in development.
The EPAD loyalty programme: sharing experiences across Europe

The final event of the day was a colloquium to inform the partners of communication activities and ongoing efforts to engage public support for the project.

The first speaker was Jean Georges, Executive Director of Alzheimer Europe and co-leader of EPAD’s Dissemination work package (WP6). He explained that WP6 is now updating the communication strategy, in order to raise awareness of EPAD and to change the way we communicate about Alzheimer’s dementia and Alzheimer’s disease.

The next speaker was Prof. Craig Ritchie, Professor of the Psychiatry of Ageing at the University of Edinburgh. He described the activities of the PREVENT project, a cohort study that aims to identify biological and psychological factors which may increase the risk of dementia in later life. The project has a very high retention rate and Prof. Ritchie attributed this result to a very open and transparent approach of the project team toward the participants. He was convinced that such an approach would also be successful in the EPAD trial centres.

This sentiment was echoed by Prof. Miia Kivipelto (Professor of Clinical Geriatric Epidemiology, Karolinska Institutet), who presented the “Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability” study. This project ran during 2009–2014 with a group of 1,260 people at risk of developing dementia. It was clear that the trial participants were very pleased to be involved in the project: Prof. Kivipelto said they were very grateful for the care they received, but also appreciated the provision of information and results in simple language.

The final speaker was Ms Maria Escrivá, Communication Specialist at the Barcelonaβeta Brain Research Center (BBRC), who presented the activities around the ALFA study. This is a primary prevention study in healthy adult children of people with Alzheimer’s disease. More than 6,500 participants were recruited via a public press conference and advertisements. Ms Escrivá said that they are very enthusiastic about being part of the study, citing very high participation in a loyalty programme that includes face to face meetings, news updates and dedicated events.

AMYPAD: defining the utility of PET imaging

On day two, the delegates held discussions on the legal issues around data sharing and sample access, the ethical considerations of disclosing the risks of developing dementia and the establishment of participant panels at the European and local level, as well as future communication activities. This was followed by a presentation on AMYPAD, a proposed companion project to EPAD that was awaiting approval from IMI, the Innovative Medicines Initiative.

AMYPAD (Amyloid imaging to prevent AD) aims to determine the clinical utility of amyloid PET imaging in patient management and risk stratification. The project partners – which include AE and many others from EPAD – will conduct up to 6,000 PET scans using imaging agents from GE Healthcare and Piramal.

Planning and cooperation

Day three focused on addressing issues to be resolved and a presentation on how the EPAD partners are cooperating with other dementia research projects. These include the current AETIONOMY and EMIF consortia, which are also funded by IMI. The delegates also held work package meetings to prioritise their upcoming activities and these were presented in the final session of the conference. The next EPAD General Assembly will take place in Stockholm, Sweden in 2017.

Further information about EPAD can be seen in the special supplement that accompanies this magazine and on the website http://ep-ad.org/
EMIF hosts “E-magining the Future of Health Data” conference in Budapest

On 16–17 March 2016, thought leaders in the field of electronic health records and real world evidence met in Hungary to discuss how to maximise the benefits offered by harnessing available health data, while also solving issues around its reuse and work with regulators to provide the right evidence. They concluded that whatever the power of digital technologies and no matter the size of the data mountains, the true potential of digitised or machine-readable information relating to health will not be realised without the key ingredient of trust. Nigel Hughes, Scientific Director RMEDS (Real World Evidence, Medical Affairs, Established Products, Statistics) at Janssen Research and Development, reports on the event.

Real world data provides the potential to identify high-risk populations and, in advance of symptoms, monitor and predict the onset of disease.

Enabling the re-use of existing health data

The IMI-EMIF (European Medical Information Framework) has put engendering trust at the centre of the programme’s vision of creating the European hub for health and care data intelligence, from which new insights into diseases and their treatment will flow. In support of these objectives, EMIF’s 2016 symposium in Budapest explored how real world health care data can be used to inform the development of new medicines and underpin approvals, access and use – across the product life cycle.

The EMIF programme is laying the foundations for an EU-wide ecosystem that will open up access to enable re-use of existing health data. It is doing this by addressing both technical issues and governance, with the aim of creating a trusted, federated system from which all stakeholders can benefit.

The EMIF-AD vertical examines how to accomplish this specifically in the Alzheimer’s disease context. To ensure that the work undertaken by EMIF has relevance – and can shed light on – unmet medical needs, EMIF-AD is assessing if existing datasets and bio-banks can be used to identify early markers of Alzheimer’s disease, while a second project,
EMIF-Metabolic is studying risk markers for developing metabolic complications of obesity.

These elements of EMIF are underpinned by the EMIF-Platform, in which a number of tools, for example, to support biomarker discovery, and a common data model, are being developed.

**Collaboration: a key element in the EMIF project**

The Budapest symposium focused on how this existing health data could be applied to inform and optimise the development of new medicines and underpin access, pharmacovigilance and demonstrations of effectiveness in the real world.

In a day of high-level discussion and debate by experts across the healthcare chain, a series of points emerged as needing attention to address barriers to the re-use of data, and support interactions with regulators, health technology assessment organisations and access bodies, to ensure they have the right evidence and maximise the benefits of data re-use for the good of patients.

Among the discussions held during the conference, an emphasis was placed on the value of the collaboration that EMIF promotes. In reference to a project in Alzheimer’s disease that aims to develop new outcome measures, identify sources of outcome data and establish a framework around which to gather new data, Richard Bergström, Director General EFPIA, noted: “Individual companies can’t do these things...There’s too much to do.”

This sentiment was echoed by Simon Lovestone, Professor of Translational Neuroscience, University of Oxford Department of Psychiatry, who provided an interview in the run-up to the conference, sharing the role that EMIF has played in supporting research in Alzheimer’s disease. An academic co-coordinator of EMIF, Lovestone and his research group have been working on biomarkers in people with Alzheimer’s Disease (AD) for the past ten years – accordingly, one of his particular responsibilities in EMIF is for Work Package 3: Biomarkers. Lovestone has first-hand experience in how the sharing of health data can help researchers advance their work more efficiently and effectively. “For me, one of the first and most material advances of EMIF has been the ready access to large amounts of data and, most importantly, samples attached to that data,” he said.

“EMIF has brought together a group of people that enabled identification of the right cohorts through the cohort selection tool, or the EMIF catalogue,” he explained. “In a study that we’re doing at the moment we’ve already completed a study of 500 individuals and we’re now embarking on a study of 1000 individuals.” This includes some very specific data that allows the researchers to quantify the amount of pathology in an individual’s brain, where they also have good quality clinical data and where there are samples available. With EMIF, the group was able to identify these cohorts very quickly and was able to contact the right people to confirm the samples – all of which have now been aggregated and sent to Lovestone’s lab for analysis. “This has saved us literally years and years of work, and has saved literally hundreds of thousands, if not millions, of euros were we have had to collect all the associated data specifically for this study,” says Lovestone.

**Toward a paradigm shift for R&D**

In recognition of the scale of such research the pharma industry, working within IMI, is gradually redefining what constitutes pre-competitive and competitive R&D. Alzheimer’s disease represents a potent exemplar of this shift, said Bart Vannieuwenhuyse, Senior Director Health Information Sciences, Janssen.

In addition to Big Data for Better Outcomes, EFPIA members are working together in Alzheimer’s disease consortia in projects including Pharma-Cog, which is looking for biomarkers of efficacy for new treatments; AETIONOMY, which aims to redefine the classification of Alzheimer’s disease to support more personalised treatments; EPAD (European Prevention of Alzheimer’s disease), which is pioneering a novel, flexible approach to clinical trials in Alzheimer’s disease using an adaptive approach; and EMIF, which is linking and analysing relevant data.

As a result of the two-day conference, a series of action points was developed for further consideration:

**Demonstrate there are benefits for all**

If trust is central to achieving EMIF’s objectives, then demonstrating that there are clear benefits for all partners in the re-use of data is a prerequisite. And the interests of all stakeholders must be balanced via a quid pro quo.

**Openness and transparency hold the key**

The essential requirement is to pull public and private data resources together, to enable collaboration and joint problem solving, as well as to have clarity of purpose on real world data use within health research.

“For me, one of the first and most material advances of EMIF has been the ready access to large amounts of data and, most importantly, samples attached to that data.”

**SIMON LOVESTONE**
The true potential of digitised or machine-readable information relating to health will not be realised without the key ingredient of trust.

The nature of drug development needs to evolve
Real world data provides the potential to identify high-risk populations and, in advance of symptoms, monitor and predict the onset of disease. Future drug discovery needs to be informed by such real world insights, as much as it is informed by disease symptomatology today.

Establish the context for making greater use of real world data and share the risks
Deployment of real world data in drug discovery and development requires people to work on consensually agreed research questions that reflect not the individual requirement of academics or companies, but the views and needs of regulators and patients.

Social media could be accessible within certain rules
Data from social media represents an invaluable source of real world data. However, it is noisy, and scientists do not like it as they see it as being subjective and biased. Effort is needed to determine how and when social media outputs are useful, for example detecting adverse events or understanding what aspects of their disease most burden people with long-term conditions.

Ensure data are fit for purpose
It is necessary to address issues of quality control and quality assurance of data. There should be collective agreement, supported by regulators, on acceptable data standards for specific purposes.

There is an urgent need to increase skills levels
There is plenty of data, but very few people with the expertise to interpret and exploit it to generate evidence and promote public health. This gap urgently needs to be filled.

Promote the importance of re-using health data
There is individual as well as societal benefit in allowing re-use of data. Education should support the public in understanding the benefits to them and society of real world data-driven research. People should be shown what broad consent could mean for them and given a voice in how, and for what purposes, data are used.

Know where your data are coming from
Data has context; why was it collected? What was collected? It is critical to understand this context in selecting the appropriate databases for a particular piece of research.

Collect examples of real world evidence in practice
Reaching the stage where real world evidence is routinely applied will vary from one healthcare system to another. It is necessary to collect real life examples that demonstrate the advantages and will motivate busy professionals to change their practices, but more importantly understand the need for high quality medical record keeping to support real world data access and use.

In summary, there is huge potential value in using real world data to optimise the product life cycle, but much more work to be done to achieve this.

Additional outputs from the event, including a full event report, presentations and pictures, can be seen at http://vitaltransformation.com/2016/03/emif-e-managing-the-future-of-health-data/ and more information about the EMIF project is available at http://www.emif.eu/
Policy Watch

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31 A new leader and fresh objectives for the World Dementia Council
33 Council of Europe issues recommendations on human biological materials research
Denmark: a dementia-friendly nation

On 21 September 2016, Denmark announced the launch of a new action plan on dementia with comprehensive and far-reaching objectives to support people with dementia and their families. Alzheimer Europe is very grateful to Ms Sophie Løhde, Danish Minister for Health and the Elderly, for providing this overview of the new plan.

Dementia and Alzheimer’s disease has climbed to the top of the agenda – not only in Denmark but all over the world.

We all know a person who is, or has been affected by dementia – a terrible disease that turns the lives of those affected, as well as their relatives, upside down.

Today, an estimated 35,000 Danes live with dementia. Unfortunately, it is suspected that this number in reality could be much higher since many people live with the disease without having been diagnosed, and that many more will get dementia in the years to come.

This means that we are facing a great challenge, which raises many pressing questions: How can we detect and diagnose more persons with dementia? How do we create better physical surroundings for people with dementia? How to give better advice, assistance and support to those who are caring for a person with dementia? And how do we combat the stigmatisation that also surrounds the field of dementia?

The challenges are many. This is why the Danish government has decided that Denmark needs a new action plan on dementia towards 2025.

The action plan is based on three overall objectives:

First of all, Denmark must become a dementia-friendly nation where people with dementia can live a safe and dignified life.

Secondly, the treatment and care of people with dementia must be based on the needs and values of the individual person, and treatment must be...
provided in a coherent way that focuses on prevention and early intervention and is based on the newest knowledge and research.

The third objective focuses on the active involvement and support of the relatives. Focusing on relatives is important when it comes to dementia since they face a very special challenge. Not only do they have to handle that a person close to them is severely ill, at the same time they also have to deal with their own grief of losing touch with a beloved person.

