

DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE



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Adam Vojtěch

Czech Republic Minister
of Health gives an
insight into the
country's new national
dementia strategy



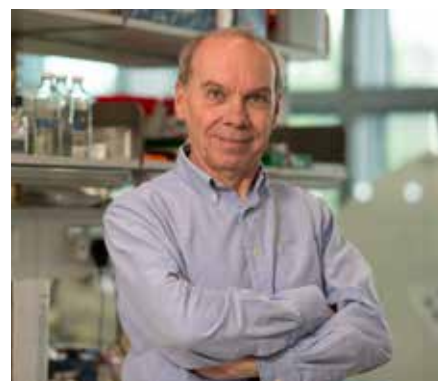
Stefan Eriksson

and his family share their experiences of
life after his diagnosis of dementia



Sirpa Pietikäinen MEP

hosts lunch debate on diagnosis as a focus of
European dementia research projects



Michel Goedert

talks to Alzheimer Europe about his work
in dementia research after he received the
2019 Royal Medal for Biological Sciences

Contents

- 3 Welcome
by Iva Holmerová, Chairperson of Alzheimer Europe

Alzheimer Europe

- 4 Lunch debate explores findings from European research projects on improving the diagnosis of dementia
8 Alzheimer Europe launches new 2019 Yearbook showing the prevalence of dementia in Europe
9 Alzheimer Europe launches new report promoting inclusive research in the field of dementia
10 INTERDEM network celebrates 20 years
13 Patient engagement in research and development: “What’s in it for you?”

Policy Watch

- 15 Czech Republic finalises second national dementia strategy (2020–2030)
17 Governmental Expert Group on Dementia meets for a third time
18 Second EU Joint Action – “Act on Dementia” – draws to a close
21 World Health Organization hosts bi-regional workshop on dementia in Malta
22 World Dementia Council discusses progress in making dementia a global priority
23 Expert report calls for coordinated public education and research programmes to promote brain health
25 Dementia research investment needs to reflect the enormous cost of dementia care

Dementia in Society

- 26 Putting a face to commitment – Jeremy Hughes reflects on 10 years with the Alzheimer’s Society
27 Tau, tangles and dementia: a conversation with Michel Goedert
29 Behind the headlines: Making sense of new aducanumab trial data
32 Living with young-onset dementia in Sweden
34 A human rights-based approach to dementia in Ireland
36 Deaf sign language users with dementia: challenges in accessing healthcare and support
39 Dementia in the arts: An interview with celebrated author Nicci Gerrard

Spotlight on the 29th Alzheimer Europe Conference

- 42 Alzheimer Europe Conference takes place in The Hague under the banner “Making valuable connections”
44 The conference focused on diagnosis, technology and e-health, inclusion and prevention
50 Inspired by connections
51 Special symposia held during #29AEC
54 European research collaboration in Alzheimer’s disease and beyond presented at #29AEC
58 Congratulations to the winners of the poster awards!
60 Snapshots
61 Top tweets from #29AEC
62 Facts and figures

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Welcome



Iva Holmerová, Chairperson

I am delighted to welcome you to the 32nd edition of *Dementia in Europe* – the Alzheimer Europe magazine.

The first section highlights some of our efforts to make dementia a European priority, including our December 2019 lunch debate, which focused on the diagnosis of dementia in European research projects, including presentations on the Models of Patient Engagement for Alzheimer's Disease (MOPEAD) project, the second EU Joint Action on dementia and the Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD) project. I would like to thank Sirpa Pietikäinen MEP (Finland) for hosting, as well as MEPs Dominique Riquet and Younous Omarjee (France) and Matt Carthy (Ireland) who attended or were represented at the event.

This section also looks at Alzheimer Europe's latest publications. The first is the 2019 Yearbook which provides a timely update of dementia prevalence statistics for Europe and provides projections for the future. We also present our 2019 ethics report, focused on the promotion of inclusive research in the field of dementia. The report is primarily aimed at researchers, members of research ethics committees and funders, calling on these groups to examine their beliefs, perceptions and assumptions.

We also hear from two significant research initiatives in which Alzheimer Europe is involved: The INTERDEM network, which celebrated its 20th anniversary in 2019 and the

PARADIGM project, which extols the benefits of public patient involvement in research.

The Policy Watch section opens with the fantastic news that my own country, the Czech Republic, has finalised its new national dementia strategy. At an international level, this section also looks at the recent meeting of the Government Expert Group on Dementia, which met for the third time in December 2019, discussing issues including palliative care and dementia data registries. The Scottish Government then writes about the conclusion of second EU Joint Action on Dementia, sharing key findings from its work on implementing good practice in dementia care.

Continuing on the theme of collaboration, we have two interesting articles on how dementia is being prioritised at an international level. The first of these articles covers the World Health Organization (WHO) bi-regional workshop on dementia, hosted by Malta in September 2019. In the second, Lenny Shallcross talks about the World Dementia Council summit in Japan in October 2019, as well as sharing their plans for 2020.

Finally, we hear from the authors of the Time Matters report on the importance of brain health policy, including policy recommendations to encourage people actively participate in maintaining their brain health, whilst James Pickett shared the results of an analysis into global levels of dementia research funding.

Our third section, Dementia in society, starts with an interview with Jeremy Hughes as he comes towards the end of his successful tenure at the Alzheimer's Society (UK) – we wish him all the very best in his future endeavours! We then move onto an interview with the esteemed scientist, Michel Goedert, who was awarded the 2019 Royal Medal for his outstanding contribution to dementia research, specifically on the build-up of tau protein in the brain.

Going behind the headlines, Project Officer Angela Bradshaw takes a closer look at results from Biogen's Phase III clinical trials

of Aducanumab, presented at the 12th Clinical Trials in Alzheimer's Disease (CTAD) conference in December 2019, including the views of three external experts in the field of dementia.

In this section, we are also delighted to hear from two members of the European Working Group of People with Dementia (EWGPWD), with Chairperson Helen Rochford-Brennan sharing her thoughts on a human rights symposium organised by Trinity College Dublin, and Stefan Eriksson and his family discussing how life has changed since his diagnosis of young-onset dementia.

A joint article by Emma Ferguson-Coleman and Avril Hepner looks at their respective work on how deaf people living with dementia can be better supported. In our final article in this section, an interview with author Nicci Gerrard (aka Nicci French) provides a touching glimpse into the subject matter of, and her motivations for writing her book, "What Dementia Teaches Us About Love".

The final section shines a spotlight on the biggest ever Alzheimer Europe Conference, which took place in The Hague, last October. Co-hosted by our colleagues at Alzheimer Nederland, the "Making valuable connections" conference (#29AEC) welcomed over 950 delegates from 46 countries, sharing knowledge, learning from each other and networking across the three days. The spirit of collaboration is alive and well in the dementia community, which gives me hope for our ongoing efforts.

The Alzheimer Europe team and I wish you all the very best in 2020 and look forward to working with you, to help ensure dementia remains a priority at a European level.

Happy reading!



Lunch debate explores findings from European research projects on improving the diagnosis of dementia

Alzheimer Europe and the European Alzheimer's Alliance (EAA) organised a lunch debate, hosted by Chairperson of the EAA Sirpa Pietikäinen MEP.

On 10 December, Alzheimer Europe held its final lunch debate of 2019, entitled "Improving the diagnosis of dementia – Findings from European research collaborations". A total of 95 people attended the debate, including national member organisations, government experts on dementia, academics, industry representatives and policy makers.

Sirpa Pietikäinen MEP (Finland), Chairperson of the European Alzheimer's Alliance (EAA) and Board member of Alzheimer Europe opened the session and welcomed everyone. She highlighted the new term of the European Parliament and the European Commission, outlining the challenges and opportunities this presented in making dementia a policy priority in Europe.

Ms Pietikäinen noted that the lunch debates allowed the experiences and expertise of a broad range of stakeholders to be shared, with a common aim of improving the lived experience of people with dementia.

In relation to the subject of the lunch debate, Ms Pietikäinen highlighted that emerging research indicates that dementia develops

in individuals 10–20 years before symptoms emerge. As such, there needs to be a change in the approach to diagnosis to allow individuals to plan for future care and decision making. She outlined that such changes also raise issues concerning a patient's right to know about their risk factors as well as other ethical issues, need to be addressed.

She also commented briefly on the need for multidisciplinary involvement to support people with dementia to be able to live at home for as long as possible. As part of this, Ms Pietikäinen noted that practice-based research must ensure that health practitioners are skilled and able to deliver appropriate care and support.

Ms Pietikäinen concluded her remarks by noting that the Innovative Medicines Initiative (IMI 2), funded as a public-private partnership through the Horizon 2020 research programme, had been successful in bringing together different sectors in dementia research. She emphasised that such an approach should continue in the forthcoming Horizon Europe programme, for example through the proposed Innovative Health Initiative (IHI) partnership.



Mercè Boada presents findings from the MOPEAD project

Models of Patient Engagement for Alzheimer's Disease (MOPEAD)

Professor Mercè Boada is coordinator for the Models of Patient Engagement for Alzheimer's Disease project (MOPEAD) on behalf of Fundació ACE. In her introduction, Prof. Boada, explained the work of the project towards providing a step change in patient engagement, supporting a paradigm shift from late-stage diagnosis to early diagnosis.

The project ran between October 2016 and December 2019, involving institutions and organisations from 14 countries, including study sites in Germany, Netherlands, Spain, Slovenia and Sweden.

Prof. Boada noted that the under-diagnosis of Alzheimer's disease (AD) continued to be widespread, underlining that it is crucial to understand the obstacles to patient engagement. The project therefore aimed to raise awareness of cognitive decline, improve timely diagnosis through citizen participation and provide strategies to plan actions aimed at early detection.

The project pre-screened more than 2,000 people through four different approaches (referred to as "runs"). Each was launched in the five participating countries, with each run following individual protocols:

- Run 1 – Online screening
- Run 2 – Open House days at memory clinics
- Run 3 – General Practice settings
- Run 4 – Diabetologists' offices.



MEP Sirpa Pietikäinen welcomes delegates to the lunch debate



Pierre Krolak-Salmon presents on the 2nd EU Joint Action on Dementia

Out of the 2,847 people that participated in the pre-screening approaches, 398 were referred to a memory clinic for a full neuropsychological evaluation that involved a common protocol. This included MRI scans, testing of the APOE status, as well as CSF profiles (referred to as AD biomarkers), in addition to neuropsychological assessment. The individual results of the models are now being compared and contrasted to identify ways to improve early detection and diagnosis of AD.

Presenting preliminary findings from the project, Prof. Boada introduced some of the challenges and opportunities identified. The first run showed variability between countries, including in relation to ethics committee consent because of patient confidentiality concerns. In the second run, advertising campaigns were useful in attracting participants, with staff from the clinics finding the approach easy to fit into their practice. The third run presented difficulties due to different public health systems, patients declining to consent to long or invasive procedures and local clinicians reporting a lack of time to manage patients with early dementia or MCI. The fourth run presented specific challenges as a result of the complex and diverse relations between memory clinics and tertiary endocrinology units.

Prof. Boada concluded her presentation by noting that the MOPEAD project was intended to build synergies with other IMI projects to reduce costs and time for professionals, highlighting the status of the project as an open access study, allowing its data

banks to be used by academics, researchers, stakeholders, patient organisations and pharmaceutical companies.

As part of this event, MOPEAD distributed its Recommendations for Policy Makers and Regulators, as well as a document on Public Education/Awareness Strategies.

Act on Dementia

Professor Pierre Krolak-Salmon, work package lead for diagnosis and post-diagnostic support in the 2nd European Joint Action on Dementia (2016–2019), presented on the project's work on the role of primary care in diagnosing dementia in a timely manner.

Prof. Krolak-Salmon noted that GPs were found to have a poor understanding of diagnosis pathways, particularly the difference between routine and research cases. In addition, there was no consensus among GPs about commonly-used cognitive tools, with existing tools found to be time consuming. Furthermore, he noted that different responses, depending on the result of testing, were also not well understood by GPs.

The benefits of an early diagnosis were outlined in some detail, including the right of individuals to know of their condition; safety for patients and caregivers; future planning; accessing care pathways (e.g. day care, memory clinics, mobile teams, etc.); understanding the changes taking place; accessing psychosocial and pharmacological interventions; and participating in research.

As part of this, Prof. Krolak-Salmon outlined survey findings which showed that 62% of respondents worried about getting dementia, 70% suggested it was difficult to find out about the latest medical research developments and 75% of respondents had no idea how to become involved in research.

Prof. Krolak-Salmon explained work which had been undertaken to pilot an “anti-stigma” dementia training programme for GPs in France, Poland and Bulgaria. Findings from this work showed an increase in GP confidence regarding dementia, as well as a significant reduction in stereotyping, compared to GPs who undertook standard dementia training.

The complexity of care pathways was briefly explored, with a key message that access to pathways for care and support were centred around GPs and on receiving a diagnosis. As such, a significant focus of the work package was on developing a graduated dementia diagnosis strategy, comprising three key stages. Importantly, the approach was agreed with the national college of GPs in France. The first level involved interviews in primary practice settings, utilising autonomy, cognition and behaviour testing. Second-level tests involved further testing (e.g. blood testing, MRI scans etc.), mostly provided by specialists (e.g. neurologists and geriatricians). For more complicated diagnoses or other conditions, the third stage involved additional testing, including CSF, PET scanning, etc. For each stage and each outcome, specific pathways and responses are indicated to ensure the patient receives appropriate support.

Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD)

Dr Gill Farrar, project co-lead for Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD), introduced the five-year project (2016–2021), consisting of two main studies to deliver on three objectives:

- Evaluate the usefulness of β -amyloid imaging in diagnostic certainty and patient management
- Investigate the natural history of disease and methods to enrich secondary prevention studies
- Quantify treatment-induced changes and patient-specific efficacy.



Gill Farrar speaks about the work of the AMYPAD project

The first study is the diagnostic and patient management study which hypothesises that people would receive improved diagnoses if PET scanning were done at an earlier stage of the condition, with the secondary end points for the study being: diagnosis and confidence; patient management; health economic outcomes; and quantitative imaging. Dr Farrar noted that about 30% of diagnoses for AD were incorrect and that a key focus of this work would be not only to improve accuracy of diagnosis but also to shift the approach from differential diagnosis and early diagnosis, towards one of risk profiling.

This first study aims to recruit 900 participants across Europe, focusing on those with subjective cognitive decline (SCD), mild cognitive impairment (MCI) and dementia, with 611 currently recruited and recruitment continuing until June 2020. From the 611 people recruited thus far in the study, preliminary results have shown approximately 50 percent of scans return a negative result and 50 percent return a positive result.

The second study, focused on prognostic and natural history, aims to understand the role of amyloid PET imaging in predicting progression within each domain of a so-called AD risk-probability spectrum. AMYPAD will select and follow-up a natural history

population ranging from cognitively normal, through SCD towards MCI due to early AD, in order to better understand the natural history of the early disease phases and define the optimal window of opportunity for secondary prevention of AD through β -amyloid imaging.

It is intended that 2,000 people will take part in the study. To date, 599 have been informed, with 369 having consented. Therefore, there will be a focus on recruitment into the study in the next steps of the project.

The outcome measures for the second study examine the effect of amyloid on global cognitive performance (e.g. memory, executive function, language, etc.), as well as further analysis considering PET scanning in predicting diagnosis and function decline, brain atrophy, tau levels etc.

Dr Farrar concluded by noting that the diagnostic study had shown both a positive and negative predictive value in a real-life setting, as well as being cost-effective in implementation and reimbursement possibilities. For the prognostic study, the work will continue to identify the value of quantitative PET in pre-clinical/prodromal AD, how best to measure the impact of treatment, and who is most at risk of developing dementia.

Closing remarks

Alzheimer Europe Chairperson Iva Holmerová closed the session by thanking the speakers for their informative presentations and everyone for attending, highlighting the importance of collaboration between partners when conducting dementia research. She noted the crucial importance of continued political and financial support for programmes such as Horizon Europe for dementia research. Prof. Holmerová also specifically thanked MEPs Sirpa Pietikäinen and Dominique Riquet for attending, as well as representatives of the offices of MEPs Matt Carthy and Younous Omarjee.



Iva Holmerová, Alzheimer Europe Chairperson, prepares to thank the speakers and host

Acknowledgements

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Highlight photos



Carol Hargreaves asks a question about the Joint Action results



Full house for the lunch debate



Sabine Jansen speaks to a member of the German Government



Jean Georges thanks participants for attending



Jayne Goodrick puts a question to Pierre Krolak-Salmon



Members of the EWGPWD and their supporters, together with the lunch debate speakers



Nelida Aguiar asks a question to Gill Farrar



Delegates were given copies of the findings from the MOPEAD project



Helen Rochford-Brennan, Chris Roberts and Jayne Goodrick

Alzheimer Europe launches new 2019 Yearbook showing the prevalence of dementia in Europe

Following on from the work published as part of EuroCoDe more than a decade ago, Alzheimer Europe has published its 2019 Yearbook providing updated prevalence statistics for Europe and individual countries.

Countries	Yearbook 2019				EuroCoDe 2008	
	Men	Women	Total	% of population	Total	% of population
Total EU and non-EU	3 130 449	6 650 228	9 780 678	1.57	10 935 444	1.75

A comparison of the difference in total numbers reached when applying the Yearbook 2019 and EuroCoDe prevalence estimates.

Over the past three decades, a number of significant pieces of work have been undertaken to estimate the prevalence of dementia at a European level, including:

- EURODEM study in the early 80s (updated in 2000)
- Alzheimer Europe’s project, European Collaboration on Dementia – EuroCoDe (2006–2008)
- The 1st EU Joint Action on Dementia – ALCOVE (2011–2013).

As the most recent of these studies is six years old, Alzheimer Europe recognised the importance of establishing more recent dementia prevalence estimates, using the most up-to-date academic literature on the subject.

The 2019 Yearbook, details the work undertaken by Alzheimer Europe to update the figures, including outlining methodological approach used (based on the EuroCoDe project). The prevalence estimates calculated using this approach were then applied to the most recently available population figures (2018 data from the United Nations World Population Prospects), on a country by country basis. Additionally, the prevalence rates using the EuroCoDe estimates were calculated.

Whilst the prevalence rates between the 2019 Yearbook rates and the EuroCoDe study are not remarkably different (though the former were lower across the vast majority of age ranges), when both were applied to population data for 2018, the difference in the cumulative numbers is striking.

Specifically, the EuroCoDe prevalence estimate provides a figure of 10,935,444 people with dementia for the whole of Europe (EU28 + 9 non-EU countries) in 2018, which compares with a figure of 9,780,678 when using the new prevalence estimates, a difference of over 1 million people.

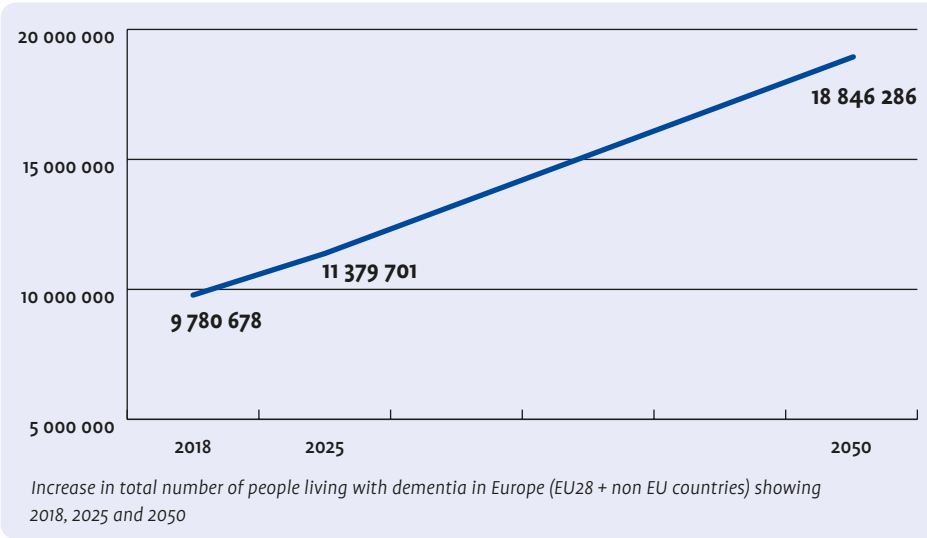
Looking towards 2025 and 2050, we applied the new prevalence estimates to projected population data for each country, establishing an estimate of the numbers of people who will have dementia in these years (in a scenario where prevalence rates among the age groups remain static).

In doing so, the report identifies that among the countries included, the total number of people living with dementia in Europe will increase to 11,379,701 by 2025 and to 18,846,286 by 2050. In other words, the number of people living with dementia will almost double by 2050.

The figures within the report are broadly consistent with other studies, which projected similar long-term increases in the number of people living with dementia. The decrease in prevalence (across the age ranges) compared with the EuroCoDe estimates is also consistent with a number of high-profile studies which have suggested that the prevalence rates of dementia may be decreasing.

Despite this decrease, the ageing demographics projected in Europe over the coming years means that the overall numbers of people living with the condition are set to increase considerably. As such, the report argues that governments must take action to invest and redesign services to ensure that they deliver the support and meet the needs of people living with dementia.

The Yearbook 2019 can be downloaded from www.alzheimer-europe.org/Publications



Alzheimer Europe launches new report promoting inclusive research in the field of dementia

Alzheimer Europe, working with its ethics working group, has developed a new discussion paper, examining the challenges in recognising diversity and promoting inclusive research in the field of dementia. Here the group gives an overview of some of the key issues highlighted in the paper.

The promotion of inclusive research, involving a wide range of people with dementia, is part of a more global aim to ensure that research per se is ethically sound. All research must be worthwhile, effective and conducted in an ethical manner. Much of the widely used ethical guidance on research was developed in the context of biomedical and clinical research. Such guidance has been meaningfully applied in numerous other research domains but research is constantly evolving, along with knowledge, attitudes and practices linked to the involvement of people with dementia in research.

The avoidance of harm and respect for autonomy are amongst the most fundamental ethical principles of research but the manner in which they are pursued is not always conducive to the promotion of inclusive research. In some cases, exclusion is the result of measures actually designed to protect research participants from harm, and may be due to structural discrimination or lack of awareness of their needs, interests, circumstances or difficulties. The requirements and methods needed for inclusive research must nevertheless correspond to those required for good quality and hence ethical research. Unsound research would be unethical as it would needlessly expose people to risk, inconvenience and burden. Ethically sound involvement in research is about how people with dementia are treated but also about who sets the research agenda, who is involved, at what stage and in what capacity. This applies to Public Involvement (PI) (i.e. acting in an advisory capacity), as

well as to research participation (i.e. providing research data).

People with dementia from minority and marginalised groups continue to be under-represented in research. Their absence means that the experience, perspectives and needs of large numbers of people with dementia in Europe are being ignored. People with dementia form a diverse heterogeneous group made up of people with multiple/intersecting identities and characteristics such as different ethnicities, ages, genders, disabilities, levels of education and socio-economic backgrounds etc. These multiple characteristics and factors need to be considered when trying to attract a diverse set of people to research. However, focusing on individual characteristics runs the risk of locating 'the problem' in the individual, thus detracting attention from the way that structures, organisations, procedures and systems create problems and lead to discrimination and marginalisation. This is exemplified in the oft-used phrase 'hard to reach' which could be interpreted as blaming some people for low levels of involvement (e.g. implying that they have made themselves inaccessible or are unwilling to get involved), which is simply not the case.

There are several factors which may make it more difficult, and hence less likely, for some people with dementia to contribute towards research. The concepts of equality and equity are particularly relevant in this respect. Equality involves treating everybody in the same

way without taking into account differences between people, which may be inherent, linked to circumstances or structurally determined. As depicted in the image below, treating everyone equally, without taking into account their individual needs and wishes, does not really reflect equal opportunity. Equity is about taking measures to ensure fairness and equality in outcomes. Issues related to inequity need to be addressed when striving for true equality.



