

# DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE



**Issue 31**  
October 2019



## Hugo de Jonge

Dutch Minister of Health,  
Welfare and Sport talks  
about a more dementia-  
friendly Netherlands



### Gerjoke Wilmink

Alzheimer Nederland Executive Director  
reflects on the organisation's 35 years  
supporting people with dementia



### Debbie Abrahams MP

discusses findings of UK inquiry into how people  
with dementia are treated, compared with others  
with disabilities



### Elly Katrín Guðmundsdóttir

Chairperson of Iceland's new dementia working  
group talks about what the group means to her

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# Welcome



Iva Holmerová, Chairperson of Alzheimer Europe

I am pleased to welcome you to the 31<sup>st</sup> edition of *Dementia in Europe* – the Alzheimer Europe magazine.

The first section of our magazine highlights some of our efforts to ensure dementia remains a European priority. It begins with an update on progress in reconvening the new European Alzheimer's Alliance, the non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) to support Alzheimer Europe and its members to make dementia a policy priority in Europe. This section also highlights some of the work to engage with MEPs as the new parliamentary term commences and the political agenda for the next five years is shaped.

We are pleased to present two new EU-funded projects in which we are actively involved, Alzheimer's Disease Detect and Prevent and VirtualBrainCloud. This first section concludes with an in-depth look at our ethics report on making services and support for people with dementia appropriate for people from all ethnic communities. The work for this report was carried out by an expert working group set up by Alzheimer Europe last year.

The Policy Watch section presents a "who's who" of some of the key leaders and decision-makers in the European Union following

the European Parliament elections in May 2019 and the appointment of key Commissioners for the next five years. It also includes an update on the Governmental Expert Group on Dementia, which met for the second time in June 2019. The meeting was attended by representatives from 20 European countries, as well as work package leads from the 2<sup>nd</sup> European Joint Action on Dementia and representatives from the World Health Organization (WHO). Conversations focused on timely diagnosis and post-diagnostic support, care coordination, residential care and dementia-friendly communities. It is truly heartening to see the willingness of so many countries to use this important platform to exchange knowledge and expertise.

We then take a look at the ins-and-outs of data-sharing in clinical research projects. The work we are doing in this area, which will be published at the end of 2019, is made possible thanks to a grant from Gates Ventures. Our policy section concludes with a piece about the policy outcomes of a recent Spominčica (Alzheimer Slovenia) conference, "In the Rhythm of the Human Brain", held in Ljubljana earlier this year under the honorary patronage of Prime Minister Marjan Šarec, who was a keynote speaker.

Our third section, *Dementia in Society*, begins with a piece about policy campaigning at local and national levels. Two of Alzheimer Europe's national members associations, The Alzheimer Society of Ireland and Muistiliitto – Alzheimer Society of Finland, highlight the impact such campaigns can have in terms of concrete outcomes. Next, Debbie Abrahams MP, Co-chair of the UK Government's All Party Parliamentary Group (APPG) on Dementia, reveals some of the key findings of the group's report, "Hidden no more: Dementia and disability". The report highlights the fact that people with dementia are treated differently to those with other health conditions or disabilities.

We then turn our attention to Iceland, where a new working group of people with dementia was formed at the start of the year. I would like to congratulate our colleagues at Alzheimer Iceland for convening this group and thank them for paying tribute to Alzheimer Europe's European Working Group of People with Dementia (EWGPWD), which they say was the inspiration for the Icelandic group. You can read about the group's aims and progress made so far. Last but not least, two of my Alzheimer Europe colleagues, project officers Angela Bradshaw and Cindy Birk, have put together a discussion piece on gene therapy for Alzheimer's disease (AD). Readers can find out more about what gene therapy is, and whether or not it might be useful in the future treatment of AD.

Our final section shines a spotlight on the Netherlands and on Alzheimer Nederland, examining the excellent work taking place in the country. Alzheimer Nederland is co-hosting our 29<sup>th</sup> Alzheimer Europe Conference "Making valuable connections" (#29AEC) in The Hague. As well as looking at the history and work of our co-hosts, this section includes an interview with people living with dementia, who share their reflections following the "Dementia Event" – a national gathering for and by people with dementia. Finally, we are delighted to have an interview with the Dutch Health Minister, as well as an update on the country's national dementia strategy – the Deltaplan Dementie.

If you are reading this magazine at our conference, I warmly welcome you to The Hague.

Happy reading!



# Engaging with European Alzheimer's Alliance members to make dementia a European Priority

With the European Parliament now sitting for the new term (2019–2024), Alzheimer Europe has been working to re-establish the European Alzheimer's Alliance.



Following the European elections in May 2019, Alzheimer Europe has been working with its members to ensure that dementia remains a priority at a European level. This work builds on the foundations laid during the #DementiaPledge2019 campaign, in which we asked candidates to commit to joining the European Alzheimer's Alliance (EAA) and working with us if elected.

As a result of this campaign, the EAA now has 91 members and we are working to ensure they understand the importance of dementia across a range of policy areas, as well as what they can do as parliamentarians to ensure it remains a priority.

## Letters sent to all Members of the European Parliament

Following the commencement of the new parliamentary term at the beginning of June 2019, Alzheimer Europe divided MEPs into three categories:

- MEPs who had signed the #DementiaPledge2019
- MEPs who were previously members of the EAA but did not sign
- MEPs who were neither members, nor signed the pledge.

We then wrote to the first two categories of MEPs and provided template letters for our members to write to all of the MEPs in

their countries. These letters highlighted the importance of treating dementia as an area of priority, including within the Horizon 2020/Europe research programmes, the European Pillar of Social Rights and the Health Programme. The letters also contained four specific asks:

- Raise a question during hearings of candidates for the Council of Commissioners, asking how they will ensure dementia is prioritised within their remit.
- Ensure that dementia is considered during the course of the work of the European Parliament committees on which they sit.
- Engage with their country's national Alzheimer's/dementia organisation to find out what is happening in their country, including how to take part in dementia-inclusive initiatives.
- Attend Alzheimer Europe's lunch debate on 10 December 2019 in the European Parliament in Brussels, which will examine the benchmarking of national dementia policies.

## EAA members on key committees of the European Parliament

Alzheimer Europe has been monitoring the developments within the European Parliament to identify decision makers who are well placed to ensure that dementia remains a policy priority at a European level.

One aspect of this work has been to identify EAA members who sit on relevant committees of the European Parliament. Here, we have provided an indication of the committees most relevant to dementia policy areas and the number EAA members who sit on each committee:

- Employment and Social Affairs committee (EMPL) – Eight EAA members sit on this committee
- Environment, Public Health and Food Safety committee (ENVI) – Eight EAA members sit on this committee
- Industry, Research and Energy committee (ITRE) – Ten EAA members sit on this committee
- Internal Market and Consumer Protection committee (IMCO) – Seven EAA members sit on this committee.

Having these connections will allow Alzheimer Europe to better engage with decision-makers within the parliament, particularly when seeking to influence legislation at the committee stages.

## EAA Chair and Vice Chairs

As we announced in Dementia in Europe 30 (June 2019), Sirpa Pietikäinen MEP (Finland) has agreed to become the chair of the EAA in the year ahead. To ensure that we have a balance of representation across the political spectrum, Alzheimer Europe has also written to EAA pledgees from the EPP, S&D, Reform Europe, the EFA/Greens and GUE/NGL inviting them to become Vice Chairs of the group. Once confirmed, Alzheimer Europe will post the details of the full make-up of the group on its website.

## Next steps for the European Alzheimer's Alliance

Over the coming months, the European Commission will set out its legislative agenda and the policy priorities, which will be pursued over the course of the next five years. Once details have been announced, Alzheimer Europe will identify the implications for dementia policy, working with members of the EAA to ensure that these policies reflect the priorities of people with dementia, their families and carers.

In the policy section on pages 13–18, we provide a “who's who” guide to the new Commission and Parliament, outlining some of the key decision-makers and politicians who will play an influential role in shaping European policy and legislation, and who can ensure that dementia remains a priority.



# Alzheimer Europe involved in two new projects – Alzheimer’s Disease Detect and Prevent and VirtualBrainCloud

Alzheimer Europe spoke to the project leads for each of these two Horizon 2020-sponsored initiatives – Kim Baden Kristensen for Alzheimer’s Disease Detect and Prevent and Petra Ritter for VirtualBrainCloud – to discuss concrete objectives, as well as their own hopes and expectations.

## Alzheimer’s Disease Detect and Prevent



Alzheimer’s Disease  
Detect & Prevent

The Alzheimer’s Disease Detect and Prevent project (ADDP) arrives on the scene at an exciting time for brain health research. In keeping with recent changes in the conceptualisation of and terminology related to Alzheimer’s disease (AD), ADDP is pursuing the ambitious aim of developing a digital tool to improve the detection of AD prior to the possible onset of AD dementia and combining this with programmes for reducing lifestyle risk factors related to developing AD dementia (see Table 1, overleaf, for further information on new/current definitions related to AD).

The project officially started on 1 November 2018 and is a 2-year project. It has a budget of EUR 3.5 million, distributed across 6 partners, with Danish digital therapeutics company Brain+ leading the consortium.

Alzheimer Europe is a partner in this project and is contributing towards the communication and the patient involvement activities. The latter, is being accomplished by means of a Patient and Public Involvement (PPI) approach. AE has already organised a

consultation with its European Working Group of People with Dementia.

### What are the key achievements of the project so far?

**Kim Baden-Kristensen:** The project has been progressing fast since kick-off in late 2018. Together with researchers at the University of Oxford, the team at Brain+ has been developing and testing various prototypes of the proposed AD detection tool in order to gain insight into the type of format that provides the best user experience, whilst remaining robust for detecting subtle cognitive changes in Alzheimer’s disease. A fully gamified and user-tested AD detection prototype will soon be ready.

The next step is to conduct three scientific studies, which will validate the new technologies. Two of these studies will be designed to validate the AD detection tool (led by the University of Oxford and Aarhus University) and the third one, to validate the AD risk reduction programmes (led by the University of Nottingham). We have worked to harmonise and align these studies, so that they provide mutually-supporting data and validation. So far, the research team at Aarhus University has successfully recruited participants for the validation study and the study will start soon.

Working closely with the European Brain Council and Alzheimer Europe, we have produced and implemented a dissemination plan. This



Kim Baden-Kristensen speaking at the IMI Stakeholder Forum, Brussels, 12 June 2019

includes presenting the ADDP project at key events and the launch of a project website.

Alzheimer Europe and the University of Nottingham have conducted Patient and Public Involvement (PPI) workshops and we are beginning to gain more insight into the perspectives of people with dementia and their carers with regard to the digital tool. This work has yielded some great insights into how people think about Alzheimer’s dementia, and the idea of taking preventative measures.

### What are your expectations from, and hopes for the project?

**KBK:** I believe that early detection is one of the keys to tackling Alzheimer’s dementia. There is currently no cure and the impact of Alzheimer’s dementia (financially, emotionally and in terms of quality of life, among other things), on those who develop it, their families and on society as a whole, is huge.

A body of scientific evidence is emerging, indicating that brain health can be significantly improved through the use of effective lifestyle interventions, and our project aims to significantly help this process, by means of a scientifically-validated, easily-accessible and user-friendly digital tool for use by the public and medical professional alike. Our aim and hope is that the digital platform we are developing will, first, accurately identify individuals with Alzheimer’s disease, prior to the onset

of dementia, at an earlier stage than standard neuropsychological assessments currently allow. The platform will then recommend and provide personalised cognitive, behavioural and lifestyle interventions that can help to reduce the risk of disease progression.

We hope that by making this tool publicly available, it will also help raise awareness of the importance of brain health and, motivate people to take positive action to reduce their own personal risk of developing dementia.

How the AD detection and risk reduction platform will be made available to the public in the most efficient manner is something we are working on. The AD detection test could potentially serve as a pre-screening/warning tool that aids clinicians, as well as supporting the healthcare system in its early detection efforts. In addition, we hope to encourage individuals to take up effective intervention programmes earlier in life, and thus reduce their risk.

## How will this project benefit people with dementia and people with neurodegenerative diseases in general?

**KBK:** The project primarily aims to detect Alzheimer's disease at the preclinical or prodromal stage, so we can intervene as early as possible. The hope is that people who are identified by the technology as being in one of these two stages of Alzheimer's disease, or being at higher risk of progressing from Alzheimer's disease to Alzheimer's dementia, will immediately be able to take positive action to improve their brain health. This action could be anything from seeking immediate medical advice, to engaging in the risk-reduction programmes currently under development in this project. Ultimately, we are seeking to find an effective means to halt or at least delay Alzheimer's disease progression, by guiding people to make potentially large and impactful changes to their lifestyles,

for example changes in diet, increasing physical exercise or improving sleep hygiene.

My personal belief is that many of the things that reduce the risk of developing dementia, will also have a positive impact on health for people who have already received a diagnosis of dementia. This, however, remains to be seen and requires much more work and research.

Regardless of the situation of any one person, I believe and hope that our project and the digital platform that we are developing will be able to provide long-term health benefits, by helping people reduce lifestyle risk factors and lead healthier lives.

## Project partners

Brain+, University of Oxford, Aarhus University, University of Nottingham, Alzheimer Europe, European Brain Council.



### Alzheimer's Disease Detect and Prevent

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## Acknowledgement



This project is funded by the European Union's Horizon 2020 research and innovation programme – Fast Track to Innovation (FTI), grant agreement 820636.

**Table 1: New definitions of AD taken from Alzheimer Europe's 2016 "Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease"**

### Preclinical state

The long asymptomatic stage between the earliest changes underlying AD pathology and the first cognitive symptoms. This has two sub-groups:

- The asymptomatic at risk group which includes people with pathological/abnormal changes in their brains, specific to AD but without clinical symptoms of AD
- The pre-symptomatic group which includes people who carry a dominant genetic variant of AD but do not yet have clinical symptoms of AD. This genetic variant is rare and does eventually lead to AD dementia, but accounts for less than 1.5% of AD dementia cases

### Prodromal AD (IWG) or Mild Cognitive Impairment (MCI) due to AD (NIA-AA)

The early symptomatic, pre-dementia phase of AD. During this phase, clinical symptoms are present but not severe enough to affect activities of daily life and are associated with specific biomarker changes.

### AD dementia

The stage of the disease in which cognitive symptoms are severe enough to affect not only memory but also daily life activities.

## VirtualBrainCloud



The annual worldwide cost of Alzheimer's dementia was EUR 777.81 billion in 2015. This number will rise to EUR 7.4 trillion in 2050. Early diagnosis would save up to USD 7.9 trillion in medical and care costs by 2050 in the US alone. However, the emergent pathology is highly variable across people, necessitating individualised diagnostics and interventions. The VirtualBrainCloud addresses this by bridging the gap between computational neuroscience and subcellular systems biology, integrating both research streams into a unifying computational model that supports personalised diagnostics and treatments in neurodegenerative disease.

The VirtualBrainCloud not only integrates existing software tools, it also merges the efforts of two big EU initiatives, namely "The Virtual Brain" (the brain simulation platform of the Human Brain Project) and the European

**“VirtualBrainCloud will develop and validate a decision support system that provides access to high quality multi-disciplinary data to clinicians.”**

Prevention of Alzheimer's Dementia (EPAD) initiative.

VirtualBrainCloud will develop and validate a decision support system that provides access to high quality multi-disciplinary data to clinicians. The result will be a cloud-based brain simulation platform to support personalised diagnostics and treatments in neurodegenerative disease. The EU PRACE (Partnership for Advanced Computing in Europe) initiative will provide the required computing infrastructure. The VirtualBrainCloud will develop robust solutions for legal and ethical matters by interacting with EU projects such as European Open Science Cloud, 'cloud4health', patient organisations and ELIXIR, an organisation that manages and safeguards EU research data.

Our software developers have already produced highly successful brain simulation and clinical decision support tools. The resulting software will be a cloud-based computational modelling system that is tailored to the individual, and bridges multiple scales to identify key mechanisms that predict neurodegenerative disease progression and serves as Precision Decision Support System.