Dialogue and involvement have been essential in the process of creating this plan. We have found it very important to give a voice to all the different kinds of ‘experts of everyday life with dementia’ – to hear from the people this is all about. That is why people with dementia, their relatives, and also the skilled professionals in the field have been given the opportunity to contribute with their knowledge and experience and express their wishes for future efforts in the field of dementia.

We have also sought inspiration in other countries that have come far in relation to handling the future challenges on dementia, such as Norway, Sweden and England.

Overall, Denmark’s national action plan on dementia will focus on improving the quality in all aspects and initiatives taken against dementia. This applies to early detection, diagnosing and treatment of dementia, but it also applies to the care and nursing of persons with dementia. And finally it applies to the relatives of people with dementia, both in terms of increased involvement and support.

Most importantly the aim of Denmark’s new national action plan on dementia is to make a real difference in the everyday life for all persons affected.

Ole Christensen, MEP (Denmark) comments on the new national action plan on dementia

As the living age of Europeans continues to rise to a yet unknown stage, the number of dementia patients is increasing as well. Sadly, we know that this disease has severe implications, not only on the lives of the persons diagnosed with dementia, but also on their families. In order to combat and prevent this disease we have to act and we have to act now.

Therefore, I am pleased that a majority of the Danish political parties are earmarking EUR 60 million over a 3-year period through the national dementia strategy.

With the help of the national dementia strategy, support will be provided to families, money will be earmarked for improving research on Alzheimer and other forms of dementia, and a stronger focus on prevention will be provided. These are major improvements.

I sincerely hope that the Danish dementia strategy will show capable of creating better lives for many of those patients who suffer from this terrible disease.
Living well with dementia in Flanders: a government blueprint

The Flemish government updated its Dementia Plan at the end of June 2016. “Continuing To Build A Dementia-Friendly Flanders Together” is based on the foundations of the first Dementia Plan of 2010, but adds new aspects such as prevention, representation and quality care. This article looks at the main elements of the new plan, described by Hilde Lamers, Director of the Flanders Alzheimer’s Society and Jurn Verschraegen, Director of the Flanders Centre of Expertise on Dementia.

All the specialists agree: dementia is set to be the biggest health challenge of the 21st century. This means that we will see more people with dementia at the bank, at the supermarket, at the restaurant, etc. The Flemish government is responding to this with its policy for elderly people.

Paying attention to dementia is the sensible approach, as informal carers and professionals alike will need to be able to deal with dementia appropriately. It is the responsibility of all governments, healthcare providers, patient organisations such as the Flanders Alzheimer’s Society (the Flemish section of the Belgian National Alzheimer’s Society LINAL), the Flemish and regional centres of expertise on dementia, but also of society as a whole to let people with dementia keep a valuable place in society and to provide the necessary care and support together. This is quite a challenge!

A comprehensive care policy for people with dementia

The Flemish government’s focus is on ensuring the appropriate assistance is provided to people with dementia and their environment. This all depends on optimal care and support, which should be controlled by the persons with dementia and their environments and should be determined by their actual care and support needs. These are important aspects of a comprehensive care policy recently established by the Flemish government in an updated Dementia Plan.

The numbers are clear: 36 million people currently have some form of dementia worldwide and the World Health Organization (WHO) is expecting this figure to quadruple by 2050. Flanders has not escaped this trend: 122,000 Flemish people currently have dementia and some form of dementia has been detected in a quarter of all people over the age of 80. By 2030, the number of Flemish people with dementia is expected to have risen by a quarter. Around 2060, the number of people with dementia living in Flanders will have exceeded 250,000. 70% of all Flemish people with dementia live at home with or without the support of family or carers.

The Flemish government updated its Dementia Plan at the end of June 2016: “Continuing To Build A Dementia Friendly Flanders Together” is based on the foundations of the first Dementia Plan of 2010 and adds more contemporary aspects such as prevention, representation and quality care. The choice to build on the existing plan should certainly be welcomed. It validates the choices made previously and fosters the continuity of the Flemish policy on dementia.

A working group of various Flemish stakeholders evaluated the previous plan and indicated which actions had and had not been taken. During the previous legislature, the Dementia Plan was followed up with a Transition Plan to increase the resilience of carers through psychoeducation and to develop the expertise of basic workers to meet the required standards of family care services, national health insurance services, etc. This attracted attention to the promotion of expertise on dementia in daily care and the support of people with dementia still living at home. A dementia reference network for these organisations has been developed further, so that staff can easily contact an expert in a specific field. Finally, the Flanders
Transition Plan invested in further establishing the dementia centres of expertise, which are driving this change together with the Flemish centre. In addition, there is cooperation with the Flanders Alzheimer’s Society – a patient organisation – in order to account for the perspective of the person with dementia and his or her environment.

**Focusing on dignity and quality of life**

Human dignity and quality of life remain important in the updated plan and its implementation. The competencies and capabilities of the person with dementia are important. The individual with dementia’s own view and control of living life as his or her own person is respected and encouraged. This also means that organised care and support must focus on the person’s own needs and expectations, rather than on his or her disease or condition.

Like the previous plan, this plan sees a nuanced representation of the condition as a prerequisite. This is reflected in a commitment by the government and healthcare organisations to use the term “people with dementia” rather than “dementia patients” or “demented”. In 2011, Flanders launched the campaign “Forget the dementia – Remember the person” using non-stigmatising counter-frames: these are alternative ways of looking at dementia that better reflect the reality and the person behind the condition. The associated web platform will be updated further and will address other target audiences such as media professionals and educators. A photo database which can be seen at [www.onthoumens.be/help-mee/hulpmateriaal/fotos/fotos-van-persoenen-met-dementie](www.onthoumens.be/help-mee/hulpmateriaal/fotos/fotos-van-persoenen-met-dementie) provides nuanced images. The way dementia is discussed determines the extent to which people feel appreciated as individuals. Attention is also paid to culture-sensitive care.

**Dementia-friendly communities in Flanders**

This representation is also extended to dementia-friendly municipalities: communities can use a digital application on the web to show how they are implementing this commitment in their policies. Candidate municipalities who want to become dementia-friendly are encouraged to set up initiatives to achieve this in consultation with VVSG (the Association of Flemish cities and municipalities), the regional centres of expertise on dementia and the Flanders Alzheimer’s Society.

Seven out of ten persons with dementia live at home, possibly surrounded by family, friends and acquaintances. The Flemish government will develop a comprehensive reference network to help carers provide good dementia care. This will strengthen both the autonomy of the persons with dementia and their carers. The plan strives towards coordinated, targeted care and customised support during the entire dementia process.

**Research and early onset dementia**

The plan also gives special attention to early onset dementia. There are an estimated 5,400 people with this condition in Flanders. A quality-guaranteed network is being set up for them on [www.jongdementie.info](www.jongdementie.info) on issues such as psychosocial counselling, buddies and accessible information.

Flanders also continues to support scientific research into dementia and dementia care. This is necessary if we want to deal with people with dementia in a well-informed way and if we want to eradicate dementia one day.

The plan will be implemented immediately and will be monitored continuously by the Flanders Centre of Expertise on Dementia in consultation with the Flemish government. The plan will be evaluated at an interim stage together with all stakeholders. The government chose to integrate the proposed action within the existing, available budgets as much as possible. We will continue to build a dementia-friendly Flanders across all policy areas and levels, together with people with dementia, their families and many other stakeholders.

One small final comment is that we have gradually come to realise that people with dementia should also be involved in the preparation of such a plan. Of course they were represented by the Flanders Alzheimer’s Society, but we could take this one step further by encouraging people with dementia to take on a role themselves in this regard. Patient organisations and other organisations in Flanders are currently working on this and we sincerely hope that people with dementia will be directly involved in a follow-up plan. Surely we must be able to achieve what seems to be a matter of course abroad? Slowly, but surely!
From initiative to policy: Slovenia’s National Dementia Strategy

Slovenia’s National Dementia Strategy was officially adopted on 25 May 2016. Štefanija Lukič Zlobec, President of Alzheimer Slovenija – Spominčica, describes the process of how the strategy evolved from an initiative to a national policy.

In May 2016, Minister of Health Milojka Kolar Celarc officially signed the “Strategy for coping with dementia in Slovenia until 2020.” In 2009 we became aware of the need for a Slovenian Dementia Strategy. Three Spominčica members – Dr Ales Kogoj (founder of the association), a neurologist and myself as acting president of the association – presented the initiative to the Parliamentary Health Committee. As we would also need political support, we contacted several members of the Slovenian Parliament.

Following a suggestion from members of the Health Committee, the Minister of Health established a Dementia Working Group of ten specialists from different dementia fields in January 2010. This Working Group finalised the Slovenian Dementia Strategy in December 2015 and it went on to public consultation for one month.

In May 2016, Minister of Health Milojka Kolar Celarc officially signed the “Strategy for coping with dementia in Slovenia until 2020” and in June she nominated 16 representatives to an Action Group for preparation of a Dementia Strategy Action Plan. The Action Plan is due to be completed by June 2017 – and we are on the job!

Preparation and groundwork

Spominčica made its first contacts with Alzheimer Europe (AE) in 2009 and was accepted as a full member at AE’s Annual Conference in Vienna in 2012. At that time, we also proposed to host an AE conference in Slovenia. This became reality when Spominčica co-hosted the 25th Alzheimer Europe Annual Conference in Ljubljana in September 2015, under the Honorary Patronage of President Borut Pahor. The event attracted 572 delegates from 45 countries, including 26 people with dementia. At the same time, we also hosted the Annual Conference of the Mediterranean Alzheimer’s Alliance, with delegates from 20 Mediterranean countries.

From 2010, the Dementia Working Group worked very hard and encountered various difficulties – but also received lots of ideas, information and suggestions from Alzheimer Europe and its members. For example, we put together a considerable lobbying effort in Slovenia, thanks to a suggestion from our Irish friends at an AE meeting. We also reviewed existing European dementia strategies and made use of their experiences and best practices. We
received additional help from Alzheimer’s Disease International (ADI): when Executive Director Marc Wortmann visited Ljubljana to lend his support, we had the opportunity to meet President Pahor in the presidential palace.

During this time, we also worked to raise awareness of dementia among the Slovenian public. We are very pleased that Spominčica now has over 20 branches and is active throughout the country with a telephone helpline, self-help groups, education activities, Alzheimer Cafés and the Spominčica magazine. Our efforts are aimed at supporting people with dementia and their carers, but also toward raising awareness and contributing to a dementia-friendly society. We are glad to have the support of various media organisations to help us disseminate news of our activities.

In 2015 we also launched a vast public awareness campaign in support of AE’s Glasgow Declaration campaign. Our campaign was tremendously successful: Spominčica gathered the highest number of signatures per capita and we were also first in the absolute number of signatures collected – 1,752. In addition, we managed to attract the Slovenian Members of the European Parliament, all of whom signed the Glasgow Declaration.

Keeping up the momentum

Our public events have always been popular and we are continuing to leverage them to gain awareness.

Spominčica and University Psychiatric Clinic Ljubljana have prepared and organised seven psychogeriatric meetings in the last 17 years. These are aimed at individuals who are professionally or otherwise in touch with persons with dementia and their carers. The 8th Psychogeriatric Conference, took place on September 16–17 in Terme Dobrna, entitled “Live with dementia in dementia friendly environment”. The conference mainly focused on exchanging information and experiences from various professions related to dementia. The sessions contributed to promoting quality and the humane care of people with dementia, as well as improving the quality of life of their families.

In 2017, Spominčica will celebrate 20 years of providing help and support to persons with dementia and their carers.

For all of us in the dementia field, the adoption of the Dementia Strategy was very important. Public recognition makes it much easier to pursue our activities, even if there is still plenty of work ahead to attain the objectives of the strategy.
Switzerland evaluates progress of its national dementia strategy

On 2 May 2016, the Swiss Ministry of Health (Federal Office of Public Health – FOPH) hosted a meeting in Bern to assess the state of implementation of Switzerland’s “National Dementia Strategy 2014–2017”. Jean Georges, Executive Director of Alzheimer Europe, attended the event.