Visualisation of equality and equity
taken from [www.medium.com/@CRAIG/
the-evolution-of-an-accidental-meme-ddc4e139e0e4](https://www.medium.com/@CRAIG/the-evolution-of-an-accidental-meme-ddc4e139e0e4)

In 2019, Alzheimer Europe's ethics working group developed a discussion paper. The members of this group included Dianne Gove, Mohammed Akhlak Rauf, Ann Claeys, Corinna Porteri, Ingrid Hellström, Jennifer van den Broek, Karen Watchman, Karin Jong-smaa, Krista Tromp, Saloua Berdai Chaouni and Jean Georges. Valuable input was also provided by the European Working Group of People with Dementia and a few independent experts. The discussion paper is targeted at researchers, members of research ethics committees and funders. The conduct of inclusive research calls for members of these groups to examine their own beliefs, perceptions and assumptions about people who may have very different characteristics, lives, histories and cultures to their own. Creativity, flexibility and commitment, as well as appropriate adaptation (along the lines of 'reasonable accommodation' in the United Nations Convention on the Rights of Persons with Disability) and appropriate investment of time, effort and money is also needed to promote inclusive and ethically sound research involving people with dementia.

The discussion paper can be downloaded from www.alzheimer-europe.org/publications

INTERDEM network celebrates 20 years

Myrra Vernooij-Dassen, INTERDEM Chair, Esme Moniz-Cook, Co-chair and Rabih Chattat, Board member highlight some of the network's key achievements of the past 20 years.

INTERDEM, is a pan-European network of clinical and social care academics with a research focus on the psychosocial care of people with dementia and those that support them. Over its near 21 year history it has successfully brought together dementia care researchers from across Europe to share, collaborate in new research and to disseminate findings. In this way INTERDEM contributes to placing the psychosocial needs of people with dementia and their relatives, on the European research agenda.

At the turn of the century there was a growing number of people with dementia, and policy makers were becoming increasingly aware about the impact of the condition. At

the time, there was just one drug thought to help in a small way, and little knowledge about how to support people with dementia and their families. Worldwide there was a huge gap to fill. Following a preliminary investigation "Early Detection and Psychosocial Rehabilitation to Maintain Quality of Life in Dementia", the multi-professional pan-European network of dementia

researchers INTERDEM (Early detection and timely INTERvention in DEMentia) was founded in Hull, United Kingdom (1999). Our aim was to guide research and related practice activities, with a mission to develop and disseminate early, timely and quality psychosocial interventions in order to enhance practice and policy. We also aspired to place people with dementia and their supporters at the centre of European research.

Strategy

How did the initiative work? Meeting to develop ideas and to collaborate was considered to be crucial. The first steps were taken in the year 2000 where the Fundacion INTRAS (Spain) brought its creativity and generosity, through organising a meeting and hosting of the INTERDEM website to allow communication and activities to begin.

“Ensuring dementia researchers have the tools they need to move forward successfully is of paramount importance for the future of the field...In order to prepare the next generation for dementia research, the INTERDEM Academy is a new and vibrant initiative.”



INTERDEM Annual Meeting, 23 October 2019, The Hague

Soon, we achieved funding from the EU, for two small projects. These allowed us to have further meetings, to grow capacity across Europe, and to develop larger collaborative projects. We embarked on a project collaboration (EuroCoDe) with Alzheimer Europe and started joining their annual meetings. A more formal organisation was set up, with a small board, and a structured yearly members' meeting, at which new initiatives were developed. To engage in the European grant competition, INTERDEM organised meetings to write collaboratively. These efforts have reaped rewards, in the form of joint projects, and publishing of high quality collaborative articles, as well as special issues with position papers on special topics. For example we have published two Manifestos to guide psychosocial dementia research; two books on translating research on timely interventions into practice; and numerous intervention articles.

“Given the huge impact of dementia worldwide, and the absence, to date, of a significant breakthrough in curative solutions, a way forward may be to seek better understanding of the interaction between biomedical and psychosocial paradigms.”

Timely interventions

The focus was on developing psychosocial interventions to be used in health and social care practice. These covered a wide range of topics, including: the experience of living with/adjusting to/coping with a dementia for both the person with dementia and carers; the organisation of care services; and training / education for those providing care. Particular attention was given to specific intervention approaches, such as: for “behaviour that challenges”; cognitive stimulation; and occupational therapy. Currently

technology, community environmental interventions, social health, intercultural aspects of interventions, and prevention, are areas of special interest, each with a dedicated taskforce assigned to it.

Methodology is key in scientific research. INTERDEM took a critical stand towards prevailing methods such as the randomised controlled trial, by exploring the value of qualitative approaches and promoting the use of implementation science, which pays special attention to the context of interventions thus avoiding the failure of promising interventions. We contributed to this methodological debate with a focussed taskforce and articles such as “Raising the standard of applied dementia care research” and consensus papers on outcomes measures.

European perspective and education

The European perspective has always been prominent. The majority of the 220 members of INTERDEM are from the most active countries in European dementia research. 23 countries are represented (19 EU countries) in our membership, demonstrating a dominant pan-European perspective. INTERDEM has a memorandum of Understanding (MoU) with Alzheimer Europe – a partnership which strengthens both the European and the Patient and Public Involvement (PPI) perspective, with key joint articles on PPI and outcome measurement. Our pan-European grants and the connections between members and European organisations such as the EU Joint Programme – Neurodegenerative Disease Research (JPND), The European Alzheimer Disease Consortium (EADC), and the European Association of Geriatric Psychiatry, further strengthen our European-focussed infrastructure.

Ensuring dementia researchers have the tools they need to move forward successfully is of

paramount importance for the future of the field. This may be achieved through teams where junior researchers collaborate with and are mentored by senior research teams. In order to prepare the next generation for dementia research, the INTERDEM Academy is a new and vibrant initiative.

The focus, so far, has been on the effectiveness of interventions rather than on the mechanisms by which these may work. Psychosocial interventions could be improved by considering the underlying mechanisms of change including those associated with dementia pathology. Given the huge impact of dementia worldwide, and the absence, to date, of a significant breakthrough in curative solutions, a way forward may be to seek better understanding of the interaction between biomedical and psychosocial paradigms. A hypothesis about the influence of social health on cognitive reserve could guide new interventions.

Over the past 20 years, INTERDEM has become a platform for the exchange of new knowledge and for building collaborations and careers. Its driving force is the engagement of European researchers in a network that has become greater than the sum of its parts – that is, INTERDEM inspires its members and receives inspiration in return.

The INTERDEM network, at the European level, plays an important role in disseminating new knowledge, stimulating and informing researchers and policy makers about new evidence-based interventions for the care of people with dementia, their relatives and care organisations. Through Alzheimer Europe, we also engage with the members of the European Working Group of People with Dementia (EWGPWD), who are positive in their review of our dissemination activities.

“INTERDEM has a memorandum of Understanding (MoU) with Alzheimer Europe – a partnership which strengthens both the European and the Patient and Public Involvement (PPI) perspective.”

Reflections on 20 years of INTERDEM



Esme Moniz-Cook, INTERDEM Co-chair

I discovered through case studies that interactions for some people with dementia are shaped by their beliefs traditions and cultures – and that others (carers) might misunderstand the role of these (unconscious) beliefs by ascribing behaviour to the dementia rather than to the needs of the person. Europe provides – like no other– a rich tapestry of cultures, traditions and languages from which we may learn from each other on how to overcome some of the societal challenges associated with dementia. An early understanding of each person and family to prevent the challenges of this condition through timely knowledge and support, has been the hallmark of what I had hoped for at the inception of INTERDEM in 1999. Now we need to recover from the continued societal fear of dementia. People with dementia across Europe have, I believe, a strong contribution to make to future psychosocial research, if we are to understand how they – living in their environments – might improve knowledge on reducing or overcoming the disabilities associated with dementia.



Rabih Chattat, INTERDEM Board member

The future challenge and hope for INTERDEM will be: connecting psychosocial and biomedical research and recognising common ground; enhancing the partnership and the collaboration between researchers and people with dementia; and the implementation of research results across European countries.



Jean Georges, Executive Director, Alzheimer Europe

Big congratulations are due to the INTERDEM leadership and the whole team for their achievements over the past twenty years. Alzheimer Europe has been lucky to have been closely associated with this fantastic network of researchers from the early beginnings and our joint work on the EuroCoDe project (European Collaboration on Dementia). I am truly impressed how both organisations are working together to improve the lives of people living with dementia, combat stigma, develop meaningful outcomes and promote a holistic approach to dementia research. Together, we are undoubtedly stronger and I look forward to our continued collaboration.



Myrra Vernooij-Dassen, INTERDEM Chair

I am most proud, over the past 20 years of INTERDEM, of: development of effective interventions to support people living with dementia; addressing new potential for interventions including social health; stimulating interdisciplinary research; addressing methodological problems in intervention research; the dedication and growth of the INTERDEM network; and the INTERDEM Academy for young researchers.

Patient engagement in research and development: “What’s in it for you?”

Nicole Goedhart is a researcher and lecturer focusing on the inclusion of citizens in vulnerable circumstances in research and policymaking. Lidewij Eva Vat is a researcher and trainer in meaningful and sustainable patient and public engagement. Both are based at the Athena Institute, VU Amsterdam. In this article, they explore the importance of patient engagement in research.



About Patient Engagement and the PARADIGM project

Patient engagement, or involvement, in research is defined as research carried out *with* or *by* people with a lived experience (e.g. affected by a health condition) rather than *about*, *for* or *to* them. As with other health conditions, there is growing evidence of the importance of involving people affected by dementia in research in this way. Understanding and demonstrating the impact and added value of such involvement, for all the different stakeholders involved, is crucial for enhancing partnerships and showing its value. However, there is no consensus on what to evaluate and how best to evaluate the collaboration.

The PARADIGM project is a European public-private partnership that is developing ways to ensure that patients are meaningfully involved in medicines development. One of the main aims of the project is to develop a monitoring and evaluation framework including metrics to measure the “return on engagement” for all involved. Five patient organisations are partners in the project, two of them (Alzheimer Europe and Hospital Sant Joan de Déu) represent the need of potentially vulnerable groups with specific needs (i.e. people affected by dementia and young patients).

What is the evidence?

We reviewed the literature on monitoring and evaluation of patient engagement and

involvement, to identify possible measures and methods. We also summarised the positive and negative impacts for various stakeholder groups (researchers, patients, pharmaceutical companies, regulators, decision-makers). Examples of reported benefits for people with lived experience are: empowerment, enhanced well-being, and learning about research and about their condition. Examples of reported challenges relate to confusion due to lack of clarity about roles, disappointment due to mismatched expectations and the lack of inclusion of vulnerable or hard-to-reach groups (e.g., those who do not speak English, people who are not able to travel, read or write or may experience cognitive problems).

Most of the evaluation studies which we reviewed were conducted by researchers and pharmaceutical companies, and the involvement of people with a lived experience was scarce. This is an important issue as the perceived value of engagement and the relevant metrics for people with lived experience might differ from those of the other stakeholders involved. For example, researchers and pharmaceutical companies might value

“The PARADIGM monitoring and evaluation framework can be used as a map that shows what to monitor and evaluate to understand if an engagement practice works the way it was intended.”



“Trees of Impact” created at the EWGPWD consultation, 11 December 2019, Brussels

evidence that patient engagement improves the quality and efficiency of research, whilst people with the lived experience may value influencing the research agenda to develop medicines for unmet needs.

What do people with dementia hope to get in return?

To better understand what people affected by dementia find relevant to measure, we carried out two consultations in collaboration with Alzheimer Europe:

The first consultation involved representatives of national Alzheimer associations who were present at an event organised by Alzheimer Europe for its members in Brussels. When asked what they hoped their organisation could get in return for being involved in research, many hoped to gain information about the progress and results of clinical studies. Another relevant aspiration was to gain more credibility to support discussions with other stakeholders (e.g., regulators, donors).

The second consultation was carried out with members of Alzheimer Europe's European Working Group of People with Dementia (EWGPWD) and their supporters, at one of the regular meetings of the group, in Brussels.

Using an interactive participatory approach, we asked them what they would like to get in return for collaborating with researchers and we created three Trees of Impact, gathering their responses on the 'leaves'. People with dementia and their supporters hope to make a difference for the lives of people affected by dementia (e.g. to cope better with the condition, to develop better medicines and to have a better future for generations to come). They also hope to learn from other people affected by dementia and from researchers. Members of the EWGPWD also said that participating in research gave them an enjoyable break from their daily lives, fun and meaningful relationships, friendships and opportunities for networking.

How can the PARADIGM monitoring and evaluation framework be used?

The PARADIGM monitoring and evaluation framework can be used as a map that shows what to monitor and evaluate to understand if an engagement practice works the way it was intended and to measure the value for all people involved. Every engagement initiative is unique and therefore, the framework should be tailored to the context and the expectations of the people involved. We are currently testing the framework with various patient engagement initiatives and groups.

“Examples of reported benefits for people with lived experience are: empowerment, enhanced well-being, and learning about research and about their condition.”

An online tool will soon become available to help engagement initiatives to select meaningful metrics for monitoring and evaluation (summer 2020). This will include co-designed metrics to measure the return on engagement. This may contribute to making the involvement of people with a lived experience the norm; not only the right thing to do but also the right thing to do for people with dementia, researchers, their organisations and their communities.

For further information about the literature review

Vat LE, Finlay T, Jan Schuitmaker-Warnaar T, et al. Evaluating the “return on patient engagement initiatives” in medicines research and development: A literature review. *Health Expect.* 2019;00: 1–14. www.doi.org/10.1111/hex.12951



Camilla Habre, Ana Diaz, Nicole Goedhart and Lidewij Eva Vat at Alzheimer Europe's Alzheimer's Academy, 11 December 2019

Acknowledgement

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PARADIGM – Patients Active in Research and Dialogues for an Improved Generation of Medicines – is an IMI-funded European project. It began on 1 March 2018, for 30 months. Alzheimer Europe is a partner and is involved in all work packages of this project.

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Czech Republic finalises second national dementia strategy (2020–2030)

Following the completion of its second national dementia strategy, the Czech Republic Minister of Health, Adam Vojtěch, has spoken to Alzheimer Europe to explain the new strategy, including how it was developed and how it aims to improve the lives of people with dementia.



Towards an implementable dementia plan

The urge to address dementia by a national policy first materialised in the dementia strategy for the years 2016–2019. This document drew attention to weaknesses of the system in the Czech Republic: mainly, a lack of epidemiological surveillance, delayed diagnosis, insufficient post-diagnostic support and lack of coordination in care. However, the strategy was not specific about the steps required in order to strengthen the system. For that reason, when I was appointed Minister of Health in 2017, I found myself facing the same issues and pressing need to take action on dementia. In the same year, the World Health Organization (WHO) published its global action plan on the public health response to dementia (2017–2025) that was supported by resources for countries determined to properly address dementia.

I believe in strong international collaboration and based on our great experience with WHO (through involvement in an ongoing major reform of Czech mental health care), we decided to rebuild our dementia strategy according to the principles published in a WHO guide towards a dementia plan.

Strong stakeholder engagement

Fragmentation of services and responsibilities among many specialists, as well as health and social care, makes dementia a field where it is easy to get lost regardless of whether you are a person with dementia, a family carer, a medical specialist, a social service provider or a policy maker. To put it differently, the policy response needs to be interdisciplinary and well-coordinated.

Consequently, in January 2019, we appointed a coordinator whose main responsibility was to bring a wide range of stakeholders to a round table and to develop a new strategy based on their insights. The Ministry is committed to lead the process of improving management of dementia in the Czech Republic. At the same time, we recognise the importance of key stakeholders as architects of change. The role of the Ministry of Health in the dementia strategy development was mainly to create a space for multidisciplinary discussion, while navigating towards a commonly accepted consensus, to provide data for evidence-based actions and to identify funding options. After constructing a situational analysis according to Global Dementia Observatory (GDO) indicators and identifying the gaps in the system,

we simply asked the stakeholders: “How can the Ministry help?” Then we carefully listened and crafted the new dementia strategy together. By being transparent and open to suggestions, we empower the stakeholders and their organisations to take an active role in implementation of actions identified, proposed and defended by them on a broad expert platform. After almost a year from choosing this path, we witnessed how well the stakeholder engagement works. Not only that, we developed a handful of actions to be taken forward in the next decade, alongside stakeholder-suggested examples of previous good practice and initiatives that are already ongoing. By incorporating these into the strategy, we proclaim governmental support and intention to scale them up.

Smooth transition from development to an implementation phase

A national dementia strategy for the years 2020 – 2030 is near to its launch. In the document, the Czech Republic commits to achieve five interrelated strategic aims: decrease diagnostic gap and strengthen post-diagnostic support; educate care professionals and create educational resources for informal caregivers; set-up epidemiological surveillance and intensify dementia-related research; increase dementia awareness and prevention; and, ensure that the rights of people with dementia are being protected.

The document has three parts. In the first part, we envision how we want to address dementia in 2030. The second part of the strategy presents situational analysis for the year 2019. Reading these two parts provides a clear answer to the two essential questions: from where we depart and where we head to. The third part identifies very specific actions about how to travel there and achieve our aims.

With regard to our experience with the previous strategy, we pay special attention to the transition between a development and an implementation phase. It is reassuring to know that some of the activities are already in progress even before the official governmental approval of the strategy, and others are being prepared. To name a few examples, from 2020, general practitioners will be reimbursed for cognitive testing, which will hopefully increase referral to specialists and consequently narrow



Adam Vojtěch

the diagnosis gap. To strengthen post-diagnostic support, we are piloting multidisciplinary teams. At the same time, a project aiming to create interdisciplinary guidelines determining the role of different actors in the system and which will help them to navigate it, is under development. To set up regular epidemiological surveillance, the Institute of Health Information and Statistics will annually report data from the nation-wide health care register. To increase dementia awareness, we are currently creating a logo of the strategy – designed by an artist living with cognitive impairment himself – that can be used by organisations implementing various activities that are in line with the strategy, to provide a uniting theme.

To ensure continuity during the whole decade when the strategy will be in force, we defined a sixth strategic aim that provides technical support for its implementation. The support consists of actions such as anchoring the role of the coordinator for dementia as a focal

“ We find international collaboration to be an important and beneficial support, so the intention is to further strengthen the collaboration with the World Health Organization, Alzheimer Europe and hopefully also to form new partnerships.”

point and a person responsible for creating and evaluating implementation plans. The coordinator will also actively seek good practice in the Czech Republic and abroad. We find international collaboration to be an important and beneficial support, so the intention is to further strengthen the collaboration with the World Health Organization, Alzheimer Europe and hopefully also to form new partnerships. Importantly, the coordinator will take part in a newly formed governmental advisory committee that supervises the ongoing reform of mental health care. As many structural changes planned by the strategies for mental health and dementia are overlapping, we need to exploit synergies between activities proposed by these two documents.

Lastly, a decade is quite an extensive time horizon which demands openness to new trends, ability to make adjustments and to finalise some of the actions scheduled later in time. To that end, I will institutionalise the work of the stakeholder platform, transforming it into an official ministerial advisory group, that will together with the coordinator ensure the required continuity as well as flexibility of the dementia strategy. To put it differently, we aim to create a document with clear vision and actions that are foreseeable now as well as to establish a mechanism to promptly react, to incorporate the newest developments and to face challenges as they come.

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Governmental Expert Group on Dementia meets for a third time

Alzheimer Europe is delighted to continue its work with representatives from governments across Europe, to provide a policy platform to exchange knowledge and information on the latest national and international developments on dementia.

The European Group of Governmental Experts on Dementia held its 3rd meeting on 10 and 11 December 2019 in Brussels. In total, 15 European countries were represented at the meeting, in addition to representatives from the 2nd Joint Action on dementia (Act on Dementia), the World Health Organization (WHO) and Alzheimer Europe.

Charles Scerri (representing Malta) chaired the two-day meeting, with the group hearing about national programmes of work, as well as European and international projects. In relation to national programmes of work, the group had previously indicated that it would be most useful for examples to be shared in relation to palliative care and data registries of people with dementia.

The WHO updated attendees on the progress made in implementing its “Global action plan on the public health response to dementia 2017–2025”, including progress on the implementation of the Global Dementia Observatory and the knowledge exchange platform. In addition, the group also heard about the first bi-regional workshop on dementia which took place in September 2019, co-hosted by the WHO and the Maltese Government. You can read more about this event on page 21.

The first thematic topic discussed by the group related to palliative care, with countries sharing their experiences of implementing policies to ensure that high quality palliative care was accessible for people with

dementia and appropriately responded to their needs. As an introduction to the discussion, Professor Lieve Van den Block, the coordinator of the Palliative Care for Older People in care and nursing homes in Europe (PACE) project, presented the findings and policy recommendations following the completion of the project. A significant focus of this discussion was on the way in which palliative care was delivered, which is often driven by other models of disease progression that are not necessarily suitable for people with dementia. As such, it was acknowledged that improving staff training is vital, as is a shift in the approach of palliative care services.

The second major theme concerned the use of data registries of people with dementia. As part of this topic, Dr Lewis Killin of the University of Edinburgh provided an overview of different data registries in the UK, noting that there were distinct categories of registries, including those intended for clinical use and those focused on research. He pointed out that there is often a disconnect between what information is expediently collected for clinical purposes, compared to what may be needed for research protocols.

As part of this presentation, Dr Killin provided an overview of the Scottish Brain Health Register, a recent development within Scotland, aiming to address some of these issues; improve the understanding of population level trends in brain health; facilitate research participation; and improve clinical care.

The group also heard from the 2nd Joint Action on dementia which had recently published its conclusions and findings, as the project entered its dissemination phase. The work and findings across four work package areas was presented, covering diagnosis and post-diagnostic support; crisis and care coordination; residential care; and dementia-friendly communities. You can read more about the work and findings of the 2nd Joint Action on pages 18–20.

The group will meet again in June 2020 in Brussels.



Second EU Joint Action – “Act on Dementia” – draws to a close

The 2nd EU Joint Action, which ran from March 2016 until December 2019, has drawn to a close. In this article, the Scottish Government provides an overview of the work undertaken by the project and some of the key findings which have emerged.

The 2nd European Joint Action on dementia (“Act on Dementia”) ran between March 2016 and December 2019. The project was funded by the EU through the EU Health Programme, with the aim of promoting collaborative actions among Member States to improve the lives of people living with dementia and their carers. It provides practical guidance for policymakers developing and implementing their national dementia plans, policies and strategies. It aims to provide cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

The Scottish Government was responsible for co-ordination of the project (Work Package 1), as well as having responsibility for dissemination of the findings of the work (Work

Package 2). Both work packages aimed to ensure that people and organisations providing institutional or statutory care for people with dementia, and officials and politicians within EU Member States who have the responsibility for health and social care services, know about the work of the Joint Action. It also ensured that the learning from the Joint Action is shared widely so that people living with dementia and the people who care for them benefit from improved services.

Evaluation of the project (Work Package 3) was carried out by AQUAS (Agència de Qualitat i Avaluació Sanitàries de Catalunya). This work was led by Dr Maria-Dolors Estrada Sabadell, with the intention of maximising methodological quality of the outputs of the project (evidence and testing of best

practices) in a participative way with partners. Additionally, AquAS sought to define a strategy to measure the impact of Act on Dementia within the frame of the project.

Four key work areas were also created to help improve the lives of people living with dementia (work packages 4–7).