### What is the background to the VirtualBrainCloud project?

**Petra Ritter:** More and more people are being diagnosed with neurodegenerative diseases such as Alzheimer's disease (AD). We now know that there is no single cause for these



Petra Ritter

complex diseases. However, we still don't fully understand how interactions between genes, proteins and metabolites in the brain can lead to the development of these conditions. Another problem is that people in the early stages of neurodegenerative disease can have varying and subtle symptoms, making it hard for clinicians to accurately diagnose and treat patients.

In developing the VirtualBrainCloud project, we wanted to capture some of these individual differences using a computational brain modelling approach. The main goal of this project is to create a cloud-based computational platform for biomedical research



VirtualBrainCloud project General Assembly meeting, Barcelona, 6 September 2019



“In developing the VirtualBrainCloud project, we wanted to capture some of these individual differences using a computational brain modelling approach.”

and clinical decision-making, allowing us to dynamically map gene, protein and metabolite changes to specific neurodegenerative disease diagnoses. VirtualBrainCloud is a first step to reach our vision of future healthcare where regular, minimally-invasive health profiling allows early diagnosis and personalised, patient-specific treatment.

### Who are the partners involved in the VirtualBrainCloud project?

**PR:** The VirtualBrainCloud project brings together clinicians, bioinformaticians, biologists and computer scientists from existing programmes such as the Human Brain Project, EPAD and AETIONOMY, two Innovative Medicines Initiative-funded projects. The EU PRACE (Partnership for Advanced Computing in Europe) initiative will help build the cloud computing infrastructure using their

high-performance computer clusters. We will also work with data protection specialists and Alzheimer Europe on the legal and ethical aspects of the project.

### What are the objectives and actions that will be undertaken by the project?

**PR:** In the first stage of the project, we will use multi-disciplinary data from large cohorts of participants with dementia and other neurodegenerative diseases, including imaging, EEG, biomarker, genomic and proteomic data. Based on these large datasets, we will develop disease progression models, particularly focusing on the preclinical stages of disease.

In the second stage of the project, we want to model the interacting molecular and cellular events that occur during the development of neurodegenerative diseases and relate these to large-scale changes in the brain. To achieve this, we are going to use advanced text mining approaches to extract information from the literature, then combine this with molecular information from biomedical databases.

Our ultimate goal is to enable the creation of personalised brain network simulations for people in the early stages of

neurodegenerative disease, using the VirtualBrainCloud computational platform and statistical modeling software. The VirtualBrainCloud integrates existing software tools and platforms to provide access to high quality clinical multi-disciplinary data to integrate them and make them useful in clinical practice. By simulating the brain in this way, we hope to better predict how individual neurodegenerative disease patients might progress, allowing clinicians to prescribe more rational and targeted therapies.

### Project partners

Charite Universitätsmedizin Berlin, Université d'Aix Marseille, Fraunhofer SCAI, University of Oxford, Forschungszentrum Jülich GmbH, Institut du Cerveau et de la Moelle Epinière (ICM), Institut National de Recherche en Informatique et Automatique (INRIA), Fundació Institut de Bioenginyeria de Catalunya, Hel싱in Ylöpistio, Università Degli Studi di Genova, Universidad Complutense de Madrid, Codebox Computer-dienste GmbH, Codemart SRL, Eodyne Systems SL, Universität Wien, TP21 GmbH, Alzheimer Europe.



### Acknowledgement



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 826421.



#### Virtual Brain Cloud

 [www.cordis.europa.eu/project/rcn/219020/factsheet/en](http://www.cordis.europa.eu/project/rcn/219020/factsheet/en)  
 @TVB\_cloud



# Making services and support for people with dementia appropriate for people from all ethnic communities

In 2018, Alzheimer Europe set up an expert working group to write a comprehensive report aimed at improving the situation of people with dementia and carers from minority ethnic backgrounds. In this article, T. Rune Nielsen, Sahdia Parveen, Carolien Smits and Dianne Gove highlight some of the key messages from the report and describe the future goals of the expert working group.

People from minority ethnic groups have a right to receive good quality and appropriate dementia care and support, starting with timely and accurate diagnosis. This does not always happen. Alzheimer Europe set up an expert working group to write a comprehensive report aimed at improving the situation of people with dementia, their carers or supporters and professional carers from minority ethnic backgrounds, through the identification and promotion of intercultural care and support. Intercultural care and support, in the context of this project, is about looking at ways to respect and respond to the cultural diversity of people with dementia, their relatives and friends and of those caring for or supporting people with dementia. This

requires cultural awareness, cultural sensitivity, cultural competence, willingness and motivation, as well as support from policy makers and funders.

## The need for culturally appropriate diagnostic tools

There is evidence that people from minority ethnic groups do not receive the same standard of diagnostic evaluations for dementia and may be more likely to be misdiagnosed. Several factors seem to contribute to this, including linguistic and cultural factors affecting evaluations; the way that interpretation is provided, with a heavy reliance on assistance from relatives;

compliance of people with dementia from minority ethnic groups with the diagnostic process; difficulties distinguishing depression from early dementia; and the lack of culturally appropriate assessment and diagnostic tools. As people from minority ethnic groups often do not get a timely, accurate and full diagnosis, their chances of accessing appropriate treatment, support and care are greatly reduced.

Although biomarkers are increasingly playing a role in the diagnostic workup of dementia, dementia is still very much a clinical diagnosis which relies on verbal interaction, observation of behaviour and cognitive assessments. The lack of access to professional interpreters and culturally sensitive screening and diagnostic tools is a major challenge facing general practitioners (GPs) and specialists across Europe.

Using relatives as interpreters may be a practical and readily available solution in everyday clinical practice but interpretation is a complex skill which requires specialised training. Assessment and diagnosis may be improved in some cases if good quality interpretation is provided. Most assessment and diagnostic tools for dementia, which are used for people from minority ethnic groups, have not been validated for those groups. Although some tools have been translated into a range of languages used by minority ethnic groups, this alone does not make them culturally appropriate.

Language is not the only factor affecting the appropriate use of assessment and diagnostic



1<sup>st</sup> Meeting of Expert Working Group, Bradford, 18 May 2018

## Members of the expert working group:

Jean Georges (LU)\*  
Daphna Golan-Shemesh (ISR)  
Dianne Gove, Chair (LU)  
Michal Herz (ISR)  
Siiri Jaakson (FIN)  
Ripaljeet Kaur (UK)  
Debi Lahav (ISR)\*  
T. Rune Nielsen (DK)  
Sahdia Parveen (UK)  
Charlotta Plejert (SWE)  
Mohammed Akhlak Rauf (UK)  
Carolien Smits (NL)

\*Not pictured

“In addition to individual and community barriers, minority ethnic communities experience a number of health care related barriers. There have been several reports to suggest that communities perceive services and health care professionals to lack cultural sensitivity and knowledge, leading families to mistrust health care professionals and drop out of services.”

tools. Other issues, such as cultural and educational bias, need to be considered as well.

Despite the huge increase in the number of people from minority ethnic groups likely to develop dementia in the next few decades, little research has been dedicated to the development of culturally sensitive (or culturally fair) tools. This is fortunately starting to change, with several assessment and diagnostic tools having been developed and validated across several minority ethnic groups in Europe during the last five years. Examples include the Rowland Universal Dementia Assessment Scale, the Cross-Cultural Dementia Screening Tool, the European Cross-Cultural Neuropsychological Test Battery and the Multicultural Cognitive Examination.

None of these tools include any culture-specific information and can be used across several languages and with people with limited or no education and/or literacy. The results obtained from such tools should never be considered as a stand-alone measure of cognitive function or be used to determine whether a person has dementia but should be combined with a complete diagnostic evaluation conducted by a qualified health care professional. The introduction and implementation of these new tools is an important step forward to enable equal access to accurate diagnosis and appropriate treatment, support and care for people from minority ethnic groups.

### Barriers to help-seeking and service uptake

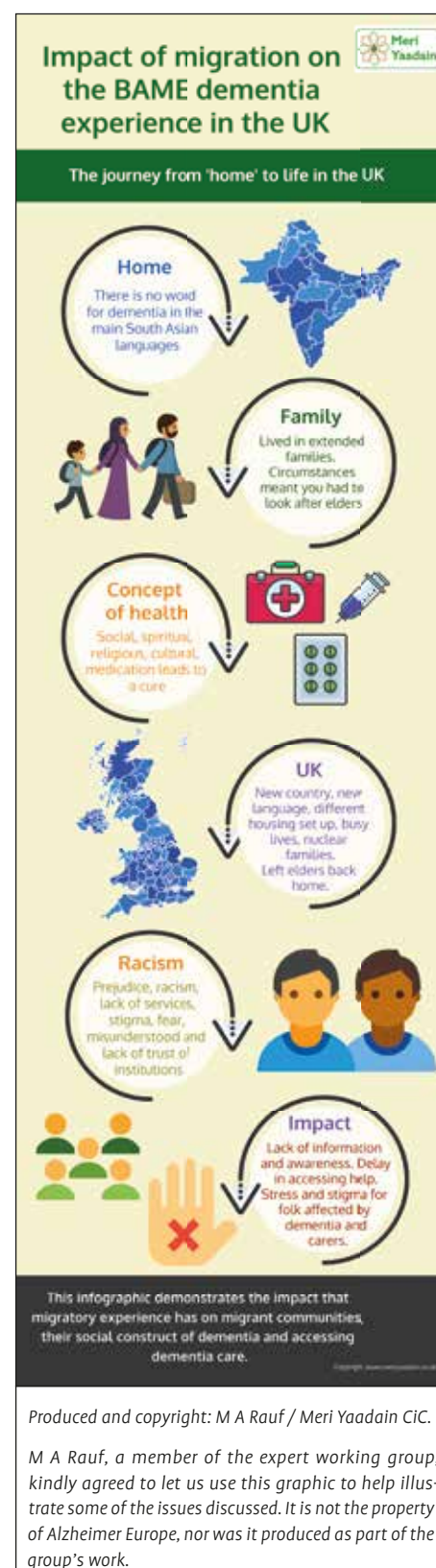
There is considerable evidence to suggest that minority ethnic communities do not seek support from services until they reach a “point of crisis”. There are a number of barriers that prevent minority ethnic communities from seeking help. These include: barriers at the personal level, such as a lack of understanding about dementia and a lack of awareness of available services; barriers at the community level such as stigma and

beliefs that one should care for one’s own family members, and finally; health system level barriers such as mistrust of health care professionals caused by cultural insensitivity, and lack of appropriate services.

There has been considerable focus on the understanding of dementia in minority ethnic communities. There is substantial evidence to suggest that there is a poor understanding of what dementia is amongst minority ethnic communities. The problem is often made worse by the fact that there is no actual word for “dementia” in many languages spoken by minority ethnic communities. The words used to translate or describe dementia are often derogatory or inaccurate, leading to further confusion. The causes of dementia are also less well known amongst minority ethnic communities and many are unaware of the risk factors associated with dementia. Research suggests that individuals from minority ethnic backgrounds believe symptoms of dementia to be a normal part of ageing. Other misconceptions include dementia being a punishment from God and dementia being a mental disorder and thus shameful.

“People from all ethnic groups should have access to care and support which corresponds to their cultural beliefs, traditions and ways of life.”

As well as a lack of understanding of dementia, significant barriers exist at the community level for families. There is considerable stigma attached to dementia due to the conceptualisations of the condition discussed above. Furthermore, many minority ethnic communities subscribe to the cultural value of “filial obligation”, which means that family members consider it their duty to provide care for relatives. This prevents many from accessing



negative impact on wellbeing in family carers, and on quality of life for the person living with dementia.

In addition to individual and community barriers, minority ethnic communities experience a number of health care related barriers. Several reports suggest that there is often a perception in the community that health care professionals lack cultural sensitivity and knowledge, which in turn leads to a mistrust in health care professionals and a dropping out of services.

By delivering culturally appropriate and targeted dementia awareness initiatives within the community, dementia awareness can be improved and stigma reduced. This approach has been successfully utilised in Bradford (United Kingdom), for example. By working in partnership with minority ethnic communities, existing services can be culturally adapted to meet the needs of more diverse groups. To remove language-related barriers, services should provide translated materials, offer access to bilingual workers and, where

possible, work with local community groups. Education and training should be made available to support health care professionals to provide culturally sensitive care. By removing barriers at these three levels, timely access to support for minority ethnic communities can be improved.

### Improving support to and from professional carers

Most of the care offered to people with dementia from minority ethnic groups is provided by spouses, partners and relatives. Health and social care professionals can help improve the quality of life of both the person with dementia and the informal carer, but they need to be motivated and skilled in order to provide care that is truly appreciated. Professional caregivers may put a lot of energy into providing person-centred and intercultural care to all their clients, but research has shown that many health and social care professionals in Europe have a limited understanding of dementia and may know little of services for people with dementia, especially specific services for people with dementia from minority ethnic groups.

Professionals often feel frustrated because of communication problems related to language difficulties and to different perspectives on dementia and care. They require cultural competence: a combination of cultural awareness; awareness of their own prejudices and tendency to stereotype; the ability to transfer information that can be understood; knowledge about when to seek external help; and the ability to adapt to new situations in a flexible and creative manner. The latter is key to handling ethical dilemmas. In the case of minority ethnic groups, such dilemmas and the ways to address them may, in part, be influenced by conflicting cultural values and perspectives, as well as communication problems.

A person may, for example, refuse intimate personal care from a health care professional of the opposite sex, or a relative may insist on care that seems to be in contradiction with the interests of the person with dementia. Another example concerns behaviour that appears to be out of character (e.g. a Hindu lady asking to be served beef for dinner, a Sikh man not wanting to wear his

turban). These issues are difficult to negotiate and debate has not resulted in a clear consensus. Furthermore, professionals need to balance ethical considerations with practical, financial and procedural constraints (e.g. interpreters are often not available on a 24-hour basis).

The acquisition of cultural and ethical competence represents a challenge for professionals from the majority ethnic group. However, whilst professional carers from minority ethnic groups often have the advantage of having knowledge of the language and the cultural perspective of the person with dementia and the informal carer (e.g. in the case of cultural and ethnic matching), they may also face challenges. They may, for example, experience tensions between high expectations from their cultural peers with regard to the care they provide, and their own ethical and practical considerations. Care needs to be taken to ensure they are not made responsible for all clients from minority ethnic groups, given that individuals and groups may differ widely.

In recent years, the number of migrant carers and live-in carers has increased in several European countries. These carers may be seen as solutions to national care staff shortages, but their arrival evokes debate. Some migrant carers may have had to leave their own dependent relatives to earn a living far away from home. Their perceptions of dementia and dementia care sometimes differ to those of the people for whom they are caring and this may have

“By working in partnership with minority ethnic communities, existing services can be culturally adapted to meet the needs of more diverse groups.”



“Training of staff will not suffice to provide person-centred and intercultural care. Further policy measures need to be taken both by the authorities and by care organisations, to facilitate a high standard of care.”

an impact on the care they provide, but also on their own self-esteem. A live-in carer lives in the home of the person receiving care. They are potentially vulnerable to exploitation and abuse, particularly those who are expected to provide care more or less round the clock and who have no stable residency rights.



Professional training and intercollegiate learning/group supervision may facilitate cultural competence and thus improve quality of care. Involvement of informal carers in the design and implementation of training programmes may improve their effectiveness. Evidence-based training programmes need to be developed. Implementation is a major future challenge. However, training of staff will not suffice to provide person-centred and intercultural care. Further policy measures need to be taken both by the authorities and by care organisations, to facilitate a high standard of care, and support the financial and legal rights of professional and informal carers, and people with dementia.

“As people from minority ethnic groups often do not get a timely, accurate and full diagnosis, their chances of accessing appropriate treatment, support and care are greatly reduced.”

### What next?

People from all ethnic groups should have access to care and support which corresponds to their cultural beliefs, traditions and ways of life. We hope that the comprehensive report (which is available in English,

“If policy makers and high-level health and social care professionals are not convinced of the value and urgent need for intercultural care and support, and do not have a clear understanding of how to provide it, large sections of our society will continue to receive inappropriate and inadequate dementia care and support.”