Pascal Strupler, Director of the Federal Office of Public Health, welcomed the audience and invited them to discuss the implementation of the Swiss “National Dementia Strategy 2014–2017”. The discussions focused particularly on the new insights regarding prevention, quality of care and research, but also to what extent the National Dementia Strategy (NDS) takes the above-mentioned aspects into consideration.

Switzerland, like many other European states, has developed a national dementia strategy. Among these strategies there is a broad consensus both in terms of objectives and in terms of areas of action. Jean Georges, Executive Director of Alzheimer Europe, confirmed this general analysis and highlighted that, in principle, the focus was placed on persons affected by dementia. These strategies identified the following challenges:

- improvement of the quality of life for those affected
- reduction of stigmatisation through greater public awareness
- financial guarantee and support for the caregiving relatives
- health care research and, to some extent, fundamental research

According to feedback from experts in the audience, most of these challenges have been included in the NDS. It should also be noted that the essential points from the Paris Declaration on the political priorities of the European Alzheimer Movement adopted in 2007 have been taken into account. This is not the case for all strategies. Alzheimer Europe hence particularly valued that the Swiss strategy focuses on the dignity of the people affected by dementia as well as the quality of life of these people and their relatives.

Furthermore, Alzheimer Europe emphasised the following important topics which are included in the NDS: public awareness, de-stigmatisation, caregiving relatives, coordination, specific care related to dementia in long-term care facilities and in hospital intensive care settings and quality of care and support. Switzerland’s strong commitment regarding international cooperation is also noteworthy, as it is crucial to learn from one another in this regard.

The Swiss National Dementia Strategy

Approximately 119,000 people in Switzerland live with dementia. The main objective of the strategy is to support those affected by dementia and enhance their quality of life, while consistently considering their individual circumstances. At the end of 2013, the National Health Policy Dialogue approved the “National Dementia Strategy 2014–2017”. The strategy defines four areas of priority action:

- health awareness, information and participation
- needs and appropriate services
- quality and professional skills
- data and knowledge transfer

An English summary of the strategy is available at http://bit.ly/2dLR6Tc

For further information, please contact: demenzstrategie@bag.admin.ch
Slovakia conference aims to advance national dementia strategy

In May 2016, the Slovakian government hosted a symposium to showcase progress and address challenges in developing its national dementia strategy. Dr Charles Scerri, Honorary Secretary of Alzheimer Europe, was a guest speaker and provided a report from the event.

The “National program: to conquer Alzheimer’s disease and other forms of dementia” symposium took place on 18–20 May 2016 and was organised by the Institute of Neuroimmunology of the Slovak Academy of Sciences and the MEMORY Centre, under the auspices of the Ministry of Education, Science, Research and Sport. The event took place shortly before Slovakia took over the EU Presidency and the government had previously announced that dementia would continue to be a priority during its term.

The symposium was chaired by Professor Michal Novak, Head of the Institute of Neuroimmunology, while Darina Grniakova, Head of the Slovak Alzheimer’s Society, was a member of the organising committee. According to Prof. Novak, there are some 60,000 people with dementia in Slovakia. While the overall population is in decline, the number of retirees is set to increase by one million people by 2060. Prof. Novak said this could no longer be ignored and also showed the urgent need for a Slovakian national dementia strategy.

The agenda offered a complete overview of the activities taking place in Slovakia to deal with the challenges of dementia. This included the activities of the MEMORY Centre, a specialised facility using non-pharmacological therapies for people with dementia. Scientific and research aspects were also discussed, such as immunotherapy, testing for primary progressive aphasia, the role of nucleic acids and biomarker discovery for earlier diagnosis.

This event also featured presentations from visiting speakers about international organisations such as Alzheimer Europe and the status of national dementia strategies around the world.

Dr Scerri spoke about Alzheimer Europe’s work to make dementia a national and European priority, citing epidemiological data from the European Cooperation in Dementia (EuroCoDe) study and the increasing public health impact of dementia in the EU. He also outlined the key achievements since AE launched the Paris Declaration in 2006. These include various EU research collaboration programmes and a growing number of national dementia strategies in European countries. AE’s 2014 Glasgow Declaration campaign was a further call for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also called upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Dr Scerri said: “Alzheimer Europe welcomes the commitment of the Slovak government to maintain dementia as a priority during its EU Presidency term. International cooperation is clearly essential in facing the challenges of dementia; no single country or organisation can succeed on its own.”
Dutch EU Presidency conference focuses on “Living well with(out) dementia”

On 9–10 May 2016, the Ministry for Health, Welfare and Sport of the Netherlands hosted an international dementia conference in Amsterdam. The main themes were innovation in health care and in society as a whole, to ensure that people with dementia can continue to function independently in society for as long as possible.

The conference was opened by Martin van Rijn, State Secretary for Health, Welfare and Sport. He welcomed over 140 delegates from around the world, including people with dementia and representatives from numerous national Alzheimer associations in Europe. He also presented an agenda centred on integrated and holistic approaches to dementia, which would contribute to sustainable and affordable care.

National, European and global visions on dementia

The first speaker was John F. Ryan, Acting Director of the European Commission’s Public Health directorate, who presented current EU initiatives and activities in supporting dementia research and care. This was followed by a worldwide vision, presented by Dr Shekhar Saxena, WHO Director of the Department of Mental Health and Substance Abuse and Dr Yves Joanette, Chair of the World Dementia Council. Mr van Rijn came back with an overview of activities in the Netherlands, such as the launch of a national campaign to develop a dementia-friendly society. This new campaign is supported by various public and private partners, who were on hand to show how their organisations are initiating dementia-friendly initiatives all around the Netherlands. Mr van Rijn later presided over the launch of the dementia-friendly campaign, which is also covered in this article.

The first plenary session ended with an interview with Mr Chris Lammers, who is living with Alzheimer’s disease. He said that his diagnosis was the beginning of a new life and that his most important message to others is to “create more openness about the disease”.

“Care should be based on a strong connection to the way people with dementia used to live their lives.”

MARIE ANTOINETTE BACKES, CARER

Living well without dementia

The conference was structured around three key themes and “Living well without dementia” was the first to be addressed. Dr Tiia Ngandu from Finland’s National Institute for Health and Welfare presented “Scientific evidence on prevention” and this was followed by “Prevention of carers’ stress” by Dr Anne Margriet Pot from the WHO. Delegates were then invited to attend separate sessions dealing with various aspects of dementia prevention.
The afternoon plenary session ended with the personal story of Mr Henk van Pagee, who was in the early stages of Alzheimer’s disease. He shared his experiences during the diagnostic process and described how he and his wife have learned to live with the symptoms: “Don’t get angry, be amazed at what happens to you.”

Prevention: you’ll never walk alone
In this session, Prof. Alexander Kurz from the Technical University of Munich gave an update on the RHAPSODY project, which aims to improve care for people with young onset dementia by supporting their carers. Prof. Craig Ritchie from the University of Edinburgh presented EPAD, another EU-funded project that aims to improve the chance of successfully preventing Alzheimer’s dementia and to better understand early aspects of Alzheimer’s disease before dementia develops. They were followed by Leiden University’s Ms Laura Steenbergen, who presented “A healthy diet for a healthy life: promoting social cognition and mental well-being in the elderly through tryptophan and probiotics”.

Prevention and lifestyle
This session began with Prof. Frans Verheij from Maastricht University, who spoke about IN-MINDD, a project that seeks to promote long-term brain health and prevent or delay the onset of dementia by combining social innovation, multifactorial modelling and clinical expertise. Dr Charles Alessi, a Senior Advisor for Public Health England, presented “Prevention of dementia in public health care” and showed various tools to raise awareness of risk reduction. These included the UK Dementia Friends campaign message “what to do at age 40 for profit in later life”. Prof. Erik Scherder from VU University spoke about the effect of physical exercise on brain health: he showed that aerobic physical activity is associated with better cognitive functioning and a decrease in dementia incidence.

Living well with dementia at home
The second day began with a plenary session around this second main theme. Prof. Myra Vernooij-Dassen from Radboud University spoke about treatment and support for people with dementia while the latest insights on diagnostics were presented by Prof. Philip Scheltens from VU University.

Mr Peter van Vegten ended the plenary with his personal experiences as an informal carer of his wife, who developed cognitive complaints 19 years ago and was diagnosed with Alzheimer’s disease 11 years ago. Contact with other caregivers of people with dementia served as a support for Peter, as he could talk about daily struggles and learn from others’ experiences and suggestions. He felt that his experience was more important and significant than that of many professional carers he met. Peter emphasised that the case manager should be present in the diagnosis process and that caregivers should be informed of the prognosis.

“We want both more research into a cure, and better care which leads to a more meaningful life right now”
MARTIN VAN RIJN
As on the first day, the agenda continued with two further sessions:

**Diagnosis, co-morbidity and care**

Prof. Sube Banerjee from the Brighton and Sussex Medical School presented “Improving diagnostics and follow-up”, which stressed the importance of a timely and high-quality diagnosis for people with dementia symptoms. He was followed by Prof. Cornelia van Duijn of Erasmus University, who spoke about the CoSTREAM project: this five-year effort will investigate the metabolic relationships between Alzheimer pathology and stroke, which often co-occur. Dr Marjolein de Vugt from Maastricht University presented the ACTIF Care project – funded by JPND – which will seek insights into international differences in dementia care, to eventually establish international best clinical practice recommendations and optimise the costs and consequences.

**Better diagnostics, then what?**

Dr Mária Čunderlíková began this session by presenting “All under one roof”, referring to the Bratislava Memory Center. The Slovakian NGO provides a comprehensive range of services, including social services (day care for AD patients, cognitive training), counselling, a psychiatric clinic and training for caregivers and social health care workers. Prof. Rose-Marie Droës from VU University spoke about MeetingDem, another JPND project that aims to implement and evaluate the Meeting Centres Support Programme for people with dementia who live at home and their carers. Finally, Prof. Wiesje van der Flier from VU University gave an overview of the ABIDE project, whose aim is to identify the most efficacious tests – and when to administer them – for accurate and timely diagnoses of dementia.

**Living well with dementia in care homes**

The final plenary session was launched by Prof. Iva Holmerová from the Czech Centre of Gerontology. She spoke about the challenges and ethical dilemmas faced by care professionals in dementia homes all over Europe. She also cited Alzheimer Europe’s recent work to identify these dilemmas and develop quality indicators for dementia care. Prof. Lieve Van den Block from Free University Brussels spoke about PACE, the “Palliative Care for Older People” project that aims to improve the quality of life of people with dementia for as long as possible.

The last speaker was Ms Marie Antoinette Backes, who has worked for over 35 years in caring for the elderly, including her mother, who has dementia and was ultimately admitted to a nursing home. Ms Backes has been the director of several care organisations but currently works as a care consultant. In daily practice, she noted that care is often very task-oriented, without enough attention for individual contact and the person behind the dementia. She believed that care should be based on a strong connection to the way people with dementia used to live their lives.

The two last sub-sessions were as follows:

**Improving institutionalised care and prevention/avoidance of hospitalisation**

Prof. Sophia de Rooyl, from Groningen’s University Medical School, presented “Hospital@Home”, a project investigating the effectiveness of post-diagnostic, hospital-level care at home. The next speaker was Prof. Raymond Koopmans from Radboud University, who spoke about the challenges of treating and supporting institutionalised people with young onset dementia – such as the high use of psychotropic medicines. Dr Marjolein van Vliet from Vilans Consulting continued with a talk about the consequences of improper uses of these drugs and of physical and verbal restraints.

**Quality of life for everyone**

Dr Georgios Meditskos presented the DEM@care project, which is developing technological solutions to aid in the diagnosis and management of people with dementia. These are based on multi-sensors that provide remote monitoring of daily activities and provide feedback about cognitive, behavioural and functional problems. He was followed by Dr Jenny van der Steen from VU University, who presented the Namaste Care Family programme for people with advanced dementia and their families. The programme aims to improve their quality of life by engaging senses such as touch and smell in a calming environment. The last speaker was Dr Tonnie Coppus from Radboud University, who focused on the rising occurrence of dementia in people with intellectual disabilities such as Down’s syndrome. She noted that co-morbidities are often under-reported and under-diagnosed in this population, leading to a lack of proper care and support.