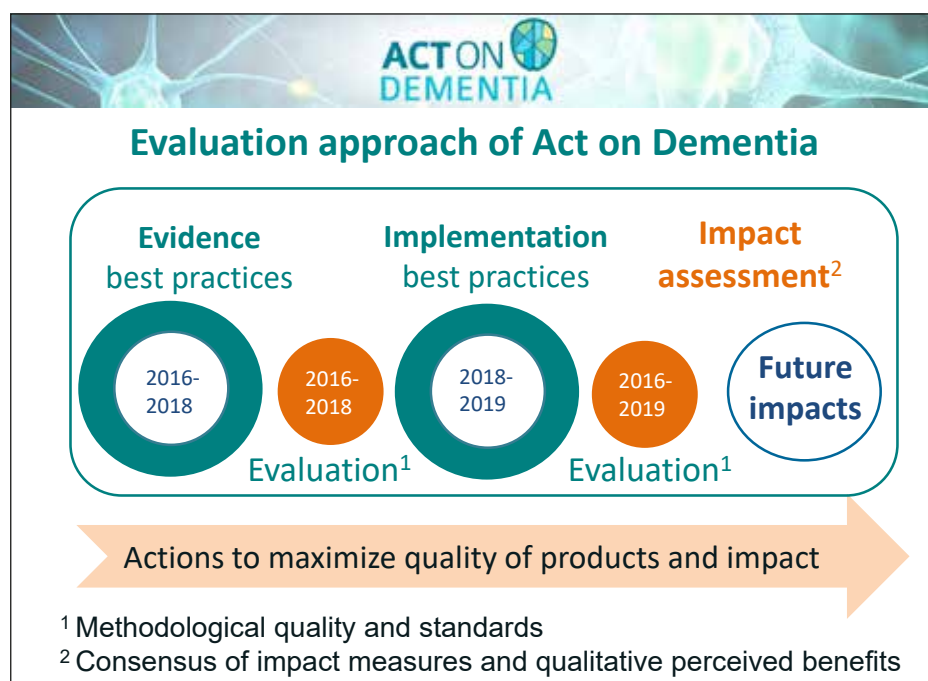
Diagnosis and Post Diagnostic Support – (Work Package 4)

Dementia diagnosis rates vary greatly between Member States and in many places, post-diagnostic support is non-existent, or underdeveloped. Where a diagnosis occurs later or is communicated poorly and without subsequent interventions, the risk of institutionalisation or other poor outcomes for the person and their family is significant. This is not optimal for either the person living with dementia, or the health and social care system.

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

As such, Work Package 4 focused on this theme, led by Professor Pierre Krolak-Salmon from the Institute for Elderly, Clinical and Research Memory Centre of Lyon. Joint Action pilot sites in a number of countries (France, Greece, Italy, Norway, Poland and Bulgaria) testing evidence-based approaches to improve diagnoses of dementia within primary care settings, including training resources, new pathways of diagnosis and use of different tools.

One aspect of the Work Programme was for General Practitioners (GPs) to undertake anti stigma-training to reduce stereotypical assumptions around dementia and to improve



Evaluation approach for Act on Dementia

both their confidence and ability when a patient presents with a possible dementia. Prof. Krolak-Salmon noted that as a result of the anti-stigma training, GPs showed better impact on stereotypes than classical academic training, reinforcing the benefits relating to a timely diagnosis of neurocognitive disorders being much higher than risks’.

Additionally, primary care collaborations between GPs and nurses, which changed the process for attaining a diagnosis in primary care settings, were tested. Prof. Krolak-Salmon reported positive results thanks to these changes, highlighting that the collaborations optimised the detection and diagnosis of neurocognitive disorders in primary care environments, providing benefits in relation to achieving a timely diagnosis of neurocognitive disorders.

Another strand of work, included enhancing the detection and diagnosis among nursing home residents through teleconsultations and specialist interventions. Prof. Krolak-Salmon has expressed his hope that telemedicine will help nursing homes to deal with behavioural conditions and, as an indirect effect, better detect neurocognitive disorders.



Geoff Huggins speaks about the Joint Action at the 29th Alzheimer Europe Conference

Crisis and Care Coordination – (Work Package 5)

People living with dementia need varying levels and types of care as the disease progresses. In most health and care systems, dementia care will be provided by a range of providers, each working under different eligibility and funding rules and often without clear co-ordination. This results in an experience that can feel fragmented, and increases confusion due to the different care providers, their systems and points of contact. For many families, informal carers often have to take on responsibility for care co-ordination themselves. It is also important that physical environments are adapted to enable people to live well and safely at home.

In situations of crisis, where the person with dementia, or their primary carer has an acute episode of illness or trauma, the person with dementia may be admitted to hospital or a residential care institution. Admission to institutional care is often unnecessary, and the result of either limited access to alternative and more appropriate care, or lack of care co-ordination between health and care providers. Family care-givers often report significantly increased anxiety, apathy, resistance to care, and distress in these types of crisis situations. Crisis support models and better practice can significantly reduce strain on care-delivery systems by incorporating non-pharmacological interventions, assisting families with communication, and reducing family distress during a crisis.

This work was jointly led by Professor Nicola Vanacore in Italy, and Jacqueline Hoogendam in the Netherlands, and was aimed at improving crisis response services and care co-ordination for people with dementia by developing good practice recommendations based on reviews of academic literature and guidelines on dementia care using a standardised tool, and surveying relevant organisations in the EU.

The good practice recommendations helped shape the direction of five pilot programmes, conducted in care settings in Bulgaria, France, Scotland, Italy and the Netherlands. The pilot

programmes focused on improving crisis and care co-ordination for people with dementia but were tailored to country-specific needs. Initiatives included education packages for professionals, support for GPs through connections to dementia specialists and co-ordinators, and support for informal carers.

A video explaining the work of a particular DEC (Diagnostic Expert Centre) Team in the Netherlands is accessible on the Act on Dementia website. Each element of the team explain their role and the positive outcomes from their approach

Residential care – (Work Package 6)

As dementia progresses, many people in the later stages require round the clock care, and, depending on circumstances, this may lead to admission to a residential care establishment. A large proportion of nursing and residential care home residents have dementia (in some countries up to 80%). As it is a progressive condition with no cure, many people with dementia who are admitted to a care or nursing home will remain there for the rest of their lives.

It is important to ensure that high quality professional care, including palliative care, delivered with dignity and compassion, is available in residential and nursing care establishments. A specific issue for people with dementia in residential care is the over-use of psychoactive medication to manage stress and distress behaviours. It is important that people with dementia in these settings are prescribed such medication only as a last resort, that there is a range of alternative psychosocial interventions available and that when psychoactive medication is used, its use is reviewed regularly.

Work in this area was led by Øyvind Kirkevold from The Norwegian National Advisory Unit on Ageing and Health. A key aim of the work was to address behavioural and psychological symptoms of dementia (BPSD) in residential care settings by promoting the biopsychosocial model and person-centred care. But also to consider how best to sustain these improvements beyond the testing phase.

Pilot projects were carried out in five countries, in partnership with Alzheimer Europe. Those in Bulgaria, Greece and Romania focused on translating, adapting and developing models and testing their feasibility and usefulness in residential care homes. In the Netherlands and Norway, the aim was to ensure wider implementation of existing models to address BPSD, and to evaluate an e-learning programme on palliative care in nursing homes (Norway only). A key recommendation is that European countries develop teaching and training programmes for addressing BPSD in residential care based on evidence and the experiences of the pilot projects.

Dementia Friendly Communities – (Work Package 7)

Dementia friendly communities (DFC) can help to support people with dementia to live more independent and fulfilling lives in their own communities. Evidence has shown that appropriate support in the community can reduce the number of people with dementia being admitted to hospital and delay entry into care homes. As more Member States look at the costs of caring for people with dementia, there is an opportunity to develop alternative community support, to empower people with dementia to actively participate in society and remain independent for as long as possible, thereby also reducing stigma, isolation and fear by increasing community awareness and understanding.

A clear and concise evidence-based report with recommendations was produced on what works in promoting, nurturing and sustaining dementia friendly communities. For example, defining what ‘good’ looks like for a system-wide approach, understanding how good practice is sustained and promoting the various benefits, including economic benefits, for communities of being dementia friendly.



Joint Action Work Package Leads at the Alzheimer Europe Conference in the Hague

Led by David Nuttall, Deputy Director of Dementia and Disabilities at the UK Department of Health, the DFC model has been piloted in three countries – Bulgaria, Greece and Italy. The model is based on the “four cornerstones” of people, places, networks and resources, with people living with dementia being central. The pilot sites represent a mix of large and small populations, urban and rural settings, and communities with different cultures and systems.

Evaluation

Dr Maria-Dolors Estrada Sabadell and Dr Vicky Serra-Sutton of AquAS led on ensuring a high level of methodological quality was promoted, both in relation to agreeing models of best practice, as well as about how pilot-testing was conducted.

In assessing the overall impact of the Joint Action it was noted that the voices of 25 people involved specifically in dementia policies, research/academic institutions and Alzheimer societies across Europe have reinforced that Act on Dementia has had a demonstrable impact. This include improving

collaborations among regions, learning processes and the validation of existing dementia plans (including those in the process of implementation).

Dissemination

The findings from all phases of work on this project have been largely positive and encouraging. The focus is now on persuading decision makers to learn from this body of work. Full reports are available for each Work Package along with summary versions, and are all available to be downloaded from the Act on Dementia website.

Short videos are also available from several test sites which are easy to digest and provide a better understanding of the impact of taking part in the Joint Action. The hope is to broaden the public reach of the project results, making them accessible to a wider audience including carers and people with dementia and their families.

All resources from the Joint Action, including work package reports, videos etc. are available at www.actondementia.eu

Acknowledgement



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World Health Organization hosts bi-regional workshop on dementia in Malta

Working with the Maltese Government, the World Health Organization organised a two day workshop, bringing together stakeholders from across the European and Eastern Mediterranean regions to address dementia, hearing about work to improve the lives of people with dementia and their carers underway at both an international and national level.



Hana Marie Broulikova speaks during the workshop

On 15 May 2017, the Presidencies of the Council of the European Union 2016–2017, Malta, the Netherlands and Slovakia signed a Joint Statement on Dementia. The Statement called on European Member States to: support international cooperation in dementia research; exchange and implement best practices in dementia care, diagnostics and prevention; support people with dementia to live the best possible quality of life; raise public awareness of dementia; and, create dementia friendly societies. On 29 May 2017, the 70th World Health Assembly endorsed the “Global action plan on the public health response to dementia 2017–2025”, thereby committing to reaching global targets across seven key action areas, including the development of national strategies and plans.

To support the implementation of the global dementia action plan, the Government of Malta’s Parliamentary Secretariat for Persons with Disability and Active Ageing hosted the “Workshop on the implementation of the global action plan on the public health response to dementia in the World

Health Organization’s (WHO) European (EURO) and Eastern Mediterranean (EMRO) regions” in Valletta, Malta. The two-day workshop, organised by the WHO, took place on 9–10 September 2019 and brought together 32 key stakeholders from 11 countries across WHO’s EURO and EMRO regions. Countries included Bulgaria, the Czech Republic, Croatia, Malta, North Macedonia, Slovenia, Turkey, Jordan, Morocco, Qatar and Tunisia. Participants included people with dementia, policymakers, healthcare practitioners, academic researchers, as well as civil society representatives.

In line with the global dementia action plan and its targets, the focus of the workshop was to discuss mechanisms to strengthen countries’ comprehensive, multisectoral public health responses to dementia. The workshop facilitated information and knowledge exchange, including lessons learned and good practices amongst participants, to strengthen the development of both regional and country-specific responses to dementia. It also provided participants with

an overview of the WHO’s global dementia action plan, including its overarching targets and key actions areas, as well as available WHO tools and resources.

The workshop was organised into seven sessions that included country and WHO presentations, a panel discussion, as well as perspectives from a person living with dementia, Alzheimer Disease International and Alzheimer Europe. The sessions also allowed for group work and informal networking. The first day of the workshop was dedicated to dementia as a national and regional public health priority and included sessions focused on: building the rationale for a dementia plan, establishing mechanisms and partnerships to develop a dementia plan, and developing a dementia plan. The second day of the workshop focused on specific issues around building dementia care pathways, supporting dementia carers, and dementia risk reduction, awareness and friendliness.

The workshop provided an excellent opportunity for participants to network and make new personal connections, supporting collaborative working to address dementia on both a local and global scale. It also facilitated the cross-pollination of ideas and innovations, and fostered new opportunities for collaboration both across sectors and WHO regions. Most importantly, however, workshop attendees were able to build capacity and exchange knowledge, which will help strengthen the development and implementation of comprehensive public health responses to dementia at both national and regional levels. As a statement of the success of the workshop success, the WHO is currently exploring opportunities with the State of Qatar to host a similar multi-regional workshop in 2020.



Attendees of the bi-regional workshop in Malta

World Dementia Council discusses progress in making dementia a global priority

Lenny Shallcross, Executive Director of the World Dementia Council (WDC), has spoken to Alzheimer Europe about the work of the organisation, the Tokyo summit which took place on 18 October 2019 and the priorities of the WDC for 2020.



For readers who may not be familiar with the World Dementia Council, can you explain its background, aims and objectives?

In 2013, during the UK's presidency of the G8 (as it then was), then UK Prime Minister David Cameron hosted a summit in London focused on dementia. It was the first time that dementia had been on the agenda at one of the international governmental meetings. There, the G8 agreed key commitments, set out in the declaration and communique, on how global action could turn the tide on dementia by 2025. After the summit, the World Dementia Council (WDC) was established by the UK Government, with the role of supporting and challenging the international community to meet the summit ambitions.

The WDC has a membership of leaders in dementia, drawn from around the world. Members are drawn from academia, industry, finance, healthcare, civil society, the care industry, and include people who are living with dementia.

Members come from every continent of the world and from both high income and low- and middle-income countries. In addition, the Council has a number of government members, and the World Health Organization (WHO) and the Organisation for Economic Co-operation and Development (OECD) are also members.

The WDC held a high-level summit in October 2019 in Tokyo – what was discussed and agreed at this meeting?

This was the second summit the WDC has hosted looking at the progress towards the 2025 commitments governments made in 2013. In 2018, we hosted a summit in London, five years on from the G8 meeting and launched a report, "Defeating dementia: the road to 2025", that evaluated the progress being made and some of the challenges ahead. At both our London meeting, and our Tokyo meeting, we brought together governments, academia, industry and policy experts to reflect on the global priorities to help tackle dementia and accelerate international progress.

In Tokyo, a number of governments participated and outlined how they were working to address the dementia challenge. The Government of Japan, Government of the Netherlands, and Government of Australia presented on their national challenges and dementia policy frameworks.

The 2019 summit, held in conjunction with Janssen Neuroscience and Japan's Health and Global Policy Institute (HGPI), examined some of the challenges around establishing

research partnerships and sharing data. We heard from two important European examples of research partnerships – JPND and the Innovative Medicines Initiative – in both of which Alzheimer Europe is an important partner. Alongside this, the meeting considered key developments in data sharing. Data sharing holds huge potential to accelerate research, but important regulatory, cultural, and funding barriers must be addressed. On this matter, the summit saw Shionogi and Johnson & Johnson announce an important industry commitment agreeing to share data samples by establishing a clinical sample access agreement.

Also at the summit, the WHO launched a new dementia-friendly toolkit, which has just begun field testing. In conjunction with a number of organisations, the WDC is conducting a global evidence gathering exercise that seeks to assess the effectiveness of dementia-friendly initiatives.

What do you see as the priorities for the WDC into 2020 and beyond?

We have reason to be hopeful. We know more about the basic science of the brain and the early development of the disease than ever before. In 2018, the Alzheimer's Association and the National Institute on Ageing launched the first research framework that defined Alzheimer's by a set of biomarkers. Technology and big data are helping to accelerate research. At the same time, there is more attention on raising awareness of dementia and helping people live well in the community. Progress has been possible because every part of the dementia movement has helped keep the focus of national governments on dementia. We need to collectively continue pressing governments to act on dementia.



Caroline Edwards of the Australian Government, Dutch Deputy Prime Minister and Minister of Health Hugo de Jonge, and Ryoji Noritake of Health and Global Policy Institute, at the Tokyo Summit



World Dementia Council
Leading the Global Action
Against Dementia

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Expert report calls for coordinated public education and research programmes to promote brain health

An international multidisciplinary group of experts has presented an evidence-based position for policy recommendations encouraging individuals to participate actively in maintaining their brain health. The team behind “Time matters: a call to prioritize brain health” shares its findings and results.

An increasing socioeconomic challenge

Neurodegenerative diseases are not an inevitable consequence of normal ageing but they are becoming more common as people live longer. In 2016, 3.5% of total global deaths were registered as attributable to dementias (including Alzheimer’s disease), making dementia the fifth highest cause of death. According to estimates from the World Health Organization, this total will rise to 7.1% by 2060.

The impact of an ageing population is that the socioeconomic cost of neurodegenerative disease is increasing. The financial cost of such diseases to society is considerable, both in terms of direct (e.g. medical) and indirect (e.g. sick leave) healthcare costs and the significant loss of workforce hours.

“People ought to have greater awareness and understanding of the risk factors that can affect their brain health and what can be done to maintain it and to help prevent neurodegenerative diseases.”

Professor Gavin Giovannoni

However, it is important to remember that the cost of neurodegenerative diseases is

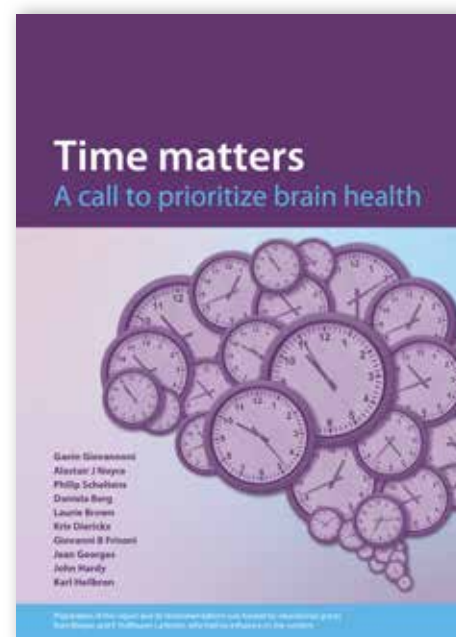
not just financial; health-related quality of life for those living with these diseases may be severely impacted as well. This can lead to a loss of independence and increased reliance on support from healthcare professionals and carers, who in turn may also be negatively impacted.

Brain healthy lifestyles

“People ought to have greater awareness and understanding of the risk factors that can affect their brain health and what can be done to maintain it and to help prevent neurodegenerative diseases,” said Gavin Giovannoni, a Neurologist from Queen Mary University of London and Chair of the author group.

According to the Alzheimer’s Research UK Dementia Attitudes Monitor, the general public currently unaware that over a 10 to 20-year period in midlife, lifestyle changes can reduce the risk of developing neurodegenerative disease, before signs and symptoms appear. The “Time Matters” report examines how the long period of deterioration that happens with many neurodegenerative diseases gives a window of opportunity during which patients and their families can take action to change the course of disease.

“We cannot change our genetic make-up, but we can help reduce the risk of developing neurodegenerative diseases ourselves by taking exercise, keeping socially active, eating healthily, reducing alcohol intake,



Time Matters report

“We cannot change our genetic make-up, but we can help reduce the risk of developing neurodegenerative diseases ourselves by taking exercise, keeping socially active, eating healthily, reducing alcohol intake, stopping smoking and keeping our brains active.”

Alastair Noyce

stopping smoking and keeping our brains active,” explained Alastair Noyce, from Queen Mary University of London and Co-Chair of the author group.

Future proofing healthcare systems

In order to avert a health crisis, reduce the burden of disease and plan effectively for healthcare services in the future, the report sets out a series of recommendations, including:

- Improve public understanding of how to protect brain health through lifestyle measures – such as exercise and a healthy diet

- Prepare for the likely increased demand for genetic testing by those wanting to understand their risk of a neurodegenerative disease
- Conduct research to identify accurate and cost-effective tests for disease detection and diagnosis
- Provide access to available and effective treatments in a timely manner
- Provide accessible holistic care, including prevention information, treatment options and support
- Develop, validate and approve tests, tools and apps for monitoring brain health.

It is clear that new policies, collaboration and further investment are needed in the prevention and treatment of neurodegenerative diseases in order to reduce their impact. Research to develop new treatments and other

tests to facilitate earlier diagnosis must continue, and health systems must prepare now for the time when such tests are available.

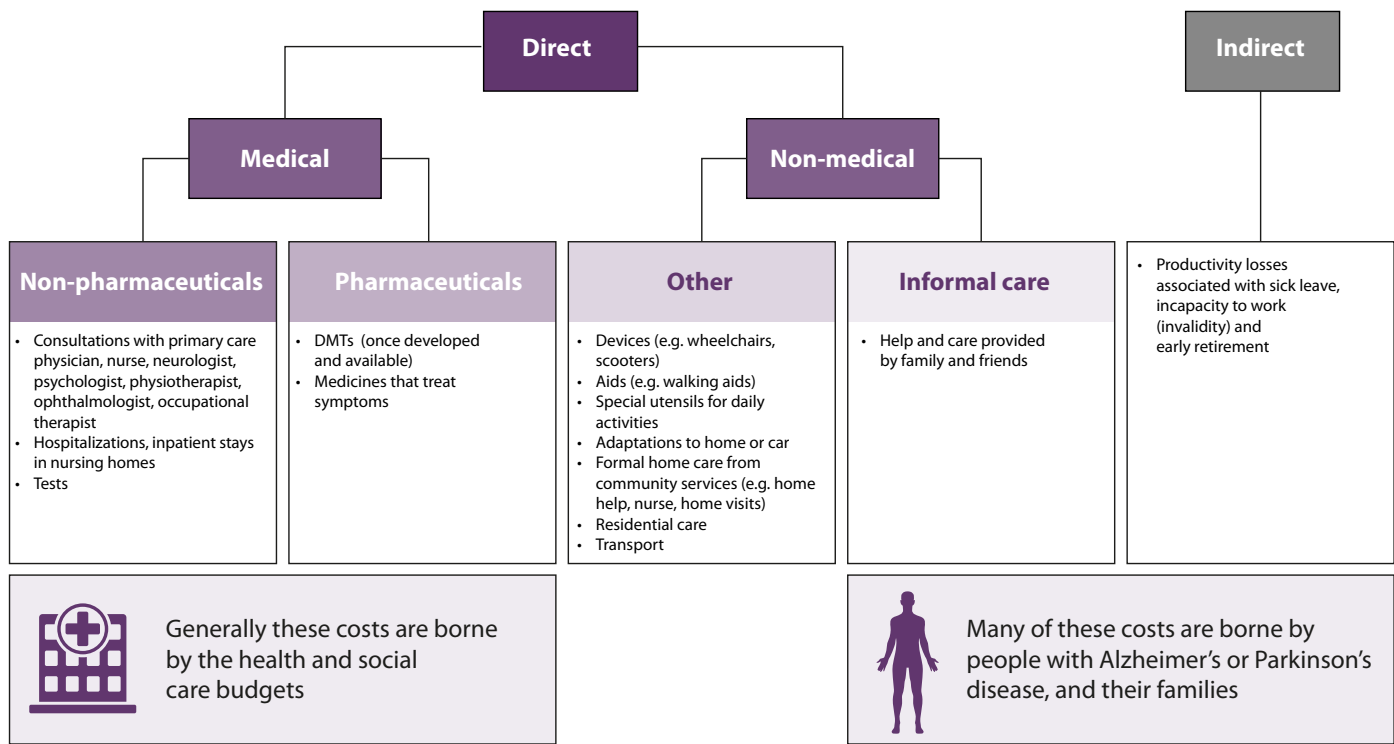
Professor Philip Scheltens, Director of the Alzheimer Centrum Amsterdam and Co-chair of the report, explained “we are on the cusp of having blood tests readily available that will easily and accurately help to diagnose patients with neurodegenerative diseases, such as Alzheimer’s. They have the potential to act as tools to help find out if people need any further, more involved, diagnostic tests.”

In the interim, the best opportunity to limit the harmful impact of these diseases on brain health is primary prevention through lifestyle changes to reduce the impact of risk factors. What’s good for your heart is generally good for your brain.

To sign up for updates in this programme of work and to read Time matters: a call to prioritize brain health in full please visit: www.oxfordhealthpolicyforum.org

“ We are on the cusp of having blood tests readily available that will easily and accurately help to diagnose patients with neurodegenerative diseases, such as Alzheimer’s. They have the potential to act as tools to help find out if people need any further, more involved, diagnostic tests.”

Philip Scheltens



The total societal costs of neurodegenerative diseases

Acknowledgement

Preparation of the report was funded by educational grants from Biogen and F. Hoffmann-La Roche, who had no influence on the content.