French and German) and current repository of initiatives will contribute towards achieving this goal. However, if policy makers and high-level health and social care professionals are not convinced of the value and urgent need for intercultural care and support, and do not have a clear understanding of how to provide it, large sections of our society will continue to receive inappropriate and inadequate dementia care and support. These key players do not always have the time or motivation to read through lengthy reports.

For this reason, and thanks to continued funding from the Robert Bosch Stiftung, Alzheimer Europe will be developing concise summaries targeted at policy makers and at high-level health and social care professionals. Alzheimer Europe will also be further developing its searchable web database of good initiatives of intercultural care and support. The work will be carried out by the expert working group, whose members are listed above along with valuable input from the European Working Group of People with Dementia.

Alzheimer Europe would like to thank these two groups for their past and ongoing contribution to this work. The database will be further elaborated throughout 2019 and 2020. We would therefore be pleased to hear from you about other initiatives and relevant materials in Europe. Please send any information or feedback to: [dianne.gove@alzheimer-europe.org](mailto:dianne.gove@alzheimer-europe.org)



The report (in English, French and German) can be downloaded freely at: [www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports](http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports)

The current repository of intercultural care initiatives can be found at: [www.alzheimer-europe.org/Ethics/Database-of-initiatives-for-intercultural-care-and-support](http://www.alzheimer-europe.org/Ethics/Database-of-initiatives-for-intercultural-care-and-support)

Further details of the experts in the working group can be found at: [www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice](http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice)

### Acknowledgements



The report received funding under an operating grant from the European Union's Health Programme (2014–2020) and from the Robert Bosch Stiftung



# Who's who in the EU?

Following the European Parliament election in May 2019, the European Union has been underway with the process of deciding who the key leaders and decision-makers for the next term will be. In this article, Alzheimer Europe takes a look at some of the key people.

In this article, Alzheimer Europe provides an overview of some of the key actors within both within the European Parliament and the European Commission, who will ultimately shape the policy and legislative agenda over the next five years. Their actions, choices and decisions across a range of policy areas will invariably impact upon the field of dementia.

Alzheimer Europe has focused on specific policy remits within the Parliament and the Commission, only including those purviews

which have the greatest relevance for dementia policy. The rationale and the importance of each position in relation to dementia has been included in the profiles below.

At the time of writing, the following members were either in post (in the case of the President-elect of the Commission and the Chair of the European Parliament committees) or were announced as candidates from their respective countries and had been selected by Ms von der Leyen for the specific Commissioner/Vice-President post.

For prospective Commissioners, it is important to note that these are subject to change; candidates may be withdrawn and are subject to a confirmatory vote (as part of the College of Commissioners as a whole) by the European Parliament.

Whilst the Council of the European Union, in its various configurations, is also central to the decision-making process for policy and legislative matters at a European level, its members are determined by the composition of governments at a national level, therefore are not included in this article.

The article is divided into two sections. The first examines the key Commissioners-designate (as they were at the time of writing) grouped together by their seniority i.e. President, Executive Vice-Presidents, Vice-Presidents and Commissioners, whilst the second examines the key committee Chairs.

## Key Commissioners-designate



### Ursula von der Leyen

**Position:** President-elect of the European Commission

**Country:** Germany

**European Party:** European People's Party

**Background:** Ms von der Leyen is a physician by background and served within the German Federal Government in a number of capacities since 2005. Her roles during this time have included Minister of Family Affairs, Senior Citizens, Women and Youth, Minister of Labour and Social Affairs, and, most recently, Minister of Defence.

Following the nomination of Ms von der Leyen by the European Council, the European Parliament voted to approve her nomination as the next President of the European Commission on 16 July 2019.

**Relevance:** As the head of the European Commission and the chair of the College of Commissioners, the role of the President of the Commission is one of the most publicly visible and is also one of the most powerful. Ultimately, the President controls the policy agenda of the Commission during their term, overseeing the policy and legislative initiatives which it proposes. Her first publication "A Union that strives for more: My agenda for Europe" serves as the political guidelines for the future next Commission and contains six headlines:

- A European Green Deal
- An economy that works for people
- A Europe fit for the digital age
- Protecting our European way of life
- A stronger Europe in the world
- A new push for European democracy.



## Margrethe Vestager

**Position:** Executive Vice-President – Europe Fit for Digital Age

**Country:** Denmark

**European Party:** Renew Europe

**Background:** Ms Vestager was first elected to the Danish Folketing in 2001, serving in a number of Ministerial positions. She has served as Minister for Economic Affairs and the Interior, Minister for Education and Minister for Ecclesiastical Affairs. Since 2014, she has served as European Commissioner for Competition, a role she will retain in her new position.

**Relevance:** The Europe Fit for a Digital Age portfolio will have particular relevance for work related to how big data can be used to develop new technologies and business models, as well as human and ethical implications for artificial intelligence; the latter to be actioned within the first 100 days of the new Commission. The portfolio also identifies the need to maximise investment in research and innovation in achieving the policy objectives.

## Valdis Dombrovskis

**Position:** Executive Vice-President – An Economy that Works for People

**Country:** Latvia

**European Party:** European People's Party

**Background:** Mr Dombrovskis has served as Minister of Finance, as well as Prime Minister of Latvia, in addition to having served a term as a Member of the European Parliament. He is currently the European Commission's Vice-President for the Euro and Social Dialogue (with responsibility for Financial Stability, Financial Services and Capital Markets Union).

**Relevance:** The Economy that Works for All portfolio will have responsibility for the European Social Rights, with the Vice-President tasked with coordinating the action plan to implement the Pillar. Additionally, the role will have a significant focus on the EU's relationship with social partners and will look to strengthen the role of social dialogue. As part of the remit, Sustainable Development Goals will be worked into the European Semester process.



## Věra Jourová

**Position:** Vice-President for Values and Transparency

**Country:** Czech Republic

**European Party:** Renew Europe

**Background:** Ms Jourová has served as a member of the Czech Chamber of Deputies, as well as Minister for Regional Development. Her current role within the European Commission is as the Commissioner for Justice, Consumers and Gender Equality.

**Relevance:** The Values and Transparency remit has a specific focus on the rule of law and right, with a specific focus on the EU's accession to the European Convention on Human Rights, as well as the monitoring of compliance with the Charter of Fundamental Rights. There is also a focus on improving European Citizens' Initiatives and improving transparency of the legislative process.

## Dubravka Šuica

**Position:** Vice-President for Democracy and Demography

**Country:** Croatia

**European Party:** European People's Party

**Background:** Ms Šuica has previously served as Mayor of Dubrovnik, as a member of the Croatian Parliament and currently, she is a Member of the European Parliament.

**Relevance:** The Democracy and Demography portfolio has been specifically tasked with the presentation of a Green Paper on ageing looking at long term impacts,

including care and pensions, and whether the social protection systems can deal with the changing demographics.

The role also is due to produce a report on the impact of demographic change within the first six months of the Commission – there will also be a mapping exercise to identify countries most in need of reforms and investment.



## Helena Dalli

**Position:** Commissioner for Equality

**Country:** Malta

**European Party:** Party of European Socialists

**Background:** Ms Dalli served as a member of the Maltese Parliament, having held the positions of Minister for Social Dialogue, Consumer Affairs and Civil Liberties and Minister for European Affairs and Equality.

**Relevance:** The Equality portfolio will have a focus on combatting all forms of discrimination and will be responsible for

the introduction of new anti-discrimination legislation. The Commissioner will lead on the EU's implementation of the United Nations Convention on the Rights of Persons with Disability (UNCPRD) to which the European Union and all its Member States are party. The Commissioner will also have responsibility for ensuring the implementation of the Work-Life Balance Directive.

## Mariya Gabriel

**Position:** Commissioner for Innovation and Youth

**Country:** Bulgaria

**European Party:** European People's Party

**Background:** Ms Gabriel's background is as a teaching and research assistant. She has served as an MEP since 2009. Since 2017, Ms Gabriel has served as the European Commissioner for Digital Economy and Society.

**Relevance:** This Innovation and Youth portfolio will have responsibility for the oversight of the Horizon Europe research programme, coordinating with Member

States, civil society and other EU institutions. There is also a focus on working with Member States towards a European Research Area, as well as ensuring that research, policy and economic priorities go hand in hand. The Commissioner is also expected to maximise the potential of exchange programmes to foster international cooperation in education, research and innovation.







## Sylvie Goulard

**Position:** Commissioner for the Internal Market

**Country:** France

**European Party:** Renew Europe

**Background:** Ms Goulard previously served as an MEP until 2017, before briefly being appointed as Minister of the Armed Services. She currently serves as a Deputy Governor of the Bank of France.

**Relevance:** The Internal Market portfolio will include a focus on the digital transition, ensuring that values are respected as new technologies develop, whilst ensuring investment in frontier of technologies,

such as high-performance computing, data-sharing and data-usage tools. As part of this, the Commissioner will lead work on the approach to artificial intelligence and on a new Digital Services Act. There will also be a focus on day-to-day functioning of the single market, specifically, on the implementation and enforcement of rules at the European, national, regional and local levels.

## Johannes Hahn

**Position:** Commissioner for Budget and Administration

**Country:** Austria

**European Party:** European People's Party

**Background:** Mr Hahn previously served as Minister for Science and research in the Austrian Federal Government, before moving to the European Commission to undertake the role of Commissioner for Regional Policy. He is currently the European Commissioner for European Neighbourhood Policy and Enlargement Negotiations.

**Relevance:** A key focus of this portfolio will be concluding the negotiations on the 2021–2027 Multiannual Financial Framework (MFF), ensuring it is streamlined, simpler to understand and more flexible. The Commissioner is also expected to work with other Commissioners to ensure coherence between individual sectoral programmes in the MFF.



## Stella Kyriakides

**Position:** Commissioner for Health

**Country:** Cyprus

**European Party:** European People's Party

**Background:** Ms Kyriakides worked in the Ministry of Health between 1976 and 2006, before being elected to the Cypriot House of representatives, where she is an incumbent member. She has also served as President of the Parliamentary Assembly of the Council of Europe between 2017 and 2018.

**Relevance:** The Health portfolio sets the direction of future health policy within the EU. Specifically, the Commissioner has been tasked with ensuring that Europe

has the supply of affordable medicines to meet its needs, as well as focusing on the implementation of the new regulatory framework on medical devices. There is also a focus on utilising e-health to provide high-quality healthcare and reduce inequalities. A key project will be the creation of a “European Health Data Space” to promote health-data exchange and support research on new preventive strategies, as well as on treatments, medicines, medical devices and outcomes.



## Key European Committee Chairs



### Pascal Canfin MEP

**Position:** Chair of the Environment, Public Health and Food Safety committee (ENVI)

**Country:** France

**European Party:** Renew Europe

**Background:** Mr Canfin previously served as an MEP, before taking up a role in the French Government as Minister for Development. Most recently, Mr Canfin was head of the WWF in France before being elected to the European Parliament in May 2019.

**Relevance:** The ENVI committee has a broad scope of policies within its remit. However,

the public health aspect of its work covers all health matters in which the EU is involved. This committee will have a key role in overseeing proposals related to the future work of Health Programme (or associated work as part of the ESF+ programme), as well as in advocating for a better funding settlement for health as part of the Multi-annual Financial Framework (MFF).



### Adina-Ioana Vălean MEP

**Position:** Chair of the Industry, Research and Energy committee (ITRE)

**Country:** Romania

**European Party:** European People's Party

**Background:** Ms Vălean previously served in Romania's Chamber of Deputies before being elected to the European Parliament in 2007, following the country's accession into the European Union.

**Relevance:** The ITRE committee will be important in the finalisation of the Horizon Europe programme. Although the

Commission, Council and Parliament have already reached a partial agreement over the future of the research programme, details around the financing are yet to be agreed. The committee will therefore have a key role in ensuring that dementia research, as well as health research more broadly, are prioritised within the Horizon Europe budget.

### Lucia Ďuriš Nicholsonová MEP

**Position:** Chair of the Employment and Social Affairs committee (EMPL)

**Country:** Slovakia

**European Party:** European Conservatives and Reformists

**Background:** Ms Ďuriš Nicholsonová is a journalist by background, as well as having served in the Slovakian Chamber of Deputies since 2010, including as State Secretary at the Ministry of Labor, Social Affairs and Family. She was elected to the European Parliament in May 2019.

**Relevance:** The EMPL committee will be central to all matters related to social policy at a European level, including those related to the European Pillar of Social Rights, discrimination and employment. The committee will also have a key role in relation to the ESF and future ESF+ programme, including examining the level of funding allocated through the MFF.





### Petra de Sutter MEP

**Position:** Chair of the Internal Market and Consumer Protection committee (IMCO)

**Country:** Belgium

**European Party:** Greens/EFA

**Background:** Ms de Sutter is a physician by background, as well as having served in the Belgian Senate from 2014, prior to her election to the European Parliament in 2019. Ms de Sutter is also a member of the European Alzheimer's Alliance.

**Relevance:** Many issues pertaining to dementia research are intertwined with matters related to the single market and the rules which govern it. Issues such as cross-border collaboration, data-sharing (including GDPR) and system interoperability, will feature in the work of IMCO. Similar issues also exist for policy matters such as the ability to use and transfer e-health records across the EU.

#### Alzheimer Europe's next steps

The European Parliament has to give its consent to the entire College of Commissioners, including the High Representative of the Union for Foreign Affairs and Security Policy/ Vice-President of the European Commission. Hearings by the European Parliament Committees, in which the European Parliament

will question and scrutinise the candidates will take place at the end of September and beginning of October.

Once confirmed in their positions, Alzheimer Europe will write to each Commissioner asking them to commit their support for

prioritising dementia within their portfolio. In addition, Alzheimer Europe will invite to the Commissioners and committee Chairs to be interviewed for Dementia in Europe to share how they will ensure that dementia is represented with their specific remit.

**Our mission is clear.  
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# Governmental Expert Group on Dementia meets to discuss policy developments across Europe

Following a successful inaugural meeting of the Governmental Expert Group on Dementia in December 2018, Alzheimer Europe was delighted to work with colleagues in the Dutch, Italian and Scottish Governments to bring the group together for the second time.

The European Group of Governmental Experts on Dementia held its second meeting on 17 and 18 June 2019 in Amsterdam, Netherlands, with 20 European countries represented. In addition, representatives from the 2<sup>nd</sup> European Joint Action on Dementia: Act on Dementia, the World Health Organization (WHO) and Alzheimer Europe were also present.

The group met for the first time in December 2018 as a response to the decision of the European Commission to disband its condition-specific expert groups in favour of a broader health prevention of non-communicable diseases group. The health ministries of Italy, The Netherlands and Scotland (UK), along with Alzheimer Europe, agreed that such a platform was vital for the exchange of knowledge and expertise between countries.

During the course of the meeting, the four work packages of the 2<sup>nd</sup> Joint Action on Dementia were discussed, focusing discussions on diagnosis and post-diagnostic support; crisis and care coordination; residential care; and, dementia friendly communities.

For each topic, work package leaders presented to members of the group, updating them on the latest progress and findings from their project area, with representatives from countries then sharing related work and good practice which was taking place within their countries. Following this, members used the open forum discussions to engage in discussions and questions about challenges and successes on specific issues.

In this section, we provide an overview of some of the discussions and themes which emerged throughout the course of the discussions on the day. We have also included two examples, from the Czech Republic and Sweden, of work which was discussed on the day.

## Timely diagnosis and post-diagnostic support

Work package lead Pierre Kolak-Salmon presented on diagnosis and post-diagnostic support, noting that the conceptual view of dementia is beginning to shift, requiring a change in approach to the diagnosis and treatment of dementia. The work package covered a number of areas including piloting new training programmes for GPs around their understanding of dementia, attempting to establish a graduated approach to diagnosis (as well as improving GPs knowledge of different diagnosis strategies), as well as reviewing the diagnostic value of existing diagnostic tools.