**International cooperation on dementia**

The final plenary session focused on how dementia is becoming an international public health concern. Dr Dirk Pilat, a Deputy Director of OECD, showed how his organisation measures performance in dementia care across its member countries and...
seeks to improve the way data is shared, stored and used. The OECD is also looking to adapt the current regulatory barriers for the development of new dementia medicines. The EU is also a big international supporter of dementia research and care: Dr Ruxandra Draghia-Akli, Director of the European Commission’s Health Directorate, noted that the EU has invested EUR 800+ million in dementia research via the Seventh Framework (FP7) and Horizon2020 programmes. She also mentioned various public-private partnerships that are accelerating the delivery of innovative treatments. The final speaker was Prof. Michal Novak from the Slovak Academy of Sciences. He presented his country’s programme on Alzheimer’s disease, specifying that research, clinical procedures and social services would be priorities during Slovakia’s EU Presidency term.

The conference ended with a speech by Mr Erik Gerritsen, Secretary General for Health, Welfare and Sport in the Netherlands. He presented a short video of conference highlights and reminded the delegates of the importance of investing in research as well as care and social innovation. He particularly highlighted the growing role of ICT devices in improving the lives of people with dementia. Mr Gerritsen thanked the delegates for their participation and closed the conference.

Alzheimer Europe was represented by Chairperson Heike von Lützau-Hohlbain, Vice-Chairperson Iva Holmerová, Honorary Secretary Charles Scerri and Executive Director Jean Georges.

This article was mainly based on the official conference report – see link below. Alzheimer Europe is grateful for the contributions of Dr Jacqueline Hoogendam, Senior Policy Advisor at the Dutch Ministry of Health, Welfare and Sports.

http://english.eu2016.nl/documents/publications/2016/05/09/living-well-without-dementia

“A new dementia-friendly campaign launches in the Netherlands”

On 9 May, a new dementia-friendly campaign was launched in the Netherlands. The five-year action will be co-managed by Alzheimer Nederland within the country’s national Dementia Delta Plan.

The campaign was officially launched by Martin van Rijn, State Secretary for Health, Welfare and Sport, during the Netherlands’ EU Presidency conference “Living Well With(out) Dementia”.

Mr van Rijn said that “Together, we can make the Netherlands dementia-friendly. In this country, 70% of people with dementia live at home. We all need to show extra consideration for people with this disease. They live in our village, our neighbourhood, our street. Sometimes they need people who realise what’s going on when they are confused at the hairdresser’s or board a bus having forgotten their destination. We are those people, those helping hands.”

There are an estimated 260,000 people with dementia in the Netherlands and their number will increase to 400,000 by 2050. People live for an average of eight years with dementia, of which six years are spent at home and two years are in a care institution.

Enhancing knowledge and awareness of dementia is part of the reform of long-term care in the Netherlands, which is designed to improve the standard and durability of care and get more people involved.
135 MEPs support a declaration to make dementia a European priority

In April 2016, 11 Members of the European Parliament submitted a Written Declaration aiming to make dementia a top EU priority. While the Declaration failed to attract the required support, Alzheimer Europe is grateful to the MEPs that showed their support to people with dementia and their carers.

Written Declaration 0027/2016 specifically called upon the Council and the Commission to make combating Alzheimer’s disease and other types of dementia a top priority of the European Union and also to put further emphasis on cooperation among Member States in the areas of research, care and prevention. The Written Declaration included the following statements:

• every year 1.4 million Europeans develop some form of dementia, with the World Health Organisation estimating that 6.4 million people are living with dementia in the European Union
• by 2050 the number of people over 65 in Europe will be three times higher than in 2003, and five times higher in the case of the over 80s, thus widening the pool of people at risk of dementia
• dementia and its related health consequences have a tremendous impact on the people affected, their families, caregivers and society as a whole, and studies have shown that improved cardiovascular risk factors and higher education levels can lead to a reduction in national dementia cases
• the Council and the Commission are hence called upon to make combating Alzheimer’s and other types of dementia a top priority of the European Union, and to put further emphasis on cooperation among Member States in the areas of research, care and prevention
• this declaration, together with the names of the signatories, is forwarded to the Council and the Commission

The declaration required the support of the majority of MEPs in order to proceed further. By the closing date of 11 July 2016, 135 (of 751) MEPs had expressed their support. This was clearly short of the majority and caused the declaration to lapse on the same day.
Alzheimer Europe wishes to thank all the signatories for expressing their support to improve the lives of people with dementia and their carers in all European countries.

Austria: Heinz K. Becker, Barbara Kappel
Belgium: Tom Vandenkendelaere, Hilde Vautmans, Lieve Wierinck
Bulgaria: Iskra Mihaylova, Vladimir Urtuchev
Croatia: Ivan Jakovčić, Dubravka Šuica
Cyprus: Neoklis Sylikiotis
Czech Republic: Jan Keller, Kateřina Konečná, Jiří Maštálka, Stanislav Polčák, Olga Sehnalová, Pavel Svoboda, Pavel Telička, Evžen Tošenovský, Tomáš Zdechovský
Denmark: Christel Schaldemose
Estonia: Yana Toom
Finland: Heidi Hautala, Liisa Jaakonsaari, Anneli Jäätteenmäki, Merja Kyllönen, Sirpa Pietikäinen, Pirkko Ruohonen-Lerner, Hannu Takkula
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Germany: Maria Heubuch, Dietmar Köster, Jo Leinen, Renate Sommer, Axel Voss
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Hungary: István Ujhelyi, Lara Comi, Andor Deli, György Hölvenyi, Ádám Kősa, Csaba Molnár, Péter Niedermüller, Tibor Szanyi
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Sweden: Peter Lundgren, Jasenko Selimovic
United Kingdom: Martina Anderson, Diane Dodds, Neena Gill, Ian Hudghton, Afzal Khan, David Martin, Linda McAvan, Catherine Stihler, Keith Taylor, Julie Ward
WHO Executive Board gives green light to global dementia policy

On 30 May 2016, the WHO Executive Board unanimously adopted a draft decision to develop a global action plan for dementia. The decision will be submitted for approval at the 70th World Health Assembly in May 2017.

The vote to adopt the draft decision took place just after the 69th World Health Assembly in Geneva. However, the text of the decision (see below) was drafted during a WHO Ministerial Panel meeting dedicated to "Alzheimer’s disease and other related diseases" on 23 May. This Panel was convened by the Swiss government and co-sponsored by the governments of Canada, Monaco, Panama and Zambia.

Swiss Federal Councillor Alain Berset welcomed the delegates and WHO Director General Margaret Chan made a statement identifying dementia as a key health priority for all governments.

She was followed by a number of Ministers of Health, who recalled the commitment of their respective governments to dementia, stressed the importance of greater global and European collaboration on dementia and gave their support for the development of a resolution on dementia at the next World Health Assembly. This approach was supported by:

- Sabine Oberhauser, Federal Minister of Health of Austria
- Tedros Adhanom, Minister of Foreign Affairs of Ethiopia
- Hermann Gröhe, Federal Minister of Health of Germany
- Lydia Mutsch, Minister of Health of Luxembourg
- Justyne Caruana, Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing of Malta
- Edith Schippers, Minister of Health, Welfare and Sport of the Netherlands
- Sylvia Mathews Burwell, Secretary of Health and Human Services of the United States of America

Alzheimer Europe was represented at the World Health Assembly and the Ministerial Panel by Executive Director Jean Georges.

Text of the WHO draft decision

Dementia
Draft decision proposed by the delegations of Austria, Canada, Denmark, Dominican Republic, Ethiopia, Finland, Germany, Japan, Republic of Korea, Luxembourg, Malta, Monaco, Netherlands, Panama, Switzerland, United Kingdom of Great Britain and Northern Ireland, United States of America, Uruguay and Zambia.

The Executive Board, having considered the report by the Secretariat on Dementia (Document EB139/3):

(1) noted that the response to the global burden of dementia can be greatly enhanced by a shared commitment among Member States and all other stakeholders to put in place the necessary policies and resources for care of people with dementia, to promote research, to find disease-modifying treatments or cure, and to give adequate priority to action against dementia in national and global political agendas;

(2) decided to request the Director-General to develop with the full participation of Member States and in cooperation with other relevant stakeholders a Draft Global Action Plan on public health response to Dementia, for consideration by the Seventieth World Health Assembly, through the 140th session of the Executive Board.
A new leader and fresh objectives for the World Dementia Council

The World Dementia Council was re-formed in 2016, bringing together a broad range of global leaders with experience of dementia. Alzheimer Europe spoke to new Chairman Yves Joanette about the WDC’s work to help make dementia a global health priority

The WDC has recently been re-formed. Can you give us a brief overview of the new organisation?

The WDC was established after the G8 dementia summit led by the UK Government to support the efforts of the World Dementia Envoy, Dr Dennis Gillings, by drawing together international expertise, simulating innovation and coordinating international efforts to identify a disease-modifying therapy or cure by 2025.

As it is increasingly recognised that a global, collaborative approach to dementia is essential – as reflected by the first WHO Ministerial Conference on Global Action Against Dementia attended by over 80 member states – the WDC has evolved, re-forming in March 2016 to become truly globally representative and independent of the UK Government. The role of the UK Dementia Envoy is now undertaken by David Mayhew, while the Council has elected me as Chair and Raj Long as Vice-Chair.

The membership of the Council has increased from 18 to 24 covering six continents, with greater representation from low- and middle-income countries (LMIC) given the fact that by 2050, the majority of the cases of dementia will be in LMIC. The re-formed WDC brings together the broadest range of influential global leaders from all sectors, with expertise in and experience of dementia.

The Council is supported by a number of Associate Members which include the Governments of Australia, Japan, Mexico, the Netherlands, Canada and the UK. Other Associate Members include the OECD, WHO and Young Leaders Network. Though non-voting, their role is crucial in helping to ensure the WDC’s agenda aligns with other important global dementia initiatives, providing the Council with important advice, guidance and intelligence.

Prior to March 2016, the Council was supported by the UK Department of Health. The WDC now receives funding from an array of different governments, stakeholders and organisations so as to ensure it is fully autonomous. We will shortly be incorporating as a not-for-profit organisation under UK charity law. The Council as a whole will remain sovereign.

Where does the WDC stand in relation to other global organisations such as the WHO or Alzheimer’s Disease International (ADI)? How will these bodies establish a common agenda to work together?

The role of the WDC is to tackle areas where our members have a unique added-value, such as identifying and promoting new and innovative funding models, and bringing together all stakeholders within an integrated drug development environment.

We have already made real progress with this, having contributed to the creation of the Dementia Discovery Fund – the first to bring together private, public and philanthropic investment. This initiative has raised USD 100 million and achieved an unprecedented collaboration of 11 international medicine regulators from ten agencies. The Council also played an important role in bringing together regulators in order to identify the best option to accelerate the procedure from research to the market for the future drugs that could help attain the 2025 goal.

At the same time, the WDC works to connect the dots to ensure a truly global approach. A recent example of this is linking the Atlantic Philanthropy-supported Global Brain Health Institute (which trains and supports a new generation of leaders to translate research evidence into effective policy and practice) with the AARP-Age UK Global Council on Brain Health – an independent organisation which provides information on how all of us can maintain and improve brain health.

The Council is very cautious about not duplicating any other efforts. By having the WHO as an Associate...
Member, and with six council members belonging to organisations which are part of ADI, we ensure lines of communication are open in order to work towards a common agenda.

Who is Yves Joanette? What is your vision of the way forward for the WDC?

I trained as a Cognitive Neuroscientist and Neuroimager and since childhood have always been fascinated by the brain. When I started out, dementia was poorly understood and frankly an unfashionable research area. However, as the field evolved, there has been an increasing interest in brain ageing and I came to see dementia as the quintessence of the brain’s complexity, nor could I ignore the social challenge it poses to those diagnosed, their families and carers.

As my career developed, I’ve always been an advocate of global collaboration. In my former role as President and CEO of the Quebec Research Fund, and now as Scientific Director at the Canadian Institutes of Health Research (CIHR) Institute of Aging, my philosophy has been that for the benefit of patients, we have a responsibility to work together not against each other. As an example, my team and I have contributed to make Canada the first non-European country to join JPND.