Dementia research investment needs to reflect the enormous cost of dementia care

In November 2019, an analysis of global dementia research investment was published in The Lancet journal, by James Pickett, Head of Research at Alzheimer's Society (UK) and Carol Brayne, Professor of Public Health Medicine at the University of Cambridge. James Pickett highlights some of their key findings.



Amongst G7 countries only the US is keeping pace with this investment. Latest figures show that the UK Government invests around GBP 85 million (EUR 99.82 million approx.) in dementia research per year, which reflects about 0.25% of the cost of dementia to the UK. In comparison, they invest about GBP 270 million (EUR 316.96 million approx.) per year into cancer research, which is equivalent to 1.5% of the cost of cancer.

Our analysis also showed that, globally, only 5% of all dementia research addresses health and social care challenges faced by people living with dementia today. There are now an estimated 50 million people living with dementia globally, and this research should not be considered less important, as it can make a tremendous difference to people's lives.

Dementia is now rightly recognised as one of the largest economic, medical and social issues facing us in the 21st century. With a current lack of availability of treatments or interventions that can stop or even slow the rate of progression of disease, research is a key priority in a global response to dementia.

Myself and Carol Brayne, Professor of Public Health at the University of Cambridge recently completed an analysis of dementia research funding by G7 countries (Canada, France, Italy, Germany, Japan, UK, US). The analysis, published in the Lancet journal, is based on data collected in Europe and Canada as part of the EU Joint Programme – Neurodegenerative Disease Research (JPND) and as part of the US' National Plan to Address Alzheimer's Disease.








The G8 (now G7) hosted a summit on dementia in 2013 and committed to significantly increasing research funds towards finding effective treatments. Looking at research investment at two timepoints, before and after the summit (2011 and 2016), investment by the G7 governments has more than doubled, to over EUR 1.3 billion. This has been driven strongly by increases from the US and to a lesser extent the UK. However, falling investment is reported in France, Germany and Italy between 2011 and 2016.

Since 2016, the US in particular has significantly further increased funds for dementia research and a budget of USD 2.8 billion (EUR

2.52 billion approx.) was recently announced for 2020. The recently elected UK government has pledged to double dementia funding in the next decade, spending an additional GBP 800 million (EUR 940 million approx.) Central funding from EU programmes has also increased, from EUR 56 million to EUR 98 million during this period, but scientists have expressed concern about the lack of focus on brain health in future EU research frameworks.

Alzheimer's Disease International and other organisations have called for governments to commit to funding research to the level of 1% of the economic cost of dementia.

Overall, we should be proud of the collective efforts that have been made on dementia in the last decade. The amount spent on dementia research is only one metric and it is often difficult to apportion broader neuroscience research funding to diseases. Ultimately, we will measure progress in the availability of treatments and the life satisfaction of people affected by dementia. However, this should stand as a reminder for us not to be complacent about keeping up efforts on dementia research, nor about considering strategies to make sure research into helping those living with dementia, both today and in the future, is adequately supported.

G7 nations	Investment in dementia research 2016	Change since 2011	Proportion on care research
	\$1,207m (€1,091m)	+144%	3%
	£130m (€159m)	+93%	14%
	€106m	-12%	8%
	€30m	Not reported	3%
	€14m	-38%	9%
	€4m	-13%	5%
	Not reported	Not reported	Not reported
Total	€1,374m	+137%	5%

Putting a face to commitment – Jeremy Hughes reflects on 10 years with the Alzheimer’s Society

In September 2019, it was announced that Jeremy Hughes would be stepping down as Chief Executive of the Alzheimer’s Society, after 10 years in the role. Alzheimer Europe caught up with him to ask about his time with the society, what he is most proud of having achieved there and what the future holds for him.



Jeremy Hughes has been CEO at the Alzheimer’s Society for a decade

You’ve been CEO of the Alzheimer’s Society for 10 years – what initially attracted you to the role?

I had personal experience from my dad having dementia. And I could see the injustice of people not getting the support they needed. Very few people were talking about dementia and I wanted to make that change.

What have you enjoyed the most about the role?

The most rewarding thing is when people who previously have not felt they can make a difference come to realise that they can play a part in making the world a better place for people affected by dementia. And what is inspiring is the wide range of people who get involved. Some are researchers who discover they can have a career seeking out treatments for dementia or exploring how technology can improve care and support. Some are people living with dementia who, whilst facing the daily challenges of living with the disease, find a new voice to share their lived experience and that of their family

caregivers. But involvement in Alzheimer’s Society’s ‘dementia movement’ goes much wider. It includes everyone from business leaders to faith groups, from those providing sport and leisure facilities to those trying to make hospital stays more supportive for people with dementia.

What will you look back on as your greatest achievement during your time with the Society?

There is so much Alzheimer’s Society does that it’s hard to pick out one thing! But if forced to, I’d say this has to be Alzheimer’s Society’s Dementia Friends programme. This is changing the way the UK – and the world – thinks, acts and talks about dementia. Today over three million people in the UK have become Dementia Friends through attending a 45 minute awareness raising programme run by one of our amazing volunteer ‘Dementia Friends Champions’ or by taking part online. Up to 1,000 people become Dementia Friends every day. And every person is asked to make a commitment to action, playing their part to improve the lives of people affected by dementia. Our research shows that this is making a difference.

People with dementia are starting to feel better supported by the community around them. Family caregivers are feeling less isolated and alone and so become better able to cope. As well as the individual Dementia Friends, we also have over 400 villages, towns and cities across the country committed to becoming ‘dementia friendly communities’. I am pleased to say that we have also

inspired and supported over fifty countries all around the world to develop Dementia Friends initiatives.

What do you see as the biggest challenge for your successor?

Two things stand out. First is the need to raise more funds. We need to invest more in research from the charity as well as getting the Government to contribute more to our world leading Dementia Research Institute and other research centres – our Centres of Excellence – which are powering research breakthroughs to find a cure and improve care. Alzheimer’s Society is also committed to offering direct support to everyone diagnosed with dementia, and that will be over one million people across the UK in a few years’ time. So we need to raise more money: more people giving a regular gift of just a few pounds every month, and thousands more joining our Memory Walks and other fund-raising events during the year.

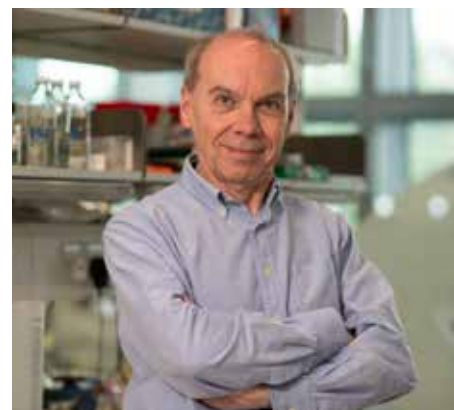
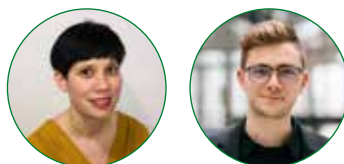
The second is to get far better support for people affected by dementia from our health and social care services. Our social care system is in a shocking state, on the brink of collapse. We still have most people struggling to pay for their dementia care with no state support – if they can access it at all, that is. It is not paid for by the National Health Service. This is outrageous. Why are people with dementia forced to spend hundreds of thousands on care that would have been free if they’d developed another condition like cancer? We also need to gear up our health service to use the research evidence to tell people how they can reduce their risk of developing dementia or slow down its progression. And we need to ensure the NHS is ready for the disease-modifying drugs that I am confident we will have for at least some people with dementia in the next few years.

What does the future hold for you?

Whilst stepping down from the CEO of Alzheimer’s Society after ten years, I won’t be stopping my commitment to make the world a better place for people affected by dementia. I look forward to continuing to play my part on the World Dementia Council and also supporting the work of Alzheimer’s Society and our sister organisations across Europe and around the world.

Tau, tangles and dementia: a conversation with Michel Goedert

After winning the 2019 Royal Medal for Biological Sciences, Michel Goedert spoke to Angela Bradshaw and Christophe Bintener of Alzheimer Europe about his research.



Michel Goedert

“It’s hard to describe the feeling of excitement when you discover something new; when you are the only person in the world who has a new piece of knowledge. As a scientist, these are the moments that one works towards.”

As a past winner of the Potamkin Prize, European Grand Prix for Research and Lundbeck Foundation Brain Prize, Professor Michel Goedert is no stranger to the art of scientific discovery. Over the last four decades, his ground-breaking work on the form and function of Tau has greatly improved our understanding of Alzheimer’s disease (AD) and other dementias.

From Luxembourg to Cambridge

Michel Goedert’s path to scientific acclaim started in Luxembourg, where he was born in 1954. While at secondary school he took part in several contests for budding scientists, winning the 5th European Contest for Young Scientists and Inventors in 1973 for work on crown galls, tumours on flowering plants such as apple and eucalyptus trees. This work formed the basis for Michel’s first publication, which appeared in 1973 in the “Annales de Microbiologie” of the Institut Pasteur. The same year, after completing his high school diploma at the Lycée Athénée, he left Luxembourg to attend medical school in Basel, Switzerland. Having travelled east to attend medical school, he then returned westwards, to study for a PhD at the University of Cambridge in the UK. It was at the end of his doctoral studies that he found himself at a crossroads in his career; “At one point, I felt I had to decide whether I wanted to practice medicine – or do research,” he says, in fluent English that hints at his Luxembourgish

origins. “I decided on the research path, but I have always felt that studying medicine was hugely beneficial: it has given me a much broader outlook on research.”

Michel Goedert completed his PhD in 1984, the same year that amyloid beta was identified as the main component of amyloid plaques. However, the molecular constituents of neurofibrillary tangles remained a mystery. These tangles were first described by Michael Kidd in 1963, when he observed “dense bundles of fibrils, coiled into ‘squash racket’ shapes” in brain samples from people with AD.

Tangled Tau – early discoveries

Casting his mind back to the early days of his career at the Medical Research Council Laboratory of Molecular Biology (MRC LMB) in Cambridge, Michel Goedert recalls his discovery of Tau in neurofibrillary tangles, from the brains of individuals with AD. For him, this discovery in 1988 was a “eureka” moment, paving the way for further scientific advances on the genetics of Tau. “Our work led to the identification and sequencing of the 6 different forms of Tau that are expressed in the human brain”, he explains, “although it wasn’t until 1998 that we understood the significance of Tau in AD, dementia and other neurodegenerative diseases.”

In June 1998, Michel Goedert and others showed that mutations in the Tau gene were

associated with familial forms of frontotemporal dementia. “Although familial cases of frontotemporal dementia are rare, the fact that each was characterised by Tau aggregation told us that this phenomenon was important and closely related to the origin of disease” he says. “Together with our earlier work, this proved that Tau dysfunction causes neurodegeneration and dementia.”

However, Tau is not the only protein string to his scientific bow. As well as neurofibrillary tangles, Michel Goedert and his research group were also investigating Lewy bodies, spherical masses found within the neurons of people with Parkinson’s disease and Lewy body dementia (LBD). In 1997, causative mutations in the alpha-synuclein gene were identified in people with familial Parkinson’s disease (PD). Shortly thereafter, Michel Goedert’s group discovered that Lewy bodies in PD and LBD were composed of aggregated alpha-synuclein proteins. Together, these observations had a significant impact on the PD field – but also had broader implications, as he explains; “The discovery that mutations in the tau and alpha-synuclein genes cause rare cases of inherited disease with abundant filamentous inclusions made of either tau or alpha-synuclein showed that the formation of similar inclusions is probably central to the more common sporadic forms of these and other diseases, including Alzheimer’s and Parkinson’s.”

From Tau to tauopathies: structural determinants of disease

Although Michel Goedert's work had clearly identified Tau aggregation as a pathological hallmark of dementia, many outstanding questions remained. In particular, the structure of Tau proteins in neurofibrillary tangles had yet to be elucidated. In healthy individuals, Tau is a fairly simple, unstructured protein that supports microtubules, molecular tracks that transport cargo inside neurons. However, in AD and other "tauopathies" that cause dementia, Tau adopts a tortuous, disorganised structure that destabilises microtubules – sending cellular cargo off-track and inducing neuronal dysfunction. By determining the structure of Tau in neurofibrillary tangles, could we understand more about how this tangling arises and, perhaps, prevent it from happening?

To address this question, Michel Goedert, in collaboration with Sjors Scheres at the MRC LMB, turned to electron cryo-microscopy, which allows scientists to see the structures of filamentous aggregates. Using this Nobel prize-winning technique, they collected over 2,000 high-magnification images of Tau from brain samples donated by a person with AD. These images, published in *Nature* in 2017, revealed that tangled Tau filaments have an unexpectedly high level of structural complexity, resembling stacks of opposite-facing C shapes. Electron microscopy studies on samples from a further 17 people with AD showed strikingly similar Tau filament structures, indicating the existence of a common Tau fold in AD.

Two further papers, published in *Nature* in 2018 and 2019, elucidated the structures of Tau filaments in Pick's disease and chronic traumatic encephalopathy; more recently, the team also elucidated the structures of Tau filaments in corticobasal degeneration. Each of these diseases is associated with cognitive impairment. Astonishingly, these studies showed that Tau filaments adopt specific structures that are unique to each disease. In other words, the conformation of Tau within filaments is a distinct and defining feature that distinguishes these tauopathies from other conditions – and from each other.

This discovery could have important implications for people living with dementia, and the clinicians trying to diagnose and treat them: for starters, it unlocks the potential to design disease-specific PET tracers, which are crucial for early diagnosis and timely therapeutic intervention.

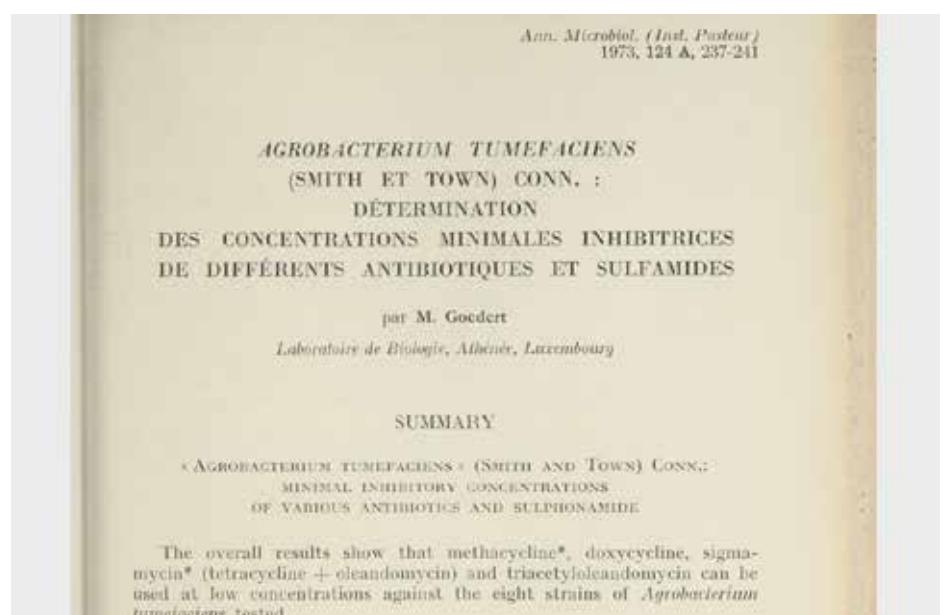
So, what are the remaining mysteries around Tau that still intrigue Michel Goedert? "Well, tauopathies are human diseases and at the end of the day, one has to be able to use scientific knowledge to intervene therapeutically or diagnostically. Unfortunately, that hasn't happened yet," he says. "So, we probably need to better understand the mechanisms of disease, in order to better intervene in the disease process."

However, he cautions against the concept of 'curing' dementia, particularly in symptomatic cases of disease. "For me, the future lies more with prevention of diseases that cause dementia," Michel says, "And to achieve this, we need better diagnostic methods to identify people with these diseases – as well as a preventative treatment." These could include combination therapies, that target multiple systems: "Reducing amyloid, Tau and neuroinflammation could whittle the disease down, such that there are fewer cases and it becomes more manageable."

Looking back – reflections on academia

Between 2003 and 2016, as well as leading his own research group, Michel Goedert was the Head of the Division of Neurobiology at the MRC LMB in Cambridge. Since 2014, he has also been an Honorary Professor of Experimental Molecular Neurology at Cambridge University. During this time, he has supported many scientists who have also gone on to make substantial contributions to the dementia field. Benjamin Falcon, who worked on the structural studies of Tau, has recently started his own research group at the MRC LMB. "Michel has been a fantastic Mentor and the depth of knowledge and experience he brought to my PhD studies was invaluable," Ben says. "His advice has really helped me formulate my own research goals and direction."

What final words and advice does Michel Goedert have for those wishing to pursue a research career in academia? "Being an academic can be quite a lonely thing: in reality, research is not that glamorous and if you don't like doing what you do, it can be very painful," he reflects. "So, you need the drive and resilience to keep going. At the end of the day, one needs to believe in what one is doing – and just continue doing it."



Michel Goedert's 1973 article in *Annales de Microbiologie*, published when he was 18 and a student at the Lycée Athénée in Luxembourg

Behind the headlines: Making sense of new aducanumab trial data

In December 2019, Biogen presented topline results from its Phase III clinical trials of aducanumab, at the 12th Clinical Trials in Alzheimer's Disease (CTAD) conference. These results are a turnaround from earlier analyses, which had led to the company pulling the plug on both trials. Angela Bradshaw of Alzheimer Europe takes a closer look at what happened and asks three external experts in the field to comment.



On 22 October 2019, Biogen's announcement of its plans to seek regulatory approval for aducanumab was heralded by many as a turning point for the Alzheimer's disease (AD) community. The reasons for this were twofold: first and foremost, aducanumab – if approved – would be the first disease-modifying AD therapy to reach the clinic. Of the more than 20 disease-modifying therapies that have been tested in large phase III clinical trials so far, aducanumab would be the only drug to make it through the pipeline to regulatory submission. In addition, since aducanumab functions by clearing aggregated amyloid- β proteins in the brain, Biogen's announcement represents for some the long-awaited validation of the "amyloid hypothesis", which states that accumulation of amyloid- β is the primary cause of AD.

March 2019: Biogen pulls the plug on aducanumab

However, 7 months earlier the headlines on aducanumab were far less positive. On 21 March 2019, Biogen (with its Japanese partner, Eisai) announced its decision to discontinue EMERGE and ENGAGE, the global phase III trials designed to evaluate the safety and efficacy of aducanumab in participants in the early stages of AD. Biogen's decision to halt these clinical trials was based on the results of a futility analysis conducted by an independent data monitoring committee. Futility

analyses are pre-planned when setting up a clinical trial and are carried out by performing statistical tests on interim clinical trial datasets, to predict whether a trial is likely to achieve its primary endpoints. The futility analyses suggested that neither EMERGE nor ENGAGE would meet its primary endpoints upon completion – hence Biogen's decision to halt these studies.

October 2019: Aducanumab is resurrected

So, what prompted the sudden turnaround between March and October 2019? Well, it all comes down to numbers. The futility analysis was based on data from 1,748 participants who had completed an 18-month study period by December 26, 2018. Post-hoc analyses from the futility tests were "trending positive" for EMERGE – but not for ENGAGE, hence the decision to pull the plug on both clinical trials.

However, the picture changed when Biogen obtained additional data from an extra 318 participants who remained on trial between December 2018 and March 2019. Now, there was a clear association of high-dose aducanumab treatment with reduced cognitive decline in EMERGE participants, as measured by CDR-SB score (Clinical Dementia Rating – Sum of Boxes) and other cognitive function tests. The ENGAGE results remained negative, although in their October press release Biogen stated that the results of ENGAGE were

consistent with EMERGE in a small subset of participants exposed to the highest dose of aducanumab. In other words, they believe that treatment with a high dose of aducanumab, for a sufficiently extended period of time, will reduce cognitive decline in early AD.

Armed with the results of this newly-positive analysis, Biogen shared its clinical trial data with officials at the US Food and Drug Administration (FDA) during two face-to-face meetings held in June and October 2019. After the second meeting, the FDA told Biogen that it was "reasonable" to file for aducanumab approval – leading to the 22 October announcement that could be a game-changer for the AD drug development field.

This announcement was met with widespread excitement and enthusiasm, as it could lead to the approval of the first new treatment for AD in over 15 years. At the same time, some voices urged caution, arguing that the EMERGE and ENGAGE data were far from clear-cut. In the ENGAGE trial, why were some cognitive scores showing signs of improvement following aducanumab treatment, when others showed a slight worsening? Was the small, 0.4-point improvement on the CDR-SB test scale actually meaningful in terms of cognitive function? Could the statistical acrobatics required to perform this unconventional analysis of trial data have introduced sources of bias?

December 2019: It's all in the numbers

Fast forward to 5 December 2019, and the 12th annual Clinical Trials in Alzheimer's Disease (CTAD) Conference in San Diego. All eyes were peeled on the plenary room, where Samantha Budd Haeberlein (Biogen's Head of Late Stage Clinical Development) was presenting the complete set of top-line results from EMERGE and ENGAGE. In her presentation, Budd Haeberlein spent a long time describing the dosing regimen for the two trials, particularly highlighting a protocol amendment ("Pv4") that was enacted in March 2017. When Pv4 was instituted, ENGAGE (the negative trial) had already enrolled almost 49% of its participants. However, EMERGE (the positive trial) was lagging behind, with only 37% enrolment. The Pv4 amendment increased the target dose for ApoE4 carriers to 10mg of aducanumab per kilogram of



Biogen's Samantha Budd Haeberlein presents aducanumab results at CTAD 2019

“From the standpoint of a regulatory authority, responsible for spending the taxpayer's money effectively, it will be important to minimise any uncertainties about efficacy.”

Lutz Frölich

weight (10mg/kg), rather than the previous maximum dose of 6mg/kg. A small numerical difference, perhaps – but one with a big impact on the cumulative exposure to aducanumab.

Pre-Pv4, the median cumulative dose of aducanumab was 116mg/kg over 78 weeks on trial. Post-Pv4, the median cumulative dose of aducanumab rose to 153mg/kg. Due to the timing of the change to Pv4, Budd Haeberlein explained, a greater number of participants in EMERGE benefited from high-dose aducanumab for the full 78 weeks. This difference, she argued, was one of the main reasons why EMERGE showed a beneficial effect of aducanumab, but ENGAGE did not. In other words, ENGAGE failed because fewer of its participants received the most effective dose.

To support this claim, Budd Haeberlein focused on the cognitive test scores of a small group of participants from the failed ENGAGE trial who were enrolled after the Pv4

amendment, and therefore received the highest dose of aducanumab for 78 weeks. These results showed a similar reduction in cognitive decline compared to the high-dose arm of the EMERGE trial. A further positive signal came from the PET imaging results: in both studies, even low doses of aducanumab led to the clearance of amyloid plaques. There was also an effect on biomarkers for neurodegeneration, such as CSF phospho-Tau, suggesting that removing amyloid may have downstream effects on other key proteins involved in neurodegeneration.

Aducanumab in the court of public opinion

Based on these results – and perhaps as an effort to win over sceptics at the FDA – Biogen is now planning a follow-up study to allow anyone in previous aducanumab trials access to the medication. On an optimistic note, the financial markets responded positively to the CTAD data: Biogen's share price rose by 3% during Budd Haeberlein's presentation, indicating that investors are hopeful about the prospects of aducanumab

being approved. However, press opinion was much more nuanced. Time magazine's article on aducanumab was entitled “Biogen explains how its Alzheimer's drug went from poor to promising”, while the headline for Derek Lowe's damning commentary piece in Science Translational Medicine was, simply, “They Don't Know”.

Jason Karlawish took a different view in his STAT news piece, arguing that “as long as the benefits are judged to outweigh the risks, aducanumab won't just treat individuals with AD. It will treat our Alzheimer's culture”. His point references the stigma that surrounds AD: “A drug that targets a pathology targets stigma. It offers some explanation for what's wrong, the hope of treatment, and a means to rethink and even rename a disease.” In short, while aducanumab may not be the long-awaited silver bullet that will cure or prevent AD, the very existence of a disease-modifying treatment might fundamentally change society's view of this stigmatising condition.