In the open discussion, countries shared their specific challenges with an emerging consensus that no “one size fits all” existed which addressed all issues. Behaviour change in professionals was agreed as a matter which was as important as clinical knowledge. The position of GPs within healthcare systems, their role in the diagnostic process and the effective use of their finite time, were also explored.

## Crisis and care coordination

Jacqueline Hoogendam, work package lead for the crisis and care coordination

work-stream, updated the group on its development of work to provide clear, evidence-based recommendations on how to effect change and improve care coordination and crisis response services for people with dementia. The key findings of the project had so far been the need to tailor support to needs of the individual, develop dementia care pathways, ensure support for carers in order to reduce carers stress and the need for ongoing monitoring of the support provided to make sure it is appropriate.

During the course of the open discussion, there was debate around the best approach to care coordination, with specific focus on the level of specialism required for service delivery. There was an evident divide between countries which use case management specialism by default for all persons with dementia, compared to those countries which only use specialists for more complex cases. Additionally, the use of data in health systems was seen as a key area of focus for the future of the group, learning from countries which had adopted this approach.

## Residential care

Oyvind Kirkevold, work package lead for residential care, presented on the progress of his the Joint Action (in particular around training for staff in relation to behavioural and psychological symptoms of dementia) explaining that the process of pulling together the conclusions was underway. Drawing out the overarching themes from the work, it was noted that teaching, training and reflection for staff improved quality and care, however, required dedicated effort and resources. Furthermore, the need for training programmes to be flexible and adaptable to different contexts was identified as crucial to their success.

During the open discussion there was broad agreement about the importance of implementation, with many countries noting that guidelines and policies were in place but that the challenge lay in implementation and oversight. The importance of upskilling staff was seen as important, however, the challenges of behaviour change within a care environment, especially among more experienced members of staff, was noted as a challenge.



### Dementia friendly communities

The open discussion between members focused on matters relating to how to demonstrate the benefit of dementia friendly communities and the difference these made to people's day-to-day lives. The group noted the different approaches taken between countries, with some adopting a standards-based approach, whilst others linked the initiatives into service delivery. Additionally, members acknowledged that there is a need within this area of work to balance the rights of the individual and ensure they are included within their communities, without an excessive focus being placed on the individual's diagnosis of dementia.

Another topic of discussion was around how best to align dementia inclusive initiatives, including dementia friendly communities and dementia friends, with other work-streams which may have similar objectives and target demographics, e.g. age-friendly communities.

### WHO Global Action Plan on Dementia

Stéfanie Freil, of the WHO introduced the Global Action Plan on Dementia (2017-2025),

noting the wider policy context of the document, including the Sustainable Development Goals (SDGs) and the Mental Health Action Plan.

The WHO has developed tools and resources to support countries in implementing the seven action areas of the plan: increasing prioritisation and awareness of dementia; reducing the risk of dementia; diagnosis, treatment and care; support for dementia carers; strengthening information systems for dementia; and research and innovation.

Focus was given the progress in establishing of a Global Dementia Observatory, a data and knowledge exchange platform which will offer access to key dementia data from Member States. Additionally, the presentation highlighted the recent publication of the iSupport resource for carers, which aimed to provide both an online and physical resource for informal caregivers of people with dementia. Additionally, it was highlighted to the group that WHO's had recently published guidelines on risk reduction and cognitive decline and dementia.

### Future meetings of the group

The group agreed to continue with a format of two meetings per year, taking place in central locations in Europe. It was further agreed that Alzheimer Europe would continue to provide a secretariat role for the organisation of the group.

The group proposed a number of areas which the group hoped to address in future meetings including:

- Palliative care/end of life care.
- Data/metrics/measurement, understanding change, benefit value and improvement.
- A final session to conclude and reflect on the second Joint Action on Dementia.
- Registry and data collection – how this works and how it is set up. Could be part of metrics, surveillance, brain health registries.

The group will meet, for a third time, in December 2019 in Brussels, Belgium. These meetings will coincide with the Alzheimer's Association Academy, Company Round Table and Lunch Debate meetings which will take place on 10 and 11 December 2019.



Governmental expert group meeting, Amsterdam, Netherlands



### **Hana Marie Broulíková, Coordinator, National Action Plan for Alzheimer's and related diseases, Ministry of Health talks about the development of the Czech National Action Plan for Alzheimer's Disease and Related Illnesses 2020–2030**

After encountering serious issues in implementation of its previous version, the Czech Republic is currently revising the National Action Plan for Alzheimer's Disease and Related Illnesses (Plan). Unlike in the case of its predecessor, the works on the Plan follow guidelines, recommendations and tools recently issued by the World Health Organization (WHO). The process proceeds step by step as recommended by Towards a Dementia Plan: A WHO Guide and by the Global Dementia Observatory initiative. In line with the recommendations, the Czech Republic goes through the following stages to achieve a feasible Plan: situation analysis, setting priorities, creating strategic framework, assessing resource needs, and obtaining political and stakeholder approval. The situation analysis was undertaken by collecting Global Dementia Observatory indicators, which enables systemic identification of existing gaps as well as an international comparison.

During the whole revision process, intensive effort is being made to enhance stakeholder engagement as low buy-in hindered success of the 2016–2019 Plan.

This has been achieved by appointing a dementia coordinator responsible for the Plan development and by establishing a broad stakeholder platform that regularly meets to discuss the progress with respect to formulating vision, goals, objectives and activities of the Plan. Two of the platform meetings were organized as workshops attended by an international expert from WHO Dr Anne Margriet Pot, who brought her experience and fresh perspective to the process of development. Importantly, supervisors from key Czech organizations led narrowly focused working groups in their areas of expertise. Consequently, stakeholders are expected to have strong incentives to apply for funding that will be allocated to

implementation of specific activities and dissemination of the Plan to the target groups will likely be easier.

The Plan will consist of three parts: an introduction describing our vision and guiding principles, a situation analysis, and a proposal of recommendations. This last part will contain specific activities to be implemented in order to achieve the goals of the Plan. Remarkably, the Plan will exploit synergies with the ongoing reform of mental health care represented by the National Action Plan for Mental Health until 2030. An example of such synergy is the provision of community services, which are a priority for both strategy documents. The Plan was introduced to the wider public on the occasion of the World Alzheimer's Day on September 21, 2019.

### **Frida Nobel, Medical Officer, National Board of Health and Welfare, outlines Sweden's new model for standardised health and social care pathway for persons with dementia**

In Sweden, current costs for society are approximated to be EUR 6 billion per year, whereof the municipalities cover approximately 85 %. Sweden has had national guidelines on dementia care since 2010, with the recommendations based on a review of current knowledge in medical science and health economics.

In May 2018, Sweden decided on, for the first time, a national strategy for dementia. This strategy includes areas like cooperation between caregivers, building of new knowledge, follow up of care outcomes, improvement for family caregivers, development of digital tools, and how the society in general can become more dementia-friendly. The first step in the dementia strategy was to develop a model for standardised health and social care pathway for people with dementia.

In June 2019, the National Board of Health and Welfare published a model for a

standardised health and social care pathway, including support and follow up. One aim of the model is to standardise care pathways for a person with dementia throughout the progression of the disease from diagnosis until the end of life. Another aim is to include successful examples how to cooperate between different caregivers, for example between regions and municipalities, between several levels of care and between different categories of health and social care professionals.

The model is based on person-centered care for persons with dementia, however, the interventions in the care pathway may differ for individuals since the individual needs are different.

In brief, the model describes the following:

- What should be offered - a standardized health and social care pathway, including support, follow up, treatment, etc.

- How can the identified required interventions be performed – with collaborating teams both on steering levels and on specialist professional levels, for example "dementia teams" including nurses, occupational therapists, social care coordinators and when needed for example physicians, dentists, physiotherapists etc.
- Which "tools" to make individual care plans can be used – existing forms to simplify planning when a person needs care from both the healthcare and the social care.

A key aims of this model is to create a foundation for further development, both at the local (municipal) and regional level. Additionally, the models aims to support the knowledge development at national level to make access to care more equal across the country.

# From single participants to Big Data: data sharing in dementia research

Angela Bradshaw, Project Officer at Alzheimer Europe, takes a look at the benefits of and barriers to sharing data from clinical research studies.



“We could enable faster progress on all fronts of the Alzheimer’s fight by facilitating more data-sharing.”

*Bill Gates*

In his landmark 1906 lecture, Alois Alzheimer described the case of a 51-year-old woman severely affected by the symptoms of a condition we now know as Alzheimer’s disease (AD). Alois Alzheimer’s first study on AD had a single participant: Auguste Deter. Nowadays, clinical studies commonly include hundreds and sometimes thousands of participants, depending on study phase and design. For example, the recent Phase II trial of BAN2401, an anti-amyloid immunotherapy, enrolled 856 participants with mild cognitive impairment. Cohort studies can be larger still: the European Prevention of Alzheimer’s Dementia (EPAD) longitudinal cohort study has already enrolled over 1,800 participants, aiming to characterise the earliest stages of AD. Both are dwarfed by genome-wide association studies (GWAS): a recent GWAS study identified new risk factors

for AD by analysing genetic data from 314,278 individuals in the UK Biobank cohort.

However, size isn’t everything: when it comes to clinical studies, the type of data you collect is just as important as the number of participants. A 2018 report by the Tufts Centre for the Study of Drug Development showed an 86% increase in the average number of clinical endpoints in trials registered between 2001–2005 and 2011–2015. This means that a single trial participant may undergo MRI scans, cognitive assessments and biomarker tests; they may have their DNA sequenced, their blood pressure measured or their physical activity mapped. By linking the data from these tests, clinical researchers aim to obtain better insights into the cause, development and prevention of multi-factorial diseases such as AD.

## Why share data?

As illustrated above, modern-day clinical studies have multiple endpoints, generating vast quantities of complex data. However this comes at a correspondingly high cost: a recent study estimated that a single drug efficacy trial costs an average of USD 19 million, although this figure increases substantially for longer or larger trials involving participants with complex diseases. Recognising the scale of investment in clinical trials, the last two decades have seen increasing calls for these valuable data sets to be shared.

The benefits of sharing clinical study data are clear: research can be validated, the returns on investment are increased and, importantly, new hypotheses can be generated by linking datasets from different trials, accelerating scientific innovation. Moreover, data sharing today can lead to better treatments for the patients of tomorrow. For example, secondary analyses of trial data have highlighted the inefficacy of drugs like Tamiflu, while post-hoc analyses have shown the benefit of adding donepezil to memantine therapy for AD patients. Crucially, data sharing honours the generosity of trial participants, who contribute their time and undergo risky procedures for the sake of medical progress.

“Most participants didn’t see data sharing as a reason NOT to participate in a study, with some saying that it would actually encourage them to sign up.”



“Encouragingly, at the time of writing, 61.5% of due trials had reported results to the EU clinical trials database within the [legally required] 1-year timeframe, up from 50% in 2018.”

### Data sharing in practice: the UK Biobank

The last decade has seen the creation of several platforms for clinical data sharing. The Global Alzheimer's Association Interactive Network platform (GAAIN) houses data descriptors (or “metadata”) from almost 500,000 participants in clinical dementia studies, provided by 51 GAAIN data partners. This “closed” model of data sharing means that the data partners control access to the raw data, whilst enabling researchers to explore metadata and create new cohorts across multiple data sources.

Conversely, the UK Biobank platform exemplifies an open model of data sharing. Established in 2006 by Sir Rory Collins, UK Biobank collects and anonymises longitudinal health data and biological samples from 500,000 participants aged between 40–69 years. The electronic health records of participants are directly linked to the UK Biobank database, providing a record of disease events, drug prescriptions and deaths. This database also contains the DNA sequencing data from all 500,000 participants, facilitating large-scale genetic studies. Of particular relevance to AD, UK Biobank collects imaging data and is aiming to obtain brain MRI scans from 100,000 participants by 2020.

From the outset, UK Biobank has made all its anonymised data openly available to bona fide researchers, subject to verification that the research is health-related and in the

public interest. Importantly, researchers are obliged to return their findings to UK Biobank once their research is complete, so other scientists can benefit. For example, Regeneron and GlaxoSmithKline recently completed exome sequencing of 50,000 UK Biobank participants: this data has now been incorporated back into the UK Biobank for use by the global health research community. 1,463 applications for data access have been submitted since 2012: of these, 71 relate directly to AD. To date, 802 papers using UK Biobank data have been published in peer-reviewed journals, identifying new genetic risk factors for disease and paving the way for improved, targeted therapies.

### In support of data sharing: the participant perspective

Given the well-publicised benefits, many clinical study participants are understandably keen for their data to be shared. At a 2017 data sharing summit organised by the New England Journal of Medicine, trial participants re-iterated their belief in sharing data and experiences in order to help themselves and fellow patients, encouraging researchers to look beyond concerns around loss of data authorship and patient confidentiality. Highlighting the importance of considering the patient voice in debates around data sharing, Sharon Terry (a patient advocate) stated “Trial participants are not patients in the traditional sense of the word. It really should be looked at as a partnership.”

A follow-up survey confirmed the willingness of many trial participants to share data: fewer than 8% of the 771 respondents felt that the potential negative consequences of data sharing outweighed the benefits. The desire to help others was a dominant theme, with several respondents urging greater cooperation and less competition among researchers. An earlier focus group study of participants in the ACT (Adult Changes in Thought) ageing

and dementia cohort identified scientific advancement, research efficacy and health improvements as important outcomes from data sharing: one participant stated “...I think there does have to be an open exchange of information in order for some of these really significant things to happen for peoples’ benefit”. Importantly, most participants didn’t see data sharing as a reason NOT to participate in a study, with some saying that it would actually encourage them to sign up.

### Next steps

Researchers, trial participants, clinicians and policy-makers broadly agree that responsible data sharing can accelerate scientific progress, leading to medical improvements that directly benefit patients. Despite this consensus view, sharing individual participant data from clinical studies is far from common practice. In a 2017 Springer Nature survey, 39% of the 2,683 respondents working in the medical sciences did not share data via repositories or other data sharing platforms. So, what can be done to encourage data sharing from clinical studies?

The first step is to understand what data is being shared, and what isn’t. Alarming, a 2018 study revealed that only 50% of clinical trials registered in the EU had reported results summaries in the EU clinical trials database (EUCTR) within a year of completion, as required by law. In response, several EU and US groups have set up Trials Trackers to independently monitor compliance with clinical trials reporting rules. To assess data sharing from Industry-sponsored drug trials, researchers in the US have recently developed a scorecard to measure clinical trial data sharing policies and practices in pharmaceutical companies. Encouragingly, at the time of writing 61.5% of due trials had reported results to the EUCTR within the 1-year timeframe, up from 50% in 2018. It is hoped that the good pharma scorecard will show a similar upward trend when it comes to data sharing.

The next step is to understand why data isn’t being shared. Frequently-cited reasons include participant confidentiality issues and the technical difficulties of sharing data, as well as the high financial cost of data sharing: when studies end, so do the associated

“Medical progress thrives when the evidence base is complete and openly accessible, allowing researchers to build on, challenge and refine the findings of their peers. As our technical data processing capabilities increase, so will the rewards for responsibly sharing that data, paving the way for new diagnostics, treatments and care.”



funding streams, which means that data sharing can be financially unsustainable in the long term. Worryingly, many clinical triallists feel that academic systems do not adequately incentivise data sharing. A huge amount of effort is required to set up and run clinical trials: triallists therefore expect that they will be able to publish several papers using these valuable datasets, building their academic careers and reputations.

Using this knowledge, we need to develop improved environments, methods and policies for data sharing. To overcome motivational barriers, methods to better incentivise data sharing have been proposed, such as

**“Frequently-cited reasons why data isn’t being shared include participant confidentiality issues and the technical difficulties of sharing data, as well as the high financial cost of sharing data”**

ensuring clinical triallists act as data stewards and are fully credited when their data are re-used. When it comes to patient privacy issues, Artificial Intelligence may provide novel solutions: computer scientists from the AETIONOMY project are aiming to create a virtual dementia cohort that could simulate real patients. Finally, a number of EU-funded initiatives to support data sharing from a technical perspective are well underway: Alzheimer Europe was a partner on the

EMIF project, which worked to collate and harmonise data from AD cohort studies.