I was nominated by the UK Government to sit on the WDC when it originally formed in May 2014. In March 2016 I was elected Chair by the members, which was a real honour. Raj Long, Senior Advisor at the Bill & Melinda Gates Foundation, was elected Vice Chair. Raj and I make a good pair as we have different skill sets.

What are the WDC’s main priorities? How will they be delivered and their effectiveness measured?

The vision of the WDC is to achieve a world where society, governments, industry, researchers and health and care systems have worked together to transform the prospects for people affected by Alzheimer’s and other forms of dementia so that the diseases no longer destroy lives in the way they do today. We have five core priorities:

- advancing levels of innovative and global public and private finance
- increasing the speed and reliability of delivering innovative medicines through efficient and effective integrated drug development
- fostering a culture of open science and collaborative global research, including the use of big data approaches
- ensuring the quality of life and delivery of quality care for people living with dementia and their carers
- reducing the risk of dementia through lifestyle and other approaches

Following our recent meeting in Toronto, where the overall strategy was agreed, we have established global teams that are working right now to set objectives and deliverables.

How are people with dementia involved in WDC activities? How important is their participation?

The WDC strongly believes in the importance of the voice of those individuals living with dementia in helping to identify and take forward global priorities. What’s important to us is that we have continuous input from people with dementia and that they are involved in all our decision making. We have two Council members who are living with dementia – Hilary Doxford from the UK and Kate Swaffer from Australia. We also gain a breadth of insight from our members – clinicians, researchers, care providers, the leaders of patient organisations and others who are at the front line, working with people with dementia on a daily basis.

People affected by dementia are the experts on what it is like to live with dementia and we, as a Council, need to have that insight to inform our work.

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YVES JOANETTE
On 11 May 2016, the Committee of Ministers of the Council of Europe adopted a new set of recommendations to its 47 member States on the removal, storage and use of human biological materials for research purposes. Their purpose is to safeguard the rights of persons who contribute such materials but also provide adequate access to biological materials for researchers.

The new recommendations take into account new developments in the field of biobanking, such as the increasingly diverse origin of biological materials stored in collections, the difficulty to guarantee non-identifiability of such samples, the increasing amount of research involving materials coming from different collections, and the importance of research on biomaterials removed from persons not able to consent.

Biomedical research on materials of human origin is a powerful tool to improve human health and healthcare systems, the new legal instrument acknowledges, and the development of collections and cross-border flow of such research materials is increasing. However, this raises questions of the risk for private life of the persons concerned, as well as of the autonomy that these individuals have over their biological materials once they have been removed.

The purpose of these new recommendations is to spell out and safeguard fundamental rights of the persons whose biological materials are intended for biomedical research. Their dignity, integrity and privacy must be guaranteed, while at the same time the researchers should benefit from the access to biological materials.

The new legal instrument sets out the conditions for obtaining and storing materials for future research as well as for using them in specific research projects, in particular regarding appropriate information and consent of the persons concerned.

The governance of collections is an important theme covered by the document. Taking into account the trend of developing collections of biological materials of human origin at national level, the Recommendation stresses in particular that their governance should be guided by the principles of transparency and accountability. Information about the management of collections should be publicly available, and clear procedures for storing, accessing, using and, where appropriate, transferring the collection materials should be put in place. Each collection should be subject to independent oversight.

The Committee of Ministers recommends to member States adapting their laws and practices and promoting the establishment of codes of good practice to ensure compliance with these recommendations. The current Recommendation succeeds Recommendation Rec(2006)4; it was developed following a public consultation process involving all the stakeholders, in particular medical associations, scientists, ethics bodies and patient organisations.

The full text of the new Recommendation can be seen at https://search.coe.int/cm/Pages/result_details.aspx?ObjectId=090000168064e8ff
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Alzheimerforeningen: 25 years of dedicated commitment for people living with dementia

Alzheimerforeningen, the Danish Alzheimer Association, has a long legacy of helping to improve the lives of people with dementia in Denmark. In this article, CEO Nis Peter Nissen provides an overview of the association’s work.

When Ann Overby was diagnosed with Alzheimer’s disease she began to paint. Optimistic and colourful paintings full of funny figures and hidden symbols. She explains that when she paints, the colours make her happy.

Two of her paintings can now be seen in the Alzheimerforeningen office in Copenhagen. When members, guests and staff look at the paintings they very often smile. They can see the joy, hope and happiness in the colours.

The paintings of Ann Overby thereby remind us all about a very important aspect of dementia: people living with dementia can – as everybody else – give us something that enriches our lives. We also use the story of Ann Overby and her paintings as a symbol of what the association’s work is all about.

People living with dementia, as their loved ones, hope for a cure to stop the disease. But they also want to be seen as the persons they are – as Ann, the painter – and not just as someone with a serious illness. They want to be respected and included and they want to take part in shaping their own future for as long as possible.

For 25 years this has been one of the main agendas of Alzheimerforeningen, founded in 1991 as a member association to fight Alzheimer’s disease and other dementias and to work for a better treatment, improve care and respect of people living with dementia.

Dementia Friends in Denmark

Today the association has 13,000 members, 12 local branches, 50,000 followers on Facebook and 13,500 Dementia Friends. The Dementia Friends campaign was started in 2016 and is inspired by and with good advice from the UK Alzheimer’s Society. The goal is to find 100,000 Dementia Friends by the end of 2020 – a little more than one friend to every person living with dementia in Denmark.

Alzheimerforeningen has four major activities: support and advice to people with dementia and careers, fund-raising for research, information about dementia and advocacy towards local, regional and national policymakers.

The association has a telephone hotline and an internet helpdesk, runs activity centres, seminars and physical training courses for people with dementia, educates staff at nursing homes about dancing and dementia and organises dementia cafés and career support groups all over the country. In 2015, a new initiative focusing on children and teenagers of parents with dementia was launched in three major cities.

Ride for a cure

An Alzheimer Research Fund has been established with a special Alzheimer Award and major research grants awarded each year on World Alzheimer’s Day. In 2016, a special ride for a cure fund-raising event was organised at the Danish Dressage Championships.

Fighting stigma and changing the perception of dementia is an important part of the work done by Alzheimerforeningen. 25 years ago, most people thought of dementia as a natural part of being old and public care for people with dementia was organised mainly as help to people of old age. Many things have happened since then, but people living with dementia still struggle with taboos and misunderstandings. The Dementia Friends campaign is one of many activities that is altering the image of dementia, but also working with social media, PR
Involving people with dementia

In 2009 Alzheimerforeningen began lobbying for a national dementia strategy and action plan. With help from Alzheimer Europe's report on European prevalence figures, the association succeeded in convincing the parliament and in 2010 the first Danish National Dementia Action Plan was published. In 2015 during the general election the Danish Alzheimer's Association began to campaign to put dementia on the Prime Minister's agenda. After the election the Prime Minister announced that the Government would draw up a new dementia action plan. The new Dementia Action Plan was published in September 2016.

Involving people with dementia

For ten years, Alzheimerforeningen has organised a nationwide Tænketank (think tank) with people living with dementia and their carers. The think tank participants discuss important aspects of life with dementia, leading to answers and suggestions to problems the association should attend to. The think tank was also active in formulating wishes and suggestions to the dementia action plan. Alzheimerforeningen organised three dialogue think tank meetings where persons living with dementia had the opportunity to address the Minister of Health and members of the national parliament directly. The dialogue meetings participants suggested among other things better help with transport and access to more meaningful daily activity. Both of these initiatives are now included in the final National Dementia Action Plan.

The successful empowerment campaign continues and Alzheimerforeningen is now lobbying to establish a national dementia council with representatives of people living with dementia. In this way the association tries to make an important contribution to the association of people living with dementia in the way the association works.

National dementia action plan

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Alzheimer’s and the Mediterranean: specific needs, common solutions

The Monegasque Association for research on Alzheimer’s disease (AMPA), published the first “Alzheimer and the Mediterranean” report (ALZMED) and officially launched the Mediterranean Alzheimer Alliance (MAA) on World Alzheimer’s Day during a press conference in Paris. This unprecedented initiative in the Mediterranean aims to make Alzheimer’s disease a public health priority in this region.

The MAA was launched by AMPA in 2013 and currently has 17 member countries. It is the only network composed of Alzheimer associations, scientific experts and healthcare professionals from each country. One of its first achievements was the publication of this report.

In many Mediterranean countries, there is still little knowledge about the problems surrounding Alzheimer’s disease, which remains underestimated and insufficiently documented.

1. An alarming rise in the number of people with dementia

In 2015, 46.8 million people were thought to have Alzheimer’s disease and related disorders around the world. This number is set to double every twenty years to reach 131.5 million people in 2050. According to the latest international data, the number of people with dementia is set to be even more significant in low and middle-income countries. In Italy, the number of people with dementia is set to increase by 83.08% by 2050. In Lebanon, this increase may be 310%.

2. A disease that is still not recognised as a priority

The ALZMED report notes that many Mediterranean countries do not currently recognise dementia as a public health priority. Only seven countries have launched a national dementia strategy. By developing such strategies, Mediterranean countries will be in a better position to meet the specific needs of people with Alzheimer’s disease and their carers, to develop new methods of care and earmark the funding needed to reform social protection systems.

3. The difficulty to assess the financial impact of Alzheimer’s disease

On an international level, studies have estimated the total cost of Alzheimer’s disease and related disorders at USD 818 billion. Worldwide, 80% of these costs are social care costs and informal care costs while only 20% are direct medical costs. Most countries in the Mediterranean region follow this pattern, but family care costs are slightly higher in North Africa. The report highlights the lack of national studies regarding the cost of Alzheimer’s disease and related disorders in the Mediterranean, which need to be developed further.

4. The importance of timely/early diagnosis

It is considered that an early diagnosis of Alzheimer’s disease enables care to be optimised. The report confirms that people in the Mediterranean region are still receiving a late diagnosis. The main reasons are the lack of training among general practitioners, the limited number and unequal distribution of diagnosis centres and inadequate diagnosis tools, which are not always appropriate to the needs of each country.

5. The faltering familial solidarities

The strength of the family and intergenerational solidarity, which is still particularly pronounced in the Mediterranean area, is also one of the elements underpinning the unity of the region. However, under the burden of disease, family solidarity is starting to falter, due to recent demographic changes in the Mediterranean. The report shows that family carers...
in the Mediterranean suffer from a lack of status recognition from the national authorities.

**6. Institutional healthcare supply and services which are not specific to dementia**
In the Mediterranean area, hospitals are largely responsible for caring for people with dementia. Despite a few exceptions, home-based care and institutional healthcare supply are very rarely suited to the specificities of dementia. When they do exist, these facilities and services are unequally distributed throughout each country.

**7. A general lack of training among professionals**
The ALZMED Report notes that the number and geographical distribution of professionals does not allow the specific requirements of dementia to be met. Moreover, it highlights the lack of specific training among all types of professionals in the Mediterranean region.

**8. Unequal access to medical treatment and psychosocial interventions**
To date, no cure for Alzheimer’s disease exists. Four drugs on the market delay the progression of certain symptoms. The ALZMED Report shows that these drugs are not available in all countries. Moreover, refund mechanisms vary from country to country and sometimes families have to bear the entire cost of the drugs. Regarding psychosocial interventions, their geographical distribution is unequal in each country due to the lack of trained professionals or adapted services.

**9. A lack of biomedical, fundamental and clinical research**
Biomedical, fundamental and clinical dementia research is not currently a priority in the Mediterranean area. There are few Mediterranean research teams currently exploring these pathologies. The report notes that the Mediterranean way of life (diet, physical and social activity, well-being, quality of life, family and inter-generational solidarity, etc.) should be examined in order to develop future research programmes in the Mediterranean area.

**10. A persistent negative image and lack of awareness**
In the Mediterranean, Alzheimer’s disease is still associated with senility, which is seen as a natural consequence of ageing. For the general public, dementia is often perceived as a form of psychosis and conjures up images of violence or even witchcraft. The ALZMED Report underlines the lack of knowledge among the general public on Alzheimer’s disease which leads to a persistent stigmatisation.

**11. The need to develop adequate legal safeguards and a specific ethical reflection**
The ALZMED Report notes that certain rights are guaranteed in all countries (right to health, legal protection systems, etc.). However, legal measures for anticipating their needs are rare in most Mediterranean countries. The report insists on the need to structure a specific ethical reflection, which still remains embryonic in the Mediterranean.