“There is no way we can predict what the FDA will do with these results. Will they require a new trial; will they approve the drug under specific conditions? What we can say is that if aducanumab is approved it will be the very first disease-modifying drug for AD.”

Philip Scheltens

So, how convincing was Biogen's presentation at the CTAD conference? Did they persuasively show that aducanumab is, in fact, an effective disease-modifying treatment for AD, worthy of approval by the FDA? To find out more, we approached three clinical experts in the AD field.

Lutz Frölich, Head of the Department for Geriatric Psychiatry at the Central Institute of Mental Health, Mannheim

The presentation of the data at CTAD has convinced me as a clinician and a researcher that the drug works as intended. In other words, it slows down the progression of disease with relevant effects on clinical symptoms at an acceptable risk. That the data from both identically-designed clinical trials were not similarly positive, however, could be explained in a plausible way. It is still a matter of debate whether this is enough to convince authorities responsible for registering drugs. Formally speaking, we have results from two interrupted clinical trials, where several methodological shortcomings might have skewed the results.

At the very least, however, we can agree that the drug is safe enough, if prescribed to the right patients in the way which has been outlined in the two trials. From the standpoint of a regulatory authority, responsible for spending the taxpayer's money effectively, it will be important to minimise any

“What these data tell me is that we now need a trial examining the efficacy and safety of the high dose (that appeared to hint at efficacy) versus placebo.”

Rob Howard

uncertainties about efficacy. From my standpoint as a physician, however, who wants the best for his patients but has few drugs to offer, the balance between uncertainties and potential benefit shifts to wanting to prescribe this drug right now. The AD community will have to see how to reconcile this in the most appropriate way.

Rob Howard, Professor of Old Age Psychiatry at University College London

Results released from the EMERGE and ENGAGE trials do not convincingly establish that aducanumab has efficacy in the slowing of AD progression and I would not expect the FDA to give approval at this stage. What these data tell me is that we now need a trial examining the efficacy and safety of the high dose (that appeared to hint at efficacy) versus placebo. Ideally, this should be conducted with 2 years of follow-up, to maximise the chances of detecting disease modification and to evaluate the medium-term safety of

aducanumab. The FDA and European Medicines Authority will need this information to make an informed decision about whether or not to approve the drug.

Philip Scheltens, Professor of Cognitive Neurology and Director of the Amsterdam Alzheimer Center

Firstly, I would say that the timing of the futility analysis was very unfortunate, as it happened shortly after the implementation of Pv4. This has resulted in one positive trial and one negative trial. There is no way we can predict what the FDA will do with these results. Will they require a new trial; will they approve the drug under specific conditions? What we can say is that if aducanumab is approved it will be the very first disease-modifying drug for AD and that it will have a profound impact on healthcare systems in terms of costs of drug, costs of infusions and MRI monitoring.

We have already seen that the October announcement from Biogen invigorated the AD research community and a general sense of optimism and energy was apparent also at the CTAD conference. My personal view is that we need to prepare for a future with aducanumab (and hopefully many other drugs) available to treat our patients, and that we should now start discussing the healthcare consequences of these drugs with our respective governments.



Packed auditorium during Biogen's presentation of Aducanumab trial results at CTAD 2019

Living with young-onset dementia in Sweden

Stefan Eriksson, member of the European Working Group of People with Dementia (EWGPWD), lives in Floda, in the west of Sweden. He was diagnosed with dementia at 51. Stefan, Karin and their daughter Janni (who accompanies Stefan to EWGPWD meetings) share how the diagnosis affected the family and how they are learning to live as well as possible with dementia.

The diagnosis changed the lives of the Ahlgren-Eriksson family overnight. But with the support of their daughter Janni and their two sons, Karin and Stefan created a new life for themselves built from strong bonds of love and a commitment to improving the lives of others in the same situation.

"It makes no difference if I swear, cry or get angry. I may as well make the best of the situation and try to be there as much as I can for Mum and Dad. I have learned to be both sad and uplifting," says Janni Ahlgren, 27, of the two years since her father Stefan Eriksson, 53, was diagnosed with Alzheimer's. They had, of course, already began to notice that Stefan would forget where he'd left his keys at their terraced house in Floda, in the

“I won't die with my sickness, I will live with it.”

Stefan Eriksson

west of Sweden. Colleagues commented that he seemed to have difficulties focusing, and Noah found it embarrassing that his dad was so "ditzzy" that he couldn't remember the names of friends from his hockey team, despite Stefan being so involved in training and matches. Stefan was also very busy at work at that time.

"Sometime he'd go to work in the middle of the night to find time for everything that he had to do. I thought that he was run-down



Karin and Stefan

from overwork, and I nagged him to make a doctor's appointment," recalls Karin Ahlgren, 52. Eventually, her husband went to the doctor, and soon after, the news arrived that changed their lives forever.

The diagnosis

"Stefan was examined in summer 2017, and in September we got the news that he had Alzheimer's disease. The emotional impact was terrible, and at the same time Stefan had to quit his job and he lost his driving license. None of his insurance policies were applicable in his situation, so in practice we lost his income. It was several body-blows all in one go," says Karin, who also lost her beloved father around the same time.

Most people diagnosed with Alzheimer's disease are over 65, but the number of younger people being diagnosed is increasing. In Stefan's case, there were no known risk factors.

"Stefan has always been very physically active. He ate healthily, didn't smoke and there are no hereditary indicators. He was just a picture of health," says Karin.

“A lot of people think everything is doom and gloom, but our relationship has never been stronger.”

Karin Ahlgren



Janni and Stefan

A positive approach

In the middle of the chaos there was still comfort, and a determination to stay as close as possible.

“When the world fell apart for us, Janni had a completely different way of thinking. She has always been positive and has become our rock. Many friends, neighbours and relatives have disappeared out of our lives, because they didn’t know how to deal with Stefan’s illness, but Janni has always helped us to see the possibilities.”

Stefan has always had many hobbies and commits himself to everything he does. Now he has found new interests on his doorstep.

“I grow vegetables in pallets in our garden – tomatoes, potatoes, onions...it has been a good summer for gardening. I have always exercised a lot – cycled and lifted weights – and I have continued with those,” he says with a broad smile.

Some challenges

While day-to-day life has begun to take a new shape for Stefan, Karin, Janni, and her brothers Kim, 28, and Noah, 17, several challenges remain.

“In our municipality, there aren’t any day-centres near here that properly provide for younger people with Alzheimer’s. There are a lot of people in Dad’s situation but the only activity that he has been invited to, is solving crosswords. It really isn’t the kind of

intellectual stimulus that will prevent his brain from deteriorating,” says Janni.

Karin and Janni also talk about carers who appear to lack knowledge of cognitive illnesses, of bad experiences in short-term accommodation, and of doctors who want to help, but don’t seem to have the answers to their many questions.

Stefan, Karin and Janni have chosen to take these negative experiences in their stride. That has meant involving themselves with the Swedish Alzheimer’s society (Alzheimer Sverige), writing to politicians, and finding other ways to raise questions about quality of life for people with cognitive disabilities and their relatives. Their commitment began with an unexpected meeting.

Support from Alzheimer Sverige

“We got a tip about a lecture at Alzheimer Sverige, and we were greeted there by the chairman, Krister Westerlund. ‘Welcome youngsters!’ he said, and he pulled out a basket full of cakes. It was the first time we met someone who was acting positively in our new situation, and it meant a huge amount to us,” says Karin who has fought hard to balance her full-time work as an after-school

“It makes no difference if I swear, cry or get angry. I may as well make the best of the situation and try to be there as much as I can for Mum and Dad. I have learned to be both sad and uplifting.”

Janni Ahlgren

teacher with taking care of their home, and managing Stefan’s health and wellbeing.

Even while Janni, Karin and Stefan were telling us about the tough challenges they face, they often shared smiles, and touched and hugged each other. Love and warmth give this family a rare strength.

“A lot of people think everything is doom and gloom, but our relationship has never been stronger. No matter what, I am Stefan’s princess. All we need to be happy today is a pot of coffee that we can take down to the pier by the water,” concludes Karin.

“I won’t die with my sickness, I will live with it” – Stefan Eriksson

“In our municipality there aren’t any day-centres near here that properly provide for younger people with Alzheimer’s. There are a lot of people in Dad’s situation but the only activity that he has been invited to, is solving crosswords.”

Janni Ahlgren

Karin Ahlgren’s advice for relatives of younger people with Alzheimer’s:

- Try to find a connection to others in the same situation, even if they’re a little older. It’s very valuable to meet other people who know exactly what you’re going through.
- Set boundaries when required.
- It’s easy for someone with Alzheimer’s to lose their self-confidence. Take one day at a time and try to find alternative solutions.
- Be accepting and open about your new situation. Find ways to live with the illness, not die with it.
- It isn’t advice, but I want to thank our wonderful friends Anki and Krille. They have been there the whole time and treat Stefan exactly the same as they did before his diagnosis.

Acknowledgements

Alzheimer Europe is grateful to Alzheimer Sverige for translating this article from the original Swedish and for allowing us to publish it in our magazine.

A human rights-based approach to dementia in Ireland

On 8 November 2019, Trinity College Dublin held a symposium on “Dementia and Human Rights”. Helen Rochford-Brennan, who was a speaker at the event, has written this report. Pat McLoughlin (CEO, The Alzheimer Society of Ireland) also comments on progress made in the area of human rights and dementia in Ireland.



A one-day symposium on the topic of Dementia and Human Rights took place in Trinity College Dublin, on 8 November 2019, and was attended by a large multi-disciplinary audience of doctors, nurses, architects, solicitors, social workers, occupational therapists, psychologists, health care assistants and others. Like in other European countries, dementia continues to be highly medicalised in Ireland and for the first time, this symposium brought together international and national experts to interrogate dementia from a human rights, disability and ethics perspective.

The keynote address was given by Steven R. Sabat, Professor Emeritus of Psychology at Georgetown University, Washington, who talked about dementia as a disability and the importance of seeing the person rather than the pathology. He said: “Although a diagnosis of dementia entails some specific and significant dysfunctions in certain cognitive abilities, it is just as clear that people diagnosed with dementia are like ourselves in all the ways that really matter.” Professor

Sabat reminded the audience that people diagnosed with dementia share numerous valued attributes in common with people not diagnosed and they can teach us a lot about our shared humanity.

Prof. Sabat’s thought-provoking address was followed by an equally powerful presentation made by Dr Helen Rochford-Brennan, former Chairperson of the Irish Dementia Working Group and current Chairperson of the European Working Group of People with Dementia (EWGPWD). She began her speech by quoting the words of Terry Pratchett, “So much universe, so little time”, which resonate with her. She also thanked Professor Suzanne Cahill for the invitation to participate at the symposium and Trinity College, where she started her journey into research. She raised issues that are important to all people with dementia in Ireland, from the time of diagnosis, when people are often denied their human rights. They are not always respected, or informed, or treated with dignity and very often they have to navigate

complex systems with little support. Dr Helen Rochford-Brennan is passionate about people with dementia being involved in all aspects of the disease from diagnosis to dying, and she appealed to researchers committed to public and patient involvement (PPI) principles, to be fully inclusive of people living with dementia. She said: “the lived experience is very ‘trendy’ at the moment; everyone wants a person living with dementia on their project or panel, but engagement is only meaningful if the decision-making power is shared”.

In her appeal for dignity enhancing care and greater government investment in home care services, she stressed the importance of her social health and her right to live at home in her community of Tubbercurry, she commented: “the State thinks it’s okay for me to have a right to live in a nursing home but not to have a right to live in my own home”.

There are 55,000 people living with dementia in Ireland. About 4,000 of these people have young onset dementia, a rare form of dementia sometimes known as “working life dementia” since it occurs in younger people many of whom are still working and have young dependent children as well as financial commitments including mortgages. Governmental support is required for this group of people hugely overlooked in Irish society.

Why a human rights approach?

On the topic of human rights and dementia, symposium organiser, Professor Suzanne Cahill said:

“The theme of this symposium has been chosen carefully, as conventionally, dementia is seen as a syndrome caused by a disease and not as a disability or a disability/human rights issue. While the disease framing makes us think about plaques and tangles, brain scans, drugs and passivity, the human rights framework is based on dignity, autonomy, citizenship, participation and personhood. It requires governments to treat all people fairly, never to discriminate and the goal is to promote human flourishing and a good quality of life”. She went on to say that the human rights approach is not exclusive: “it builds on medicine, nursing, disability, economics, social work, law, engineering, architecture and so on.”



Jacinta Dixon, Tina Leonard, Prof Steven Sabat, Helen Rochford-Brennan, Dr Suzanne Cahill

Personhood principles in dementia care

The morning session included a highly engaging presentation given by Health Economist, Professor Eamon O'Shea, the author of Ireland's first Action Plan on Dementia (1999) and an expert who has played a very significant role in influencing Irish aged care and dementia care policy over the last three decades. Prof. O'Shea discussed the complexities involved in operationalizing personhood principles in dementia care and the importance of respecting the individual's rights to autonomy and to citizenship, at all times, including their right to live at home or in a place of their choice: "we should never underestimate the importance of home". The morning session ended with a very insightful and practical hands-on presentation delivered by a well-known Irish solicitor, John Costello who competently brought the audience up to speed on the intricacies of the Assisted Decision-Making Capacity Act (2015) still not fully implemented in Ireland.

Policy-making and government funding

During the afternoon, the focus of the symposium shifted to policy-making, the UN Convention on the Rights of Persons with Disabilities and their relevance to people living with dementia and to other thought-provoking topics including advanced care planning.

Senator Colette Kelleher started the afternoon by drawing on the work of C. Wright Mills and, in the context of dementia, suggesting that all personal troubles are public issues that need careful political attention. She reminded the multi-disciplinary audience of the type of juggling that often occurs within government circles when scarce resources are in demand. Although she argued that some recent progress has been made in Ireland, in terms of ring-fenced funding being allocated by the Department of Health to extend The Alzheimer Society of Ireland Dementia Advisor services, she also stressed that a lot more is needed.

Panel discusses autonomy, personhood and the value of the social model of disability

The final session in this symposium and perhaps one of the most memorable and entertaining was a panel discussion which brought together some key stakeholders in the field of dementia policy and practice in

Ireland namely the CEO of The Alzheimer Society of Ireland, Pat Mc Loughlin; the CEO of Nursing Homes Ireland, Tadhg Daly; the Chairperson of Ireland's National Dementia Strategy Monitoring Group, Susan Scally; a well-known independent researcher, Dr Maria Pierce, who is also a family caregiver; and Neil Murphy from the National Disability Authority in Ireland, alongside Professor Steve Sabat. A carefully-selected Chairperson, well-known in Irish circles, Professor Des O'Neil (Geriatrician and author) came to the fore, posing several expected along with other unexpected questions to the diverse panel, who were kept on their toes. Topics explored included: panellists' views of their own mortality, the meaning of autonomy and decision-making in the context of dementia, the importance of preserving personhood with advanced dementia and the value of the social model of disability for people living with the condition. The symposium was very positively evaluated with requests for more events of this genre to take place in Ireland.

“Conventionally, dementia is seen as a syndrome caused by a disease and not as a disability or a disability/human rights issue. While the disease framing makes us think about plaques and tangles, brain scans, drugs and passivity, the human rights framework is based on dignity, autonomy, citizenship, participation and personhood.”

Suzanne Cahill

Pat McLoughlin, CEO, The Alzheimer Society of Ireland.



"In The Alzheimer Society of Ireland's Charter of Rights we make it clear that people with dementia have the same human rights as every other citizen. In April 2016,

The ASI and our Irish Dementia Working Group published a Charter highlighting the rights of people with dementia, which calls for greater participation, accountability, non-discrimination (equality),

empowerment and legal recognition for the rights of people with dementia. These principles are based on internationally agreed human rights.

"The Charter is a tool for those who support people with dementia, policy makers and service providers. For example, here at The ASI we are currently evaluating our 50 day care services across 23 counties operating from one to five days a week. This evaluation is guided by a human rights-based approach and The ASI's Charter of Rights, which sets out the rights of people with dementia, is reflected in our evaluation of day care services. This evaluation, guided by the Charter, seeks

to understand day care from the perspectives of people with dementia and carers with strong emphasis on the voice and the lived experiences of people.

"There has been a shift in the last 15 years, not only in Ireland but also internationally, from a paternalistic treatment-focused approach to one informed by a human rights perspective. The ASI is committed to the Charter in our service development. We should use a rights-based approach to make sure that people who will be affected by decisions around policy, strategy, services, support or legislation have the opportunity to be involved from the beginning."

Deaf sign language users with dementia: challenges in accessing healthcare and support

In this article, Emma Ferguson-Coleman (University of Manchester) and Avril Hepner (BDA Scotland) discuss the challenges of a small cultural and linguistic minority group of Deaf people who use British Sign Language (BSL) in the UK in reaching a diagnosis of dementia and subsequent support for Deaf people and their families.



There are approximately 87,000 BSL users resident in the UK and within this group, there are an estimated 450–850 Deaf BSL users who are living with dementia, either in the community with their families or within residential care.

Dr Emma Ferguson-Coleman, a Deaf research associate within the Social Research with Deaf People (SORD) group at the University of Manchester, was one of the plenary presenters at the 29th Alzheimer Europe Conference in The Hague. In her presentation on “Navigating everyday challenges of life-story work with Deaf sign language users with dementia” she drew attention to the fact that Deaf British Sign Language (BSL) users consistently experience unequal access to health and social care provision, because their language and communication needs are inadequately met and their cultural identity is not recognised by the mainstream.

Avril Hepner is a Deaf British Sign Language (BSL) user with a passion for BSL. She is the Community Development Manager for the British Deaf Association (BDA) Scotland, where she has worked for 15 years. She manages a dementia-related project in Scotland for the BDA. She has a great personal interest in developing appropriate support packages for Deaf carers after a diagnosis of dementia for their Deaf family members. Having cared for her late father, who was Deaf and lived

with dementia, she had to fight for an appropriate assessment and conclusive diagnosis for her father after he developed Alzheimer’s disease.

Who are Deaf sign language users and what are the challenges when living with dementia? Emma Ferguson-Coleman tells us

Deaf people belong to a visual community, where they share stories with one another to confirm their lifelong identities and reaffirm their wellbeing. They share the same cultural histories that are different from the mainstream population (such as attending Deaf boarding schools from a young age, attending Deaf clubs in each residential town, accessing Deaf sports clubs and tournaments and so on). This shared cultural history is not always known about or understood by the mainstream, which often impacts on the opportunity to be valued as a Deaf citizen.

As signed languages are not fully integrated within healthcare provision, for example, in the UK, BSL/English interpreters are not always booked for appointments with clinicians, or information disseminated about dementia is not always provided in BSL. This means that access to information about dementia is extremely limited, which then has an impact on opportunities to discuss this condition with healthcare professionals and families whenever any concerns may arise.

The majority of support services and care homes in the UK for people with dementia are designed for the needs of the hearing population, which can mean that Deaf people living with dementia may decline very quickly in such environments, because of a lack of communication and stimulation in their own language.

Research has been carried out with older Deaf people about their preferred options for residential care. A project conducted in 2011 called ‘Older people who use BSL: Preferences for residential care provision in Wales’, it was found that the maintenance of cultural and social networks of BSL users is a primary preventative measure in supporting older Deaf people’s health and wellbeing; there were fears that moving into a residential care facility (with hearing people) would mean a loss of contact with Deaf cultural and social networks. The concern was not about the loss of communication opportunities in BSL, but the loss of a sense of belonging; and that the loss of BSL as a part of everyday life and the loss of contact with life-long friends who were BSL users was considered to be language deprivation.

At present, there are two residential homes in the UK that currently provide support for Deaf people with dementia but places are very limited. In Europe, there is a specialist residential care unit in the Netherlands that offers support to older Deaf people with a separate clinic for those with additional needs (www.degelderhorst.nl).

One research study, the ‘Deaf with Dementia Project’ (funded by Alzheimer’s Society, UK) conducted several research interviews with Deaf people with dementia and their families. The interviews found out that care service providers did not book BSL/English interpreters, which enforced written communication on pen and paper that was not understood by the Deaf carer, as English was their second language (BSL is their first language). One family discussed how their Deaf family member with dementia was referred to a local day centre but they could not access the creative group, as there was no BSL/English interpreter present. The “Neighbourhoods and Dementia” study, funded by ESRC/NIHR, included a work programme developing life story work with



Emma Ferguson-Coleman presents in BSL at the 29th Alzheimer Europe Conference

Deaf people with dementia and their carers. This study found that Deaf carers remain very much in need of culturally appropriate support packages after a diagnosis of dementia for their Deaf family members.

Moving forward – Avril Hepner tells us how BDA Scotland is looking to respond to unmet needs

There are currently no cognitive assessment facilities in Scotland tailored for Deaf people who use BSL; the National Cognitive Disorders clinic for Deaf patients is based in London. Avril had to wait three months for a Deaf psychologist to come up to Scotland to formally diagnose her father. Avril's father was initially assessed through a local Memory Clinic in Glasgow, Scotland, using the usual tests with a BSL/English interpreter present and the family was given an initial diagnosis. However, Avril demanded access to a specifically tailored BSL assessment for her father, as she was not sure that the assessment process had been culturally or linguistically appropriate for his needs:

"Although it looked like my dad was responding to the tests, my suspicion was that he was mirroring or copying what the sign language interpreter was signing, which gave a

false picture as to how well he understood the questions or commands."

Healthcare professionals who carry out cognitive functioning assessments need to be aware that some standard test questions may be difficult for a Deaf person to understand, due to cultural and linguistic differences. It is prudent to ask for advice from BSL/English interpreters and local Deaf organisations, as well as family members/carers, about the best way to phrase questions. For example, rephrasing the question, "Who is the Prime Minister?" to, "Who lives at number 10 Downing Street?" is more

likely to be understood clearly by a Deaf person. This is because Deaf people do not have access to information that is usually absorbed by hearing people via auditory means such as the radio or through overheard conversations, which can have an impact on their everyday knowledge. Another example would be the question, "What season is it today?". Deaf people may not have had access to this word in their formative years so it may be better to pose the question "Is it autumn or summer now?" This does not change the actual question but offers a more accessible format in how it is asked.



Avril Hepner presents at the Join Us for the Deaf Dementia Journey launch of the dementia toolkit, 6 September 2019

Avril also attended many hospital appointments with her father. At times, she had to take on a dual role of firstly being his daughter and carer, but secondly, also ensuring that her father had full access to what was happening for him:

“I was faced with the responsibility of ensuring that BSL/English interpreters were booked. My father was in hospital for the last six weeks of his life. When I visited him I could see other families having real quality time with their loved ones but when I was there, much of my time was taken up in making sure that the appropriate support was in place. Those concerns made me anxious, and my time with my father was overshadowed by this.”

In response to the need for providing accessible support for Deaf people with dementia and their families, the British Deaf Association (BDA) in Scotland recently launched its first ever user-friendly dementia toolkit. It was created by and with Deaf people who care for or have cared for someone with dementia and who use British Sign Language (BSL). This is part of the ‘Transforming the Deaf Dementia Experience’ project, which is currently funded by the Life Changes Trust (2017 to 2020).

Accessible information about dementia and other health conditions for Deaf people should ideally be led by and created by Deaf people, so in developing this toolkit resource, BDA Scotland drew on the expertise of a Stakeholder Group which consisted mainly of Deaf carers. Some of the members contributing were no longer active carers, yet still became very emotional, visibly upset and angry when reflecting upon their own personal experiences. A common thread amongst these carers was the lack of support available to them at that time. We became aware that a more sensitive, measured approach was required to provide support to set up a Deaf Carer’s Support Group for dementia.

The project has met with some challenges, particularly around identifying and arranging to meet Deaf people living with dementia. Those that BDA Scotland did meet reported feeling helpless, and shared the view that very few people within the Deaf community really understand what dementia is or how it can affect Deaf people. Isolation from one’s own community can also result in community



The BDA is grateful to its stakeholder group of carers and professionals who supported the development of the toolkit

members having little opportunity or experience of communicating and interacting positively with Deaf people living with dementia. Avril shares her experience of this isolation:

“Out in the community, Deaf people are not as aware of the signs and symptoms of dementia. It affected my father socially when he attended his local Deaf club, as people were puzzled at the changes in his behaviour.”