Medical progress thrives when the evidence base is complete and openly accessible, allowing researchers to build on, challenge and refine the findings of their peers. As our technical data processing capabilities increase, so will the rewards for responsibly sharing that data, paving the way for new diagnostics, treatments and care.

## Acknowledgement



Thanks to support from Gates Ventures, Alzheimer Europe is currently conducting a project on data sharing in dementia research.



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# Spominčica hosts neurological diseases conference in Slovenia

On 25 May 2019, Spominčica held a conference entitled “In the rhythm of the human brain” in Ljubljana. It is the first time that five different neurological diseases were presented and discussed together: dementia, Parkinson’s disease, multiple sclerosis, Huntington’s disease and spinal muscle atrophy.

“We are here today not only to remember, but to talk throughout the day and to share our experiences and also to see how to deal with this problem further. The law on long-term care has a lot to be resolved.”

## Prime Minister Marjan Šarec

The conference, sponsored by ROCHE, was held under the honourable patronage of Mr Marjan Šarec, the Slovenian Prime Minister, who also addressed the 300 attendees who took part in the conference, comprising members of the general public, people

living with the conditions, family members, experts and policy makers. Guests at the conference included Mr Aleš Šaberder, Minister of Health, Dr Tomaž Pilberšek, Secretary of State for Health, Mrs Breda Božnik, Secretary of State for Ministry of Labour, Family and Social Affairs and Dr Aiga Rurane, representative of World Health Organization (WHO) in Slovenia.

## Prime Minister address to the conference

Mr Šarec told the conference: “When looking deeper, we see that not everyone can enjoy the beauty of the day. A certain percentage of our population is affected by one or another disease. And the diseases we are addressing today are on the rise, a huge



Prime Minister Marjan Šarec addresses attendees

burden, especially for relatives”. He shared a personal story with the conference, explaining that his wife’s grandmother, who was affected by dementia later in life, had recently passed away. He told the conference that she had taken care of the farm all her life and that she was extremely bright and energetic. In the end, she didn’t know anyone or know where she was, which greatly pained those who knew her.

The Prime Minister also told attendees: “We are here today not only to remember this, but to talk about it throughout the day and to share our experiences and also to see how to deal with this problem further. The law on long-term care has a lot to be resolved”. He also highlighted that Mr Šaberder had made clear that the Long-term Care Act, which had been awaited for almost 15 years, should be developed. The Prime Minister thanked the organisers for the invitation to be honorary patron of the event, noting that “honour will shift to action, especially in the field of diseases and diseases that are on the rise today.”

## Dementia focused session

Sessions opened with a medical expert presenting the disease, followed by a panel discussion with patients, caregivers, experts and policy makers. At the end of the sessions, the audience were invited to pose questions



The dementia panel discussion (from left to right): Maja Južnič Sotlar, moderator; Janja Romih, Ministry of Labour, Family and Social Affairs; Mihela Španja, wife of the first Slovenian EWGPD member Bojan Španja; Dr Milica Gregorič Kramberger, University Medical Center Ljubljana; Štefanija L. Zlobec, Spominčica; Prof Peter Pregelj, University Psychiatric Clinic Ljubljana; Tomaž Gržinič, Member of EWGPWD.

concerning diagnosis, treatment and living with the disease. Tomaž Gržinič, member of the European Working Group of People with Dementia (EWGPWD) and Mihela Španja, wife of the first Slovenian EWGPWD member Bojan Španja, participated in the dementia panel together with Dr Milica Gregorič Kramberger (leader of Models of Patient Engagement for Alzheimer's Disease – MOPEAD project in Slovenia), Prof. Peter Pregelj, University Psychiatric Clinic Ljubljana, Štefanija Zlobec, President of Spominčica and Janja Romih, representative of the Ministry of Labour, Family and Social Affairs.

They concluded that the burden on family carers should be reduced with adequate

community based services and additional institutional care facilities for persons with dementia. It was noted that the Ministry was aware of the problems and was preparing an action plan for the next financial review. Experts and representative of the Ministry thanked Spominčica for the important work in the community and also for moving forward dementia in the political agenda in Slovenia.

### Conclusions

A key achievement of the conference was the engagement of patients and their caregivers who co-created and participated in the panel discussions, helping to identify the current gaps in social care and healthcare

services, as well as stressing the importance of affordable and dementia-friendly facilities and services that promote social inclusion, dignity and quality of life of each individual. It is the desire of all involved to repeat the conference next year.

“Honour will shift to action, especially in the field of diseases and diseases that are on the rise today.”

*Prime Minister Marjan Šarec*





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Attendees included (from left to right): Štefanija L. Zlobec, President of Spominčica; Marjan Šarec, Prime Minister; David Krivec, Secretary General of Spominčica; Aleš Šabeder, Minister of Health; Breda Božnik, State Secretary of Ministry of Labour, Family and Social Affairs; Dr Aiga Rurane, representative of WHO in Slovenia; Dr. Tomaž Pilberšek, Secretary of State, Ministry of Health.



## Policy campaigns – do they work?

What impact does policy campaigning really have at national level? Alzheimer Europe spoke to two of its national member associations about recent policy campaigns each had run, asking what the outcomes were and what real impact they had been able to achieve.

### Promoting Dementia-Inclusive Communities at the heart of The Alzheimer Society of Ireland's Local Election Campaign 2019



In May 2019, The Alzheimer Society of Ireland (ASI) called on all candidates in the local elections to promote dementia-inclusive communities if they were elected. This support from local representatives in communities around Ireland is extremely important to help the 55,000 people living with dementia.

With dementia being a growing issue and the majority of those with dementia living in the community, it was identified that there is a need for a “whole community response” to dementia. Local councillors, who are working every day in their own communities, are witnessing the issues families are facing.

The ASI campaign team, led by our Head of Advocacy & Public Affairs Tina Leonard and

“Following our campaign, Dublin City Council, the largest administrative council in Ireland, decided to take a leadership role on dementia issues. They worked with us to include dementia-specific tips in their ‘Age Friendly Communication’ booklet.”

Advocacy Manager Avril Easton, consulted with key policy makers in devising the local election campaign. They identified specific deliverable actions for councillors to take:

1. Sign up and become a Dementia: Understand Together Community Champion (“Dementia: Understand Together” is a public support, awareness and information campaign in Ireland);
2. Engage with local dementia service-providers to identify facilities where dementia-inclusive initiatives could be held and link with other Community Champions to offer these;
3. Encourage public-facing staff (e.g. in libraries), to participate in dementia-awareness training;
4. Finally, The ASI called on local councillors to lobby their own parliamentary party to make dementia a priority.

#### Grassroots network

Another pivotal part of the campaign was mobilising the grassroots network of The ASI. We did this by designing and producing 3,000 voter prompt cards which were distributed

“Given the local nature of the elections, we knew that securing local media coverage was going to be essential to the success of the campaign.”

to our services, branches, directors, members of the Irish Dementia Working Group (IDWG) and Dementia Carers Campaign Network (DCCN), as well as other volunteers. We also contacted our 10,000 e-Campaigners and informed them about the local and European campaigns and how they could get involved.

Given the local nature of the elections, we knew that securing local media coverage was going to be essential to the success of the campaign. We issued 27 unique press releases (1 national and 26 county-specific ones) and identified local spokespeople that could liaise with local media. Overall, there were 13 print articles, 2 featured online and there were a number of local radio interviews.

“We have heard from politicians and constituents that the issue of dementia is being raised on doorsteps more than ever.”

Vice-Chair of the IDWG, Kathy Ryan, who helped to promote the local election campaign on behalf of The ASI, believes that making communities more dementia-aware is so important, especially in rural Ireland



Tina Leonard and Avril Easton



where those with dementia can often experience social isolation and loneliness. The local election campaign was particularly poignant for Ms Ryan, as the last time the local elections were held was in 2014, the same year she received her dementia diagnosis.

### Dementia-aware

“The vast majority of people diagnosed with dementia want to live in their own home and stay active in their own community. In order for this to happen we need our communities to become more dementia aware,” Ms Ryan said. “When a community is dementia aware, it makes the difference between us living as well as possible or staying at home behind closed doors, which has a hugely negative impact on our health and wellbeing. This is why these local elections are so very important. Newly-elected councillors can ensure that local communities make dementia a priority.”

### Campaign outcomes

An example of one outcome from the local election campaign was that elected councillors in Dublin City Council, the largest

“Dublin City Council also committed to making its staff members dementia aware. We co-ordinate awareness sessions as part of the “Dementia: Understand Together” campaign. As this was a key ask in our campaign, it is great to see it begin to have a meaningful impact on people’s lives.”

administrative council in Ireland, decided to take a leadership role on dementia issues. They worked with The ASI to re-write their “Age Friendly Communication” booklet to include dementia-specific tips. It was launched at a celebratory event at the start of July, at which The ASI CEO and Alzheimer Europe Board member Pat McLoughlin spoke of the importance of integrating dementia knowledge into guidelines on communicating.

Dublin City Council also committed to making its approximately 5,000 staff members dementia-aware by asking them to attend a dementia awareness session. The ASI co-ordinates dementia awareness sessions for staff as part of the “Dementia: Understand Together” campaign. As this was a key ask in the local election campaign, it is great to see it begin to have a meaningful impact on

people’s lives. The first awareness session took place on 11 July 2019, with more to follow. As the largest council in the country, it is expected that other councils around the country will follow Dublin City Council’s leadership on dementia and The ASI will promote and facilitate this.

Although, it is often difficult to measure the overall success of campaigns such as these, anecdotally we have heard from both politicians and constituents that the issue of dementia is being raised on doorsteps more than ever. We look forward to working closely with many more local councils and councillors over the next five years, to ensure that dementia is given priority in local communities.

For more information on The Alzheimer Society of Ireland’s local election campaign, go to: [www.alzheimer.ie](http://www.alzheimer.ie)



Kathy Ryan and Kevin Quaid, members of the Irish Dementia Working Group

“When a community is dementia aware, it makes the difference between us living as well as possible or staying at home behind closed doors, which has a hugely negative impact on our health and wellbeing. This is why these local elections are so very important. Newly-elected councillors can ensure that local communities make dementia a priority.”

Kathy Ryan



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## Campaigning for a new memory programme and for better care in Finland



**In the spring of 2019, the Alzheimer Society of Finland (Muistiliitto) campaigned on several important issues. The current national Memory Programme is ending in 2020 and a new programme is needed.**

In Finland, 2019 started with revelations of neglect, inadequate care and insufficient staffing at care homes around the country. These issues were discussed in the media and memory-related diseases were the focus of many articles.

In February, the Minister of Family Affairs and Social Services, Annika Saarikko invited care providers, third sector organisations, municipalities and trade unions to discuss the situation together. We participated in this working group and told other participants about our workbook for professionals, "The Criteria for Good Care and Life". It is aimed at people working in homecare services and nursing homes, to help develop and evaluate their work with people diagnosed with memory-related diseases and their carers.

### Commitments made to improve care

The working group committed to a list of 25 measures to improve care, both in private-ly-owned facilities and in public care facilities.

Good care was also part of our national parliamentary elections campaign. These elections were held in April. We wanted to make candidates aware of memory-related issues and to inspire them to work as "memory defenders". Local associations were encouraged to reach out to the candidates using Twitter.

The goal was to make sure that a person with a memory-related disease has the right to



Muistiliitto election campaign buttons

self-determination and equal practices, to live in a memory-friendly Finland and to get care and support in the right place, at the right time.

### New government programme – positives and negatives

After the elections, the new government was formed. The government programme was released in July 2019, including a promise to rebuild the public's trust in quality, timeliness and availability of services for older people. We were happy to see that preventive measures against memory-related diseases will be brought into step with prevention of other

**"The new government has promised to rebuild the public's trust in quality, timeliness and availability of services for older people."**

chronic diseases.

Unfortunately, a new national memory programme is not on the government's agenda. Instead, the government wants to prepare a horizontal programme on ageing, in collaboration with ministries, municipalities, third sector organisations and other actors.

The work in Finland continues. The working group continues to try to instate the list of 25 commitments made on improving care. Finland's new Minister of Family Affairs and

**"The work in Finland continues. The working group continues to try to instate the list of 25 commitments made on improving care."**

Social Services Krista Kiuru chairs the group and our Executive Director, Katariina Somu, takes part in the meetings.

We also need to make sure that if there is no national memory programme, the planned programme on ageing takes people with memory-related diseases into account. It also needs to include the special features of prevention and care of memory-related diseases.



Krista Kiuru



### Alzheimer Society of Finland (Muistiliitto)

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**"We were happy to see that preventive measures against memory-related diseases will be brought into step with prevention of other chronic diseases."**

# UK inquiry looks at societal barriers preventing people with dementia from enjoying their full rights

In June 2019, the UK government’s All Party Parliamentary Group (APPG) on Dementia published a report, “Hidden no more: dementia and disability”. The report found existing legal safeguards in the UK are failing people with dementia, who aren’t able to assert their rights to be treated fairly and equally. Alzheimer’s Society caught up with Debbie Abrahams MP, Co-chair of the APPG on Dementia, to tell us more.



Debbie Abrahams MP

loss of identity. One person with young-onset dementia told us – “I applied for so many jobs and I just got rejections. I used to lecture at a university and now I can’t get a job collecting trolleys. Any job is worthwhile. Not having a job destroys self-esteem.”

## What were the key findings and recommendations of the “Hidden no more: dementia and disability” report?

Dementia is a disability, according to the Equality Act 2010 and the United Nation’s Convention on the Rights of Persons with Disabilities. However, the APPG’s year-long inquiry, which culminated in this report, found that society is lagging behind in this understanding and failing to uphold the rights of people with dementia.

Shockingly, 98% of the 2,500+ inquiry respondents thought that people living with dementia are treated differently to people with other health conditions or disabilities, despite their rights. The respondents believe that this is due

to the ‘hidden’ nature of dementia, and the stigma surrounding the condition.

A central finding of this report is that the public, employers, organisations, governments and public bodies need to be more aware of, and recognise, the rights of people with dementia. Action needs to be taken across a number of key areas to ensure that people with dementia receive the protections and safeguards that legislation and convention provide.

## Employment

The first area we explored was employment for people living with dementia. Employment can give people a sense of purpose, as well as income, and without this, people can feel a

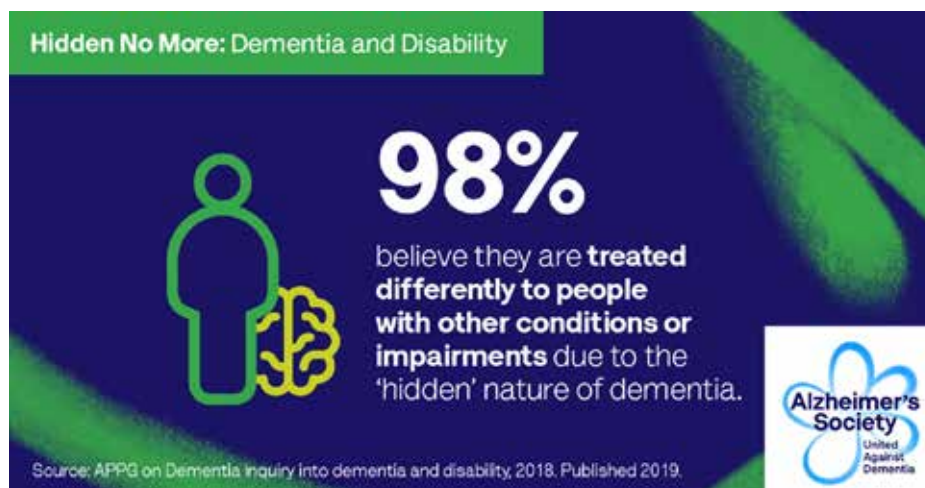
This inquiry found that there needs to be more awareness of the employment rights of people with dementia and more support to implement them. Government has a hugely important role to play, through both guidance and support for employers.