Finally, the report makes recommendations on a regional and international level in order to anticipate solutions and provide better support and care for people with dementia.

The Mediterranean Alzheimer Alliance calls on each Mediterranean country:

- to recognize Alzheimer’s disease and related disorders as public health priorities
- to develop a comprehensive national Alzheimer strategy or plan adapted to the needs of people with Alzheimer’s disease and their families, with specific and long-term funding
- to promote early/timely diagnosis for people with Alzheimer’s disease and related disorders.
- to develop and diversify the range of services, care and support throughout the territory
- to train all medical, medico-social and social professionals in the specificities of Alzheimer’s disease and related disorders
- to make available existing treatments throughout each country and to encourage the development of standardised and assessable psychosocial interventions
- to encourage more scientific and academic partnerships in the Mediterranean area on the prevention of Alzheimer’s disease
- to recognise the specific rights of family carers and promote awareness campaigns for the general public on Alzheimer’s disease and related disorders

This report makes recommendations on a regional and international level in order to anticipate solutions and provide better support and care for people with dementia.

The “Alzheimer and the Mediterranean” report was distributed to the public health authorities of each Mediterranean country and to all the relevant public, private and associative stakeholders on World Alzheimer’s Day. The report is available for download on the AMPA website: [http://ampa-monaco.com/files/MAA_Rapport_GB_web_sml.pdf](http://ampa-monaco.com/files/MAA_Rapport_GB_web_sml.pdf)
From carer to Chairperson in Germany

Monika Kaus became the new Chairperson of the German Alzheimer Association in early 2016. She is a former Treasurer of the association and also cares for her mother, who is living with dementia. In this article, Monika recalls how she first learned about Alzheimer’s disease and how the association is helping to improve the lives of all people with dementia in Germany.

From family carer to civil engagement

It all began in the 1990s when my mother started to forget things and her behaviour became a little strange. We first thought that was normal for her age but when her condition became more serious we went to a Memory Clinic. In 2000 she was diagnosed with Alzheimer’s disease. Until 2004 she lived, with some support, in her own home, but when the little difficulties of daily life increased, she moved to a nursing home in Wiesbaden, where she lives until now. During these years I experienced all the problems of a family carer, including the difficult arrangement of job and care and the permanent concern of what might happen next.

In 1999 I became a member of the local Alzheimer’s Association in Wiesbaden and served as a member of the board from 2005–2009. I also got involved with “Forum Demenz Wiesbaden”, a network of institutions from the municipality, medical professions, social workers etc. which aims to improve the situation of people with dementia and their families in Wiesbaden, a city of about 290,000 inhabitants.

As a delegate of Alzheimer Association Wiesbaden, I participated in the annual meetings of Deutsche Alzheimer Gesellschaft and in 2006 became a member of the board as Honorary Treasurer. From my professional career at a major German bank, I brought in experience in the field of fundraising and stressed the importance of transparent finances for self-help organisations. In November 2015, when Heike von Lützau-Hohlbein stepped down, I was elected as chairperson of Deutsche Alzheimer Gesellschaft.

The situation of Deutsche Alzheimer Gesellschaft

In my role as chairperson, I am able to continue the good work of the last years. The board consists of seven people from different professional fields who nearly all have experience as carers of persons with dementia. The advisory board consists of 12 renowned experts in the fields of psychiatry, gerontology, biology, law, ethics and care. Our central office in Berlin has a staff of 14 people who run a national telephone helpline, do public relations work, organise meetings and conferences, etc. We also maintain our excellent relationships with the relevant ministries and organisations in the field of health and social policy. Meanwhile, our 136 member organisations all over Germany do local work such as counselling, running groups for carers and people with dementia and public relations.

Towards a national dementia strategy for Germany

Unfortunately, Germany is lagging behind other European countries concerning a national dementia strategy. However, there are dementia strategies in the federal states of Bavaria, Saarland and probably soon in Schleswig-Holstein. In addition, there exists since 2012 the “Alliance for people with dementia”, whose partners are the leading organisations in the fields of welfare, medicine, civil engagement, employers, unions, etc. The Alliance is an initiative of the Federal Ministry of Health and the Federal Ministry for Families, Seniors, Women and Young People and as representative of DALzG I am honoured to co-chair this association. In 2014 an agenda

“An important goal is to strengthen the awareness of the problems which people with dementia and their carers have to face.”

MONIKA KAUS
with 155 measures was adopted. The outcomes will be evaluated continually and the Alliance will meet three times a year to discuss priorities. In 2018, I very much hope that we will be able to agree on a National Dementia Strategy.

Challenges and projects for the next years

Like most European countries, Germany is challenged by the problems of an aging population. Currently there are about 1.6 million people with dementia and in 2050 this number will rise to 3 million, assuming no breakthroughs in prevention or therapy occur. Furthermore, there will be fewer family carers and there is already an acute shortage of professional carers.

An important goal is to strengthen the awareness of the problems which people with dementia and their carers have to face. Another is to make clear that dementia has many faces and that people with dementia have different needs in the course of their diseases. The UN Convention on the Rights of Persons with Disabilities (CRPD) is also a good guideline for people with dementia: in this sense we support the inclusion of people with dementia in civil society and favour dementia-friendly communities. We’ll also make efforts for better participation of people with dementia in the work of our Alzheimer Associations.

In autumn 2016 we are going to start the campaign “Demenz Partner”, inspired by the English campaign “Dementia Friends” and hope for a broad participation.

Another priority will be a focus on dementia in migrants, especially from Turkey and Eastern Europe. These people have lived and worked for a long time in Germany and naturally dementia is a challenge for them as well. Our cooperation with the Turkish Alzheimer Association, which started two years ago, is only one of the ways that we offer support for people with dementia whose roots are in other countries and cultures.

In a time when the concept of European cooperation is questioned from different sides, I would like to highlight my support for international cooperation. And in this sense, I am proud that Deutsche Alzheimer Gesellschaft will host the Alzheimer Europe Conference 2017 in Berlin.
Ms Cheles Cantabrina Alútiz took over as President of Spain’s CEAFA in January 2016. In this article, she describes how the implementation of “Model 2020” is reducing the dependency of elderly people with Alzheimer’s disease – and making CEAFA the national reference entity on dementia.

I could hardly have imagined back in 1995 when my father and I started a pilgrimage from doctor to doctor looking for answers to the alarming changes in the personality of my mother, that my fight against Alzheimer’s disease (AD) would reach this degree of involvement. Especially since that at that time we did not even know what disease it was. In 2000, a doctor diagnosed her with AD and directed us to the newly-created association of relatives in our city. Years later, my father would also develop AD, so I became the main caregiver of both for seven years. At his death, I decided to continue the fight from another position. On 1 January 2016, I became the president of the Spanish Confederation of Alzheimer’s (CEAFA) for a term of three years.

Future vision: CEAFA’s Model 2020

My team and I have the responsibility to set the bases and start developing the CEAFA Model 2020. This is an organisational model that was adopted at the same meeting at which we were elected and was the basis of our electoral programme. The core idea of the model is that CEAFA becomes an active agent of change that will influence the agenda of the Spanish social and health policy and make AD a priority in this field.

Model 2020 comes from the Shared Project, started in 2013 and whose aspiration was to turn CEAFA into a reference entity on AD in Spain by 2020. I believe, however, that this goal has been overtaken by reality: at this point, there is no doubt that when an authoritative voice in the field of AD is required, people refer to CEAFA. This is not something circumstantial based on a moment of passing interest, but the result of the work being done during 25 years by more than 300 associations that form CEAFA throughout the national territory, by the 19 federations and the Confederation itself.

The recognition that we have achieved is of course very gratifying but also a real challenge: now the questions we must answer are more complex and require higher quality responses. This means more and better knowledge, well-trained staff members and efficient and fluid channels of communication to provide the excellent results that are expected of us.

Revitalising the organisation

Knowledge management has thus become the cornerstone on which we must act and we are devoting most of our assets to this purpose. That means we must transform a structure to satisfy the needs of claim, representation and defence into another that provides expert knowledge on all the issues that concern us. This year, our big challenge has been to build the framework that will allow us to act as an engine of revitalisation in 2017. We will adapt the model of the organisation of the Board of Directors to the new reality, readjust our technical structure, develop our communication channels and hopefully end our financial uncertainty.

In this regard, we have undertaken a project to ensure economic stability and we will submit a plan that culminates in financial independence of the organisation.

An active agent of change

Model 2020 also compels us to turn CEAFA into an active agent of change, which will require an improved communication plan. Right now, we are outlining the basis of a plan that allows the strategic exchange of information both within the organisation itself and outward. This will help us to promote internal cohesion and also consolidate the image of CEAFA, so as to generate social impact and awareness.

“CEAEFA is a major challenge for CEAFA is to prevent situations of economic, social and emotional insecurity, which become aggravated with the onset of AD.”

CHELES CANTABRANA ALÚTIZ
At the same time, we have started to form technical teams that will design a framework of knowledge exploitation. When I finish my mandate in 2018, the organisation must be prepared to have a verifiable institutional weight, to influence policy decisions made in social and health matters and propose a model for a national dementia strategy.

We have already begun to work on this. Currently, CEAFA actively collaborates with the State Group Dementias (GED), an association that is laying the foundations of a national strategy. GED has formed six working groups that focus on epidemiology, diagnosis and treatment, legislation, socio-health coordination, non-drug therapies and clinical and social research. CEAFA’s contribution to these groups goes beyond mere technical contribution; we are acting as a catalyst that energises processes and ensures the active participation of our structure through the preparation and discussion of proposals, as well as encouraging collaboration and activating implementation deadlines.

**Working to reduce dependency**

The increasing aging population has put the focus on dependency of the elderly: more than half of Spaniards aged 80 and over have trouble performing activities of daily life. This represents 9% of the current Spanish population. Among these people, over 70% of dependence cases are due to AD. Elderly dependant people are often faced with a loss of purchasing power and social isolation, because they can no longer work every day and because the structure of Spanish families has changed. The latter is quite significant because family support has traditionally been very strong in our country.

A major challenge for CEAFA is to prevent these situations of economic, social and emotional insecurity, which become aggravated with the onset of AD. We are working to differentiate dependency from disability in the social, economic and legislative areas. Our overall aim is to demonstrate the unique aspects of dependency and then define appropriate treatment and support for these people.

In closing, I believe that CEAFA’s Model 2020 represents a framework for transformation and improvement, offering the four elements that characterise value innovation as quoted by Chan Kim: “High social value, high ethical value, high value technical / technological and efficiency with respect to costs.”

“Model 2020 leads us to turn CEAFA into an active agent of change.”

CHELES CANTABRANA ALÚTIZ
Providing high-level support for Swiss people with dementia and their families

Dr Stefanie Becker is the new Director of the Swiss Alzheimer Association (SAA), with 25 years’ worth of experience in applied gerontology research. This knowledge will surely be beneficial as she takes the helm of an association that is perceived as the main representative of people affected by dementia in Switzerland. In this interview, we asked Stefanie about the implementation of the Swiss National Dementia Strategy and other related SAA activities.

What is your background?

I’m a trained psychologist and gerontologist and hold a PhD in Psychology from the Karl-Ruprechts University of Heidelberg in Germany. In 2016 I “celebrate” my 25th year of experience in applied research in various fields of gerontology. I financed my post-graduate studies by working as an untrained caregiver in an elderly home, which helped me to gain a lot of insights into this really important and demanding profession. Still today I profit from the experience gained during that time.

Later on, my employers included the University of Heidelberg, the German Centre for Research on Ageing and the research group of Psychogeriatrics at the Centre of Mental Health, a psychiatric clinic in Mannheim. I also worked with professional caregivers in providing stress management assistance and training for about seven years, which allowed me to better understand their working conditions – also very valuable experiences for my work today.

During my working life I have also handled several consultancy projects, such as developing and implementing dementia strategy and concepts in different nursing homes and a hospital, developing curricula for training caregivers, designing specialised dementia care units and quality evaluation in different gerontological fields. Throughout my career I always made it a point to never lose sight of the praxis and gained important insights by my diverse experiences.