As a solution to this challenge, BDA Scotland now delivers BSL dementia-friendly training to Deaf clubs and groups in urban and rural areas, encouraging attendees to explore attitudes towards dementia within the Deaf community. This BSL dementia training is not only delivered to the Deaf community but also to healthcare professionals working in care homes and organisations.

Members of the Deaf community also experience a lack of/limited access to resources in BSL. There is a lack of accessible information on websites with a focus on dementia and on the websites of dementia support groups. To address this, BDA Scotland has created numerous BSL video resources, which can be found at <https://bda.org.uk/dementia/>. These videos include, for example, BSL versions of the bookcase analogy (Alzheimer’s Society, UK) and Brain Fog.


Additionally, BDA Scotland carried out one-to-one interviews with Deaf carers during Carers Week (a national initiative that increases awareness of the needs of carers for people

with health conditions) and posted these videos online via its Facebook page. These have been viewed 37,524 times (at the time of writing, 20 January 2020), which demonstrates the phenomenal impact of accessing information about dementia in BSL. From this impact, BDA Scotland has learned that this format of sharing information is far preferable to directly translated information in BSL, which is not user-friendly and is difficult to engage with. The Deaf Carers Toolkit is available to download at <https://bda.org.uk/dementiatoolkit/>

More information

For more information about Transforming the Deaf Dementia Experience project, contact Avril Hepner at cado.sthscot@bda.org.uk

 @BritishDeafAssociation

 @BDA_Deaf

For more information about research with Deaf people with dementia and their families, contact Dr Emma Ferguson-Coleman at emma.ferguson-coleman@manchester.ac.uk



Dementia in the arts: An interview with celebrated author Nicci Gerrard

Alzheimer Europe speaks to Nicci Gerrard (a.k.a. Nicci French, when writing psychological thrillers such as the Frieda Klein series, together with her husband Sean French) about her new non-fiction book “What Dementia Teaches Us About Love”.

Many people know you as Nicci French, author of psychological thrillers. Your book “What Dementia Teaches Us About Love?” is quite a departure from that style of writing. What prompted you to write this book and how was it to write something so different and so personal?

I was a journalist before I became Nicci French and I have continued writing pieces for the newspaper where I worked about issues that I most care about. So in a way, I've always had this other voice.

Perhaps I wouldn't have written “*What Dementia Teaches Us About Love*” – or “*Words Fail us*” in Dutch – if I hadn't had that other voice. But it grew out of a very personal experience. My father, John Gerrard, had Alzheimer's. He lived, and mostly lived well, with the illness for more than ten years – at home with my mother, who he had been married to for 61 years at the time of his death. He walked by the river, worked in his garden,

watered the tomatoes, fed the birds, built bonfires, and stared for hours at tiny insects or wildflowers. He saw his friends, teased his grandchildren, and told stories about his past, which remained vivid to him. Although he was gradually going towards the darkness and was sometimes scared, sometimes felt ashamed, he was mostly happy. Then he went into hospital with leg ulcers which were slow to heal. He was there for nearly five weeks, and because of strictly enforced visiting hours and an outbreak of norovirus, there were many days when he didn't see his family at all. With no-one to help him eat, drink, walk; no-one to speak to him, read to him, hold his hand, look him in the eye, he catastrophically declined. He went in healthy, mobile, articulate and *living* with dementia. When I collected him, he was immobile (he couldn't walk, or stand on his own two feet, or lift his head from the pillow), inarticulate (he couldn't put a sentence together), skeletal and wrecked. He was no longer living with dementia, but dying with it.

“I learnt so much from all the people who were so honest and generous with their experiences. There were the doctors, the nurses, the scientists, the artists, the philosophers, who have given me new ways of seeing an illness which is everywhere. Above all, there were those men and women living with dementia and their carers.”

His dying took nine months, during which time he lay in a little room downstairs while his family tried to do all the things we hadn't done for him while he was in hospital. It was too late. We were too late. When he eventually left us it was both a sorrow and a blessing. And yet my father was gone and yet he was there, he was absent and yet present, he had lost everything and yet in some strange way he retained his self, this essence that made him John Gerrard. After he died, I knew that there was a book I could write, a book about the meaning and the cost of dementia, and about what it teaches us about ourselves, about what we value and about being human. But I didn't know whether I would write it. My

“We need to share stories more, talk more openly about it. So I feel privileged to be part of this new conversation.”



Nicci and her father John

father was a very private man and I had no desire to write a memoir. Instead, I set up a campaign that fights for more compassionate care for those with dementia when they go into hospital. It was my way of trying to atone, I guess, for what had happened to him. I was trying to rescue him, though of course he was beyond rescue.

And it was during those years of campaigning, when I was spending so much of my time talking about dementia, reading about it, spending time with people who live with it and with their carers, that I knew I had to write a book – after all, that’s what I do, I write about what I don’t understand, what I want to explore. And I knew that my book had to be full of other people’s thoughts and ideas and stories, and that it wouldn’t answer questions but ask them. Although I would never have written my book without my father, and although he is there as a guide and a ghost, and the book starts with him, ends with him and is haunted by him, it isn’t about him. It’s about all of us. And it was my way of trying to make sense of what is apparently senseless, find kindness in something apparently so cruel. You could say that I had to write this, that it was given to me.

Writing it was sometimes quite harrowing – people go through such heartbreak. At the same time, it was also uplifting – people have such courage, such hope, such love. Of course, I found it personally painful at times as well, and was also very aware that this wasn’t

“My father was gone and yet he was there, he was absent and yet present, he had lost everything and yet in some strange way he retained his self, this essence that made him John Gerrard.”

only my story to tell. Once I’d finished, I sent the manuscript to my siblings. If they had objected, I would simply have thrown the whole thing away.

You spoke to many people living with dementia, during the writing of this book. Were there any encounters which particularly marked you?

Oh yes! Almost all of them. I felt I learnt so much from all the people who were so honest and generous with their experiences. There were the doctors, the nurses, the scientists, the artists, the philosophers, who have given me new ways of seeing an illness which is everywhere. Above all, there were those men and women living with dementia and their carers, who can become like missing people in our society. Some of the stories are ones of pure suffering and loss, others were ones that were very optimistic. I understood from them how dementia need not be a death-sentence, but the beginning of a new chapter, and how the shame and stigma of the illness is a blight. I think – I hope – that I have become more attentive to the vulnerability and frailty that is all around us but that is too easy to turn away from, that I now seek to reach out a helping hand to those I see who are in confusion or distress.

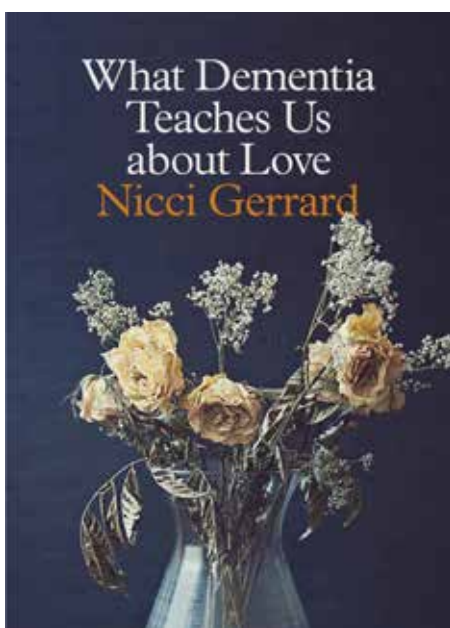
Has writing the book, and the response you have had since its publication, helped you to process the experience of living through your father’s illness?

The first thing to say is that I have had some amazing conversations with people at events I’ve done. The book has somehow grown since its publication – men and women who have never before spoken about their particular experience, stand up in public and share their stories. There was a woman the other

day who had just been diagnosed with early onset dementia and she talked about it in front of an audience of hundreds because they were giving her a safe and understanding space. It was the first time she had ‘confessed’ it. It was very brave. We need to share stories more, talk more openly about it. So I feel privileged to be part of this new conversation. As for my father – honestly, I will always feel that I let him down, though I also understand we didn’t know until too late what we should have done. At the same time, I am now able to remember all the selves he was – not just the wrecked old man I brought home to slowly die, but the happy, healthy, vigorous, dignified, eccentric, absent-minded, slightly mystical man I was lucky enough to have as a father.

You set up “John’s Campaign”, following your father’s death. Has the campaign helped to set change in motion, with regards the crisis in hospital care that you identified? What has been the most positive outcome of the campaign, so far?

Yes – John’s Campaign has a single principle which, like a Trojan Horse, is trying to bring more compassionate care into hospital (and in the UK, one in three beds are occupied by someone living with dementia). This principle is that the carer of someone with dementia should have the same rights as a parent or a child to accompany them when they go into hospital. As simple and obvious as that. It seems mad that there should have to be a campaign for something as blindingly obvious, but it took me and my friend Julia four years and more to achieve what we set out to bring about, which was a welcome for carers in every hospital in the country, an acknowledgement that they are a valuable part of the team of support round a patient. Hospitals are hazardous for someone who is old, confused, often scared and very vulnerable and it is a nonsense that those who know them best are kept away at their time of greatest need. Hospitals are places of cure but many people who are in hospital now need the kind of vigilant and constant care that doctors and nurses, however wonderful, cannot



“There is a real sense that there is a conversation going on now about dementia, about old age, about dying, that we have long avoided.”

“I am now able to remember all the selves he was – not just the wrecked old man I brought home to slowly die, but the happy, healthy, vigorous, dignified, eccentric, absent-minded, slightly mystical man I was lucky enough to have as a father.”

give. People with dementia have to be treated as people – precious and precarious – as well as patients.

Because we were joined by a great army of nurses, doctors, carers, and became a movement for change, the campaign has been pretty successful: every acute hospital in the country has now signed up to it. It's in the written constitution. Of course, there's always more that needs to be done. You never

arrive at a point and think everything is perfect. I'd say the most positive achievement – apart from having every hospital now signing up to our demands, is that the culture around care is changing.

From your perspective, what is the most important thing policymakers can do to improve the situation for people with dementia and their families?

Oh well, really we need a revolution in kindness. Aside from that, I'd say money – and the recognition that dementia is an *illness*. When people get cancer, they are looked after from the diagnosis onwards. When people get dementia, they often have a diagnosis and are then – well, just left to get on with it. This makes it infinitely lonely and terrifying. We need to do better. Much much much better.

At a special symposium during the 29th Alzheimer Europe Conference in The Hague, you were interviewed about “What

Dementia Teach Us About Love”, by our colleagues at Alzheimer Nederland. What was your experience of being at the conference and of being the focus of this symposium?

I loved being there and above all, I loved hearing what different people have to say about an illness of which almost everyone has some kind of experience. There is a real sense that there is a conversation going on now about dementia, about old age, about dying, that we have long avoided.

“I set up a campaign that fights for more compassionate care for those with dementia when they go into hospital. It was my way of trying to atone, I guess, for what had happened to him.”



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human health care

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About Eisai

Eisai is a leading global research and development-based pharmaceutical company headquartered in Japan. We define our corporate mission as ‘giving first thought to patients and their families and to increasing the benefits health care provides’, which we call our *human health care* philosophy. With over 10,000 employees working across our global network of R&D facilities, manufacturing sites and marketing subsidiaries, we strive to realise our *human health care* philosophy by delivering innovative products in various therapeutic areas with high unmet medical needs, including oncology and neurology.

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Alzheimer Europe Conference takes place in The Hague under the banner “Making valuable connections”

The 29th Alzheimer Europe Conference brought together a record 954 participants from 46 countries. The conference opened on the evening of 23 October 2019.



Marjolein de Vugt delivers the first keynote speech

The 29th Alzheimer Europe Conference (#29AEC) “Making valuable connections” was formally opened on the evening of 23 October 2019. 954 participants from 46 countries attended the conference, at which 287 speakers and 241 poster presentations shared their research, projects and experiences, all in an atmosphere of collaboration.

Iva Holmerová, Chairperson of Alzheimer Europe, opened the conference, extending a special welcome to the 36 people with dementia who were among the delegates, as well as their supporters. She noted that public awareness of dementia has increased in recent years, and that the number of national dementia strategies is growing, across Europe, as is the number of dementia-friendly initiatives in many countries. She was also pleased to share that policy-makers have begun to acknowledge that, due to the complex nature of dementia, better coordinated research is needed, coupled with increased funding. All of this needs to happen in the modern, fast-paced and sometimes confusing context in which we all live, she commented. As a final point, she highlighted the importance of better

awareness of dementia, not only for the sake of people with dementia and their relatives, but for the sake of society as a whole, which, she said, must find ways to overcome hurdles and to fill the gaps in its understanding.

Following Iva Holmerová’s opening speech, delegates were also welcomed by Gerjoke Wilmink, Executive Director of Alzheimer Nederland; Myrra Vernooij-Dassen, Chairperson of INTERDEM; Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD); Kavita Parbhudayal, Deputy Mayor of The Hague; and Theo van Uum, Director of Long-term Care at the Dutch Ministry of Health, Welfare and Sport.

Alzheimer Nederland celebrates 35 years

Gerjoke Wilmink referred to Alzheimer Nederland’s 35th anniversary, and drew delegates’ attention to the organisation’s role as one of the co-founders of Alzheimer Europe and as hosts and co-organisers of the 1st Alzheimer Europe Conference, which took place in Friesland. Alzheimer Nederland believes

that learning and exchanging knowledge/experiences are of paramount importance in strengthening the dementia movement. “That’s why we think this conference is so important and that’s why we have our own track with innovations and good practice examples”, she said. She also mentioned Alzheimer Nederland’s national “Dementia Event”, organised annually, especially for people with dementia and their carers. This year’s edition was held in the same venue as the Alzheimer Europe Conference, just prior to the opening ceremony.

Moving things forward in the dementia field – the INTERDEM approach

Myrra Vernooij-Dassen spoke on behalf of INTERDEM (Early detection and timely INTERvention in DEMentia). She emphasised the importance of taking responsibility to move the field forward, mentioning three ways in which this could be done: Firstly, more individualised interventions need to be developed, based on a better understanding of both the variety of ways in which people may be affected by dementia and of the mechanisms of change underlying effective interventions. These interventions include cognitive, functional and social interventions and can use adapted new technologies. Secondly, models of co-production in dementia research and in implementation of research findings could also be developed. Finally, she stressed that the next generation of dementia care researchers should be stimulated, educated and mentored.

The value of patient and public involvement

Helen Rochford-Brennan addressed delegates from her perspective as a person living with dementia. She highlighted the value of the



Opening Ceremony speaker panel

voice of people living with dementia, in particular drawing attention to the benefits of patient and public involvement (PPI). She also stressed that more communication and knowledge-sharing in the research community is vital, to avoid “reinventing the wheel”. Researchers need to branch out beyond their current pool of contacts, to move things forward, she said. “We know Europe is becoming more diverse, but researchers need to seek out those new voices and not take the easy option by asking the same people over and over again.” Helen Rochford-Brennan is also keen to ring the changes in other areas where she feels there is room for improvement. There is a growing preference among her peers for moving away from “dementia friendly” and towards “dementia inclusive” societies and initiatives, for example. Finally, she addressed national policymakers, encouraging them to focus on dementia plans rather than strategies. This would have both economic and practical benefits, she concluded.

Dementia as a priority for the Dutch Government

Kavita Parbhudayal, Deputy Mayor of The Hague, responsible for Care, Youth and Public Health took the floor next, extending a warm welcome to delegates in The Hague and encouraging them to make the most of the city during their time there. Following her, Theo van Uum from the Dutch Ministry of Health, Welfare and Sport assured delegates that dementia, in all of its aspects, is

a priority for the Dutch Government. The Government’s mission, he said, is to ensure that people with dementia and their relatives feel included in society; to provide quality dementia support and care; to support scientific research into possible cures and/or methods of prevention, to speed the process up. This mission feeds into the country’s new dementia strategy, which has three pillars: The first, “Dementia and society”, aims not only to create a dementia-friendly society, but also to empower people with dementia to continue to be active and to use their abilities, thus enabling them to continue to be part of society and to have a meaningful life, with dignity. The second pillar, “Dementia and care”, focuses on good quality care and support, using innovation and taking into account labour market challenges. The third and final pillar is, “Dementia and research”, which seeks to intensify dementia research in both national and international collaborations.

Effectively supporting family carers through the medium of eHealth

In her keynote presentation on “eHealth as effective support for family carers”, Marjolein de Vugt, Professor of Psychosocial Innovations in dementia at Maastricht University Medical Center+, emphasised the need for a more balanced view of dementia and its impact. While the dominant view on dementia places much emphasis on suffering and loss and while there is no cure

for the disease, it does not mean that people with dementia are without hope, or lost. “There can certainly be room for positive experiences and a meaningful life despite the illness”, she said, and eHealth can contribute to this. It enables a more affordable and personalised delivery of care by increasing socio-economic inclusion, patient empowerment, and access to services and information in daily life.

Three elements are important to maximise the potential of eHealth interventions to support carers of people with dementia: They need to be delivered at the optimal time; they should match the needs of potential users; and they must be accessible.

In closing, Marjolein de Vugt stressed that the main hindrance to the use of eHealth interventions in daily dementia practice is a lack of research into its implementation. This, coupled with a number of implementation barriers, needs to be overcome in order to move forwards.

Following the keynote lecture, delegates enjoyed the welcome reception in the foyer, accompanied by members of the Odensejazzband – a group of professional jazz musicians from Amsterdam, the majority of whom have memory problems. A small team from Alzheimer Indonesia also regaled guests by performing the “Poco-poco” (also known as “Senam Ceria”), a popular traditional dance from Eastern Indonesia.



Packed auditorium for the opening ceremony

The conference focused on diagnosis, technology and e-health, inclusion and prevention

The 4 plenary sessions at #29AEC took place on 24 and 25 October 2019, covering topics related to diagnosis and post-diagnostic support; technology and e-health, dementia-inclusive societies; and dementia prevention.

Diagnosis and post-diagnostic support

The first plenary session on “Diagnosis and post-diagnostic support” was chaired by Gerjoke Wilmink (Netherlands) and opened with a presentation on “Improving the diagnosis, post-diagnostic support, care and inclusion of people with dementia: the findings of the 2nd European Joint Action on Dementia”, given by Geoff Huggins, the Director of the NES Digital Service. The findings of the Joint Action that he shared, were: There is already knowledge in place about how to offer good quality care for people living with dementia, so the challenge for health care systems is not about knowing what to do, but rather it is about implementation and change; The Joint Action

demonstrates that implementing the same or a similar evidence base in different environments will get different outcomes; Properly involving people living with dementia and their families is always of value and leads to outcomes more in line with their wishes; and finally, local leadership really matters. The EU Joint Action “Act on Dementia” began in March 2016 and ends this year. Its main aim is to promote collaborative actions among Member States to improve the lives of people with dementia and their carers.

Wiesje van der Flier, head of clinical research at the Alzheimer Center Amsterdam at Amsterdam UMC, was next up to the lectern, presenting “Research leading to better

“ Understanding intercultural care needs, requires an awareness of faith, language and wider cultural norms and how they influence conceptualisation as well as coping with dementia.”

Mohammed Akhlak Rauf

diagnosis and care in memory clinics – findings from the ABIDE project”. The Alzheimer’s Biomarkers In Daily practice (ABIDE) project found that, while advances in early and accurate diagnosis of Alzheimer’s disease are among the largest research successes in the field, they also come with new challenges – for example, the advance of diagnostic tests means there are more choices to be made. Wiesje van der Flier shared that an audiotape study, completed by the ABIDE researchers, revealed that shared decision-making in the context of dementia diagnosis is not yet common practice. In response to this, the project has developed a simple list of topics to discuss during the diagnostic process and a “conversation-starter” for the



Plenary 1 speaker panel (left to right): Gerjoke Wilmink, Geoff Huggins, Henry Brodaty and Wiesje van der Flier



Plenary 2 speaker panel (left to right): Marco Blom, Emma Ferguson-Coleman, Charles Scerri, Dag Aarsland and Wijnand IJsselsteijn

diagnostic encounter, both of which aim to empower patients and carers, and to promote shared decision-making. Finally, she said that, through the use of “big data”, the project developed statistical models that can be used to enhance interpretation of diagnostic test results (e.g. MRI, CSF biomarkers). This will support clinicians to provide personalised diagnostic care and to explain what results mean to patients and carers. The project developed an online tool, “ADappt”, to help facilitate the use of these models.

The third and final presentation, “After the diagnosis... what next? Post-diagnostic support for people with dementia and their families” was delivered by Henry Brodaty, Professor of Ageing and Mental Health, at the University of New South Wales (UNSW Sydney). He drew delegates’ attention to the fact that, despite multiple guidelines about making a diagnosis being available worldwide, guidance for the diagnostic process and post-diagnostic care and communication is sadly lacking. People diagnosed with dementia and their families and carers frequently voice dissatisfaction with the lack of communication, guidance, referral, information about management and prognosis, as well as the lack of support for living well with dementia. He introduced the COGNISANCE

project, which aims to fill this gap by co-designing with people living with dementia, families and health care practitioners, and looking to implement and evaluate a package to improve post-diagnostic care. The project, which covers five countries (Australia, UK, Netherlands, Poland and Canada), is funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND) and funded within each participating country. The aim, once the project is completed, is to make a successful package available for local adaptation worldwide.

The plenary session ended with an award ceremony. ZonMw – The Netherlands Organisation for Health Research and Development, gave an award to the ABIDE project. The award was presented to Wiesje van der Flier, principal investigator, by Henk Smid, Director of ZonMw and Saskia Danen, patient representative from Alzheimer Nederland. The project was funded by ZonMw and Alzheimer Nederland. A short video about the project was also shown.

Technology and e-health

The second plenary session focused on “Technology and e-health” and was chaired by Charles Scerri (Malta). The

opening presentation, by Wijnand IJsselsteijn, Professor of Cognition and Affect in Human-Technology Interaction at Eindhoven University of Technology, looked at “Warm technology and co-design with people with dementia”. He began by emphasising that, while some of us, as we age, will experience cognitive decline and/or dementia, this does not define who we are. “As we are focusing our scholarly and design efforts to improve the lives of people living with dementia, we are acutely aware that ageing does not equate to deterioration.” It may, however, be a part of it, he conceded. The best technology design efforts should, therefore, not focus solely on the support, substitution or amelioration of functional decline, but on better ways of affirming old age – of remaining open and attached to the world and to other people. With this in mind, there is a need to reimagine the roles of technology in old age, and to challenge the dominant but problematic rhetoric of technology as a solution for an aging population. He highlighted the concept of “warm technology” – a framing of technology that intentionally challenges the prevalent connotation of technology as rational and efficient, yet impersonal, complicated and disconnected from an individual’s lived experience – and looked at its possible applications in dementia care. Wijnand

Ijsselstein also discussed the person-centred process of designing for and with people living with dementia – “a process based on mutual trust, dignity, and personal history, context and preferences.”

“The quality of dementia care remains poor, even in many countries with strong health and social care systems, but, more encouragingly, over 90% of OECD countries have at least some dementia-inclusive initiatives in place.”

Elina Suzuki

Dag Aarsland took the floor next, for his presentation “What role for ‘wearables’ in the detection of people at risk of dementia and in monitoring disease progression?”. Dag Aarsland is Head of Department of Old Age Psychiatry at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London. He began by stating that measures of functional impairment in Alzheimer’s disease (AD) are made less accurate, or at least more difficult to achieve, by the fact that they rely

on direct clinical observation or on caregiver recall. This is especially relevant because the presence of functional impairment is required for a diagnosis of AD, yet studies of activities of daily living have found functional impairment occurs during pre-clinical AD.