## Social protection

The next area we looked into is social protection, or welfare benefits as it is also known. The cost of living with a disability can be devastating. Being able to access extra financial support can provide a lifeline for people with dementia and can help people to continue getting out and doing the things they enjoy.

One of the key challenges for people affected by dementia is knowing what financial support they are legally entitled to. Too often, people affected by dementia are left with no formal support after a diagnosis. One family member told the APPG that they felt “people with dementia are effectively ignored by the disability benefits system.”

To address this, the report recommends that there needs to be more support to help people find out what financial help they are entitled to, as well as how to make a successful claim. Local authorities will be key to achieving this change. People with dementia deserve to be assessed by professionals who understand the condition, without having to undergo unnecessary reviews or reassessments.





## Social care

A further key issue was social care. The focus of the report is on the barriers faced by people with dementia with regard to fully participating and feeling included in the community and society. However, there was a lot of feedback about inadequate or inaccessible social care for people affected by dementia living in England. The report therefore calls on the government to urgently produce a long-term plan for addressing the social care crisis.

## Transport

Another area we explored was transport. Good quality public transport can have a huge impact on the lives of people affected by dementia. Yet, we heard many stories of how poor or inaccessible transport is preventing people with dementia from participating in society. This is despite rights to accessible transport being enshrined in the UK's Equality Act 2010.

The report stresses the importance of any changes to bus and community transport services being mindful of reasonable adjustments to ensure the services are still accessible. There must also be an increase in societal awareness of the condition to reduce the stigma and discrimination that people with dementia face and feel while using public transport.

## Housing

Housing was also extensively mentioned in our report. We found that people with dementia are frequently being denied their right to live independently in their own homes, where they are able to make their own choices. It is important that people with dementia are supported as much as possible to stay living in their own homes or are supported to access suitable housing.

People living with dementia must have access to adaptable housing, trained home-care staff, and specialised supported housing schemes.

## Community life

The final area we looked at was community life. The report found that communities must increase their awareness and understanding



of dementia. We also believe that people need to be supported through the development of inclusive communities, where no one is excluded nor has to face dementia alone.

## How were people affected by dementia involved in this report?

As part of this inquiry, the APPG launched a call for evidence, from anyone with an interest in dementia – personally or professionally.

We received an unprecedented amount of feedback via an online survey, focus groups, written evidence and an oral evidence session. The amount of feedback received was one of the largest responses to any APPG inquiry, and I think this really highlights the importance of this issue.

## How was the report received?

The report has been very well-received, both locally and nationally. We have had lots of interest from parliamentarians and local government officials who are keen to pursue the report's recommendations. I hosted a Westminster Hall debate in July 2019, where the report was welcomed by a cross-party group of MPs. It also received national and local media coverage. We hope that this helped to raise wider awareness of dementia as a disability, and subsequently the rights of those living with dementia.

Crucially, it was also well-received by people affected by dementia. There were many people affected by dementia at our launch

event, some of whom shared their stories and insights into why this report is so important. We also consulted with the 3 Nations Dementia Working Group ([www.3ndementiaawg.org](http://www.3ndementiaawg.org)), run by people living with dementia in England, Wales and Northern Ireland, throughout the report-writing process, and have the group's full support for taking these recommendations forward.

## What are the next steps?

Over the coming months, the All Party Parliamentary Group on Dementia will be working closely with Alzheimer's Society to turn this report's recommendations into reality. We have several meetings planned with senior government officials, as well as cross-party commitments to debates, and to bring forward pieces of legislation. I hope that this work will make a lasting difference to the lives of people living with dementia and their carers and supporters.



## Iceland forms a working group of people with dementia

Sigurbjörg Hannesdóttir, project and training manager at Alzheimer Iceland, and her predecessor Sirrý Sif Sigurlaugardóttir, a gerontological social worker, tell us about the first ever working group of people with dementia to be formed in Iceland.

Prior to forming the working group of people with dementia, the possibility of having such a group in Iceland had been raised a number of times in recent years, within Alzheimer Iceland. The main inspiration for these discussions and, ultimately, for the creation of the group itself, was the European Working Group of People with Dementia (EWGPWD). There was, however, a barrier to getting people involved. The discussion around dementia was still quite negative at that time (around 2010). Thankfully, much has changed since then and, in 2017, there was a growing number

of members asking for a platform for people with dementia. The voice of those with young onset dementia was particularly loud.

“This is a group for people with dementia and it must be tailored to their needs.”

The first meeting of the group was in January 2019. It was held in the premises of Alzheimer Iceland. Seven people attended,

“The group wants to be the voice of dementia in the community, and to cooperate with other groups and associations, at an international level.”

three individuals with dementia and four family members. The main goal of the meeting was to introduce the members of the group to one another, and to allow them to express their ideas and/or expectations for future meetings. Alzheimer Iceland was pleased with the new initiative and was willing to help the group in any way it could. The focus of the group was on issues regarding employment, such as employers' reactions, and participation in the labour market; family impact; and parents with dementia bringing up children/adolescents.

Special attention was paid to human rights issues and to promoting better awareness of the various types of dementia. The group wants to be the voice of dementia in the community, and to cooperate with other groups

Pioneers, Reykjavík marathon, 22 August 2019



and associations, at an international level. The working group also wanted to be a part of Alzheimer Iceland and to be able to have access to the facilities at the association. With the permission of Alzheimer Europe, the guidelines for participating in the EWGPWD were translated and adapted for Iceland, and are being used by the new group.

“The group wants to be the voice of dementia in the community, and to cooperate with other groups and associations, at an international level.”

At its first meeting, the group decided to meet at least 6 times per year, taking December and the summer months off. The group is

now a division under the Icelandic association with Ellý Katrín Guðmundsdóttir as its Chair and Jónas Jónasson as its Vice-Chair. Two individuals from the group are sponsored by Alzheimer Iceland to attend the Alzheimer Europe Conference each year.

### The Road Ahead

The working group has found a name, they call themselves “Frumkvöðlar” (Pioneers). The Pioneers participated in the Reykjavík marathon, which is held every year in Iceland.

### World Alzheimer’s Day, 21 September 2019

Alzheimer Iceland hosted a conference in Reykjavík on World Alzheimer’s Day, 21 September 2019. The theme of the conference was “I am still me”, focusing on the human rights of people with dementia. The Pioneers took part in the conference and there was a

panel where they were able to tell their stories, together with their family members. The conference was open to everyone and is well-known in Iceland. In 2019, 300 people attended the conference.

### The future

The Pioneers are discussing the criteria for participation in the group. There are more and more people with young onset dementia contacting Alzheimer Iceland to ask for information, and the group wants it to be open for everybody diagnosed before the age of 65, which is defined as early diagnosis. If participation increases, there are many possibilities to accommodate this, for example the group could be split by age or interest. No person with dementia in the group is required to be accompanied by a spouse or other supporter/carer. This is a group for people with dementia and it must be tailored to their needs.

### Profile

Sigurbjörg Hannesdóttir is a project and training manager at Alzheimer Iceland

She is an occupational therapist and studied in Esbjerg, Denmark.

She has a broad experience working with older people in nursing homes.

Sigurbjörg Hannesdóttir is also the president of The Icelandic Gerontological Society – Öldrunarfræðafélag Íslands (ÖLD), a position she has held since 2014.



“The main inspiration for these discussions and, ultimately, for the creation of the group itself, was the European Working Group of People with Dementia.”

### Profile

Sirry Sif Sigurlaugardóttir is a gerontological social worker in the municipality of Skagafjörður, Iceland. Previously she worked as a project and training manager at Alzheimer Iceland.

She has a masters degree in social work, from the University of Iceland. Her dissertation focused on evidence-based practice in gerontological social work. Sirry Sif Sigurlaugardóttir is a Board member of the Icelandic Gerontological Society.



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Excerpt from an interview published in a popular Icelandic newspaper, the “Morgunblaðið”, on 22 August 2019

“I am not the same as I used to be”

“It is difficult to put a timeline on the changes that have occurred in me over the last two years. I’m not the same as I was, but part of me still exists. After I told everybody that I have Alzheimer’s disease, I experienced a feeling of freedom, and the shame that I experienced from having the disease disappeared”, says Ellý Katrín Guðmundsdóttir, who was diagnosed with Alzheimer’s disease four years ago, then 51 years old.

“After I told everybody that I have Alzheimer’s disease, I experienced a feeling of freedom, and the shame that I experienced from having the disease disappeared.”

### Ellý Katrín Guðmundsdóttir

Ellý spoke publicly about her illness at the Icelandic Genetics Research Conference two years ago, and now plans to participate in the Reykjavik Marathon with the “Don’t Forget the Joy” running team, to raise money Alzheimer Iceland. The running group is running the marathon for the third time, and was founded by Stefán Hrafnkelsson after he was diagnosed with Alzheimer’s disease when he was 58 years old. Now five more people who have been diagnosed with Alzheimer’s and their families are joining the running group. “Don’t Forget the Joy” refers to the importance of not forgetting that joy is still possible, even though the memory is affected.

Before Ellý was diagnosed, she worked as a secretary for the city council, reportedly receiving a lot of support from them. She still works part-time, at 60%, in the department of environment and planning. Ellý declares herself to be passionate about environmental issues, and she studied environmental law in the USA in 1994. In addition to this work, Ellý and Magnús participate in a group, working within a



Magnús Karl Magnússon and Ellý Katrín Guðmundsdóttir, Morgunblaðið, 22 August 2019

special department of Alzheimer Iceland, which goes by the name “Pioneers”. The group includes twelve people, six individuals diagnosed with Alzheimer’s and their spouses.

“Eight people were in the group initially and the group will expand further. Today, the Pioneers are individuals between 50 and 66 years of age. The group meets monthly, and outside meetings, they also get together for fun”, says Magnús Karl Magnússon, Ellý’s husband, who stresses the importance of interacting with people in a similar position; people who are still active in life. Ellý Katrín adds that she is the only one in the Alzheimer’s group who is still in employment.

Ellý Katrín says she is glad to have stepped forward and spoken up about Alzheimer’s disease. She “comes to the door as she is dressed” (an Icelandic saying), it is in her nature. It was good to “come out of the closet”, she says.

Magnús adds that, although the process of diagnosis was underway and the “hiding” was over, the positivity and *joie de vivre* that had always characterised Ellý were diminished. Magnús felt similarly to his wife, and says it changes a lot, now that everything is “out in the open” with friends, family, and the wider community. The answer to a simple question like “what’s new?” is different when something is actually wrong. Ellý says that many people have stopped her in the street, especially the older generation,

and thanked her for telling her story at the Icelandic Genetics Research Conference.

Magnús says many things have changed since Ellý’s diagnosis. He has stepped aside in various managerial positions, focusing instead on the work and hobbies that he finds the most interesting.

“Many people have stopped [Ellý] in the street, especially the older generation, and thanked her for telling her story.”

Elly and Magnús live a healthy life and focus on a so-called “mind diet” – a diet that fits well with the nutritional goals of the Medical Director of Health – eating raw healthy oils, less red meat and more fruits and vegetables. “Like blueberries”, Ellý chips in, adding that the diet includes one glass of red wine a day. “Every night we have our glass of red wine, talk about the day and listen to good music”, say Ellý and Magnús, who work closely together on their goals “and focus on enjoying the moment and the one that gives life value.”

The “Don’t Forget the Joy” running group raised IKR 1,817,850 (EUR 13,105.71) for Alzheimer Iceland and have helped increase public awareness of dementia in Iceland.

# Gene therapy for Alzheimer's disease: hope or hype?

Angela Bradshaw and Cindy Birck of Alzheimer Europe explore and explain recent developments in the gene therapy field.

Advanced therapies that use genes as medicine have long been touted as the next big thing in the treatment of inherited diseases. This promise is now bearing fruit: in November last year, the European Medicines Agency (EMA) approved Luxturna, the first gene therapy for an inherited retinal disease. Luxturna, appropriately named after the Latin word for light, delivers a working copy of a gene that is dysfunctional in people with a rare inherited form of blindness. In Phase III clinical trials, a single injection of Luxturna in each eye resulted in a gain of functional vision in 93% of the trial participants.

The key to Luxturna's efficacy is the vector it uses to deliver its DNA payload. Similar to a majority of gene therapies, Luxturna harnesses the inherent propensity of viruses to enter cells quickly and stealthily. In addition, viruses have evolved over millennia to preferentially infect different organs in the body – providing researchers with a veritable arsenal of vectors to choose from. By carefully selecting a virus that naturally infects the eye, the developers of Luxturna achieved the medical holy trinity: a treatment that effectively delivers the right gene, to the right tissue, at the right time.

Gene therapies are also being developed for acquired diseases such as cancer, heart failure and non-familial forms of Alzheimer's disease (AD). However, AD therapeutics are faced with a physical obstacle in the form of the blood-brain barrier, which acts as the brain's first line of defence against blood-borne pathogens. The multifactorial nature of AD throws another spanner in the gene therapy works. For example, we now know that inflammation, vascular dysfunction and genetics all play a role in the development of AD. Risk factors for AD include diabetes, hypertension, cardiovascular disease and female gender, among others. AD therefore has a plethora of cellular, biochemical, structural and genetic causes – unlike the inherited blindness that Luxturna

aims to treat, which is caused by a single dysfunctional gene. The choice of which gene to use as therapy for AD is therefore a source of contention that has yet to be fully resolved.

## Gene replacement therapy: NGF and APOE2

Against this challenging backdrop, development of the first AD gene therapies were based on the observation that cholinergic neurons are lost from the basal forebrain during AD development. Researchers aimed to accurately hit the same biological target as drugs such as donepezil and rivastigmine, by protecting and regenerating cholinergic neurons. Named CERE-110, the first AD gene therapy consisted of a virus that delivered the nerve growth factor gene directly to the brains of participants, via an injection into the forebrain area. Although the approach was deemed safe and tolerable after Phase I trials completed in 2010, trials of CERE-110 did not progress beyond Phase II, as no improvement in clinical outcomes was observed. Proponents argued that the

trial was underpowered to detect efficacy. Moreover, they suggested that targeting cholinergic neuron loss may not be sufficient to halt cognitive decline in participants with established AD.

So, back to the drawing board. Researchers identified a new gene target; this time, one that is directly linked to the most prevalent genetic risk factor for AD, ApoE. We each possess two copies of the ApoE gene, which comes in three flavours (or variants): ApoE2, ApoE3 and ApoE4. In 1993, a landmark study showed that individuals with two copies of the ApoE4 variant were at much higher risk of developing AD at a younger age than peers without ApoE4. However, the ApoE2 variant appeared to be neuroprotective: individuals with ApoE2 were at much lower risk of developing AD, even if they had one ApoE4 copy.

Starting in September 2019, a Phase I clinical trial will test a new gene therapy designed to harness the protective power of ApoE2. In this trial, which is co-funded by the Alzheimer's Drug Discovery Foundation, participants with two copies of ApoE4 will receive increasing doses of a viral vector encoding ApoE2. This vector, called AAV10, was chosen based on its improved affinity for neurons compared to AAV2, the vector used in the CERE-110 trials. Another key improvement is the delivery approach. Instead of focusing on a small area of the brain as the CERE-110 trials did, the ApoE2 gene therapy will be delivered to the



subarachnoid cisterns. These structures are filled with cerebrospinal fluid, which bathes the entire brain and will hopefully ensure a widespread distribution of the ApoE2 therapy. Results are due to be published in 2022.

### From gene replacement to gene silencing and beyond

The CERE-110 and ApoE2 trials are based on the principle of gene replacement. However, this is not the only game in town when it comes to gene therapy. In August 2018, the EMA approved Onpatro, a gene silencing therapy for hereditary transthyretin-mediated amyloidosis (hATTR). Rather than increasing the quantity of a therapeutic “good” gene, Onpatro is designed to silence the expression of a pathological “bad” gene – in this case transthyretin, which promotes the formation of amyloid clusters in people with hATTR.