How did you arrive at the Swiss Alzheimer Association?

After five years at the University of Applied Sciences in Bern, heading the launch and development of the “Institute Age” – which offers applied research for gerontology, including dementia – I was keen to apply my expertise in gerontology to practical work with and for elderly people. Additionally, I had gained experience of working in a non-profit association through my four-year presidency of the Swiss Society of Gerontology. This equipped me with valuable experience and sensitivity for a national association like the Swiss Alzheimer’s Association (SAA).

My new colleagues welcomed me very warmly. After two months of “internship”, as I called it, I was much more familiar with SAA’s numerous and diverse topics. But after nine months there are still new aspects coming up. I really am very honoured and proud of having the opportunity to work for SAA.

What are your first impressions?

I believe that SAA is a truly unparalleled organisation in the landscape of Swiss service providers. It is in a unique position between practical knowledge, advocacy on the political level and scientific gerontological expertise (comprising socio-psycho-medical aspects – the order of appearance matters here!). The SAA has a vast know-how, which it effectively employs by counselling and provision of services regarding all questions concerning dementia diseases.
dementia diseases. Our Association is nationally perceived as THE representative of the people affected by dementia, including patients and their relatives and we have a very large network of partner organisations and important stakeholders in Switzerland, also on an international level. Paradoxically, the Association is not yet sufficiently recognised for its expert knowledge, especially when it comes to more research-related questions.

Can you give us a brief profile of the Swiss Alzheimer Association?

The Swiss Alzheimer’s Association today counts more than 10,000 members, which make up a dynamic and diverse organisation. We are composed of the headquarters and 21 cantonal sections, which act as autonomous units. Thus, the individual units are very heterogeneous in their offers and financial abilities.

Our activities include the provision of service and advice to directly support people with dementia and their relatives in everyday life, for example group offers like self-help groups for family members or Alzheimer cafés on a regular basis or specialised holidays. We also advocate for the consideration of the specific needs of people with dementia and their relatives, the promotion of their rights and optimising the diversity, accessibility and quality of care at the political level. For example, the Association is one of the initiators of the Swiss “National Dementia Strategy 2014–2017”, which aims to lower barriers faced by people with dementia in our society. We are also heavily involved in the implementation of this strategy. More specifically, we focus on distributing information and providing educational material about dementia, especially to those who have not yet been exposed to this topic.

More broadly the Association campaigns for a dementia-friendly society. We seek to encourage the participation of people with dementia in society and to foster the acceptance of people with dementia, including the promotion of dementia-friendly living conditions in their direct environment. The Association also collaborates with the Ministry of Health to develop a label to distinguish “dementia-friendly” products and services.

What are the biggest challenges for Swiss people with dementia? How can the association help to solve them?

The biggest challenges lie especially at the beginning of the disease. These include access to diagnosis as early as possible and, particularly important, the provision of support directly after diagnosis.

We see an increasing number of people who develop dementia before their 60th birthday, so still during their professional life. It will hence be important in the future to educate employers and to develop best practice models to enable people with dementia to stay in their working environment as long as possible, albeit possibly with different tasks.

Currently, the necessary counselling and assistance cannot be covered by health and social care insurance. Thus, people with dementia often rely on the help and care of their relatives. This often leads to capacity overload and precarity of the caretaking relatives, which in turn jeopardises the efficacy of home care. This situation is clearly unsustainable, particularly as Swiss healthcare insurers chiefly call for a “care at home before institutionalised care” approach.

The National Dementia Strategy has stimulated many processes to increase and enhance offers and services available for people with dementia and their relatives. However, there are not enough reputable providers on the market, so the offers often lack transparency and are hard to assess in terms of quality. The SAA is working to counter this trend by developing a “dementia-friendly” label to establish and assert quality standards in order to support people with dementia and their caregivers find the help they need for their individual situation.

Where do you see the Swiss Alzheimer’s Association in five years?

I see the Association as the overarching national expert with strong cantonal sections for people with dementia and their relatives. We will continuously and actively provide high-level support for people with dementia and their relatives, as well as second-level counselling for other service providers and multipliers. By this I see the Association as a national centre of competence and reference for professionals, politicians and researchers and working very closely with people with dementia as counsellors. Lastly, I hope that we’ll stay a reputable partner for international cooperation with Alzheimer Europe.

“We seek to encourage the participation of people with dementia in society and to foster the acceptance of people with dementia, including the promotion of dementia-friendly living conditions in their direct environment.”

STEFANIE BECKER
Lilly and Alzheimer’s Disease

For more than 25 years, Lilly has been committed to Alzheimer’s disease (AD) research and development, during which we’ve made significant scientific advances. We recognize the significant burden AD causes for patients, caregivers, and our society and remain committed to making life better for those affected by AD around the world.

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Alzheimer Europe lunch debate focuses on the human rights of people with dementia


MEPs speak out on implementation of the UNCRPD

Ireland launches a Charter of Rights for people with dementia
Alzheimer Europe lunch debate focuses on the human rights of people with dementia

On 28 June 2016, AE held a lunch debate entitled “Using the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to support the rights of people living with dementia” in Brussels. The debate was co-hosted by MEPs Marisa Matias (Portugal) and Sirpa Pietikäinen (Finland).

Helke von Lützau-Hohlbein, Chair of Alzheimer Europe, opened the debate with a welcome for the participants as she presented the agenda. She also introduced the first speaker, Helen Rochford Brennan, Chair of the Irish Dementia Working Group and also a Vice-Chairperson of the European Working Group of People with Dementia.

In turn, they introduced her to the Irish Dementia Working Group, which was created by the Alzheimer Society of Ireland (ASI) in 2013.

Joining the group was clearly a turning point, which Ms Rochford Brennan described as the beginning of her “adventure with dementia”. This has featured media work, participation at conferences, political advocacy and other activities. She eventually came to be the head of the Irish Dementia Working Group and also joined the European Working Group of People with Dementia in 2014.

Ms Rochford Brennan pointed out that people with dementia are more than just a condition, they are citizens who want active lives. Both ASI and the Irish group are working toward this aim, even if stigma continues to be an issue in Ireland. She added that she was glad to see that people with dementia are citizens who want active lives. “My journey shows that people with dementia are more than just a condition, they are citizens who want active lives.”

HELEN ROCHFORD BRENNAN
Enhancing the rights of people with dementia

The next speaker was Jill Stavert, Professor of Law and Director of the Centre for Mental Health and Incapacity Law at Edinburgh Napier University. Her presentation “Human Rights and disability rights for people with dementia” focused on how elements of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) might be used to support the rights of people living with dementia.

The UNCRPD was originally launched in 2006, aiming “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

The Convention and its Optional Protocol were adopted by the EU in 2010 – the first international human rights convention to be signed and ratified by the European Union. This included a provision to submit periodic reports detailing the measures taken to implement the articles of the convention. The first such report was submitted in 2014 and the UN responded with a series of recommendations in 2015. One of these was to enact the European Accessibility Act, which is also covered in this article. At the time of the lunch debate, a resolution to implement the UN recommendations was being discussed in the European Parliament.

The UNCRPD can potentially keep the rights, will and preferences of the individual at the centre of all decisions.”

JILL STAVERT

Prof. Stavert pointed out that EU Member States may be bound individually or via EU membership and pointed out the following definitions from the UNCRPD text:

**Disability** “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.”

“**Persons with disabilities** include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

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She then reviewed several articles of the UNCRPD that are particularly significant for people with dementia:

**Article 12: The right to equal treatment before the law**

Persons with disabilities (including mental disorders) must have the ability to make decisions and act and to have such decisions and actions respected and enforced under the law where necessary.

The right to exercise legal capacity must not be removed on the basis of mental capacity assessments (including no functional capacity or “best interests” assessments). In addition, substitute decision-making regimes (e.g. guardianship, trusteeship, involuntary psychiatric treatment) must be abolished. Every person has the right to support for legal decision-making, which should be tailored to individual needs for all legal issues. If it is impossible to ascertain the will and preference of the individual, then a process of “best interpretation” is required.

**Article 13: Access to justice**

Persons with disabilities must have effective access to justice on an equal basis with others – including procedural accommodations – whether they are direct or indirect participants, including as witnesses.

In addition, governments must provide the appropriate training for those working in the administration of justice, including police and prison staff.

**Article 19: Living independently and being included in the community**

Every person must have the opportunity to choose his/her place of residence and who he/she lives with. All people must have access to in-home services to support living and inclusion in the community, including personal assistance if needed.

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1 On 7 July 2016, the European Parliament adopted a resolution based on the report, calling on the European Commission and the EU Council to fully implement the UN’s recommendations.
In addition, people with disabilities must have access to the same community services and facilities that are available for the general population, in order to prevent isolation or segregation from the community.

**Article 27: Work and employment**

This article prohibits discrimination in the workplace and promotes favourable work conditions, including labour and trade union rights. All people must have access to employment in both the public and private sectors, while governments must provide programmes for vocational and professional rehabilitation, job retention and return-to-work programmes.

**A European policy of person-centred decision making**

Prof. Stavert pointed out that the European Court of Human Rights (ECHR) has also been developing the rights of persons with mental disorders, particularly since 1979. This work includes rights to liberty, respect for private and family life/autonomy, freedom from inhuman or degrading treatment/dignity, fair trial and non-discrimination.

She noted that there are several inconsistencies between the UNCRPD and the ECHR. These differences would have to be resolved, specifically in the areas of supported decision-making and support in the exercise of legal capacity.

Prof. Stavert concluded that the elements of the UNCRPD would help to keep the rights, will and preferences of the individual at the centre of all decisions. It would also improve independent advocacy, advance directives/statements and powers of attorney.


**The European Accessibility Act: putting policy into practice**

The next speaker was Jonathan Stabenow from the Cabinet of Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility at the European Commission. He presented “The European Accessibility Act (EAA): putting the UNCRPD into practice at EU level”.

This is a proposal for legislation based on Article 9 of the UNCRPD: “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communication, including information and communication technologies systems, and to other facilities and services open or provided to the public”.

The objective of the EAA is to prevent and remove barriers for persons with disabilities, so they can access products and services. The act will also make it easier for industry and service providers to distribute products and services such as:

- computers and operating systems
- cash machines and check-in machines
- telephones and smartphones
- banking and travel services
- e-commerce

Better access will help people with disabilities to participate in society on an equal basis with others, to have better access to education and to enter the labour market more easily.

The proposed EAA legislation was published by the European Commission in December 2015, following the regular legislative procedure involving the European Parliament and the Council of the European Union. Once it is adopted, all EU Member States will be required to amend their national laws.
More information about the EAA is available on http://ec.europa.eu/social/main.jsp?catId=1202

Rights for every person, in every situation

The presentations were followed by closing remarks from the host MEPs.

Ms Pietikäinen was pleased to see that we have come a long way since 30 years ago, when people with dementia were subject to derision and discrimination. In today’s Finland, the negative connotations of the word “dementia” are causing it to be replaced by “memory-disabling disease”. She said that it is very important to ensure the provision of rights for every person, in all situations.

Ms Matias added that we, as a society and as individuals, still have plenty of capacity to improve the lives of people with dementia. She cited the importance of better education about accessible products and services, so that people who live with dementia and also their carers can be included in the everyday life of their community.

Alzheimer Europe was pleased to welcome 60 delegates to the lunch debate, including MEPs Therese Comodini Cachia (Malta), Nessa Childers (Ireland), Sofia Ribeiro (Portugal), Marek Plura (Poland) and representation from MEPs Olga Sehnalová (Czech Rep.) and Dieter-Lebrecht Koch (Germany). We were also glad to see Dr Jacqueline Hoogendam and Mr Bart Ooijen – both Senior Advisors at the Dutch Ministry of Health, Welfare and Sports – as well as representatives from the pharmaceutical industry and colleagues from 18 AE member associations.

The next AE lunch debate will take place on 6 December 2016.

The UNCRPD is an international human rights treaty adopted by the United Nations in December 2006 and is seen as a global tool for achieving domestic social change. To date, it is the only human rights treaty ratified by the European Union (EU) as a whole. All EU Member States have signed it and 27 Member States have ratified it as well. The EU is now under the obligation to ensure that the CRPD provisions are fulfilled at EU level and that EU legislation is in line with the CRPD. Vanessa Challinor, Policy Officer at Alzheimer Europe, speaks about how this can be achieved.