Measuring cognition, behaviour and other clinically relevant domains in people diagnosed with AD in their everyday environments through the use of Remote Measurement Technologies, provides the opportunity to capture detailed data over numerous time points, which is a distinct improvement on the current means of assessment, he said. He then introduced the RADAR-AD project (Remote Assessment of Disease And Relapse – Alzheimer’s Disease). “RADAR-AD’s tailored combination of devices and smartphone applications will act as a powerful new tool in personalised medicine by offering the right treatments to the right patients for maximum effectiveness and minimum waste”, he concluded.

Marco Blom, Scientific Director and Head of National Services at Alzheimer Nederland, was up next. He gave a presentation on “Identifying the needs and views of carers of people with dementia: the online platform of Alzheimer Nederland”. With the help of many family carers, and with the driving principle

of delivering relevant information and functionalities for carers, Alzheimer Nederland has been able to develop a highly successful online platform. In its first full year (2016), the platform reached 322,000 unique visitors. The number is steadily growing, with 624,000 in 2017 and almost a million in 2018. As at the end of September 2019, more than 800,000 unique visitors had contacted the online platform, meaning that Alzheimer Nederland expects to reach its 1 millionth visitor for this year, sometime next month (November).

Taking into account the time people are active on the platform, the total time spent on the platform is more than 42,000 hours. “We deliver a great job in supporting family carers of people with dementia”, he was proud to say. In the near future, the plan is to build a dedicated website section, developed together with and aimed at people with dementia themselves. Furthermore, Alzheimer Nederland wants to provide information, content and functionalities on a more personal basis, for instance aimed at younger people who have a parent or grandparent with dementia, as well as people with young onset dementia.

Emma Ferguson-Coleman, who is a Deaf research associate within the Social Research with Deaf People (SORD) group at



Plenary 3 speaker panel (left to right): Jim Pearson, Bernd Heise, Elina Suzuki, Julie Meerveld and Mohammed Akhlak Rauf



Plenary 4 speaker panel (left to right): Tiia Ngandu, Sebastian Köhler, Marco Blom and Meike Vernooij

the University of Manchester, closed the second plenary session, giving delegates some insight into “Navigating everyday challenges of life-story work with Deaf sign language users with dementia”. She drew attention to the fact that “Deaf British Sign Language (BSL) users consistently experience unequal access to health and social care provision, because their language and communication needs are inadequately met and their cultural identity is not recognised by the mainstream.” Inequities of access, service provision and effective outcomes can be exacerbated when Deaf people live with dementia, she said. In closing, Emma Ferguson-Coleman highlighted positive steps that can be taken to promote the inclusion of Deaf people with dementia and their carers within mainstream service provision.

Making our societies more dementia-inclusive

The third plenary session “Making our societies more dementia-inclusive” was chaired by Jim Pearson (Scotland, UK) and opened with a presentation by Bernd Heise, a member of the European Working Group of People with Dementia (EWGPWD), who shared his expectations from dementia-inclusive communities, with the audience. A

dementia-friendly community, he said, may be built from several single initiatives, if they can work together towards a common goal. “Such communities are founded on the consensus of all responsible persons and on greater persistence”, he stressed. He also emphasised that a truly “dementia-friendly” community requires the full inclusion of people with dementia (hence the term “dementia-inclusive”) and must promote their existing skills and interests.

Mohammed Akhlak Rauf, Founder & Director of Meri Yaadain CiC, used his presentation to discuss “Embedding intercultural care to support dementia care amongst minority ethnic communities”. He began by drawing attention to the impact that migration and migratory history have had on the level of trust accorded to statutory agencies. This lack of trust understandably reduces the uptake of health and social care services among migrants and people from minority ethnic communities, including those living with dementia. “Questions should be asked as to why minority ethnic groups are absent from services”, he urged.

He also highlighted the importance of considering the needs of people with dementia and their family carers and of incorporating these

into research, planning, design and delivery, from the off, rather than such supports being an “add-on” or an extra specialism, as is so often the case. In conclusion, Mohammed Akhlak Rauf stated that “understanding intercultural care needs requires an awareness of faith, language and wider cultural norms and how they influence conceptualisation as well as coping with dementia.”

Julie Meerveld, Manager of Regional Support and Advocacy at Alzheimer Nederland, presented “The Dutch National Programme for a dementia-inclusive society – a collaboration involving national and local authorities, associations and companies”. Alzheimer Nederland began its national campaign to make Dutch society more inclusive for people with dementia, in 2016, with the goal of educating the public about dementia and how to communicate better with people living with dementia. The campaign has been a success, she was pleased to say.

After three years of campaigning, 80% of the public in the Netherlands is aware of the campaign, 280,000 people have signed up to support the campaign and 58% of those have completed training courses. 350 companies are also involved, training their employees and informing their customers. “It works. Dutch

society has become a more dementia-friendly society, because the public and dementia friends feel more confident and able and family carers feel more supported and more able to ask for outside help", she said.

Alzheimer Nederland has been monitoring progress via panel consultation and research involving members of the public and informal carers. "Our three vital ingredients are: a large-scale scope of the campaign to create a responsive basis, close collaboration with companies and the twelve different online training courses and one offline training" she concluded.

Elina Suzuki, an Advisor to the Director of Employment, Labour and Social Affairs at the Organisation for Economic Co-operation and Development (OECD), was the final speaker at this plenary session. She presented on the state of dementia care and dementia-friendly initiatives across OECD countries. She reported that the quality of care for people living with dementia remains poor, even in many countries with strong health and social care systems. She also spoke about the rising interest in developing dementia-friendly initiatives in OECD countries, noting that at least 90% of OECD members reported having at least some dementia friendly initiatives in their countries.

How can research lead to better prevention?

The last plenary session posed the question "How can research lead to better prevention?" and was chaired by Marco Blom (Netherlands). It began with a presentation on "Multidomain lifestyle interventions to prevent cognitive impairment and dementia: From FINGER to World-Wide FINGERS", given by Tiia Ngandu, Research Manager and leader of the Dementia Prevention group at the Finnish Institute for Health and Welfare in Helsinki. She emphasised the importance of finding effective preventive interventions for dementia and Alzheimer's disease (AD), given the growing number of cases, worldwide. The multifactorial etiology of dementia and late-onset AD mean that multi-domain interventions targeting several lifestyle-related and vascular risk factors are most likely to be effective, she said.

“Following their assessment by a clinician, those diagnosed with dementia and their families or care partners frequently voice dissatisfaction with lack of communication, guidance, referral, information about management and prognosis, and a general lack of support for living life well with dementia.”

Henry Brodaty

"FINGER" is a pioneering trial providing the first evidence that a multi-domain lifestyle intervention may prevent cognitive impairment. The FINGER intervention, she commented, also has a beneficial effect on daily functioning, health-related quality-of-life and reduces the development of new chronic diseases. The implementation of the FINGER model in a public health context is ongoing and the FINGER model is being adapted and tested in new trials around the world, within the framework of "World-Wide FINGERS" network. In closing, Tiia Ngandu urged all stakeholders to work together to promote better brain health and dementia prevention.

Next, Meike Vernooij, Professor of Population Imaging at the Erasmus University

Medical Center, discussed "The role of imaging in epidemiological studies: findings of the Rotterdam Scan Study". She began by stating that the use of non-invasive imaging in population studies can help unravel preclinical brain changes in asymptomatic people, and as such can improve our understanding of the etiology of Alzheimer's disease, as well as improving risk stratification and prediction of the disease. Besides informing researchers about (preclinical) disease, this so-called "population imaging" can also help us to better understand the (normal) brain ageing process, she said. This has value in clinical practice in the context of assessing whether an individual has brain tissue loss that is normal for their age. New advanced image processing methods that apply artificial intelligence techniques "may lead to



Iva Homerová and Gerjoke Wilmink close the conference and invite delegates to #30AEC in Bucharest in 2020

detection of new biomarkers that may further improve risk prediction”, she told the audience. It is imperative, however, to keep in mind that the quality of data used will impact results, and therefore to be aware of how results have been generated.

Sebastian Köhler, Associated Professor at the School for Mental Health and Neuroscience at Maastricht University and Senior Researcher at the Alzheimer Centrum Limburg at Maastricht UMC+ used his session to stress the importance of immediate action, where dementia prevention is concerned. “Our own research shows that most people think dementia is inevitable. We need to inform the public better about what can be done to reduce the risk and create awareness”, he urged. There is consistent evidence that several lifestyle factors improve brain health later in life, he said, and that, while there is currently no sure way of predicting who will or will not develop dementia and that a healthy lifestyle is not a guarantee, it does lower the risk. In conclusion, he said that without a game-changing drug, which has not yet materialised, promoting a brain-healthy lifestyle is “the best and only the only option we have.”

Empowerment and wellbeing among people with dementia

Following the final plenary, a second keynote presentation was delivered, this time

by Debby Gerritsen, Professor of Wellbeing among Frail Elderly People and People with Chronic Illnesses in Long-term Care, at the Department of Primary and Community care of the Radboud University Medical Center in Nijmegen. Her presentation, “Empowerment and wellbeing among people with dementia”, emphasised that the healthcare sector and healthcare professionals need to focus more on people’s strengths and their need to feel useful, rather than on what they are no longer capable of. She also highlighted the importance of specifying what empowerment means and includes for people with dementia, and how it can be shaped in the relationship between the individual and the people in their environment.

Join us for #30AEC in Bucharest!

The three-day conference was formally closed by Alzheimer Europe Chairperson Iva Holmerová and Alzheimer Nederland Executive Director Gerjoke Wilmink, who thanked speakers and poster presenters for sharing their research, projects and experiences. Iva Holmerová thanked Alzheimer Nederland for co-hosting the 29th Alzheimer Europe Conference and said a special thank you to the various sponsors of the conference:

The European Union Health Programme (2014–2020), Roche, Eisai, Biogen, Janssen, Amgen, Otsuka, the Alzheimer Europe Foundation,



Debby Gerritsen delivers second keynote speech

The Hague Convention Bureau, The City of The Hague, Skyteam, and Lufthansa.

She then invited all delegates to mark the dates of the next Alzheimer Europe Conference (#30AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 20 to 22 October 2020.

“A dementia-friendly community requires full inclusion of people with dementia and has to promote their existing skills and interests.”

Bernd Heise



Wiesje van der Flier accepting award from ZonMw on behalf of the ABIDE project

Inspired by connections

One of the highlights of the Alzheimer Europe Conference was a symposium organised by the European Working Group of People with Dementia (EWGPWD). The session was called “Inspired by connections”.



The group gets a standing ovation

Members of the EWGPWD discussed how people with dementia connect to their communities and looked at the importance of these connections for maintaining a meaningful and full life and for continuing to contribute to society. One of the areas mentioned several times during the session was transport. Members of the group feel strongly that this is a key factor in living well with dementia, as it affects whether or not they can maintain social connections, access medical appointments and other important events, and remain as independent as possible.

The symposium was chaired by Helen Rochford-Brennan (Ireland). Angela Pototschnigg (Austria), Stefan Eriksson (Sweden) and Chris Roberts (United Kingdom) gave presentations during the session, while Tomaž Gržinič (Slovenia), Petri Lampinen (Finland), Idalina Aguiar (Portugal) and Geert van Laer (Belgium) made their contributions via the medium of video clips filmed at the group's most recent meeting. The group hopes that their short speeches and video clips will inspire people with and without dementia, to find new ways to connect with each other. The four videos are available on Alzheimer Europe's YouTube channel.

“Even a person with dementia can do unimaginable things. You might need support, but you are still able to do it.”

*Tomaž Gržinič,
Member of the EWGPWD*

“The common theme here today is connections. We are very sociable animals, us humans, so it's no surprise that we all need to belong to something – to be connected to others.”

*Chris Roberts,
Vice-Chair, EWGPWD*

About the group



The European Working Group of People with Dementia was set up by Alzheimer Europe in 2012. It is composed entirely of people with dementia, nominated by their national Alzheimer associations. They work to ensure that the activities of Alzheimer Europe reflect the priorities and views of people with dementia. The group's Chairperson is also on the Board of Alzheimer Europe.

Current EWGPWD members, as well as previous members of the group, have actively participated in Alzheimer Europe's conferences since 2012, supported Alzheimer Europe in engaging MEP candidates on the topic of dementia during European election campaigns in 2014 and 2019, and contributed to consultations for European projects in which the organisation is involved. They have also contributed to research conducted by external organisations and have represented the group at a number of international dementia-related events.

Alzheimer Europe thanks the group for its hard work, particularly in the area of patient involvement, which is an important part of what we are striving for – giving a voice to people living with dementia. We would also like to thank the supporters who accompany EWGPWD members to meetings.

Special symposia held during #29AEC

On 24 and 25 October 2019, during the 29th Alzheimer Europe Conference (#29AEC), 11 special symposia were held. This article gives an overview of a selection of these symposia.



Clinical trials in Alzheimer's disease

Clinical trials in Alzheimer's disease

This Special Symposium, which was sponsored by a grant from Janssen, focused on the past, present and future of clinical trials in Alzheimer's disease. To complement the Special Symposium, conference bags included a copy of the Clinical Trials Supplement, accompanying the October 2019 edition of our Dementia in Europe magazine. The Symposium was chaired by our Executive Director, Jean Georges.

Brian Inglis, a Scottish participant in the EPAD (European Prevention of Alzheimer's Disease) longitudinal cohort study, kicked off the Special Symposium by speaking about his experiences of this clinical study. He spoke about what motivated him to participate in Alzheimer's disease research, giving an overview of what is involved in being an EPAD participant. He then highlighted some of the personal benefits, opportunities and learnings that he gained from participating in EPAD.

The next speaker, Simon Lovestone, Professor of Translational Neuroscience at the University of Oxford, is one of the academic partners of the EPAD consortium. In his presentation, he took stock of what we have learned from

unsuccessful clinical trials for Alzheimer's disease. He emphasised three important points: firstly, we have learned that better drugs need to be developed, by diversifying the types of therapy under development and by focusing on improved targets for intervention. Secondly, we have learned that it is important to treat the right people: in the past, trials have recruited participants who are not affected by the pathology that the drug aims to treat. Clinical trials should therefore capitalise on recent advances in biomarker research, which will improve our ability to monitor the efficacy of treatment and accurately diagnose Alzheimer's disease at much earlier stages of disease development. Thirdly, we have learned that

collaboration is key: drug development is a hugely costly process but by working together in public-private consortia such as EPAD and EMIF (European Medical Information Framework) we can accelerate the development of new therapies for Alzheimer's disease.

Philip Scheltens, Director of the Alzheimer Center Amsterdam at Amsterdam UMC, closed the Special Symposium with a talk on new avenues for Alzheimer's research. He spoke about the failure of clinical trials investigating drugs such as crenezumab, solanezumab, verubecestat and lanabecestat, all of which target amyloid beta. He finished his presentation by highlighting some of the clinical investigations currently underway, identifying new targets for therapy and lifestyle interventions aimed at preventing or delaying the onset of Alzheimer's disease dementia.

The 2nd European Joint Action on dementia

A Special Symposium was organised by the 2nd European Joint Action on dementia – "Act on Dementia". Since its inception in 2016, the Joint Action has been promoting collaboration among EU Member States to improve the lives of people living with dementia and their carers. Act on Dementia comes to a close this year and this symposium was an opportunity to showcase its results and findings.

The symposium was jointly presented by Geoff Huggins, Director of the NES Digital Service (which is part of NHS Scotland and has responsibility for developing Scotland's National Digital Platform); David Nuttall, Department of Health and Social Care, UK Government; Pierre Krolak-Salmon, Institut du Vieillissement, Lyon, France; Nicola



The 2nd European Joint Action on dementia

Vanacore, National Institute of Health, Italy; Oyvind Kirkevold, Aldring og Helse, Oslo, Norway; Mireia Espallargues and Vicky Serra-Sutton, Avaluacio Sanitaries de Catalunya, Spain; and Gillian Barclay, Scottish Government, Edinburgh, UK.

The session began with an overview of the main priorities of the Joint Action, which include improving dementia diagnosis process and delivery; post-diagnostic support; addressing delays in detection and diagnosis in ambulatory care settings; improving crisis response services and care coordination; addressing behavioural and psychological symptoms in residential care settings; and collating evidence-based information and recommendations on promoting, nurturing and sustaining dementia-friendly communities.

The presenters highlighted some of the strategies used to address these priority areas, such as collaborating with international experts, training GPs, nurses and nursing home staff, and developing good practice recommendations and dementia care guidelines based on literature reviews. The Joint Action pilot programmes in care settings in Bulgaria, Romania, France, Scotland, Italy and the Netherlands include education packages for professionals, as well as support for GPs and informal carers. Details of pilot projects in Bulgaria, Greece and Romania were shared. These projects adapted and tested models to address the behavioural and psychological symptoms of dementia in residential care homes.

The symposium kicked off with information about the dementia-friendly communities piloted by the Joint Action in Bulgaria, Greece and Italy. Despite the varied mix of



Alzheimer Cafe with author Nicci Gerrard

population sizes, urban/rural settings and cultures across the three countries, people living with dementia are always at the heart of these communities.

Data sharing in dementia research

This Special Symposium, which was sponsored by a grant from Gates Ventures, was chaired by Angela Bradshaw of Alzheimer Europe. Focused on the topic of data sharing, the Symposium aimed to provide a broad overview of the state-of-the-art on health data sharing, from clinical research to data protection and, finally, the views of patients.

First to speak in the Symposium was Pieter Jelle Visser, Associate Professor at the Alzheimer Center of Amsterdam University Medical Center. Highlighting the lack of effective drug therapies for Alzheimer's disease, he underlined the importance of accessing large clinical datasets to speed up research. He discussed a number of recent initiatives aimed at facilitating data sharing, including Dementias Platform UK (DPUK), the Netherlands Consortium of Dementia Cohorts and the European Medical Information Framework – Alzheimer's disease (EMIF-AD) project. He

concluded his presentation by giving some examples of how data sharing has advanced our understanding of Alzheimer's disease.

Moving on from these concrete exemplars of data sharing in clinical research, Manuela Mayrhofer of the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) focused on the legal frameworks that underpin responsible data sharing in health research. She started by outlining one of the central ambitions of the General Data Protection Regulation (GDPR): to strike a balance between the protection of individuals' personal data, whilst also enabling the free movement of this personal data. Next, she spoke about the scope of the GDPR; who and what it affects, and how it imposes data protection obligations and responsibilities on researchers and organisations. To finish her presentation, she discussed some recent data scandals, outlining how the EU are handling these situations to ensure our data is held, processed and shared securely.

Nicola Bedlington of the European Patients' Forum (EPF) drew this Special Symposium to a close by speaking about the views of patients and the general public on data sharing. Nicola started off by presenting the work that the EPF has undertaken with their member organisations, enabling them to understand the general views of patients on the sharing of their health data. She then introduced the audience to the 'Data Saves Lives' initiative, a multi-stakeholder platform hosted by the EPF that aims to provide up-to-date information about health data in an accessible format. Nicola drew the Special Symposium to a close by providing a snapshot of the EPF's various digital health projects, all of which aim to ensure a strong patients' voice in driving change for the benefit of patients.



Data sharing in dementia research

Alzheimer Cafe with author Nicci Gerrard

Alzheimer Nederland, co-host of the 29th Alzheimer Europe Conference, held three special symposia, during the event, the first of which, “Alzheimer Café on hospital care and dementia”, was held on 24 October from 12.15–13.45. In a special edition of an Alzheimer Cafe, the famous writer Nicci Gerrard was interviewed about her latest book, “What Dementia Teaches Us about Love”. The book gained a lot of attention in the media and among the general public.

After her own father dying from dementia, she set out to explore the illness. Her book is an attempt to understand and is filled with stories, both moving and optimistic, from people living with dementia to those planning for the end of life, from the scientists unlocking the mysteries of the brain to the therapists using art and music to enrich the lives of affected people; from the campaigners battling for greater compassion in care to the families trying to make sense of dementia. The book explores memory, language, identity, ageing and the notion of what it truly means to care.

After the interview delegates were invited to participate in a lively discussion and to ask questions. You can read Alzheimer Europe’s own interview with Nicci Gerrard, about “What Dementia Teaches Us About Love” on pp. 39–41 of this magazine.

Deltaplan Dementie

The second Alzheimer Nederland symposium focused on the Netherlands’ national dementia strategy, the “Deltaplan Dementie”. It was held on 24 October from 17.45–19.00 and speakers at the session were Philip Scheltens (Deltaplan Dementie), Marianne De Visser (ZonMW Program Committee), Dinant Bekkenkamp (Alzheimer Nederland) and Karlijn Kwint (Vilans). All four speakers are closely involved in the implementation of the Deltaplan.

The Deltaplan was launched in 2012, to address and manage the growing problem of dementia in the Netherlands. This second national strategy was launched by the Ministry of Health, Welfare and Sports and comes to an end next year. It relies on three main pillars, focussing on, respectively: Scientific



Innovations in dementia care

research (basic research, prevention, finding a cure for dementia, research with a focus on treatment, support and quality-of-life); improving care; and creating a dementia-friendly society. The plan has a dedicated budget of around EUR 90 million, financed by the government and by private organisations.

The Deltaplan Dementie is also a cooperative network with member organisations in the fields of science, education, healthcare, healthcare insurance and business, as well as patient organisations.

Innovations in dementia care

The third and final symposium organised by Alzheimer Nederland, “Innovations in dementia care in the Netherlands”, was held on 25 October from 12.15–13.45. Speakers at the session were Bere Miesen (The Hague), Bernadette Willemse (Reigershoeve), Simone De

Bruin (RIVM – Netherlands National Institute for Public Health and the Environment) and Willem Draaisma (Participe).

One of the Dutch innovations examined during this session was the concept of the “Alzheimer Cafe”, presented by Bere Miesen, the “founding father” of these Cafes. New developments in small-scale housing and care farms as an alternative to regular day-care and nursing home facilities were also presented. Small-scale housing is now used in many nursing facilities. Care farms are a more recent addition, with some promising initiatives ongoing, both in the Netherlands and internationally.

Since innovation can also mean expanding on ideas from other countries, the final speaker examined how the Danish concept of “Odensehuizen” was picked up and developed into a new facility in the Netherlands.



Deltaplan Dementie

European research collaboration in Alzheimer's disease and beyond presented at #29AEC

Neuronet, a coordination and support action bringing together 15 IMI consortium projects working on neurodegenerative disease, held four parallel sessions as part of the Alzheimer Europe Conference.

When it comes to neurodegenerative conditions (such as Alzheimer's disease) there is little to no way to avoid being affected by them, either directly or indirectly. Dementia alone is already estimated to directly affect over nine million people in Europe, subsequently impacting carers and whole families. Unfortunately, development of treatments takes years and so far there are no cures available.

On 24 and 25 October 2019, a group of 14 experts in neurodegeneration research set out to present on efforts in tackling the challenges around the high-unmet medical need of people affected by such conditions. The expert presentations were held throughout four parallel sessions organised by Neuronet at Alzheimer Europe's Annual Conference under the banner "Making valuable connections".

Neuronet is a coordination and support action funded by the Innovative Medicines

Initiative (IMI), bringing together 15 European IMI consortium projects working on neurodegenerative diseases, encompassing over EUR 290 million in research funding.

Opening session – Breaking down silos and establishing valuable connections with the patient community

The opening session set the scene, providing a bird's-eye view on European research collaboration in Alzheimer's disease (AD) and beyond.

The Innovative Medicines Initiative and its neurodegeneration portfolio

The first presenter was Elisabetta Vaudano, Principal Scientific Officer at IMI, an EU public-private partnership funding health research and innovation. She introduced its neurodegeneration research portfolio and explained how it aims to accelerate innovation in dementia research by enabling

collaborative research between industry, academia and patient organisations as well as SMEs. IMI has invested significantly in a broad portfolio of projects on neurodegeneration with a specific focus on AD. They are now starting to harvest the first results from these initiatives.

Neuronet – Efficiently Networking European Neurodegeneration Research

The second presentation was given by project coordinator Carlos Diaz from Synapse Research Management Partners SL (SYN-APSE), introducing Neuronet itself. He explained that Neuronet aims to set up an efficient platform to boost synergy and collaboration across the IMI projects of the neurodegenerative diseases portfolio. This will assist in identifying gaps, multiplying the portfolio's impact, enhancing its visibility and facilitating dovetailing with related initiatives in Europe and worldwide. In order to be able to do so, Neuronet set up a Scientific Coordination Board formed by the leaders of the 15 IMI neurodegeneration projects. This Board provides expert guidance and recommendations in terms of scientific and strategic evaluation of synergies and priority areas for the whole programme.