Onpatro is classed as a small interfering ribonucleic acid (siRNA), a class of drugs that function by targeting specific gene products for molecular destruction. The beauty of siRNAs is their adaptability: they can be designed to specifically match – and destroy – any gene product within the cell. Antisense oligonucleotides (ASOs) work on a similar premise, and the first Phase I/II ASO trial for AD is currently ongoing. Developed by the biotechnology company Ionis Pharmaceuticals in collaboration with an academic team in St. Louis, BIIBo80 is an ASO against Tau that is administered to research participants with mild AD. Researchers hope that BIIBo80 will reduce Tau levels in the brains of these participants, slowing down AD progression; results are due in 2020.

In their quest for better therapeutic approaches, researchers are now looking beyond viral gene therapy and gene silencing technologies, towards genome editing. Genome editing is based on a straightforward concept: using molecular tools to modify, delete or rearrange the DNA of a living organism. In 2012, Emmanuelle Charpentier and Jennifer Doudna showed how the bacterial CRISPR/Cas9 system could be used as a “cut and paste” tool in mammalian cells. Elegant yet simple, this system uses short RNA sequences to “guide” molecular Cas9 scissors to edit specific regions of the genome, helped by the host DNA repair machinery.

The next question was how to get these molecular tools to the right tissue, at the right time. In response, scientists went back to their viral gene therapy arsenal. Using viral vectors that targeted the brain, researchers showed they could use CRISPR/Cas9 to disrupt the mutant amyloid precursor protein gene in animal models of familial AD. The results from these and other similar preclinical studies are encouraging: good reductions in amyloid deposition and no detectable off-target effects – so far.

However, there are potentially far-reaching consequences when using CRISPR/Cas9 in humans, as genome editing using this technique is irreversible. In November last year, the scientific and medical communities reacted in uproar when Dr He Jiankui announced that he had performed genome editing in human embryos, resulting in the live birth of twin girls. Dr He reported that he had successfully ‘enhanced’ these babies, inactivating their CCR5 genes and thereby protecting them from being infected with HIV. In response, the European Societies of Gene and Cell Therapy released a consensus statement condemning germline genome editing as irresponsible, risky and ethically unjustifiable.

To address these legitimate ethical concerns, researchers are now developing reversible RNA editing approaches. In an article published in the *Science* journal this July, the Zhang lab described a new RNA editing approach they call ‘RESCUE’. RESCUE uses a Cas9-related protein, Cas13, to specifically edit RNA instead of DNA. By focusing on RNA, the intermediary between DNA and protein, RESCUE can intercept and correct flawed messages from our genes – without causing irreversible genetic changes. This brings us back to ApoE: the good ApoE2 variant and its bad sibling, ApoE4. ApoE2 and ApoE4 are genetically identical apart from two small “spelling mistakes” in the ApoE4 sequence that have huge consequences in terms of AD risk. Remarkably, Zhang was able to use RESCUE to repair these spelling mistakes in cells, transforming pathological ApoE4 into beneficial ApoE2.

As the newest kid on the block, RESCUE therapies will not be hitting the pharmacy shelves anytime soon – and the siRNA and viral gene

therapy trials are still in Phase I/II, a long way from the clinic. Nevertheless, technological advances in gene therapy have opened up new therapeutic frontiers, providing treatment options for diseases previously thought to be incurable. With 6 gene therapy products approved since 2016, and 232 gene therapy clinical trials initiated in 2018 alone, the time is now ripe to assess whether people with AD could benefit from these advances.

### Profile



Dr Angela Bradshaw is a project officer at Alzheimer Europe, collaborating on the VirtualBrainCloud and Neuronet projects. She is also an honorary Lecturer at the University of Glasgow, where she formerly led translational research projects on gene therapy for vascular disease. She holds a PhD in vascular biology from the University of Cambridge.

### Profile



Dr Cindy Birck is a project officer at Alzheimer Europe. She holds a PhD in Systems and Molecular Biomedicine with special interest in neurobiology. She is currently collaborating in different research projects supported by Alzheimer Europe including EPAD, AMYPAD and PRODEMOS. She is also leading the Alzheimer Europe database on clinical trials in Europe.



# Alzheimer Nederland celebrates 35th anniversary – “We have already accomplished a great deal together”

Alzheimer Nederland, co-host of #29AEC, is a patient organisation as well as a health fund. In its 35 years of existence, the organisation has been of great help to people with dementia, as well as to their loved ones. Executive Director Gerjoke Wilmink reflects on the occasion.

“In January 1984, a Dutch television show (*Koos Postema in gesprek*) raised the topic of dementia for the very first time. Until then, dementia was mostly just considered a symptom of old age. In the studio, a psychiatric geriatrician, neurologist, brain researcher and general practitioner talked about Alzheimer’s disease. The response was overwhelming: after the broadcast, the telephone hotline of Stichting Korrelatie – an organisation that provides anonymous, professional, psychological and psychosocial assistance – received 20,000 calls from viewers. Suddenly, the problems people were experiencing with their father, mother or partner had been given a name. The need for information was enormous. The idea to set up a foundation along the lines of the Canadian model was born soon after, during a congress on dementia.

By the end of December 1984, the Alzheimer Foundation – renamed Alzheimer Nederland in 2000 – had become a reality. The foundation’s objectives were: to break the taboo on dementia, to provide information and advice, to encourage contact with others and to promote scientific research. We still do this today, in a great many ways.

“The branches all focus on the same themes, but also address local issues.”

Over the years, Alzheimer Nederland has played a major role in the recognition of dementia as a brain disease. What’s more, dementia is a condition that not only affects the elderly, but also young people. We no longer talk about

“As a health fund, we spend more money on scientific research every year. Last year, this came in at over EUR 5 million. This makes us the largest private funder of research into dementia.”

demented people, but about people with dementia. You have been diagnosed with a disease, but your disease doesn’t define who you are. That’s a big difference.”

## Employees and volunteers

“Alzheimer Nederland is a patient organisation as well as a health fund. About 100 people work at our head office in Amersfoort, and more than 4,500 volunteers are committed to our cause throughout the country. They do a phenomenal job, and some of them have been with us for 35 years. We greatly appreciate their knowledge and skills. From the very beginning, volunteers have been involved with the Alzheimer Hotline, which can be reached daily. Many caregivers call with questions about their loved ones with dementia, or to have someone to tell their story to.

Our Alzheimer Cafe, a Dutch invention, are also run by volunteers. The cafes provide monthly meet-up places for caregivers, social workers and people with dementia. They are accessible, educational and sociable events. Visitors can listen to lectures and talk to others who are dealing with the same or a similar situation. There are now 246 of these cafes scattered throughout the country, which means there is always one nearby.

Through these well-attended Alzheimer Cafes our organisation is close to people everywhere. The volunteers are our eyes and ears. They know what’s going on in their respective areas and they represent, on a local level, the interests of people with dementia and their loved ones. This is extremely important, because the policy of social support is organised locally in the Netherlands, and may vary from one municipality to another. We also have a strong lobby in The Hague for advocacy at a national level. We have already accomplished a great deal together.”



Alzheimer Nederland staff team



*Alzheimer Nederland wants people to be able to recognise dementia and know how they can help*

### Alzheimer Nederland branches

“Our organisational structure works well. Alzheimer Nederland has 48 branches, each with their own board. I appoint the chairpersons myself, and stay in close contact with all of them. Together, we form a univocal club. Five regional coordinators maintain contact with the branches and I attend the regional meetings every year. This keeps me informed about what is going on throughout the country. The branches all focus on the same themes, but also address local issues. If there are a lot of young people with dementia in an area, more attention is paid to them. We respond to local needs: there are regions that prefer the name Alzheimer Meeting Point instead of Alzheimer Cafe. In areas with a high migrant population, we organise Alzheimer Tearooms with Turkish or Moroccan/Arabic as the language of choice. We wholeheartedly support such regional adaptations.”

### Dementie.nl

“In addition to the Alzheimer Cafes and Alzheimer Hotline, Alzheimer Nederland also provides a great deal of online information. In addition to the website [www.alzheimer-nederland.nl](http://www.alzheimer-nederland.nl), we also operate the successful [www.dementie.nl](http://www.dementie.nl) platform for everyone who is dealing with dementia. The need for information and online assistance is huge. Even though the website was launched only three years ago, it

“We want as many people as possible to be able to recognise dementia and know what they can do to help.”

has already been consulted over 1 million times a year. We intend to expand this platform with a separate section for people living with the early stages of dementia next year.”

### Largest private funder of research

“As a health fund, we spend more money on scientific research every year. Last year, this came in at over EUR 5 million. This makes us the largest private funder of research into dementia. In order to raise funds, we organise a yearly door-to-door collection and a television show. We are the initiators behind the research agenda used at the national level, which we draw up in consultation with our members. As it turns out, not just doctors and scientists, but also people with dementia themselves and their caregivers prioritise a cure for dementia. Even though the latter group will no longer benefit from it, they too desire a solution for future generations.

In 2000, we were involved in the opening of the first Alzheimer Centre at Maastricht

University. There are now five such research centres, linked to a memory clinic. Besides Maastricht there are Alzheimer Centres in Amsterdam, Nijmegen, Rotterdam and Groningen. In addition to fundamental research into the effects and cure of dementia, we also support applied research into prevention, diagnostics and patient support.

Our broad research agenda also stood at the basis of the national Dementia Delta Plan, which was launched in 2013. More than 70 expert organisations work together on research, care improvement and a dementia-friendly society. Government funding for this plan occurs primarily through ZonMw. This funding organisation for health research and development invested EUR 60 million in dementia research. In addition Alzheimer Nederland invested another EUR 12 million, often in cooperation with ZonMw. The Dementia Delta Plan ends in 2020, so we are now working on a follow-up plan comprising a new research agenda.”

### Scientific breakthrough

“A very important breakthrough that we owe to scientific research is the capacity to diagnose dementia much earlier and with more certainty. Different forms of dementia have different symptoms and causes, and we are now able to better distinguish between them. This is mutually beneficial for researchers who can build on this knowledge and patients who benefit from more carefree years of life. The sooner someone knows that he or she has dementia, the better he or she can adjust to it. For example, by adopting lifestyle patterns that are useful later on in the disease process.



*Gerjoke Wilmink (right) is a guest on a radio programme, together with Silvy Ramsche (left) who has dementia*

Scientific research in the field of prevention has also enabled us to take significant steps forward. We now know the main risk factors that contribute to the development of dementia: diabetes, cardiovascular problems, smoking and physical and social inactivity. The thought that lifestyle is a factor would have been summarily dismissed 35 years ago. But through the years this notion has gained traction, fostered more interest and has since also been scientifically proven. A healthy lifestyle really can delay the development of dementia.

A cure for dementia will require much more money for fundamental research. I am, however, convinced that it is possible. Just look at other formerly incurable diseases. Curing those was also preceded by a great deal of research. Alzheimer Nederland is strongly committed to this. The expectation for the medium term is that we can prevent certain forms of dementia if addressed at an early stage. These include hereditary variants of Alzheimer's disease and the preliminary phase of frontotemporal dementia."

### Dementia-friendly society

"There has been a process of empowerment of people with dementia over the years. They appear in the media and, starting last year, they have their own Dementia Event. Rules and regulations are also being adapted; in 1984 you were no longer allowed to drive after the diagnosis of dementia. This changed in 2010: you are now allowed to still drive a car after passing a driving test. Alzheimer Nederland wants people with dementia to participate longer and to

**“We are jointly responsible for our fellow human beings with dementia. Everyone in our country will have to deal with the disease in one way or another.”**

remain included. This is something that we are all responsible for as a community.

One in five Dutch people will develop dementia, which makes the chances of meeting someone who has the disease quite high. And while it is true that we now know much more about dementia than we did 35 years ago, we sure are not there yet. With our current campaign 'Seeing is 1, doing is 2' we are working – in conjunction with the Ministry of Health, Welfare and Sport and pension administrator PGGM – on a dementia-friendly society.

We want as many people as possible to be able to recognise dementia and know what they can do to help. We recommend approaching people with dementia in a 'GOED' way, which stands for: 'Geruststellen' (*reassure*), 'Oogcontact maken' (*making eye contact*), 'Even meedenken' (*empathise*) and 'Dank je wel zeggen' (*saying thank you*). There are now more than a quarter of a million dementia friends. We also provide practical training to staff in professions that often deal with people with dementia. From train conductors to bank employees and from hairdressers to supermarket employees, they all benefit from learning how to detect dementia in their customers and knowing how to respond appropriately."

### Residential facilities

"Another challenge for the future is the development of proper housing facilities. We expect the number of people with dementia in the Netherlands to double between 2010 and 2040, from 280,000 to more than half a million. Two thirds of people with dementia live at home, a figure that might increase to three quarters in the future. In itself, it is a good development that people spend fewer years in institutional care. We do, however, need a solution for the interim phase. The current transition from one's own home to a traditional nursing home is often extremely jarring. Small-scale housing is therefore high on our wish list, and we are hard at work lobbying to realise this. Housing facilities that allow people with dementia to remain active while also having access to medical care benefits both them and their caregivers.

**“We were involved in the opening of the first Alzheimer Centre at Maastricht University. There are now five such research centres, linked to a memory clinic.”**

We are jointly responsible for our fellow human beings with dementia. Everyone in our country will have to deal with the disease in one way or another: as a patient, as a caregiver or as part of someone's circle of family and friends. Dementia concerns us all."

### Milestones of Alzheimer Nederland over the years

- \* **1984:** Establishment
- \* **1985:** Lectures
- \* **1987:** Start Alzheimer Hotline
- \* **1991:** International Conference (ADI) in Amsterdam RAI
- \* **1993:** First information campaign 'Wij steunen bij dementie' (*we provide support with dementia*)
- \* **1995:** Coffee campaign on World Alzheimer's Day, raising 80,000 guilders
- \* **1997:** First Alzheimer Cafe in Leiden
- \* **1999:** Taboo-breaking TV series 'Leven met dementie' (*living with dementia*) attracts 300,000 viewers per episode
- \* **2000:** Establishment of 1<sup>st</sup> Alzheimer Centre in Maastricht
- \* **2002:** First nation-wide door-to-door collection
- \* **2002:** Alzheimer Europe Conference in Maastricht
- \* **2005:** National Dementia Plan
- \* **2006:** 100<sup>th</sup> Alzheimer Cafe
- \* **2011:** Opening 4<sup>th</sup> Alzheimer Centre (Rotterdam)
- \* **2013:** Start of Dementia Delta Plan
- \* **2016:** Start of Samen demetievriendelijk (*dementia friendly together*)
- \* **2018:** First Dementia Event for and by people with dementia



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### Personal commitment

Gerjoke Wilmlink has been Executive Director of Alzheimer Nederland since September 2018. Before that, she worked as director at Nibud, the National Institute for Budget Information, for 18 years. Gerjoke has experienced the impact of dementia up close: “My mother lived with dementia. She passed away three years ago. My father took charge of providing and organising her care. [And we also had a good case manager.] At the time, my father obtained a lot of information from Alzheimer Nederland. He also visited Alzheimer Cafes. My mother decisively refused to come along. She denied her illness for a long time.

Around the same time, one of my neighbours was also living with dementia. Because he didn't have any close relatives, the neighbourhood banded together to take care of him. I remember him bringing me flowers twice on my birthday. The way his memory failed him made a big impression on me.

My mother's dementia was a ten-year process. I noticed my mother leaving reminder notes all over the house. I only found out why she did that later. This was when we were on a family holiday in the south of France. We called my uncle Theo, who lived in South Africa, from our holiday home. He was ill and we stayed in regular contact. The next day my mother said: “Don't forget, we still have to call Theo.” When we answered that we had already done so the day before, I saw my mother become very sad. She realised at that moment that she didn't remember, and that we were all witness to it. It was a painful and sad moment for all of us.