How the CRPD can support the lives of people living with dementia

The CRPD calls for a fundamental shift in terms of societies approach and understanding to disability. It describes disability as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Dementia is increasingly being viewed as having a rights-based dimension and there is an ongoing “dementia as a disability” debate. The CRPD could be used as an advocacy tool for strategies to ensure that people with dementia enjoy human rights and access to services on an equal basis with others, including accessible and dementia-friendly communities. It could also be useful in countries where stigma is still attached to dementia. For instance, the CRPD could help to improve health outcomes, such as reducing the use of restraints and anti-psychotic medicines.

There is a shift in tone in the way dementia is perceived, including the voice of the person with dementia: referring to “dementia as a disability” reframes dementia so that it is no longer seen as an inevitable part of old age. People with dementia have the right to services irrespective of age and “dementia as disability” would include people with younger onset dementia.

Implementing the convention in Europe

In August 2015, the United Nations Committee on the Rights of Persons with Disabilities reviewed the European Union’s policies to protect and promote the rights of 80 million persons with disabilities in Europe. Following the review, the committee issued a list of recommendations, known as

UNCRPD articles that are relevant to the lives of people with dementia

- Article 9: Accessibility
- Article 12: Equal recognition before the law/legal capacity
- Article 13: Access to justice
- Article 14: Liberty
- Article 15: Freedom from cruel, inhuman or degrading treatment
- Article 16: Freedom from exploitation, violence and abuse
- Article 17: Personal integrity
- Article 19: Independent living
- Article 20: Personal mobility
- Article 27: Work and employment

All EU laws, policies and programmes must be compliant with the UNCRPD
Concluding Observations, to which the EU should respond within four years.

The European Parliament has already reacted to the UN’s recommendations, in the form of a report drafted by Belgian MEP Helga Stevens, the first female deaf Member of the European Parliament. Her report outlines the Parliament’s views on how the EU can act to better implement the CRPD. On 7 July 2016 the European Parliament adopted a resolution based on this report, calling on the European Commission and the EU Council to fully implement the Concluding Observations.

The resolution is far-reaching and comprehensive, stating that the EU should lead the way as far as respect and promotion of human rights are concerned. It shifts disability from a mere medical approach to a more social approach and the treaty mandates that all EU laws, policies and programmes must be compliant with the CRPD. This will clearly require massive changes at micro and macro EU levels, with a large number of stakeholders involved.

The text of MEP Stevens’ report was drawn up with the involvement of disability organisations from across Europe, in line with article 4.3 of the CRPD: “Foreseeing that persons with disabilities through their representative organisations should be closely consulted and actively involved in the development and implementation of legislation and policies to implement the CRPD”.

Ms Stevens, who is a co-chair of the European Parliament’s Disability Intergroup (an informal cross-party grouping) also worked with colleagues across the political spectrum and from various EU countries to achieve a balanced report. A record number of Parliamentary Committees were also involved, illustrating that disability is not only a “social” topic but one that involves all areas of life.
MEPs speak out on implementation of the UNCRPD

Nine members of the European Alzheimer’s Alliance (EAA) were amongst the numerous MEPs who spoke in favour of the EU implementing the UNCRPD during the European Parliament debate. In addition, MEPs Marian Harkin (Ireland) and Marek Plura (Poland) have contributed short statements for this issue. Alzheimer Europe is very grateful for all of these contributions on behalf of people with dementia and their families.

Opinion: Marian Harkin

This significance of the European Union’s accession to the Convention should not be underestimated. It is a seminal step in the progression of the fundamental rights of persons with disabilities within the EU by bringing EU law in line with the provisions of the Convention.

The Convention stands out from other Human Rights treaties as people with disabilities and their representative organisations were very much a part of and involved in its drafting. The Stevens Report was no different as it took into account the views of many of the relevant stakeholders and furthermore all Committee meetings were accessible to persons with disabilities.

For me the three most important issues that the Stevens Report deals with are:

1. The need to have a comprehensive and cross cutting review of all EU legislation and funding programmes to ensure they comply fully with the CRPD
2. The need to develop a comprehensive CRPD strategy with a clean timeframe, benchmarks and indicators, and
3. The need to ensure a structured dialogue with disability organisations in this entire process

These three proposals should help ensure that the CRPD becomes an evolving process not just a worthy document that is left on a shelf.

Opinion: Marek Plura

I consider the European Parliament’s adoption of the UNCRPD implementation report as an important step towards the improvement of the situation of people with disabilities and their families. The engagement of NGOs, including representatives from the milieus of people with disabilities was priceless, as I used many of their ideas and remarks while working on the amendments and the opinion of the Transport and Tourism committee. The report outlines areas in which further actions can be taken, allowing people with disabilities and their families to fully explore their potential and to participate in social and cultural life. One out of six Europeans is disabled, and taking into account the rising number of illnesses linked with brain disorders, such as Alzheimer’s, Parkinson’s, dementia, depression, MS, etc., as well as the ageing of the population, this proportion will likely become increasingly significant. It is necessary to use best practices and search for creative solutions based among others on new technologies, in order to find solutions that will allow people with disabilities to live as independently as possible and allow their caretakers to better balance their tasks with other aspects of their social and professional lives.
While according to the principle of subsidiarity, there is no need to decide at the European level on the details of support systems offered by specific Member States, it is the European institutions’ responsibility to determine the direction of future actions and standards according to which an inclusive society should be built. A good example of this are the works on the European Accessibility Act, during which a vast scope of approaches is presented. Accessibility in the physical environment and in communication and informational technologies are equally important. A strong voice as well as support from NGOs are needed here. Europe needs to understand that access to products and services for all EU citizens is not a luxury, but the realisation of basic human and citizen rights.
Ireland launches a Charter of Rights for people with dementia

In April 2016, The Alzheimer Society of Ireland (ASI) and the Irish Dementia Working Group\(^1\) launched a Charter of Human Rights for People with Dementia. This charter was influenced by the Scottish Charter of Human Rights developed by the Cross-Party Group in the Scottish Parliament on Alzheimer’s. The launch event, held in Dublin, was attended by over 90 delegates including representatives of the Irish Dementia Working Group, carers, ASI branch representatives and Board members, ASI staff and wider stakeholders.

As in Scotland, the charter was created to demonstrate the importance of a parity of rights for the 55,000 people with dementia in Ireland. It states that people with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else. For this reason, it was an honour to have former Irish president and former UN Human Rights Commissioner, Mary Robinson, launch the Charter. Mrs. Robinson described the charter as “a welcome initiative in championing the human rights of both people with dementia and their carers”.

Helen Rochford-Brennan, Chair of the Irish Dementia Working Group and Vice-Chair of the European Working Group of People with Dementia, also spoke at the launch and highlighted the importance of recognising the human rights of people with dementia to challenge the stigma they face and to ensure they can continue to live with the dignity and self-determination.

The PANEL approach and human rights

The charter has been informed by the “PANEL” approach to human rights-based policy and practice, endorsed by the United Nations. A human rights-based approach is about ensuring that both the standards and the principles of human rights are integrated into policymaking as well as the development of services for people living with dementia.

Adopting the PANEL approach to human rights means that people living with dementia are given greater opportunities to participate in shaping the decisions that impact on their lives as well as providing

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1 The Irish Dementia Working Group is a group of people who have been diagnosed with dementia that meet to share their experiences and advocate on issues that are important to them. The working group is resourced and supported by The Alzheimer Society of Ireland.
a resource to those responsible for upholding people’s rights and ensuring that people are empowered to utilise their rights. The key PANEL principles include participation, accountability, non-discrimination, empowerment and legality. These principles are included in the charter to draw attention to the human rights of people living with dementia:

**Participation**
People with dementia have the right to be provided with accessible information and necessary supports to enable them to exercise their right to participate in decisions and policies which affect them.

People with dementia have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.

**Accountability**
Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfilment of their human rights and adequate steps should be adopted to ensure this is the case.

**Non-discrimination**
People with dementia have the right to be free from discrimination based on any grounds such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, membership of the Travelling community, civil and family status.

**Empowerment**
People with dementia have the right to access appropriate levels of care providing protection, rehabilitation and support.

People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

People with dementia have the right to access opportunities for community education and lifelong learning.

People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service.

**Legality**
People with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else.

Where someone lacks capacity to take a specific action or decision due to their cognitive condition, anyone acting for them must have regard for assisted decision making (capacity) legislation in Ireland.

Where rights are not observed, a person with dementia should have the right to seek remedy through effective complaint and appeal procedures.

**Rights and living well with dementia**
The Irish Dementia Working Group continues to disseminate the charter and incorporate the PANEL principles in their advocacy work to enhance the lives of people living with dementia.

The Chair of the Irish Dementia Working Group, Helen Rochford Brennan, spoke at an Alzheimer Europe event in Brussels, in which she briefed MEPs on the content and significance of the Charter for dementia policy. She spoke about the importance of including the PANEL approach when developing services and supports for people living with dementia as well as highlighting many of the human rights issues she faces on a daily basis.

Helen spoke about basic rights and living well with dementia, noting how she still has the right to travel and the right to be a part of her community. But she stated that these basic rights, and others outlined in the charter, are dependent upon government and policy makers to create a society and community that supports the rights of people living with dementia.

A Commitment to Neurology

For nearly 70 years, Novartis has been a leader in neurology. Our neuroscience products have touched the lives of millions of patients worldwide. In the field of dementia treatment and prevention, we continually strive to translate scientific innovation into therapies and technologies that matter.
Our members are helping people with dementia and their carers in 32 countries

- **AUSTRIA – VIENNA**
  - Alzheimer Austria

- **BELGIUM – BRUSSELS**
  - Ligue Nationale Alzheimer

- **BOSNIA & HERZEGOVINA - SARAJEVO**
  - Udruženje AIR

- **BULGARIA – SOFIA**
  - Alzheimer Bulgaria

- **BULGARIA – VARNA**
  - Foundation Compassion Alzheimer

- **CROATIA – ZAGREB**
  - Alzheimer Croatia

- **CYPRUS – LARNACA**
  - Pancyprian Alzheimer Association

- **CZECH REPUBLIC – PRAGUE**
  - Czech Alzheimer’s Society

- **DENMARK – HELLEUP**
  - Alzheimerforeningen

- **FINLAND – HELSINKI**
  - Muistiliitto

- **FRANCE – PARIS**
  - Association France Alzheimer

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

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

- **ICELAND – REYKJAVIK**
  - The Alzheimer’s Association of Iceland

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

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

- **ITALY – MILAN**
  - Federazione Alzheimer Italia

- **ITALY – ROME**
  - Alzheimer Uniti Onlus

- **JERSEY – ST HELIER**
  - Jersey Alzheimer’s Association

- **LUXEMBOURG – LUXEMBOURG**
  - Association Luxembourg Alzheimer

- **MALTA – MSIDA**
  - Malta Dementia Society

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

- **NETHERLANDS – AMERSFOORT**
  - Alzheimer Nederland

- **NORWAY – OSLO**
  - Nasjonalforeningen Demensforbundet

- **POLAND – WARSAW**
  - Polish Alzheimer’s Association

- **PORTUGAL – LISBON**
  - Alzheimer Portugal

- **ROMANIA – BUCHAREST**
  - Societatea Alzheimer

- **SLOVAKIA – BRATISLAVA**
  - Slovak Alzheimer’s Society

- **SLOVENIA – LJUBLJANA**
  - Association “Forget-me-not”

- **SPAIN – MADRID**
  - Fundación Alzheimer España

- **SPAIN – PAMPLONA**
  - C.E.A.F.A.

- **SWEDEN – LUND**
  - Alzheimerforeningen i Sverige

- **SWEDEN – STOCKHOLM**
  - Demensförbundet

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

- **TURKEY – ISTANBUL**
  - Alzheimer Vakfı

- **UNITED KINGDOM – EDINBURGH**
  - Alzheimer Scotland

- **UNITED KINGDOM – LONDON**
  - Alzheimer’s Society
27th Alzheimer Europe Conference
Care today, cure tomorrow
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