Patient and Public Involvement in the IMI research portfolio

The third speaker highlighted IMI's awareness that involving the patient community in its research projects is indispensable. Ana Diaz, Project Officer at Alzheimer Europe presented on patient and public involvement (PPI) in the IMI research portfolio. As co-coordinator of the European Working Group of People with Dementia, she gave concrete examples of how people with dementia can actively and meaningfully contribute towards the research process as part of a true partnership between them, researchers, policy makers and other members of society.

From risk to dementia – Understanding disease progression and its causes

The second session dove into the world of hands on work in research projects, showcasing connections and sparking ideas for further collaboration.



Carlos Diaz, Elisabetta Vaudano, Ana Diaz



Maria Eugenia Saéz Goñi, Angela Hodges, Martin Hoffmann-Apitius

ADAPTED – Alzheimer’s disease apolipoprotein pathology for treatment elucidation and development

Maria Eugenia Saéz Goñi from the bioinformatics research centre in Andalusia presented the first project, entitled “ADAPTED”. The ADAPTED project investigates the function of the APOE gene, which is an area of AD research that has previously received little attention. Carrying the genetic variant known as APOE ε4 is the most prevalent genetic risk factor for developing AD, but little is known about precisely why this is. ADAPTED uses the combined expertise of researchers across different fields to systematically investigate APOE biology, and aims to provide the research community with a new generation of human cell-based tools to investigate the causes and progression of the disease.

PHAGO – Targeting TREM2 and CD33 of phagocytes for treatment of Alzheimer’s disease

Angela Hodges from Kings College London spoke about the PHAGO project. One of the project aims is to gain profound knowledge about the role of the innate immune receptors TREM2 and CD33 in AD. The other aim is to develop novel and innovative tools which might help to pave the way for new therapeutic strategies. PHAGO has already started to generate TREM2 and CD33 reporter systems and assays to support screening and drug development pipelines. The project also established a knowledge platform with data from partners, enriched with literature data from public resources.

AETIONOMY – Disease Mechanisms for Patient Subgroup Identification and Disease Progression Modeling

Martin Hofmann-Apitius from the Fraunhofer Institute for Algorithms and Scientific Computing introduced the activities and learnings from the completed AETIONOMY project. Data and knowledge about disease mechanisms are frequently scattered, biased, heterogeneous and sometimes simply wrong. AETIONOMY therefore aimed to pave the way towards a new approach to the classification of neurodegenerative diseases, particularly Alzheimer’s and Parkinson’s diseases, thereby improving drug development and increasing patients’ chances of receiving a treatment that works for them. In this pursuit, the project developed two key tools:

- The AETIONOMY Knowledge Base, a unification point of the knowledge and data management on neurodegeneration with a main focus on Alzheimer’s and Parkinson’s diseases.
- A mechanistic interpretation of multiscale, multimodal clinical data, representing essential pathophysiology mechanisms of neurodegenerative diseases (NeuroMMSig). It is the largest inventory of computable disease mechanisms underlying neurodegeneration worldwide.

Improving data access and the development of predictive models

The following session brought together project leaders from the United Kingdom, the Netherlands and Belgium.

EQIPD – Data quality in preclinical research

Malcolm Macleod from the University of Edinburgh introduced the EQIPD project, which aims to tackle the challenge of a slowing in the development of new medicines throughout the past decade. The project aims to tackle the root of this problem and reverse this trend. It is conducting systematic reviews of data from published and unpublished experiments to evaluate the performance of key preclinical experimental approaches. The team is also conducting a series of *in vivo* experiments (Open Field, Sleep Wake EEG and Irwin test) across multiple academic and industry labs to explore reasons for different findings across labs. In



Malcolm Macleod, Dominique Lesuisse, Jacoline Bouvy, Pieter Jelle Visser, John Gallacher

addition to this, they are developing the content and governance of a research quality system suitable for implementation across different types of labs.

EMIF – European Medical Information Framework

Pieter Jelle Visser from Amsterdam UMC highlighted the learnings from the completed European Medical Information Framework (EMIF) project. EMIF aimed to develop a common information framework of patient-level data that links up and facilitates access to diverse medical and research data sources, opening up new avenues of research for scientists. The project focussed initially on questions relating to obesity and AD to provide a focus and guidance for the development of the framework. During its project lifetime, EMIF developed the EMIF Data Catalogue and made it publicly available to the research community. The EMIF Data Catalogue is a text-book example of EMIF's mission to improve identification, access and assessment, and (re)use of health data within the European Union.

ROADMAP – Real world outcomes across the AD spectrum for better care: Multi-modal data access platform

John Gallacher from the University of Oxford introduced the ROADMAP project, completed in 2018. Currently, strictly controlled clinical trials are used to assess the safety and benefits of potential AD treatments for patients. However, clinical trials do not provide information on the health benefits for patients in their daily lives, the “real world”. The ROADMAP project aimed to deliver a series of methods and tools to allow the scalable, transferable integration of real world data on patient outcomes. The tools were developed and tested through pilot exercises. The project conducted patient engagement activities and addressed ethical, legal and social implications of adopting a real world evidence approach to AD. One of its key outputs is an Interactive Data Cube that offers an overview of available European real-world data on AD.

IM2PACT – Discovery of blood-brain barrier targets and transport pathways to treat neuro/metabolic diseases

The final speaker at this session, Dominique Lesuisse from Sanofi spoke about the

IM2PACT project. The blood-brain barrier (BBB), as the name suggests, tightly controls access to our brains, allowing nutrients and essential substances through, but blocking pathogens, for example. Getting medicines through this protective shield is a major challenge for drug developers, particularly those developing biopharmaceuticals, which are based on large molecules like proteins and antibodies. The goal of IM2PACT is to advance our understanding of the BBB to facilitate the development of more effective treatments for a range of neurological and metabolic disorders.

Diagnosis, patient engagement and trials

The concluding Neuronet session at the Alzheimer Europe Conference revolved around research projects that directly involve patients.

AMYPAD – Amyloid imaging to prevent Alzheimer's disease

As first speaker in this session, José Luis Molinuevo from the BarcelonaBeta Brain Research Center introduced the AMYPAD project. He explained that a common sign of AD is deposits of a protein called beta amyloid in the brain. The AMYPAD project studies the clinical value of using an imaging technique called positron emission tomography (PET) to scan people's brains

for these deposits, for the purposes of diagnosis and patient monitoring. The project is carrying out amyloid PET imaging on a large number of people who are suspected to be in the early stages of AD. AMYPAD works closely with the EPAD project.

EPAD – European prevention of Alzheimer's dementia consortium

Craig Ritchie from the University of Edinburgh introduced the EPAD project. This project is pioneering a novel, more flexible approach to clinical trials of drugs designed to prevent Alzheimer's dementia. The goal of the initiative is the prevention of dementia in people with evidence of AD (such as biomarker abnormalities) who still may have little or no clinical symptoms. EPAD aims to establish a European-wide cohort of at-risk subjects, of which many will be invited to participate in a trial to test new treatments for the prevention of Alzheimer's dementia. The project's cohort study has already screened 2,000 research participants and has 29 Trial Delivery Centres open as at the start of 2020. A proof of concept trial is planned and the project has already opened applications for external researchers to access baseline data from its first 500 participants.

MOPEAD – Models of Patient Engagement for Alzheimer's Disease

Mercè Boada from Fundació ACE presented the MOPEAD project. This project has established multiple regional project sites



John Gallacher



José Luis Molinuevo, Craig Ritchie, Mercè Boada, Dag Aarsland

(Germany, Netherlands, Slovenia, Spain and Sweden) to test models for the early identification of mild Alzheimer's dementia as well as prodromal AD. They include online screening, open house initiatives at memory clinics, and the involvement of general practitioners as well as diabetologists' offices. The advantages and obstacles of each of the models encountered in the five countries are now being compared to identify ways to improve early detection and diagnosis of AD. The project also plans to provide access to its research data to the scientific community.

RADAR-AD – Remote Assessment of functional decline in Alzheimer's Disease

Dag Aarsland from King's College London concluded the last session with a presentation of the RADAR-AD project. This project aims to improve AD assessment and care. The project will do so by looking at how digital technologies – such as smart phones, wearables and home-based sensors – can be used to measure the progression of disability associated with AD. It is currently unclear how to maximise their potential in this area and the project hopes to find this out.



More information about the research projects and the Innovative Medicines Initiative can be found at: www.imi-neuronet.org

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“Neurodegenerative diseases are an area of major unmet medical need and have been a priority for IMI since the very beginning. By bringing together IMI's excellent projects in this important area, Neuronet will help the projects to collectively make progress and give new hope to the millions of people in Europe and beyond who are affected by these diseases.”

Pierre Meulien, Executive Director, Innovative Medicines Initiative



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Congratulations to the winners of the poster awards!

The Alzheimer Europe Foundation is pleased to present the winners of the poster competition, as voted by delegates at #29AEC.

Each year, following the Alzheimer Europe Conference, the Alzheimer Europe Foundation awards prizes to the top four poster presentations, as voted by delegates. The winner for each day of the poster presentations (24 and 25 October) was awarded EUR 750 and the runner-up for each day was awarded EUR 250.

Winners

Thea Debono for “The Effects of Animal-Assisted Therapy (AAT) on the behaviour of older persons living with dementia within a Maltese Long Term Care (LTC) facility”

This poster presented a study designed to investigate the effects of Animal Assisted Therapy (AAT) on the behaviours of older persons living with dementia within a Maltese Long-term Care (LTC) facility.

A series of 12 AAT sessions took place with 6 older persons living with moderate to severe dementia, residing in the Dementia Unit of the LTC facility. Observations of Behavioural and Psychological Symptoms of Dementia (BPSD) by staff and relatives prior to the AAT sessions, and by the researcher during/post AAT sessions were recorded. A 6-year-old, mixed breed Chihuahua dog, assisted in the project.

An overall decrease in frequency and sometimes cessation in negative behaviours of the older person participants was noted. There also was an improvement in social interaction.

Monika Wilhelmi for “Hands-on Dementia. The interactive way to understand dementia. A method to feel the symptoms of dementia”.

This poster was presented by psychological psychotherapist Monika Wilhelmi. It asks

the audience to think about what people with dementia experience every day. It is not always easy to understand what moves people with dementia and what motivates their actions, but understanding is the key to entering someone else's world. It was for this purpose that the interactive training material “Hands-on Dementia” was developed.

Using 13 common situations, Hands-On Dementia simulates different symptoms of dementia, allowing trainees to experience what happens and how it feels when the most basic things become difficult, helping them to develop more understanding and empathy. There are important moments of self-reflection but also medical and psychological information. Hands-on Dementia exists in German, French, English and Italian. A translation into Dutch is in progress. Hands-On Dementia was developed by Leon Maluck, a 21-year-old student of psychology.

Runners-up

Gillian Council for “The Tipi Project: connecting people to nature”

People living with dementia are amongst the population of people who are at risk of becoming socially isolated, lonely and depressed, and as a result often develop a more indoor lifestyle. Accessing and spending time outdoors is an important part of living well with dementia and has been proven to enhance mental, physical and social well-being. The Tipi Project aims to enable people living with dementia and their families to spend time in the outdoors in a supportive and social environment.

A Tipi tent is used as an outdoor learning space to run groups for people living with dementia and their families. The idea

of having a non-permanent structure like this is so that it can be immersed into a woodland or forest surrounding to create an outdoor/indoor effect and provide a stimulating environment. People get an “evolutionary and relaxing response from socialising and eating lunch prepared on a log fire”, all in the comfort and safety of the Tipi shelter.

Marjolein Scholten and Simone de Bruin for “Green Care Farms, a new old housing concept?”


Over the last years, quality of long-term care services, including those provided to people with dementia, has been criticised. The focus of the debate is that care environments, including the services offered, are insufficiently aligned with the preferences and needs of people with dementia. However, a growing body of evidence suggests that the care environment affects outcomes in people with dementia, and should therefore be considered as an active component of care. Consequently, there have been a number of innovations in dementia care, both for people with dementia using community-based services and for those living in nursing homes. One example of such an innovation is the “green care farm (GCF)” – a farm that combines agricultural activities with care services for a variety of client groups, including people with dementia.

Over the years, research has been performed in the Netherlands to better understand the value of GCFs for people with dementia. Also in other countries, including Norway, the US, and Japan, initial evaluations are taking place. This poster presents the lessons learned from GCFs as an alternative to more traditional dementia care environments.

Sharing the winnings

Some of them generously decided to donate all or part of their prize money:

- Gillian Council donated her winnings to Alzheimer Scotland
- Thea Debono donated part of her winnings to the Malta Dementia Society
- Marjolein Scholten and Simone de Bruin donated their winnings to Alzheimer Nederland.



The Effects of ANIMAL ASSISTED ACTIVITY

ON THE BEHAVIOUR OF OLDER PERSONS LIVING WITH DEMENTIA WITHIN A MALTESE LONG-TERM CARE FACILITY

AUTHORS

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BACKGROUND

Non-pharmacological therapies are being explored as an adjunct or even replacement for the pharmacological management of older persons living with dementia in LTC facilities as a mode of treatment and to improve quality of life. AAI is one of these promising therapies that has not yet been fully investigated especially in LTC facilities.

AIM

This study investigated the effects of Animal Assisted Activity (AAA) on the behaviours of older persons living with dementia within a Maltese Long-term Care (LTC) Facility.

METHODOLOGY

6 participants from a Dementia Unit within a Maltese LTC Facility agreed to participate as in table 1.

Gender	Age range	Diagnosis Range	BI 100 range	AMTS Score range
4 females - 2 males	80-90	Moderate-Severe Dementia	0-65	AMTS 0-7

Being the first study of its nature in the local context, a qualitative prospective approach was used. Following a pilot study on 2 other residents, a series of 12 AAA sessions (table 2) were administered by the researcher with the help of a 6-year-old white mixed breed Chihuahua female dog. The sessions lasted 1 hour. Observations of Behavioural and Psychological Symptoms of Dementia (BPSD) by staff and relatives prior to the AAA sessions, and by the researcher during and after the administration of the AAA sessions were recorded using a researcher-directed diary.

Activity
'Meet and Greet'
'Petting and Holding' x 2
'Waiting Kneel' x 2
'Grooming Kneel' x 2
'Play with Me' x 2
'Reminiscing' x 2
'Goodbyes'

RESULTS

The study showed that with AAA there was an overall decrease in frequency and sometimes cessation in negative behaviours of the older person participants; there also was an improvement in social interaction.


BPSD	Response to AAA
Aggressive Behaviours	Decreased in frequency or disappeared
Physically nonaggressive Behaviours	Decreased in frequency
Verbally Agitated Behaviours	Decreased in frequency
Social Interaction	Improved
Communication	Improved

A number of factors were noted to influence the effect of the AAA sessions:

- severity of dementia** – the more severe, the less the response
- mobility** – immobile participants responded less to activities that required help with mobility
- the personalities and prior habits of the participants** – sessions that were meaningful to the participant were most useful.

CONCLUSION

The results of this study support the fact that AAA improves BPSD in older persons living with dementia in a local LTC facility and these activities work best if tailored to the needs and characteristics of the individual patient. Further studies on a larger cohort and over a longer time span are needed as well as studies on the duration of the effects of AAA after cessation of the activities.



CareMalta


Thea Debono – The Effects of Animal Assisted Activity

P09.5 Monika Wilhelmi
Hands-on Dementia

The interactive way to understand dementia

A method to feel the symptoms of dementia

WHA4 D8 PERS6NS 9ITH DEM2NT7A FE5L LI4E AN9 E3PERIENCE EA2H DA1?




The teaching material Hands-on-dementia was developed for health care professionals and relatives to gain a deeper understanding and empathy for people who suffer from dementia.

With the help of Hands-on Dementia you can experience the symptoms of dementia:

How does it feel ...

- when everyday situations become a problem?
- when all efforts are in vain?
- to lose your self confidence?
- to feel ashamed?
- to feel insufficient?

- to fail?
- to endure the feeling of hopelessness?
- to lose any interest and joy?
- when familiar things turn into a challenge?
- when desperation makes you angry?



Der interaktive Weg Demenz zu begreifen

Monika Wilhelmi – Hands-on Dementia

The Tipi Project: connecting people to nature

Gillian Council & Kenny Wright

Our belief is that access to the outdoors is a human right and that people living with dementia and their carers have the right to this opportunity as much as everyone else.

300+ people affected by dementia **have benefitted from this project**

As soon as I arrive at the tipi, that's me, I'm home.

I wish I could come to the tipi every day.

3 mins Green spaces can **reduce stress levels and blood pressure**

Scots Pine trees emit a pheromone that makes you feel good

I haven't seen my husband laugh and smile like that in a long time.

She was much more animated than usual on the way home and was telling her son all about her adventures.

Spending time outdoors can reduce the risk of depression by 30%

Watch the Tipi Project Springwatch news feature

The aim

The aim of the Tipi Project is to enable people living with dementia and their families to spend time in the outdoors in a supportive and social environment.

The project

We currently run a monthly group for people with dementia and their families and we have been meeting since September 2017. We use a Tipi tent as an outdoor learning space to run the group. It acts as the platform to reconnect people to the outdoors. The idea of having a non-permanent structure like this is so that it can be immersed into a woodland or forest surrounding to create that outdoor/indoor effect and provide a stimulating environment. The structure is heated by a wood burning stove allowing us to run all year round the evolutionary and relaxing response people get from socialising around a log fire is intangible. We heat food for lunch over the fire adding to the genuine camp-like experience. We can have exposure to and feel the benefits of the outdoors with the comfort and safety of shelter. The suitable layout of the structure is optimal for positive interactions and the setting is free from modern day sounds and stresses. We provide a multi-sensory absorptive and social experience with a strong focus on therapeutic intervention. Each month we try different activities, learn new skills and take walks in the surrounding woodlands.

The outcome

The Tipi Project has been so successful, and the benefits unquestionable. We are at the stage of taking the Tipi to other environments to offer a similar experience to people living with dementia in different care settings.

Gillian Council – Tipi Project

PO17.3 Green Care Farms: a new old housing concept?

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Background

- Quality of long-term dementia care services is being critized.
- Dementia care environments are insufficiently aligned with the preferences and needs of people with dementia.
- Growing body of evidence suggests that the care environment affects outcomes in people with dementia, and should therefore be considered as an active component of care.
- Dementia care models are increasingly directed towards small-scale and homelike environments.
- Increasing number of innovations in dementia care in the Netherlands, including green care farms.

What is a green care farm?

A farm that combines agricultural activities with care and support services for a variety of client groups, including people with dementia.




Types of green care farms and related nature-based services

- Green care farms providing 24-hour nursing home care.
- Green care farms providing adult day services.
- Social entrepreneurs offering adult day services in a green environment (e.g. city farm, city garden, park).
- Nursing homes opening up their gardens to people with dementia living in the community.
- Social care organizations organizing green activities (e.g. green maintenance, walks in green environments, visit to a children's farm or city farm).
- Citizens who, together with other agencies, offer nature-based Adult Day services in a community garden.

Types of clients

- People with dementia using services of green care farms differ from people using regular adult day services (Table 1).

Table 1. Characteristics of participants of green care farms and regular adult day services.

	Green care farm	Regular adult day services
People with dementia		
Sex (% men)	85%	47%
Age	73 years	85 years
Marital status (% married)	97%	29%
Living situation (% with partner)	97%	29%

Evidence synthesis

- Several studies have been conducted in the Netherlands to understand the value of green care farms for people with dementia and their family caregivers.
- Services at green care farms support contact with nature and animals, time spent outdoors, activity engagement, physical activity, structure, social interactions, healthy eating, a sense of meaning in life and a focus on normal daily life.
- Services at green care farms stimulate respite, reassurance and maintenance of family carers' own activities and social contacts.

Main lessons learned

- Green care farms have a wide range of benefits that might affect the health and wellbeing of people with dementia and their family carers.
- Several characteristics of green care farms can be implemented in other dementia care settings.
- To realize innovation in dementia care it is important that not only the physical environment but also the social and organizational environments are supporting the process of change.

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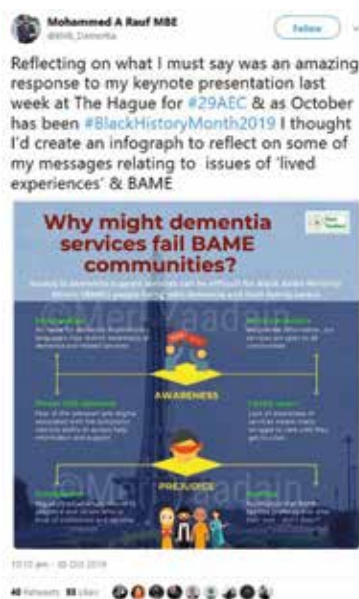
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Snapshots



Top tweets from #29AEC

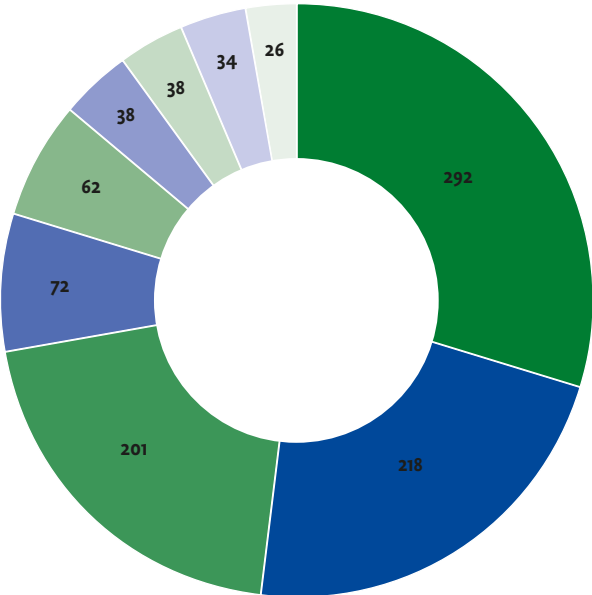


Facts and figures

Country	Attendees
TOTAL	981
Netherlands	292
United Kingdom	155
Germany	50
Belgium	38
Slovenia	33
Italy	30
Ireland	29
Spain	26
Norway	25
France	23
Malta	23
Luxembourg	22
Denmark	21
Switzerland	19
Finland	18

Country	Attendees
Taiwan	18
Iceland	16
Austria	14
Sweden	12
USA	11
Australia	11
Poland	11
Portugal	10
Czech Republic	10
Canada	8
Hong Kong	7
Greece	6
Indonesia	6
Estonia	5
Hungary	4

Country	Attendees
Japan	4
Bosnia and Herzegovina	4
Israel	2
Cyprus	2
Jersey	2
Romania	2
Macedonia	2
Netherlands Antilles	2
Brazil	1
Singapore	1
Turkey	1
New Zealand	1
China	1
Bulgaria	1










































Academics/Researchers	292
Health or social care professionals	218
Alzheimer association staff and volunteers	201
Students	72
Industry representatives	62
Policy makers	38
People with dementia	38
Carers	34
Civil servants	26

97 % of delegates would recommend future Alzheimer Europe Conferences to their colleagues.

88% of delegates rated the opening ceremony, keynote lectures, plenaries and closing ceremony of the conference to be good/very good.

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	DENMARK – COPENHAGEN Alzheimerforeningen		LUXEMBOURG – LUXEMBOURG Association Luxembourg Alzheimer		SWEDEN – LUND Alzheimer Sverige
	ESTONIA – TALLINN NGO Living with Dementia		MALTA – MSIDA Malta Dementia Society		SWEDEN – STOCKHOLM Demensförbundet
	FINLAND – HELSINKI Alzheimer Society of Finland (Muistiliitto)		MONTENEGRO – PODGORICA NVO Futura		SWITZERLAND – BERN Association Alzheimer Suisse
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