Looking back on her period of illness, I now feel I could have made more of an effort reading up on it. If I had known more about the symptoms of dementia, I might have been able to be more sympathetic to my mother. I remember being angry with her on occasion, for example when she would repeatedly accuse me of getting rid of her shoes or scarves. Or when, after a long journey through a blizzard, she would throw me



out because I – as she put it – interfered too much with her life. I now realise that there was nothing she could do. We supported my father as best we could by regularly relieving him as caregiver. Having time for oneself is very important for caregivers. They often miss out on this because they immediately feel guilty when they ‘abandon’ their loved one for a little while. However, experience and research inform us that caregivers are able to keep on caring for longer, and can ultimately do more for their loved ones, if they have regular moments to take care of themselves as well.”



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## “Dementia Event” shows the need for contact and ongoing participation

The very first Dementia Event was organised on 5 September 2018, a national gathering for and by people with dementia, in the town of Radio Kootwijk. Two of the organisers, Silvy Ramsche and Christa Reinhoudt, look back on a meaningful and successful day.



Christa Reinhoudt at the Dementia Event

“An important wish of many people with dementia is to get the chance to do what they can still do. Helping organise an event can be one such thing. So when Silvy Ramsche (65) and Christa Reinhoudt (49), both diagnosed with Alzheimer’s disease, were approached by Alzheimer Nederland to join the Dementia Event programme committee, they were immediately up for it. They were more than happy to give their input on what this unique day, organised for people with dementia by people with dementia, should look like. Christa: “What resonated with me was the opportunity to meet people with dementia, without there being people without dementia present.” Silvy: “Yes. Peers banding together.” Christa: “There were people from all parts of the country, of all ages, men, women. A very diverse group, both during the preparations as well as during the event itself.”

The ten members of the committee met eight times. The professional support at the meetings included representatives of Alzheimer Nederland.

### Living with dementia

Christa was diagnosed with Alzheimer’s two years ago. “For a brief moment I felt relief”, she says, “because it explained why I was increasingly making mistakes in my work as a coordinator. I wasn’t crazy; there was something wrong in my brain. Then it dawned on me that I had Alzheimer’s. A terrible disease. I feared I had only five years left. What was I going to do? I was only 47 years old, and my children were still living at home.”

“ I don’t look like someone with dementia, but really, who does?”

Christa Reinhoudt

Silvy: “I also thought my days were numbered. I cried for six months after being diagnosed with Alzheimer’s. I was completely out of it, overwhelmed with sadness. But at some point the tears dried up. And I went on with my life. I told everyone around me that I have dementia. In my neighbourhood there are a lot of elderly people. I am definitely not alone in having dementia.”

Christa: “In my surroundings, hardly anyone knew. And when I did tell people, they didn’t believe me because I am still so young. This is no longer the case though, I am now very open about having dementia.”

### The Dementia Event

The goal of the Dementia Event was clear in advance: bringing people with dementia together to talk. The committee put together a varied programme. Speakers with dementia shared personal stories, brain researcher professor Erik Scherder emphasised the importance of exercise and singer Willeke Alberti regaled the audience with her most beautiful songs. After a joint lunch, visitors were given the opportunity to continue their discussions in small groups. The location for the event was the historic building of Radio Kootwijk. An appropriate place, as the site of

this former broadcasting station has been refurbished by volunteers with dementia.

Both ladies felt right at home with all those other people with dementia at the Dementia Event. The room was packed, over two hundred people showed up. It made Christa feel good. “I thought: so these are all people with dementia. I am not the only one. I really liked that community aspect. Just like at a pop concert. All these different people with one binding factor: dementia. Everyone was very involved.”

Silvy was chairman of the day, together with journalist Frénk van der Linden. A brave step for Silvy: “I have always been very shy. I was always too afraid to speak in front of an audience, or even colleagues for that matter. But I really wanted to do this, because it was so important to me.” Christa: “You did really well and got everything across very clearly.” Silvy jokes: “Let’s hope it stays that way. But seriously, I loved it. It was a revelation for me. I was out there on stage holding a microphone in front of more than two hundred people. And I wasn’t even nervous; I was determined. I just thought: ‘I’m doing this.’ Frénk helped me get started a little, but it was smooth sailing from there.”

“ I really enjoy meeting so many others people who are going through the same thing.”

Silvy Ramsche

Christa helped out in getting the discussions going at the various tables. “When you have all these people living with the same condition in one room, you don’t want them just making small talk.” The committee had thought of discussion topics beforehand. Such as: Is there something specific that helps you deal with the impact of the disease in your daily life? What tips do you have for others to overcome practical bottlenecks? And what do you do to keep in touch with people in your immediate vicinity, such as family and friends? Ideas and frustrations were written on pieces of paper and stuck to a wall.

“I was out there on stage holding a microphone in front of more than two hundred people. And I wasn’t even nervous; I was determined.”

*Silvy Ramsche*

Christa: “I walked around and would join different tables to ask questions. Personally I felt the need to talk to people of my own age, so I sought them out. From my former profession as a pastoral worker I already knew many stories of the elderly, but I was very curious about the experiences of younger people with dementia. People who, like me, have a family with children living at home. What does

the disease mean to them as parents? That’s what I wanted to talk about. I met a woman with young children. It was nice talking to her about raising kids. As a mother with dementia, you lose a certain authority. If you can’t remember it all, then what’s the use? We both recognised that feeling. Our conversation was very valuable to me.”

There was a separate programme for the caregivers who had accompanied the participants. Silvy, laughing: “That wasn’t easy for some of them.” Christa agrees: “They would come over and look in on us anyway, out of curiosity, or concern. The organisation kindly referred them back to the other room and kept them informed there on everything that was going on with us.”

### A manifesto for dementia

The programme committee had also drawn up a manifesto to which visitors could react. The manifesto includes ten requests from people with dementia to the people around them in society. ‘Support us where necessary, so that we can participate as long as possible in daily life’, is one of them. ‘Talk to us, not about us’, is also an important point. And: ‘We struggle with our self-confidence. Please don’t behave in such a way as to make us even more insecure.’ Christa recognises this: “When I go grocery shopping on my own, I often get confused at the register. Suddenly I am unsure whether I’m in the right lane, which really



*Silvy Ramsche holds the microphone for an attendee*

annoys the people who are in line behind me. Also, I don’t always remember how the PIN device works. When I ask a cashier what to do, they laugh at me nine times out of ten. They think I am kidding. At first this made me angry. But nowadays I ignore it, I am just not in the mood for complicated discussions. I don’t look like someone with dementia, but really, who does? It is good that employees are being trained to recognise the symptoms. That will allow them to better assist us.”

Silvy has handed the manifesto over to the National Ombudsman, Reinier van Zutphen, after a live radio broadcast (*Spraakmakers, Radio1*). He included it in his report ‘Borg de Zorg’ (*Safeguarding Healthcare*) with recommendations to the Minister. The first Dementia Event has therefore also sent out an important signal to politicians.

This year, the second edition of the Dementia Event will take place on 23 October in the World Forum in The Hague. The programme includes a lecture on what is still possible with dementia, as well as music, dance, art and workshops. Christa has no need for it anymore: “I now go to day treatment for young people with dementia. There I have plenty of contact with people with dementia my age.” Silvy, on the other hand, is happy to be back. “I really enjoy meeting so many others people who are going through the same thing.”

“What resonated with me was the opportunity to meet people with dementia, without there being people without dementia present.”

*Christa Reinhoudt*



*Attendees listen to a speaker during the Dementia Event*



# Health Minister discusses the Netherlands' journey towards becoming dementia-friendly

The Dutch Minister of Health, Welfare and Sport, Hugo de Jonge, spoke with Alzheimer Nederland about the progress towards creating a more dementia-friendly Netherlands, bringing together a broad coalition of stakeholders to play their part.

In the Netherlands, good care is an important matter for everyone. Virtually all research into what people consider important that has been conducted in recent years places good care at the top of the wish list. The Dutch system for health insurance, which all 17 million people use, is driven by solidarity. Young pays for old. Rich for the poor. Healthy for the sick. We take care of each other.

**“More research is needed to find a medicine or treatment that makes the disease manageable and to prevent dementia. That is why we are going to double the research budget.”**

However, availability of good care is not a matter of course. The demand for care is increasing, certainly because we are getting older. Care for people with dementia is a major point of attention in this regard. One in five people in the Netherlands develops dementia, everyone is confronted with it in their immediate environment. Dementia is well on its way to becoming the number one public disease.

## Practical steps

A few years ago, the business community, science, government, patient organisations and healthcare providers started a Deltaplan Dementie (the Dutch dementia strategy) together. The plan has three pillars: more

research into dementia, better care for people with dementia and making our society friendlier to people with dementia. Plans have been made and implemented, results have been achieved and are currently being evaluated: what has worked and what will the course look like in the coming years?

Making society more friendly to people with dementia - how do you do that? In the first place in a practical way. The Dutch Railways (NS), large supermarket chains, municipalities, banks and all kind of services have embraced the assignment. There are now dementia-friendly cash registers, entrance gates at railway stations and counters in a variety of services. Last month, a nationwide campaign was launched to help public transport staff and travellers to become more dementia-friendly. Such adjustments make the world accessible to people who can no longer keep up with the complexity.

## Remaining active within communities

But for people living with dementia, maintaining control over one's own life is not enough. Just like any other person, they want to be of value. For their family, friends, neighbours, and for society. And it is just as important for them as for everyone else to be active and meaningful. In the first stages of the disease, people can often continue to



Hugo de Jonge

work, in their own job or as a volunteer. There are projects in which people with dementia participate in forest maintenance or work at a farmers' market. An older man reads to toddlers and now feels part of the community again. Not only in the playgroup, but in the entire neighbourhood. When the children see him on the street they shout: "Hi grandpa! When will you come and read to us again?" Such seemingly small things are very important.

The Deltaplan Dementie helps people to maintain control over their lives and their self-esteem. This approach made us think. Can't we better facilitate the possibilities of people with dementia? What if we can find meaningful activities for every person with dementia? What if we can help people affected by dementia at a young age to continue to perform their paid job? What if we adapt the environment to make it easier for people with dementia to stay mobile and independent? You could make clear direction indicators to help find your way to the supermarket, the mall, the park or the library. You could create enough places to sit and

**“No one can ignore dementia and the devastating impact it has. That is why we need the help of companies, institutions, chain stores, carriers, neighbours, friends, relatives and loved ones to face this enormous challenge. We need society.”**

rest for a while. You could ensure that people in the neighbourhood know what to do if someone needs help.

All these ideas are part of the policy course of the ministry for the future. The starting point is that we want to help people with dementia to continue to participate in society, by taking advantage of their options and, where necessary, adapting their environment. In addition, we must focus on the care and support for people with dementia and those around them. We want to maintain the quality of care by introducing more proven care concepts, paying more attention to care from social networks and by better anticipating the growing number of people with dementia. Great research has already been done into new care concepts. We now know ways to improve the quality of life of people with dementia, whereby the workload for employees and informal caregivers decreases, as well as reducing healthcare

“Just like any other person, [people with dementia] want to be of value. For their family, friends, neighbours, and for society. And it is just as important for them as for everyone else to be active and meaningful.”

costs. We focus our efforts on that, because every person with dementia deserves the best possible quality of life.

### Funding for future research

Dementia comes in many forms. It is a huge problem that the coming decades will only get bigger. To cope with that problem we must find a solution, a treatment that works, an answer to the questions that are still there. That answer is not yet available. More research is needed to find a medicine or treatment that makes the disease manageable and research to prevent dementia. That is why we are going to double the research

budget. The Netherlands is a small country, our contribution is certainly not the largest in absolute numbers. But if we all take such a step, starting in Europe, and focus our mutual attention on dementia research that does justice to the impact that the disease has more and more in our societies, then I am convinced that we can have a big impact.

But we need more than money. No one can ignore dementia and the devastating impact it has. That is why we need the help of companies, institutions, chain stores, carriers, neighbours, friends, relatives and loved ones to face this enormous challenge. We need society. Only together we can make a difference.

**We remain committed to transforming Alzheimer's disease**  
*and to preserving what makes people who they are*



Date of preparation: September 2019 NP/AZD/1908/0016

# Deltaplan Dementie underpinned by policy pillars of research, care and awareness raising

As the Deltaplan Dementie moves towards its final stages, Philip Scheltens, Director of the Alzheimer Centrum Amsterdam, and Marco Blom, Deputy Director – Research and National Services, Alzheimer Nederland, reflect on the priority areas and work of the strategy since its launch in 2012.



Philip Scheltens

The Deltaplan Dementie is the second national dementia strategy launched by the Dutch Ministry of Health, Welfare and Sports. It is an eight-year programme which will last until 2020 and was developed to address and manage the growing problem of dementia in the Netherlands. However, it was not the first national program on dementia.

“On our way out, we were accompanied by the director of ZonMw (The Netherlands Organisation for Health Research and Development). He congratulated us not only on the result but also - much to our surprise - on the pace of the process.”

*Philip Scheltens*

As early as in 2005, a four-year programme called Landelijk Dementie Programma (LDP) was launched to improve care for people with dementia and their caregivers, with a strong focus on their expressed needs and problems. It came with a budget of EUR 2.8 million and led to many improvements in local and regional care. However, it was discontinued following a policy shift to the broader concept of frail elderly. Philip Scheltens, director of the Alzheimer

Centrum Amsterdam was the initiator of the plan and took the initiative for building a network of public and private stakeholders. Right from the start, he invited Alzheimer Nederland to join the initiative.

It took almost two years to get the plan started. Philip Scheltens: “I still remember the day when Marco Blom and I left a dementia conference and went to the secretary of state Martin van Rijn to hear the final decision of the ministry on the budget for the Deltaplan Dementie: EUR 32 million for the first four years. On our way out, we were accompanied by the director of ZonMw (The Netherlands Organisation for Health Research and Development). He congratulated us not only on the result but also - much to our surprise - on the pace of the process.”

## Dementia research as a priority

The Deltaplan Dementie is, by comparison to many other national strategies, rather unique in its heavy focus on scientific research. The research varies from basic

research into prevention and finding a cure for dementia, through to research with a focus on treatment, support and quality of life. The budget provided by the ministry for Memorabel, the research programme of the Deltaplan Dementie, totalled EUR 60 million. In the history of dementia research in the Netherlands this was unheard of. The dementia research community were given a great opportunity to give the best of their ideas and effort to address relevant topics. Together with the strategic research agenda of the Joint Programme Neurodegenerative Diseases (JPND), the national research agenda developed by Alzheimer Nederland underpins Memorabel.

In addition to the budget provided by the government, there is also budget delivered by private partners, including businesses and health insurers. Alzheimer Nederland is by far the biggest private funder within the Deltaplan Dementie. Marco Blom, Deputy Director – Research and National Services: “When the Deltaplan Dementie comes to an end in 2020, we will have spent around EUR 15 million on dementia research. The



Marco Blom



combination of public and private funding enables dementia researchers to play an active role in finding solutions for people with dementia, today and in the future. The contribution of the Netherlands in the JPND programme is a good example of this.”

### Other policy priorities

After securing the budget for the research program, it took a while before other parts of the Deltaplan commenced. It was only in 2016 that the program ‘Samen dementievriendelijk’, aimed at making the Netherlands more dementia-friendly, began. However, it was positive that the Deltaplan Dementie was open to this new idea and adopted it, with the ministry allocating a budget of EUR 10

million to conduct the five-year programme. The third pillar of the Deltaplan Dementie focuses on improving dementia care. A EUR 15 million programme, ‘Dementiezorg voor Elkaar’, is led by five national institutes in which several projects are run (e.g. setting up a new dementia care standard and the development of a registry to measure the quality of care on a regional level).

Combining the pillars of scientific research, improving care and a dementia friendly society is very useful within a national strategy. Philip Scheltens: “We need to keep an eye on both the patients of today as well as future generations. Prevention and cure are the ultimate goal. It is the most powerful way of finding a solution to the growing number

of people with dementia. To my opinion, every national strategy (also the next strategy in the Netherlands) should have a clear focus on scientific research.”

“The combination of public and private funding enables dementia researchers to play an active role in finding solutions for people with dementia, today and in the future.”

*Marco Blom*



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01-2019 JB7976 INT'L ENGLISH

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